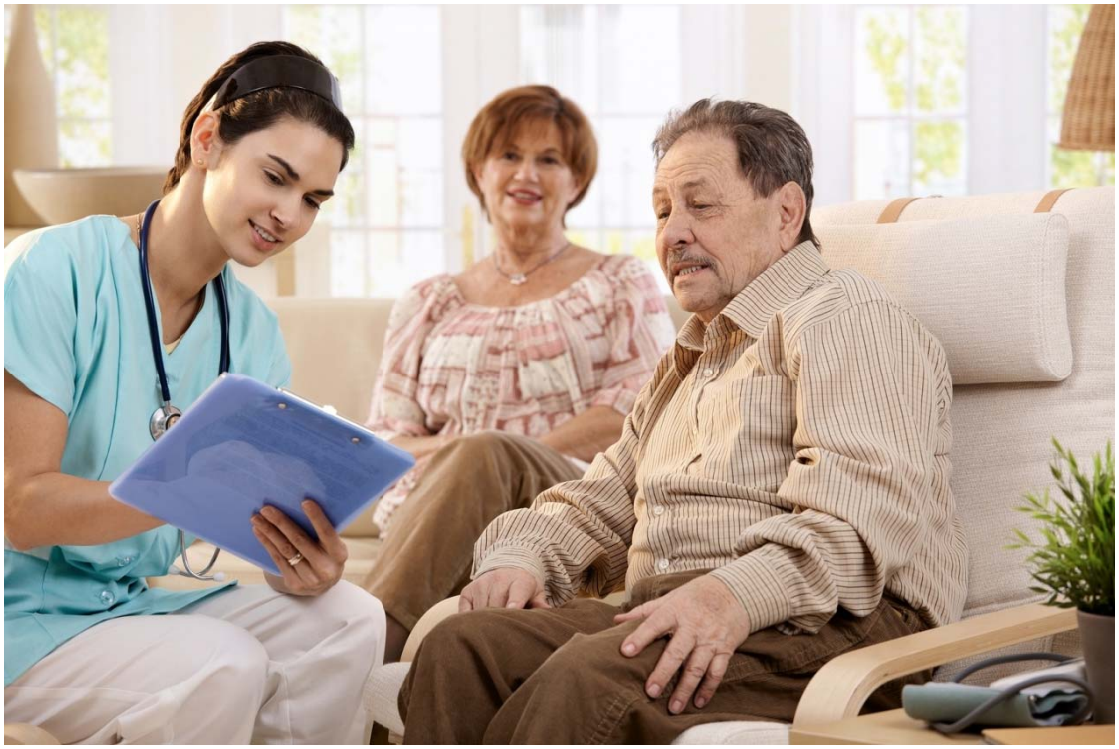
KCE REPORT 190S

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

DEVELOPMENT OF A POSITION PAPER FOR CHRONIC CARE IN BELGIUM

APPENDIX





KCE REPORTS 190S
HEALTH SERVICES RESEARCH

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Center

DEVELOPMENT OF A POSITION PAPER FOR CHRONIC CARE IN BELGIUM

EDITORS: DOMINIQUE PAULUS, KOEN VAN DEN HEEDE, RAF MERTENS

CONTRIBUTING AUTHORS: FELICITY ALLEN, SIBYL ANTHIERENS, LIESBETH BORGERMANS, ANJA DESOMER, SOPHIE GERKENS, GENEVIEVE HAUCOTTE, JAN HEYRMAN, JEAN MACQ, GEORGES OSEI-ASSIBEY, VINCIANE QUOIDBACH, ROY REMMEN, OLIVIER SCHMITZ, HILDE SPITTERS, LINDA SYMONS, THERESE VAN DURME, FLORENCE VANDENDORPE, BERT VRIJHOEF

COLOPHON

Title:	Development of a position paper for chronic care in Belgium – Appendix
Editors:	Dominique Paulus, Koen Van den Heede, Raf Mertens
Contributing authors:	Felicity Allen (Abacus International®), Sibyl Anthierens (Universiteit Antwerpen), Liesbeth Borgermans (FOD Volksgezongdheid – SPF Santé Publique), Anja Desomer, Sophie Gerkens, Genevieve Haucotte (INAMI – RIZIV), Jan Heyrman (KULeuven), Jean Macq (UCL), George Osei-Assibey (Abacus International®), Vinciane Quoidbach (Cabinet de la Ministre des Affaires Sociales et de la Santé Publique), Roy Remmen (Universiteit Antwerpen), Olivier Schmitz (UCL), Hilde Spitters (Universiteit Tilburg), Linda Symons (Universiteit Antwerpen), Therese Van Durme (UCL), Florence Vandendorpe (UCL), Bert Vrijhoef (Universiteit Tilburg)
Reviewers:	Members of the consultative and scientific sections of the Observatory for Chronic diseases
External experts:	Daan Aeyels (Huis voor Gezondheid), Jean-Pierre Baeyens (Belgische Vereniging voor gerontologie en geriatrie), Claudine Baudart (Association des infirmières indépendantes de Belgique), Luc Berghmans (Observatoire Santé du Hainaut), Anne Beyen (Regionaal Ziekenhuis Heilig Hart Tienen), Jan De Maeseneer (UGent), Claude Decuyper (Fédération nationale des infirmiers de Belgique), Marc Dooms (Belgische Vereniging van Ziekenhuisapothekers), Aurore De Wilde (Fédération Nationale des Infirmiers de Belgique), Xavier De Bethune (ANMC), Micky Fierens (Ligue des Usagers des Services de Santé), Johan Hellings (ICURO), Evelyne Hens (Socialistische Mutualiteit), Lon Holtzer (Associatie K.U.Leuven / Vlaamse Overheid), Tom Jacobs (Domus Medica), Luc Lefèbvre (Société Scientifique de Médecine Générale), Luc Maes (E-Health), Guillaume Mathot (Société Scientifique des Jeunes médecins généralistes – SSMJ), Frank Nobels (OLVZ Aalst), Christian Swine (Cliniques Universitaires UCL Mont-Godinne), Jean-Luc Vachiery (Hôpital Erasme), Isabelle Van der Brempt (SPF Santé publique – FOD Volksgezondheid), Luc Van Gorp (Katholieke Hogeschool Limburg / Wit-Gele Kruis Vlaanderen), Ilse Weeghmans (Vlaams Patiëntenplatform), Johan Wens (Universiteit Antwerpen)
Acknowledgements:	Pierre-Yves Bolen (Région Wallonne), Brigitte Bouton (Région Wallonne), Chris Decoster (FOD Volksgezondheid – SPF Santé publique), Ri De Ridder (RIZIV – INAMI), Stephen Mitchell (Abacus International®)
External validators:	Prof. Dr med. Reinhard Busse (Department of Health Care Management Berlin, Germany), Prof Bart Criel (Institute of Tropical Medicine, Antwerpen), Prof. Martin Fortin (Département de médecine de famille, Université de Sherbrooke, Canada)
Stakeholders:	Johan Abrahams (St-Elisabeth Woon- en zorgcentrum Hasselt), ,Claudine Baudart (Association des infirmières indépendantes de Belgique), Marie-Claire Beaudelot (Cliniques Universitaires Saint-Luc), Guy Beuken (UCL), Corinne Bouuaert (ULG), Pierre Chevalier (UCL), Marleen Cloes (Ligue en faveur des insuffisants rénaux), Bart Coessens (Woon- en zorgcentrum St-Bernardus, Bertem), Leentje Cools (Samenwerkinginitiatief EersteLijnsgezondheidszorg Amberes, Antwerpen), Sofie De Mars (Ziekenzorg CM), Jos Desmedt (Huisartsengroepspraktijk Het pleintje Booischot), Tine Devlieger (Universiteit Antwerpen), Ingrid Druyts (Vereniging Huisartsenkringen Zuiderkempen), Caroline Ducenne (asbl Aidants Proches, Belgrade), Anne Gillet-Verhaegen (GBO / Cartel), Marleen Haems (Kovag), Sabine Henry (Ligue Alzheimer), Jannie Hespel (Thuishulp

	vzw Socialistische Mutualiteiten), Hilde Lamers (Alzheimer Liga), Marina Lermytte (De Volksmacht Turnhout), Jean Loiseau (Association des gestionnaires Publics de Maisons de Repos et de Maisons de Repos et de soins de la Province de Liège), Kara Mazlum (Dionysos), Saphia Mokrane (Entraide Marolles), Valentine Musette (Fédération des Associations de Médecins Généralistes de Bruxelles), Christine Ori (asbl Aides et soins à domicile Liège-Huy-Waremme), François Poncin (Réseau-Hépatite C Bruxelles), Ilse Pynaert (Lokaal Multidisciplinair Netwerk Oost-Meetjesland & West-Meetjesland), Janneke Ronse (UGent), Ferdinand Schreurs (ABSYM – BVAS), Jean-François Soupart (Forum des Associations de Généralistes), Paul Van den Heuvel (Ziekenhuis Netwerk Antwerpen), Kristien Van Deyk (UZ Leuven), Omer Van Haute (UZ Gent), Chris Van Hul (Landsbond van de Onafhankelijke Ziekenfondsen), Karin Van Sas (Praktijkhuis Baarle), Alfred Velz (Cabinet du Ministre de la Famille, de la Santé et des Affaires sociales de la Communauté germanophone), Patrick Verdonck (Domus Medica).
Members of the Steering Group (also invited as stakeholders):	Jean-Pierre Baeyens (Belgische Vereniging voor gerontologie en geriatrie), Jacques Boly (ANMC), Chris Decoster (FOD Volksgezondheid – SPF Santé publique), Ri De Ridder (RIZIV – INAMI), Olivier Grégoire (FOD Volksgezondheid – SPF Santé publique), Micky Fierens (Ligue des Usagers des Services de Santé), Yolande Husden (Cabinet Région Wallonne), Marie-Claire Minne (Fédération Wallonie-Bruxelles), Philippe Henry de Generet (Cabinet du Ministre du Gouvernement de la Région de Bruxelles-Capitale), Sophie Lokietek (Service Public de Wallonie, DG05), Louis Paquay (Wit-Gele Kruis), Vinciane Quoidbach (Cabinet de la Ministre des Affaires Sociales et de la Santé Publique), Dominique Sege (Coccom), Saskia Van Den Bogaert (FOD Volksgezondheid – SPF Santé publique), Isabelle Van der Brempt (SPF Santé publique – FOD Volksgezondheid), Ilse Weeghmans (Vlaams Patiëntenplatform)
Conflict of interest of experts and stakeholders:	Invited experts, stakeholders, members of the Steering Committee and the Observatory for chronic diseases were contributing with their valuable experience and knowledge of the field. In that respect they might have interests in the domain of chronic care, linked to their function in the healthcare sector. None of them has declared other conflicting interests, likely to undermine the value of his contribution to this project.
Conflicts of interest declared by the validators:	Reinhard Busse received funding linked to the authorship of the Observatory/WHO publication on “Tackling Chronic Disease in Europe” (2010) and for several presentations on the topic (invited).
Layout:	Ine Verhulst

Disclaimer:	• **The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.** • **Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.** • **Finally, this report has been approved by common assent by the Executive Board.** • **Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.**
Publication date:	19 December 2012
Domain:	Health Services Research (HSR)
MeSH:	Chronic Disease; Health Care Reform; Organization and Administration
NLM Classification:	W.84.3
Language:	English
Format:	Adobe® PDF™ (A4)
Legal depot:	D/2012/10.273/85
Copyright:	KCE reports are published under a “by/nc/nd” Creative Commons Licence http://kce.fgov.be/content/about-copyrights-for-kce-reports. 
How to refer to this document?	Paulus D, Van den Heede K, Mertens R. Development of a position paper for chronic care in Belgium - Appendix. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE). 2012. KCE Report 190S. D/2012/10.273/85. This document is available on the website of the Belgian Health Care Knowledge Centre.

TABLE OF CONTENTS

1. HIGHLIGHTS FROM FOUR COUNTRIES – THE CHRONIC CARE MODEL IN USE 7
1.1. OBJECTIVE AND RESEARCH QUESTIONS 7
1.2. METHODS 7
1.3. MAIN CHARACTERISTICS OF THE COUNTRIES 10
1.4. THE NETHERLANDS 11
1.4.1. Stakeholder Collaboration: shared Vision & Leadership 12
1.4.2. Shared Data & Performance Measurement 13
1.4.3. Engaging Consumers 14
1.4.4. Improving Healthcare Delivery 14
1.4.5. Aligning Finance & Insurance 15
1.4.6. Outcomes 16
1.4.7. Summary 18
1.5. DENMARK 19
1.5.1. Stakeholder Collaboration 20
1.5.2. Shared Data & Performance Measurement 22
1.5.3. Engaging Consumers 22
1.5.4. Improving Healthcare Delivery 23
1.5.5. Aligning Finance & Insurance 23
1.5.6. Outcomes 24
1.5.7. Summary 26
1.6. QUEBEC 27
1.6.1. Stakeholder Collaboration: shared Vision & Leadership 28
1.6.2. Shared Data & Performance Measurement 30
1.6.3. Engaging Consumers : some illustrations 30
1.6.4. Improving Healthcare Delivery 31
1.6.5. Aligning Finance & Insurance 32
1.6.6. Outcomes 33

1.6.7. Summary ... 35
1.7. PENNSYLVANIA ... 36
1.7.1. Stakeholder Collaboration: Shared Vision & Leadership ... 37
1.7.2. Shared Data & Performance Measurement ... 38
1.7.3. Engaging Consumers ... 39
1.7.4. Improving Healthcare Delivery ... 39
1.7.5. Aligning Finance & Insurance ... 40
1.7.6. Outcomes ... 40
1.7.7. Summary ... 42
1.8. FUTURE ACTIONS IN THE 4 COUNTRIES ... 43
1.8.1. Future Actions in the Netherlands ... 43
1.8.2. Future Actions in Denmark ... 43
1.8.3. Future Actions in Quebec ... 44
1.8.4. Future actions in Pennsylvania ... 44
1.9. DISCUSSION ... 45
1.9.1. Implementation of the elements of the CCM ... 45
1.9.2. Outcomes of redesigning chronic care management ... 47
1.9.3. Barriers in redesigning chronic care management ... 47
1.9.4. Lessons learned ... 48
2. OVERVIEW OF KCE REPORTS ... 54
2.1. QUALITY AND ORGANIZATION OF TYPE 2 DIABETES ... 54
2.2. CLINICAL QUALITY INDICATORS ... 55
2.3. MEDICATION USE IN NURSING HOMES ... 55
2.4. CHRONIC LOW BACK PAIN ... 56
2.5. PERSONAL CONTRIBUTION FOR HEALTH CARE IN BELGIUM. IMPACT OF SUPPLEMENTS ... 56
2.6. CHRONIC CARE OF PERSONS WITH ACQUIRED BRAIN INJURY BETWEEN THE AGE OF 18 AND 65 YEARS ... 57
2.7. ORGANIZATION AND FINANCING OF MUSCULOSKELETAL AND NEUROLOGICAL REHABILITATION IN BELGIUM ... 58

2.8. PHYSICIAN WORKFORCE SUPPLY IN BELGIUM: CURRENT SITUATION AND CHALLENGES . 59
2.9. FINANCING OF THE CARE PROGRAM FOR GERIATRIC PATIENTS IN CLASSIC HOSPITAL.... 60
2.10. QUALITY DEVELOPMENT IN GENERAL PRACTICE IN BELGIUM: STATUS QUO OR QUO VADIS?..... 61
2.11. EFFECTS OF THE MAXIMUM BILLING SYSTEM ON HEALTH CARE CONSUMPTION AND FINANCIAL ACCESS TO HEALTH CARE..... 62
2.12. QUALITY INSURANCE FOR RECTAL CANCER-PHASE 2:DEVELOPMENT AND TESTING OF A SET OF QUALITY INDICATORS..... 62
2.13. LONG STAY PATIENTS IN PSYCHIATRY T-BEDS 63
2.14. COMPARISON OF THE COST AND THE QUALITY OF TWO FINANCING SYSTEMS OF PRIMARY HEALTH CARE IN BELGIUM 64
2.15. DIFFERENTIATED PRACTICE IN NURSING: OPPORTUNITIES AND LIMITS 64
2.16. CONSUMPTION OF PHYSIOTHERAPY AND PHYSICAL AND REHABILITATION MEDICINE IN BELGIUM 65
2.17. FATIGUE SYNDROME: DIAGNOSIS, TREATMENT AND ORGANIZATION OF CARE..... 65
2.18. MAKING GENERAL PRACTICE ATTRACTIVE: ENCOURAGING GP ATTRACTION AND RETENTION 66
2.19. FINANCING OF THE GERIATRIC DAY HOSPITAL..... 67
2.20. PHARMACEUTICAL AND NON-PHARMACEUTICAL INTERVENTIONS FOR ALZHEIMER'S DISEASE, A RAPID ASSESSMENT 67
2.21. ORGANIZATION OF PALLIATIVE CARE IN BELGIUM 68
2.22. USE OF POINT-OF-CARE DEVICES IN PATIENTS WITH ORAL ANTICOAGULATION: A HEALTH TECHNOLOGY ASSESSMENT 69
2.23. ADVANTAGES, DISADVANTAGES AND FEASIBILITY OF THE INTRODUCTION OF 'PAY FOR QUALITY' PROGRAMMES IN BELGIUM 70
2.24. FINANCING OF HOME NURSING IN BELGIUM 70
2.25. FINANCING OF HOME NURSING IN BELGIUM 72
2.26. THE REFERENCE PRICE SYSTEM AND SOCIOECONOMIC DIFFERENCES IN THE USE OF LOW COST DRUGS 73
2.27. A FIRST STEP TOWARDS MEASURING THE PERFORMANCE OF THE BELGIAN HEALTHCARE SYSTEM..... 73
2.28. SEAMLESS CARE FOR MEDICATIONS 74

2.29. EMERGENCY PSYCHIATRIC CARE FOR CHILDREN AND ADOLESCENTS 75
2.30. THE BELGIAN HEALTH SYSTEM IN 2010 75
2.31. CARDIAC REHABILITATION: CLINICAL EFFECTIVENESS AND UTILIZATION IN BELGIUM 76
2.32. ORGANIZATION OF MENTAL HEALTH CARE FOR PERSONS WITH SEVERE AND PERSISTENT MENTAL ILLNESS. WHAT IS THE EVIDENCE? 76
2.33. MENTAL HEALTH CARE REFORMS: EVALUATION RESEARCH OF "THERAPEUTIC PROJECTS" 77
2.34. QUALITY INDICATORS IN ONCOLOGY: TESTIS CANCER 78
2.35. QUALITY INDICATORS IN ONCOLOGY: BREAST CANCER 78
2.36. PHARMACOLOGICAL PREVENTION OF FRAGILITY FRACTURES IN BELGIUM 79
2.37. DEMENTIA: WHICH NON-PHARMACOLOGICAL INTERVENTIONS 80
2.38. DIAGNOSIS AND TREATMENT OF VARICOSE VEINS IN THE LEGS 80
2.39. ENTITLEMENT TO A HOSPITAL INSURANCE FOR PERSONS WITH A CHRONIC ILLNESS OR HANDICAP 81
2.40. RESIDENTIAL CARE FOR OLDER PERSONS IN BELGIUM: PROJECTIONS 2011-2025 81
2.41. ORGANIZATION OF CHILD AND ADOLESCENT MENTAL HEALTH CARE: STUDY OF LITERATURE AND AN INTERNATIONAL OVERVIEW 82
2.42. AFTER-HOURS PRIMARY CARE: WHICH SOLUTIONS? 82
2.43. THE ORGANIZATION OF MENTAL HEALTH SERVICES FOR CHILDREN AND ADOLESCENTS IN BELGIUM: DEVELOPMENT OF A POLICY SCENARIO 83
3. SYSTEMATIC REVIEW: METHODOLOGY, RESULTS BY DISEASE, QUALITY APPRAISAL AND TABLES OF EVIDENCE 85
3.1. LIST OF ABBREVIATIONS FOR THE SYSTEMATIC REVIEW 85
3.2. METHODS 86
3.2.1. Search strategies 86
3.2.2. Assessing methodological quality and risk of bias 86
3.2.3. Data extraction 87
3.3. SEARCH RESULTS 87
3.3.1. Systematic reviews 87
3.3.2. Randomised controlled trials 89

3.4. RESULTS : EFFECTIVENESS OF PATIENT EMPOWERMENT : ANALYSIS BY DISEASE 91
3.4.1. Interventions for chronic disease in general 91
3.4.2. Asthma 92
3.4.3. COPD 94
3.4.4. Diabetes 96
3.4.5. Heart failure 98
3.4.6. Hypertension 99
3.4.7. Angina 100
3.4.8. Stroke 100
3.4.9. Irritable bowel syndrome (IBS) 101
3.4.10. Kidney disease 102
3.4.11. Chronic pain 103
3.4.12. Painful musculoskeletal conditions (including rheumatic diseases and arthritis) 103
3.4.13. Fibromyalgia 104
3.4.14. Multiple sclerosis 105
3.4.15. Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) 106
3.4.16. Chronic neurological conditions - fatigue 106
3.4.17. Schizophrenia 107
3.5. SEARCH STRATEGY, QUALITY APPRAISAL AND DATA EVIDENCE TABLES 108
3.5.1. Quality appraisal for included systematic reviews 108
3.5.2. Data extraction table of included systematic reviews 113
3.5.3. Quality appraisal for included RCTs 144
3.5.4. Data extraction table of included RCTs 151
3.5.5. Search Strategy 175
4. ORGANISATION OF CHRONIC CARE IN BELGIUM: SWOT ANALYSIS AND COORDINATION STRUCTURES/PROGRAMMES 183
4.1. STAKEHOLDERS CONSULTED DURING BRAINSTORMING SESSIONS (MICRO AND MESO LEVEL) 183
4.2. STAKEHOLDERS CONSULTED DURING STAKEHOLDERS GROUP MEETINGS (MACRO LEVEL) 186

4.3. OVERVIEW OF THE DATA COLLECTED DURING THE BRAINSTORMING SESSIONS AND DE STAKEHOLDERS GROUP MEETINGS 188
4.3.1. Reform proposal 1: A polyvalent multidisciplinary primary care team is at the center of a system caring for people with chronic care needs 191
4.3.2. Reform proposal 2: A case manager for all patients with chronic condition(s) 194
4.3.3. Reform proposal 3: mid-level scale initiatives to improve seamless care between hospital and home care are needed 196
4.3.4. Reform proposal 4: the right environment according to the needs of people with chronic health problem 197
4.3.5. Reform proposal 5: creation of new functions at primary care level 202
4.3.6. Reform proposal 6: Specialized hospital functions 203
4.3.7. Reform proposal 7: need to clarify the role of patient associations and to offer respite care possibilities for informal caregivers. 206
4.3.8. Reform proposal 8: moving froma individual provider and service-based to a team and patient-based payment system 209
4.3.9. Reform proposal 9: shared medical file across lines and across disciplines 213
4.3.10. Reform proposal 10: aggregated patient data at health facility and local system levels for quality management purpose 213
4.4. THE ADAPTED CHRONIC CARE MODEL AND THE RELATION WITH THE THEMES FROM THE BRAINSTORMING SESSIONS 216
4.5. BELGIAN COORDINATION STRUCTURES AND PROGRAMMES 217
4.5.1. Belgian coordination structures 217
4.5.2. Belgian coordination programmes financed by the NIHDI 219

LIST OF FIGURES

Figure 1 – Chronic care model 7
Figure 2 – Results of searches and selection of systematic reviews 88
Figure 3: Results of searches and selection of RCTs 90

1. HIGHLIGHTS FROM FOUR COUNTRIES – THE CHRONIC CARE MODEL IN USE

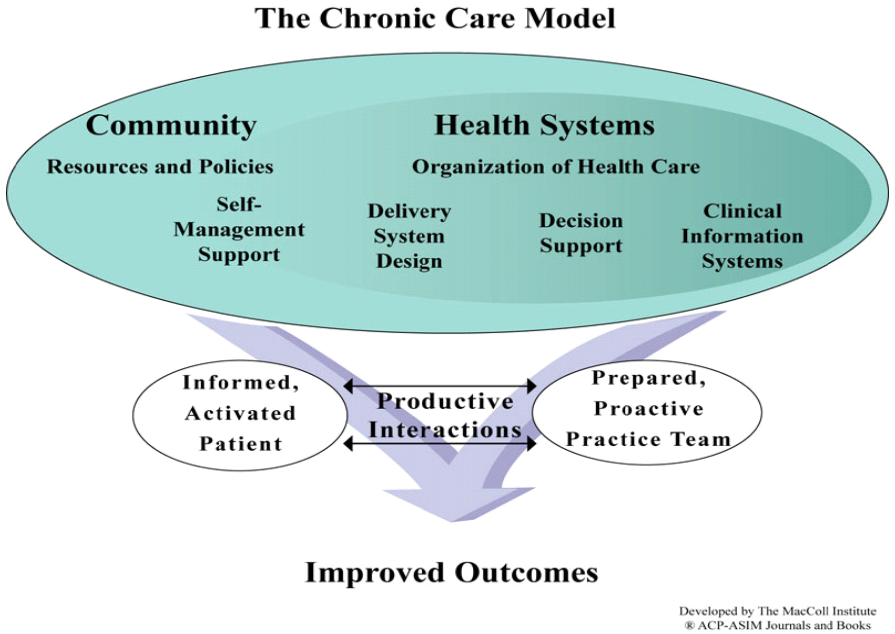
1.1. Objective and research questions

The *objective* of this part is to describe the policies for improving the quality of chronic care in the Netherlands, Denmark, the United States (Pennsylvania) and Canada (Quebec) and to compare the policies in terms of the implementation of elements of the Chronic Care Model (CCM) (Figure 2). The objective is to understand the ways in which four frontrunner countries act upon the challenge of redesigning healthcare systems to meet the needs of people with chronic conditions.

This part addresses the following two research questions:

- What policies for improving the quality of care for people with non communicable chronic diseases are being implemented in the Netherlands, Denmark, Pennsylvania and Quebec?
- To what extent do these policies aim to and/or have resulted in the implementation of elements of the CCM and with which impact on outcomes?

Figure 1 – Chronic care model



1.2. Methods

This cross-sectional research is a scoping study based on a combination of methods and sources including literature (Medline), government documents and personal communications about disease management programs (DMPs).

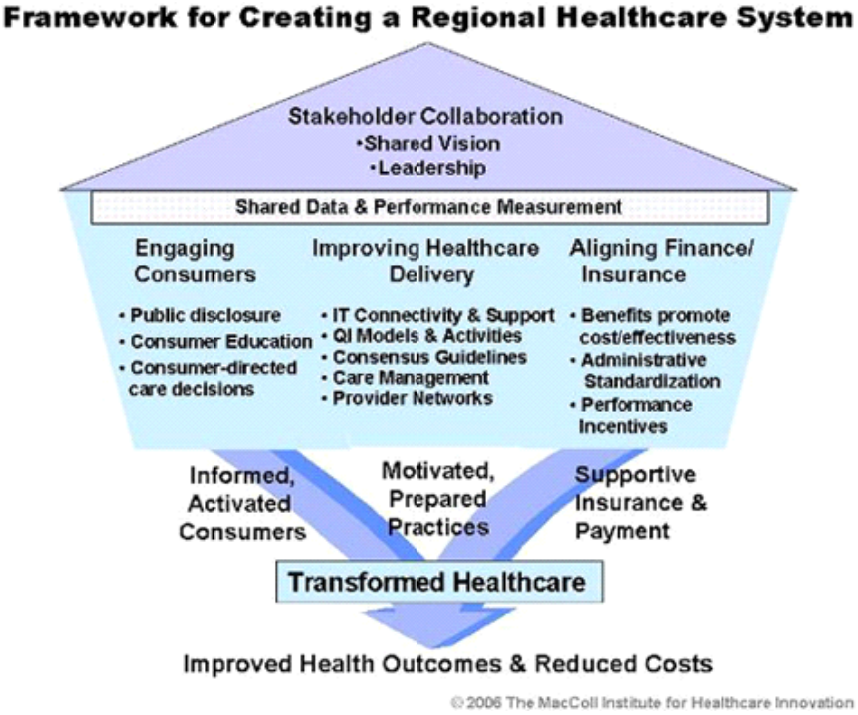
First Dr. Ed Wagner (MacColl Institute, Seattle) and Dr. Ellen Nolte (RAND Cambridge) were consulted for the selection of the policies or countries to compare, Criteria for selecting large scale changes were: the presence of a country of state wide policy plan, the allocation of financial resources for executing the policy plan, and the presence of reports regarding the progress in redesigning chronic care. Both recommended to include Denmark, The Netherlands, the province of Quebec in Canada, and the state of Pennsylvania in the United States as being good examples of

countries or states where large scale changes take place regarding the care for people with chronic conditions.

Table 1 shows the used terminology regarding the search for papers by country. Per country three experts were consulted for the literature regarding policies in their country. Their background was policy, medicine, or scientific research.

This work mainly relies on the framework of creating a regional health care system [1,2]. This framework is used to describe the policies for improving the quality of care for people with non communicable chronic diseases as implemented in the Netherlands, Denmark, the United States (Pennsylvania), and Canada (Quebec) (1st research question). This framework describes that improvement strategies regarding chronic care will need to systematically coordinate actions across multiple strategy areas: data-sharing for performance measurement, engaging consumers, improving health care delivery, and aligning benefits and finances (Figure 2). Experts were asked to provide feedback on the description of the country they reside.

Figure 2 – Framework for creating a regional healthcare system



In order to assess to what extent these policies aim to and/or have resulted in the implementation of elements of the CCM and with which impact on outcomes (2nd research question), the CCM is used (Figure 1). For this, the existing usage of the elements of the CCM, as described in Assessment of Chronic Illness Care Version 3.5, are applied [1].

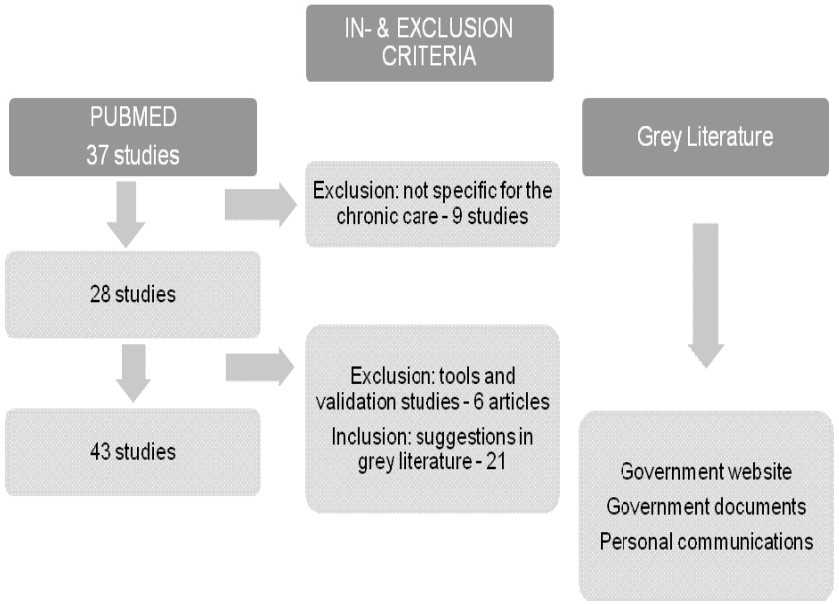
Table 1 – Overall term chronic care: search Outcomes by country*

	Synonyms for the approach	Specified by country
Terms that (or synonyms of which) were used as subject headings and/or text words	Chronic care model	Netherlands
	Disease management	Denmark
	Integrated care	Pennsylvania (USA)
	Programmatic approach	Quebec (Canada)
	Organization Chronic care management	
"Chronic care" AND ("Chronic care model" OR "Disease management" OR "Programmatic approach" OR "integrated care" OR organization OR "Chronic care management") AND country		

**Only studies from 2008 until now are included*
Only Dutch and English written articles and papers are included

Figure 3 shows which search strategies have been used to receive an overview regarding research studies and grey literature. The strategy for each country have been added (available upon request). Within the grey literature the Governmental websites have been used as basis. These websites led to other papers among disease management initiatives.

Figure 3 – Overview of strategies for literature search



1.3. Main characteristics of the countries

Background information regarding the four countries are first summarized: number of residents; percentage gross national product (GNP) spent on healthcare; type of healthcare system; basic insurance scheme and supplementary insurance (see table 2).

Table 2 – Background data of countries and their healthcare systems

Characteristic	The Netherlands [3-6]	Denmark [7-9]	Pennsylvania (USA) [10]	Quebec (Canada) [11, 12]
Number of residents (year)	16.7 million (2011)	5.5 million (2011)	12.6 million (2009)	8,0 million (2010)
% GNP for health care (year)	9% (2008), around 14% (2010)	9% (2007)	15% in USA (2008)	10% in Canada (2008)
Type of health care system	National health insurance system	National health insurance system, public, financed by local and national taxes	Medical care- health insurance; - directly pay for the medical care. Private is dominant over public. Health care facilities mainly owned and operated by private sector.	Universal coverage for medically necessary health care services provided on the basis of need.
Basic Insurance scheme	Mandatory basic health insurance	Role government is mainly regulate, supervise finance	Different Types of Insurance coverage: Service plans, HMO: Health Maintenanc Organizat° Preferred Provider Organizat° (PPO). Medicare2 - Federal program that covers individuals ≥ 65y, and some disabled individuals. Medicaid3 - Program for the low-income and disabled.	Medicare – funded health care system, interlocking set of the ten provinces, and the three territories in health insurance plans. Medicare – designed to ensure that all residents have reasonable access to medically necessary hospital and physician services, on a prepaid basis
Supplementary	Voluntary supplement	Reimbursement level and	Health centres:	System provides

Characteristic	The Netherlands [3-6]	Denmark [7-9]	Pennsylvania (USA) [10]	Quebec (Canada) [11, 12]
insurance scheme	ary insurance packages (additional costs)	salaries are agreed through negotiations between Danish Regions and different professional associations	primary medical and dental care for all. Services on a sliding fee scale – based on ability to pay.	access to universal, comprehensive coverage for medically necessary hospital and physician services

1.4. The Netherlands

The findings for the Netherlands regarding the policies for improving the quality of care for people with non communicable chronic diseases are summarised in Figure 4 according to the Framework for creating a regional healthcare system. The findings for each of the elements of the framework are further described in more detail.

Figure 4 – Framework for creating a Regional Healthcare System in the Netherlands

Stakeholder Collaboration: shared vision and leadership		
	Ministry of Health Stakeholders Patients Care Providers Health Insurance companies	
Shared Data & Performance Measurement		
	Visible Care Information systems: KIS/HIS) Quality of integrated care Vital health	
Engaging Consumers	**Improving Healthcare Delivery**	**Aligning Finance & Insurance**
Self-management care Individual treatment plan DIEP	Standards for care Care groups Disease management chronic diseases At one level	Bundled payment of chronic care Feedback towards health insurance companies Financial incentives Integrated diabetes care
Outcomes		
	Programmatic approach Self-management/care KIS/HIS Standards of care Care groups Bundled payment of chronic care Health insurers Financial incentives	
Future Actions		
	DISMEVAL – validation of chronic care evaluations Evaluating the implementation of disease management harmonize pricing mechanisms with bundled payment	

1.4.1. Stakeholder Collaboration: shared Vision & Leadership

1.4.1.1. Ministry of health: programmatic approach for integrated care

Given the lack of coordination in chronic care and the expected increase in the number of people in need for chronic care [13], the Dutch government started to redesign the healthcare delivery system in 2008 to improve the quality of care for chronic diseases and to increase the integration of chronic care delivery. This was done by introducing a programmatic approach for chronic care, which aims to offer an integrated care package for various phases of treatment of patients with a chronic disease. This approach is a program of prevention, self-management and evidence based care, which are components derived from the CCM. Within the programmatic approach, the patient is regarded as the centre for organizing care. Medical practitioners, nurses, dieticians and other care providers work together as one team. The team adjusts the supply and demand of care for every patient. Essential for the functioning of the team is the individual health plan for the patient. Next to this, the plan enables the patient to know which care to expect and to get more involved in his/her treatment through self-management [14].

In 2008 two instruments were introduced to tackle existing barriers and to generate a culture of change among stakeholders. These two instruments are quality measures and bundled payment of integrated care [15]. Furthermore, self-management and a strong coordination between prevention and cure are regarded as essential for patient centered, integrated care [16]. Next, improvements in clinical information systems and decision support are in need for improvement 5 in order to deliver sustainable chronic care.

The Dutch Ministry of Health expects the programmatic approach to improve the level of communication between healthcare providers involved in the delivery of chronic care. This should result in a decrease in the number of complications, hospital visits, improvement in the quality of life of patients and a less expensive health care system. Corresponding to this adaptations of several health care legislations need to occur [17]. To meet the collaborating level the programmatic approach describes a change in the delivery system needed to occur. Therefore care groups, standards of care and practice supporters in general medical practices have been started. The introduction of policies to implement the CCM in the Netherlands is oriented towards single disease with diabetes attracting most attention. Also, the care for people with Chronic Obstructive Pulmonary Disease (COPD) and vascular risk are in a reorganization phase. The care within the programmatic approach of other chronic diseases, such as dementia, is awaiting to get in progress.

1.4.1.2. Local Government

A crucial role is accredited to the local government to reinforce the collaboration between cure and prevention. Prevention needs to be a more common and part of regulated health care. The local government is stimulated to introduce a more integrated health care policy; i.e. a healthier environment [18]. The national government would like to see an improved collaboration and integration between the Municipal Health Services, primary care and occupational health services. The expectation is that people will become more consciousness what kind of impact behavior change has on improving their health, on prevention of workplace absenteeism and on occupational reintegration. According to the national government health is the responsibility of individual citizens [18]. Further development of a well organized and integrated primary care setting is seen as a necessity for chronic care management [18]. Again the local government is regarded responsible for this cohesion in coordination and continuity of care.

1.4.1.3. Examples

By means of organizing national conferences the Dutch Ministry of Health has been supporting the debate on chronic care redesign. Also, it has financially stimulated various experimental programs, directed by The Netherlands Organization for Health Research and Development (ZonMw), in order to gain experience and information on how to best improve the organization of chronic acre delivery. The program disease management chronic care is a collaboration of the Ministry of Health, ICTRegie, PICASSO COPD (an initiative of Pfizer, Boehringer Ingelheim and research institute Caphri) and the section health foundations which started since 2010. In a later stage the projects New Instruments in health care (in

Dutch: Nieuwe Instrumenten in de Gezondheidszorg (NIG)) have been added. The project focuses on innovative medical technology devices within the Netherlands and is aiming to show results from a different perspective [19].

The national government also supports the evolvement of 'standards of care', protocols for the organization and collaboration in primary care, including quality measures. Examples are the development of the standard of integrated diabetes care by the National Diabetes Federation, the standard of vascular risk management by the platform Vital Veins (in Dutch: Vitale Vaten) [20, 21] and the development of the standard for integrated care for people with COPD [22, 23].

1.4.2. Shared Data & Performance Measurement

1.4.2.1. Visible Care

The programmatic approach is aiming at more transparency within the Dutch healthcare system. Therefore, Visible Care (in Dutch: Zichtbare Zorg), a program of the Healthcare Inspectorate, acting upon instructions from the Ministry of Health, has developed so called minimum datasets for various diseases. These datasets consist of process or outcome indicators, representing a level of quality of care a healthcare organization is expected to achieve. Organizations have to enter their data into these datasets. This provisional minimum dataset [24] is part of the dossiers of chronic care of visible care. In other words, the aim is to use the dataset to improve information exchange between organizations and health insurers as well as between care providers themselves [14]. The way these datasets get developed and implemented is subject of debate.

1.4.2.2. Information systems: KIS/HIS

Together with the development of care groups, described in subsection 'improving healthcare delivery', information systems are being developed and implemented to support the integrated care system by means of producing relevant data to take informed decisions. A distinction can be made between integrated care information systems (KIS) and general practitioner information systems (HIS) [25]. The latter are stand alone systems, while the integrated care information system does allow (partial) exchange of data among various healthcare providers and sometimes also patients.

1.4.2.3. Quality of integrated care

The program Integrated diabetes care (in Dutch: Ketenzorg Diabetes) has been launched by Netherlands Organisation for Health Research and Development, acting upon the instructions of the Ministry of Health to see how this will influence the multi disciplinary collaboration [16]. Within this program 15 projects have started to experiment with integrated care in different areas of the Netherlands to work with the bundled payment diabetes care. The health insurers make a deal with the care group. The care group is a collaboration of general practitioners, practice supporters, nurses specified in diabetic and other health care providers as is explained later on. This care group is responsible for good patient care.

Until 2012 the bundled payment is experimental [14]. The National Institute for Public Health and the Environment (RIVM) has been invited to evaluate working with the bundled payment diabetes care. This evaluation consists of an effect evaluation, evaluation of costs of diabetes care and a process evaluation [26]. In 2012 a National Evaluation Committee will advise the Minister regarding the opportunities and/or weaknesses of this payment system for the future.

1.4.2.4. Examples

VitalHealth is the first KIS supplier in the Netherlands. This system is currently one of the few communication standards which make it possible to exchange information between care providers involved in the delivery of integrated care. The Netherlands is lacking a national electronic patient dossier (EPD). During the launch of the system there has been a lot of resistance. On one hand there were problems with digitalizing the information, on the other hand there was ethical resistance [18].

1.4.3. Engaging Consumers

1.4.3.1. Self-management/Care

For the Dutch Ministry of Health self-management is a key word in the programmatic approach. People with a chronic disease are able to have a great impact on their own health. By having the ability to influence their own life, it is believed that chronically ill patients are able to fit their illness into their life. Self-management stimulates the chronic ill patient to be active, to search for solutions and to work together with care providers. In other words the patient and the care providers will become partners. In addition, to be able support self-management in patient, care providers need to master different competencies to become a partner for patients. Therefore, professionals need additional education to be able to take on this role [18].

1.4.3.2. Individual treatment plan

As part of the programmatic approach, the patient will have one central contact within the care system in order to minimize the level of fragmentation for patients. The idea behind this plan is that patient and team of care providers together define an individual treatment plan, which consists of the care the patient needs to receive in combination with the belonging care provider. The treatment plan should fit to the patient's personal needs and wishes and should consist of measurable targets [14].

1.4.3.3. Examples

DIEP

One of the best known projects focusing on self-management in the Netherlands is the diabetes interactive education program (DIEP). This is a self-management program which is used as a supportive method of self-management, to educate people with type 2 diabetes and their care providers [27,28]. Also the National Diabetic Action program (2009-2013) is aiming at strengthening the role of the patient through education, at increasing the quality of self-management education and training on instructions of the Ministry of health and the National Diabetes Federation (NDF).

Another example is the self-management program of the Dutch Patient Consumer Federation (NPCF), which is launched in 2009 and with the patient organizations and care professionals both as target group. The implementation of the program is done by the Quality Institute for Health Care (CBO). The aim of the program is to enhance the quality of life by embedding the chronic disease in a patient's life. To reach this aim web-based tools are being developed for patients and supportive for professionals. [18].

1.4.4. Improving Healthcare Delivery

The programmatic approach is expected to stimulate collaboration between care providers and to enable discussions about the best treatment protocol for patients. One care provider of the team serves as contact person for a patient. This person coordinates the individual care of the patient and is often being performed by the general practitioner or practice supporter [14]. This requires care providers to define their tasks and responsibilities in order to be able to work as a team.

Further, in order to assess and further improve the quality of care for care providers, the organizational strength of primary care needs to be increased to enable care providers to act pro-actively and to actually manage the population of people with chronic diseases.

It is expected that through effectively implementing disease management, the growth of the number of people with chronic diseases will reduce, complications and co-morbidity will be prevented or postponed, quality of life will be improved, and the patient is able to manage its own health [14].

1.4.4.1. Standards of care

In 2009 the Health Minister announced to the Parliament that bundled payment would be introduced on a permanent basis for several chronic diseases as of 1 January 2010. Standards of care for the disease in question are crucial to introduce bundled payment, a standpoint shared by the Dutch Healthcare Authority (NZa, 2009b). ZonMw has started the coordinating platform Standards of care, acting upon instructions of the Ministry of Health [26]. Care standards are the base for the programmatic approach and have as main aim to improve the quality of care for people with chronic diseases [18]. The measures are based on guidelines and

consensus and describe to which requirements care for a specific disease has to adhere, seen from the perspective of the patient [23]. The Standards of care include three main parts: prevention and care for a certain chronic disease, the organization of prevention and care, and the relevant quality indicators. A general model for care standards has been developed, which provides for every chronic disease a framework, including a general and a disease-specific part. Furthermore, it describes which care available is for a patient, which role a patient has in its treatment process and what kind of support a patient can expect. In addition, the care standard could give ideas about organizing and structuring care [18, 23].

Every Standard of care consists of a part for the patient and a part for care providers. These standards are actualized regularly as wishes and expectations of people with a chronic illness change constantly. Furthermore, these Standards of care are the base for the bundled payment of integrated care as mentioned in the next paragraph, financial incentives. These Standards of care do not exist for all chronic diseases yet, although developments in practice settings are proceeding at a rapid pace. Furthermore multi morbidity, which is often seen in patients with chronic diseases, pleads for a integrated approach of care standards [23].

Nowadays the Standards of care are implemented for diabetes, part of the diabetes foundation of the Netherlands[a], vascular risk management, platform vital veins[b] and COPD, part of the Asthma foundation of the Netherlands[c].

1.4.4.2. Care groups

In order to deliver high quality chronic care, care providers will need to unite into so called care groups. These care groups consist mainly of primary care providers in a particular region who contract chronic care with the care insurers by means of a bundled payment arrangement. This means that a process is negotiated for the delivery of chronic care for patients with diabetes, COPD or vascular risk.

1.4.4.3. Examples

Disease management chronic diseases

In 2008, the national government assigned ZonMw to experiment with disease management initiatives in the Netherlands. The care groups are guided by Vilans as part of the program Disease management chronic diseases of ZonMw until April 2012. More than twenty care groups do participate. This project is aiming to bring together expertise within different organizations and with this how care of chronic ill patients could be improved [29]. Part of this scientific experiment is the implementation of one or more components of the chronic care model. Results from this experiment are expected to be presented in 2012.

At one level

Another example is the program 'At one level' (in Dutch: Op een lijn). This approach started by ZonMw on instructions of the Ministry of health in 2009 until 2013 [30]. The program aims to support organizational consolidation through innovation and entrepreneurship of the primary care in line with the programmatic approach as the Ministry of Health has stated. This should result in improved synchronization between health conditions and care at home and the care demand of the locals. Specific attention is on six chronic diseases and care of the elderly.

1.4.5. Aligning Finance & Insurance

1.4.5.1. Bundled payment of chronic care

The Dutch government has started with a new payment system in 2008 [26]. This implies that a contractor (i.e. care group) makes a stable price deal with an insurance company. The Standard of care is used as base for the complete treatment of a patient population for a certain disease. In this way the bundled payment stimulates the care providers to work together instead of everyone having different financial incentives. In 2010 the bundled payment regime for care groups was implemented nationally.

[a] http://www.dvn.nl/over-dvn/organisatie/producten/diabetes-zorgwijzer

[b] http://www.vitalevaten.nl/home.html

[c] http://www.astmafonds.nl/samen-de-zorg-verbeteren/zorgstandaard-copd

1.4.5.2. Feedback towards Health Insurance companies

Based on medical guidelines and standards, the Healthcare Inspectorate (IGZ) has developed indicators to assess health care quality, which resembles the Quality and Outcomes Framework of the United Kingdom It includes multidisciplinary evidence based guidelines, process protocols and performance indicators. As the empowerment of patients plays a crucial role in chronic care management they are involved in the development of quality indicators [5].

1.4.5.3. Financial incentives

To stimulate the development of necessary structures and processes for the delivery of chronic care, specific financial incentives (so called resources for practice innovation) are developed. Primary care providers, such as general practitioners, are able to apply for these when they plan to undertake innovative interventions for chronic patients [5]. Through these incentives the care providers are for example able to employee a practice supporter in general practices, to lower the work pressure of the general practitioner and to make the primary care more structured.

1.4.5.4. Examples

Integrated diabetes care

The program Integrated diabetes care, initiated by ZonMw, aims to evaluate the introduction of bundled payments for integrated diabetes care. This experiment provide a financial incentive to a restricted number of care groups in order to contract integrated diabetes care by means of a bundled payment [26]. This pilot is being evaluated by the National Institute for Public Health and the Environment (RIVM) (see 'outcomes'). The introduction of bundled payments for chronic care in the Netherlands is being evaluated by a National Committee, with results becoming available in 2012. Furthermore, in the drafted law 'client and quality of care' seems to have as aim to stimulate the empowerment of the individual patient.

1.4.6. Outcomes

The chronic care model is increasingly applied in the Netherlands as roadmap to improve the quality of chronic care and its delivery in a more integrated manner. The Ministry of Health has a clear view how to get the different approaches into place and therefore finances several initiatives (see above). Given that the development and implementation of integrated care is ongoing, only preliminary results are known at the moment.

1.4.6.1. Programmatic approach

From the DISMEVAL study it was found that diabetes care management programs consist of a selection of components which make up the CCM or integrated care approach [31]. Consequently, 'full' integrated care in the Netherlands does not seem to be offered to patients yet.

Improved outcomes

Drewes et al. studied if a higher number of components of chronic care management are associated with improved patient outcomes. They concluded that the presence of multiple components of the CCM is associated with improved outcomes [20]. In addition, according to a study of Lemmens et al. the number of components of the chronic care model used is not the only influencing variable. Also how the components are implemented and integrated impacts the effect [22]. Another study of Lemmens et al. showed when better adjustments were made between the implemented intervention and the bottlenecks, more positive changes outcomes occurred [32].

The Ministry of Health regards the Diabetes care project in Zwolle as best practice. This project is facilitated by the programmatic approach and consists of three main parts, a structural multi- disciplinary approach, a digital care program to be followed by the patient and an integrated information and communication system.[d] The programmatic approach resulted in effective and efficient care on different levels [16].

[d] www.diabeteszorgbeter.nl

Barriers for implementation

The Dutch national healthcare system as such seems to be a barrier to be able to bring elements of the model into practice as various incentives are lacking. Also the fragmentary nature of primary care and the lack of collaboration between care providers in different areas of care and cure may have a negative impact. Third, the tight labor market might influence the uptake of the CCM in daily practice [18].

Next to barriers there are also a few components of the chronic care model which have not brought in practice yet, such as ICT, coordination of care and proactive patient specific care. Furthermore the government is currently seeing the general medical practices as centre, but also hospitals could take over the role to coordinate total care [18].

1.4.6.2. Self-management/care

DIEP is a project for diabetes care and aims to empower patients through self-management. The results of DIEP show that patients are positive about the project as it increases self-management and their knowledge of diabetes. However, the main barrier of the project seems to be lack of time of care providers to make use of the program as part of their activities 27, 28.

Blanson and Henkemans studied the value of self-management. On the short run self-management has the potential to reduce care supply and remain quality of care. On the long term, self-management could be labor-saving for professionals in care .[33].

1.4.6.3. KIS/HIS

As a result of the political resistance against a national EPD system, multiple regional systems have become in use which make it more difficult to exchange information between regions and care providers. Another barrier to introduce ICT systems in primary care is the willingness of care providers to use advanced possibilities of ICT [18].

1.4.6.4. Standards of care

The way the care system is organized is a barrier to integrate Standards of care as mentioned before 6. As the Ministry of Health acknowledges the importance of the bundled payment system which should correspond with the Standards of care, the Standards of Care Coordination Platform at the Netherlands Organisation for Health Research and Development (ZonMw) was launched [19,26]. The impact of this platform is unknown yet. GPs considered the early inclusion of patients at risk appropriate to initiate interventions aimed at diminishing risk factors for diabetes [18].

The Standard of care for diabetes enlists preventive intervention as part of the bundled payment arrangement for diabetes. However, this seems to be in contradiction with one of the mandatory rules, which states that treatment cannot begin until a formal diagnosis of diabetes has been made. Such a dividing line is seriously at odds with the programmatic approach supported by the Ministry, which envisages a complete continuum of care ranging from early detection, indicated and treatment-related prevention, self-management towards treatment and care [34].

1.4.6.5. Care groups

General practitioners are playing a dominant role in care groups. However, they should not be the single players within this group, as multidisciplinary care groups, representing all ‘core disciplines’, are necessary to perform multidisciplinary care [17].

1.4.6.6. Bundled payment of chronic care

The Dutch mandatory health insurance package contains a compulsory policy excess. All GP care in the bundled payment arrangements is not subject to the excess, whereas all other care is. As it is not clearly defined which services belong to GP care and which do not, this results in problems [18]. Furthermore, looking at the integrated character of the bundled payment it seems to be contradicting to make this distinction. These also give problems at the payment side. As a result the Minister decided in 2010 to keep the bundled care packages outside the compulsory excess. Following from this decision, as not all bundled payment contracts include the same components and this is not yet synchronized, inequities rise among diabetes patients in the Netherlands[18].

Moreover, the evaluation report by the National Institute for Public Health and the Environment (RIVM) shows it is unknown if savings on macro costs of health care through bundled payment schemes will occur. The targets the Minister of Health has set are even unlikely to achieved and could possible even rise [26].

On the other hand, the evaluation report indicated that bundled payment is a possible way to cooperatively deliver care, which might be regarded as a condition for integrated care [26]. However, the improved process indicators and the increased shared responsibility represent the added value of bundled payment [18].

Also, the financial part plays a role here as care needs to be on prevention as well as on cure. The policy and the accompanied finances is covering bundled payment of chronic care within the standards of care, but not the whole standards of care as such. Only a patient who is diagnosed with the chronic disease is covered in this policy, a person with high risks is not [18,26]. Another discussion is the role insurance companies might play in drawing up the standards [26].

1.4.6.7. Health insurers

Bargaining and the market position might be a risk on the market integrity between individual health care providers and care groups. The health care and service providers improved their record-keeping habits in the course of the evaluation. The Dutch basic health insurance packages need a reexamination as the current bundled payment schemes may not cover all the preventive treatments in the basic packages [18].

1.4.6.8. Financial incentives

The Dutch government has several financial incentives to start integration into the chronic care delivery system. As these financial incentives are segmented and the stability of these incentives are not ensured in 2010 these incentives have been replaced by the new integrated payment system [15]. The effect of this replaced payment system is not yet evaluated.

1.4.7. Summary

In 2008 the Dutch Ministry of Health revealed a new vision on chronic care in terms of the programmatic approach for chronic care i.e. an integrated package of various phases (prevention, self-management, evidence based cure and care) of a continuum of care for patient with a chronic disease. The programmatic approach is derived from the Chronic Care Model;

- To implement the programmatic approach two instruments were introduced on a national level by the Ministry of Health: quality measures and bundled payments of integrated care for diabetes, COPD and vascular risk management. Local initiatives are stimulated against the vision of redesigning chronic care within local neighborhoods including an important role for primary care;
- First attempts are made to collect data in a standardized way in order to measure performance. Notwithstanding the development of national care standards, performance measurements only takes place regarding diabetes management on an experimental base on local level;
- Also regarding the engagement of patients with a chronic disease, initial attempts are being made: individual treatment plans are promoted as part of national care standards, however only a minority of patients actually have such a plan;
- The role of primary care receives specific attention in order to strengthen its activities regarding the organization of chronic care. This is getting shape by the development of care groups.
- Preliminary results regarding the impact of integrated care for chronically illness show modest improvements in process and outcomes of care. Also, barriers for implementing integrated chronic care are identified (e.g. lack of incentives, lack of collaboration between providers, fragmented primary care) as are components of the Chronic Care Model which are underdeveloped (ICT, coordination of care, proactive patients).

1.5. Denmark

Framework for creating a Regional Healthcare System in Denmark

Figure 5 – Framework for creating a Regional Healthcare System in Denmark

Stakeholder Collaboration; shared vision and leadership

- Ministry
- National Board of Health
- Stakeholders
- Patients
- Care Providers
- Health Insurance companies
- Chronic disease pathway programs
- Health care centre Østerbro
- Implementation and integration of rehabilitation programs

Shared Data & Performance Measurement

- National Indicator Project
- IT support
- KOALA

Engaging Consumers	Improving Healthcare Delivery	Aligning Finance & Insurance
Patient education classes and increased self-management	Shared decision making	Financial incentives among GPs
Guided Self-Determination	E-referrals	Fee for chronic disease management programs in primary care
	Integration of services	Quality improvement incentives through benchmarking of providers

Outcomes

- Stakeholder collaboration
- Independent work GPs
- Integrated effort for people with chronic diseases
- IT
- Engage the patient
- Sharing
- Improving health care delivery
- Shared Decision-Making

Future Actions

- Recommendations National Board of Health
- Investigating wider range of implementation problems and validation

1.5.1. Stakeholder Collaboration

Shared Vision & Leadership

1.5.1.1. National Government

In Denmark the role of the central Government in healthcare is almost exclusively to regulate, supervise and finance care. Denmark has set the aim to develop national disease management with local specifications to be implemented in the existing organization of healthcare. The leadership for this journey has been taken up by the National Board of Health [35]. Distribution tasks are laid down in the Danish Health Act to obtain a stronger central control in the traditionally highly decentralized Danish system. It determines the regional and municipal responsibility in the healthcare area [36]. The delivery of coordinated health services is an explicit aim of this Act as is also seen in different policy documents and reports [36-39].

The regions manage somatic and psychiatric healthcare services in public hospitals and primary health services. This is funded by the national Government and the municipalities. The regions are responsible for the development and implementation of overall strategies for prevention and treatment of chronic conditions, including disease management programs [7,35]. This is also a task for the municipalities together with the establishment of healthcare centres [7]. The Organization of General Practitioners is on several parts supportive of this development. The main stakeholders within this approach are health professionals working in hospitals, general practitioners, and health professionals employed in the municipalities [35].

In 2002 the Ministry of Interior and Health has released the document: Health throughout life – targets and strategies for public health policy of the government of Denmark 2002-2010. The program, as described in this document, specifically focuses on efforts to reduce major preventable diseases and disorders. On top of that, the aim of the program is to improve the quality of life of the population through more systematic efforts in terms of counseling, support, rehabilitation and other patient-oriented measures. In line with the CCM, this program is aiming at providing the sick individual with knowledge and tools to be able to promote his/her own health status and health care and to not further lose functions. It has therefore a special focus on health-related behavior [40]. The focus of the 'Health throughout life'-program is on the following diseases: type 2 diabetes; cancer; heart disease; osteoporosis; musculoskeletal diseases; allergy diseases; psychological diseases; and COPD [40]. As part of the new Government platform 2007 the Danish government launched two new large initiatives to follow up on "Healthy throughout life". Firstly, in January 2008 the government appointed a committee consisting of experts in the field of health promotion and disease prevention program, health economics and representatives from both the public and private sector. Secondly, the government will, on the background of the committee's recommendations, publish a new public health and disease prevention program including clear aims for future efforts [38].

1.5.1.2. Local Government

In 2007 a reorganization of the municipalities took place, which has led to more healthcare tasks for the local government. This resulted in the formation of so called healthcare centres. The focus of these centres is currently on prevention and rehabilitative services for people with a chronic disease. The social services, delivered by municipalities include also chronic diseases [41]. The GPs are functioning as a gate to other healthcare professionals and have been a key feature of the Danish system [41]. It is expected that greater integration between the primary and secondary healthcare sectors will occur, whilst primary healthcare is already integrated with the social services [39].

A system of mandatory regional health care agreements was put in place, replacing the previous health plans, to strengthen the coherence between prevention, treatment and care [7]. In 2005 a report was released by the National Board of Health putting the focus on the improvement of care for people with chronic conditions [7]. In so doing regional experiences have been taken into account, such as the use of the Chronic Disease Self-management support program based on the Chronic Disease Self-Management program (CDSMP) developed at Stanford University in the USA [7,42] The report emphasizes that the individual patient should be able to manage his health condition and maintain a life on his own and receive support to take his own responsibility and to make well-informed choices

[43]. Following the recommendations of the National Board of Health, the focus should be on the organization and provision of health care and the options of strengthened and supported self-management [36]. The program enhances the role of the civil society – the social networks, the workplace, private organizations et cetera – given that lifestyle cannot be changed without regard for the social context in which people live. Simultaneously, all healthcare providers need to obtain or posses relevant competencies. The interaction between patients and healthcare professionals should lead to consistency between efforts to ensure that the health professionals and the patients involved have a uniform, common goal.

1.5.1.3. Examples

Chronic disease pathway programs

The National Board of Health has launched a generic model for chronic disease pathway programs, a framework for disease specific programs, in 2008. This model is inspired by the CCM and includes a description of the entire treatment process, evidence-based recommendations, task responsibility and coordination and communication among all involved stakeholders. As this is a national program, specification at local level needs to occur. This will follow from the implementation process [35, 38]. The National Board of Health expects to take responsibility for the development of national disease programs in collaboration with regional and municipal authorities.

Diabetes mellitus has been selected as pilot for the development of pathway descriptions by the National Board of Health. Diabetes mellitus is targeted by the systematic quality development in general practice, in the National Indicator Project (NIP) and in the Danish Quality Model. As part of the pathway program these initiatives should be connected during implementation in a certain organization [36]. As such coherence of the different aspects of the program will be ensured; the patient and health professional aim at the same objective and the individual program aims at the best achievable results.

Health care centre Østerbro

This centre covers different facilities and therapies to patients with a range of chronic conditions. The city's Health and Social Administration, municipal hospital and GP's work together to create the local chronic care project 'Integrated effort for people with chronic diseases' (SIKS). Within this project the GP is referring the patient to the centre. The aim is to enhance integrated care pathways and promote rehabilitation of patients with one or more chronic conditions and by this to make a shift from care in hospitals towards care in the community. The provision of integrated care to patients is ensured through this interdisciplinary and inter-sectoral cooperation. In addition, the centre guides the patient in self-management [7]. The project takes into account several aspects of the CCM, such as self-management (personal action plans, patient education, health professionals are competent to support patient with their self-management), delivery system design (coordination of care, team based care, risk stratification) and decision support (specialist in place, defined care pathways, program evaluation, guideline training for health professionals and competencies in place) [37]. The expectation is that the healthcare centre will result in fewer hospitalizations over the long term and that rehabilitation program might help to prevent disease progression and hospitalizations.

Implementation and integration of rehabilitation programs – quality improvement

In the *Implementation and integration of rehabilitation programs* three organizations collaborate to improve the quality of healthcare through implementation and integration of rehabilitation programs for patients with COPD, type 2 diabetes, chronic heart failure. A fourth program aimed at preventing falls in elderly people. To support integrated care proven management practices were implemented. Also clinical guidelines for each chronic condition were developed. Furthermore, self-management and personal action plans were part of the program to support patients. These plans were defined together with healthcare professionals. Patient education and teaching programs were integrated in the program. On top of that teamwork, to optimize care, and identical performance measures were used to support quality development processes in and between organizations [44].

1.5.2. Shared Data & Performance Measurement

The Danish documentation of services delivered in the primary care sector is not yet systematic and disease-related [7]. However, collaboration between national, regional and municipal authorities launched a national strategy for digitalization of the Danish healthcare service in December 2007 [39]. This cross-governmental organization will facilitate the implementation of specific action plans involving common ICT-solutions for all actors in national health care of several systems; system for exchange of messages, an e-safety standard, an e-journal system making information from certain hospital IT-systems accessible for GPs and a patient medical card. All of this is combined in an overall framework, with requirements of individual players in each segment of the healthcare service (e.g. in relation to the interfaces and functionalities of local solutions). Each actor remains responsible for the development, implementation and operation of it all in accordance with the national plan and the joint initiatives www.nsi.dk. Through collaboration further national coordination will occur in a field where regions and general practitioners previously have largely developed their own solutions [39].

1.5.2.1. Examples

National Indicator Project

The Danish National Indicator Project (NIP), established in 1999, measures performance. It looks at the quality of care provided by the hospitals to groups of patients with specific medical conditions. It aims to create awareness in patients, families, doctors, nurses and other healthcare professionals about the extent to which the completion and outcomes of the treatment are up to the standards from a well-functioning healthcare service. The focus is on courses of treatment which are adequate or in need for improvement. The indication should be done by a health specialist who is working regularly with the diseases. The examination of the results will be performed by all healthcare professionals of a patient.

From 2000 onwards, quality standards, indicators and prognostic factors have been developed. The quality of care is nowadays measured for eight diseases some of them are chronic, such as COPD, diabetes and heart failure. During 2009 quality indicators for depression and birth have also been developed [45].

IT support

Another example is the development of IT support for communication and sharing information between institutes to decrease boundaries within the Danish health care system. The project is focusing on chronic patients with implantable cardioverter-defibrillator (ICD) as they make often use of different healthcare providers [46].

KOALA

A third example is the KOALA project, which on one hand assesses the feasibility of introducing a nationwide web-based tool to record and assures quality of data in the recovery programs and on the other hand evaluates if the Danish guidelines for community based COPD rehabilitation is used correctly. The program exists from 2007 onwards and in 2010 33 healthcare centres were involved [47]. Development of tele-medical solutions may introduce new possibilities for integration [39].

1.5.3. Engaging Consumers

As part of the released report focusing on the regional support in 2005, diseases-specific education classes have been offered, including on chronic diseases. The aim was to reduce hospitalizations and length of stay [7]. The national objective is patient involvement at all levels, organizational and individual, regional and municipalities and cooperation of all stakeholders [43].

Stanford Chronic Disease Self-Management Program (CDSMP)

This national program (see above) focuses on the disease specific patient education and active involvement of patients in monitoring and treatment [43]. The process of how the CDSMP is taught has been found effective. It consists of a six week workshop given in a community centre and facilitated by two trainers, one or both without a health professional background and with a chronic disease. The focus of the workshop is on aspects such as coping strategies, possible exercises and nutrition, right medication, communication with the surrounding and evaluation of new treatments. The sessions require active participation and build on mutual support and confidence to be able to manage on a health life [48, 49].

Example: guided Self-Determination

This method focuses on self-management in patients. The Guided Self-Determination (GSD) is used by the Steno Diabetes centre and is developed to facilitate problem solving between patient and professional to overcome barriers. The aim of this project is to empower patients with diabetes by developing life skills. This is reached by guiding both stakeholders in the process, using individual and common potentiality [50, 51].

1.5.4. Improving Healthcare Delivery

The main stakeholders within the implementation of disease management programs are health professionals working at hospitals, general practitioners, and health professionals employed in the municipalities [35]. The GPs are functioning as a gate to other healthcare professionals and have been a key feature of the Danish system [41]. It is expected that greater integration between the primary and secondary healthcare sectors will occur from disease management programs, whilst primary healthcare is already integrated with the social services [39].

It was found that Danish health professionals spend between 0.5 and 2.5 hours a day advising patients on lifestyle changes. However, other services that might play a role in self-management support are not always pointed out in this respect.

Sharing Decision-Making in Chronic Care

To get more insight into patients' decision making a person-centered communication and reflection model was developed. It identified Shared Decision-Making in chronic care, gaining insight for professionals [51].

Facilitate referrals and discharges

The cross-governmental organization has started a strategy to digitalize the Danish healthcare service. So far this has facilitated use of E-referrals and discharge letters, and has enabled patient records to be exchanged between practices while there have been legal and technical barriers to full sharing of electronic medical records [39].

1.5.5. Aligning Finance & Insurance

The way the healthcare system is financed has been changed as a result of a structural reformation of counties in Denmark. Financing occurs through a combination of a national kind of health tax (80%), region grants and municipality funding (20%). The municipality funding was intended to increase prevention and through this reduction of hospitalization rates. The national incentive should contribute to a more transparent healthcare expenditure. So far, no results are available [7]. Some examples of incentives are displayed below.

Financial incentives among GPs

The fee covered the different aspects of the disease management program and is based on the needs of the individual patient. This requires more of the GP in the area of program appropriateness, good documentation and patient follow-up. Nonattendance of the patients during the program must be checked, which is a new task for Danish GPs and asks for collaboration between the different stakeholders in the disease management program and self-management of the patient [7].

Financial incentives for the municipalities at the local level of health care delivery

Financial incentives for healthcare delivery at the local level delivery exist for the municipalities. This consist of co-financing for region health services, introduced by the healthcare Act, and should create financial opportunities to stimulate preventive services which ultimately is expected to result in decreased hospitalization [35].

Fee for chronic disease management programs in primary care

A financial incentive for chronic disease management programs in primary care has been created. Incentives exist for GPs to improve quality of care for diabetes patients [7]. An incentive for GPs has been organized when participating and reporting patient data in a shared database. An advantage for the GPs to participate is that they are enabled to follow the progress of their patients and to compare their outcomes with those by others. Also, a fee has been set for disease specific cross-sectoral services. The idea behind this is that it will result in improved healthcare as patients are offered preventive treatment and follow-up after hospitalization [35, 39].

The arrangement with the GPs is currently only for diabetes patients, while in a later stage this will be extended towards patients with other chronic diseases [39].

Quality improvement incentives through benchmarking of providers

A non-financial incentive for quality improvement is benchmarking of providers. The aim is to increase the clinical databases benchmarking between providers and to enhance the quality of care. This clinical quality database exists of 32 databases nationwide and is part of the National Quality Project. Through these databases data are collected and analysis can be performed for specific patient groups. This provides for example information about necessary healthcare improvements and total quality of treatments. The databases are the responsibility of the regions [52]. The above mentioned NIP is part of this database.

1.5.6. Outcomes

1.5.6.1. Stakeholder collaboration

The National Board of Health has started to implement the CCM in Denmark. However, reluctance occurs sometimes within health professionals in hospitals as it is unclear to them how their work and the funding of hospitals will be affected by the delivery of care according to the CCM. This concern is also due for GPs working as private entrepreneurs in primary care, as it is unknown what the implications of increased regulation and quality monitoring of the sector are. However, the biggest challenge for GPs lays in the need to comply to the clinical guidelines, as these are used to a higher level of self governance and professional authority [37].

1.5.6.2. GPs work independent

The general practitioners work independent which can lead to a barrier to collaborate and to participate in team-work [9]. All decisions regarding the practice are up to the GP. As a result, implementation of initiatives in primary healthcare may be hindered [39]. Even though GPs are the centre of the primary care, they will not be able to coordinate the network, as they do not have the dominating competence.

Re-arranging the continuum of healthcare could lead to problems when the patient enters this continuum at the wrong time of place and will not be followed by a GP. The national e-health initiative may solve some problems in communicating and informing each other, but this raises other challenges as ethics and working practices of GPs and hospitals need to be taken into account. As patient mobility has increased, standardization seems to be a necessary procedure to keep a consistent system at a local level. Consequently, the standardized structure is even important as the underlying structure for the more informal and personal communication [39].

1.5.6.3. Integrated effort for people with chronic diseases – SIKS

At the start of the project, previously identified barriers for integrated care were taken into account. To enhance the integration of healthcare, new management practices were developed or improved as for the Østerbro healthcare centre described below. An effort was made on vertical and horizontal communication, which resulted in improvements. Also collaboration between the participating organizations was supported [7].

It was found that knowledge-sharing meetings are important for integration. As a result of all used methods to increase integration, patients were positive with the healthcare centre rehabilitation programs. Also, the GPs were supportive towards the rehabilitation programs and valued it for their patients. Cohesion between GPs and the healthcare organizations needs further strengthening [44].

1.5.6.4. Improving health care delivery

Strandberg-Larsen et al. concluded that the aim to dissolve barriers in health care delivery across sectors is not yet achieved from the view of the major professional healthcare stakeholders. Solutions could be stewardship, financial incentives, and broadening the health information technology to increase cohesion between healthcare organizations [8].

Implementation of activities within health care centres

The National Institute of Public Health has conducted an evaluation study in 18 health care centres. The aim was to assess the degree of implementation of the concept of the health care centre and, if feasible, to assess the impact of the rehabilitation programs provided [7]. Aarestrup et al. found some positive effects after evaluation. In general, the health care centres have succeeded in implementing activities according to project

plans. Collaboration has taken place with several stakeholders, especially general practitioners, hospitals, other municipal institutions, patients and voluntary organizations. Coherence across healthcare providers has been limited. The experiences so far could be used by municipalities which consider to establish a healthcare centre in the future to find the best fit on needs and local conditions [54].

Evaluation at Østerbro health centre

The CDSMP has been evaluated to see whether this program was transferable to the Danish cultural social and health related context [7]. As preliminary results of the CDSMP were also positive for Denmark, the program is widespread implemented in the healthcare system under a national license [36]. The preliminary findings show an impact of the physiotherapy training programs as improvements for COPD and diabetes [7].

1.5.6.5. Shared data en performance measurement : Information technologies

Bodker et al. see various challenges of IT support for shared care. There seem to be structural problems, the lack of involvement of GPs as well as what is meant with shared, integrated care in a specific project. Therefore, common thoughts need to be on what will and need to be shared. Also, they suggest to divide shared care into the epidemiological and the operational level [55].

The Danish healthcare system uses health information technology tools that allow general practitioners to coordinate with healthcare professionals. Outside the practices this tool is not widespread nor is it inter-sectoral. Furthermore, the study of Strandberg-Larsen et at. tried to select features within the tool to see cross-system use. They conclude that the lack of association could imply an insufficient development of this technology to have impact on the level of clinical integration. This should be further investigated to see future possible impact [8].

Findings of the IT project with implantable cardioverter-defibrillator

The main conclusions were:

(1) most of the data produced and recorded as part of the care process is context-specific and often difficult to interpret unless one is an expert on the subject. Sharing these types of data across institutional and professional boundaries is not feasible;

(2) a small subset of data can still make sense across the different contexts and be of use to others. These data are good candidates for sharing;

(3) in addition, there appears to be a need for creating new types of data specifically designed to meet the coordination needs across different contexts and expert domains;

(4) the dilemma is, however, that the production of these new types of data must not require too much extra work [46].

Results from the Koala project

The KOALA project shows preliminary results. The municipalities are in general interested in the project at the level of data recording and sharing and as a quality instrument. Referral and baseline assessments of patients with COPD in a community setting should be improved [47].

1.5.6.6. Engaging consumers, Engage the patient

Results of using the Guided-Self Determination method show that (diabetes) patients improve their life skills. Empowerment was improved, as seen by the shared decision making, the settled conflicts between life versus disease and the relationships between patients and professionals[51].

Self-management is part of chronic care to ensure an informed and activated patient. Vedsted et al. scrutinized systematic literature reviews about self-care in general practice [56]. They found effects on clinical and patient related measures and health services utilization. Most effect was seen in interventions using health care professionals to provide education about action plans and medical treatment. Patient-led-education did not show effect on clinical outcomes but on patient-related measures.

1.5.6.7. Importance of person-centered communication

Findings indicate that the use of the person-centered communication and reflection model in chronic illness care can improve care through shared decision-making and problem solving. The key aspect of shared decision making is the focus on patient perspectives and sharing decisions concerning difficulties in living with the chronic illness. Communication can bridge the gap between the patient and professional point of view. There is a need for comprehensive changes with strategies as using a combined disease-life approach, using precise communication adapted to the patient, reflecting on the difficulties a patient encounters and challenging the patient to reflect on his decisions. Zoffmann et al. expect the model to be applicable in chronic illness care in general, providing professionals with an overall picture of the choices, barriers, and pitfalls in communication and reflection that are crucial for determining whether decision-making and problem solving [57].

1.5.6.8. Aligning finance & Insurance

Our search has not resulted in outcomes on this item. Notwithstanding the introduction of financial incentives, it is not clear how these incentives are applied nor which impact, if any, has resulted from these.

1.5.7. Summary

- The Danish Ministry of Inferior and Health has laid down its policy aims regarding chronic care in multiple documents e.g. the Health Act and Health Throughout Life. Important policy issues are the strengthening of the role of healthcare providers and their collaboration and coherence regarding chronic care on regional level and the role of patients in terms of the strengthening of their ability to promote one's own health within the healthcare and social context;
- To improve chronic care management use is made of a generic model for chronic disease pathway programs inspired by the Chronic Care Model and rehabilitation programs for diagnosed patients, including self-management and personal action plans and important roles for GPs and municipal health centres;
- A national strategy was launched in 2007 to facilitate a more systematic and disease related documentation of services across organizations. Until so far, performance measurement takes place on national level for eight disease including COPD, diabetes, and heart failure;
- Also on national level, the Stanford Chronic Disease Self-Management Program (CDSMP) has been introduced, to establish a framework for patient involvement;
- Due to an increased attention on lifestyle changes the role and competencies of health professionals, their interaction with each other and with patients has been examined and resulted in the introduction of for example shared decision making;
- Various incentives have been introduced in the system in order to improve the quality of chronic care. Examples of these are: financial incentives for GPs and municipalities, and quality improvement incentives through benchmarking;
- Preliminary results have revealed solutions to overcome main barriers for integrated care delivery (e.g. financial incentives and HIT), a modest impact of healthcare centres on health outcomes, and the lack of competencies among GPs to coordinate primary care networks.

1.6. Quebec

Figure 6: Framework for creating a Regional Healthcare System in Quebec

Stakeholder Collaboration: shared vision and leadership
Ministry - Reforms
Community, care providers and system
Patients
System managers
Physicians
Nurses
Pharmacists
Montreal Stroke Network
SIPA
CURATA

Shared Data & Performance Measurement
Telehealth
MOXXI
LOYAL

Engaging Consumers	Improving Healthcare Delivery	Aligning Finance & Insurance
The diabetes referral centre	Primary healthcare organization	Government-funded DM programs
My Tool Box	CSSS/Local Network	
Priisme	RUIS	
ROCQ	Family Medicine groups/ Network clinics	
	TEAM/VESPA	

Outcomes
Montreal Stroke Network
SIPA
CURATA
Telehealth
MOXXI
The diabetes referral centre
PRIISME
ROCQ
CSSS
TEAM/VESPA

Future Actions
Further insights of value and efficacy of team-delivered healthcare
More focus on team-delivered care
Increased understanding causes of care gaps

1.6.1. Stakeholder Collaboration: shared Vision & Leadership

1.6.1.1. Health Care in Canada

Integrated delivery systems have been part of the planning and delivery of health services in most Canadian provinces since the 1970s. Disease management programs are seen as one solution for improving the quality of patient care and outcomes and for reducing costs. Disease management is seen as a system of coordinated interventions and communications for populations with a focus on self-care and empowerment. Evidence-based practices, economic and humanistic outcomes, are combined, measured and used in interventions together with participating stakeholders [58].

Various strategies were carried out by provincial governments since the 1970s, with the establishment of the Regional health authorities as most essential one. These authorities provide geographically-based coordination and integrated services. However, there is a lack of key components of integrated delivery systems, such as integration of physicians and drugs in most provinces. Also a start has been made in promoting multidisciplinary primary care practices and a variety of other integrated care strategies, such as chronic disease management [59].

In 1984, services were fragmented and the culture of acute care reinforced when the Canada Health Act equated 'accessible' health care services with all 'medically necessary' hospital and physician services. In addition, variation exists between provinces as it is their own responsibility [59]. From 2000 on the Canadian healthcare is changing as the population is aging and age-related chronic diseases are increasing. Access to care is becoming more difficult: 25% of the habitants in Quebec have no general practitioner (GP) [60]. Also, the costs of care are rising. The Gross National Product for health care was 10% for Canada. This results in a growing desire for a more efficient and effective health system for health professionals and other stakeholders [61].

1.6.1.2. Quebec

The Ministry of Health and social services has the authority over most health and social services. From 1970 on Quebec began to implement a regional structure to coordinate and integrate health and social services, by starting local community centres and the creation of regional authorities. The local centres took care of the clinical and social services and developed community-based action. As of 2000, the budget for integrated care increased, resulting in Reforms in 2005 among others [58, 59]. The Commission of Study for health and Social Services (CSSS) aimed to position Quebec as leader of integrating disease management, with a focus on the exploration of an optimal use of medicines and a drug policy was released in 2007 [58].

Multidisciplinary teams in primary care

Also, multidisciplinary team-based practices in primary care are initiated by the province, to provide incentives to private group practices in primary care through public policies [59]. The local services still play a major role in promoting integrated care, provide multidisciplinary care and are responsible for care coordination bridging hospitals and community-based agencies. A joint partnership started between 1991 and 2001. During this time, the federal health Transition Fund implemented integrated care network initiatives, for elderly, diabetes and cancer patients. As a consequence, innovations in the system and the sharing of best practices in care continuity were stimulated, resulting in smooth implementation of the Reforms which started in 2005.

Health and social service centres

These current reforms are designed to reinforce primary care, improve social service, health care integration and their efficiency and on the other hand to respond more effectively to the raised demand of health care. As a result, local community centres, acute hospitals and long-term hospitals merged into 95 health and social services centres (Centre de Santé et des Services Sociaux) [59]. These CSSS exist as local health networks and raise the possibility to implement innovative models of care delivery [62]. They bring all care providers in a certain region together.

University initiatives for chronic care

In addition large university-affiliated hospitals were merged into four university-based healthcare networks (RUIS). Furthermore, the University of Montreal has launched a disease management research group (Groupe de recherche en gestion thérapeutique), aiming to adopt the advances of integrated disease management programs in Quebec [58]. In the current reforms there is also a place for the family medicine groups and network clinics. These focus on reinforcing access and keep the care continuity.

Policies and framework for chronic care

Several Acts have been revised and policies have been developed to help achieve integrated care, prioritizing mental health and chronic care programs. Within the chronic care program several projects have been initiated, starting with a provincial public health program plan in 2001. In 2007, Quebec framework for preventing and managing chronic disease was published afterwards. The available money has been used to promote good health habits and better detection or prevention of diseases [59]. During project development the existing healthcare structure and processes are taken into account as well as previous results. Patients and their surrounding play a central role in all partnerships and projects [58]. To deliver chronic care multidisciplinary teams are used [61.] In Quebec public-private partnerships are common in disease management.

Some examples

- The Montreal stroke network

The Network validated models that build upon continuity of services and care to efficiently and effectively optimize chronic disease management and control costs for populations with specific needs, including stroke. Creating stroke care continuums represent highly relevant solutions to deal with predictors of discontinuous care i.e. the involvement of multiple care providers from different disciplines and organizations [62]. The chronic disease management model has been used as framework.

In 2005 various stakeholders were brought together in a stroke working group to fill up the gap in information, relationships and management, to improve the continuity of care between the different care providers. The working group could expand after substitute funding from the Canadian Institute of Health Research and intentional communities of practice were formed. This network is still growing. The network has switched from prevention to social participation, taking patient groups better into account. The communities of practice form the base of learning organizations and several outputs have been developed and implemented. Also an e-collaborative platform has been started [62].

- System of Integrated Services for the Frail Elderly (SIPA)

SIPA is a model of integrated care for the elderly with severe disabilities. It is community-based and patient focused. The aim was to ensure comprehensive, continuous care and mobilizing a needs-based, flexible, and rapid response. SIPA was responsible for the delivery of all services. The project consists of multidisciplinary care provider teams in CSSS. Case managers play a crucial role in the coordination and follow-up. The setting, the patient, the central role of the GP and the information system play an important role in this project. The project was implemented in parts of montreal, in partnership with scientific teams and the Health and Social Services Board [58, 63]. GPs received specific fees. The SIPA team was accountable for service utilization in terms of hospital stays as well as services provided in the community [63].

- Curata: integrated approach to improve the appropriate utilization of anti-inflammatory/ analgesic Medications

This integrated approach has been set up for the treatment of osteoarthritis in Quebec. The program has as aims to improve primary care physicians' ability to identify patients with osteoarthritis and to choose appropriate pharmacological and non-pharmacological therapies using an evidence-based decision support algorithm.

The program had several interventions relating to the CCM such as patient care, educational tools for pharmacists and patients, training workshops for physicians and outcomes evaluation tools. Furthermore, one of the interventions is the development of the evidence-based treatment algorithm. Several stakeholders participate, such as healthcare providers, patients, pharmacists and Health and Social Services Ministry of Quebec[58].

1.6.2. Shared Data & Performance Measurement

Knowledge transfer and organization readiness to deliver the best possible chronic care, based on the evidence, are necessary [64]. Motivating organizations to integrate new research-based knowledge on optimal chronic care in practice seems to be a way to overcome this gap. Knowledge translation plays here an important role to ensure that users are aware of the existing evidence and know how to use this in relation with managing chronic conditions [64].

Gagnon et al. aimed in their study at assessment tools based on a theory about organizational readiness that would be used to assess an organization prior to implementing evidence-based and scientifically-informed knowledge related to the core elements of the CCM.

Examples of shared data and performance measurements are:

Telehealth

The Ministry of health and social services asked the university-based healthcare networks (RUIS) to develop the telehealth services. These services should enhance the accessibility and delivery of healthcare in Quebec [65]. One of the RUIS developed a strategic plan including services' coordination and integration. This reorganized plan included a new role, the clinical telehealth coordinator to support services' coordination and integration. This role is essential to ensure well-coordinated, time-efficient, and accessible patient care as the structures towards adaptation of telehealth is a major concern in promoting these services. Therefore, this coordinator seems to be important for continuity and sustainability in integration within the network. For an effective telehealth service in provision and utilization, an integrated care system network is mandatory[65].

Medical Office of the twenty-first century (MOXXI)

MOXXI is an interactive system of electronic prescribing and integrated drug and disease management. MOXXI is aiming at reduction of drug-related illnesses and improvement of management of chronic diseases. The project has been in various stages and is financed by the Canadian Health Infostructure Partnership Program.

It focuses on the application of information technology to drug and care management and consists of various components, such as electronic prescriptions and reminders for physicians and on the other hand enhancement of the patient's role through self-management and feedback on compliance of medication uptake. Another component is the utilization of evidence-based asthma and diabetes guideline through the advanced decision-support system. McGill University researchers have initiated and implemented the project together with several stakeholders [58].

Loyal

Lowering blood pressure by improving compliance with hypertension therapy through the assistance of technology-enhanced tools (LOYAL) aims to improve the health and well-being of hypertensive individuals and reduce therapeutic non-compliance. Patients are provided with blood pressure monitors, integrated telephone support system for automated reminder, feedback and education material. It has been started in 2002 , funded by the industry and conducted by the Research Centre of the University of Montreal Hospitals [58].

1.6.3. Engaging Consumers : some illustrations

1.6.3.1. The diabetes referral centre

In Quebec, the diabetes referral centre is an example of contemporary CDMP running in the health and social services centre du Sud-ouest Verdun since 2007. It consists of individual and group knowledge exchange on lifestyle modification and other therapies and is linking primary multidisciplinary community teams and secondary care. Program information is disseminated to all stakeholders, including results of clinical and administrative outcomes after six and 12-months, initiating a culture of continuous quality improvement [66].

1.6.3.2. My Tool Box

This a standardized and proven effective patient self-management program developed at Standford University. The aim is to help patients and families to be more active participants in their own health. Satisfaction, involvement and empowerment seem to be improved. The program is being used throughout Canada. Patients and care providers indicate communication as being highly important. The assumption of My Tool Box is that providing patients with access to their own health information enables better patient understanding of disease risk and concomitant therapeutic benefits [67].

1.6.3.3. Programmes régionaux intégrés d'information, de suivi médical et d'enseignement (Priisme)

The comprehensive « Programmes régionaux intégrés d'information, de suivi médical et d'enseignement » aim to improve the management of chronic diseases asthma, COPD and diabetes. The focus is on disease management e.g. self- management, based on the primary care structure. Nolte, 2008 The program was launched in 1999, funded by the industry. Governance is by a steering committee of regional health authority representatives, health institutions, community groups, private medical clinics, individual providers and industry [58].

1.6.3.4. Recognizing Osteoporosis and its Consequences in Quebec (ROCQ)

The project “Recognizing Osteoporosis and its Consequences in Quebec” (ROCQ) aims to improve the diagnosis and treatment of osteoporosis in women aged 50 years and older with fragility fractures and a high risk of further osteoporosis-based complications. The program started in 2003 [58]. The assumption is that ROCQ will result in improved knowledge among the target group [58].

1.6.4. Improving Healthcare Delivery

Montague et al. found that physicians are not always supportive towards disease management in particular for team care involving also non-physician professionals. Stampa et al. looked into the incentives and barriers for active participation of GPs in integrated health services networks (IHSNs) as they play a crucial role in the success in the delivery of these networks [63]. The target group they used consisted of GPs who were enrolled in SIPA, one of the mentioned examples before.

1.6.4.1. Primary healthcare organization

These organizations vary in their performance with respect to client affiliation, utilization of services, experience of care and perceived outcomes of care [68]. In the province of Quebec a shared opinion of front-line leaders is to create multidisciplinary family medicine care teams and integrated care initiatives, for example electronic prescription programs; protocols for specific patient populations and patient self-management, with support networks and information systems that include electronic health records and patient education centres to stimulate patient motivation and self-efficacy [61].

1.6.4.2. Health and social services centres – Local Networks

The Health and social services centres (CSSS) are responsible for planning and coordinating all health and social services in their local networks and for collaborating with their health and social network partners. The CSSS are a collaboration of local community health centres, residential and long-term care centres and the community hospitals within a given territory. Partnerships are built, which are essential to the operation of the networks [7]. The regional authorities are mainly responsible for supporting and coordinating their local networks and monitoring network and service performance in their territory, which is very beneficial as they are now a large autonomy in planning an organizing services and activities [68]. CSSS in Quebec have four objectives: 1) to provide a complete package of services to certain target groups; 2) to make use of care models aiming for comprehensive, ongoing and personalized case management; 3) to create a circumstance encouraging continuity of care; 4) to develop integrated structures matching with the environment [7].

The main challenge for the years to come will be to increase coordination between these different components [7]. Also an effort needs to be made regarding accountability, implementation of best practices and creating electronic clinical records [59].

1.6.4.3. University-based healthcare networks (RUIS)

Each RUIS centre offers ultra-specialized care, coordinates training and research, and provides coverage for part of the province's 18 regional health authorities [59]. One of their tasks is to develop telehealth services [65].

1.6.4.4. Family Medicine Groups

Family medicine groups (FMGs) aim to increase the access to healthcare and to make it more continuous, especially the care of patients with chronic diseases. The focus of these FMGs is to work as a multidisciplinary team and to increase the effectiveness of healthcare [59]. GPs collaborate in a centre and offer extended services. Other examples are that FMGs have extended opening hours and appointments are not mandatory [59]. Especially regarding the care for chronic patients, nurses and GPs work together. The FMG policy focuses on the agreement between the public healthcare clinics and the provincial government. The FMG themselves work together with the Local Centres and intend to be complementary to these CSSS [68]. FMGs in Quebec are very similar to Ontario's Family Health Teams.

Active participation of GPs is important for the success of these multidisciplinary teams [63] but the role of nurses becomes more and more important to support physicians at different levels of the care process. Also the role of nurse practitioners is encouraged, but not yet fully enrolled in the clinics [59].

1.6.4.5. Network clinics (or associated medical centres)

The Network clinics are funded by the Montreal Regional Health Agency. These network clinics are complementary to the FMGs. These clinics focus on the more vulnerable patients as well as on providing basic technical support [68]. Network clinics are larger than FMGs and nurses play a larger role. The networks have collaborations for the delivery of psychosocial services and with laboratories for technical support [59].

1.6.4.6. Toward Excellence in Asthma Management programme (VESPA)

The VESPA programme ("Vers l'Excellence dans les Soins aux Personnes Asthmatiques"), aims to optimize asthma care, to improve the quality of life of patients and to alleviate the socio-economic burden associated with asthma. The programme is an initiative of the Quebec Asthma and COPD Network, Merck Canada and Astra-Zeneca. Several stakeholders are involved, such as the patients, regional health authorities, patient advocacy associations and the provincial asthma education network [58].

1.6.5. Aligning Finance & Insurance

1.6.5.1. Financing of initiatives

In comparison with the USA, Canada has no commercial disease management organizations, although the pharmaceutical industry, academic, government and/or community partners have initiated several programs in collaboration. Furthermore, a Canadian Council for Research in disease management has recently been created by a group of Canada's research-based pharmaceutical companies [58].

1.6.5.2. Additional incentives for multidisciplinary team practices

These incentives are available since 2000. As a result, the CSSS and FMGs were initiated in 2005 funded by the Canadian government [59]. Additional funding comes from the Montreal Regional Health Agency to enable the start-up of network clinics in the region [68]. A program to develop an electronic database is funded by the Canadian Health Infostructure Partnership Program.

1.6.6. Outcomes

1.6.6.1. Stakeholder collaboration

Successes and challenges

At the Canadian level several successes of chronic disease management have been reported so far, such as community based partnerships with a mutual goal, professional care, patient self-management; measured and shared information on practices and outcomes; and visible leadership [66]. On the other hand, challenges remain at the level of engagement of all stakeholders, shown effects for effective team care; usable information systems, and increased education for both patients and caregivers [66]. This is in accordance with a study of Montague et al. (2009) in Quebec, who studied the public's perception of their health status and all stakeholders' views of the burden and effective management of chronic diseases [63]. They found that more than half of all stakeholders had a positive view towards the implementation of disease management programs as well as towards initiatives to improve the healthcare of chronic patients. This included coordinated interventions to improve home, community and self-care; increased wellness promotion; and increased use of clinical measurements and feedback to all stakeholders. Regarding the value of team care, including the use of non-physician professionals to provide patient care, the public and doctors were less supportive stakeholders; increased patient involvement in decision-making and the use of electronic health records to facilitate communication are in room for improvement. Notwithstanding not all stakeholders being positive, integrated disease management becomes more common.

Barriers: independency, lack of support

The Quebec reforms and clinical integration are still in implementation stage. GPs often work independently. Improved access and enhanced continuity of healthcare remain a point of attention. Also the increased turnover of staff in reaction on the reforms is acting as a barrier. The regional health authorities play a role here, because of their lack of support regarding the merge of organizations. Consecutive reforms have not achieved a culture change yet regarding collaboration and multidisciplinary teams. Reasons for this are a lack of interest of physicians and different cultures within organizations [59]. Furthermore, it is unknown if the regional health authorities are achieving effective service coordination and integration [59]. This is common in disease management programs during the process of change [66].

Specific examples

- Montreal Service Network

One of the Montreal service networks was very successful in the collaboration of stroke care delivery. Another network had success in the development of a bilingual training session and was offered to more than 120 nurses. Sharing of 'know-how' had a positive impact on clinical practice and was appreciated by participants. It showed positive results on problem-solving, capacity and trust. Also participants were most positive of the increased sharing of 'know-how' and the understanding how to implement best-practices. At organizational level more efficiency, savings of cost and enhanced service delivery were seen [62]. Nowadays the goal is to increase collaboration of stakeholders in Quebec and enhance the engagement to become the best practice for stroke care. To reach the latter, an enhanced understanding of successful development of integrated organizations need to occur as well as the use of e-collaborative platforms[62].

- System of Integrated Services for the Frail Elderly (SIPA)

So far SIPA has resulted in a decrease in hospital wait times, improved home healthcare and access to home care, no increase in overall costs and improved integration and continuity of care [58, 69]. A positive effect was also found in accessibility of community-based health and social services and a reduction of 50% was seen in acute hospitalization of elderly. Also a positive effect was found for provider satisfaction [69]. Stampa et al. found improvements regarding the participation of GPs and integrated health services networks within SIPA [63]. GPs play a crucial role in the success of integrated networks. Furthermore, intention of GPs to participate is not the same as actual participation. The participation of GPs in an integrated setting is complex and depending on several factors. Active GP participation in the study is mostly depending on collaborative practices, patients in the integrated setting, relation with the case manager in the network and their attitude towards SIPA. However, all GPs were positive about SIPA. Challenges were the high expectations of GPs as well as lack

of information about the program and difficult cooperation between physicians [63].

- Curata

Evaluation has shown an improvement in physicians' level of knowledge and use of evidence-based outcomes [58, 70].

1.6.6.2. Shared data & Performance measurement

Gagnon et al. aim to develop a framework which could be used as tool to assess organizational readiness for knowledge transfer. The tool must be in line with the Canadian healthcare and possible services planning to better implement evidence-based outcome related to chronic care improvement [64].

Telehealth

Telehealth is used as a tool to meet up with the increased pressure to improve access and continuity of services. Telehealth supports the development of a new professional role. This complex role must be undertaken by persons who meet the competencies, clinical as well as strategic. Here an opportunity is seen for nursing administrators. Furthermore, the results show that a clearer concept of a Telehealth program with clear descriptions of the roles should be made before its implementation [65].

Medical Office of the twenty-first century (MOXXI)

This interactive system of electronic prescribing and integrated drug and disease management show positive results; high satisfaction of quality care, good interaction with patients and good relationship with the pharmacists. Future research will be performed on the cost-effectiveness of the program. The hypothesis is that a positive result in medication mistakes using electronic prescribing and improvements in prescription adherence will occur. These are likely to produce a cost-effective system (Health Canada, Health and the Information Highway Division 2004). The idea is that the impact of this program can be expanded to other chronic diseases [58].

1.6.6.3. Engaging consumers

The Diabetes Referral centre

Initial results have demonstrated significant improvements in lifestyle habits, clinical control indicators and patient satisfaction. A great challenge, however, remains the lack of a system-wide information system to facilitate more facile data collection and dissemination. Ahmed, 2010 Quick improvements are not always able to make, because of the lack of flexible and robust measurement and communication systems, which in turn intervenes with the promise that primary care reduces mortality and other secondary interventions [66].

Additionally, Ahmed et al. pointed out that CDMP can only work when active case finding in the general population is part of an overall strategy to manage the whole patient population. Best model consists of 'rationale for data collection', technology in an electronic health records, sharing and security via communication, standardization which is still questionable, change management which has also barriers.

Programmes régionaux intégrés d'information, de suivi médical et d'enseignement (Priisme)

Results have been found for education of patients and health professionals. Also a decrease of 30% in use of the hospital could be seen in asthma-related illnesses [58].

1.6.6.4. Improving health care delivery

Due to public-private partnerships positive process changes can be seen on practices and satisfaction among stakeholders. In 2008 disease management was still very new in Quebec and Canada. Available evidence on that moment suggested that disease management partnerships are efficient in knowledge creation and its transfer into the care system. Gogovor et al. suggested that future projects have the possibility to use this knowledge and go from there [58].

There is also increasing evidence that teams, including patients, can improve clinical and fiscal outcomes in chronic disease management and prevention [66]. The proposed redesign is often focused on shared goals, community-based partnerships with patient self-management and effective communication systems – all key ingredients of effective CDMP.

Health and social services centres

Delegating task towards nurses is one of the concerns among physicians, as this has been the tradition that GPs/family doctors. It is challenging to develop and implement new roles and competencies for nurses and for other health providers other than physicians [7]. The collaborative approach of the volunteers from clinic practices, academia, and governments, with the support of the primary care professional associations, the pharmaceutical health care industry, governments, charities, and scientific organizations, has been associated with marked improvements in the management and outcomes of Canadians with hypertension [71].

Toward Excellence in Asthma Management (TEAM) (Vespa)

A lot has been learned from the results of TEAM so far about the knowledge and care of disease in Quebec. The program has been extended. The university-based networks continue education and the integrated clinical group practices [58, 60].

1.6.7. Summary

Notwithstanding the existence of integrated delivery systems in Canada since the 1970s, disease management programs and multidisciplinary primary care practices were introduced in Québec to diminish the fragmentation and to increase the accessibility of chronic care;

- Quebec has been implementing regional community centres to coordinate, improve and integrate health and social services as well as multidisciplinary team-based practices in primary care to reinforce primary care;
- Further organizational expansion took place when local community centres, acute hospitals and long-term hospitals merged into health and social services centres or local health networks which nowadays also include family medicine groups;
- Performance measurement and data collection takes place on project base and are sometimes part of telehealth experiments;
- Initiatives are launched to redesign primary care and to create multidisciplinary teams or network organizations in order to provide accessible, comprehensive, ongoing and personalized care. For these initiatives financial incentives were created;
- Preliminary results show results and room for improvement. The Quebec reforms are characterized as 'being still in its implementation phase' given that structural integration is mostly achieved and clinical integration still being in its infancy. Simultaneously, results show improvement regarding accessibility, reduction in hospitalization rate for elderly, improved knowledge of physicians, satisfaction of patients and healthcare providers, increased use of telehealth, involvement of nurses and no increase in costs;
- Challenges remain regarding an overall strategy to manage the whole patient population, organizational readiness regarding actual change, and data collection.

1.7. Pennsylvania

Given the limited number of references and the type of references (i.e. presentations), the data from Pennsylvania are more briefly described. Notwithstanding, results are reported to provide an overview of initiatives regarding the integration of care in Pennsylvania.

Figure 7 – Framework for creating a Regional Healthcare System in Pennsylvania

Stakeholder Collaboration: vision and leadership		
	Ministry - Launch of Reforms	
	Stakeholder	
	Community, care providers and system managers	
	Patients	
	Physicians	
	Nurses	
	Pharmacists	
	Montreal Stroke Network	
	SIPA	
	CURATA	
Shared Data & Performance Measurement		
	Telehealth	
	MOXXI	
	LOYAL	
Engaging Consumers	**Improving Healthcare Delivery**	**Aligning Finance & Insurance**
The diabetes referral centre	Primary healthcare organization	Government-funded DM programs
My Tool Box	CSSS/Local Network	
Priisme	RUIS	
ROCQ	Family Medicine groups/ Network clinics	
	TEAM/VESPA	
Outcomes		
	Montreal Stroke Network	
	SIPA	
	CURATA	
	Telehealth	
	MOXXI	
	The diabetes referral centre	
	PRIISME	
	ROCQ	
	CSSS	
	TEAM/VESPA	
Future Actions		
Understanding facilitators and barriers of disease management		

1.7.1. Stakeholder Collaboration: Shared Vision & Leadership

1.7.1.1. Chronic Care Initiative

In 2007 the Cost Containment Commission developed a strategic plan to effectively implement chronic disease management in Pennsylvania. The prescription for the healthcare system of Pennsylvania is a set of integrated strategies to eliminate inefficiencies in the healthcare system, better manage chronic conditions, eliminate health facility acquired infections, enact common sense insurance reforms and offer access to affordable health care insurance for the uninsured, with the aim to offer access to healthcare for every Pennsylvanian. This is done by combining the CCM and the patient-centered medical home model. On the initiative of the Pennsylvania Department of Health (Governor of Pennsylvania, the Chronic Care Commission, and the Governor's Office of Health Care Reforms), in collaboration with healthcare professionals, payers and physician professional organizations, regional rollouts of the Chronic Care Initiative are implemented. This is done by a public-private partnership including insurers, healthcare organizations, health systems, educational institutions and government agencies. The Chronic Care Initiative has four strategic objectives according to the Chronic Care commission, which could be summarized as a focus on achieving a change in infrastructure and improve outcomes for patients [72].

In January 2008 the Governor's office of health care reform convened insurers and providers to establish incentives for CCM-driven Patient-Centered Medical home (PCMH). More than 150 primary care practices in its multiple regional collaborative are enrolled, who committed for three years. The program can be seen as an example to change primary care delivery with a result to improve the health of patients. Diabetes is used as target disease. In 2007 the characteristics of a practice-based care model were described and distributed to four physician membership organizations of whom the majority provide primary care in the USA. [73].

This initiative uses the Physician Practice Connections Patient-Centered Medical Home of the National Committee of Quality Assurance (NCQA) as a validation tool to see if the newly delivered care is more effectively managed. Improving Performance in Practice (IPIP) provided support services during the preparation phase and helps the practices to succeed the implementation of the initiative. The NCQA has as mission to improve the quality of health care: it works in collaboration with federal and state lawmakers and executive agency personnel. The public policy team provides information at government level and national work includes medicare advantage plans, health information technology and delivers reforms such as PCMH. NCQA reviews are mandatory for all health plans in Pennsylvania [74].

Collaboration exists between the Pennsylvania Homecare Association (PAHA) and the Health Sciences Institute to deliver Chronic Care Professional certification and a staff accreditation program to Pennsylvania's home healthcare agencies. This certification supports the chronic care initiative as it builds on the strengths of the homecare industry. It contains a new learned model, the STEEEP framework (safety, timeliness, effectiveness, efficiency, equitability, patient centeredness), to be skilled, which lead to the patient's multidisciplinary case conference to formulate a best practice intervention plan to achieve positive patient outcomes. Furthermore, homecare providers have a front-line position in chronic care which makes them in the best position to support physicians in evidence-based patient care, through management and enhance self-management of the patient. [75].

Other stakeholders to meet the aim of the Governor's Office of Health Care Reform are Pennsylvania Health Care Cost Containment Council, the Ministry of health, Public Welfare, and Insurance and the Patient Safety Authority. The prescription for Pennsylvania also includes [73]:

- new laws to provide transparency in health quality and to protect patients from health facility-acquired infections;
- changes in scope of practice laws to allow several health professionals to practice to the full extent of their education and training;
- developing a statewide health information exchange;
- payment reform, including the Medicaid program no longer paying for so called never events.

Patient-Centered Medical Home

Health care settings which implement the PCMHs provide comprehensive primary care. The health care system as such is used as base, and the PCMH is coordinated and integrated into this. The physician is leading the team of health professionals and the patient (and his family) is actively involved. The provided care is evidence-based, health information technology is used and there is an ongoing measurement to be able to continuously improve the quality of care [76].

South East Pennsylvania (SEPA) implementation of the chronic care model

SEPA consists of the five-county metropolitan Philadelphia region and 25 practices focusing on diabetes. Gabbay et al. (2011) evaluated to what extent this intervention had an effect on the structural transformation of primary care practices applying CCM driven Patient-Centered Medical home [76]. The program consisted of five parts, the learning collaborative, the monthly reporting of quality indicators, improving performance through practice coaches, national committee for quality assurance physician practice connections patient-centered medical home recognition and multi-payer financial reimbursement. Funding came from six organizations, all private insurers. IPIP measures were used to receive common reporting.

1.7.2. Shared Data & Performance Measurement

1.7.2.1. The role of technology

Innovative technology can be seen as an easy supplement to current chronic disease management as long as it is shaped and implemented carefully. It has low costs and is flexible. It can have a positive impact on provided health care for health professionals and patients [77].

- The implementation of technology in diabetes care has shown positive effects. The CCM relies on the use of technology with disease-specific registries for both public and private health systems to facilitate tracking and the provision of quality longitudinal care.
- The Department of Veteran Affairs is a good example of effective implementation of IT and registries on a large-scale in chronic care. Especially effective here is the electronic medical registry system.
- Introducing technology in chronic care is also promising for a better understanding of how to use financial incentives, given that it provides a (better) linkage between improved practice, provider processes and patient outcomes.
- Next to a better electronic registration system, static and interactive websites and telemedicine can improve chronic care.
- Also, the active participation of patients through technology via self-management can have a positive impact on chronic care as technology has the possibility to empower patients to learn new practices and routines related to their illness on an educational and motivational level. Furthermore, microprocessor technology (e.g. mobile phones) can have an instant impact on self-management and thus dealing with chronic care.
- On the level of decision support and clinical system information, technology has the possibility to impact on chronic care. For example, via emerging technologies that adds intelligence via guideline-directed alerts and reminders, interactive workflow and care coordination, registries that comprehended data, such as health data and cost data. Personal health records can improve the communication between all health professionals and patient as it enables better synchronized care.

1.7.2.2. Practice Transformation Support (including technology)

A partnership is started between the Pennsylvania Academy of Family Physicians with the Pennsylvania chapter of Improving Performance in Practice (IPIP) to provide Practice Coaches and a web-based patient registry to the practices to complete the disease management program [78]. Practice Transformation Support has the objective to provide practice coaches and patient registry to the practices. It is partnered with Improving Performance in Practice (IPIP) [79].

1.7.2.3. Improving Performance in Practice (IPIP)

The IPIP program was designed to bring together stakeholders within PA and provide a better infrastructure for primary care within the state [72]. In first instance, this program provides support services to the Pennsylvania Chronic Care Initiative and data management for all practices and interventional coaching services for low-performing practices www.pafp.com together with education for health professionals and improvements in collaborative data sharing. The Pennsylvania Primary Care Coalition (Academy of Family Physicians, Chapter of American College of Physicians,Chapter of the American Academy of Pediatrics) jointly applied for the IPIP program [72]. It is funded by the Pennsylvania Department of Health and most of the insurers.

1.7.3. Engaging Consumers

The diabetes education and treatment initiative was launched in 2005. The three components of the program are implementation of the CCM, an evidence-based approach that allows for the electronic tracking, monitoring, and evaluation of client services; the provision of intensive education by culturally competent health educators; and the use of a home visit diabetes counseling program that provides peer health education or "promoters" to enhance self-management strategies.

1.7.3.1. Example

DYNAMIC: diabetes programme

The program aims to improve patients' self care and to reduce clinical inertia through provider use of standardized clinical guidelines to achieve better diabetes outcomes [80]. A model of diabetes type 2 management was evaluated including nurse case management and motivational interviewing with the aim to make a behavior change happen.

1.7.4. Improving Healthcare Delivery

Patient-Centered Medical Home, based on CCM, is implemented in health care organizations. The aim is to enhance access to primary care, to improve communication between patient and health professionals and to make healthcare more continuous [1]. The NCQA rated the Patient-Centered Medical Homes of Pennsylvania as being an appropriate strategy for quality improvement [1].

Sochalski et al. studied the effect of chronic care management programs on hospital readmission and readmission days compared with usual care. Several practices have been taken into account. Some of these used multidisciplinary teams whereas others focused on in-person communication [81]. Zinszer et al. studied the competencies of health professionals via ongoing education, about information of the CCM specifically on skin and wound care for diabetes and provided an educational activity to enhance the competencies. One of the objectives of this study was to apply information on the CCM to assess and evaluate tools to patient care scenarios [82].

1.7.4.1. Example

Multifaceted diabetes care intervention

Piatt et al. (2010) looked at three different interventions to improve diabetes care in an underserved suburb in Pittsburg, Pennsylvania between 1999 and 2005. One of these interventions is the implementation of the CCM [83]. Patients follow the intervention for 1 year, with a 3-year follow up. The CCM intervention focused on patient and provider education. In addition, other elements of the CCM were provided in the community. The health professionals were encouraged to restructure the follow up of their patients. Also a special diabetes educator was available in the practice for patients and care providers, for six months.

The education curriculum for the patients was based on the University of Michigan Diabetes self-management education curriculum, aiming at empowerment [83]. This program aims to increase diabetes self-care through the facilitation of knowledge, skill, and ability. It combines the needs, goals, and life experiences of the patient and is guided by evidence-based standards. The aims of the program are to support informed decision-making, self-care behaviors, problem-solving and active collaboration with the health care team and to improve clinical outcomes, health status, and quality of life [84].

1.7.5. Aligning Finance & Insurance

The Pennsylvanian Governor's Office of Health Care Reforms is funded through the state budget process. In 2010 affordable Care Act established Centre for Medicare and Medicaid innovation. In November 2010, primary care practice demonstration was advanced, an incentive to implement PCMH for 1 million Medicare beneficiaries.

1.7.5.1. Examples

Payment model

Payments are made for infrastructure costs and are based on the PPC-Patient Centre Medical Home levels of National Committee for Quality Assurance. These payments vary by region. [79].

Team-based treatment for Medicaid enrollees

Scanlon et al. determined whether multidisciplinary team-based care could reduce medical payments and improve quality for Medicaid enrollees with diabetes. This approach was based on the CCM. Aspects of the CCM were taken into account, such as patient registry, patient education, self-management skills, and multidisciplinary teams. Medicaid diabetes patients who received team-based care at the multisite rural federally qualified community health centre were compared with those who did not. Financial outcomes were compared 1 year before and 1 year after the intervention via Medicaid payments [85].

Cost-effectiveness of CCM in a military setting

Kuo et al. studied the cost-effectiveness of implementing CCM in a Diabetes Outreach Clinic on a military medical centre. A Markov decision model was developed to estimate the cost-effectiveness of this clinic in comparison with usual care. This was done over a 20 year time-span, taking into account health care system, societal perspectives such as discounting costs and benefits at 3% annually. Intervention costs and outcomes were obtained from military data, while other costs, disease progression data, and utilities came from published literature [86].

1.7.6. Outcomes

The first results of multi-payer Patient-Centered Medical home PCMH programs are positive, for example on changes in the patient's attitude within the patient self-management support, on change and care management, on implementing electronic registry functions and on improvements in communication and access.

The results, seen in diabetes care, are positive, both on health outcomes and on cost savings. A significant reduction could be seen among these highest-risk individuals for the three most critical diabetes clinical parameters: glycemic control, blood pressure, and cholesterol. Reductions for overall healthcare costs were promising for the highest risk-group [76].

1.7.6.1. Stakeholders

Chronic Care Initiative

The Chronic Care Initiative has shown improvements in primary healthcare delivery by practices which result in the improvement of the health of patients. Also, the initiators of the program are currently updating and improving the program to manage the best care for chronic disease patients. The focus is especially on collaboration and the infrastructure of primary care. Lessons for practices are the importance of pre-work, the importance of narrative reports as guidance for practice coaches, the importance of a plan and the ability to learn during this time, the importance of keeping track of data in ways to improve, importance of team meetings and reporting. The future of the initiative will include spreading to more practices and include more chronic diseases than diabetes and asthma and also focus on prevention [72].

Patient-Centered Medical Home

This program incorporates the CCM and is implemented in various regions in the U.S. It is taken up with enthusiasm and support by many involved stakeholders, such as payers, health professionals and policy makers.

South East Pennsylvania (SEPA) implementation of the chronic care model

Team-based care is seen as very positive and care management activities have been reimbursed as these activities had a high potential to have impact on diabetes control. Also the way the payment went and the involved parties, 17 organizations around the state, who invested in this initiative was a success. It provided a better understanding of dissemination and spreading [76].

Shared data & Performance measurement

The role of technology

Technology is a promising tool in the delivery of chronic care management. Siminerio et al. state that integrating innovative technology as an interoperable framework during delivery can be cost-effective on several levels, such as health system (to serve as the foundation by providing structure and goals), community (to link with community resources and establish policy), self-management support (to help patients acquire skills and confidence to self-manage), decision support (to assure that providers have access to evidence-based guidelines), clinical information systems (to provide timely access to data about patients and patient populations), and delivery system design (to restructure medical practices to facilitate team care) [77].

Improving Performance in Practice (IPIP)

Overall findings of IPIP show that practices give different patient care after the enrollment in the PA chronic care initiative, such as enhanced teamwork, improved communication between health professionals and patients. Also efficiency has been improved in several practices as the most time consuming aspects and work that raises most annoyance are tackled first [72] .

On the other hand, patients also realize the changes in healthcare and see the importance of self-management and participated in group education [72]. The coaching of IPIP lead to positive results in patients with diabetes at the level of several common complications related to this disease as well as on self-management [87]. A challenge remains regarding the transition from paper to electronic records.

Engaging consumers

DYNAMIC

Stuckey et al. hypothesized that enhanced nurse case management will both improve self-care and reduce emotional distress for patients with diabetes. They state that when proven effective improved nurse case management could be translated to other chronic illnesses [80].

Improving healthcare delivery

Sochalski et al. found that the practices using multidisciplinary teams or in-person communication had significantly fewer hospital readmissions and readmission days than when usual care was provided [81]. Improvement on care management of chronic disease was seen when education was added to residency training programs. Furthermore, the focus slowly shifts from acute illness care towards chronic disease care. It was further understood through the CCM that patients need time with their providers, regular assessments of clinical, behavioral, and psychosocial variables, and ready access to other resources such as pharmacists, nutritionists, and social workers. Awareness is raised that the underlying psychosocial components (depression) in chronic ill patients, such as diabetes patients, are necessary to be acknowledged and that chronic diseases come often together. Through this acknowledgement clinicians can better manage their patient's disease, encourage self-management, and improve long-term outcomes while decreasing risk factors for additional co-morbidities[82].

TEAMcare

TEAMcare is a successful approach to chronic care. This collaborative approach works to manage chronic diseases. A nurse and patient make together a step-by-step plan with achievable goals to reduce complaints. The patient receives specific coaching by a nurse care manager who monitors the patients' complaints. This nurse collaborates with the GP as target goals are not reached.

Multifaceted diabetes care intervention

After the three year follow up, sustained improvements could be observed in the CCM intervention group on several biological aspects and on self-management in terms of self monitoring of blood glucose. The latter is supporting the effectiveness of the used diabetes self-management education program [83].

Aligning finance & Insurance

Team-based treatment for Medicaid enrollees

Clinical indicators as Hba1c, Body Mass Index and blood pressure were improved in the intervention group. In both groups, a small drop could be seen in Body Mass Index. Using an intervention based on the CCM model did not show a significantly lower total Medicaid and Medicare expenditures in comparison with the control group at all levels except for the hospital-based outpatient visits. Here a small significant reduction was found in payments of the intervention group [85].

It was discussed that this exceptional improvement of BMI is noteworthy as care improved without an increase of costs in care. It was hypothesized that better lifestyle management may have been the big driver. Furthermore, it is found that though short-term savings are unlikely, the care management has improved for the better of the patient. The long-term savings are not yet clear, but the results show payers as Medicaid and Medicare receive more value for their dollars due to the intervention based on CCM [85].

Cost-effectiveness of CCM in a military setting

Looking at the cost-effectiveness of a diabetes outreach clinic compared with usual care shows to be economically reasonable when the CCM model is used [86].

1.7.7. Summary

In 2007 the Pennsylvania Department of Health launched a strategic plan to effectively implement chronic disease management by combining the Chronic Care Model and the patient centered medical home. This strategic plan includes a new way of care delivery and organization, new laws to provide transparency in health quality, changes in scope of practice, development of statewide health information exchange, and payment reform;

- A public-private partnership including insurers, healthcare organizations, health systems, educational institutions and government agencies was created for that purpose;
- In 2008 more than 150 primary care practices were enrolled in a demonstration program aiming to deliver proactive, planned care and improve patient outcomes with diabetes as target disease. Participating practices receive support services in order to succeed the implementation of the new model of care delivery;
- The implementation of information technology in diabetes care is stimulated in all elements of the Chronic Care Model;
- Engagement of patients takes place via intensive education by culturally competent health educators;
- Preliminary results are positive: improved patient's attitude regarding and performance of self-management, professionals' readiness to change, teamwork, communication between professionals and patients, health outcomes and cost savings for the highest risk group;
- Challenges remain regarding practice change, dissemination to more practices, and the inclusion of more diseases and expanding to focus to prevention.

1.8. Future Actions in the 4 countries

In this section future actions regarding chronic care improvement for each of the four countries or regions are presented, as retrieved from the included literature.

1.8.1. Future Actions in the Netherlands

In redesigning chronic care in the Netherlands first and most attention has been paid to care for diabetes patients. In a later phase care for patients with COPD and vascular risk management were object of similar, national improvement strategies. It is uncertain, if and when the care for people with other chronic disease, such as heart failure and dementia, will profit from national incentives for quality improvement. The awareness of the limitations of single disease oriented approaches is raising and increasingly attention is paid to multi-morbidity. The National Platform of Standards of Care is preparing a strategy to integrate single disease oriented standards and redesign strategies.

The evidence base for chronic care improvement strategies in the Netherlands is limited. A few large scale based studies are underway and aim to support policy makers in making better informed decisions regarding chronic care management. The first report of RIVM revealed that bundled payment stimulates the implementation of the standard of care for diabetes in the Netherlands and as such, a more systematic delivery of diabetes care. The evaluation also showed undesired side-effects of integrated care: the potential for double insurance claims and 'bypass constructions' (claiming fees for diabetes services in circumvention of the bundled payment agreements). Therefore, one of the recommendations by the researchers was to harmonize the existing pricing mechanisms with bundled payment arrangements [26]. In 2012, the National Evaluation Committee of Integral Financing of chronic care will advise the Minister of Health on the status of the bundled payment scheme once the experimental phase comes to an end. The development and validation of evaluations methods for disease management is one of the aims of DISMEVAL. This project focuses on existing projects in six European countries, including Denmark and the Netherlands. DISMEVAL in the Netherlands is testing two evaluation designs on data of 18 regional care groups (over 106,000 patient), which have contracted disease management for diabetes by means of the bundled payment scheme [31]. Results from DISMEVAL will become available in 2012. Also Lemmens et al. are conducting an evaluation study regarding disease management initiatives in the Netherlands. The objective of this study is to evaluate a large scale implementation of disease management programs in various Dutch regions between 2009 and 2011. The aim of this study is to get a better understanding of the mechanisms of disease management, the feasibility, and cost-effectiveness of a disease management approach to improve health care and the factors that determine success and failure of disease management programs. Whereas DISMEVAL will contribute to policy development, the study of Lemmens et al. will be of use for decision makers and managers during the implementation and integration of Disease Management Programs into the health care system [22].

1.8.2. Future Actions in Denmark

The National Board of Health mentions several improvements to be made in chronic care management [36]. First, the focus should be more on self-management, organization of care, use of decision support systems (guidelines, DMPs), supportive community and policy framework or IT-systems. The focus should be on enhanced support of the individual with a chronic condition to maximize his/her self-care potential, through education and rehabilitation. Patient education models and regional networks can stimulate this. Further, adaptation to special needs of chronic disease management should be taken into account, such as primary care setting, good coordination with sectors and across regions. More support of interdisciplinary working, drawing on the professional skills of nurses and other health care workers, in collaboration with GPs and patients needs to happen. Here, the local community should motivate patients to pursue active self-management and should facilitate healthy lifestyles. The National Board of Health made also recommendations aiming to strengthen information collection methods [7].

Some of these recommendations have been converted into programs. Evaluations of these projects, initiated by the Government, are expected to present their findings in 2013. Enhanced insight and understanding will be obtained on implementing programs based on the CCM. Given that the

results from these evaluations are not yet available, actions for the nearby future are based on the experiences with existing programs in Denmark.

However, studies on integrated healthcare services in Denmark have primarily been case studies identifying problems of information exchange between sectors and describing disease specific gaps in the health care system. The gaps are typically described as related to structural and cultural barriers [8], but it would be interesting to investigate the wider range of the problem. Furthermore Strandberg-Larsen points out that the current methods which are used are relatively resource-intensive. Similar to the Netherlands, experts in Denmark focus on the applicability of evaluation methods to support chronic care management. An ideal method should be practical and relatively simple to use, especially for non-scientific use e.g. on-going monitoring conducted by health system planners. In addition, new measures need to be developed for areas that are as yet covered inadequately [8]. Criteria for the development of existing and new measurement methods have been suggested. A range of broadly validated methods for a specific purpose can be useful to both evidence-based healthcare system management and continuous research efforts within the field of integrated care and ultimately to the benefit of the recipients of care [9].

1.8.3. Future Actions in Quebec

Increased support from the government and regional authorities should lead to integrated care. A special role is seen for the regional authorities as they will have to recruit and mobilize efficient clinical staff, including physicians [59]. However, as was seen in a specific case of stroke care, very little standardization or systematization with respect to approaches to stroke care exist [62]. By developing more standardized tools it is expected that disparities in care and health-related quality of life will improve. The ongoing participation of Heart and Stroke Quebec within the MSN is expected to facilitate timely, bi-directional communications between MSN members (clients, clinicians, investigators) and decision- and policy-makers.

In addition to the improvement of integrated care also further insights are needed of the value and efficacy of team-delivered healthcare and its important components [63]. Also, actions are required on more inter-professional education of health human resources and more practical information systems have to become available to all stakeholders [66]. Hollander et al. mention the particular requirement of and desire for enhanced collaboration with professional providers. In the near future knowledge transfer could act as an important tool for non-professional caregivers for patients with chronic diseases [88].

Furthermore, it is believed that the focus should be more on team-delivered care. Patients and non-professional caregivers should be considered as team members and foster understanding of team theory to ensure a shared perspective of contentious issues such as shifting power for decision making to patients [66].

Gogovor et al. mention the need to increase knowledge of the underlying causes of care gaps and greater concentration on the measurement of clinical, humanistic and fiscal outcomes in comparison with the causal links to disease management structures and processes [58]. Also, the global economic impact of project should be taken into consideration. So far none of the reviewed projects has evaluated the economic impact of chronic care management. As this is an increasing area of interest for payers in the health system [58], a focus on this type of information is desirable.

1.8.4. Future actions in Pennsylvania

Future actions follow from three different projects. First, results from the Chronic Care Initiative/IPIP will be available in 3 years from now. These statewide results of financial investment by insurers and several other organizations will provide direction on future steps that need to be taken regarding the primary care payment system for residents of PA [72].

Second, the SEPA project needs to continue monitoring the intervention and fully assess the impact of the improvements in clinical payments. One of the possibilities in payment is a shift from per-member per-month care management fees to shared savings, and a combined focus on health care utilizations, efficiency, cost and quality of care. Also facilitators and barriers of this initiative will be mapped in a future evaluation. Focus will be paid on identifying the highest-cost individuals, making more use of community resources and making care management a daily routine [76].

Also the multifaceted diabetes care intervention focuses on future actions. According to Piatt et al. it is important to understand if improvements in

outcomes are sustained and what type of patient profit most this multifaceted diabetes care interventions. A Better understanding of how to deliver what care to whom will reduce the proportion of adults with diabetes [83].

Third, Scanlon et al. report on the possible savings from team-based treatment for Medicaid enrollees. Although this study did not show immediate cost reduction effects, it was reasoned that long-term savings might be expected from this intervention. In so doing, Scanlon et al. underline the importance of applying a long term focus when evaluating chronic care management initiatives, given that policy makers and purchasers (including those in the Medicaid and Medicare programs) often believe in cost reduction at the short term [85].

1.9. Discussion

In this study the policies for improving the quality of chronic care in the Netherlands, Denmark, the United States (Pennsylvania) and Canada (Quebec) are described and compared in terms of the implementation of elements of the CCM. Data on policies for improving the quality of chronic care was collected by means of a literature search and with the guidance of experts from the selected countries. By making use of the framework for creating a regional healthcare system [2], an attempt was made to better understand the ways in which the selected regions act upon the challenges of redesigning healthcare systems in order to meet the needs of chronically ill.

The three strategies or pillars of the framework for creating a regional healthcare system will all benefit from the pooling of clinical and cost data to support clinical care and for performance measurement. These three strategies are:

- direct support of practices and active programs of practice change,
- changes to benefits and provider payment to make them more conducive to system change,
- consumer encouragement of cost-effective care through advocacy and purchasing [2].

Each of the strategies are aimed at one of three key sets of stakeholders in transforming care i.e. consumers, providers, and purchasers/health insurers [2]. The framework describes four interrelated strategies to improve chronic care management within a region: performance measurement, engaging consumers, supporting delivery system improvement, and aligning benefits and payment [2].

1.9.1. Implementation of the elements of the CCM

As a result from developing and implementing multiple strategies to improve chronic care management, it can be concluded that most or all of the six areas of the CCM gain attention: self-management support, decision support, delivery system design, clinical information systems, health care organization, and community resources.

1.9.1.1. Health systems: organization of healthcare

- The Netherlands

In 2008 the Dutch Ministry of Health revealed a new vision on chronic care in terms of the programmatic approach for chronic care i.e. an integrated package of various phases (prevention, self-management, evidence based cure and care) of a continuum of care for patient with a chronic disease. To implement the programmatic approach two instruments were introduced on national level: quality measures and bundled payments of integrated care for diabetes, COPD and vascular risk management. Local initiatives are stimulated against the vision of redesigning chronic care within local neighborhoods including an important role for primary care.

- Denmark

The Danish Ministry of Inferior and Health has laid down its policy aims regarding chronic care in multiple documents e.g. the Health Act and Health Throughout Life. Important policy issues are the strengthening of the role of healthcare providers and their collaboration and coherence regarding chronic care on regional level and the role of patients in terms of the strengthening of their ability to promote one's own health within the healthcare and social context. To improve chronic care management use is made of a generic model for chronic disease pathway programs and rehabilitation programs for diagnosed patients, including self-management and personal action plans and important roles for GPs and municipal health centres. Various incentives have been introduced in the system in order to improve the quality of chronic care. Examples of these are:

financial incentives for GPs and municipalities, and quality improvement incentives through benchmarking.

- Québec

Notwithstanding the existence of integrated delivery systems in Canada since the 1970s, disease management programs and multidisciplinary primary care practices were introduced in order to diminish the fragmentation and to increase the accessibility of chronic care. Further organizational expansion took place when local community centres, acute hospitals and long-term hospitals merged into health and social services centres or local health networks which nowadays also include family medicine groups.

- Pennsylvania

In 2007 the Pennsylvania Department of Health launched a strategic plan to effectively implement chronic disease management by combining the Chronic Care Model and the patient centered medical home. This strategic plan includes a new way of care delivery and organization, new laws to provide transparency in health quality, changes in scope of practice, development of statewide health information exchange, and payment reform. For this, a public-private partnership including insurers, healthcare organizations, health systems, educational institutions and government agencies was created.

1.9.1.2. Clinical information systems

In the Netherlands first attempts are made to collect data in a standardized way in order to measure performance. Performance measurements only takes place regarding diabetes management on an experimental base on local level. In Denmark a national strategy was launched in 2007 to facilitate a more systematic and disease related documentation of services across organizations. Until so far, performance measurement takes place on national level for eight disease including COPD, diabetes, and heart failure. Also in Quebec performance measurement and data collection regarding chronic care management takes place on project base and are sometimes part of telehealth experiments. In Pennsylvania the implementation of information technology in diabetes care is stimulated in all elements of the Chronic Care Model.

1.9.1.3. Decision Support

In the Netherlands a lot of effort is spend in the development of national care standards in order to support healthcare providers to implement the programmatic approach and redesign practice.

In Denmark, Quebec and Pennsylvania decision support is mainly being filled by means of professional guidelines.

1.9.1.4. Delivery system design

In the Netherlands the role of primary care receives specific attention in order to strengthen its activities regarding the organization of chronic care. This is getting shape by the development of care groups.

In Denmark there is increasing attention for lifestyle changes. In consequence the role and competencies of health professionals, their interaction with each other and with patients has been examined and resulted in the introduction of for example shared decision making.

In Quebec initiatives are launched to redesign primary care and to create multidisciplinary teams or network organizations in order to provide accessible, comprehensive, ongoing and personalized care. For these initiatives financial incentives were created.

In Pennsylvania more than 150 primary care practices were enrolled in a demonstration program in 2008 aiming to deliver proactive, planned care and improve patient outcomes with diabetes as target disease. Participating practices receive support services in order to succeed the implementation of the new model of care delivery.

1.9.1.5. Self-management support

In the Netherlands, individual treatment plans are promoted as part of national care standards, however only a minority of patients has actually such a plan.

In Denmark, the Stanford Chronic Disease Self-Management Program (CDSMP) has been introduced on national level, to establish a framework for patient involvement.

In Pennsylvania engagement of patients takes place via intensive education by culturally competent health educators.

1.9.1.6. Community: resources and policy

In the Netherlands, Denmark and Pennsylvania emphasis for redesigning chronic care is put on the health system with modest initiatives in the community at this moment.

Quebec has been implementing regional community centres to coordinate, improve and integrate health and social services as well as multidisciplinary team-based practices in primary care to reinforce primary care.

1.9.2. Outcomes of redesigning chronic care management

In all four countries only preliminary results have been presented until now.

- In the Netherlands results regarding the impact of integrated care for chronically illness show modest improvements in process and outcomes of care.
- In Denmark results have revealed solutions to overcome main barriers for integrated care delivery (e.g. financial incentives and HIT), a modest impact of healthcare centres on health outcomes, and the lack of competencies among GPs to coordinate primary care networks.
- In Quebec reforms are characterized as 'being still in its implementation phase' given that structural integration is mostly achieved and clinical integration still being in its infancy. Simultaneously, results show improvement regarding accessibility, reduction in hospitalization rate for elderly, improved knowledge of physicians, satisfaction of patients and healthcare providers, increased use of telehealth, involvement of nurses and no increase in costs.
- In Pennsylvania preliminary results are positive: improved patient's attitude regarding and performance of self-management, professionals' readiness to change, teamwork, communication between professionals and patients, health outcomes and cost savings for the highest risk group.

1.9.3. Barriers in redesigning chronic care management

- In the Netherlands barriers for implementing integrated chronic care are identified (e.g. lack of incentives, lack of collaboration between providers, fragmented primary care) as are components of the Chronic Care Model which are underdeveloped (ICT, coordination of care, proactive patients).
- In Denmark challenges remain regarding an overall strategy to manage the whole patient population, organizational readiness regarding actual change, and data collection.
- Challenges in Quebec are the development of an overall strategy to manage the whole patient population, organizational readiness regarding actual change, and data collection.
- In Pennsylvania challenges exist regarding practice change, dissemination to more practices, and the inclusion of more diseases and expanding to focus to prevention.

In all four regions the systematic collection of meaningful data in order to redesign seems to be troublesome. Currently, aggregate measures of quality or efficiency are generally missing or get collected for research purposes only. Clinical data on individual patients reside in disconnected provider record systems.

However data collection is required :

- to provide a feedback to the providers on their performance,
- for financial incentives,
- for the purchasers and insurers to have access to data to guide payment and quality improvement activities;
- for consumers: to have access to their medical record wherever they receive care [2].

1.9.4. Lessons learned

This study shows that in all four regions multiple policy measures are introduced regarding the three stakeholders and consequently all three strategies of the framework for creating a regional healthcare system. In more general, a shift towards consumer involvement was found in all four regions.

- Policies regarding providers encompass quality improvement strategies (e.g. standards of care, evidence based guidelines), motivation and support of providers to redesign their delivery systems (e.g. collaboratives and/or physician networks) and to a lesser extent the building of clinical data systems.
- Strategies for insurers aim to remove some of the disincentives, redundancies and inefficiencies in current health insurance and payment. Ideally, these should reduce costs as well as encourage a transformation of care, especially if accompanied by incentives for improvement. The experiment regarding the bundled payment scheme in the Netherlands is an example of such strategy.

Practices redesigned in accord with the CCM generally improve the quality of care and the outcomes for patients with various chronic illnesses [89]. In all four regions the building of evidence regarding the impact of redesigning chronic care management has only just started. Consequently, policy makers lack adequate information to take decisions.

The CCM is not a discrete, immediately replicable intervention; it is a framework within which care delivery organizations translate general ideas for change into specific applications [89]. As a result, the specific practice changes associated with a particular CCM element vary from organization to organization and from country to country. Furthermore, practices redesigning chronic care management in accord with the CCM make changes across multiple elements of the CCM.

In all four regions, chronic care management remains work in progress89. According to the authors, the four strategies (i.e. performance measurement, engaging consumers, supporting delivery system improvement, and aligning benefits and payment) are synergistic [2] but further research is necessary to shed light on this question.

REFERENCES

1. Group Health Research Institute. *Improving Chronic Illness Care*. 2011 cited 2011 11 October; Available from: http://www.improvingchroniccare.org/index.php?p=Survey_Instruments&s=165.
2. California HealthCare Foundation (CHCF), *It takes a region: creating a framework to improve chronic disease care*, 2006, CHCF.
3. National Institute for Public Health and the Environment (RIVM). *Zorgbalans*. 2011 cited 2011 October 2011; Available from: http://www.gezondheidszorgbalans.nl/kosten/zorguitgaven/zorguitgaven-bbp/.
4. Schafer, W., et al., *The Netherlands: health system review.* Health systems in transition, 2010. 12(1): p. v-xxvii, 1-228.
5. Tsiachristas, A., et al., *Towards integrated care for chronic conditions: Dutch policy developments to overcome the (financial) barriers.* Health policy, 2011. 101(2): p. 122-32.
6. van de Ven, W.P., et al., *Risk adjustment and risk selection in Europe: 6 years later.* Health policy, 2007. 83(2-3): p. 162-79.
7. Nolte, E., C. Knai, and M. McKee, *Managing Chronic Conditions, Experience in eight countries*, O.s.s.n. 15, Editor 2008, World Health Organization 2008, on behalf of the European Observatory on Health Systems and Policies: Copenhagen. p. 202.
8. Strandberg-Larsen, M., *Measuring integrated care.* Danish medical bulletin, 2011. 58(2): p. B4245.
9. Strandberg-Larsen, M. and A. Krasnik, *Measurement of integrated healthcare delivery: a systematic review of methods and future research directions.* International journal of integrated care, 2009. 9: p. e01.
10. Pennsylvania Department of Health. *Department of health*. 2011 cited 2011 November; Available from: http://www.portal.state.pa.us.
11. Health Canada. *Health Canada*. 2011 cited 2011 November; Available from: http://www.hc-sc.gc.ca/index-eng.php.

12. Sante et Services Sociaux Quebec. *Sante et Services Sociaux Quebec*. 2011 cited 2011 November; Available from: http://www.msss.gouv.qc.ca/en/index.php.
13. Netherlands Organisation for Health Research and Development (ZonMw), *Voorstel voor een Stimuleringsprogramma Zorgverbetering Chronisch Zieken*, 2006, Nederlandse organisatie voor gezondheidsonderzoek en gezondheidsinnovatie: The Hague.
14. Rijksoverheid. *Chronische Ziekten - Samenhang in de zorg*. 2011 cited 2011 October 31; Available from: www.rijksoverheid.nl/onderwerpen/chronische-ziekten/samenhang-in-de-zorg.
15. Klink, A., *Voorhangbrief keten-DBCs en huisartsenbekostiging*, Ministerie van Volksgezondheid Welzijn en Sport, Editor 2009: Den Haag. p. 18.
16. Klink, A., *Voortgangsbrief 'programmatische aanpak van chronische ziekten'* Ministerie van Volksgezondheid Welzijn en Sport, Editor 2010: Den Haag. p. 11.
17. Ursum, J., et al., *Nivel Overzichtstudies Zorg voor chronisch zieken* 2011, Nivel: Utrecht.
18. Raad voor de Volksgezondheid en Zorg, *Bekwaam is bevoegd - Innovatieve opleidingen en nieuwe bereoepen in de zorg*, 2011, Raad voor de Volksgezondheid en Zorg: Den Haag. p. 88.
19. Netherlands Organisation for Health Research and Development (ZonMw). *Disease management chronische ziekten*. 2011 cited 2011 4 november; Available from: http://www.zonmw.nl/nl/programmas/programma-detail/diseasemanagement-chronische-ziekten/.
20. Drewes, H.W., et al., *Differences in patient outcomes and chronic care management of oral anticoagulant therapy: an explorative study.* BMC health services research, 2011. 11: p. 18.
21. Schouten, L.M., et al., Short- and long-term effects of a quality improvement collaborative on diabetes management. Implementation science : IS, 2010. 5: p. 94.
22. Lemmens, K.M., et al., *Evaluation of a large scale implementation of disease management programmes in various Dutch regions: a study protocol.* BMC health services research, 2011. 11: p. 6.
23. Netherlands Organisation for Health Research and Development (ZonMw), *Zorgstandaarden in model - Rapport over het model zorgstandaarden bij chronische ziekten*, 2010, ZonMw: Den Haag. p. 73.
24. Zichtbare Zorg. *Chronisch zorg*. 2011 cited 2011 6 november; Available from: http://www.zichtbarezorg.nl/page/Eerstelijnszorg/Chronische-zorg.
25. Zorg Portaal. *Volledige HIS-KIS koppeling op basis van OZIS operationeel in Friesland*. 2011 cited 2011 6 november; Available from: http://site.zorgportaal.nl/index.php/zorgkrant/nieuwsl-lijst/2545-volledige-his-kis-koppeling-op-basis-van-ozis-operationeel-in-friesland.
26. Struijs, J.N., J.T. van Til, and C.A. Baan, *Experimenting with a bundled payment system for diabetes care in the Netherlands - The first tangible effects*, 2010, National Institute for Public Health and the Environment: Bilthoven. p. 180.
27. Heinrich, E., et al., *Evaluation of the web-based Diabetes Interactive Education Programme (DIEP) for patients with type 2 diabetes.* Patient education and counseling, 2011.
28. Ovink, T.P.E. and E.P.A.J. Denis-Thissen, *TPE, DAWN en DIEP: focus op zelfmanagement-educatie en -ondersteuning.* DiabeteSpecialist, 2009. 30: p. 22-23.
29. Vilans. *Begeleiding praktijkprojecten Diseasemanagement chronische ziekten*. 2011 cited 2011 6 november; Available from: http://www.vilans.nl/Pub/Home/Over-Vilans/Opdrachten/Begeleiding-praktijkprojecten-Diseasemanagement-chronische-ziekten.html.
30. Netherlands Organisation for Health Research and Development (ZonMw), *Op één lijn, meer gezondheid en participatie door sterke organisatie van zorg dicht bij huis*, 2009, ZonMw: Den Haag.

31. Elissen, A.M.J., et al., *Going beyond the 'grand mean', Advancing approaches to disease management evaluation in the Netherlands*, 2011, Maastricht University: Maastricht. p. 127.
32. Lemmens, K.M., et al., *Application of a theoretical model to evaluate COPD disease management.* BMC health services research, 2010. 10: p. 81.
33. Blanson Henkemans, O.A., et al., *Zelfmanagement als Arbeidsbesparende Innovatie in de Zorg*, in *KvL/P&Z 2010.017*2010, TNO: Leiden. p. 96.
34. Klink, A. and J. Bussemaker, *Programmatische aanpak van chronische ziekten*, M.o. Health, Editor 2008: The Hague. p. 12.
35. Frolich, A., M. Strandberg-Larsen, and M.L. Schiotz, *The Chronic Care Model - A new approach in DK.* Health Policy Monitor, 2008: p. 7.
36. The National Board of Health, *Chronic Disease Management - A National Strategy*, Edition, Editor 2007, The National Board of Health: Copenhagen. p. 21.
37. Frolich, A., et al., *A retrospective analysis of health systems in Denmark and Kaiser Permanente.* BMC health services research, 2008. 8: p. 252.
38. Ministry of Health and Prevention, *Health Care in Denmark*, 2008, Ministry of Health and Prevention: Copenhagen. p. 62.
39. Wadmann, S., M. Strandberg-Larsen, and K. Vrangbaek, *Coordination between primary and secondary healthcare in Denmark and Sweden.* International journal of integrated care, 2009. 9: p. e04.
40. World Health Organization. *Public health services - Denmark 2007*. 2011 cited 2011 November; Available from: **http://www.euro.who.int/en/what-we-do/health-topics/Health-systems/public-health-services/facts-and-figures/denmark-2007**.
41. Strandberg-Larsen, M., M. Bernt Nielsen, and A. Krasnik, *Are joint health plans effective for coordination of health services? An analysis based on theory and Danish pre-reform results.* International journal of integrated care, 2007. 7: p. e35.
42. Lorig, K.R., P.D. Mazonson, and H.R. Holman, *Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs.* Arthritis and rheumatism, 1993. 36(4): p. 439-46.
43. National Board of Health. *National Board of Health, Denmark*. 2011 cited 2011 17 November; Available from: **http://nationalboardofhealth.dk/English.aspx**.
44. Frolich, A., et al., *Integration of healthcare rehabilitation in chronic conditions.* International journal of integrated care, 2010. 10: p. e033.
45. National Indicator Project. *The National Inidicator Project*. 2011 cited 2011 17 November; Available from: **http://www.nip.dk/about+the+danish+national+indicator+project** .
46. Nohr, C., et al., *Shared experience in 13 local Danish EPR projects: the Danish EPR Observatory.* Studies in health technology and informatics, 2001. 84(Pt 1): p. 670-4.
47. Godtfredsen, N.S., et al., *Chronic obstructive pulmonary disease (COPD) rehabilitation at primary health-care centres - the KOALA project.* The clinical respiratory journal, 2011.
48. Lorig, K.R., et al., *Chronic disease self-management program: 2-year health status and health care utilization outcomes.* Medical care, 2001. 39(11): p. 1217-23.
49. Lorig, K.R., et al., *Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial.* Medical care, 1999. 37(1): p. 5-14.
50. Steno Diabetes Centre. *Steno*. 2011 cited 2011 17 November; Available from: **http://www.stenodiabetescentre.com/documents/article_page/document/gsd.asp**.

51. Zoffmann, V. and M. Kirkevold, *Realizing Empowerment in Difficult Diabetes Care: A Guided Self-Determination Intervention.* Qualitative health research, 2011.
52. Merkur, S., et al., *Quality in health care systems - with an emphasis on policy options for Austria*, 2008, London School of Economics and Political Science. p. 143.
53. Strandberg-Larsen, M., et al., *Denmark: Health system review. Health Systems in Transition*, 2007, European Observatory on Health Systems and Policies. p. 187.
54. Aarestrup, A.K. and T. Curtis, *Health care centres - a new organizational frame for municipal health promotion and disease prevention in Denmark*, in *The 6th Nordic Health Promotion Research Conference*2009: Gothenburg.
55. Bodker, K. and M.F. Granlien, *Computer support for shared care of diabetes: findings from a Danish case.* Studies in health technology and informatics, 2008. 136: p. 389-94.
56. Vedsted, P., B.S. Jorgensen, and L. Rytter, *Support for self-management in chronic disease?.* Ugeskrift for laeger, 2010. 172(6): p. 444-9.
57. Zoffmann, V., I. Harder, and M. Kirkevold, *A person-centered communication and reflection model: sharing decision-making in chronic care.* Qualitative health research, 2008. 18(5): p. 670-85.
58. Gogovor, A., et al., *Contemporary disease management in Quebec.* Healthcare quarterly, 2008. 11(1): p. 30-7.
59. Jiwani, I. and M.J. Fleury, *Divergent modes of integration: the Canadian way.* International journal of integrated care, 2011. 11(Spec 10th Anniversary Ed): p. e018.
60. Breton, M., et al., *Primary Care Reform: Can Quebec's Family Medicine Group Model benefit from the experience of Ontario's Family Health Teams?* Healthcare policy = Politiques de sante, 2011. 7(2).
61. Ahmed, S., et al., *Changing healthcare: stakeholder perceptions of the burden of chronic disease and the value of teams, measurements and communication.* Healthcare quarterly, 2009. 12(2): p. e1-e13.
62. Poissant, L., et al., *Synergizing expectation and execution for stroke communities of practice innovations.* Implementation science : IS, 2010. 5: p. 44.
63. de Stampa, M., et al., *Fostering participation of general practitioners in integrated health services networks: incentives, barriers, and guidelines.* BMC health services research, 2009. 9: p. 48.
64. Gagnon, M.P., et al., *Measuring organizational readiness for knowledge translation in chronic care.* Implementation science : IS, 2011. 6: p. 72.
65. Payette, C., et al., *Exploring perceptions of healthcare professionals in the implementation of a new professional role of clinical telehealth coordinator within a university integrated healthcare network.* Telemedicine journal and e-health : the official journal of the American Telemedicine Association, 2010. 16(5): p. 614-9.
66. Ahmed, S., et al., *Advancing the chronic care road map: a contemporary overview.* Healthcare quarterly, 2010. 13(3): p. 72-9.
67. Montague, T., *Patient-provider partnerships in healthcare: enhancing knowledge translation and improving outcomes.* HealthcarePapers, 2006. 7(2): p. 53-61; discussion 68-75.
68. Levesque, J.F., et al., *Assessing the evolution of primary healthcare organizations and their performance (2005-2010) in two regions of Quebec province: Montreal and Monteregie.* BMC family practice, 2010. 11: p. 95.
69. Beland, F., et al., *A system of integrated care for older persons with disabilities in Canada: results from a randomized controlled trial.* The journals of gerontology. Series A, Biological sciences and medical sciences, 2006. 61(4): p. 367-73.
70. Beaulieu, M., et al., *CURATA: A patient health management program for the treatment of osteoarthritis in Quebec: an integrated approach to improving the appropriate utilization of anti-inflammatory/analgesic medications.* The American journal of managed care, 2004. 10(8): p. 569-75.

71. *2009 Canadian Hypertension Education Program recommendations: an annual update.* Canadian family physician Medecin de famille canadien, 2009. 55(7): p. 697-700.
72. Bricker, P.L., et al., *Collaboration in Pennsylvania: rapidly spreading improved chronic care for patients to practices.* The Journal of continuing education in the health professions, 2010. 30(2): p. 114-25.
73. National Academy for State Health Policy. *National Academy for State Health Policy*. 2011 cited 2011 November; Available from: **www.nashp.org**.
74. NCQA. *Measuring quality. Improving health care*. 2011 cited 2011 November; Available from: **www.ncqa.org**.
75. National Health Association. *Health science partners with Pennsylvania homecare association in chronic care initiative*. 2011 cited 2011 November; Available from: **http://healthscience.org/**.
76. Gabbay, R.A., et al., *Multipayer patient-centered medical home implementation guided by the chronic care model.* Joint Commission journal on quality and patient safety / Joint Commission Resources, 2011. 37(6): p. 265-73.
77. Siminerio, L.M., *The role of technology and the chronic care model.* Journal of diabetes science and technology, 2010. 4(2): p. 470-5.
78. Bailit, M. *Overview of medical home projects and demonstrations to date*. 2009 cited 2011 November; Available from: **http://www.academyhealth.org/files/SQII/MedicalHomeSummit030209.pdf**.
79. Health Care Conference Administrators. *Improving Performance In Practice*. 2011 cited 2011 November; Available from: **www.ehcca.com**.
80. Stuckey, H.L., et al., *Diabetes nurse case management and motivational interviewing for change (DYNAMIC): study design and baseline characteristics in the Chronic Care Model for type 2 diabetes.* Contemporary clinical trials, 2009. 30(4): p. 366-74.
81. Sochalski, J., et al., *What works in chronic care management: the case of heart failure.* Health affairs, 2009. 28(1): p. 179-89.
82. Zinszer, K.M., J.L. Mulhern, and A.A. Kareem, *The implementation of the chronic care model with respect to dealing with the biopsychosocial aspects of the chronic disease of diabetes.* Advances in skin & wound care, 2011. 24(10): p. 475-84.
83. Piatt, G.A., et al., *3-year follow-up of clinical and behavioral improvements following a multifaceted diabetes care intervention: results of a randomized controlled trial.* The Diabetes educator, 2010. 36(2): p. 301-9.
84. Funnell, M.M., et al., *National standards for diabetes self-management education.* Diabetes care, 2009. 32 Suppl 1: p. S87-94.
85. Scanlon, D.P., et al., *Financial and clinical impact of team-based treatment for medicaid enrollees with diabetes in a federally qualified health centre.* Diabetes care, 2008. 31(11): p. 2160-5.
86. Kuo, S., et al., *Cost-effectiveness of implementing the chronic care model for diabetes care in a military population.* Journal of diabetes science and technology, 2011. 5(3): p. 501-13.
87. Pennsylvania Academy of Family Physicians. *Pennsylvania Academy of Family Physicians*. 2011 cited 2011 November; Available from: **www.pafp.com**.
88. Hollander, M.J., G. Liu, and N.L. Chappell, *Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly.* Healthcare quarterly, 2009. 12(2): p. 42-9.
89. Coleman, K., et al., *Evidence on the Chronic Care Model in the new millennium.* Health affairs, 2009. 28(1): p. 75-85.

2. OVERVIEW OF KCE REPORTS

This appendix details the recommendations from the main KCE reports on chronic care. All recommendations have been classified into one of the categories proposed by the chronic care model.

For each report the interested reader can find the scientific report and related conclusions via the link proposed in the tables.

2.1. Quality and organization of type 2 diabetes

Quality and organization of type 2 diabetes care (KCE-27-2006)

The full report can be found on: https://kce.fgov.be/publication/report/quality-and-organization-of-the-care-for-diabetes-2

Recommendations for national policy:

- Transition from symptom-focused care to global proactive, patient-focused and integrated care with patient education, systemic follow-up and secondary/tertiary prevention of complications (domain tailored delivery system design)
- Patient-empowerment and support from relatives: process criteria for treatment fidelity (registration of the GMD/DMG, frequency of consultations), synchronized interventions to support the patient (patient educations, intensive follow-up) (domain self-management)
- Transition towards primary care multidisciplinary team (in collaboration with circles, local discussion platforms (LOKs/Glems) or diabetes networks (domain tailored delivery system design)
- Central role of GP (and primary care setting) and integration of diabetes care in basic and postgraduate education (domains appropriate workforce)
- Crucial role of diabetes educator (recognition in Belgian law) (domain appropriate workforce)
- Provision of education in diabetes care for residential staff (domain appropriate workforce)
- Definition of role of diabetes-specialists: coaching and training of all members of multidisciplinary team and development of guidelines for referral of patients to a specialist (domains appropriate workforce and quality processes)
- The development of shared care protocols within the multidisciplinary teams (domain quality processes)
- The development of a polyvalent clinical information system and its accessibility for the health care providers (crucial for integrated patient care) (domain clinical information systems)
- Development of systems for quality monitoring and evaluation (indicators, standards and evaluation criteria) (domain quality processes)
- Existing initiatives must be replaced by national initiatives with a central communication platform collaborating with the existing diabetes organizations (domain tailored delivery system design)
- Financial support for teams with activities outside the traditional fee-for-service system (domain appropriate financing)

2.2. Clinical quality indicators

Clinical quality indicators (KCE-41-2006)

The full report can be found on: https://kce.fgov.be/publication/report/clinical-quality-indicators

Recommendations:

- Need for a clear vision and development of strategy about quality policy in health care (domain tailored delivery system design)
- Identification of priority areas that need quality monitoring (based on explicit health objectives)(domains tailored delivery system design and quality processes)

Recommendations for development clinical quality indicator (QI) system (domain quality processes)

- Objectives and use of QI: decided and explicit in advance+ neutral evaluation of consequences on quality of health care
- Need for valid and complete database: standardized registration methodology and data analyses + timely feedback to its users + coordination of registration and feedback
- High quality evidence: importance for development of QI+ transparent involvement of clinical experts (final selection and formulation QI)

Efforts on level of clinical excellence and on level of resources necessary to initiate a credible and professional quality system (domain quality processes)

2.3. Medication use in nursing homes

Medication use in nursing homes (KCE-47-2006)

The full report can be found on: https://kce.fgov.be/publication/report/medication-use-in-rest-and-nursing-homes-in-belgium

Recommendations:

RVT formulary:

- measures should be taken to increase implementation and impact (domain quality processes)
- larger role of medical coordinator (domain appropriate workforce)
- pivotal role of formulary in knowledge transfer of best practices towards prescribing physicians and in local implementation of prescription guidelines and quality control systems (domain quality processes)
- close collaboration with scientific, professional associations (domain tailored delivery system design)
- provision of evidence summaries on appropriateness by independent drug information and pharmacovigilance centers and increase of awareness for risks associated with drug utilization in elderly (domain clinical information systems)

Generic drugs (domain decision support):

- local agreements could increase their use
- investigation of possibilities for applying unit-dose (packaging per individual patient)

Medical staff: (domain appropriate workforce)

- better training in pharmacology of nursing staff and enhanced communication can improve the quality of pharmaceutical care
- clinical pharmacists should assist and participate in all stages of medication use process

Financing system (domain appropriate financing)

- exploration of other financing systems, besides fee-for-service system, such as case-mix budgeting and reference pricing

2.4. Chronic low back pain

Chronic low back pain (KCE-48-2006)

The full report can be found on: https://kce.fgov.be/publication/report/chronic-low-back-pain

Recommendations on:

- Need for awareness of all care providers on the dangers of inactivity among patients, the uselessness of applying multiple diagnostic procedures, the evidence in favor of certain conservative treatments and the absence of such data for many other applied interventions
- It is crucial to get patients back to work as quickly as possible
- Close cooperation needed between occupational physicians and physicians in the curative sector
- Current data sources are too fragmentary

2.5. Personal contribution for health care in Belgium. Impact of supplements

Personal contribution for health care in Belgium. Impact of supplements (KCE-50-2006)

The full report can be found on: https://kce.fgov.be/publication/report/personal-contribution-for-health-care-in-belgium-impact-of-supplements

Recommendations on:

Transparency: (domain appropriate financing)

- Large variation in supplements affects patient's choices
- Clear regulation necessary on the data collection on supplements
- More transparency in price setting (also for the ambulatory care)

Protection mechanisms: (domain tailored delivery system design)

- Actual system of MAB only protects for high out-of-pocket payments, not for supplements

- Duration of hospital stay must be taken into account in new protection systems (in case of chronic and psychiatric patients)
- Better protection of patients with recurrent hospital admissions
- Regulation should make a clear distinction between indispensable and non-indispensable costs
- Be aware of social stratification in choice of rooms, which could lead to differences in quality of care and care provision
- Regulation of supplements in ambulatory care

Supplemental hospital insurance: (domain tailored delivery system design)

Clear regulation necessary to improve accessibility for everybody (domain tailored delivery system deisgn)

2.6. Chronic care of persons with acquired brain injury between the age of 18 and 65 years

Chronic care of persons with acquired brain injury between the age of 18 and 65 years (KCE-51-2007)

The full report can be found on: https://kce.fgov.be/publication/report/chronic-care-of-persons-with-acquired-brain-injury-between-the-age-of-18-and-65-y

Recommendations:

Residential care: (domain tailored delivery system design)

- Need for specific units for young persons with acquired brain injury (ABI) (18-65y) with separated communities (leefgroepen), sufficient and competent staff and adapted infrastructure
- Age-base criterion in order to maintain the positions for persons <65y
- The conversion of RVT/MRS beds into ABI-beds in a limited number of geographically spread recognized institutions
- Support for the staff for specific competences: organization of modified age-specific day activities, stimulation of social contact, support by psychic/psychiatric/cognitive problems

Residential care for specific subgroups: (domain tailored delivery system design)

- Specific units for persons with severe behavior problems in small departments, spread over Belgium, for temporarily and permanent stay
- Evaluation of these units via pilot projects
- Development of supportive network for ABI-persons, staying in other care sectors
- Creation of permanent stay in Sp-services for persons with severe physical care dependency (high medical and nursing needs)
- Specialization of certain institutions in residential care for persons with a degenerative disease
- Expand NIHDI-convention for specific MS-centers to all MS-patients staying in care homes (RVT/RMS centers)

Home care: (domain tailored delivery system design)

- demand for additional professional support and for temporarily relief of the volunteer aid by respite care

- Need for day centers
- Demand for more care options and individual-based care (zorg op maat)

Coordination between different care settings: (domain tailored delivery system design)

- Recognition of specific expertise centers
- Development of a network between centers
- Expansion of SEN (Steunpunt Expertise Netwerken) for ABI-persons (domain tailored delivery system design)

2.7. Organization and financing of musculoskeletal and neurological rehabilitation in Belgium

Organization and financing of musculoskeletal and neurological rehabilitation in Belgium (KCE-57-2007)

The full report can be found on: https://kce.fgov.be/publication/report/organisation-and-financing-of-musculoskeletal-and-neurological-rehabilitation-in-

Recommendations:

Regulation: (domain tailored delivery system design)

- Need for a global concept in Belgium

Financing: (domain appropriate financing)

- Need for differentiation of financing systems Need for transparency of financing systems and based on delivered services in function of the needs of the patient
- Need for geographically spread centers over Belgium (determined by the Conventions)
- Integration of monodisciplinary therapy under the supervision of the rehabilitation physician in the multidisciplinary treatment
- Shift from 7/7 financing to 5/7 or day hospitalization to promote weekend stay at home

Rehabilitation: (domain tailored delivery system design)

- The establishment of three specialized centers for spinal cord injuries
- “Stratification model” for sub-acute rehabilitation with a general, specific and high specific level, organized in a network. Determinants are complexity of rehabilitation needs and incidence/prevalence.
- The intake and referral of patients in the system must be based on a patient classification system (PCS). This classification system must include the medical diagnosis, a measurement instrument for the functional needs and possibilities of the patient and a certain additional data (like co-morbidities, age, contextual factors).
- Making the registration of the medical diagnosis and co-morbidities on short-term mandatory, would be a progress for the evaluation of the provision of services (better assessments of incidence and prevalence of reimbursement categories)
- On short term, systematic registration in post-acute phase with a measurement instrument like FIM/Barthel-index is recommended (both in hospitalization

as in ambulatory care)

- In evaluation of the quality of the organizational and financing system must be taking into account the outcome of treatment, quality of life, perception of the patient on quality of care etc.
- The registration systems used in other countries could be an example for Belgium
- Restart of the visitation commissions is recommended
- The organization of networks for the continuity of care
- Estimations on the number of rehabilitation centers: 20-30 on specific level, 3-5 on high specific level (in which the rehabilitation of complex pathologies is centralized). General rehabilitation must be broadly accessible (via acute hospitals)
- Proposition of financing (domain appropriate financing): on general level a fee-for-service or a mixed system with relative high fee-for-service component, on specific and high specific level a mixed system with partly a fixed financing and partly fee-for-service financing (or envelope financing for high specific centers)

The differentiation in individual treatment and group sessions is recommended (also on the level of rate) (domain tailored delivery system design)

2.8. Physician workforce supply in Belgium: current situation and challenges

Physician workforce supply in Belgium: current situation and challenges (KCE-72-2008)

The full report can be found on: https://kce.fgov.be/publication/report/physician-workforce-supply-in-belgium-current-situation-and-challenges

Recommendations:

- Need to enhance the coordination and harmonization of routine data collection on the 'stock and flows' of the medical supply (domain quality processes)
- Role of the national Register of the Medical Profession: data on head counts, actual level of activity, attrition or migration rate should be validated and made publicly available to stakeholders and researchers (domain clinical information systems, tailored delivery system design)
- complementary data collection needed for more specific information on practice arrangements, workload indicators or certain determinants of medical productivity (domain quality processes, appropriate workforce)
- Regular surveying (quantitative and qualitative) of a sample of health care practitioners (similar to the Netherlands and France) (domain quality processes)
- Identification and monitoring of indicators on health needs, such as disease trends or new clinical management (domain quality processes)
- The collected data must feed the forecasting model so as to reflect as much as possible the system as a whole and to produce useful scenarios. It is also important to evaluate the uncertainty of the model by deterministic sensitivity analysis or stochastic simulation. Other types of models should also be considered, such as the effective demand-based approach which accounts the health needs and the economic parameters.(domain quality processes)
- Need for the development of a national workforce planning framework, which would be integrated, consistent and evidence-based (decisions are informed by sufficiently reliable information and robust methodologies) and evolutive (flexible and adaptive to rapidly changing health system). The Committee of Medical Supply Planning should be empowered for this role as developer of a national framework. (domain appropriate workforce, quality processes)

2.9. Financing of the care program for geriatric patients in classic hospital

Financing of the care program for geriatric patients in classic hospital (KCE-73-2008)

The full report can be found on: https://kce.fgov.be/publication/report/financing-of-the-care-program-for-geriatric-patients-in-classic-hospital

Recommendations:

Definition and identification of geriatric patient: (domain decision support)

- Definition of SBGG-BVGG
- Screening: ISAR (version of BGMST), SHERPA (with Mini-Mental State) but requires extra staff
- Identification of geriatric problems: BGMST

Internal liaison geriatrics (liaisongeriatrie) (domains decision support, appropriate workforce and tailored delivery system design)

- Screening with measurement instrument of each patient of 75 years and older at admission in hospital
- The demented patient in a nursing home and the patient admitted with a hip fracture can be determined as geriatric
- Every patient, identified as geriatric, must be seen by the geriatric nurse of the liaison team
- The liaison nurse reports daily to the geriatrist and the liaison team meets every week
- The liaison nurse plays an active role in the different multidisciplinary care teams in the hospital
- The liaison team consist of a geriatrist and at least 1 to 2 VTE nurses. The composition of the multidisciplinary team can be determined by the institution.
- Need for a more decentralized model for geriatrics
- Need for sensitization for geriatric culture

Financing instruments (domain appropriate financing)

- APS instrument most appropriate (most valid, adapted at G-departments, taking in account the specificity of each patient, cost-effective, easy control of data and implementation)

Proposition to reform financing of acute geriatric departments (domain tailored delivery system design)

- Conditions: additional research and validation

Reformations: collection of additional data, improvement of the distribution of justified days between geriatric departments, more reasonable distribution of the financing of staff on the acute geriatric departments (taking in account the specificity of the patients, the treatment and the needs) (domain quality processes)

2.10. Quality development in general practice in Belgium: status quo or quo vadis?

Quality development in general practice in Belgium: status quo or quo vadis (KCE-76-2008)

The full report can be found on: https://kce.fgov.be/publication/report/quality-development-in-general-practice-in-belgium-status-quo-or-quo-vadis

Recommendations

Role of the authorities:

- major conditions to implement quality development in general practice: will of the authorities, a clear leadership and a national quality policy (domain tailored delivery system design and quality processes)
- Need for definition of the stakeholders' role, a time schedule for implementation, the balance between summative and formative assessment, taking into account the potential negative consequences of both types of assessment (domain tailored delivery system design)
- The solution should take root within the existing structures (for example the accreditation bodies of the NIHDI of the Ministry of Public Health). A first phase would include the setting of a quality platform with many representative stakeholders in order to look for synergy and develop concrete proposals (domain quality processes)
- IT developments for the data collection and quality measurement should be discussed within the Be-Health Program (domain clinical information systems)
- Financial support or reallocation of existing budgets is needed to achieve a significant improvement of the quality of care in terms of process and outcomes (domain appropriate financing)
- IT providers should answer to strict conditions that allow a data extraction from routinely collected data (domain clinical information systems)

Role of the profession: (domain appropriate workforce)

- A professional culture is the driving force for setting up quality initiatives in general practice. The profession has to participate in the definition of quality initiatives and to propose efficient tools to improve quality.
- The academic and GP bodies have a definite role to play to teach the future GPs about the concepts of quality development and are competent for developing balanced sets of indicators including clinical and non clinical indicators

Role of the practices and GPs

- The introduction of practice based quality development is necessary to foster quality improvement in Belgium. The practices should be aware of the formative and summative consequences of the quality measurement (domain quality processes)
- The practices should have the necessary organization for performing quality development activities (domain tailored delivery system design)
- The accurate registration of data by the GPs is a condition to measure quality from records routinely collected (domain clinical information systems)

2.11. Effects of the Maximum Billing system on health care consumption and financial access to health care

Effects of the Maximum Billing system on health care consumption and financial access to health care (KCE-80-2008)

The full report can be found on: https://kce.fgov.be/publication/report/effects-of-the-maximum-billing-system-on-health-care-consumption-and-financial-ac

Recommendations:

Improvements of the maximum billing system (domain appropriate financing):

- Simplification of administrative complexity (due to expansion of the system)
- Taking into account the number of households with more than 5% of OOP-payments (especially chronically ill and psychiatric patients) and the persistency of OOP-payments over time
- Introduction of an additional lower MAB-ceiling of 250euro for the poorest households
- Need for research specific on the poorest households
- Need for research on the coverage by the complimentary insurance

Need for linking the data on the health expenditures to the data on the revenues (and the information on morbidities). This kind of dataset will refine the microsimulation model, in order to analyze coherently future policy recommendations (domain appropriate financing)

2.12. Quality insurance for rectal cancer-phase 2:development and testing of a set of quality indicators

Quality insurance for rectal cancer-phase 2: development and testing of a set of indicators (KCE-81-2008)

The full report can be found on: https://kce.fgov.be/publication/report/quality-insurance-for-rectal-cancer-phase-2-development-and-testing-of-a-set-of-q

Recommendations on:

- Modification of some indicators and PROCARE data/variables necessary
- Modifications needed to improve the performance of data registration: web application, simplification of registration form, decrease of number of variables
- Coupling between BCR database and other administrative databases is feasible and reliable, coupling with TC database is rather limited
- Re-evaluation of relevance and interpretation of indicators needed in 2009 to select key-indicators for implementation
- PROCARE registration need to be guaranteed for international population-based comparison

2.13. Long stay patients in psychiatry T-beds

Long stay patients in psychiatry T-beds (KCE-84-2008)

The full report can be found on: https://kce.fgov.be/publication/report/long-stay-patients-in-psychiatry-t-beds

Recommendations:

Role and place of T-beds in het provision of services

- Need for debate if long-term stays in T-beds (>6y) needs to be seen as a hospital service
- Broader research needed to determine if patients with a long-term stay (>6y) need to be taken care of in T-beds or in alternative care settings
- Two priority key-points: do persons with mental disabilities need to be taken care of in T-beds and what are the most appropriate care services, support and care trajectories for patients who have a juridical statute?
- An integrative, scientific based vision needed on the organizational model in mental health care with an identification of all types of care services for patients with a chronic and severe psychiatric disorder and the development of a balanced care model to optimize the transition of patients out of the T-beds

Trajectories of patients (reorientation and reintegration)

- Need for debate on the interpretation of deinstitutionalization: reorientation in other care services differs from reintegration

Equity

- The development of a care model needs to take into account the social protection and social justice
- The policy of reorientation and reintegration could imply potential equity problems

Databases

- Evaluation of validity and reliability needed of the MPG database

Future research

- Need for context-sensitive analysis of social-geographical variability, taken into account the ageing population
- Need for research on the role and relevance of social networks
- Need for research on the variability in medication prescription and medication use

2.14. Comparison of the cost and the quality of two financing systems of primary health care in Belgium

Comparison of the cost and the quality of two financing systems of primary health care in Belgium (KCE-85-2008)

The full report can be found on: https://kce.fgov.be/publication/report/comparison-of-the-cost-and-the-quality-of-two-financing-systems-of-primary-health
Recommendations:

- on the short term the current manner of calculation can be maintained (domain appropriate financing)
- additional research needed on the quality aspects (domain quality processes)
- the basic lump sums need to be modified based on age and socio-economic status of the patients (domain appropriate financing)
- the social factors, which generates costs, need to be determined (domain appropriate financing)
- the modification due to bias of the denominator must be maintained and refined (domain appropriate financing)
- the savings may not lead to misplaced effects. The reorganization of savings must encourage accessibility, quality and efficiency (domain quality processes)
- the evolution in determining the lump sums need to be go together with monitoring of the evolution of the expenditures for patients per lump sum and per services (domain appropriate financing)
- Programs need to be set up for the evaluation of the quality of care (domain quality processes)
- Gradual evolution towards new lump sums is considered if these new lump sums strongly differ from the current amounts (domain appropriate financing)

2.15. Differentiated practice in nursing: opportunities and limits

Differentiated practice in nursing: opportunities and limits (KCE-86-2008)

The full report can be found on: https://kce.fgov.be/publication/report/differentiated-practice-in-nursing-opportunities-and-limits

Recommendations: (domain tailored delivery system design and appropriate workforce)

- The broader delegation of logistic and administrative tasks by local hospital management and authorities need to be encouraged
- The elementary care, which demands basic competences, should be delegated to a caretaker (zorgkundige). The role of this care provider needs to be determined: a clear description of the function, an explicit description of the role, a competence profile, training, training of nurses and the monitoring of the impact on efficiency and quality of care.
- Nurses need to be trained in delegating tasks, surveillance and to provide the necessary guidance
- The differentiation towards higher levels needs to be elaborated in order to increase the career perspectives of nurses with a masters degree and to increase the attractiveness of the profession.
- The differentiation towards lower and higher levels need a reflection on preservation of the integrated care for the patient. Pilot projects and the monitoring of the results of efficiency and quality of care is needed.

2.16. Consumption of physiotherapy and physical and rehabilitation medicine in Belgium

Consumption of physiotherapy and physical and rehabilitation medicine in Belgium (KCE-87-2008)

The full report can be found on: https://kce.fgov.be/publication/report/consumption-of-physiotherapy-and-physical-and-rehabilitation-medicine-in-belgium

Recommendations:

- No justification for the distinction between K- and M- nomenclature for the rehabilitation of uncomplicated cases following surgical interventions. The systematic choice for K-nomenclature in many hospitals has to put to an end. (domain appropriate financing)
- An adapted nomenclature should allow the appropriate remuneration of PRM specialists for following intellectual activities: medical diagnosis, drawing up rehabilitation treatment, orientation of patient to mono-or multi-disciplinary treatment, follow-up and coordination of care provided by allied health professionals (domain tailored delivery system design)
- Choice of rehabilitation should only be based on medical diagnosis, functional status and patient's environmental situation. No uniformly collected information on functional status of rehabilitation patients available (domain decision support)

2.17. Fatigue Syndrome: diagnosis, treatment and organization of care

Fatigue Syndrome: diagnosis, treatment and organization of care (KCE-88-2008)

The full report can be found on: https://kce.fgov.be/publication/report/fatigue-syndrome-diagnosis-treatment-and-organisation-of-care

Recommendations:

Belgian reference centers did not achieve to organize a gradual care organization model, so financing should be restricted:

- pilot project of a more structured care model in which the primary care plays an important role, in collaboration with the secondary care and the reference centers (domain tailored delivery system design)
- redistribution of the financing partly towards physiotherapists and psychologists (domain appropriate financing)
- structured care model must be based on scientific methods in order to obtain valid data (for cost-effectiveness) (domain tailored delivery system design)
- early treatment of CFS enhances integration into society. The results of this early treatment needs to be evaluated and compared with data in scientific literature (domain decision support, quality processes)
- more attention must be given to individual sessions, next to group sessions. Both methods must be scientifically compared for effectiveness. (domain decision support)
- No scientific evidence for the combination of CGT and GET, preference must be given to one of both therapies (domain decision support)
- Need for collection of data on the level of severity of CFS (in a pilot project) and registration of comorbidities (domain clinical information systems)
- The therapeutic manuals within the care networks must be based on the manuals of which the effectiveness is proven in clinical studies (domain decision support)

- Need for information towards the care providers concerning the value of diagnostic examinations (specific workgroup in Hoge Gezondheidsraad) (domain decision support)
- Associated comorbidities not studies in KCE-report but need for consensus about their role in communal networks (domain tailored delivery system design)
- Need for training of physiotherapists and psychologists for the treatment of CFS (important role of reference centers) (domain appropriate workforce)

2.18. Making general practice attractive: encouraging GP attraction and retention

Making general practice attractive: encouraging GP attraction and retention (KCE-90-2008)

The full report can be found on: https://kce.fgov.be/publication/report/making-general-practice-attractive-encouraging-gp-attraction-and-retention

Recommendations:

Initiatives at the level of medical faculties: (domain appropriate workforce)

- The initial selection of students should target on those with the best human qualities and profile that fists for GP specialty
- General practice should be positioned as a fully-fledged specialty within medical faculties
- Accurate information and lectures about this specialty in the curriculum
- Specific GP lectures on solutions to overcome difficulties that future GPs will encounter on the field
- GP clerkship of high quality should be encouraged

Initiatives to improve working conditions: (domain tailored delivery system design)

- Favoring the work in team or within networks
- Working in group practice
- The development of well organized out-of-hours services
- Initiatives like career breaks for a better balance with the private life
- Development of new career perspectives

Initiatives to improve the financial conditions (domain appropriate financing)

- The Belgian authorities should extend the current incentives for working in team and working in underserved areas
- Differences between incomes of GPs and other specialists should be analyzed to go towards a softening of these differences
- Valid information about the GP remuneration and diversification of payment mechanisms should be given to students

2.19. Financing of the geriatric day hospital

Financing of the geriatric day hospital (KCE-99-2008)

The full report can be found on: https://kce.fgov.be/publication/report/financing-of-the-geriatric-day-hospital

Recommendations:

Data collection: domains health system (financing) and clinical information systems

- Since 2009 compulsory registration of MKG in a GDH (domain clinical information systems)
- Need for sensibilization for the coding of characteristics, the co morbidities and the contacts with the health services of geriatric patients (domain clinical information systems)
- Yearly follow-up of the proportion of diagnosis , therapy and rehabilitation in the total number of activities (domain quality processes)
- Study on the influence of duration of admission on the financing, using the MKG data of 2004, 2005 and 2006 (domain quality processes)
- Linking the results of the validation, based on MKG of 2004, 2005 and 2006 to the registrations starting from 2009 (domain quality processes)

Pilot project:

- Decrease or suspend financing of hospitals with a significant lower occupancy rate (domain tailored delivery system design)

Financing of the pilot project:

- Need for research on the goals of GDZ, financial needs, satisfaction of patients, relatives and care providers, cost for the patient, role of other care providers, alternative financing methods, minimal norm for financing (domain appropriate financing)

2.20. Pharmaceutical and non-pharmaceutical interventions for Alzheimer's Disease, a rapid assessment

Pharmaceutical and non-pharmaceutical interventions for Alzheimer's Disease, a rapid assessment (KCE-111-2010)

The full report can be found on: https://kce.fgov.be/publication/report/pharmaceutical-and-non-pharmaceutical-interventions-for-alzheimer%E2%80%99s-disease-a-rap

Recommendations on:

Clinical practice:

- Physicians should limit the use of antipsychotics in AD patients to situations where their use is absolutely necessary. The use of antipsychotics is associated with a significant increase in mortality.
- Initiation of ChEI treatment in hospitalized medically instable AD patients should be judged carefully given the slightly increased early mortality in such patients

Reimbursement:

- Reimbursement of Ginkgo biloba cannot be justified

- The reimbursement of memantine in monotherapy should be questioned given the very weak clinical efficacy and lack of robust cost-effectiveness data
- Reimbursement of ChEIs can be continued but should be subject of a revision of reimbursement criteria as foreseen under article 38 of the law of December 21,2001
- During revision procedures, the possible benefits on behavioural disturbances in geriatric patients needs to be taken into account
- The non-pharmaceutical intervention should be implemented in Belgium, ideally as a large randomized trial

Methodological recommendations:

- Health technology assessments should include as much as possible all sources of evidence and not only trials published
- Coding of non-reimbursed prescription medicines is necessary for analyzing their use

2.21. Organization of palliative care in Belgium

Organization of palliative care in Belgium (KCE-115-2009)

The full report can be found on: https://kce.fgov.be/publication/report/organisation-of-palliative-care-in-belgium

Recommendations:

Definition of palliative patients: (domains tailored delivery system design)

- patients should be recognized as “palliative patients” when they are in an advanced or terminal stage of severe, progressive and life threatening disease whatever their life expectancy;
- this “palliative status” is different from the “terminal stage” of a disease and includes the needs assessment of the patient. This assessment should be initially performed and followed at regular intervals by the main physician in collaboration with a palliative care team;
- the meaning of “needs” should consider all dimensions, including the need for information and for social support in order to allow patients to stay at home when feasible and preferred by the patient;
- this definition of a patient who needs palliative care should be different from the definition that gives access to financial or social support, a definition that is specific for each health care system and that requires a consensus at the level of the Belgian health care system.
- Importance to identify all palliative patients, including non-oncological patients: patients with advanced chronic conditions, patients with dementia

Training of health care professionals: (domain appropriate workforce)

- courses in palliative care (“basic training”) should be included in the curriculum of all health professionals and should also be offered as continuing education by scientific societies;
- the content of this basic training should encompass common major subjects across all curricula e.g., the control of symptoms, communication skills, social problems, spiritual needs;

Organization of palliative care: (domain tailored delivery system design)

- the care model should be multidisciplinary and tailored to the individual patient
- relatives are a target group to be included in the care models in home settings in order to prevent their exhaustion and to allow the patients to stay at home when they expressed this preference;
- need for a reinforcement of links between settings to offer a continuity of care to the patient;
- standardized records are required in all settings to register and to follow advance care planning and preferred place of death

Registration: (domain clinical information systems)

- is required for all settings that benefit from a specific financing for caring for palliative patients, including the nursing homes;
- this data collection should be standardized and include data on the number of patients, their profile, the process of care and when available, quality indicators.

Cost: (domain appropriate financing)

- need for encouragement of intervention of palliative care mobile teams in hospitals in the light of the lower costs (in comparison with classical care) and the better balance between this care model and the patient's need

2.22. Use of point-of-care devices in patients with oral anticoagulation: a health technology assessment

Use of point-of-care devices in patients with oral anticoagulation: a health technology assessment (KCE-117-2009)

The full report can be found on: https://kce.fgov.be/publication/report/use-of-point-of-care-devices-in-patients-with-oral-anticoagulation-a-health-techn

Recommendations:

Organization:

- Organization of long term oral anticoagulant therapy monitoring: patients self management and to a less extent patient self testing (domain self-management)
- Many data currently unavailable in Belgium, economic conclusions based on hypothetical scenarios (domain tailored delivery system design)
- Pilot study to calculate real costs and assess financial impact: define number and characteristics of patients eligible for patient self-management or patient self-testing (domain appropriate financing)

Aspects need to be taken into account:

- Selection of patients based on personal willingness and abilities + close relatives may also be selected (domain self-management)
- Training of the patient compulsory and standardized. If the patient passes the practical test, a certification is obtained for patient self-management. This test may be less demanding in case of patient selftesting and will focus on the ability to perform the test. (domain self-management)
- Assistance and follow-up should be available for solving problems with the testing or the adaptation of the doses (domain self-management)
- An external quality control of the POC devices is needed. (domain quality processes)

Cost:

- cost items to be considered for reimbursement: patient training, the POC device, strips and quality control, and advice from a health professional. (domain appropriate financing)

POC devices:

- For the use of POC devices by a GP or in an anticoagulation clinic, the evidence is not sufficiently robust to recommend its use at present. (domain decision support)
- Regardless of the use of POC devices, the development of guidelines and training of health professionals involved in oral anticoagulation treatment monitoring are essential. (domain decision support)

Evaluation

An evaluation of these recommendations is needed when new anticoagulants become a standard of care for patients with long term oral anticoagulation treatment. (domains decision support and clinical information systems)

2.23. Advantages, disadvantages and feasibility of the introduction of 'Pay for Quality' programmes in Belgium

Advantages, disadvantages and feasibility of the introduction of 'Pay for Quality' programmes in Belgium (KCE-118-2009)

The full report can be found on: https://kce.fgov.be/publication/report/advantages-disadvantages-and-feasibility-of-the-introduction-of-%E2%80%98pay-for-quality%E2%80%99

Recommendations: (domain quality processes)

- Quality can be measured by structure, process as intermediate outcome indicators
- Everybody who achieve the quality targets need to be rewarded. The incentive should be targeted at all providers, at individual and organizational level
- The implementation of pay for quality-programs has to be done gradually and with pilot programs
- Accurate, validated and already available data are preferred. This implies an investment in IT development and an audit system
- A monitor system must be provided from the start

2.24. Financing of home nursing in Belgium

Financing of home nursing in Belgium (KCE-122-2010)

The full report can be found on: https://kce.fgov.be/publication/report/financing-of-home-nursing-in-belgium

Recommendations: (domain tailored delivery system design)

- A profound political reflection is needed on the respective roles of different health services functions and on how these functions connect within an overall vision on health services provision. One of the future challenges will be to assess to what extent the developments in tele-monitoring, patient support tools

and independent living technologies will affect on how nursing care and support can be organised and financed. This general debate will require structured negotiations between the different political levels.

- A mixed financing system in home nursing is probably the most acceptable and appropriate financing system in Belgium (+ continuously assessment)(lump sum financing for chronic care) (domain appropriate financing)
- A clearer distinction should be made between post-acute care and long term care: It could be discussed whether some specific post-acute care can also be financed via a parallel hospital financing system (DRG or case-mix). A further reflection is needed on the collaboration between hospitals and home nursing (to mobilise the necessary skills for specialised nursing care). One should also reflect on how to employ sufficiently qualified nurses in the home nursing sector (the subcontracting of specialised post acute care to home nurse providers, according to the quality standards of the hospitals).
- Long-term care payment needs to more clearly disentangle basic care and follow-up of chronic conditions from technical care to handle the current complexity and overlap in financing rules. Payment for chronic conditions should be based on an evaluation of patient dependency for lump sum financing. Technical or specialised care should be based on a fee-for service payment system with adequate tariffs
- Little is currently known on the cost structure of home nursing. It is recommended to study to what extent fees/tariffs cover real costs. A further debate needs to get form on the collection of data to document these real costs, as currently no standardised data are available for all home nursing providers. Cost calculations should take into account the organizational characteristics of the providers, e.g. the different logistic structure and the so-called back-up services of the different types of home nursing providers (large organizations, self-employed nurses) and the regional characteristics (urban/rural).
- Part of the financing can be based on dependency categories or resource utilization groups, which need to be better defined. A field study with primary data-collection is needed in a Belgian home nursing context performing a comparative validation (reliability and validity) of instruments, including an assessment of usability of different dependency scales in the daily practice of home nursing.
- In terms of quality of care, it has to be considered to what extent characteristics of the nurses such as their qualification, level of expertise and experience should be taken into account. If they are paid differently, a discussion will be needed on the criteria used to justify different payments. This debate needs to be integrated in the reflection on overall health care provision and quality of care. Within this logic, the practice of nurses combining a main job outside home nursing with a part-time job as self-employed nurse performing only specialized nursing interventions to patients at home (cherry picking) should be evaluated given the concerns with regard to the continuity and quality of care from an integrated care perspective.

Further methodological reflections are needed on how “pay for performance” or “pay for quality” can be introduced in home nursing. (domain tailored delivery system design)

Organization and financing of chronic dialysis in Belgium

2.25. Financing of home nursing in Belgium

Organization and financing of chronic dialysis in Belgium (KCE-124-2010)

The full report can be found on: https://kce.fgov.be/publication/report/organisation-and-financing-of-chronic-dialysis-in-belgium

Recommendations:

Guidelines: (domain decision support)

- Development of clinical guidelines to improve decision making including patient participation

Counseling: (domain self-management)

- Every patient informed timely, fully and objectively about different dialysis modalities
- Could be included as a requirement for all pre-dialysis patients in ambulatory care pathway for ESRD
- Inclusion of tool to assess effect of introducing counseling services in dialysis centers in data registration protocols of Belgian association for nephrology

Financing: (domains appropriate financing)

- Reimbursement of dialysis treatments should reflect real costs to hospital an patient and dialysis reimbursement should not be justified on basis of compensation for underfinanced hospital services
- Coverage of intellectual act of nephrologists and consumables by one fee for service for hospital HD should be abandoned
- The financing through a lump sum *and* a medical fee for hospital HD on the one hand and through a lump sum only for alternative dialysis modalities on the other hand should be reconsidered.
- A payment per hospital HD session, per satellite HD session and per PD week that resembles more closely the real costs of each treatment modality should be considered. A correction for co-morbidities that are clearly correlated with the costs of the ambulatory dialysis treatment can be considered. The link with the historical per diem price and the system of lump sum bonuses for hospital HD can, in the context of a complete revision of the financing mechanisms for dialysis, be abandoned.
- The reimbursement of transportation to and from the dialysis centre with private means should be reconsidered in order to better reflect the real costs of transportation to patients. If a private transportation means is shared by patients the reimbursement should only be charged to the NIHDI once.

It should be investigated why and to what extent the amounts paid to home nursing services differ between hospitals (domain tailored delivery system design)

2.26. The reference price system and socioeconomic differences in the use of low cost drugs

The reference price system and socioeconomic differences in the use of low cost drugs (KCE-126-2010)

The full report can be found on: https://kce.fgov.be/publication/report/the-reference-price-system-and-socioeconomic-differences-in-the-use-of-low-cost-d

Recommendations:

Different measure to reduce amount of reference supplements:

- Prescribers: a targeted increase of low cost prescription quota in consultation with the National Commission Physicians-Sickness Funds + Stimulate of INN prescription (domain tailored delivery system design)
- Pharmacists: allow substitution right (domain tailored delivery system design)
- Patients: increase patient's awareness of reference supplement (clear information on amount and type of supplement paid) (domain self-management)

Structure of the system:

Reference price: setting reference price with respect to price of all low cist drugs within a cluster (domain tailored delivery system design)

2.27. A first step towards measuring the performance of the Belgian healthcare system

A first step towards measuring the performance of the Belgian healthcare system (KCE-128-2010)

The full report can be found on: https://kce.fgov.be/publication/report/a-first-step-towards-measuring-the-performance-of-the-belgian-healthcare-system

Recommendations: (domain quality processes)

- The construction of a complete set of indicators must be planned and consolidated. The required staff needs to be provided
- Clear objectives needs to be determined and indicators need to searched to evaluate these objectives
- Reports need to be produced on a regular basis, taking into account the data demands by international organizations and the periodicity of some Belgian health data. A yearly report is feasible if sufficient staff is provided.
- First priority is to determine the gaps in the current report
- For the evaluation of the health care system all performance dimensions need to be considered. For some dimensions, domains of the health system or disease domains, specific working groups should be set up to guarantee the consultation of relevant indicator sources, the correct definition of selected indicators and the use of appropriate data. The involvement of patient organizations in the stakeholder group could correct the gap.
- The scope of the performance system should not only focus on health care but also comprise other aspects, like non-medical determinants of health
- The selection of indicators need to be specified on the Belgian health care policy
- In the selection of indicators a balance need to be found between the already included indicators and the new indicators. Available databases need to be consulted for the creation of these new indicators. This will demand a close collaboration with the data managers.
- The absolute precondition for a performance system is the involvement and collaboration of all health authorities.

- The working group, responsible for the selection, measurement and reporting of the performance indicators, need to be guided by a scientific consultancy board, which represents all relevant competences.
- A political work group need to be set up by the Interministerial conference to evaluate the use of the report
- The interpretation of the performance measurement demands more than only data on health care, other factors like context and non-medical determinants need to be taken into account
- Data suppliers need to be involved in the process of indicator definition and measurement
- Each data supplier need to indicate a single person of contact to facilitate data transmission
- The availability of data need to be improved
- The results need to be calculated on a national level, if necessary more detailed results can be calculated
- The results of this report are preliminary
- For the correct use and interpretation of this and future reports, a communication and distribution plan needs to be set up. The NIHDI and the federal public service need to play a pro-active role in the communication and use of the report
- Performance indicators have a warning function. The responsible services and organizations need to be identified to put action points into action

2.28. Seamless care for medications

Seamless care (KCE-131-2010)

The full report can be found on: https://kce.fgov.be/publication/report/seamless-care-with-regard-to-medications-between-hospital-and-home

Recommendations:

- A need to compile, publish and circulate good practice guidelines on seamless care with regard to medication, based on international guidelines and results of this research (domain decision support)
- Attention of care providers and patients should be drawn to the importance of the continuity of medications at the time of transition and to the shared responsibility of all (domains tailored delivery system design and self-management)
- The sharing of patient data in electronic form should become increasingly operational, with respect to the rules of safety and confidentiality (domain clinical information systems)
- Seamless care focusing on medications at admission and discharge should be formalized in clear procedures (domain decision support)
- The training of health professionals in ambulatory care or in hospitals should include aspects relating to this issue (domains appropriate workforce)

The possible financing of initiatives relating to seamless care focusing on medications between home and hospital should be subject to a credible evaluation aimed at demonstrating subsequent clinical and possibly economic effects (domain tailored delivery system design)

2.29. Emergency psychiatric care for children and adolescents

Emergency psychiatric care for children and adolescents (KCE-135-2010)

The full report can be found on: https://kce.fgov.be/publication/report/emergency-psychiatric-care-for-children-and-adolescents

Recommendations on:

General

- Urgent psychiatric care (SEPH) needs to be developed as a function and not as a fixed organizational structure: in priority ambulatory care and only if necessary in residential care, the development of this function needs to fit in the organization of mental health care for children and adolescents
- Coordination of activities and financing needed between federal level, communities and regions to develop a conceptual framework in which the function fits: structural entity covering the strategic and policy aspects to realize the organizational adaptations in mental health care
- Loco-regional level: expansion and financing of collaboration models between different types of caregivers
- Comprehensive approach in mental health care: clear distinction needed between collaboration between partnerorganizations and caregivers (network model) and collaboration for activities on individual patient level; guarantee of direct and accessible care in SEPH-function; the SEPH-function needs a list of supportive aids (mobile outreach teams, telephonic services, consultation room, observation units, normal and strong secured residential beds); emergent psychiatric care needs to be focused on ambulatory care in the environment of the child or adolescent; linkage between SEPH-function and emergency department in hospital

Geographical distribution and aids

- One SEPH-function per 150 000 minors and at least one per province, resulting in 15 psychiatric emergency care functions
- A buffer bed capacity needs to be foreseen for urgent care. The guarantee of a maximum wait time with a minimum of backup bed capacity must be done by pooling.

Registration and research

- Need for research on the needs of mental health care for children and adolescents, combined with a further development of data registration
- Need for follow-up evaluation focused on the outcomes on patient level and on the effectiveness and efficiency of the collaboration models

2.30. The Belgian health system in 2010

The Belgian health system in 2010 (KCE-138-2010)

The full report can be found on: https://kce.fgov.be/publication/report/the-belgian-health-system-in-2010

Recommendations: (domain tailored delivery system design)

- Further improvement in effectiveness of preventive care, appropriateness of care, efficiency and sustainability could further enhance the performance of the overall system

- Future changes and reforms will aim at simplifying the system in order to make it more homogeneous

2.31. Cardiac rehabilitation: clinical effectiveness and utilization in Belgium

Cardiac rehabilitation: clinical effectiveness and utilization in Belgium (KCE-140-2010)

The full report can be found on: https://kce.fgov.be/publication/report/cardiac-rehabilitation-clinical-effectiveness-and-utilisation-in-belgium

Recommendations:

Good clinical practice: (domain decision support)

- Any cardiac patient who has undergone a coronary intervention of who has been discharged after hospitalization for coronary disease or heart failure should be allowed to benefit from: medical checkup, exercise program (with advice of specialist in cardiac rehabilitation), limited number of complementary sessions to improve cardiovascular risk profile (could be in ambulatory care)
- Exercise and other rehabilitation sessions spread over several months (to ensure lifestyle changes)
- Raising GP' awareness and education in relation to importance of exercise
- GP and cardiologists should raise the patients' awareness of the importance of exercise
- Lifelong follow-up by GP necessary to maintain healthy lifestyle changes

Health insurance management: (domains tailored delivery system design)

Billing codes for cardiac rehabilitation should make a distinction between actual multidisciplinary assessment by specialist in cardiac rehabilitation, rehabilitation sessions with physiotherapist and the sessions with other health professionals

2.32. Organization of mental health care for persons with severe and persistent mental illness. What is the evidence?

Organization of mental health care for persons with severe and persistent mental illness. What is the evidence? (KCE-144-2010)

The full report can be found on: https://kce.fgov.be/publication/report/organization-of-mental-health-care-for-persons-with-severe-and-persistent-mental-

Recommendations on:

- In the balanced care model, further deinstitutionalization for persons suffering from severe and persistent mental illness is recommended
- This will only be possible with the simultaneous development of adapted care and housing in the personal environment of the patients, making optimum integration into society possible and based on the individual needs of each patient
- The authorities must continue with the elaboration of a mix of protected housing with different options in autonomy and intensity of support
- Non-residential care and support needs to be developed. Special attention is needed to support daily activities and reintegration into working life
- Intensive multidisciplinary support and coordination of care for people suffering from a SPMI who are frequently re-hospitalized must be encouraged, for instance based on the ACT model

- The financial aspect must not prevent any patient from evolving towards the most appropriate form of care
- Further development of the current care structures must be carried out systematically and in stages. Based on current scientific knowledge and available data, it is not possible to predict which forms of care and how many places will be necessary.
- Intermediate critical evaluations are needed, both on level of care process as on level of the patient. Australia could be used as a model
- It is absolutely necessary to describe explicitly in policy papers or discussions what is meant by care circuits, care networks, care coordination, integrated care or continuity of care, in order to avoid the same term being used very different organizational concepts.
- The proposed development of health care requires the necessary coordination between federal and regional policy levels.

2.33. Mental health care reforms: evaluation research of “therapeutic projects”

Mental health care reforms: evaluation research of “therapeutic projects” (KCE-146-2010)

The full report can be found on: https://kce.fgov.be/publication/report/mental-health-care-reforms-evaluation-research-of-%E2%80%98therapeutic-projects%E2%80%99

Recommendations on:

- Stimulation of the organizational innovation in mental health care by the government via structural strategic programs
- For implementation of structural programs, a continuous fine-tuning between different policy authorities is needed. This process should be supported by a permanent interministerial department.
- In the development of policy programs, more attention should be given to communication with and support to the executing sector
- Within the framework of a general common policy, separate subprograms need to be developed for age-specific target groups or specific domains
- On the level of collaboration, more attention should be given to the concrete elaboration of the configuration of the collaboration and the mutual agreements
- The role of the coordinator must be defined as a function who stimulates and supports the collaboration and not only as an administrative support.
- The conditional financing of interprofessional consultation must be maintained but refined by increasing the consultation on the evolving needs of the patient
- The involvement of primary care is a necessity in a de-institutionalized care model
- More understanding is needed in the manner how to involve patient and relatives on an efficient way during the interprofessional consultation
- Need for the development of a mutual framework for the development of a adapted care plan in mental health care
- Need for sufficient preparation and guidance in terms of respect for duty of professional confidentiality within the therapeutic teams
- Innovative projects on interorganizational and interprofessional collaboration need to be continuous evaluated, not only on policy and organizational modalities but also on impact on societal participation and wellbeing of the patient

- Need for implementation of prospective registration of patient data and exploit these data for scientific evaluations

2.34. Quality indicators in oncology: testis cancer

Quality indicators in oncology: testis cancer (KCE-149-2010)

The full report can be found on: https://kce.fgov.be/publication/report/quality-indicators-in-oncology-testis-cancer
Recommendations:
Quality of care: (domain quality processes)

- Follow-up of quality of care should be considered (most appropriate method needs to be determined)

Implementation of QI set: (domains quality processes and clinical information systems)

- Need for risk-adjustment should be thoroughly assessed
- Appropriate cut-off values defined for each QI in collaboration with College of Oncology
- Revision of existing nomenclature codes for testicular surgery to current practice standards
- Nomenclature codes for CT and MRI need to be specific to an anatomic location
- Correct use of 7th edition of TNM classification and its registration
- Adding “recurrence” to current list of variables with mandatory registration at the cancer registry

Adding to the MDT form of radiation dose and field (clinical target volume), inclusion in clinical trial

2.35. Quality indicators in oncology: breast cancer

Quality indicators in oncology: breast cancer (KCE-150-2010)

The full report can be found on: https://kce.fgov.be/publication/report/quality-indicators-in-oncology-breast-cancer
Recommendations:
Implementation of quality indicator set: Data-related actions (domains quality processes and clinical information systems)

- Modifications of nomenclature (codes for CT, MRI, percutaneous biopsy and cytological assessment specific to anatomic location)
- Cancer registration:
- use of 7th ed TNM classification and registration of cTNM and pTNM
- delay between incidence year and availability of data at 2 years or less
- availability of national data on causes of mortality and linkages with cancer registration data within delay of 2 years (according to European regulation)

- adding of variables to list of variables for mandatory registration at cancer registry: local and distant recurrence, recruitment in clinical trials, number of positive lymph nodes, resection margins after surgery, radiation dose and field
- standardization of breast pathology report required
- regular prospective surveys on selected topics (random sample of medical files)

2.36. Pharmacological prevention of fragility fractures in Belgium

Pharmacological prevention of fragility fractures in Belgium (KCE-159-2011)

The full report can be found on: https://kce.fgov.be/publication/report/pharmacological-prevention-of-fragility-fractures-in-belgium

Recommendations on:

For clinicians:

- The pharmacological prevention of fragility fractures should be targeted to high-risk patients, i.e. patients who will benefit the most from the treatment
- The individual fracture risk is assessed with clinical algorithms. BMD should be measured only in individuals presenting risk factors of fragility fractures
- All patients presenting a fragility fracture should be proposed a pharmacological prevention of further fractures. Worth mentioning, such prevention is more effective on vertebral fractures than on fractures at other sites. NNT for preventing I hip fracture is high.
- In the absence of prior fragility fractures, a strategy based on the individual absolute risk of fracture must be implemented. There is today no consensus on the definition of what a high 10-year fracture risk is. Following treatment strategy is recommended: if 10-year fracture risk is high with low BMD a treatment is recommended but only protective effect of pharmacological treatment on vertebral fractures; if 10-year fracture risk is high with BMD in normal range, a treatment is not recommended (this does not preclude clinicians from considering a treatment on individual basis); if 10-year fracture risk is low, a treatment is not recommended
- Considerations, such as patient preferences or adherence, should also intervene in the treatment decision. Absolute risk of fractures, risk reduction expected from treatment, and risk of serious adverse events should be discussed with the patient.
- The pharmacological prevention should be viewed as a component of a comprehensive management plan, which identifies primarily risk factors amendable to non-pharmacological interventions. Causes of secondary osteoporosis should also be duly identified and treated.
- Monitoring treatment with repeated DXA is not recommended and currently not enough evidence to recommend other types of treatment monitoring

For policy makers:

- The utilization of clinical algorithms for assessing the absolute 10-year risk of fragility fractures should be promoted in all individuals presenting one or more risk factors, particularly during consultations in general medicine. It should be part of the Global Medical File. The dissemination of screen-and-treat algorithm for individuals at high-risk would be an asset.
- The health services should be encouraged to consider treatment in every patient presenting a fragility fracture, e.g. by an information campaign
- Expensive molecules which clinical benefit is not supported by firm evidence should not be reimbursed except for very specific indications

2.37. Dementia: which non-pharmacological interventions

Dementia: which non-pharmacological interventions? (KCE-160-2011)

The full report can be found on: https://kce.fgov.be/publication/report/dementiawhich-non-pharmacological-interventions

Recommendations on:

Categories of interventions

- Support and training for informal caregivers, including multicomponent interventions at home: this has been shown to have among others a positive effect on institutionalization
- Training for residential care staff
- Physical activity programs at home or in residential facilities
- Cognitive stimulation/training therapy

No details on implementation but evidence that they should be

- Tailored to patients and their close informal carers to meet their needs as closely as possible
- Followed up by specially trained staff
- Continued over time, with regular contacts in order to produce significant effects

The data currently available for other non-pharmacological interventions do not allow recommendations to be made.

2.38. Diagnosis and treatment of varicose veins in the legs

Diagnosis and treatment of varicose veins in the legs (KCE-164-2011)

The full report can be found on: https://kce.fgov.be/publication/report/diagnosis-and-treatment-of-varicose-veins-in-the-legs

Recommendations on:

- Doppler ultrasound is the diagnostic technique that is currently recommended to steer therapeutic decisions in relation to varicose veins of the lower limbs
- Thermal ablation techniques (laser, radiofrequency) and sclerotherapy may be recommended as alternatives for conventional surgery: the results are comparable in the medium term and the techniques may be carried out under local anaesthesia, or even without anaesthesia for sclerotherapy
- An adjustment of the list of billing acts is required that gives these new techniques a place and promotes their use in an outpatients environment under local anaesthesia (or even without anaesthesia for sclerotherapy) for the treatment of varicose veins without complications
- Registration of serious complications and relapses is required to verify the long term safety and effectiveness of these new techniques (particularly as regards the use of foam sclerotherapy)

- The current data does not allow recommendations in connection with the use of compression in the treatment of varicose veins of the lower extremities
- Medication treatments are not recommended

2.39. Entitlement to a hospital insurance for persons with a chronic illness or handicap

Entitlement to a hospital insurance for persons with a chronic illness or handicap (KCE-166-2011)

The full report can be found on: https://kce.fgov.be/publication/report/entitlement-to-a-hospital-insurance-for-persons-with-a-chronic-illness-or-handica

Recommendations:

Article 138bis-6 (domain tailored delivery system design)

- Definition of minimum conditions for modalities of the contract to avoid the risk on differentiation
- All candidate-insurees, younger than 65years, could claim a private hospitalization insurance, with the possibility of exclusion of the costs related to a previous illness, disorder of condition
- A new evaluation should happen taking into account the Bemiddelingscommissie ziektekostenverzekering and the effects of the exemption of the 9.25% taxes for high level of protection

Publicity and transparency (domain self-management)

- Information of the general public via different information channels and tools
- Maximum of transparency by the private insurers and the national health services for the premiums, content and proportion of coverage and the general contract conditions, via a type-contract hospitalization insurance (domain **Error! Reference source not found.**)
- Reference on the websites of Assuralia and the national health services to the website of FOD Economie, Middenstand en energie (overview of the different kinds of hospitalization insurances)

Better protection of persons with a chronic illness or a handicap (domain tailored delivery system design)

- Evaluation of the costs for ambulatory care and the costs not covered by the compulsory health insurance

Protection rather task of national solidarity than by private insurers (domain tailored delivery system design)

2.40. Residential care for older persons in Belgium: projections 2011-2025

Residential care for older persons in Belgium: projections 2011-2025 (KCE-167-2011)

The full report can be found on: https://kce.fgov.be/publication/report/residential-care-for-older-persons-in-belgium-projections-2011-%E2%80%93-2025

Recommendations:

Without policy change and assuming a constant behaviour of users (domains tailored delivery system design)

- 45 000 beds should additionally be created in the residential sector for old people by 2025, i.e. an annual increase of 2 700 beds.

- The need for residential structures will be even more acute after 2025. It is therefore necessary to anticipate this development.
- The increase in the residential sector will have to consider the uneven growth of the oldest old persons (85+) and the current supply at local level.

If there is a willingness to curb the increasing use of residential structures (domain tailored delivery system design)

- Policies supporting older persons to live at home for as long as possible could be envisaged (more severe access criteria to enter in residential institutions, introduction or strengthening of a long term care insurance, administrative and financial status for informal caregiver, increase in pensions for low-income earners, development of home care or other forms of sheltered housing for old people, …).
- The impact of such policies on projected needs for additional beds in the residential sector could be evaluated with the projection model used in this study, provided that it is possible to precise how these policies would impact the transition probabilities between care levels and care settings. The assessment of new transition probabilities could result from studies that analyzed pilot projects, such as the ongoing study about the alternatives to the institutionalization of old people, led by a university group and financed by the NIHDI (Protocol 3).
- For each alternative, a particular attention to the need for qualified personnel is required.

2.41. Organization of child and adolescent mental health care: study of literature and an international overview

Organization of child and adolescent mental health care: study of literature and an international overview (KCE-170-2011)

The full report can be found on: https://kce.fgov.be/publication/report/organisation-of-child-and-adolescent-mental-health-care-study-of-the-literature-a

The recommendations are included in the second part of the report (KCE-175-2012).

2.42. After-hours primary care: which solutions?

After-hours primary care: which solutions? (KCE-171-2011)

The full report can be found on: https://kce.fgov.be/publication/report/afters-hours-primary-care-which-solutions

Recommendations on:

The development of an action plan in collaboration with all stakeholders concerned to solve the problem of after-hours in general practice

- Taking into account the patients' needs, the doctors' desires, the possibilities to collaborate with other health professionals and structures, the capacity of the authorities to meet the expense, the required changes in legislation, the deontological sides and their uniform implementation
- Different solutions have to be combined, taking into account the current local situations
- A unique call number, which offers the advantages of simplicity for the patient, security for the doctor and the registration of calls for system assessment purposes
- Define with local interested parties whether the 1733 calls should be routed to the switchboard of the local circle for primary care problems or whether a solution should be provided by the 1733 telephone operator whatever type of problem

- Legislate on the subject of the legal status of call handlers, their training and competencies and the need for a protocol to underpin their decisions
- Draw up these protocols (emergency mechanisms, referral to the first line, postponement of consultation etc)

Implementation of different solutions adapted to local situations to follow-up calls, in consultation with local circles. Multiple possibilities:

- Merging territories during slack periods
- Cooperation agreements with local hospitals during slack periods: definition of triage modalities, existence of a triage system, possibility of contact with general practitioner
- Creating organized duty centers: a geographic distribution, favor areas that have no hospitals
- Consultation by nursing staff: regulation of qualifications, review of list of acts
- Telephone consultation: protocols needed

Elements to be taken into account

- Patient: information on efficient use, accurate information specifying optimum service for the problem, possibility of home visits for patients unable to travel
- GPs: general practice needs to be made more attractive (KCE-report 90), after-hours work needs to be made more attractive in terms of working conditions, definition of status and conditions of exercise for “after-hours doctors”, information for doctors on absence of legal obligations for home visits
- Resources: adequate financing if unique call number solution is extended, optimization of use of resources during slack periods, possibility of telephone consultations, standardized financing of duty centers
- Communication technologies: availability of patient medical record for first-or second line service providers during after-hours, information for usual GPs as soon as they return to work
- Routine standardized data collection for each type of service

2.43. The organization of mental health services for children and adolescents in Belgium: development of a policy scenario

The organization of mental health services for children and adolescents in Belgium: development of a policy scenario (KCE-175-2012)

The full report can be found on: https://kce.fgov.be/publication/report/the-organisation-of-mental-health-services-for-children-and-adolescents-in-belgiu

Recommendations on:

- To strengthen the capacity to provide accessible, responsive and effective crisis and emergency care to children and adolescents
- To deepen and support the professional competences in non-specialized mental health care so as to improve the quality of assessment, care and eventual liaison with specialized services
- To expand mental health-oriented prevention, identification, intervention and promotion for infant and toddlers particularly in vulnerable and deprived populations
- To expand formal and informal support services for both children/adolescents and families

- To strengthen accountability of care providers for children with serious, multiple and complex mental health problems and to expand and reinforce capacity to provide flexible and assertive care in their natural environment
- To improve cultural and linguistic competences of children and adolescent mental health care providers and youth workers to accommodate the cultural specifications of the populations they serve
- To establish a respectful, multilateral dialogue on a shared vision for the broader child and adolescent mental health services system including all relevant stakeholders (including representatives of children and families)+ to develop an ethical charter to guide caregivers in formulating answers to the suffering of the child+ to maintain and strengthen cross-sectoral forums at different institutional levels that activate and mobilize collaboration and network formation on an ongoing basis
- To obtain good qualitative and quantitative data of the need for, offering of CAMHS and related outcomes, to effectively leverage regionally distributed care facilities and to facilitate the formation of regional care networks
- To apply and develop evaluation methods based on international best practices, reflecting national or regional specificities, and in harmony with ethical guidelines, with the aim to reinforce accountability, professionalism, quality improvement and multidisciplinarity in providing mental health care to children and adolescents
- To give a clear political signal that a culture of innovation and evidence-based practice in the Belgian CAMHS system is encouraged and rewarded, and to make this tangible by rapidly setting up actual implementation initiatives.

3. SYSTEMATIC REVIEW: METHODOLOGY, RESULTS BY DISEASE, QUALITY APPRAISAL AND TABLES OF EVIDENCE

3.1. List of abbreviations for the systematic review

LIST OF ABBREVIATIONS	ABBREVIATION	DEFINITION
	CBT	cognitive behavioural therapy
	CFS/ME	chronic fatigue syndrome/myalgic encephalomyelitis
	CSFBD	cognitive scale for functional bowel disorders
	CSM	comprehensive self-management
	CSM-IP	comprehensive self-management delivered in-person
	CSM-T/IP	comprehensive self-management delivered by telephone and in-person
	eGFR	Estimated glomerular filtration rate
	HRQoL	Health-related quality of life
	IBS	Irritable bowel syndrome
	IBS-QoL	Irritable bowel syndrome quality of life
	PSC	Pain catastrophising scale
	QoL	Quality of life
	NCD	non-communicable diseases
	RCT	randomised controlled trial
	SMS	Self-management support
	SMD	standardised mean difference
	SR	systematic review
	SGRQ	St George's Respiratory Questionnaire
	WHO	world health organisation

3.2. Methods

3.2.1. Search strategies

There is a vast amount of literature on patient self-efficacy/self-empowerment/self-management of chronic disease. In order to manage the volume of literature anticipated, the search was segmented into two phases. During the first phase, systematic reviews were included from 1999. Once relevant high quality systematic reviews were identified, a second phase identified relevant RCTs by restricting the search to more recent years (2009 to 2012).

3.2.1.1. Search for systematic reviews

The following databases were searched in January 2012 for publications in English, French, Dutch or German from the year 1999 (see illustration in 3.5.5):

- The Cochrane Library
- OVID Medline
- OVID EMBASE
- Psychinfo
- CINAHL

3.2.1.2. Search for RCTs

The Cochrane Library, OVID Medline, OVID EMBASE were searched in February 2012 for publications in English, French, Dutch or German from the year 2009. This year was chosen as the search time point as many recent systematic reviews from 2009 were identified in phase 1, therefore searching for RCTs from the last three years would capture the most recent trials.

3.2.2. Assessing methodological quality and risk of bias

3.2.2.1. Systematic reviews

The methodological quality of systematic reviews and associated risk of bias were rated using the SIGN tool[e]. This tool uses a scale of ratings (well covered, adequately addressed, not addressed, not reported and not applicable).The assessment of the risk of bias in the included systematic review was conducted by a team of two reviewers (FA,GO) who pre-agreed the ratings before beginning quality analysis.

In order for systematic reviews to be included, three of the four following criteria had to be rated as “well covered” or “adequately addressed”:

- Appropriate and clearly focused study question;
- Description of methodology; sufficiently rigorous literature searches (e.g. Cochrane, Medline, EMBASE or CINAHL or Psychinfo);
- Quality and methodological strengths and weaknesses of identified data assessed and taken into account.

The results of the quality appraisal are in appendix 3.5.1

3.2.2.2. Randomised controlled trials

The methodological quality of selected RCTs was rated using a modified version of the SIGN tool. The assessment of the risk of bias in the included RCTs was conducted by a team of two reviewers (FA, GO).

In order for RCTs to be included, three of the four following criteria had to be rated as “well covered” or “adequately addressed”:

- Randomisation
- Blinding of outcome assessment
- Treatment groups comparable at baseline
- Description of dropouts and withdrawals

The results of the quality appraisal are appendix 3.5.3.

[e] http://www.sign.ac/methodology/checklists.html

3.2.3. Data extraction

3.2.3.1. Systematic reviews

Data from systematic reviews and from trials were extracted into a specifically designed data extraction table (DET) in order to summarise key design features and results. The DET of the systematic reviews captured the following information: reference, details of searches, inclusion and exclusion criteria, and summary of specific interventions, number and types of studies included, outcomes, results of self-efficacy, clinical and health-care use and a summary of author's conclusions as well as our comments on the interpretation of results.

3.2.3.2. Randomised controlled trials

The DET for RCTs captured the following information: reference, country, patient numbers and characteristics, details of intervention, details of control, outcomes reported, time of follow-up, results of self-efficacy, clinical and health-care use and interpretation of results. The assessment of risk of bias and the data extraction were performed by two reviewers (FA, GO) into a pre-prepared Word® summary table. Extraction was verified in full by cross-checking by each reviewer. Any discrepancies were resolved through discussion with an independent third party (SM).

3.3. Search Results

3.3.1. Systematic reviews

3.3.1.1. Identified studies

A total of 4,465 citations on the topic of patient empowerment interventions for chronic diseases were identified in database searches (Figure 1). The majority of citations were excluded on the basis of title and abstract; 52 citations were retrieved in full and reviewed in more detail.

On the basis of full text, 39 reviews were included and 13 reviews were excluded.

The reasons for exclusion on full text were:

- Five studies on intervention not relevant [1-5]
- Four studies as outcomes not relevant [6-9]
- One study was a duplicate [10]
- One as study was not a systematic review [11]
- Two studies as intervention was treatment of the disease [12, 13]

3.3.1.2. Quality appraisal of the 39 reviews selected

As a first step, quality appraisal of the 39 reviews was carried out to determine their suitability for inclusion, using the SIGN tool.

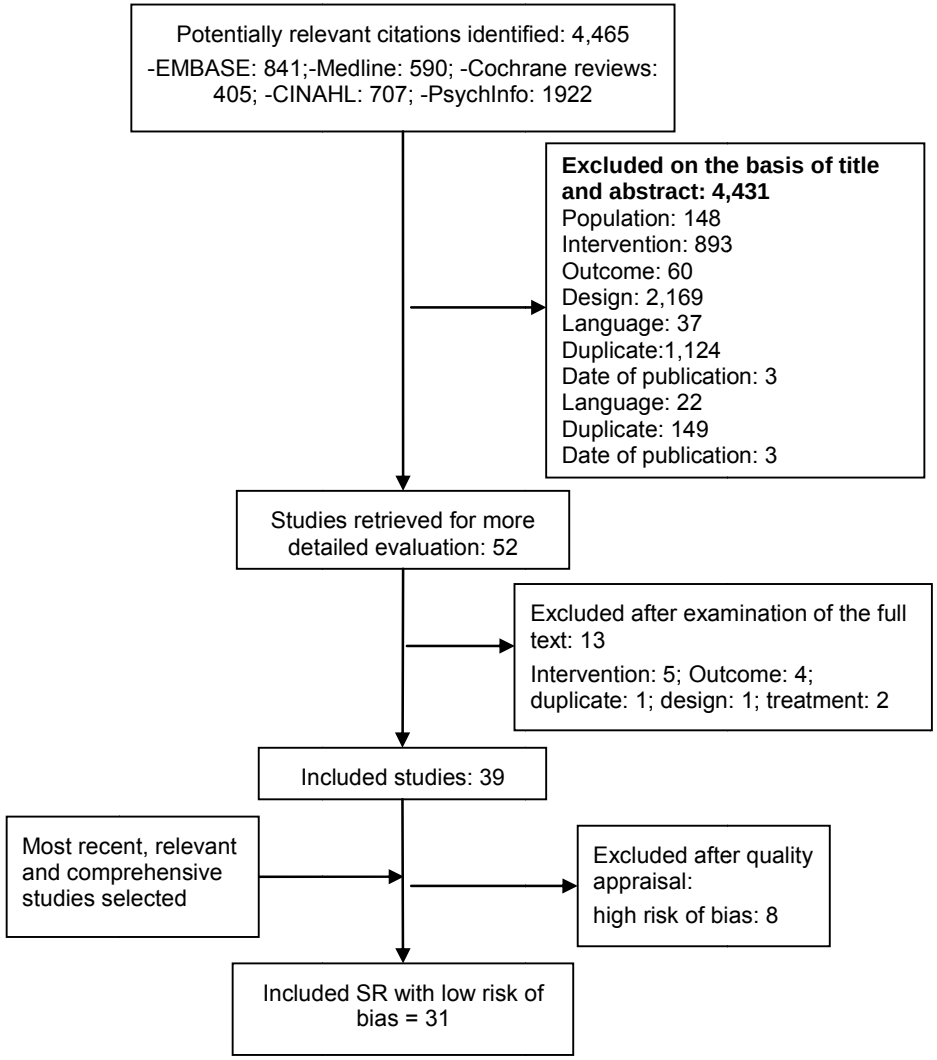
Excluded studies (n=8)

Eight studies [14-21] were excluded on being judged to have a high risk of bias (appendix 3.5.1).

Final selection: 31 systematic reviews

31 systematic reviews were included [8, 22-50]as detailed below (Figure 2)

Figure 2 – Results of searches and selection of systematic reviews



3.3.2. Randomised controlled trials

3.3.2.1. Identified studies

A total of 1675 citations of possible relevant RCTs were found from database searches (Figure 3). The majority of citations were excluded on the basis of title and abstract; 37 citations were retrieved in full and reviewed in more detail and one RCT was obtained through hand searching.

On the basis of full text, 32 were included and 6 RCTs were excluded.

The reasons for exclusion on full text were:

- Four studies as control group inadequate (i.e. contained an element of intervention) [51-54]
- One study as outcomes not relevant (educational levels) [55]
- One study as intervention was standard patient education [56]

3.3.2.2. Quality appraisal of the 31 RCTs selected

As a first step, quality appraisal of the 31 RCTs was carried out to determine their suitability for inclusion, using the SIGN tool.

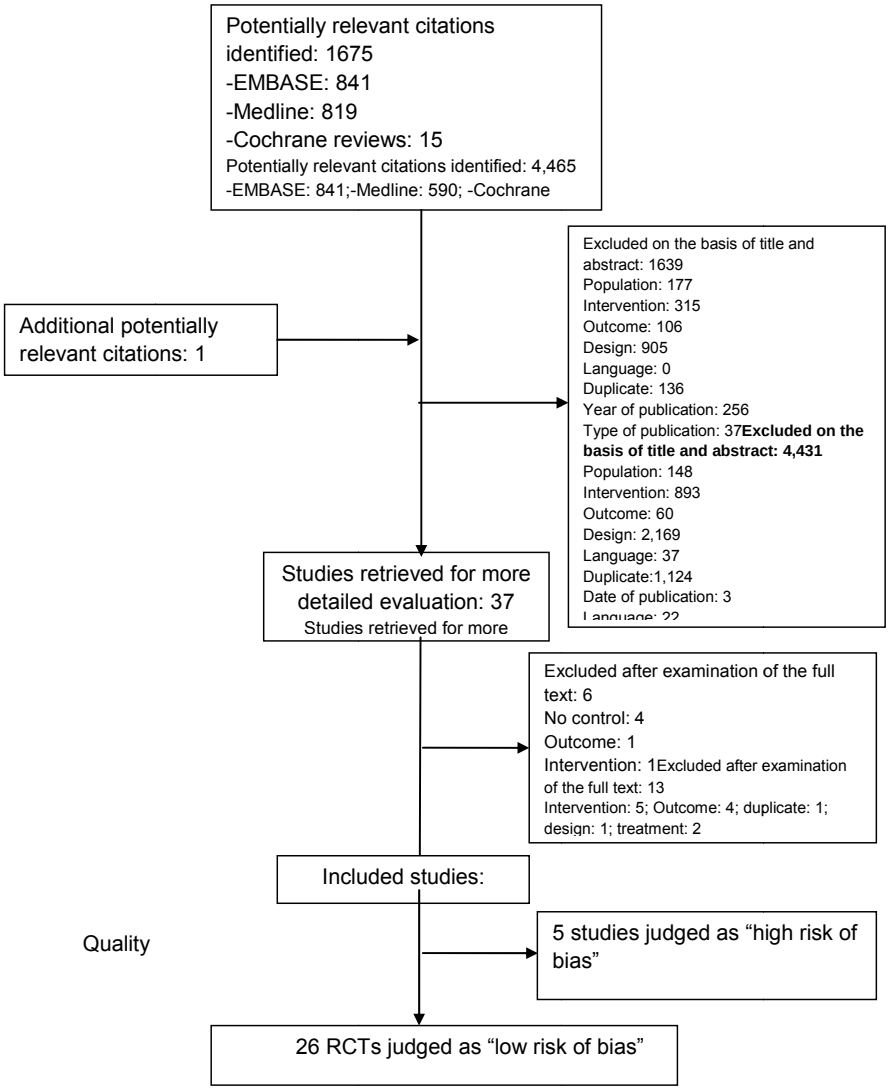
Excluded studies (n=5)

Five studies [17, 57-60] were excluded on being judged to have a high risk of bias (appendix 3.5.3).

Final selection: 26 RCTs

26 RCTs were included as detailed below (see Figure 3) [61-86]

Figure 3 – Results of searches and selection of RCTs



3.4. Results : effectiveness of patient empowerment : analysis by disease

3.4.1. Interventions for chronic disease in general

3.4.1.1. Two systematic reviews on self-management/patient education

Two systematic reviews have evaluated self-management in chronic disease, without focus on a specific condition.

Coster and Norman, 2009 [27] analysed 30 Cochrane reviews of interventions designed to improve patients' knowledge and skills to manage their chronic disease (asthma in >25% of reviews). Interventions ranged from simplistic patient education to self-management programmes providing education and practical self-management skills. In 60% of the Cochrane reviews, the authors concluded that there was insufficient evidence to answer their research question. Overall, Coster and Norman found that educational programmes including a form of self-management training, have definite benefits for patients suffering from asthma (particularly for reducing health care utilisation and improving self-efficacy) are promising for interventions for diabetes (particularly for improving HbA1c levels and reducing medication use), epilepsy (particularly for improving disease knowledge and coping skills)and mental health (particularly for decreasing relapse and readmission rates). It was not possible to identify what elements are required for a successful intervention. Whether group or individual education is superior appears to be dependent on a number of factors, including disease area and patient group. The authors emphasise the potential importance of nurses in the delivery of self-management education and training.

In their review, Dennis et al 2008 [31] did not set out to investigate self-management or patient education, but rather to identify effective interventions for chronic disease management (relevant to Australian health care policy). Dennis et al 2008 identified 141 studies and 23 systematic reviews. Their results indicate that self-management support (e.g. educational sessions and materials, motivational counselling) has the potential to improve physiological measures of disease, quality of life, health and functional status, as well as a number of other clinical outcome measures. The evidence favouring self-management support for improving process of care and patient outcomes was strongest in the disease areas of diabetes and hypertension, followed by weaker evidence for arthritis and asthma. The evidence also showed a benefit for delivery of the self-management support by multidisciplinary teams.

3.4.1.2. Patient engagement intervention for elderly people with multiple conditions

One RCT from Hochhalter et al 2010 [61] tested the efficacy of a patient engagement intervention in 79 older adults with multiple chronic conditions. Patients (≥65 years), who had to suffer from at least two of the following chronic conditions: arthritis, lung disease, heart disease, diabetes, hypertension, depression, and osteoporosis, were recruited via primary care physicians. The intervention was complex, including workshops and phone calls, with the aim of training patients to make the most of the healthcare they received (with a focus on medical appointments). A control intervention consisted of the same workshops and calls, but with a general safety content rather than a self-management content. Usual care acted as comparator. Self-report measures were collected by telephone interview at baseline and 6 months and included: Patient Activation Measure, communication with physicians scale, CDC Healthy Days Measure (HRQOL-14) and Self-Efficacy for Managing Chronic Disease. There was a statistically significant improvement in self-efficacy for self-management in the intervention group (post-hoc analysis, p=0.042). No other differences were found. The authors conclude that their intervention is promising, but requires refinement to reach more patients to make it more efficacious.

3.4.1.3. Peer-led self-management training : effect at home, no effect by phone

One larger RCT from Jerant et al 2009 [62] evaluated peer-led self-management training in 415 subjects. Patients (≥40 years) had to suffer from at least one of the following conditions: arthritis, asthma, COPD, congestive heart failure, depression, and diabetes. Participants were recruited from a primary care network via announcements and phone calls. The chronic disease self-management programme used as the intervention (Homing in on Health), consists of weekly sessions, with the

aim of mastering fundamental self-management tasks. They were either delivered at home (intervention A) or via telephone (intervention B). Trial duration was 1 year. Primary outcomes were the Medical Outcomes Study 36-Item short-form health survey's physical component (PCS-36) and mental component (MCS-36) summary scores. Secondary outcomes included the EuroQol EQ-5D and visual analog scale (EQ VAS), hospitalizations, and health care expenditures.

Compared with usual care:

- The Homing in on Health delivered by telephone had no significant effects on any outcomes.
- Homing in on Health delivered in the home led to significantly higher illness management self-efficacy at 6 weeks (Effect size (ES=0.27; 95% CI, 0.10-0.43) and at 6 months (0.17; 95% CI, 0.01-0.33), but not at 1 year. In-home HIOH had no significant effects on PCS-36 or MCS-36 scores and led to improvement in only 1 secondary outcome, the EQ VAS (1-year ES=0.40; CI, 0.14-0.66).

The authors conclude that the cost-effectiveness of peer-led illness self-management training is questionable from the health system perspective.

3.4.1.4. Chronic diseases: summary of two systematic reviews and two RCTs

- The body of literature showed an impact of the self-management interventions on self-efficacy. The impact on other outcomes varied between diseases.
- Overview of Cochrane reviews on self-management showed an impact of self-management interventions, particularly for asthma, with promising results for diabetes, epilepsy and mental health. It was not possible to identify the elements required for a successful intervention.
- Another systematic review also found that self-management support improves physiological measures of disease, quality of life, health and functional status (diabetes, hypertension, arthritis, asthma)
- A patient engagement intervention for elderly people with multiple conditions increased self-efficacy for self-management, but did not show any other differences compared with usual care.
- Peer-led illness self-management training at home (not by phone) showed only limited and short-term efficacy.

3.4.2. Asthma

3.4.2.1. Self-management patient education interventions

Three systematic reviews evaluated patient education for self-management [34, 35, 49].

- Systematic reviews on self-management education compared with usual care in adults with asthma

Gibson et al. 2009 included 36 trials with self-management interventions defined into five categories[34]: optimal self management (n=15), self-monitoring and regular review (n=7), self monitoring only (n=10), regular review (n=2) and written action plan but not optimal self management (n=2). The data was judged homogeneous enough to perform meta-analysis on certain outcomes: Compared with usual care, the intervention reduced hospitalisations (RR 0.64, 95% CI 0.50 to 0.82), emergency room visits (RR 0.82, 95% CI 0.73 to 0.94), unscheduled physician visits (RR 0.68, 95% CI 0.56 to 0.81), days off work or school (RR 0.79, 95% CI 0.67 to 0.93), nocturnal asthma (RR 0.67, 95% CI 0.56 to 0.79), and improved quality of life (standard mean difference 0.29,CI 0.11 to 0.47). Measures of lung function were little changed. The authors concluded that a combination of self-monitoring, regular medical review, and a written action plan, improves asthma health outcomes. Interventions that did not include a written action plan were not as effective.

An earlier review by Powell and Gibson 2003 [49] on the same topic included 15 trials, and came to the conclusion that optimal self-management could be achieved by either a written action plan or regular medical review. They also state that the intensity of self-management training is related to its effectiveness.

- Meta-analysis of educational interventions for the self-management of asthma in children and adolescents

Guevara et al 2003 [35] based their publication upon a Cochrane review by the same authors, including 32 trials [10]. The interventions were aimed at children, parents, or both, were symptom-based strategies and generally comprised several sessions. There was a modest to moderate improvement in self-efficacy measures reported as coping scores and health locus of control scales (standardised mean difference (SMD) 0.36, 95% CI 0.15 to 0.57) and lung function (SMD 0.50, 95% CI 0.25 to 0.75), and reduced the number of visits to an emergency department (–0.21, 95%CI –0.33 to –0.09), absenteeism from school (–0.14, 95% CI –0.23 to –0.04) and the number of days of restricted activity (–0.29, 95% CI –0.33 to –0.09).

- RCT on self-management education

Mancuso et al 2011 [63] evaluated a self-management education intervention in 296 asthma patients based on social learning theory implemented through the precede-proceed model of health behaviour. At enrolment, intervention patients were given a workbook containing 20 chapters addressing asthma knowledge and self-efficacy, then contacted weekly by telephone. Trial outcomes included difference in QoL (AQLQ tool) scores from baseline to eight week follow up and number of asthma ED visits.

3.4.2.2. Small group interactive education

One RCT from Watson et al 2009 [71] studied the effect of a small-group, interactive program of education about child asthma. They targeted either the parent or the child, or both, depending on the age of the child. The study outcomes included 12 month visits to the emergency department, use of oral corticosteroids, pediatric asthma QoL and caregivers' quality of life. In both the control and intervention groups, there was a significant improvement in total scores on the Pediatric Asthma QoL Questionnaire during the year after enrolment. Compared with the control group, there was a significantly greater reduction in the number of visits to the ED in the intervention group (p=0.0037) as well as fewer courses of oral corticosteroid therapy used per patient during the year after enrolment (p = 0.006).

3.4.2.3. Psycho-educational interventions

Smith et al 2007 [50] performed a systematic review self-management for adults with severe or difficult asthma. The authors included 17 studies, nine of which were included in at least one meta-analysis, although trial quality was generally considered poor, many trials were small-scale, and there was considerable variation in trial design. Most positive effects (on health outcomes, admissions, QoL, and psychological morbidity) were only short-term and did not include the most at-risk patients, but were also consistently confirmed by sensitivity- and subgroup-analysis, adding weight to the results. The need for further research is highlighted.

One additional RCT by Sun et al 2010 [70] studied an educational and psychological counselling intervention delivered in groups of 20 adult asthma patients in China. There were four educational sessions, followed by an individualised self-management plan developed for each patient. Psychological counselling was conducted by clinical psychologists in six one hour sessions. Asthma knowledge scores significantly improved in the intervention group three months after intervention ($p<0.001$). Mean QoL scores also significantly improved in the intervention group three months after intervention ($p<0.001$).

3.4.2.4. Culture-specific programmes

One systematic review from Bailey et al 2009 [22] studied culture-specific asthma programmes in ethnic minority groups. Interventions involved asthma education modules (identifying and monitoring asthma symptoms, understanding medications, barriers to care, use of action plans) delivered through home visits with follow up telephone calls. These interventions were adapted to suit the ethnic group and were delivered by asthma educators fluent in a particular dialect if required. This systematic review was limited to evidence from four RCTs and no strong conclusions can be drawn. However, the culture-specific programme was superior to generic programmes or usual care in all trials. Asthma quality of life scores in adults and asthma knowledge scores in children were improved. One study indicated a statistically significant reduction of exacerbations in children.

3.4.2.5. Computerised-based interventions

One systematic review by Bussey-Smith 2007 analyzed 9 RCTs on computerised asthma patient education programmes[24]. Of the nine included trials, four studied computer game interventions and seven focused on children. Interventions used were heterogeneous. The majority of trials recorded hospitalisations and acute care visits, but there was generally no significant difference between intervention and control for clinical outcomes (hospitalisations, acute care visits, medication use and lung function). Asthma symptoms and asthma knowledge were however significantly improved in five and four of the nine trials, respectively. Interactive computer games designed for paediatric asthma patients achieved a greater impact on asthma symptoms and knowledge than the two adult interventions.

3.4.2.6. Asthma: summary of six systematic reviews and three RCTs

The results of the systematic reviews may be summarized as follows:

- Successful asthma self-management interventions are made up of multiple components: patient education, self-monitoring, regular medical review and a written asthma plan.
- Self-management shown to be successful intervention producing significant improvements in favour of self-efficacy, lung function, and number of visits to an emergency department. Combination of interventions seem more effective. The intensity of self-management training seems also related to its effectiveness (multiple sessions).
- Culture-specific programmes in ethnic minority groups improve symptoms, particularly in children.
- Computerized education shows promise as an effective asthma management intervention particularly targeted for children.

Three additional RCTs show that:

- An educational and psychological counselling intervention in China improved patients' knowledge and QoL 3 months after intervention.
- A small group interactive educational programme for children and their families reduced the number of ED visits and the amount of corticosteroid use in the 12 months after the intervention in a motivated group of families.
- A self-management education programme delivered in the ED (workbook) and reinforced by telephone did not provide any benefit on patients' quality of life and health care use.

3.4.3. COPD

3.4.3.1. Self-management interventions

Three systematic reviews [23, 33, 43] and two RCTs on self-management in COPD were eligible for inclusion [66, 68]

- Patient education delivered by a health professional

Blackstock 2007 [23] identified four RCTs using didactical education and six RCTs evaluating self-management education. Patient education was defined as formal delivery of education on topics related to COPD with the aim to improve the knowledge and understanding of COPD. Self-management education was defined as "education focusing on changing health behaviours through knowledge, goal setting and development of action plans". For didactical education there were no significant improvements for any outcome, with the exception of reduced GP visits in two studies. The results for self-management interventions (multiple sessions, individual or in groups, often delivered by respiratory nurse or physiotherapist) were more promising, showing a trend towards improvements in QoL and health care use. Although no significant effects were detected, due to limited sample size, the authors recommend further research in this area.

- Self-management versus usual care

Effing et al 2007 [33] identified 14 trials (15 group comparisons). The studies were heterogeneous with regard to outcomes and study duration. Although interventions were also diverse, they can all be described as self-management education vs usual care. The intervention reduced the probability of a hospital admission (seven studies, OR 0.64; 95%CI 0.47 to 0.89). St George's Respiratory Questionnaire (SGRQ) scores were significantly improved (WMD=-2.58; 95% CI: -5.14 to -0.02) from 7 studies. The authors recommend self-management education (such programmes

were aimed at improving patient management of COPD such as smoking cessation, improving exercise, nutrition, inhalation technique, with an action plan to manage COPD exacerbations), but consider the evidence insufficient to define optimal form and contents of such interventions.

A previously published review by Monninkhof et al 2003 [43] was based on very similar criteria as the Effing et al 2009 [33] review and included nine studies. The data were unsuitable for meta-analysis and did not show an effect, or were inconclusive, for the majority of outcomes. However, the need for rescue medication was reduced and the use of oral steroids and antibiotics was increased.

- At home programme to support self-management

Bucknall et al 2012 [68] included 464 COPD patients and compared usual care with supported self-management training to detect and treat exacerbations promptly (with support for 12 months). The intervention included four 40 minute individual training sessions at home from a study nurse, monthly telephone calls, daily diary cards, and questionnaires at 6 and 12 months. Patients were recruited after hospital admission for an acute exacerbation. The primary outcome was hospital readmissions and deaths due to COPD, as assessed by Scottish Morbidity Records. Secondary outcomes were health related quality of life measures: St George's respiratory questionnaire (SGRQ), hospital anxiety and depression scale (HADS), COPD self-efficacy scale (CSES) and EuroQol 5D. No difference was found in COPD admissions or death (48% vs 47%). Due to a low rate of questionnaire completion, no conclusions on QoL could be drawn.

- A self management programme tailored to the patient

Wakabayashi et al 2011 [66] evaluated a COPD self-management program in Japanese patients older than 65 years. For the intervention group (n=42), a program was individually tailored to each patient according to the six domain scores on the Lung Information Needs Questionnaire (LINQ). The six domains covered: understanding COPD, medication, exercise, avoidance of exacerbations with an action plan and nutrition. The intervention was delivered in monthly individual sessions for six months. The usual care group (n=43) also received education based on the six domains of the LINQ that was not tailored to the patient nor did patients receive an action plan or booklets. Study outcomes included LINQ score, pulmonary function test, dyspnoea scale, exercise capacity (six minute walk test), BMI, ADL score, body mass index, airflow obstruction, dyspnoea and exercise capacity BODE index, SGRQ and comorbidities (Charlson index). The total LINQ score at 12 months significantly improved in the intervention group compared to baseline ($p<0.03$), whereas a decline was noted in the usual care group ($p<0.05$). Similar statistically significant results were seen favouring the intervention group for BODE and dyspnoea at 12 months and ADL at six months.

3.4.3.2. Group education

The RCT of Rice et al 2010 [69] found a group education program to have a significant decrease on COPD hospitalisations and ED visits.

The COPD disease management program was delivered through group education sessions compared with usual care in 761 COPD patients recruited through Veterans Affairs medical centres. The intervention consisted of a single one- to one education session including general information about COPD, direct observation of inhaler techniques, smoking cessation counselling, encouragement of regular exercise, an action plan and monthly follow up calls. Study outcomes included COPD-related hospitalisations and ED visits respiratory medication use, mortality, and change in SGRQ. After 1 year, the mean cumulative frequency of COPD-related hospitalisations and ED visits was 0.82 per patient in usual care and 0.48 per patient in disease management (difference, 0.34; 95% CI, 0.15–0.52; p=0.001). A relatively simple disease management programme for patients with severe COPD significantly reduced the composite frequency of COPD hospitalizations and emergency visits by 41% at one year follow-up. The study population consisted of veterans and was 98% male making it difficult to generalise to a 'real world' population.

3.4.3.3. COPD: summary of 3 systematic reviews and 3 RCTs

- Self-management education interventions led usually to inconclusive results given the heterogeneity of the designs and interventions. Non significant improvements were recorded for QoL and health care use. A systematic review found some benefit in reducing hospital admission and improving St George Respiratory Questionnaire.In a large RCT, supported self-management at home had no effect on COPD admissions or death.
- One RCT in elderly Japanese patients found that individualised self-management program improved patients' information, activities of daily living and symptoms at six months.
- One large RCT concluded that group education with follow-up telephone support reduced hospital admissions and ED visits at 12 months.

3.4.4. Diabetes

3.4.4.1. Educational interventions

Individual and group-based patient education measures in adults with type 2 diabetes were evaluated by Duke et al 2009 [32] and Deakin et al 2009 [28], respectively.

- Individual patient education

A first systematic review by Duke et al 2009 [32] evaluated individual education for patients with type 2 diabetes. The authors identified nine studies, six with usual care and three with group education as the comparator. The individual patient education was face to face and addressed a wide range of self-management aspects of type 2 diabetes such as diabetes control, exercise, glucose monitoring, diabetic complications, motivational and behavioural strategies. Study quality was generally low and there were no significant differences between any of the interventions, with the exception of a benefit regarding glycaemic control in patients with a baseline HbA1c>8% (education vs usual care, three trials, WMD -0.3%, 95% CI -0.5 to -0.1, p=0.007). The authors found no difference between group and individual education.

- Group-based patient education

The second systematic review by Deakin et al 2009 [28] focused on group education for patients with type 2 diabetes. The authors report on 11 trials, comparing group-based education with routine treatment or no treatment. There was a significant improvement in patient empowerment in the intervention group at four months in one RCT: score in favour of the group education programme: difference 0.3; 95% CI 0 to 0.6; p<0.001.

Meta-analysis was possible for several outcomes: Group-based education significantly reduced glycated haemoglobin (from 4 months to two years). Fasting blood glucose levels and body weight at one year were also significantly reduced, as was systolic blood pressure at four to 6 months and the need for diabetes medication. Diabetes knowledge was also significantly improved in a meta-analysis of four RCTs. The authors recommend further research to confirm their findings, which are based on a small number of studies.

3.4.4.2. Educational and psychosocial interventions

Educational and psychosocial interventions for adolescents with type 1 diabetes were reviewed by Hampson et al 2001 [36]. The 62 included studies evaluated a wide spectrum of interventions such as family therapy sessions, self-monitoring blood glucose training, diabetes club, video games and summer diabetes camps were summarised descriptively, with a focus on the 25 RCTs.

Small to moderate improvements in various diabetes management outcomes were observed with the interventions. Over half the interventions had no theoretical basis for their development. Interventions are more likely to be efficacious if they demonstrate the inter-relatedness of the different aspects of diabetes management. It remains unclear whether targeted interventions (tailored to specific patient groups) would be more successful.

3.4.4.3. Culture-specific education

- Systematic reviews of interventions tailored toward the cultural or religious beliefs, taking into account the target group's literacy skills

Hawthorne et al evaluated culture-specific health education in type 2 diabetes in a 2008 review [37]. Of the 11 included trials, ten comprised meta-analysable data. Compared with usual care, the interventions significantly improved glycaemic control (at four and six months, not significantly at 12 months), and knowledge scores. No other significant improvements (clinical or patient-related) were found. The authors concluded that, whereas there are short term benefits for glycaemic control and diabetes knowledge, long-term benefits remain unclear due to a lack of data.

Sarkisian et al 2003 [46] focused on specific self-management interventions for older Caucasian, African American or Latino adults. Eight RCTs and four non-RCTs were identified. Only 50% of the studies focused on older adults, and four studies (30%) were in Caucasian populations; there were 3 studies in African American and five in Latino populations. Meta-analysis was not possible. Improved glycaemic control with intervention versus control was reported in five RCTs. A QoL improvement was only reported in one study. The authors found indications that self-management interventions are most successful in patients with poor glycaemic control at baseline, and when the interventions are specific for the patient's culture or age-group. The involvement of spouses and adult children was also beneficial.

- Evaluation of a theory-based, literacy- and culture-tailored self-management intervention

Rosal et al 2011 [77] evaluated a theory-based, literacy- and culture-tailored self-management intervention versus no intervention in 252 low-income Latinos with type 2 diabetes. The intervention was based on social-cognitive theory and was a year-long program consisting of an intensive phase of 12 weekly sessions and a follow-up phase of 8 monthly sessions. Course materials were simplified to address literacy needs, and there were culturally tailored activities like food bingo, food preparation, and a soap opera. Outcome measures included HbA1c and lipid panel, diabetes knowledge (using a subset of items from the Audit of Diabetes Knowledge) and a 17-item tool to assess self-efficacy for dietary and physical activity change.

There was a significant difference in HbA1c change between the groups at 4 months (intervention −0.88 −1.15 to −0.60 vs control −0.35 −0.62 to 0.07, p<0.01), although this difference decreased and lost statistical significance at 12 months (p=0.293). The intervention resulted in significant change differences in diabetes knowledge at 12 months (p=0.001), self-efficacy (p=0.001), blood glucose self-monitoring (p=0.02), and diet, including dietary quality (p=0.01), kilocalories consumed (p<0.001), percentage of fat (p=0.003), and percentage of saturated fat (p=0.04). The authors conclude that literacy-sensitive, culturally tailored interventions can improve diabetes control among low-income Latinos, but that strategies to sustain improvements are needed.

3.4.4.4. Diabetes: summary of 5 systematic reviews and one RCT

- Results on education in type II diabetes patients differ between 2 systematic reviews.
  - The first one found that study quality was generally low and there were no significant differences between intervention (individual education) and control groups (group education or usual care). The exception was the patient group with the poorest glycaemic control at baseline.
  - The second one concluded that group education was successful in producing significant improvements in favour of self-efficacy, improving fasting blood glucose levels, HbA1c, diabetes knowledge and reducing systolic blood pressure. The authors recommend further research to confirm their findings, which are based on a small number of studies.
- A review concludes that small to moderate improvements are observed with educational and psychosocial interventions for adolescents with type 1 diabetes.
- Culture –specific education in diabetes
  - Evidence for improvement in glycaemic control and knowledge scores was found on the usefulness of education tailored to culture specific needs. A review found short term benefits for

glycaemic control and diabetes knowledge but long-term benefits remain unclear.

- The interventions is most successful in patients with poor glycaemic control. The involvement of spouses and adult children appears beneficial.
- There is furthermore evidence from one RCT that a culturally tailored self-management intervention improves self-efficacy, diabetes knowledge and blood glucose self-monitoring (as well as other minor endpoints), whereas HbA1c was only significantly improved short term.

3.4.5. Heart failure

3.4.5.1. Educational interventions

The systematic review of Boyde et al 2011 [26] identified 19 RCTs on educational interventions for heart failure patients. Interventions were commonly didactic sessions conducted by nurses. However, there was considerable variation in interventions and outcomes, making data synthesis difficult. A significant improvement in at least one outcome (self-efficacy, clinical, and healthcare use) was observed in 15 of the included studies, indicating at least some benefit. Knowledge levels showed a statistically significant improvement in the 8 studies that evaluated patient knowledge. Self-efficacy showed a significant improvement in one study where there was continued telephone contact six months post intervention. The most effective educational strategy could not be identified due to the heterogeneity of the data but a combination of interventions such as verbal teaching combined with video or CD-ROM would be more effective than one medium delivered alone.

3.4.5.2. Self-management interventions

Jovicic et al 2006 [38] identified six RCTs on self-management interventions that provided the patient with information on signs of heart failure, importance of daily weighing, dietary restrictions and medication regimens given by nurse with follow up visits or telephone contact. Their meta-analysis showed that the intervention:

- decreased both any cause hospital re-admissions (four studies, OR 0.59; 95% CI 0.44 to 0.80, p=0.001) and heart failure re-admissions (three trials, OR 0.44; 95% CI 0.27 to 0.71, p=0.001);
- had a not significant effect on mortality (three trials), functional capabilities, symptom status or quality of life.

A more recent review on self-management interventions compared with usual care was published by Ditewig et al 2010 [30]. The authors discuss the results of the identified 19 RCTs qualitatively and come to the conclusion that self-management reduces the number of hospital re-admissions and mortality and increases QoL, even though these changes do not always reach significance. The details of the interventions are listed by trial, but not discussed and no conclusions on the characteristics of a successful intervention are drawn.

An additional RCT from Powell et al 2010 [78] evaluated self-management counselling plus education compared with education alone in a large trial involving 902 patients with heart failure patients requiring some form of active heart failure treatment including diuretics. The primary end point was death or heart failure hospitalisation with secondary endpoints of sodium intake, self-efficacy and change in QoL. Both groups received educational materials in the mail but the intervention group was taught self-management skills (problem-solving skills and HF education in 18 two hour group meetings with 10 patients over 12 months) to implement the advice. There is no evidence from this trial that self-management counselling for HF patients is more effective than educational material alone because no difference between the groups was shown across all study outcomes.

3.4.5.3. Educational and behavioural support programme

Baker et al 2011 [72] compared a “teach to goal” educational and behavioural support programme with a 1-hour educational intervention. The “teach to goal” intervention included specific instructions to guide diuretic self-adjustment, as well as an individualised plan developed with the patient's clinician. In total, 605 patients with heart failure (HF), New York Heart Association (NYHA) Class II-IV, were randomised, after being recruited at outpatient appointments.

Compared with the control (1-hour education), the intervention led to significantly higher improvements in all outcomes: self-efficacy (increased from 4.8 to 5.8 with the intervention, vs from 5.0 to 5.4 in the control group, p<0.006); general and salt knowledge (p<0.001); self-care behaviours (from mean 4.8 to 7.6 for the intervention vs 5.2 to 6.7 for the control, p<0.001); Heart failure related Quality of life (from 58.5 to 64.6 for the intervention vs no change in the control group (p<0.001). Follow-up was however only 1 month, and no strong conclusions can be made.

3.4.5.4. Heart failure summary of three systematic reviews and two RCTs

- Self-management interventions for heart failure patients was found to reduce hospital re-admissions but less evidence was found for other outcomes such as mortality, functional capabilities, symptom status, quality of life or self-efficacy.
- Educational interventions improve at least one outcome (clinical outcome, self-efficacy, health care use) in the studies on heart failure patients. However the most effective educational strategy cannot be identified due to the heterogeneity of the data but a combination of different media (e.g. verbal teaching and CD rom) would be more effective than one medium in isolation.
- One educational and behavioural support programme.concluded to short-term benefits in self-efficacy, self-care and quality of life outcomes.

3.4.6. Hypertension

3.4.6.1. Computer-based interventions

Saksena 2010 [87] identified five projects (10 publications) evaluating computer-based interventions for subjects with hypertension. Two of the interventions had to be completed on site, under guidance, whereas three studies were internet-based (websites accessible over several months). It could not be demonstrated in any of the studies that the intervention was sufficient to change health behaviours, although individual components of the Health Belief Model (defining five elements on which an intervention should act in order to change health behaviours) were positively affected. In one trial, blood pressure control was improved (p<0.001).

3.4.6.2. Behavioural interventions

Boulware et al 2001 [25] pooled the results of 15 RCTs on patient-centred behavioural interventions. The analysis indicated that counselling is better than usual care for decreasing blood pressure. The combination of counselling and training courses led to better results than counselling or training on their own. Although the evidence is limited, the authors consider counselling to be an important addition to pharmacological therapy for the management of hypertension. The evidence on the benefit of self-monitoring of blood pressure and on training courses without counselling was considered insufficient.

One additional RCT by Bosworth et al 2009b [74] compared the effects of three interventions versus usual care in a sample of 636 hypertensive patients:

- home BP monitoring 3 times weekly,
- a behavioural intervention (bimonthly, tailored, nurse-administered telephone intervention),
- the behavioural intervention plus home BP monitoring two behavioural interventions.

At 24 months, compared with the usual care group, the percentage of patients with BP control was 4.3% (95% CI, -4.5% to 12.9%) in the behavioural intervention group, 7.6% (CI, -1.9% to 17.0%) in the home BP monitoring group, and 11.0% (CI, 1.9%, 19.8%) in the combined intervention group. Similarly, there was only a significant improvement in systolic and in diastolic BP in the combined group (-3.9 mm Hg; 95%CI, -6.9 to -0.9 mm Hg). In conclusion, combined home BP monitoring and tailored behavioural telephone intervention improved BP control, systolic BP, and diastolic BP at 24 months relative to usual care.

A second trial by the same author [73] was a 2-level cluster randomised trial, including 588 patients with hypertension who were being followed by the primary care providers included in the study.

- On level one, primary care providers received, at each visit, either computer-generated decision support (designed to improve guideline

concordant medical therapy) or simply a reminder. The active intervention for primary care providers supplied patient-specific recommendations about hypertension decision support delivered at the point of care during each patient visit.

- On level 2, patients received usual care or a bimonthly tailored nurse-delivered behavioural telephone intervention (9 modules) to improve hypertension treatment.

The results showed no significant differences in amount of change in blood pressure control in the intervention groups compared with the hypertension reminder control group.

3.4.6.3. *Hypertension: summary of two systematic reviews and two RCTs*

- One systematic review did not find any benefit of self-monitoring of blood pressure and of training courses without counselling. There is limited evidence for the combination of counselling and training courses for decreasing blood pressure.
- Another systematic review concluded that computer-based interventions are not sufficient to change health behaviours of patients with hypertension.
- In a single RCT, the combination of a behavioural intervention with home BP monitoring showed positive results on blood pressure (for ≥2 years).
- Another RCT concluded that neither decision support for primary care providers, nor a behavioural telephone intervention or a combination of both show better efficacy than usual care.

3.4.7. Angina

3.4.7.1. *Psycho-educational interventions*

McGillion et al 2004 [41] was the only eligible systematic review focusing on the benefit of psycho-educational measures in patients with chronic stable angina. Outcomes were symptoms, symptom-related stress, and physical functioning. Only four RCTs were found eligible for inclusion and the heterogeneity of outcome measures used prevented any data synthesis.

One included RCT evaluated group stress management sessions and found the intervention group to be significantly more relaxed, less stressed and experiencing fewer angina episodes compared with controls at six months. Although each study reported some positive effects of the respective patient educational measures, the included trials had a number of methodological flaws, making the results unreliable.

No RCTs were identified for patients with angina.

3.4.7.2. *Angina: summary of one systematic review*

Psycho-educational stress management intervention showed some evidence for improving angina symptoms

3.4.8. Stroke

3.4.8.1. *Self-management programmes*

Two recent systematic reviews were identified which, as part of their review, summarised available evidence on the furthering of self-efficacy by means of self-management programmes after a stroke:

- Korpershoek et al 2011 [40] conclude that, although there is evidence from a RCT that clearly demonstrates self-sufficiency is beneficial to stroke patients but overall there is a lack of evidence on self-management programmes in this area.
- Jones et al 2011 [39] come to the same conclusion as Korpershoek et al [40], as their review found some emerging evidence for a benefit of self-management programmes on self-efficacy outcomes measured by self-efficacy scales such as Falls Efficacy Scale but was limited as well by the lack of available RCT evidence.

Cadilhac et al 2011 [82] randomised 143 stroke patients, recruited from seven South Australian hospitals, to either standard care or:

- a generic self-management programme (Stanford chronic condition self-management programme),
- a stroke self-management programme (having greater contact time, only being delivered by professions skilled in stroke, providing targeted stroke-specific information each week and revisiting information).

Primary outcomes were recruitment, participation, and participant safety. Secondary outcomes were positive and active engagement in life using the Health Education Impact Questionnaire, and characteristics of QoL and mood at 6 months from programme completion. Overall, 52% completed the stroke programme and 38% completed the generic intervention (p=0.18). The authors concluded that the stroke programme was feasible but the differences in outcomes were not significant.

3.4.8.2. Stroke: summary of two systematic reviews and one RCT

There is a lack of evidence that self-management programmes improve self-efficacy after stroke.

3.4.9. Irritable bowel syndrome (IBS)

3.4.9.1. Self-management

- No evidence from one systematic review

One systematic review from Dorn et al. (2010)[29] identified 11 studies. Many of them suffered from methodological flaws. The variety of interventions (e.g. home-hypnosis, self-help support or guidebooks) and outcomes used did not allow statistical analysis. There was an possible benefit for many of the tested self-management interventions such as self-administered cognitive behavioural therapy, self-help guidebook and structured patient education, however, but the available data is insufficient to draw reliable conclusions.

- Interventions by trained nurses (face-to-face and telephone)

One tree-arm RCT by Jarrett et al 2009 [80] assessed a comprehensive self-management (CSM) program for patients with IBS. One hundred and eighty-eight patients were randomised into usual care or one of two intervention groups:

the CSM delivered in-person by trained psychiatric nurses,

CSM delivered over the telephone but including three face to face sessions,

The intervention was delivered in nine one hour sessions by psychiatric nurse practitioners. It covered four themes – education, diet (identify problems in their diet), relaxation (abdominal breathing, music relaxation) and cognitive behavioural (based on individual assessment) strategies. Outcome measurements included: gastrointestinal symptom score, QOL, cognitive beliefs, IBS symptom score, psychological distress.

At 12 months there were significant improvements in both intervention groups:

symptom score: CSM sessions delivered in-person only (CSM-IP) (-25.6, p<0.001), CSM sessions delivered by telephone and in-person (CSM-T/IP) (-28.4, p=0.006) versus UC (-9.5);

improvements in QoL compared with usual care (IBS QoL in CSM-IP (12.2, p=0.010) and CSM-T/IP (11.90, p=0.029 vs UC 7.4)

No difference was noted between the intervention groups: this programme was shown to be effective either delivered by telephone or totally in-person in improving IBS symptoms and Qol.

3.4.9.2. Structured education

Ringström et al 2010 [86] compared structured patient education ("IBS school") with written information only in 143 IBS patients (18 to 70 years old). The IBS school was based on the self-efficacy theory, the general theory of nursing and a biopsychosocial model considered to be important in functional GI disorders, and took a cognitive–behavioural approach. The IBS school consisted of six weekly 2-hour group sessions. Written information was an IBS guide book. The efficacy of the interventions was tested by questionnaires: perceived knowledge (Visual Analog Scale), IBS Severity Scoring System, IBSQoL, Visceral Sensitivity Index, and the Hospital Anxiety and Depression Scale.

The IBS school groups (vs the written information only group) showed a significantly greater reduction in IBS symptom severity (p=0.06 at 3 months and p=0.04 at 6 months) and gastrointestinal-specific anxiety (p<0.001 at 3 months and p=0.02 at 6 months), as well as greater improvement in perceived knowledge of IBS (p<0.001 at 3 and 6 months). Several aspects of HRQoL were also significantly improved. The authors conclude that a structured patient group education is superior to written information to enhance knowledge of IBS, and improve gastro-intestinal symptoms and anxiety in IBS patients.

3.4.9.3. Cognitive behaviour for self-management

Oerlemans et al 2011 [76] evaluated a cognitive-behavioural therapy (CBT) intervention for the self-management of IBS patients in The Netherlands. The Intervention group received situational feedback from a psychologist on their personal electronic diaries over the course of three weeks. The feedback focused on IBS complaints, catastrophising thoughts, dysfunctional cognitions, and avoidance behaviour and was based on cognitive–behaviour therapy. Seventy-six IBS patients recruited through the Dutch IBS patient association and through their GPs were randomised to receive the CBT intervention (n=37) or usual care (n=38). Study outcomes included IBS symptoms measured by Cognitive scale for functional bowel disorders (CSFBD), QoI assessed by The Irritable Bowel Syndrome quality of life questionnaire (IBS-QoL) and the degree of pain catatstrophising thoughts measured by The Pain Catastrophising scale (PSC). At four weeks there was greater overall QoL improvement in the intervention group (χ^2= 4.08, p<0.05).and significantly more pain improvement in the intervention than in control group (χ^2=5.44, p<0.05), however these effect differences were not seen at the three month follow up.

3.4.9.4. IBS summary of one systematic review and three RCTs

- The systematic review concludes that there is weak evidence for self-management interventions for IBS, given the methodological limitations and the heterogeneity of the interventions under study.
- A comprehensive self-management intervention delivered face to face or telephone with 3 face to face sessions showed improvement in IBS symptoms and QoL at 12 months.
- A structured education programme (“IBS School”) showed benefits for symptom severity, anxiety, knowledge and several aspects of HRQoL at 6 months.
- Cognitive behaviour therapy for IBS had a weak effect at the short-term for improving IBS QoI and pain improvement.

3.4.10. Kidney disease

3.4.10.1. Educational interventions

The systematic review of Mason et al 2008 [42] included 22 RCTs (multicomponent educational interventions with psychological elements). The data was heterogeneous and trial quality was low in many cases. The interventions (individual or group education delivered by trained health care worker ± educational materials ± psychosocial support ± follow up phone calls) appeared to be generally beneficial, with 18 trials reporting a significant improvement for at least one of the outcomes such as knowledge retention and delay in the onset of dialysis therapy. The authors consider the evidence sufficient to advocate development and implementation of educational interventions, especially for patients in early stages of chronic kidney disease.

3.4.10.2. Self-management support (SMS)

Chen et al 2011 [84] conducted a RCT with 54 incidental predialysis chronic kidney disease patients (CKD, stages III to V), recruited from an outpatient clinic in Taiwan. The SMS programme included the provision of information, reinforced learning incentives and encouraging self-care and maintenance of the therapy, implemented by a multidisciplinary team of nurses, dieticians and volunteers. There were monthly face-to-face meetings, weekly telephone support and a support group twice a month. In addition, specific measures were implemented for patients by disease stage, including lectures or discussions. The primary endpoints were absolute estimated glomerular filtration rate (eGFR) change and number of hospitalisations. Secondary endpoints included eGFR decrease of up to 50% and all-cause mortality. Duration of follow-up was 12 months.

At the end of the study, the absolute eGFR was significantly higher in the SMS group than in the control group (29.11+/-20.61 vs 15.72+/-10.67 ml/min, p<0.05). There were also fewer hospitalisations in the SMS group (18.50% vs 44.47%, p<0.05). EGFR reduction <50% was seen in 3.7% in the intervention group vs 33.3% in the control group (p<0.05). No other significant differences were found. The authors conclude that SMS programmes could play an important role in slowing chronic kidney disease progression and reducing morbidity of late-stage patients.

However these results must be viewed with caution as the small sample size meant the study was not powered sufficiently to detect between group differences.

3.4.10.3. Nurse-led case management

Chow et al 2010 [85] focused on HRQoL in peritoneal dialysis patients. Overall, 100 patients were recruited after hospital admission and randomised to either routine care or to a nurse-led case management programme. The intervention consisted of a comprehensive discharge planning protocol (involving family members) and a standardised 6-week nurse-initiated telephone follow-up regimen, with the aim of achieving of shared objectives and reinforcing of health-related behaviours. The Kidney Disease Quality of Life Short Form (KDQOL- SFTM) was used. The data were collected at T1 (discharge, baseline), T2 (6 weeks post discharge, after completion of the case management intervention) and T3 data (12 weeks post discharge).

No significant between-group differences were found, implying that standard care is not significantly worse – regarding HRQoL – than nurse-led case management in this patient group.

3.4.10.4. Kidney disease summary of one systematic review and two RCTs

- There is weak evidence to support multicomponent educational interventions for chronic kidney disease patients in the early stage of the disease.
- A small RCT concludes that self-management support can be efficacious in CKD, slowing disease progression and reducing morbidity.
- There is no evidence for a HRQoL benefit of nurse-led case management.

3.4.11. Chronic pain

3.4.11.1. Online mind-body self-care techniques

Berman et al 2009 [64] studied in a RCT the efficacy of online mind-body self-care techniques in 78 adults over 55 years of age with chronic pain. Patients were recruited from community based settings and randomised to either the intervention or a waiting list. The intervention website comprised an introductory module describing a problem-solving approach to planning for change, based on a 6-stage model. Participants were asked to try each module at least once and to use the website at least once a week for 6 weeks. Outcomes included self-efficacy (measured with the Pain Self-efficacy Questionnaire), pain intensity (measured with the Brief Pain Inventory-Short Form), depression (measured with the Centre for Epidemiologic Studies Short Depression Scale (CES-D 10), a shortened version of the CES-D), anxiety (6-item State-Trait Anxiety Inventory; STAI-6), self-awareness of responses to pain (Pain Awareness Questionnaire (PAQ) developed for the purpose of this study), self-care and satisfaction with and use of the intervention (surveys developed for the purpose of the study).

The authors found no significant between-group differences for any of the outcomes except Awareness of Responses to Pain. There were also increases in confidence with using non-medical self-care techniques to manage pain for the intervention group. Reductions in mean pain scores reported by the intervention group at log on and log off also suggest that the intervention may have an immediate impact on reducing pain. Follow-up was only 6 weeks and overall no strong conclusions can be drawn.

3.4.11.2. Chronic pain: summary of one RCT on Online mind-body self-care techniques

- The efficacy of online mind-body self-care techniques (compared with a waiting list) remains unclear.

3.4.12. Painful musculoskeletal conditions (including rheumatic diseases and arthritis)

3.4.12.1. Self-management programmes

The systematic review of Du et al 2011 [8] identified 19 RCTs evaluating self-management programmes (16 in arthritis and 3 in chronic back pain). Face-to-face group sessions were most commonly used (15 studies). Due to heterogeneity the potential for meta-analysis was limited, but the results generally favoured the intervention. The results showed that

- the evidence in chronic back pain is insufficient,
- there are significant long-term (from 6 months) benefits of self-management in arthritis (4-month meta-analysis results were not significant) particularly for reducing pain (SMD=-0.29;95% CI:-0.41 to -0.17, p=0.0003) at 6 months and 12 months (SMD=-0.29, 95% CI: -0.41 to -0.17, p=0.0003), and reduction in disability (SMD=-0.17; 95% CI: -0.27 to -0.07, p=0.0006) at 12 months.

Shin et al 2010 [47] reviewed 12 RCTs in older adults with osteoarthritis. All studies found that psychosocially focused interventions (self-management) had a positive effect on pain reduction and function improvement, although the effect was not always significant compared with the control. Additionally the results reported from the review were often qualitative making it difficult to quantitatively assess the outcome effect. Self-efficacy did show significantly improve in four RCTs, all used different measurement tools. This review concludes that there may be some evidence to advocate consistent implementation of self-management in older adults with osteoarthritis, highlighting the possible benefits regarding a reduced need for and better managed pharmacological treatment. However only short-term outcomes were assessed.

3.4.12.2. Educational interventions

Niedermann et al 2004 [44], reviewed patient education in adults with rheumatoid arthritis (11 studies), with a focus on long-term effects. Seven studies were purely educational, whereas four adopted cognitive-behavioural strategies. Three of the 11 studies specifically targeted self-efficacy with inconsistent results. The authors found no improvement in short- or long-term health status but improvement of coping in the short-term and indications for long-term psychological benefits.

Riemsma et al 2003 [45] used broadly similar selection criteria and identified 31 studies. Extensive meta-analysis was performed and led to the conclusion that, in contrast to the results for self-management programmes obtained by Du et al 2011 [8], education did not lead to long-term benefits in rheumatoid arthritis. In the short term however, there were significant benefits regarding disability, joint counts, patient global assessment, psychological status, and depression, as well as a positive trend regarding pain. These results do not agree with those of Niedermann et al 2004 [44], who identified the same studies but did not report the same outcomes as Riemsma et al 2003 [45] such as disability and joint counts.

3.4.12.3. Musculoskeletal painful conditions summary of four systematic reviews

- Self-management programmes might be beneficial at the short term for arthritis patients particulary in managing pain, disability and improve self-efficacy.
- There is a lack of evidence for the effect of self-management in low back pain.
- Two systematic reviews on educational interventions in rheumatoid arthritis show some short-term effects (coping, disability, joint counts, psychological status). There is no impact on health status.

3.4.13. Fibromyalgia

3.4.13.1. Psychoeducational interventions

One RCT from Luciano et al 2011 [75] compared a psychoeducational treatment programme with usual care in 216 fibromyalgia patients (18 to 75 years old). The intervention consisted of nine weekly 2-hour sessions, of which 5 were educational and 4 focused on autogenic training. Outcome measures were functional status and some clinical measures, assessed using a Sociodemographic Questionnaire, the Fibromyalgia Impact Questionnaire, Chronic Medical Conditions Checklist, and The State Trait Anxiety Inventory. Significant differences between the groups at post-treatment were observed (favouring the intervention) regarding physical impairment, days not feeling well, pain, general fatigue, morning fatigue, stiffness, anxiety, and depression (medium effect size in most cases). The absolute risk reduction with the intervention was 36.1% (95% CI 23.3-48.8) and the number needed to treat was 3 (95% CI: 2.0-4.3).

The authors conclude that a 2-month psychoeducational intervention leads to short-term improvements in the functional status of fibromyalgia patients.

3.4.13.2. Internet-based self-help interventions

Williams et al 2010 [79] investigated internet-enhanced behavioural self-management (versus usual care) in 118 subjects with fibromyalgia. Patients (≥18 years, fulfilling the American College of Rheumatology criteria for fibromyalgia) were recruited from a network of 54 clinics. The website took an educational self-help format comprising 13 modules (educational lectures; education, behavioural, and cognitive skills designed to help with symptom management; and behavioural and cognitive skills designed to facilitate adaptive life style changes for managing fibromyalgia). Patients were encouraged to use the site, but were not further coached.

After 6 months, the intervention significantly improved the primary outcomes i.e. physical functional status ($p<0.03$) (SF-36) and average pain ($p<0.01$) measured by the Severity Scale of the Brief Pain Inventory. The proportion of patients reporting a 30% decrease in mean pain score from baseline to 6 months was also significantly greater in the intervention group ($p<0.008$). There were no significant between-group differences in secondary outcomes fatigue, sleep problems, mood) with the exception of Patient Global Impression of Change.

3.4.13.3. Fibromyalgia: summary of two RCTs

- The efficacy of psychoeducational interventions is moderate (short-term improvements in functional status).
- Internet-based self-help intervention: improved symptoms at 6 months (pain intensity, physical functioning, Patient Global Impression of Change).

3.4.14. Multiple sclerosis

3.4.14.1. Psychological interventions

Thomas et al 2006 [48] evaluated psychological interventions in multiple sclerosis (MS) patients, based on 16 studies. Psychological interventions were broadly defined and included those that address mood and those that address cognition The review was stratified by subgroups of MS patients: patients with cognitive impairment (three studies), with moderate to severe disability (three studies), with MS (seven studies), and with depression (three studies).

Few positive outcomes were reported across the included trials. One trial found cognitive rehabilitation appears to have some positive effect on cognitive outcomes in patients with cognitive impairment. One of three trials suggested that psychotherapy may be beneficial for depression. Overall no definite conclusions can be made from this review.

3.4.14.2. Chronic disease self-management course

Barlow et al 2009 [81] randomised 216 subjects with MS, to either no intervention (waiting list; control group) or a chronic disease self-management course (CDSMC; intervention group). The course consisted of six weekly 2-hour group sessions, delivered by pairs of trained lay tutors. The course was largely interactive, encouraging participants to apply new skills. Some patients chose not to attend the CDSMC (comparison group); these patients were on average older, had suffered from MS longer and were less anxious than patients who chose to attend. Data (questionnaires) were collected at baseline, 4 months and 12 months. The authors found that the intervention improved self-management self-efficacy (effect size (ES) 0.30, $p=0.009$) and physical status (ES 0.12, $p=0.005$). There were no other statistically significant changes. However, trends towards improvement on depression (ES 0.21, $p=0.05$) and MS self-efficacy (ES 0.16, $p=0.04$) were noted. Some improvement in self-efficacy was maintained at 12-month follow up but overall effect sizes were small and few outcomes reached statistical significance.

3.4.14.3. Multiple sclerosis: summary of one systematic review and one RCT

- There is evidence that cognitive behavioural approaches and chronic disease self-management courses have little or no effect on mood and cognitive outcomes.
- One RCT found improvement self-management and self-efficacy after self-management course

3.4.15. Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME)

3.4.15.1. Self-help programme

Wearden et al 2010 [67] conducted a three arm single-blind RCT to assess the effectiveness of a pragmatic rehabilitation activity programme devised collaboratively with patients suffering from CFS/ME. The pragmatic rehabilitation programme consisted of 10 sessions delivered over an 18 week period divided into five face to face and five telephone sessions. The programme aimed towards a graded return to activity, regulation of sleep patterns, concentration component using a follow up manual and diary which was reviewed at each session. The second study group was supportive listening where a therapist provided an environment where the patient could discuss their concerns and the third arm was usual care. Pragmatic rehabilitation improved fatigue, sleep and depression during the course of the 18 week intervention but these benefits were no longer apparent at the 70 week follow up.

3.4.15.2. Self-help programme for chronic fatigue syndrome: summary of one RCT

One study on pragmatic rehabilitation showed some benefit on improving fatigue, sleep and depression but these benefits were no sustained at long term.

3.4.16. Chronic neurological conditions - fatigue

3.4.16.1. Online fatigue self-management programme

Ghahari et al 2010 [65] enrolled patients with extreme fatigue (minimum Fatigue Severity Score of 4) due to chronic neurological conditions (Parkinson's or post-polio syndrome) in a RCT. Subjects were recruited via flyers, adverts or emails and 95 participants were randomised to either control (routine care), information only (as the intervention, but without any interactive element) or online fatigue self-management. The active online intervention was developed from a face-to-face version and included blogs, group experience and facilitators. Primary outcomes were QoL, activity participation and impact of fatigue. They measured pre-test, post-test and at three months using the Personal Wellbeing Index, Activity Card Sort and the Fatigue Impact Scale. Secondary outcomes were depression, anxiety and stress (Depression, Anxiety and Stress Scale), social support (Duke Social Support Index), self-efficacy (Generalised Self-efficacy Scale) and essential computer skills (self-constructed measurement). With the exception of the Personal Wellbeing Index at post-test ($p=0.034$) and the Physical Subscale of the Fatigue Impact Scale at follow-up ($p=0.035$), both in favour for the information-only group over the control group, there were no significant differences between the three groups on primary outcomes. Repeated-measures ANCOVA showed that the fatigue self-management and the information-only groups improved over time on the Fatigue Impact Scale and the Activity Card Sort ($p<0.05$), in contrast to the control group. The authors conclude that there is little benefit for the intervention over the control.

3.4.16.2. Fatigue in chronic neurological conditions: summary of one RCT

An online fatigue self-management programme offered little benefit over information alone for two primary outcomes (Personal Wellbeing Index and Physical Subscale of the Fatigue Impact Scale) of the primary outcomes (QoL, activity participation and impact of fatigue).

3.4.17. Schizophrenia

3.4.17.1. Psychoeducation in a Chinese setting

Chan et al 2009 [83] evaluated psychoeducation for Chinese schizophrenic patients, recruited from the psychiatric out-patient department of a hospital, and their caregivers. The patients (and caregivers) were randomised (groups of 36 and 37 patients) to either usual care or the psychoeducational programme (10 sessions over 3 months). Follow-up points were immediately after the intervention (post-1), 6 months (post-2) and 12 months (post-3) after the intervention.

- For patients, significant group differences were detected by the U-test for the ROMI score (Rating of Medication Influences) at the post-1 (p=0.003) and post-2 (p=0.012) time points, the BPRS (Brief Psychiatric Rating Scale) score at the post-2 (p=0.017) time point, and at all time points (p<0.01) for the ITAQ items (Insight and Treatment Attitudes Questionnaire that assesses a patient's insight into his or her illness).
- For caregivers, significant group differences were detected by the U-test for the SES (Self-efficacy Scale) score at the post-1 (p=0.007) and post-2 (p<0.001) time points, the level of satisfaction at the post-1 (p=0.033) and post-2 (p<0.021) time points, and the FIBS (Family Burden Interview Schedule) score at the post-2 time point (p=0.043).

The authors concluded that the intervention had positive effects on both patients and carers, but that the effect might not last as long as 12 months.

3.4.17.2. Schizophrenia summary

One small RCT from China found a short-term benefit (<12 months) of psycho-education for both patients and carers.

3.5. Search strategy, quality appraisal and data evidence tables

3.5.1. Quality appraisal for included systematic reviews

	Internal validity					Overall assessment					
Study	**Appropriate and clearly focussed question?**	**Is a description of the methodology described?†**	**Literature searches adequate?‡**	**Study quality assessed and taken into account?§**	**Was pooling of data appropriate? (If applicable)**	**Bias minimisation? (++, + or -)**	**If biased, how would bias affect results?**	**Types of study included**	**Research questions answered?**	**High quality systematic review?**	**Comments**
Albano et al 2008	adequately addressed	poorly addressed	adequately addressed	not addressed	not applicable	-	results could favour either intervention if studies with high risk of bias were included	SRs, RCTs, non-RCTs	yes	no	Weak methodology
Bailey et al 2009	well covered	well covered	well covered	well covered	appropriate	++		RCTs	yes	yes	Cochrane review
Barlow and Ellard 2004	adequately addressed	poorly addressed	adequately addressed	not addressed	not applicable	-	results could favour either intervention if studies with high risk of bias were included	RCTs, non-RCTs	yes	no	Description of methodology lacking
Blackstock and Webster 2007	well covered	well covered	adequately addressed	well covered	not applicable	++		RCTs, and CCTs	yes	yes	Well conducted review
Boren et al 2008	well covered	adequately addressed	poorly addressed	not addressed	not applicable	-	results could favour either intervention if studies with high risk of bias were included	RCTs, non-RCTs	yes	no	Literature search did not include Embase
Boulware et al 2001	well covered	well covered	adequately addressed	adequately addressed	appropriate	++		RCTs, CCTs	yes	yes	
Boyde et al 2011	well covered	adequately addressed	adequately addressed	not addressed	not applicable	+	results could favour either intervention if	RCTs	yes	yes	

	Internal validity					Overall assessment					
Study	**Appropriate and clearly focussed question?**	**Is a description of the methodology described?†**	**Literature searches adequate?‡**	**Study quality assessed and taken into account?§**	**Was pooling of data appropriate? (If applicable)**	**Bias minimisation? (++, + or -)**	**If biased, how would bias affect results?**	**Types of study included**	**Research questions answered?**	**High quality systematic review?**	**Comments**
							studies with high risk of bias were included				
Bussey-Smith et al 2007	adequately addressed	well covered	adequately addressed	not addressed	not applicable	+	results could favour either intervention if studies with high risk of bias were included	RCTs	yes	yes	Pubmed, ERIC, CINAHL, Psychinfo, clintrials
Coster et al 2009	adequately addressed	well covered	well covered	well covered	not applicable	++		SRs	yes	yes	
Davis et al 2011	poorly addressed	poorly addressed	adequately addressed	not addressed	not applicable	-	validity of results is uncertain given lack of detail of methods and QA	RCTs, non-RCTs	no	no	no information provided on methodology of review
Deakin et al 2009	well covered	well covered	well covered	well covered	appropriate	++		RCTs, CCTs	yes	yes	Cochrane review
Dennis et al 2008	adequately addressed	well covered	adequately addressed	not addressed	not applicable	++		SRs, RCTs, non-RCTs	yes	yes	
Ditewig et al 2010	well covered	well covered	well covered	well covered	not applicable	++		RCTs	yes	yes	Well conducted review
Dorn et al 2010	well covered	well covered	adequately addressed	adequately addressed	not applicable	++		RCTs, CCTs	yes	yes	
Du et al 2011	well covered	well covered	Poorly addressed	well covered	appropriate	++		RCTs	yes	yes	Literature search only included medline and Embase databases but hand searching

	Internal validity					Overall assessment					
Study	Appropriate and clearly focussed question?	Is a description of the methodology described?†	Literature searches adequate?‡	Study quality assessed and taken into account?§	Was pooling of data appropriate? (If applicable)	Bias minimisation? (++, + or -)	If biased, how would bias affect results?	Types of study included	Research questions answered?	High quality systematic review?	Comments
											was carried out.
Duke et al 2009	well covered	well covered	well covered	well covered	appropriate	++		RCTs, CCTs	yes	yes	Cochrane review
Effing et al 2007	well covered	well covered	well covered	well covered	appropriate	++		RCTs, CCTs	yes	yes	Cochrane review
Gibson et al 2009	well covered	well covered	well covered	well covered	appropriate	++		RCTs, CCTs	yes	yes	Cochrane review
Guevara et al 2003	well covered	well covered	adequately addressed	poorly addressed	appropriate	++		RCTs, CCTs	yes	yes	
Hampson et al 2001	well covered	well covered	well covered	well covered	appropriate	++		RCTs, CCTs	yes	yes	HTA
Hawthorne et al 2008	well covered	well covered	well covered	well covered	appropriate	++		RCTs, CCTs	yes	yes	Cochrane review
Iversen et al 2010	well covered	poorly addressed	well covered	not addressed	not applicable	+	validity of results is uncertain given lack of detail of methods and QA	RCTs	yes	no	
Jones et al 2011	well covered	adequately covered	well covered	not addressed	not applicable	++		RCTs, non-RCTs	yes	yes	
Jovicic et al 2006	adequately addressed	well covered	well covered	adequately addressed	appropriate	++		RCTs	yes	yes	Well conducted review
Korpershoek et al 2011	well covered	well covered	Adequately addressed	adequately addressed	not applicable	++		RCTs, non-RCTs	yes	yes	

	Internal validity					Overall assessment					
Study	**Appropriate and clearly focussed question?**	**Is a description of the methodology described?†**	**Literature searches adequate?‡**	**Study quality assessed and taken into account?§**	**Was pooling of data appropriate? (If applicable)**	**Bias minimisation? (++, + or -)**	**If biased, how would bias affect results?**	**Types of study included**	**Research questions answered?**	**High quality systematic review?**	**Comments**
Mason et al 2008	well covered	well covered	well covered	adequately covered	not applicable	++		RCTs	yes	yes	
McGillion et al 2004	well covered	well covered	well covered	well covered	not applicable	++		RCTs	yes	yes	
Merinder et al 2000	adequately addressed	adequately covered	poorly covered	not addressed	not applicable	-	validity of results is uncertain given lack of detail of methods and QA	RCTs, non-RCTs	yes	no	Search limited by no Embase or Cochrane. Old review as searches were ran in 1997
Monninkhof et al 2003	adequately addressed	well covered	well covered	adequately addressed	appropriate	++		RCTs, non-RCTs	yes	yes	
Niedermann et al 2004	adequately addressed	well covered	well covered	adequately addressed	not applicable	++		RCTs	yes	yes	Embase not searched
Powell et al 2003	well covered	well covered	well covered	well covered	not applicable	++		RCTs, non-RCTs	yes	yes	search ran in Dec 2000
Riemsma et al 2003	well covered	well covered	well covered	not addressed	not applicable	++		RCTs	yes	yes	
Sarkisian et al 2003	well covered	well covered	adequately addressed	poorly addressed	not applicable	++		RCTs, non-RCTs	yes	yes	
Shin et al 2010	well covered	adequately addressed	adequately addressed	poorly addressed	not applicable	++		RCTs, non-RCTs	yes	yes	no Embase in search
Smith et al 2007	well covered	well covered	well covered	adequately addressed	appropriate	++		RCTs, non-RCTs	yes	yes	
Solomon M, 2008	well covered	poorly addressed	poorly addressed	poorly addressed	not applicable	-	validity of results is uncertain given lack of QA	ALL except editorials, letters, proceedings, not	Yes but conclusion not in line with the findings	no	

	Internal validity					Overall assessment					
Study	**Appropriate and clearly focussed question?**	**Is a description of the methodology described?†**	**Literature searches adequate?‡**	**Study quality assessed and taken into account?§**	**Was pooling of data appropriate? (If applicable)**	**Bias minimisation? (++, + or -)**	**If biased, how would bias affect results?**	**Types of study included**	**Research questions answered?**	**High quality systematic review?**	**Comments**
								peer reviewed			
Thomas et al 2006	well covered	well covered	well covered	well covered	not applicable	++		RCTs	yes	yes	Cochrane review
Yehle et al 2010	well covered	poorly addressed	adequately addressed	not addressed	not applicable	+	validity of results is uncertain given lack of detail of methods and QA	RCTs, non-RCTs	yes	no	Poor reporting of study methodology

3.5.2. Data extraction table of included systematic reviews

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
Bailey et al. 2009 Australia	Asthma Children and adults of minority groups who have asthma.	Primary and secondary	4 RCTs	Patient education An education programme is defined as a programme which transfers information about asthma in any form.	RCTs involving comparisons of specifically developed culture orientated asthma programmes with their local generic asthma education programmes or usual care, such as individual asthma education sessions delivered in participant's own dialect.	Use of a culture-specific programme was superior to generic programmes or usual care in improving : **patient knowledge** -asthma knowledge scores in children, WMD 3.30 (95% CI 1.07 to 5.53), **Clinical** - asthma quality of life scores in adults, pooled WMD 0.25 (95% CI 0.09 to 0.41), - exacerbations in a single study, reducing asthma exacerbations in children (risk ratio for hospitalisations 0.32, 95%CI 0.15, 0.70).	Current limited data show that culture-specific programmes for adults and children from minority groups with asthma are more effective than generic programmes in improving most (quality of life, asthma knowledge, asthma exacerbations, asthma control) but not all asthma outcomes.	This evidence is limited by the small number of included studies and the lack of reported self-efficacy outcomes. Overall it is difficult to make conclusions regarding the effectiveness of culture specific asthma programmes based on four RCTs when many of the statistically significant results are from one study (Canino 2008). More studies are required to address this question and to further inform relevant clinical practice and health policy.
Blackstock and Webster 2007 Australia	COPD Participants had to have a formal diagnosis of COPD	Primary and secondary	10 RCTs (13 publications)	Patient education. Patient education was defined as formal delivery of education on topics related to COPD with the aim to improve the knowledge and understanding of	Education had to be delivered by a health professional and it needed to involve at least one occasion where the patient or group had face to face interaction. Patient education was categorised	**Self-efficacy** Only one study examined self-efficacy following education and did not find any significant difference between study groups. **Clinical** This review found no significant differences between groups for cognitive	The data from this review is insufficient to make firm recommendations on the benefits associated with education for patients with COPD. No conclusions can be made as to whether group or individual tailored education results in better outcomes.	Self-efficacy was not improved through patient education compared to usual care, however only one study reported on self-efficacy. There were no significant differences between groups in health care utilization of

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				COPD. Self-management education was defined as education focusing on changing health behaviours through knowledge, goal setting and development of action plans. Didactical education was defined as education in a passive lecture format.	into self-management education and didactical education.	function, hospital admissions, length of stay, health care costs, pulmonary function, HRQoL or anxiety and depression. **Health-care use** Two studies showed some benefit in decreasing GP visits in the intervention group with one meta-analysis showing significantly more participants in the control group attended their GP greater than once in a 12 month period (26% education group vs 84% control group, p<0.0001). This study the intervention was 2 x 2hr group sessions on 2 separate days, then follow up with 1 or 2 patients with nurse.	Likewise there is uncertainty as to which professional should be delivering the education. Disease specific didactical education is likely to be of less benefit to COPD patients compared with self-management education.	HQoL except for a decrease of GP visits in the intervention group (from 2 RCTs).
Boulware et al 2001	Hypertension	Primary, secondary and tertiary	15 RCTs	Patient education Patient-centred behavioural interventions focusing on counseling, structured training courses, and patient self-monitoring of blood pressure (BP). Counseling was defined as individual	Both counseling and training interventions were multidimensional in nature, primarily advocating general, commonly accepted lifestyle practice changes: encouraging healthy diet, weight loss, exercise, and tobacco cessation.	**Self-efficacy** Counseling plus training was favored over counseling in affording more patients hypertension control (95%, 95% CI, 87 to 99) than those receiving counseling (51%, 95% CI, 34 to 66) or training alone (64%, 95% CI, 48 to 77). **Clinical** (i) Pooled results revealed that counseling was favored over	Findings from 15 RCTs suggests that counseling offers BP improvement over usual care, and that adding structured training courses to counseling may further improve BP. It seems counseling is an important adjunct to pharmacologic therapy given the reduction of	This review focused on the outcome of reducing blood pressure rather than self-efficacy outcomes. There is insufficient evidence to suggest whether self-monitoring of BP or training courses alone offer consistent improvement in BP over counseling or usual care.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				or group discussion and teaching with a personalised approach, set in a non-classroom format in which individuals or group members might often share their personal experiences. Self-monitoring of BP was defined as home BP monitoring performed by the patient for the purposes of recording or monitoring BP.	Included studies were primarily "patient-centred," that is studies that were designed to detect the effects of changes in patient behaviour on BP as a result of the intervention, not interventions in which the health-care provider was the unit of analysis.	usual care in improvements in diastolic blood pressure (DBP) (3.2 mmHg, 95% CI, 1.2 to 5.3), and systolic blood pressure (SBP) (11.1 mmHg, 95% CI, 4.1 to 18.1), (ii) Pooled results revealed that counseling was favored over training courses in improvement in DBP (10 mmHg, 95% CI, 4.8 to 15.6). (iii) Counseling plus training was favored over counseling in improvement in SBP (4.7 mmHg, 95% CI, 1.2 to 8.2).	BP shown with these interventions.	
Boyde et al. 2011 Australia	Heart failure Mean age 70.6 years, 55.3% male	primary and secondary	19 RCTs	Patient education. Educational interventions defined as a prespecified learning activity and the intervention was evaluated either directly by knowledge or self-care abilities or indirectly by readmission rates, mortality or QoL.	One on one didactic patient education (12 studies) with supplementary follow up education such as home visits, written materials, videos and telephone calls delivered by nurse predominantly. Or take home educational video (2 studies) or CD-ROMs (5 studies).	**Self-efficacy** Self-efficacy had a significantly significant improvement reported in one study only (1 hour education session with weekly phone calls for 1 month, then monthly for 6 months). Self-care showed a statistically significant improvement in 6 out of 8 studies (Video, nurse one on one education with telephone follow up) **Knowledge** Knowledge levels showed a	There was much variation in the educational interventions studied as well as the outcome measures used for evaluation making it difficult to establish the most effective educational strategy. Verbal teaching is the most common form of patient education but was the least effective, indicating it needs to be combined with a second type of medium such as multimedia.	Self-efficacy showed a significant improvement but was only reported in one study where the intervention was continued with telephone contact 6 months post intervention. Patient knowledge levels improved however there is no evidence from this review that this then improves self-care or self-efficacy.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
					Educational interventions were guided by a theoretical model in 7 studies.	statistically significant improvement in the 8 studies that evaluated patient knowledge. **Clinical** Three studies reported significantly decreased mortality. QoL improved in 2 out of 12 studies. **Health –care use** Four out of 12 studies reported significantly decreased readmission rates. NB: actual results not reported in publication.	Patient education based on educational theory with evaluation may benefit heart failure patients.	
Bussey-Smith and Rossen 2007 USA	Asthma RCTs in the English language that evaluated the use of an interactive computerised educational programme for asthma patients of any age	Primary and secondary	9 RCTs	Patient education via computer The computerised asthma patient educational programme (CAPEP) makes use of computer games and programmes tailored to the specific features of the asthma in the individual playing the game. This is made possible by incorporating the	Patient education had to involve the use of interactive computerised programme. This may include a didactic education programme that provides information about the basics of asthma, asthma medication, inhaler use, asthma triggers/allergens, or the use of an educational	**Self-efficacy** Asthma knowledge: Four studies out of 9 were associated with significant improvements in asthma knowledge **Clinical** Improvement in symptoms Five out of a total of 9 studies were significantly associated with improvement in asthma symptoms. (i) Lung function improvement Two studies (a didactic	Interactive CAPEPs appear to improve patient asthma knowledge and symptoms. However less evidence exists to support their effect on objective clinical outcomes, including hospitalizations, acute care visits, use of rescue medications, and lung function	Computerised asthma education may improve asthma knowledge and symptoms. Studies that had repeated exposure to using the CAPEPs reported significant improvement in asthma knowledge. Further research is however needed to justify its use in clinical outcomes including health care utilisation and patient self-efficacy.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				patient's own medication, allergens and/or triggers, peak flow data, and/or symptoms into the game to make the experience more relevant for the user	website as part of a video and computer patient management system, or use of a computer game which teaches users how to take appropriate medications and avoid triggers using an on-screen nurse.	education, and a personal interactive programme) were associated with improvements in lung function (p=0.02 in each study) **Health-care use** (i) Number of hospitalizations One study which used a multimedia computer game was associated with a decrease in hospitalizations (p=0.02) (ii) Acute care visits One study which used computerised asthma lessons was associated with reduction in acute care visits (p<0.01) (iii) Rescue inhaler use One study which used interactive computerised programme was associated with decrease in short-acting bronchodilator use (p=0.02)		
Coster and Norman 2009 UK	People suffering from a chronic health problem or condition, to include carers in the case of vulnerable adults or children. Included populations	Primary and secondary	30 Cochrane reviews	Educational and self-management interventions by nurses. This review adopted a broad definition of patient education to include all interventions designed to improve	Patient education ranged from general advice or was tailored for individual patients. Self-management programmes provided both education and practical self-management skills with some	**Asthma interventions** There was good evidence (3 reviews) that self-management education reduced health care utilization such as reduced hospitalisations and emergency visits. One review showed improved self-efficacy in children (Wolf 2002). There is inconsistent evidence as to whether action plans	-over half the reviews : judged by the Cochrane reviewers to provide inadequate evidence for the interventions' effectiveness (design problems) -few SR reached conclusions with regard to the key	Fewer than half the reviews were found to be effective so overall educational and self-management programs cannot be strongly recommended although the diversity across the programs makes it difficult to generalise. The majority of outcomes focussed on

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
	were: COPD, epilepsy, rheumatoid arthritis, atopic eczema, schizophrenia, bipolar disorder, stroke, HIV, back pain, hypertension			patients' knowledge and skills to manage chronic health problems. Excluded: -Psychological interventions such as psychotherapy or CBT -interventions delivered by lay people	programmes containing behavioural treatments. Interventions were delivered through written or multi-media materials, interactive sessions with professionals, lectures or a combination of these approaches.	(help patients with self-monitoring of asthma medication) can work in isolation or only as part of an optimal self-management programme. **Diabetes** Only one (Deakin 2005) out of five reviews on diabetes had positive result of group education programmes were effective at improving clinical outcomes and some psychosocial outcomes. **Epilepsy** Group education might help reduce number of seizures and improve knowledge of epilepsy but evidence is limited by low number of trials available. **COPD :** Interventions may improve knowledge, QoL and reduce hospital admission but low number of good quality trials available.	components of intervention programmes Educational programmes have some benefits for patients suffering from asthma and are promising for interventions for diabetes, epilepsy and mental health. It is difficult to describe what elements are needed to make a successful intervention. However, there is no clear evidence as to whether group or individual education is superior. Few data on cost-effectiveness	improvement in disease symptoms and health care utilisation rather than self-efficacy. Interventions for asthma, diabetes and epilepsy were found to be effective often because self-management programmes are aimed at symptom monitoring such as blood glucose which can empower the patient to manage their condition.
Deakin et al. 2009 UK	Type 2 diabetes Adults with diagnosed type 2 diabetes regardless of gender or ethnicity	Primary and secondary	11 RCTs (14 publications)	Group-based patient education	Group-based educational programmes which met the following criteria: • specific for people with type 2 diabetes; • delivered in primary or	Results of meta-analyses in favour of group-based diabetes education programmes were **Self-efficacy** **(**i) One RCT, Deakin 2003 assessed the level of empowerment and found at 4 months there was a significant difference in total	Group-based education or training for self-management strategies in people with type 2 diabetes is effective by improving fasting blood glucose levels, HbA1c and diabetes knowledge and reducing systolic blood pressure levels, and the requirement for	There was strong evidence from one study that group-based diabetes education significantly improved empowerment. Most of the outcomes used in the meta-analysis resulted from two or three studies.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
					secondary care; • based on learner/patient-centred education; • included or excluded family and friends; • had a minimum of six participants in each group; • was a minimum of one session lasting for one hour.	empowerment score in favour of the group education programme (difference 0.3;95% CI 0 to 0.6;p<0.001) (ii) Diabetes knowledge Improvement at 12-14 months (standardised mean difference SMD: 1.0; 95% CI: 0.7 to 1.2) from 4 RCTs. **Clinical** (i) HbA1c Reduction at 4-6 months (1.4%; 95% CI: 0.8 to 1.9), at 12-14 months (0.8%; 95% CI: 0.7 to 1.0) and at two years (1.0%; 95% CI: 0.5 to 1.4) from 3 RCTs. (ii) Fasting blood glucose Reduction at 12 months (1.2 mmol/L; 95% CI: 0.7 to 1.6); 2 RCTs. (iii) Systolic blood pressure Reduction at 4-6 months (5 mmHg: 95% CI: 1 to 10), 2 RCTs. **Health-care use** (i) Need for diabetes medication Reduction in need for diabetes	diabetes medication.	Therefore more studies are needed to confirm whether group education programmes are more efficacious if based on patient education incorporating empowerment.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						medication (odds ratio 11.8, 95% CI: 5.2 to 26.9) from 5 trials		
Dennis et al. 2008 Australia	Adults aged 18 years and over with one or more of the following chronic conditions: hypertension, coronary heart disease, type 2 diabetes, lipid disorders, asthma, COPD, arthritis (OA and RA) and osteoporosis.	Primary care	141 studies (study types not reported) and 23 SRs. Only studies >1990 and undertaken in Australia, Canada, The Netherlands, New Zealand, Scandinavia, UK and USA.	Chronic disease management interventions. The Chronic Care Model (Wagner 1996) was used as a framework for analysis, 6 elements of the model: self-management support, delivery system design, decision support, clinical information systems, community resources and health care organisation.	Organisational, professional or financial interventions for chronic disease delivered by non-hospital professionals. Patient-mediated interventions such as distribution of educational materials, education session, motivational counselling, brief intervention, community programs, self-management and call-back reminder notices.	This review found self-management interventions are effective in improving both process of care and patient outcomes, with the most evidence for diabetes and hypertension, some evidence for arthritis and asthma with less clear evidence for COPD. According to the of the chronic care model, effective interventions 1. Self-management support element • Patient education sessions • Patient motivational counselling • Educational material 2. Delivery system design • Multidisciplinary teams • Most evidence for effectiveness of delivery system design for diabetes, hypertension, lipid disorders and heart disease	Evidence from this review on chronic disease management in the Australia primary health care showed the interventions most likely to be effective were engaging primary care in self-management support through education and training for GPs and practice nurses and linking self-management support in care plans.	The focus of this review was on effective chronic disease management in Australian primary health care. It identified some important findings based on the Chronic Care Model but details on effective self-management interventions were not reported making it difficult to assess what aspects make up a successful intervention.
Ditewig et al. 2010	Chronic heart failure (CHF)	Primary, secondary	19 RCTs	Self-management	Studies had to describe and compare	**Self-efficacy** NR	This systematic review found that current available published	Although there were some positive findings of self-management

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
The Netherlands	Adults aged >18 years and diagnosed with CHF, regardless of severity of the disease, literacy level or ethnic group	and tertiary		Self-management refers to the individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a chronic condition, to affect the cognitive behavioural and emotional responses necessary to maintain a satisfactory QoL, so a dynamic and continuous process of self-regulation is established.	effectiveness of self-management interventions (in any format, i.e. written, verbal, visual, audio) with standard care designed for CHF patients implemented by any health professional or lay leader. Self-management interventions could be integrated in a formal CHF (disease-management) program.	**Clinical** (i) mortality One study out of 9 that assessed mortality reported a significant reduction in favour of the intervention group on the rate of deaths per observation year (p=0.006). (ii) quality of life Only 6 out of 14 studies that measured QoL reported significant improvements in QoL in intervention groups compared with controls. **Health-care use** (I) All-cause hospital readmissions Two studies (Atienza 2004, Giordiano 2009) out of 8 that assessed all-cause hospital readmissions reported significant decrease in favour of the intervention-group. Another study (Wakefield 2008) reported a significantly lower proportion of combined intervention patients were readmitted. (ii) CHF-hospitalization rate Two studies (same as above outcome) out of 4 that assessed CHF-	studies show methodological weaknesses making validation of the effectiveness of self-management interventions on mortality, all-cause hospital readmissions, chronic heart failure hospitalization rate and quality of life in patients with chronic heart failure.	interventions for CHF such as reduced hospital readmissions and improved QoL, it is difficult to make strong recommendations for self-management interventions for this chronic disease group. Many of the included studies had short follow up periods and the instruments used to assess self-management (QoL tools) may not be adequately validated to measure an effect of improved or worsened self-efficacy. In future, well-designed studies on CHF are required to determine the independent effects of self-management interventions and different combinations of interventions on clinical and patient reported outcomes

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						hospitalization rate described significant reductions in favour of the intervention-group.		
Dorn et al 2010 USA	Irritable bowel syndrome (IBS) Adults (>18 years) with IBS	Primary, secondary and tertiary	11 studies (9 RCTs, 2 non-RCTs)	Self-management Self-management strategies typically include educational materials, as well as cognitive behavioural approaches to increase patients' knowledge, bolster self-efficacy, and encourage self-management behaviours.	Comparison of one or more self-management related intervention (IBS education programme with 6 weekly sessions, single educational class, audio CD-based home hypnosis sessions, self-administered cognitive behavioural therapy, self-help guide book, support groups) to a control (including standard medical treatment and/or wait list group). Psychological therapies which may or may not be considered a component of self-management were excluded unless the psychological therapy was primarily self-administered as a means of strengthening	**Self-efficacy** (i) IBS knowledge One RCT (Ringstrom 2009) reported greater improvements in IBS knowledge in patients who received a structured IBS education compared with IBS education booklet (3 months: 74 on VAS vs 40, p<0.001; 6 months 73 vs 40, p<0.001) **Clinical** (i) IBS Symptom Severity Score (IBS-SSS) One RCT (Ringstrom 2009) reported greater improvements in IBS-SSS in patients who received a structured IBS education compared with IBS education booklet (3 months: change of -21 vs. -6; p=0.06; 6 months: change of -32 vs -13, p=0.04). Another RCT also reported greater symptom relief in patients assigned to usual care plus self-management compared with usual care	Self-management support interventions did appear to benefit IBS patients with a self-administered cognitive behavioural intervention achieving the largest benefit compared with usual care (72% vs 7% achieved adequate relief) followed by a self-help guidebook. The evidence for patient support groups and home hypnosis was inconclusive. Many of the included studies were limited by methodological flaws.	This review showed some promising self-management interventions for IBS such as self-administered cognitive behavioural therapy, self-help guidebook and structured patient education, however many studies were under-powered with small patient numbers and at risk of bias often due to a lack of blinding.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
					self-care.	alone. (ii) IBS Severity Scale One non-RCT (Palsson 2006, n=25) reported a decrease in the IBS Severity Scale (53% vs. 26%, p<0.05) at 3 months respectively in patients who received a home hypnosis programme compared with controls (standard medical care) (iii) Adequate relief One RCT (Lackner 2008) reported superior adequate relief (responders 72.0% vs. 7.4%; p< 0.05) in patients respectively assigned to self-administered cognitive behavioural therapy (CBT) vs self-monitoring control. Another RCT reported higher relief (76.7% vs. 21.2%; p< 0.05) in patients assigned to usual care plus self-management compared with usual care alone. (iv) Clinical global improvement One RCT(Lackner 2008) reported higher clinical global improvements in patients assigned to self-administered cognitive behavioural therapy		

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						(CBT) or standard CBT versus self-monitoring control		
Du et al 2011 China	Musculoskeletal pain conditions Adults (aged ≥18 years) with chronic musculoskeletal pain conditions which include arthritis(OA, RA or fibromyalgia), back pain, shoulder pain, neck pain, etc., and the symptom of pain persists for more than 3 months	Primary and secondary	19 RCTs	Self-management Studies of interventions that integrated systematic therapies into a self-management or self-care program were included. Comparison was usual care or waiting-list control.	Self-management programmes selected should lay emphasis on 8 elements: (a) self-efficacy building; (b) self-monitoring; (c) goal-setting and action-planning; (d) decision-making; (e) problem-solving; (f) self-tailoring; (g) partnership between the views of patients and health professionals; and (h) community-based and close to home. The trials in which interventions primarily focused on managing pain and minimizing disability were qualified for inclusion	Results of meta-analyses in favour of self-management compared with control were **Self-efficacy** (i) Arthritis-related pain Significant reduction in pain at 4 months from 7 RCTs (SMD= -0.23, 95% CI: -0.36 to -0.1, p=0.0003), at 6 months from 3 RCTs (SMD= -0.29, 95% CI: -0.41 to -0.17, p=0.0003), at 12 months from 3 RCTs (SMD= -0.14, 95% CI: -0.23 to -0.04, p=0.008) using visual analogue scale and visual numeric scale. (ii) arthritis-related disability Significant reduction in disability at 12 months from 3 RCTs(SMD= -0.17, 95% CI: -0.27 to -0.07, p=0.0006). (iii) Chronic back pain intensity None of the 3 studies showed significant positive effect in reducing back pain. (iv) Disability associated with	This study shows that self-management programs probably have a beneficial effect on pain and disability for chronic musculoskeletal conditions. Particularly for arthritis, results of meta-analyses show that self-management programs have a small to moderate effect in reducing pain within 1 year. Further research is needed on self-management for chronic back pain.	There is evidence that self-management has small to moderate benefit for arthritis-related pain and disability. However for chronic back pain, the evidence is insufficient. Further research on self-management for improving and disability is needed. The authors ensured that included RCTs evaluated self-management interventions that were designed to give the patient effective pain management strategies such as relaxation, exercise advice, medication advice, problem solving, decision making, action planning and self-tailoring.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						chronic back pain Only one study reported a short-term (3 months) significant positive effect in improving disability (effect size: -2.30, 95% CI:(-4.21 to -0.39)).		
Duke et al. 2009 Australia	Type 2 diabetes Adults with type 2 diabetes as defined by WHO, American Diabetes Association. Excluded maturity onset diabetes of the young and gestational diabetes.	Primary and secondary	9 RCTs	Individual patient education.	The intervention was individual face-to-face patient education (not telephone or computer-based) while control individuals received usual care, routine treatment or group education. Only studies that assessed outcome measures at least six months from baseline were included. Six studies compared individual education to usual care and three compared individual education to group education	**Clinical** (i) HbA1c In the six studies comparing individual face-to-face education to usual care, individual education did not significantly improve HbA1c (WMD= -0.1%, 95% CI: -0.3 to 0.1, p=0.33) over a 12 to 18 month period. However there was a significant benefit of individual education on HbA1c in a subgroup of three studies involving patients with higher baseline HbA1c greater than 8% (WMD -0.3%, 95% CI: -0.5 to -0.1, p=0.007) In the two studies comparing individual to group education, there was no significant difference HbA1c (WMD=0.03%, 95% CI: -0.02 to 0.1) at 12 to 18 months (II) BMI and blood pressure	This systematic review suggests a benefit of individual education on glycaemic control when compared with usual care in a subgroup of those with a baseline HbA1c greater than 8%. However, overall there did not appear to be a significant difference between individual education and usual care. In the small number of studies comparing group and individual education, there was an equal impact on HbA1c at 12 to 18 months. Additional studies are needed to delineate these findings further.	There were too few studies as well as too few outcomes reported to perform a meta-analysis on the effect of individual education on diabetes knowledge, psycho-social outcomes and diabetes complications or health service utilization and cost analysis in these studies. The focus of the findings of this review was on glycaemic control rather than patients' knowledge, self-efficacy and health care utilisation so the overall benefit from individual patient education in diabetes is limited.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						There was no significant difference in the impact of individual versus usual care or group education on BMI and systolic or diastolic blood pressure.		
Effing et al. 2009	chronic obstructive pulmonary disease (COPD) Patients with a clinical diagnosis of COPD (not asthma). Studies focusing mainly on pulmonary rehabilitation and studies without usual care as a control group were excluded	Primary, secondary and tertiary	15 group comparisons drawn from 14 controlled trials (randomised and non-randomised)	Self-management education. The interventions were categorised into COPD education and/or self-treatment guidelines. COPD education was a programme which transfers information about COPD and treatment of COPD in any of the following forms: written, verbal, visual or audio. Self-treatment guidelines included written plan produced for the purpose of patient self-management of COPD exacerbations.	The educational programmes took the format of group or individual education ± media/written communication, ± exercise sessions ± follow up sessions or telephone calls. With interventions directed towards COPD management such as smoking cessation, improving exercise, nutrition, self-treatment of exacerbations, inhalation technique or coping with activities of daily living, or a combination of these. Self-treatment guidelines (action plan) might inform	**Self-efficacy/HQoL** (i) Significantly higher reduction in total score on the St George's Respiratory Questionnaire (SGRQ) (WMD= -2.58; 95% CI: -5.14 to -0.02) respectively in self-management education vs usual care from 7 studies. **Clinical** (i) A small but significant reduction was detected in dyspnoea measured with the BORG-scale (WMD= -0.53; 95% CI: -0.96 to -0.10) (ii) No significant effects were found in either lung function or exercise capacity **Health-care use** (i) Significant reduction in the probability of at least one hospital admission among patients receiving self-management education compared to those receiving usual care (OR= 0.64; 95% CI 0.47 to 0.89).	It is likely that self-management education is associated with a reduction in hospital admissions with no indications for detrimental effects in other outcome parameters. This would in itself already be enough reason for recommending self-management education in COPD. However, because of heterogeneity in interventions, study populations, follow-up time, and outcome measures, data are still insufficient to formulate clear recommendations regarding the form and contents of self-management education programmes in COPD	There is need for more large RCTs with a long-term follow-up, before more conclusions can be drawn. Additionally many studies were not designed to measure self-efficacy so conclusions on this measure are limited.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
					patients about when and how to adjust and/or start medication in case of an exacerbation.	(ii) No significant effects were found in number of exacerbations and emergency department visits (ii) No significant effects were found in number of days lost from work		
Gibson et al. 2009 Australia	Asthma Adults over 16 years of age with asthma	Primary and secondary	36 RCTs	1.Patient education for self-management 2. self-monitoring 3.regular medical review 4.written action plan Patient asthma education is a programme which transfers information about asthma in any of these forms: written, verbal, visual or audio. It may be interactive or non-interactive, structured or unstructured. The content of the education must be related to asthma and its	Patient self-management education was either minimal or maximal. Minimal education was characterised by the provision of written material alone or the conduct of a short unstructured verbal interaction between a health provider and a patient where the primary goal is to improve patient knowledge and understanding of asthma. Maximal education is considered to be	**QoL** Compared with usual care, self-management education reduced (i) quality of life (standard mean difference 0.29, 95% CI: 0.11 to 0.47) (6 RCTs) (ii) days off work or school (RR 0.79, 95% CI: 0.67 to 0.93) **Clinical** (I) Self-management education reduced nocturnal asthma (RR 0.67, 95% CI: 0.0.56 to 0.79) (ii) Positive effect of asthma self-management education on improvement in peak expiratory flow (a measure of lung function) that achieved statistical significance at $p < 0.05$ **Health-care use**	Education in asthma self-management which involves self-monitoring by either peak expiratory flow or symptoms, coupled with regular medical review and a written action plan improves health outcomes for adults with asthma. Training programmes that enable people to adjust their medication using a written action plan appear to be more effective than other forms of asthma self-management	Self-management education that involves a written action plan, self-monitoring and regular medical review (based on recommendations in current asthma guidelines) result in improvements in self-efficacy, clinical outcomes and reduced health care use in adults with asthma. Interventions that did not contain a written asthma plan were not as effective.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				management. Self-monitoring regular measurement of PEF or symptoms Regular review-consult with doctor on regular basis Written action plan-individualised written plan for the purpose of self-management. Self-management was compared with usual care.	structured with the use of both interactive and non-interactive modes of information transfer.	Self-management education reduced (i) hospitalisations (RR 0.64, 95% CI: 0.50 to 0.82) (12 RCTs) (ii) emergency room visits (RR 0.82, 95% CI: 0.73 to 0.94) (20 RCTs) (iii) unscheduled visits to the doctor (RR 0.68, 95% CI: 0.56 to 0.81) (11 RCTs)		
Guevara et al 2003 USA Duplicate Cochrane Wolf	Children and adolescents with asthma, aged 2 to 18 years	Setting not reported assumed to be majority primary care.	32 RCTs 15 RCTs Adolescents 13 to 18 years. 12 RCTs children 2 to 5 years	Educational interventions for self management	Educational programmes most with multiple sessions and symptom based strategies. Educational interventions in self-management related to the prevention of asthma, management of asthma attacks or development of social skills. Detailed descriptions of interventions were not reported.	**Self-efficacy** Self-efficacy measures were reported as coping scores or health locus of control scales. There was a moderate improvement in self-efficacy with a standardised weighted mean difference (WMD) of 0.36 (95% CI: 0.15 to 0.57, p=0.0007) from 7 RCTs. **Clinical** A moderate improvement in lung function. Results from meta-analysis of 4 RCTs (258 patients) on lung function outcomes translated into a 0.24 litre increase in FEV_1 and a 9.5% increase in percentage predicted peak expiratory flow	Educational interventions for the self-management of asthma in children and adolescents were associated with modest to moderate improvement in self-efficacy, lung function, and number of visits to an emergency department. programmes targeted at the individual : greatest reductions in morbidity measures, programmes targeted at a group had the greatest reduction	This systematic review and meta-analysis showed statistically significant improvements in favour of most study outcomes. Multiple sessions had the greatest success at improving self-efficacy and group interventions had the greatest reduction in hospitalisations.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						rate. **Health-care use** Educational interventions were associated with a modest reduction in number of visits to an emergency department WMD -0.21 (95% CI; -0.33 to -0.09, p=0.0007) from 18 RCTs (1899 patients).	in hospitalisations. programmes comprising single sessions had the greatest reductions in morbidity measures, those comprising multiple sessions had the greatest improvement in self efficacy and the greatest reduction in n visits to ED	
Hampson et al. 2001 U.K	Type 1 diabetes Patients with type 1 diabetes aged 9–21 years (mean duration of diabetes was 4.9 years)	Primary and secondary	62 studies (25 RCTs) reported in 64 publications	Educational and psychosocial interventions for self-management. Education was defined broadly to include any intervention aimed at changing diabetes-related behaviour as well as those related more specifically to knowledge Psychosocial interventions are diverse and provide	Most of the studies used family therapy, followed by behavioural principles and the third largest used social learning theory. Minority of the studies used interventions that could not be categorised as family therapy, behavioural therapy or social learning theory, such as anchored instruction or social support.	**Self-efficacy** (i) Group-based behavioural intervention improved relative to control (usual care) on diabetes specific stress levels ($p < 0.05$) (Boardway et al. 1993). (ii) Patients in diabetes self-efficacy improved more in coping skills training plus intensive diabetes management, ($p < 0.05$), and were less upset with coping ($p < 0.001$), found coping less hard ($p < 0.01$) and diabetes had less impact on their quality of life ($p < 0.04$) compared with control (intensive management only)	Educational and psycho-social interventions have small to medium beneficial effects on various diabetes management outcomes. Quantitative and narrative analysis of the evidence suggested that interventions are more likely to be effective if they demonstrate the inter-relatedness of the various aspects of diabetes management.	Combining both medical and non-medical aspects of diabetes management was more successful for adolescents than interventions that focus on one aspect. The evidence in this review arise mainly from studies in the USA, hence it provides a starting point for the design of interventions for other countries

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				training and support in such areas as social skills, diabetes-related problem-solving and coping skills, communication skills, and individual and family based counselling.		**Clinical** (i) Diabetic control (combination of HbA1c) and doctor ratings): eight of nine family therapy patients and two of nine control (usual care) patients improved (p< 0.05) at 12 months (Ryden et al. 1994). (ii) multi-family group therapy of adolescents and parents to discuss diabetes management showed significant decrease in HbA1c at 3 months compared with no intervention (control) (p<0.05) (Satin et al. 1989). (iii) Control (usual care) group showed a significantly greater decline in metabolic control over the 18 months ($p < 0.04$) (Anderson et al. 1989). (iv) Self-monitoring of blood glucose training patients had a lower HbA1 at 1 year ($p < 0.01$) and at 2 years ($p < 0.05$) than control (usual care) (Dalamater et al. 1990). (v) Both coping skills training plus intensive diabetes management and control (intensive management only) patients had improved HbA1c over time in both		

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						groups (p < 0.001) but more so for IG1 (p < 0.04) (Grey et al. 1998). **Health-care use** (i) Individual-based education may be more costly in terms of staff involvement than group-based interventions, but they permit a more targeted approach that meets the individual's particular needs, which may be more cost-effective in the long term.		
Hawthorne et al. 2008 U.K	Type 2 diabetes Ethnic minorities with type 2 diabetes mellitus of any duration of diagnosis, with or without complications of diabetes	Primary, secondary and tertiary	11 RCTs	Culturally appropriate health education Culturally appropriate health education is defined here as education that is tailored to the cultural or religious beliefs and linguistic skills of the community being approached, taking into account likely literacy skills	Culturally appropriate health education could include adapting established health education to innovative delivery methods, such as using community based health advocates, or delivering it to same gender groups, or adapting dietary advice to fit in with the likely diet of a particular community	**Self-efficacy** (i) Knowledge scores improved in the intervention groups at 3 months, 4 RCTs (SMD 0.6, 95% CI: 0.4 to 0.7), six months 5 RCTs (SMD 0.5, 95% CI: 0.3 to 0.7) and twelve months 2 RCTs (SMD 0.4, 95% CI: 0.1 to 0.6) post intervention results from 10 RCTs (ii) no significant improvement compared with control groups in patient-based outcomes (quality of life measures, attitude scores and measures of patient empowerment and self-efficacy) **Clinical** (i) Glycaemic control (HbA1c), showed an improvement following culturally appropriate	Culturally appropriate diabetes health education appears to have short term effects on glycaemic control and knowledge of diabetes. None of the studies were long-term, and so clinically important long-term outcomes could not be studied	Only two RCTs measured patient empowerment and self-efficacy outcomes and found no significant differences between intervention and control groups. There is a need for long-term RCTs that compare different types and intensities of culturally appropriate health education within defined ethnic minority groups

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						health education at 3 months (WMD - 0.3%, 95% CI: -0.6 to -0.01), and at six months (WMD -0.6%, 95% CI: -0.9 to -0.4), compared with control groups who received 'usual care'. This effect was not significant at 12 months post intervention (WMD -0.1%, 95% CI: -0.4 to 0.2) (ii) no significant improvement compared with control groups in lipid levels and blood pressure		
Jones et al. 2011 U.K	Stroke Post-stroke patients Mean age ranged from 55 to 78 years	Primary, secondary and tertiary	22 studies in total. 19 single-arm studies, many community sample of <100 stroke patients, 2 RCTs and I non RCT	Self-efficacy and self-management Self-efficacy is defined as `people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives'.	Self-efficacy and social cognition theory as basis of self-management programmes for post-stroke patients.	**Self-efficacy** There is evidence that self-efficacy is an important variable associated with various outcomes post-stroke including quality of life or perceived health status, depression, ADL and, to a certain extent, physical functioning. Evidence from one RCT (Johnson 2007) evaluating a manual-based intervention designed to increase perceived control (n=203) showed significantly better recovery from disability compared to a decline in control group. A small non RCT (Huijbregts	There is a need for researchers, to work together with other stakeholders to develop and test interventions that can support self-management skills and confidence to make continued progress after stroke. This could help to reduce some of the negative consequences of stroke such as reduced quality of life and social isolation	Further research on self-management programmes that utilise self-efficacy as an underlying construct is needed. The majority of evidence from this review is based on small single arm studies making it difficult to assess the effectiveness of an intervention as there was no control comparison. Further RCTs evaluating self-efficacy interventions in stroke patients are required to determine what is effective in this patient group.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						2008) (n=30) studying a twice weekly 6 week group based intervention, showed the participant group improved significantly on living index, balance scale and functional independence scale.		
Jovicic et al. 2006 Canada	Heart failure patients 18 years of age or older who were diagnosed with heart failure	Primary, secondary and tertiary	6 RCTs	Self-management Self-management was defined as "decisions and actions taken by someone who is facing a health problem or issue in order to cope with it and improve his or her health."	Self-management interventions included programmes aimed at enabling patients to assume responsibility for managing one or more aspects of heart failure (e.g. symptom monitoring, weight monitoring, medication dosage adjustment and/or decision-making). Group or individual education sessions with home visit or phone call follow ups. One RCT (Ross) used an educational software with messaging communication between patients and staff.	**Self-efficacy** One study (Koelling) showed that patients in the intervention group were significantly more likely to have an action plan, perform daily weighing, monitor symptoms, exercise and not smoke. Another RCT (Ross) reported a significant improvement in adherence to general medical advice. Effect of self-management on adherence to prescribed medical advice improved, but there was no significant difference in functional capabilities, symptom status and quality of life **Clinical** The effect of self-management on mortality was not significant (OR = 0.93; 95% CI 0.57 to 1.51) **Health-care use** (i) Self-management	Self-management programs targeted for patients with heart failure decrease overall hospital readmissions and readmissions for heart failure. Results from individual studies seem to indicate that the self-management interventions with more intensive education components are more likely to show benefits	Future research is needed to assess whether improvements in mortality and quality of life can be achieved with self-management The pooled results from 3 RCTs showed a significant reduction in hospital readmissions due to heart failure. Results from other outcomes such as mortality and QoL were less conclusive based on results from the three out of six RCTs that reported these outcomes.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						decreased all-cause hospital readmissions (OR 0.59; 95% CI: 0.44 to 0.80) and heart failure readmissions (OR 0.44; 95% CI: 0.27 to 0.71). (ii) Self-management of heart failure on reported savings from reduced resource utilization ranged from $1300 to $7515 per patient per year		
Korpershoek et al. 2011 The Netherlands	Stroke Adults with stroke in all phases after stroke	Primary, secondary and tertiary	17publications 4 RCTs but majority cross-sectional studies with < 100 patients	Self-efficacy The concept self-efficacy is described as the confidence in one's ability to perform a task or specific behaviour. A high sense of self-efficacy leads to desired outcomes, such as improved health.	Self-efficacy included situation- and task-related, behaviour specific concept. The strongest way of influencing self-efficacy was mastery experience through successful performance of a task	**Self-efficacy** Self-efficacy was positively associated with activities of daily living as shown by a chronic model self-management course in a RCT (Kendall 2007) (n=110) showed positive effect of self-care as measured by the QOL self-efficacy scale: (p<0.001), social roles (p<0.001), work productivity (p<0.001) . Four self-efficacy enhancing interventions were identified but the evidence of these interventions was inconclusive. **Clinical** Self-efficacy was positively associated with mobility, quality of life and negatively associated with depression	Patients with high self-efficacy are functioning better in daily activities than patients with low self-efficacy. The evidence concerning the determinants influencing self-efficacy and the self-efficacy interventions makes clear how nurses can develop and tailor self-efficacy interventions for the clinical practice of people with stroke	This review was limited by a lack of RCT evidence. Positive findings on self-efficacy outcomes were demonstrated by one RCT. Overall, the variety of study designs, inclusion criteria and instruments used made it impossible to pool the findings.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
Mason et al 2008 UK	Chronic kidney disease (CKD) Patients in any of the following stages of chronic kidney disease: early, pre-dialysis, and dialysis. Mean age 55 years. Kidney transplant recipients were excluded because this group has additional educational needs that are beyond the scope of this review	Primary, secondary and tertiary	22 RCTs Sample sizes ranging from 10 to 335 participants.	Patient education Educational interventions for people with a chronic disease typically incorporate informational components to improve knowledge, along with a variety of psychological methods to empower patients and change behaviour.	Interventions involved components aimed at improving both knowledge and motivation. These components were used in various combinations and formats ranging in terms of complexity. Most studies used an individual rather than a group format to deliver the intervention, and all interventions took place in hospitals.	**Self-efficacy** Results from 4 studies indicated significant improvements in long-term knowledge retention in pre-dialysis care **Clinical** (i) One study was identified that involved 70 patients with an estimated glomerular filtration rate less than 30 mL/min/1.73 m2 (<0.5 mL/s/1.73 m2) during a 4-week period in pre-dialysis care (ii) Results from 4 studies in pre-dialysis care indicated at 20 years, there were significant increases in survival rates. **Health-care use** Results from 4 studies in pre-dialysis care indicated significant improvements in long-term delayed onset of dialysis therapy	Multicomponent structured educational interventions were effective in pre-dialysis and dialysis care, but the quality of many studies was suboptimal. Effective frameworks to develop, implement, and evaluate educational interventions are required, especially those that target patients with early stages of chronic kidney disease. This could lead to possible prevention or delay in progression of kidney disease.	This review showed the need for better designed RCTs evaluating self-efficacy interventions in chronic kidney disease. The included studies in this review lacked a rigorous study design and consistency between interventions in terms of theories and methods used and how they are delivered.
McGillion et al. 2004 Canada	chronic stable angina (CSA) CSA outpatients experiencing class I, II or III angina according to the Canadian	Primary, secondary and tertiary	4 RCTs	Psycho-educational Psycho-educational interventions are educational treatment programmes featuring multi-modal	One study used stress management training for angina symptoms and medication use. Another focussed on the impact of	**Self-efficacy** (i) Patients in three biweekly small group sessions on stress management and relaxation techniques reported being more relaxed (p<0.001), less stressed (p<0.05), and having fewer	Although these trials showed some positive effects for CSA patients with respect to angina symptoms, angina symptom-related distress and physical functioning,	There were some positive findings from the included studies with the intervention of psycho-educational interventions in CSA resulting in fewer angina episodes, angina

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
	Cardiovascular Society classification system for rating angina severity			self-help treatment packages; employing both information-based material and cognitive-behavioural strategies	three biweekly small group stress management and relaxation sessions on chest pain discomfort and stress. A third focussed on group/individual rehabilitation programme, and the fourth evaluated effects of a 3-week small group stress management and relaxation programme.	angina episodes (p=0.017) compared with controls at 6 months (Gallacher et al. 1997). **Clinical** (i) Group programme on stress and lifestyle management resulted in angina attacks of shorter duration than controls at 8 weeks (p<0.05) (Bundy et al. 1994). (ii) Combined group and individual rehabilitation programme resulted in improved scores for frequency (p<0.001) and severity (p<0.05) of angina, and the use of short acting nitrates (p<0.001) compared with controls after 4–12 months (Lewin et al. 1995). (iii) Three-week small group angina management programme improved scores for depression and angina frequency at 6 months (p<0.01) compared to control or usual care (Payne 1994).	methodological problems related to experimental controls, interventions, and measurement precluded generalisation. Future RCTs of psycho-educational programmes require methodologically robust methods to reduce biases and to enhance the generalizability of findings for CSA management.	attacks of shorter duration, and patients having more relaxation and less stressed. However, these results have to be interpreted with caution given the small number of RCTs, the small number of patients included in 3 of the trials and a lack of pooled common effect because of heterogeneity prevented any meta-analysis.
Monninkhof et al. 2003 Netherlands	chronic obstructive pulmonary disease (COPD), excluding studies with patients	Primary, secondary and tertiary	12 studies (8 RCTs)	Self-management education COPD education was defined as a programme which transfers information	Included studies focussed on group or individual education with/without the following; patient brochure, action plan, smoking	Meta-analysis of self-management education compared with usual care indicated the following; **Clinical** (i) St. George's Respiratory	Insufficient data were obtained to make recommendations because of the wide variation in outcome measures used and other limitations to generalisations in the	Self-management education reduced the need for rescue medication and led to increased use of courses of oral steroids and antibiotics for respiratory symptoms.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
	having asthma as the primary diagnosis			about COPD and treatment of COPD in written, verbal, visual, or audio forms.	cessation, audiotape, exercise, and nutrition .	Questionnaire (SGRQ) indicated better health-related quality of life (HRQoL); WMD = –10 (95% CI: –18.5 to –2.0). (ii) Percentage of patients who used oral steroids showed increased use; RR 1.39 (95% CI: 1.02 to 1.91). **Health-care use** (i) Number of patients with one or more admissions showed reduction; RR 0.80 (95% CI 0.43 to 1.50) (ii) Number of emergency visits per year showed reduction, WMD = –0.36 (95% CI –0.75 to 0.03)	current published literature. Further research in this area is needed.	However various self-management education programmes from group education to individual education were involved making it difficult to generalise the results. This review is similar to the Cochrane review by Effing et al. 2007.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
Niedermann et al 2004	Rheumatoid arthritis (RA)	Not reported	11 RCTs	Educational or psycho-educational interventions Any combination of learning experiences designed to facilitate voluntary adoption of behaviour conducive to health (Green 1978)	Seven RCTs provided classic education to teach knowledge and specifically needed skills , whereas 4 studies offered cognitive-behavioural therapy with focus on coping strategies and psychological support. Only 1 study, testing the effects of mailed educational leaflets, was not organised as group therapy	**Self –efficacy** (i) improve knowledge: In seven RCTs, there was significant improvement in patients' knowledge of RA and its management (Kraaimaat et al 1995; Hammond et al 1999; Helliwell et al 1999; Taal et al 1993; Lindroth et al 1997; Barlow et al 1997; Barlow et al 1998; Scholtern et al 1999). (ii) Coping Out of 6 studies that examined coping, only 3 reported significant improvements (Kraaimaat et al 1995; Parker et al 1995; Parker et al 1988). (iii) compliance Out of 6 studies that evaluated compliance, 5 reported significant improvements (Brus et al 1998; Hammond et al 1999; Taal et al 1993; Lindroth et al 1997; Scholtern et al 1999). **Clinical** All RCTs except one (Taal et al 1993) evaluated psychological health status including depression and anxiety. Two studies showed significant improvements in	Methodologically better-designed studies had more difficulties demonstrating positive outcome results. Short-term effects in program targets are generally observed, whereas long-term changes in health status are not convincingly demonstrated. There is a need to find better strategies to enhance the transfer of short-term effects into gains in health status.	No clear conclusions on the effectiveness of educational or psycho-educational interventions can be made from this review as many of the study outcomes were poorly defined and study effects were not measured long-term. Overall, judging from the evidence presented in this review, self-management with a psychological component in addition to purely education programmes appears to be more beneficial in improving knowledge, coping, compliance, and psychological health.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
						depressive disorders (Barlow et al 1997; Scholtern et al 1999), and one significant improvements in anxiety (Bradley et al 19987)		
Powell et al. 2003 Australia	Asthma in Predominantly adults (>16 years old) with asthma (defined by doctor's diagnosis or objective criteria or according to American Thoracic Society guidelines.	Primary, secondary and tertiary	15 RCTs describing 26 interventions	Self-management education Self-management education is considered to be necessary "to help patients gain the motivation, skills and confidence to control their asthma.	Six studies compared optimal self-management allowing self-adjustment of medications according to an individualised written action plan to adjustment of medications by a doctor. Three studies compared self-management options. One that provided optimal therapy but tested the omission of regular review. Another compared high and low intensity education. In a third, no difference in health care utilisation or lung function was reported between verbal instruction and written action plans.	**Clinical** Pooled results of three studies which reported peak expiratory forced flow (PEF) data significantly favoured optimal peak flow self-management over medications adjustment via regular medical review (SMD=0.16, 95% CI: 0.01 to 0.31) from 3 RCTs.	Optimal self-management allowing for optimisation of asthma control by adjustment of medications may be conducted by either self-adjustment with the aid of a written action plan or by regular medical review. Individualised written action plans based on PEF are equivalent to action plans based on symptoms.	This review focussed on clinical outcomes. The PEF data significantly favoured optimal peak flow self-management over medications adjustment via regular medical review. That is interventions that include a written action plan were more efficacious. Due to the small number of trials in each subgroup analysis and the way in which data were reported there were few studies that could provide data for meta-analyses.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
Riemsma et al. 2003 Multinational	rheumatoid arthritis (RA) Adult patients aged >18 years with clinical confirmation of the diagnosis of RA.	Primary, secondary and tertiary	50 studies from 47 trials (31 RCTs with relevant data were included)	Patient education Patient education intervention was defined as one that includes formal structured instruction on rheumatoid arthritis and on ways to manage arthritis symptoms	Patient education in the review focussed on teaching patients to adjust their daily activities as dictated daily by disease symptoms. It included elements of information only, counselling, and behavioural treatment	**Self-efficacy** (a) At first follow-up there were significant effects of patient education for scores on (i) disability (SMD = -0.17, 95% CI: -0.25, -0.09) (ii) joint counts (SMD = -0.13, 95% CI: -0.24, -0.01), (iii) pain: (SMD= 0.08, 95% CI: -0.16, 0.00). (b) At final follow up no significant effects of patient education were found. **Clinical** a) At first follow-up there were significant effects of patient education for scores on (i) patient global assessment (SMD = -0.28, 95% CI: -0.49, -0.07) (ii) psychological status (SMD= -0.15, 95%CI: -0.27, -0.04) (iii)depression (SMD = -0.14, 95% CI: -0.23, -0.05)	Patient education as provided in the studies reviewed had small short-term effects on disability, joint counts, patient global assessment, psychological status and depression. There was no evidence of long-term benefits in adults with rheumatoid arthritis.	Significant effects of patient education at first follow-up for scores on disability, joint counts, patient global assessment, psychological status, and depression. Patient education in the review was provided in addition to standard medical care so the effects of patient education as supplementary to the benefits of standard medical care must be taken into account.
Saksena 2010	≥ 18 years diagnosed by a healthcare professional as having hypertension	Not reported	4 RCTs and 1 non-RCT	Computer-based education Interventions have to be computer based Computers have to be used by patients with hypertension	Interactive computer learning tool Standard education plus computer programme	Several interventions demonstrated that different components of the HBM could be influenced through computer-based interventions. **Self-efficacy** Two studies measured changes in self-efficacy and	None of the studied computer-based interventions were able to demonstrate a change in health behaviours by itself , but this research shows that these interventions must be used in concert with provider-based health	No direct effect on health behaviour could be demonstrated. The results nevertheless indicate that computer-based education may have the potential to play an important role in self-management of subjects with

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				The intent of the programme is to educate patients about their chronic disease.	Pamphlet, website registration and orientation, access to different utilities plus home blood pressure monitoring Internet-based chronic disease self-management programme Online internet community with new information posted weekly and email newsletter	self-care behaviours. One non randomised control trial that used an online internet community (Yu) found a 8.7% improvement in self-efficacy compared with -1.5% in controls , p=0.027. **Clinical** One study showed that combining a web-based educational intervention with pharmacist care could improve BP control(p<0.001).	education in order to create lasting changes in health behaviours. In order for the full benefits of computer-based interventions to be realized, these programmes must be fully integrated into general healthcare delivery.	hypertension.
Smith et al 2007	Severe or difficult asthma	Secondary or tertiary care, research facility.	13 RCTs, 4 controlled observational studies	Psycho-educational interventions Interventions deemed to be a psycho-education on the basis that a major component of it (i) involved interaction between patient and provider (ii) involved taking an educational, cognitive, behavioural, and/or	All studies evaluated a single psycho-educational program of which three were classified as educational, four as self-management, three as psycho-social, and seven as multi-faceted .	**Self-efficacy** NR **Clinical** (i) Asthma-specific QoL Psycho-educational interventions had non-significant effect on asthma-specific QoL (SMD=0.45, 95% CI: -0.07 to 0.98), but sensitivity analysis indicated significant effects (SMD=0.36, 95% CI: 0.00 to 0.72) **Health-care use** (i) Accident and emergency (A	There is a need for further research before any changes to standard care in this patient group can be recommended.	Positive effects admissions and QoL after sensitivity analysis were only short-term and did not include the most at-risk patients or outliers.

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				social approach (iii) addressed educational, cognitive and/or social issues affecting asthma or being a consequence of asthma		& E) admissions Psycho-educational interventions had non-significant effect on A & E admissions (RR=0.79, 95% CI: 0.55 to 1.14), but sensitivity analysis indicated significant effects (RR=0.75, 95% CI: 0.56 to 0.99)		
Sarkisian et al. 2003 USA	Diabetes Mellitus Older (>55 years) African American and Latino adults with diabetes mellitus	Primary and secondary	12 studies (8 RCTs, 4 pre/post interventions)	Self-management education Self-management education programmes aimed to improve knowledge and, to a variable degree, improve biophysical markers of health (e.g. weight and glycaemic control) and psychosocial markers of health (e.g. self-reported quality of life)	Interventions in the review included educational group sessions led by a physician or nurse or dietician with/without weekly support groups, and exercise sessions. Elements of self-management included behaviour oriented, culturally-tailored, one to one counselling, group counselling, supervised exercise and family involvement.	**Self-efficacy** Improved QoL was reported in the intervention arm of I study (Gideon et al 1992). **Clinical** (i) Of the 8 RCTs, 5 reported significant improvements in glycaemic control in the intervention compared with control arm (Agurs-Collins et al 1997; Falkenberg et al 1986; Jaber et al 1996; Mazzuca et al 1986 Brown et al 1995).	Large-scale clinical trials designed according to cultural and age criteria specific for older Latinos and African Americans with diabetes are needed to determine how best to address this growing public health problem	Improved glycaemic control was reported in 5 out of 8 RCTs, although attrition was a problem in most of the studies. Large-scale clinical trials are needed to determine how best to manage diabetes in ethnic minorities. Studies on older Caucasians were also included, as were studies on mixed-age Latino and African American populations.
Shin et al. 2010 USA	Osteoarthritis (OA) Adults aged ≥65 years with OA	Primary and secondary	12 studies (rated as level A: high-quality RCT)	Psychosocially focused non-pharmacologic therapies (NPT) (includes patient education, self-management, coping skills, and social	Nine out of the 12 RCTs used education and self-management as their interventions, whilst 3 provided comprehensive interventions using	**Self-efficacy** (i) Four RCTs showed significant improvement in self-efficacy (Buszewicz 2006,Hughes et al 2004 and 2006; Keefe et al 2004), all used different measures.	Although most of the studies demonstrated the positive effects of psychosocially focused NPTs for OA patients, the evidence is modest. High-quality RCTs which	Results reported were qualitative making it difficult to measure the outcome effect. Psychosocially focused NPT may improve pain, exercise, physical function and decrease

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				support) Education about self-management and coping skills can increase patients' knowledge, efficient self-management behaviours, self-efficacy, adherence to therapies, health status, and quality of life	all four psycho-socially focused NPTs (education, self-management, coping skills, and social support) for participants and their spouses	(ii) Two studies reported significant increase in minutes of exercise per week and decrease in stiffness (Hughes 2004 and 2006) (iv) One study each reported significant improvement in objective peak physical activity (Murphy et al. 2008), performance of daily activities (Yip et al 2007), physical function (Keefe et al 2004), and pain coping (Keefe et al 2004) **Clinical** (i) Four studies reported significant decrease/improvement in pain (Hughes et al 2004 and 2006; Yip 2007 and 2008)	examined the effects of psychosocially focused NPTs only are relatively few in number. Spouses can be one of the most beneficial resources for patients by providing emotional support and encouraging patients to cope with their symptoms and maintain self-management strategies. To date, however, only a few studies examined the potential benefit of spouses involved	stiffness in patients with lower-extremity OA (knee and hip OA) in the short term. No evidence of Psychosocially focused NPT in the long term.
Thomas et al. 2006 UK	multiple sclerosis (MS) People with a diagnosis of MS (e.g. using recognised criteria such as Poser 1983, Schumacher 1965).	Primary and secondary	16 RCTs in 17 trials	Psychological interventions Psychological interventions were broadly defined and included those that address mood and those that address cognition. Cognitive factors are those relating to the mental processes of	Interventions in the review were delivered by psychologists, counsellors, medical staff, nurses, occupational therapists or other health professionals, and included elements of behavioural therapy or	**Clinical** (i) One RCT reported significantly better improvement in the mental health subscale in the cognitive rehabilitation group than the placebo group (mean ± SD) = 27% ±73% vs 9% ±41%) respectively, p=0.04) (Solari et al 2004). (ii) One RCT reported that the group receiving psycho-	No definite conclusions can be made from this review. However there is reasonable evidence that cognitive behavioural approaches are beneficial in the treatment of depression, and in helping people adjust to, and cope with, having MS.	It is difficult to drawn any firm conclusions for the effectiveness of cognitive behavioural approaches in treating MS. There may be some positive effect on decreasing depression through cognitive behavioural therapy and psychotherapy. There was a lot of variation in intervention types and outcomes reported

Reference (author, year, country)	Inclusion criteria					Results		Abacus summary
	Patient population (inclusion criteria)	Setting (primary care, secondary care)	Types and number of studies identified	Type of intervention and definition	Description of interventions	Main positive results from reported outcomes	Overall study conclusion	
				memory, concentration, reasoning and judgement	cognitive therapy or educational, counselling or rehabilitation or family therapy or any combination of these.	therapy scored significantly lower on the depression score than the placebo group (mean score 19.3 vs 23.5 respectively, p<0.05) (Crawford et al 1985). (iii) One RCT (Foley 1987) showed mean depression was significantly lower in cognitive behavioural therapy versus minimal psycho-therapy (mean 13.2 ±10.5 vs 21.6 ±14.2 respectively, standardised mean difference = 0.66 (95%CI; -0.02, 1.33).		making interpretation of the results difficult.

3.5.3. Quality appraisal for included RCTs

The SIGN RCT quality appraisal tool was used by the research team to assess the risk of bias of the study. The legend below explains the quality markers and the grading system agreed by the research team.

item	Well covered	Adequately addressed	Poorly addressed
Research question	Question clear and well explained	Question clear	Research aim not clearly stated
randomisation	Method of randomisation robust such as computer generated from a remote site	Randomisation method adequate	Poor randomisation methodology such as alternate patients

Allocation concealment	methods of concealment clearly described with strong likelihood of concealment in both investigators and participants being maintained	methods of blinding not clearly described but study described as single/double blinded	concealment of investigators and participants described but it is likely from the description reported that participants or investigators enrolling participants could possibly foresee treatment assignments
Patient group comparable	Study authors report that baseline demographics between studies were similar (with or without having performed statistical analyses), or on inspection of baseline demographics, the reviewer can see no differences between the groups that are likely to subject results to bias.	Patient demographics in each treatment arm not reported by authors as being similar, but reviewer perceives there to be little risk of bias due to any observed differences between groups studied. If patient groups are dissimilar for a demographic variable likely to cause bias, appropriate	reviewers perceives there to be differences between groups in demographics, which have not been adjusted for in analyses.
Dropouts and intervals described?	Number of withdrawals for each arm and reasons for withdrawal clearly described. Additionally, the point of withdrawal for each of those withdrawing during the study cycle is clearly described	Withdrawal numbers are described for each arm, and reasons, but no description of point of withdrawal during follow up or treatment period.	Study does not describe number or reasons for withdrawal by treatment arm; but for all patients enrolled in study as a whole.
Analyses conducted in ITT population?	If data is missing, missing data is clearly shown in results to have been imputed using appropriate methods to perform statistical analyses, using the intention to treat set or full analysis set for treatment arms.	Methods describe use of intention to treat principles, but the results do not clearly state 'n' for the treatment groups or there is evidence to show that ITT has not been performed.	'As-treated' analysis has been performed

Not addressed (i.e. not mentioned, or indicates that this aspect of study design was
Not reported (i.e. mentioned, but insufficient detail to allow assessment to be made)
Not applicable.
In order for RCTs to be included they had to score a "low risk of bias" based on 3 of the 4 had to be well covered or adequately addressed:

- *Randomisation*
- *Blinding*
- *Groups comparable at baseline*
- *Description of dropouts*

The final column in the quality appraisal table is the score of either low = "low risk of of bias" or high= "high risk of bias" based on the items above.

		Internal validity						Overall assessment			
Study	**Appropriate and clearly focussed question?**	**Randomised?**	**Observer blinded?**	**Allocation concealment?**	**Patient group comparable?**	**Dropouts and intervals described?**	**Analyses conducted in ITT population?**	**Bias minimisation?**	**If biased, how would bias affect results?**	**Research question answered?**	**Risk of bias**
Baker 2011[†]	well covered	adequately addressed	not addressed	not addressed	adequately addressed	well covered	no	some significant differences in baseline characteristics were found, adjusted in statistical analysis	No blinding could influence investigators	yes	low
Barlow 2009	poorly addressed	well covered	Not addressed	not addressed	adequately addressed	adequately addressed	yes	No details of allocation concealment or blinding. Recruitment through letter so element of selection bias	No blinding could influence investigators, subjects volunteered for study may favour intervention group	yes	low
Berman 2009	adequately addressed	poorly addressed	Not addressed	not addressed	adequately addressed	adequately addressed	yes	Study is not blinded, randomisation method poor – tossing of coin	no blinding and poor randomisation methodology could influence intervention effect	yes	low
Bosworth 2009a	adequately addressed	well covered	adequately addressed	adequately addressed	well covered	adequately addressed	yes	Good randomization process and some blinding of researchers (clinic nurses).		yes	low
Bosworth 2009b	adequately addressed	adequately addressed	adequately addressed	not addressed	adequately addressed	adequately addressed	no	No, ITT was not used	High drop-out rate at follow-up may influence intervention/treatment effect size	yes	low

		Internal validity						Overall assessment			
Study	**Appropriate and clearly focussed question?**	**Randomised?**	**Observer blinded?**	**Allocation concealment?**	**Patient group comparable?**	**Dropouts and intervals described?**	**Analyses conducted in ITT population?**	**Bias minimisation?**	**If biased, how would bias affect results?**	**Research question answered?**	**Risk of bias**
Bucknall 2012	adequately addressed	Well covered	poorly addressed	Well covered	adequately addressed	adequately addressed	no	Partial blinding, researcher collecting monthly data was blinded to patient group No, ITT used was not used.	High drop-out rate at follow-up may influence intervention/treatment effect size	yes	low
Cadilhac 2011	adequately addressed	well covered	adequately addressed	adequately addressed	adequately addressed	well covered	yes	well conducted trial ; remote randomisation and research staff were blinded to allocation group		yes	low
Chan 2009	adequately addressed	poorly addressed	not addressed	not addressed	adequately addressed	well covered	yes	blinding of researchers absent, drawing lots as randomisation method was inadequate	Non-blinding of observers and poor randomisation methodology could affect treatment effect size	yes	low
Chen 2011	adequately addressed	adequately addressed	not addressed	adequately addressed	adequately addressed	well covered	yes	No blinding of researchers	Non-blinding of investigators could affect intervention effect	yes	low
Chow 2010	well covered	adequately addressed	not addressed	not addressed	adequately addressed	well covered	yes	No blinding of researchers and unsure if concealment of allocation was carried out.	No blinding could influence investigators	yes	low
Copeland	adequately	poorly	not	not	poorly	not	yes	Inadequate		yes	high

		Internal validity						Overall assessment			
Study	**Appropriate and clearly focussed question?**	**Randomised?**	**Observer blinded?**	**Allocation concealment?**	**Patient group comparable?**	**Dropouts and intervals described?**	**Analyses conducted in ITT population?**	**Bias minimisation?**	**If biased, how would bias affect results?**	**Research question answered?**	**Risk of bias**
2010	addressed	addressed	addressed	addressed	addressed	addressed		randomisation (end number of social security number), no blinding, no reporting of attrition rates	Non-blinding of observer, allocation concealment not addressed and poor randomisation could influence intervention effect		
Davis 2010	adequately addressed	not reported	not addressed	not addressed	adequately addressed	poorly addressed	yes	Randomisation method and allocation concealment not reported	Non blinding could influence investigators	yes	high
Ghahari 2010	adequately addressed	adequately addressed	not addressed	not addressed	adequately addressed	adequately addressed	yes	Well conducted study with exception of non blinding and allocation concealment	Non blinding of observers and allocation concealment could affect intervention effect	yes	low
Hochhalter 2010	adequately addressed	well covered	adequately addressed	poorly addressed	well covered	poorly addressed	yes	Study coordinator not blinded but interviewers were blinded.		yes	low
Jarrett 2009	adequately addressed	well covered	adequately addressed	adequately addressed	well covered	adequately addressed	yes	Researcher collecting data was blinded to groups		yes	low
Jerant 2009	adequately addressed	well covered	not addressed	not addressed	well covered	adequately addressed	unclear	Non blinding of researchers or concealment of allocation groups	Non blinding could influence investigators	yes	low
Kiser 2012	adequately	well covered	not	not	poorly	adequately	no	Control group had	No blinding could	yes	high

		Internal validity						Overall assessment			
Study	**Appropriate and clearly focussed question?**	**Randomised?**	**Observer blinded?**	**Allocation concealment?**	**Patient group comparable?**	**Dropouts and intervals described?**	**Analyses conducted in ITT population?**	**Bias minimisation?**	**If biased, how would bias affect results?**	**Research question answered?**	**Risk of bias**
	addressed		addressed	addressed	addressed	addressed		higher percentage of low education, no blinding of researchers	influence research assistant		
Luciano 2011	adequately addressed	well covered	not reported	adequately addressed	well covered	adequately addressed	yes	-		yes	low
Mancuso 2011	adequately addressed	well covered	not addressed	adequately addressed	well covered	adequately addressed	no	-		yes	low
Oerlemans 2011	adequately addressed	adequately addressed	not addressed	not addressed	well covered	well covered	no	High drop-out rate at follow-up, therefore analysis cannot be defined as an intention-to-treat analysis.	Post hoc comparisons between dropouts and completers indicate that, overall, dropouts experienced a more favourable IBS-related quality of life, which may influence intervention effect	yes	low
Powell 2010	adequately addressed	adequately addressed	adequately addressed	adequately addressed	Well covered	adequately addressed	no	Patients in the education control group were 'attention control' that is they received some aspects of intervention apart from group meetings e.g. education tip sheets by mail, and	Control group received some benefits of intervention may affect intervention effect between groups	yes	low

		Internal validity						Overall assessment			
Study	**Appropriate and clearly focussed question?**	**Randomised?**	**Observer blinded?**	**Allocation concealment?**	**Patient group comparable?**	**Dropouts and intervals described?**	**Analyses conducted in ITT population?**	**Bias minimisation?**	**If biased, how would bias affect results?**	**Research question answered?**	**Risk of bias**
								follow- up telephone calls.			
Rice 2009‡	adequately addressed	adequately addressed	not reported	not reported	adequately addressed	adequately addressed	no	No mention of use of ITT in methods or results	High drop out rate could have influenced treatment effects in either groups	yes	low
Ringstrom 2010	adequately addressed	adequately addressed	not addressed	not addressed	well covered	adequately addressed	no	There was lack of blinding of participants and study personnel and use of ITT	Non-blinding of study personnel and lack of ITT analysis could both influence intervention effect	yes	low
Rosal 2011¥	adequately addressed	adequately addressed	not addressed	not addressed	well covered	adequately addressed	NR	Non blinding of study personnel and participants	Non-blinding of study personnel could influence treatment effect	yes	low
Sahebalzamani 2009	adequately addressed	not reported	not addressed	not addressed	well covered	not addressed	NR	No mention of blinding and drop-outs	study personnel and patients were not blinded and this could affect intervention effect	yes	high
Sun 2010	adequately addressed	adequately addressed	not addressed	adequately addressed	poorly addressed	adequately addressed	yes	Age of study group higher than control, researchers not blinded to intervention	No blinding could influence investigators	yes	low
Wakabayashi 2011	adequately addressed	well covered	not addressed	well covered	adequately addressed	well covered	no	Well designed study but no blinding	No blinding could influence investigators	yes	low
Watson 2009	adequately addressed	adequately addressed	not addresse	adequately addressed	adequately addressed	well covered	yes	Researchers not blinded	No blinding could influence investigators	yes	low

		Internal validity						Overall assessment			
Study	**Appropriate and clearly focussed question?**	**Randomised?**	**Observer blinded?**	**Allocation concealment?**	**Patient group comparable?**	**Dropouts and intervals described?**	**Analyses conducted in ITT population?**	**Bias minimisation?**	**If biased, how would bias affect results?**	**Research question answered?**	**Risk of bias**
			d								
Wearden 2010	adequately addressed	well covered	not reported	well covered	well covered	well covered	no	Researchers not blinded	No blinding could influence investigators	yes	low
Williams 2011	well covered	well covered	adequately addressed	adequately addressed	adequately addressed	adequately addressed	yes	Well designed study although there was no blinding of researchers	No blinding could influence investigators	yes	low
Yoo 2009	adequately addressed	not reported	not reported	not reported	adequately addressed	adequately addressed	yes	No details on randomisation, blinding or allocation concealment	Improper randomisation could favour either group. No blinding could influence investigators	yes	high

† Methods to Baker 2011 detailed in De Walt 2009 publication

‡ online appendix supplement to Rice 2010 with additional study methods reported

¥ methods of Rosal 2011 RCT were documented in a p

3.5.4. Data extraction table of included RCTs

Reference, country, N of sites	**Type of chronic disease**	**Population and participants**	**Intervention**	**Control**	**Time of follow up and main study measure**	**Results-self-efficacy/self-care/knowledge**	**Results-clinical and QoL**	**Results-health care use**	**Interpretation of value of RCT for decision making**
Baker 2011	heart failure (HF)	Total: n = 605. Intervention =272 control =259	Self-management BEI (see control)	Brief education intervention	30 to 60 days HF knowledge and self-care behaviour:	Self-efficacy: TTG group :significantly greater increase in self-efficacy than the BEI group (change	QoL improved in TTG group compared with BEI change from baseline (6.7 vs -0.66, p<0.001)	NR	Promising results for improving patient's self-efficacy, and self-

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
USA 4 sites		Setting: 4 university hospitals Current use of loop diuretics Class II-IV symptoms in the past 6 months Age: mean 61 years 52% male 37% low literacy 31% serious HF	followed by Group-Teach to Goal (TTG) education: specific instruction on daily weight monitoring and recording, diuretic self-adjustment. 5 to 8 Follow up phone calls in next month to reinforce education and guide patient toward better self-management skills. (based on social cognitive theory)	(BEI): 40 minutes long review : daily self-assessment and action planning in 4 specific domains + educational manual + new digital scale	adapted Improving Chronic Illness Care Evaluation (ICICE) telephone survey QOL: Heart Failure (HFSS)	from baseline of 1.0 vs 0.4, p=0.006), on a 10 items scale Self care: both groups improved - greater improvement in the TTG group (1.8 vs 3.2, p<0.001) on a 10 items scale .			care but the short length of follow up (1 month) make it difficult to evaluate the lasting value of this intervention. Generalisable to any hospital setting? Well to most patients (37%: low literacy)
Barlow et al 2009 UK 1 site	Multiple sclerosis (MS)	Total n=216 Intervention=78, waiting list group=64, comparison group=74 subjects with MS, mainly identified through MS Society databases, to or a Chronic Disease Self-Management Course (CDSMC; intervention group). Some patients	The CDSMC consisted of six weekly 2-hour group sessions, delivered by pairs of trained lay tutors. The course is largely interactive, encouraging participants to apply new skills.	no intervention (waiting list; control group)	Data (questionnaires) were collected at baseline, 4 months and 12 months. The primary outcomes were self-efficacy and depression; secondary outcomes were health status and self-management behaviours. Self-efficacy was assessed both	Intervention improved self-management self- efficacy (effect size (ES) 0.30, p=0.009) and physical status (ES 0.12, p=0.005). There were no other statistically significant changes. However, trends towards improvement on depression (ES 0.21, p=0.05) and MS self-efficacy (ES 0.16, p=0.04) were noted.	NR	NR	Some improvement in self-efficacy was maintained at 12-month follow up but overall effect sizes were small and few outcomes reached statistical significance. The results from this trial give no indication to recommend the CDSMC for MS patients. Larger trials are warranted.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		chose not to attend the CDSMC so formed a (comparison group; these patients were on average older, had suffered from MS longer and were less anxious than patients who chose to attend.			specifically for MS (MS self-efficacy; reference 27 in Barlow) and by a generic measure (self-management self-efficacy; reference 26 in Barlow). Physical and psychological status was measured using the Multiple Sclerosis Impact Scale (reference 28 in Barlow).				
Berman et al 2009 USA Single site	Chronic pain	Total: n=78 intervention = 41 waiting list =37 Setting: community Aged ≥55 years, with ≥1 day in the previous 30 days when pain made it difficult to do usual activities and/or at least moderate levels of pain on average, had basic familiarity with computers, and could read and	The intervention website comprised an introductory module describing a problem-solving approach to planning for change, based on the 6-stage model outlined by Prochaska et al (reference 49 in Berman). Participants were asked to try each module at least once and to use the website at least once a week for 6 weeks.	Waiting list	6 weeks Self-efficacy , pain intensity, depression, anxiety, awareness of responses to pain, self-care and satisfaction with and use of the intervention	(i) Pain intensity decreased by -0.64 ±1.48 (p=0.01) in the intervention vs -0.7± 1.82 (p=0.05) in the comparison group (ii) (i) Pain interference decreased by -1.21±2.44 in intervention (p=0.01) vs -0.88±2.08 (p=0.01) in comparison group (iii) Self-efficacy (PSEQ) increased by 1.83±8.72 (p>0.05) in intervention vs 0.56± 12.4 (p>0.05) in	(i) depressive scores decreased by -1.5± 5.82 (p>0.05) in intervention vs 0.37 ±5.14 (p>0.05) in comparison group (ii) anxiety scores decreased by -0.64± 4.74 (p>0.05) vs 0.91±3.28 (p>0.05) in comparison group		Findings confirm the feasibility of a 6-week internet self-care education programme in older adults with chronic pain but no strong evidence to recommend this intervention. However it is difficult to generalise the results given that participants were computer literate

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		understand English. Patients with chronic pain due to arthritis, spinal problems, previous injuries or surgery and sciatica				comparison group. (iv) Increase in confidence in ability to use self-care techniques to manage pain by 0.81±1.27 (p=0.01) in intervention vs -0.16±1.8 (p>0.05) in comparison group			and could read and understand English
Bosworth et al 2009a (Am Heart J) USA 1 site	Hypertension	2 level (primary care provider and patient) cluster randomised trial, including 588 patients with hypertension- had filled a prescription for hypertensive medication in the past year: 4 groups. group 1: combined provider decision support plus patient behavioural intervention, n=150 group 2: provider decision support , patients usual care, n=151.	2 Interventions; patient and provider 1.Patient: bimonthly tailored nurse-delivered behavioural telephone intervention (delivering scripted information drawn from 9 educational and behavioural modules) to improve hypertension treatment. 2. provider decision support, primary care providers received, at each visit, either computer-generated decision support (designed	Patients: Usual care Providers: Hypertension reminder	Follow up at 6 and 24 months. The primary outcome was proportion of patients who achieved a BP <140/90 mm Hg (<130/85 for diabetic patients) over the 24-month follow up.	NR	no significant differences in amount of change in blood pressure control in the three intervention groups compared with the hypertension reminder control group. In secondary analyses, rates of blood pressure control for all patients receiving the behavioural intervention improved more than for patients in the non-behavioural intervention group, but there was no between-group difference at the end of the study. There was 14.4% improvement in bp (p=0.03) in the patient behaviour intervention but no between-group differences at the end of the study.	The number of primary healthcare visits over the 24 months was similar between the 4 groups.	Limited evidence to recommend computer-based decision support management system for primary care providers or the nurse lead telephone intervention. Study population was retired veterans and predominantly male so may not be generalisable to general population.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		group 3: patient behavioural intervention, provider no hypertension reminder, n=144. group 4: provider hypertension reminder, patient usual care, n=143 mean age= 63 years 98% male 25% smokers 37% diabetes	to improve guideline concordant medical therapy) The active intervention for primary care providers supplied patient-specific recommendations about hypertension decision support delivered at the point of care during each patient visit.						
Bosworth et al 2009b (Ann Intern Med) USA 2 sites	hypertension	hypertension diagnosed for at least 12 months, hypertensive medication use. n=636 behavioural intervention, n=160, usual care, n=159, home BP monitoring, n=158, combined home monitoring and behavioural	Tailored behavioural self-management intervention (covered perceived risk for hypertension, memory, literacy, social support, relationship with health care providers, side effects of hypertensives, weight loss, reduced sodium intake, exercise, smoking cessation,	usual care or home BP monitoring (measure BP 3 times a week)	Primary outcome was proportion of patients with adequate BP control at 6, 12, 18 and 24 months. BP control was defined as systolic < mm140Hg and diastolic < 90 mmHg. Secondary outcomes were systolic and diastolic BP at each study time	NR	The combined intervention had the greatest increase in proportion of patients with BP control (11%, p=0.012), behavioural group (4.3%, p=0.34), home monitoring group (7.6%, p=0.096) all compared with usual care.	The number of outpatient visits were similar for the 4 groups	The combination of behavioural intervention by telephone and home BP monitoring was successful in decreasing BP over 24 months. The behavioural intervention was only successful when combined with BP home monitoring.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		intervention, n=159 49% African America, 66% female. Mean age 61 years	reduce alcohol intake).		point.				
Bucknall et al 2012 UK 6 sites-hospital	COPD	Total = 464 Intervention=232, control=232 Patients with COPD admitted to hospital with an acute exacerbation of COPD. FEV_1 <70%. Excluded patients with asthma or left ventricular failure, malignant disease or poor memory. mean age 69 years male 37% current smoker 39%	Self-support management programme delivered by trained nurses in four fortnightly home visits, each lasting about 40 minutes. All patients received a diary card.	Control group – managed by their GP or hospital based specialists.	Primary end point – time to first acute hospital admission with COPD exacerbation or death due to COPD within 12 months. Secondary endpoints: change in baseline in St George's respiratory questionnaire and EuroQol 5D.	No significant differences in COPD self-efficacy scales	No significant difference in risk of hospital admission or death due to COPD	No significant difference	This intervention should not be implemented into COPD patient care as no effects on outcomes were found. Also it appears difficult to encourage COPD patients to participate.
Cadilhac et al 2011 Australia	stroke	Stroke patients; mean age 69 years; 78% had stroke in last 12 months, female 59%	Stroke self-management programme (SSMP)- 8 weeks The generic programme was a Stanford chronic condition self-	generic intervention (range of topics – appropriate use of medicines, communicatio	Primary outcomes were recruitment, participation, and participant safety. Secondary outcomes were positive and active	Overall, 52% completed the SSMP and 38% completed the generic intervention (p=0.18). There were no adverse events attributable to either	NR	NR	No evidence to recommend the SSMP as there was no impact on self-management outcomes compared with

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
7 sites (hospital)			management programme. The SSMP differed from the generic programme by only includes stroke survivors, having greater contact time, only being delivered by professions skilled in stroke and trained by the National Stroke Foundation, providing targeted stroke-specific information each week and revisiting information	n, nutrition) Usual care	engagement in life using the Health Education Impact Questionnaire (ref 15 in Cadilhac), and characteristics of QoL (ref 16 in Cadilhac) and mood (ref 17 in Cadilhac) at 6 months from programme completion	intervention.			usual care.
Chan et al 2009 China 1 site	Schizophrenia	schizophrenic patients, recruited from the psychiatric out-patient department of a hospital, and their caregivers. Participants were randomised to intervention, n=36 or usual care n=37 patients: male 66%	Psychoeducation psychoeducational programme (reference 18 in Chan), which was based on the framework advocated by the Psychoeducational Working Party of the EPPIC. 10 sessions conducted weekly for 3 months, conducted by a mental health nurse	Usual care	Patient assessments: Rating of Medication Influences (ROMI), (19-item questionnaire for patient's subjective view of the reasons for taking antipsychotic medication); Brief Psychiatric Rating Scale (BPRS),(18-item	For caregivers, significant group differences were detected by the U-test for the SES score at the post-1 ($p=0.007$) and post-2 ($p<0.001$) time points, the level of satisfaction at the post-1 ($p=0.033$) and post-2 ($p<0.021$) time points, and the FIBS score at the post-2 time point ($p=0.043$). For patients,	NR	NR	The PEP intervention improved patient's adherence to medication, brief psychiatric rating and treatment attitudes. Carers showed a significant improvement in the self-efficacy rating but this effect declined after the intervention to match the control group at 12 months. The

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		mean age 35.3 years Chinese Caregivers: Female 89% Family member 97%			questionnaire - patient's mental condition) Insight and Treatment Attitudes Questionnaire (ITAQ),(11 items to assess a patient's insight into his or her illness) Caregivers, assessments: Family Burden Interview Schedule (FBIS), a 24-item scale on the burden of care); General Perceived Self-efficacy Scale (SES) is a 10-item scale, a measure for a person's competence in dealing with challenging and stressful life situations; 6 item Social Support Questionnaire	significant group differences were detected by the U-test for the ROMI score at the post-1 (p=0.003) and post-2 (p=0.012) time points, the BPRS score at the post-2 (p=0.017) time point, the ITAQ score at the post-1, post-2, and post-3 time points (all p<0.01).			generalisability of this study is limited as it is set in a China, the patients were predominantly male and the caregivers predominantly mothers.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
					(SSQ-6), to assess the number of persons available as support providers and the level of satisfaction with available support. Follow-up: immediately after the intervention (post-1), 6 months (post-2) and 12 months (post-3)				
Chen et al 2011 Taiwan 1 site	Chronic kidney disease	54 incidental predialysis chronic kidney disease patients (CKD, stages III to V), recruited from an outpatient clinic in Taiwan. Patients were randomised to either an SMS n=27 programme or not n=27	The SMS programme included the provision of information, reinforced learning incentives and encouraging self-care and maintenance of the therapy, implemented by a multidisciplinary team of nurses, dieticians and volunteers. There were monthly face-to-face meetings, weekly telephone support and a support group twice a month. In	control	The primary endpoints were absolute eGFR change and number of hospitalisations. Secondary endpoints included eGFR decrease of up to 50% and all-cause mortality. Duration of follow-up was 12 months.	CKD knowledge improved significantly compared with non-SMS patients after 12 months(10.13 vs 5.51 points, p<0.001)	At the end of the study, the absolute eGFR was significantly higher in the SMS group than in the control group (29.11+/-20.61 vs 15.72+/-10.67 ml/min, p<0.05). There were also fewer hospitalisations in the SMS group (18.50% vs 44.47%, p<0.05). EGFR reduction <50% was seen in 3.7% in the intervention group vs 33.3% in the control group (p<0.05). No other significant differences were found.	NR	SMS improved patients knowledge of their disease, improved eGFR and patients had fewer hospitalisation events compared with the control group, however theses results must be viewed with caution as the small sample size meant the study was not powered sufficiently to detect between group differences.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
			addition, specific measures were implemented for patients by disease stage, including lectures or discussions.						
Chow et al 2010 Hong Kong multicentre	peritoneal dialysis patients	Total: n=85 Intervention =43 Control =42 Setting: hospital	The intervention consisted of a comprehensive discharge planning protocol (involving family members) and a standardised 6-week nurse-initiated telephone follow-up regimen (Brooten & Youngblut 2006 in Chow), with the aim of achieving of shared objectives and reinforcing of health-related behaviours.	Patients in the control group received routine hospital discharge services	Kidney disease quality of life was measured for each patient at three time intervals: before the intervention, at completion of the 6-week intervention and 6 weeks after completion of the programme	NR	The results of the outcome measures of quality of life were mixed. A non-statistically significant main effect for intervention (between-groups) was observed in all of the parameters. However, statistically significant within-group (time) and interaction effects were observed in some variables across time, including Symptoms, Effects of Kidney Disease, Sleep, Role-physical, Pain, Emotional Well-being and Social Function (Table 3). To determine the attribution of time effects The variables that demonstrated interaction effects (P < 0Æ05) were Quality of Sleep, Staff	NR	No between group differences imply that standard care is not significantly worse – regarding HRQoL – than nurse-led case management in this patient group. Patients in this study were recruited from hospitals with specialized renal care facilities and staff. Hence results cannot be generalized for other patients in non-specialized clinical settings

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
							Encouragement, Patient Satisfaction and Social Functioning. The interaction effect for Physical Functioning showed a trend towards statistically significance (P = 0Æ06). The results confirmed that the quality of life of the intervention group patients was higher than that of the control group in about 50% of the dimensions in KDQOL.		
Ghahari et al 2010 Australia	extreme fatigue (Fatigue Severity Scale score of 4) and neurological diagnosis (multiple sclerosis, post-polio, Parkinson)	Total: n=95 fatigue self-mana-gement group (SM) =34 Self-management information only (IO) =28 Control =33 Aged ≥20 years, had self-reported access to the Internet three times per week for at	Seven-week online programme using a deconstruction-reconstruction process. Content included impor-tance of rest, communication, body mechanics, rearranging activity stations, setting priorities and standards and balancing a schedule) Information-only group: weekly information via the Internet. Content	Participants continued to receive routine care ranging from nothing to specialist care and/or community care	Outcomes were pre/post-test QoL (Personal Well being Index), activity participa-tion (activity card), impact of fatigue, depression (depression anxiety and stress scale) , social support, self-efficacy (Generalised self-efficacy scale) and essential computer skills	(i) The three groups were significantly different (F(2,86) = 3.797, p< 0.05) in their level of self-efficacy. (ii) Both SM and IO groups had higher levels of self-efficacy than the control group at post- test although after using Bonferroni for correction of multiple comparisons it showed the results to be marginal (p=0.057 for the SM	Post-hoc testing showed the difference in well-being to be between the information-only and control groups with the information-only group having significantly better outcomes (p= 0.036)	NR	No evidence to recommend this intervention due to very few significant improvements compared with the control group. There was improvement in the 'information only' group. Lack of group differences may be due the study being under-

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		least 1 hour and a minimum	identical to the written material used in the fatigue self-management programme			and p=0.058 for the IO group)			powered. Additionally, the control group showed some improvement perhaps this group was motivated to seek additional help as participants were not blinded to their groups.
Hochhalter et al 2010 USA Single site	Multiple chronic illnesses (MCI)	Total: n=79 Intervention group =26 Safety group =27 Usual care =26 Setting: hospital Aged ≥65 years and pre- treated for ≥2 of seven qualifying chronic illnesses; (1) arthritis, (2) lung disease, (3) heart disease, (4) diabetes, (5) hypertension, (6)	Intervention and safety groups attended a 2-hour workshop and participated in medical encounter phone calls. The Intervention Group discussed patient engagement concepts from publicly distributed content. The Safety Group discussed general safety (e.g., fire safety, identity theft)	Usual care as directed by physician or family doctor	6 months Health-related quality of life, Self-Efficacy for Managing Chronic Disease, Communication with physicians scale, Patient Activation Measure, Self-reported health care utilization	(i) Patient Activation Measure scores: Significant increase in standardized mean Patient Activation Measure score from Baseline to Follow-Up in all 3 groups ($p < 0.0001$). No difference between groups (ii) No significant effects or interactions of Group or Time for Unhealthy Days after accounting for the significant effects of Self-Efficacy ($p < 0.001$) and Low Self-Rated Health ($p = 0.018$). A post-hoc analysis	NR	NR	There was improvement in self-efficacy in the intervention group but overall no conclusive findings to recommend this intervention.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		depression, and (7) osteoporosis				showed a statistically significant improvement in self-efficacy for self-management in the intervention group (p=0.042). (iii) Only the Safety Group showed a significant change from Baseline to Follow-Up in the percent of group members reporting High Self-Rated Health (p = 0.013)			
Jarrett et al 2009 USA single site	Irritable bowel syndrome (IBS)	Total n=188 CSM-IP =58 CSM-T/IP =58 UC =60 Setting: university-based gastro-enterology practice >18 years of age, current IBS symptoms (Rome-II criteria), patients with co-morbidities excluded.	self-management by: 1. sessions delivered in-person (CSM-IP) 2.sessions delivered by telephone (CSM-T/IP) apart from 1st, 2nd and last session. The intervention was delivered in 9 one hour sessions by psychiatric nurse practitioners. It covered 4 themes –	usual care (UC) (continuation of treatment recommended by their health-care provider)	12-months Gastrointestinal symptom score and QOL, cognitive beliefs, IBS symptom score, psychological distress	At 12 months, there was Significant improvements in cognitive beliefs in CSM-IP vs UC (-1.11 vs -0.46, p<0.001) and CSM-T/IP vs UC (-1.01 vs -0.46, p<0.001), but no difference between CSM-IP vs CSM-T/IP	At 12 months there were significant improvements in; (i) IBS symptom score in both CSM-IP (-25.6, p<0.001) and CSM-T/IP (-28.4, p=0.006) vs UC (-9.5), but no difference in CSM-IP vs CSM-T/IP (ii) IBS QoL in CSM-IP (12.2, p=0.010) and CSM-T/IP (11.90, p=0.029) vs UC (7.4) but no difference in CSM-IP vs CSM-T/IP (iii) in psychological distress in CSM-IP (0.05, p=0.009) but not CSM-T/IP (-0.08,	NR	Self-management programme delivered by telephone or totally in-person is effective in improving IBS symptoms and Qol, however this study population is not representative of the general population as the subjects were mainly female, white and relatively well educated.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
			education, diet (identify problems in their diet), relaxation (abdominal breathing, music relaxation)and cognitive behavioural (based on individual assessment) strategies.				p=0.457) vs UC (0.13).		
Jerant et al 2009 USA 12 sites	Chronic illness	Total n=415 HIOH via home visits n=138, HIOH via phone calls n=139, usual care n=138 Setting: university-affi liated primary care network. Aged 40 years and older and who had 1 or more of 6 common chronic illnesses (arthritis, asthma, chronic obstructive pulmonary disease,	Homing in on Health (HIOH) delivered in (I homes or (ii) by telephone HIOH is similar in content to Chronic Disease self management program (CDSMP). 6 weekly sessions that aim to master self-management tasks such as exercising safely, coping with difficult emotions and using cognitive symptom management	Usual-Care group were initially visited in their home by the study nurse, and completed the follow-up telephone questionnaire s. They otherwise received care from their usual clinician	6 weeks, 6 months and 1 year illness management self-efficacy, Health status, Medical Outcomes Study 5-item general health, EuroQol	Compared with usual care, HIOH delivered in the home led to significantly higher illness management self-efficacy at 6 weeks (effect size = 0.27; 95% CI, 0.10-0.43) and at 6 months (0.17; 95% CI, 0.01-0.33), but not at 1 year	(i) In-home HIOH had no significant effects on Health survey's physical component (PCS-36) or mental component (MCS-36) summary scores, (ii) For EQ-VAS, home group scores were higher than in the control group at 6 weeks (0.41; 95% CI, 0.15-0.67; p = 0 .002); 6 months (0.31; 95% CI, 0.05-0.57; p = .02), and 1 year (0.40; 95% CI, 0.14-0.66; p = .003), and higher than in the telephone group at 1 year (0.30; 95% CI, 0.03-0.56; p = .03)	NR	This peer-led chronic illness self-management programme led to Only one significant effect on only one secondary measure (EuroQol health status measure)at 12 months. There is no evidence to recommend this intervention.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		congestive heart failure, depression, and/or diabetes mellitus) plus functional impairment.	techniques.						
Luciano et al 2011 Spain 3 sites	Fibromyalgia	Total: n=216 Intervention =108 Usual care = 108 Setting: GPs Aged 18 - 75 years, contactable by telephone, and who met the diagnostic criteria of FM established by the ACR.	psychoeducative program, nine 2 hour sessions (5 sessions of education and 4 sessions of autogenic relaxation). Education sessions contained information about symptoms, comorbid medical conditions, causes of the illness, psychosocial factors on pain and treatments. Autogenic relaxation sessions, pain relief, stress reduction.	usual care from their GP (pharmacologic and is adjusted to the symptomatic profile of the patient)	2 months functional status (FIA), The State Trait Anxiety Inventory, The Marlowe-Crowne Social Desirability Scale	Compared with the control group, the intervention group reported (i) better functional status (FIQ) than the control group (p=0.001) (ii) less physical impairment (p=0.001) (iii) less days not feeling well (p=0.001) (iv) less pain (p=0.001) (v) less general fatigue (p=0.005) (vi) less morning fatigue (p=0.001) (vii) less stiffness (p= 0.007)	Compared with the control group, the intervention group reported (i) less anxiety (p=0.001) (ii) less depression (p=0.001)	NR	Specific improvements in the short term (2 months) in this psycho-educational intervention : physical function, days feeling well, pain, general fatigue, morning fatigue, stiffness, anxiety, and depression. However, these results were reported at the end of the intervention: no longer term evidence available. A placebo effect (group dynamics) cannot be excluded
Mancus	Asthma	Total: n=296	Intervention was	Three	Asthma quality of	NR	For controls, the	During the first 8	A self-

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
o et al 2011 USA 2 sites		Intervention =148 Control=148 Setting: emergency department (ED) of 1 university hospital, and 1 church hospital. Known diagnosis of asthma, and came to the emergence department (ED) because of respiratory symptoms. Age: ≥18 years.	based on social learning theory implemented through the precede-proceed model of health behaviour. At enrolment, intervention patients were given a workbook containing 20 chapters addressing asthma knowledge and self-efficacy, then contacted weekly by telephone.	brochures from the American Lung Association, providing information about basic asthma pathophysio-logy, triggers, and use of peak flow-meters, followed by telephone follow-ups	life questionnaire (AQLQ)at 8 weeks and then at 1 year. Repeated asthma ED visits at 4, 12 and 16 weeks.		change in AQLQ scores was 1.95 95% CI: 1.74 to 2.16; p<0.001). For intervention patients the change in AQLQ scores was 1.83 (95% CI:1.64 to 2.03; p<0.001), and the difference between groups was 0.11 (95% CI –0.17 to 0.40; p=0.43)	weeks, 33 patients had at least 1 asthma ED visit, with no difference between groups (13% controls, 11% intervention patients), and 14 patients were hospitalized for asthma (10 controls, 4 intervention patients).	management education programme delivered in the ED and reinforced by telephone did not provide any benefit on patients' quality of life and repeated ED visits.
Oerlemans et al 2011 Netherlands Multi-sites	irritable bowel syndrome (IBS)	Total =76 Intervention =38 Control =38 Setting: GP surgeries Suffering from IBS according to the International Classification of	Standard care plus cognitive-behavioural therapy (CBT). Intervention group received situational feedback focused on IBS complaints, catastrophizing thoughts, dysfunctional cognitions, and avoidance behaviorr, and was	standard care only (details not reported)	4 weeks and at 3 months dysfunctional complaint-related cognitions and behaviours	Between-group comparison at 4 weeks confirmed that there was more improvement in catastrophizing thoughts ($\chi 2$= 9.33, p<0.01, df=1). This improvement in the intervention group persisted at 3-month follow-up ($\chi 2$=7.06, p<0.01, df=1).	(i) At 4 weeks there was more overall QoL improvement in the intervention group (χ^2= 4.08, p<0.05, df=1). At long-term, no significant differences between group effects were found on IBS quality of life. (ii) There was significantly more pain improvement in the	NR	A standard care plus CB is efficacious for improving IBS-related complaints and cognitions in the short-term. The study included only subgroups of IBS, e.g. diarrhoea or constipation-prone IBS, hence

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		Primary Care (ICPC) or Rome III criteria for ≥3 months Age: 18-65 years	mainly based on cognitive–behaviour therapy				intervention than in control group at 4-week follow-up (χ^2=5.44, p<.05, df=1). No significant long-term between-group effects were found		the results may not be generalizable.
Powell et al 2010 USA single site	Heart failure (HF)	Total =902 Intervention =451 Control =451 Setting: hospital HF with reduced or preserved systolic function, and receiving some form of active heart failure treatment, including diuretics, for the previous 3 months. Age: 63.6 years; Gender: 47% women	Self-management group: 18 contacts and 18 HF educational tip sheets during the course of 1 year in addition to tip sheets in groups and were taught self-management skills to implement the advice.	Education group: 18 contacts and 18 HF educational tip sheets during the course of 1 year in addition to tip sheets in the mail and telephone calls to check comprehension.	2 - 3 years Death or heart failure hospitalization during a median of 2.56 years of follow-up.	Self-efficacy scores improved by 0.2 points in both groups (p=.008 for time effect).	(i) Major depressive symptoms decreased to 90 (20%) in the self-management group and 99 (22%) in the education group (p =0.008 for time effect) (ii) Restricting sodium to ≤2400 mg/d occurred in 126 (28%) patients in the self-management group and 81 (18%) in the education group (p=0.01)	(i) No benefit of self-management compared with education (Wilcoxon p=0.46) in terms of death or heart failure hospitalization	The addition of self-management counselling to educational intervention did not reduce death or heart failure hospitalization in patients with mild to moderate compared to enhanced educational intervention alone. Both groups experienced a decrease of approx. 20% in depressive symptoms and both groups improved self efficacy scores.
Rice et	Chronic	Total: n=761	disease	usual care	12 months	NR	There were 48 deaths	(i) After 1 year,	A relatively simple

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
al 2009 USA 5 sites	obstructive pulmonary disease (COPD)	Intervention =372 Control =371 Setting: Veterans Affairs medical centers. Confirmed COPD at high risk for hospitalization as predicted by ≥1 of the following during the previous year: hospital admission or ED visit for COPD, chronic home oxygen use, or a course of systemic corticosteroids for COPD	management patients attended a single 1- to 1 education session including general information about COPD, direct observation of inhaler techniques, smoking cessation counselling, encouragement of regular exercise, an action plan and monthly follow up calls.	patients received a one-page hand-out containing a summary of the principles of COPD care and the telephone number for the 24-hour VA nursing helpline	COPD-related hospitalizations and ED visits, respiratory medication use, mortality, and change in Saint George's Respiratory Questionnaire		(13.8 per 100 patient-years) in the usual care group and 36 deaths (10.1 per 100 patient-years) in the disease management group over the 1-year study period (difference, 3.7 per 100 patient-years; 95% CI, 21.4 to 8.8; p= 0.09)	the mean cumulative frequency of COPD-related hospitalizations and ED visits was 0.82 per patient in usual care and 0.48 per patient in disease management (difference, 0.34; 95% CI, 0.15– 0.52; p= 0.001) (ii) Disease management reduced hospitalizations for cardiac or pulmonary conditions other than COPD by 49%, hospitalliza-tions for all causes by 28%, and ED visits for all causes by27% (p=0.05 for all).	disease manage-ment programme for patients with severe COPD significantly reduced the composite frequency of COPD hospitalizations and emergency visits by 41% at 1 year follow-up. Patient population may not be generalisable as all were veterans.
Ringstrom et al 2010 Sweden	Irritable bowel syndrome (IBS)	Total: n=143 Group education =72 Guidebook =71	The IBS school was designed on the basis of the self-efficacy theory, and the general theory of	The IBS guidebook cover the areas such as pathophysiology, GI	3 months, and 6 months IBS symptom severity, gastrointestinal-	Significantly improve-ment in knowledge and the satisfaction with that knowledge in IBS group vs guidebook group both at 3 and 6 months follow-up compared	(i) Significant improve-ment in GI symptom severity in the IBS school group versus the guidebook group at 6-month follow-up (– 32 vs. – 13; p=0.04).	NR	A structured patient group education is superior to written information to enhance know-ledge of IBS, and

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
single site		Patients ages 18-70, and with IBS according to the Rome II	nursing and it was performed with a cognitive–behavioural approach	symptoms, treatment options, food-related issues, as well as psychological and lifestyle factors	specific anxiety, satisfaction	with baseline ($p<0.001$ for all comparisons).	(ii) Significant reduction in the severity of GI-specific anxiety, in the IBS school group than in the guidebook group, both at 3 (– 5 vs. 1; $p<0.001$) and 6 months (– 5 vs. –1 ; $p=0.02$).		improve GI symptoms and GI-specific anxiety in IBS patients at 6 months , 3 months post intervention. However majority of the participants were from secondary and tertiary care, hence results cannot be generalised for all IBS patients
Rosal et al 2011 USA 5 sites	Type 2 Diabetes	Total: n=252 Latinos en Control intervention (LECI) =124 Usual care (UC) =128 Setting: community health centres Latino ethnicity, age ≥18 years, diagnosis of type 2 diabetes; last HbA1c (previous 7 months) ≥7.5k; no type 1 diabetes or	Literacy-sensitive, culturally tailored diabetes self-management intervention. LECI consisted of 12 weekly and 8 monthly sessions and targeted knowledge, attitudes, and self-management behaviours. It uses social cognitive theory as a framework. Addressed literacy needs by engaging	Participants in the usual care condition received no intervention	12 months HbA1c change, diabetes knowledge, blood glucose self-monitoring, self-efficacy	The intervention resulted in significant change differences in (i) diabetes knowledge at 12 months ($p = 0.001$) (ii) self-efficacy ($p = 0.001$) (iii) blood glucose self-monitoring ($p = 0.02$) (iv) diet, including dietary quality ($p = 0.01$), kilocalories consumed ($p< 0.001$), percentage of fat ($p = 0.003$), and percentage of saturated fat ($p = 0.04$).	Significant difference in HbA1c change between the groups was observed at 4 months (intervention −0.88 versus control −0.35, $p< 0.01$), although this difference decreased and lost statistical significance at 12 months (intervention −0.46 versus control −0.20, $p= 0.293$). No significant intervention effects on lipids, blood pressure, weight, or waist circumference Both groups showed significant increases in medication intensity at 12 months	NR	This culturally tailored intervention improved short term clinical outcomes in diabetes control among low-income minorities. Self-reported (diet and glucose self-monitoring) may have favoured the intervention group A short term effect on HbA1c is still noted. .

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		history of ketoacidosis, low income	subjects in activities such as foods bingo, cooking lessons, using a step counter, glucose meter.						
Sun et al 2010 China single site	Asthma	Total: n=374 Intervention =228 Control =146 Setting: asthma hospital Aged 18-70 years, with established diagnosis of asthma	education and psychological counselling. Over a 2 week period, asthma education delivered in groups of 20 in four 1 hour sessions, then a individualised self-management plan developed for each patient. Psychological counselling was conducted by clinical psychologists in six 1 hour sessions	conventional pharmacotherapy for asthma	2 weeks, and 3 months QoL, asthma-knowledge score, Psychological distress, patients' understanding of asthma	Significant improvement in asthma knowledge in intervention vs control (p<0.001) immediately after intervention, and 3 months after intervention (p<0.001)	(i) Mean QoL scores in intervention was higher compared with control group immediately after intervention (p<0.001), and 3 months after intervention (p<0.001). (ii) significant lower scores for mean profile of mood state in intervention vs control (p<0.001) immediately after intervention, and 3 months after intervention (p<0.001)	NR	An educational and psychological intervention did improve asthma patient's knowledge and QoL. The effects from each intervention type are not reported making it difficult to determine the relative effects from education or counselling.
Wakabayashi et al 2011 Japan	chronic obstructive pulmonary disease (COPD)	Total: n=102 integrated care (group I) =52 Usual care (group U) =50	Group I underwent a programme of educational sessions for 6 months and then repeatedly received an individually	Education was based on the six domains of LINQ and performed by the same	6 months, and 12 months total Lung Information Needs Questionnaire	(i) At 6-month evaluation, the mean total LINQ score for group I significantly improved (p< 0.02), including understanding of COPD and avoidance of exacer-	(i) Significant improvement was noted in severity of dyspnoea (by Medical Research Council Dyspnoea Scale, MMRC) at 12 months compared to the base-line in group I	There were no significant changes in the frequency of emergency visits for either group. No hospitalizations were noted	Integrated care focused on patient information needs for self-management in older patients with COPD can improve patient

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
single site		Setting: secondary referral clinic Aged >65 years; with history of cigarette smoking (including both current and former smokers); clinical course, symptoms and laboratory data had to satisfy the criteria for the clinical diagnosis of COPD, including airflow obstruction assessed by pulmonary function tests with post-bronchodilator inhalation.	tailored education according to the Lung Information Needs Ques-tionnaire score (LINQ)	nursing team that taught group I.	score, Activities of daily living scores, dyspnea score and the BODE index, frequency of hospitalization	bations (p< 0.01 and p< 0.02, respective-ly). No changes were observed in group U. (ii) The total LINQ score at 12 months significantly improved for group I compared to the baseline (p< 0.03), whereas a decline was noted for group U (p< 0.05). At 12 months, the two groups showed a significant difference in total LINQ score (p= 0.003)	(p< 0.01), whereas group U showed a significant worsening in MMRC at 12 months (p< 0.03). (ii) BODE (body mass index, airflow obstruct-tion, dyspnoea and exercise capacity) index scores in group I were significantly improved at 12 months compared with the baseline (p< 0.02), whereas they were significantly worsened in group U (p< 0.03). (iii) ADL (Activities of daily living) was improved in group I at 6 months (p< 0.03) and remained stable at 12 months (iv) There were no significant changes in the total SGRQ (St George's Respiratory Questionnaire (SGRQ) in either group	in group I during the initial 6-month period (p< 0.04); however, there was no significant difference between the groups during the follow-up period	information needs and health outcomes in medium to long term. Caveat in the interpretation of health care use: n emergency visits and n hospitalizations were very low
Watson et al 2009	Asthma	Total: n=398 Intervention =201 Control =197	Intervention group participated in a small-group, interactive program	Usual care recommende d by their primary care	12 month visits to the	NR	In both the control and intervention groups, we observed significant improvement in total scores on the Pediatric	(i) The number of visits to the ED decreased in both groups but significantly	Education about asthma in a small-group, interactive format, significantly

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
USA single site		Setting: university hospital. Aged 3–16 years, had physician-diagnosed asthma and had required a visit to the ED for acute asthma during the recruitment phase	of education about asthma, and targeted to either the parent or the child, or both, depending on the age of the child	physician.	emergency department, use of oral corticosteroids, pediatric asthma quality-of-life, caregivers' quality of life		Asthma QoL Questionnaire during the year after enrolment.	greater reduction in the intervention group (p=0.0037). (ii) Each group showed a significant drop in hospital admissions but no significant difference between groups (iII) Compared with the control, the intervention group used fewer courses of oral corticosteroid therapy per patient during the year after enrol-ment (p = 0.006).	reduced the need for hospital-based emergency visits. However families who participated in the program were highly motivated. It would therefore be difficult to assess the impact of our intervention in a less motivated group
Wearden et al 2010 U.K 186 sites	Chronic fatigue syndrome (CFS)	Total: n=296 Pragmatic rehabilitation (PR) =95 Supportive listening (SL) =101 General practitioner treatment as usual (GPT) = 100	PR: A programme of graded return to activity is designed collaboratively by the patient and the therapist on the basis of a physiological dysregulation model of CFS/ME.	Usual care: GPs were asked to manage their cases as they saw fit, but not to refer for systematic psychological therapies for	Assessed at entry to the trial (week 0), after treatment (week 20), and one year after finishing treatment (70 weeks from recruitment). Fatigue and physical	Compared with patients allocated to GPT, PR patients had significantly improved fatigue (treatment effect estimate −1.18, 95% CI: −2.18 to −0.18; p=0.021), and sleep (−1.54, −2.96 to −0.11; p=0.035) at 20 weeks.	Compared with patients allocated to GPT, PR patients had signifi-cantly improved depression (treatment effect estimate (−1.18, −2.16 to −0.20, p=0.018)	NR	PR delivered by trained nurse therapists improves fatigue in the short term whilst intervention is on going compared with unconstrained GPT or SL in patients with CFS/ME in primary

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		Setting: general practices Aged ≥18 who fulfilled the Oxford criteria for CFS/ME, scored ≤70% on the SF-36 physical functioning scale, and scored four or more on the Chalder et al fatigue scale.	SL: A listening therapy based on non-directive counselling in which the therapist aims to provide an empathic and validating environment in which the patient can discuss his or her concerns and work towards resolution	CFS/ME during the 18 week treatment period.	functioning	However at 70 weeks The difference was no longer statistically significant (−1.00, −2.10 to +0.11; p=0.076) (ii) Patients who received SL had significantly worse physical functioning at 20 weeks than patients who had GPT (−7.54, −12.76 to −2.33; p=0.005); but at 70 weeks PR patients did not differ significantly in physical functioning from GPT (effect +2.57, 95% CI: −3.90 to 9.03; P=0.43)			care. As there were no differences between groups at 70 weeks follow up there is limited evidence to recommend this intervention.
Williams et al 2010 USA Single site	Fibromyalgia	Total: n=118 Standard care plus web-enhanced behavioural self-management (WEB-SM) =59 Standard care =59 Setting: research centre	Internet-based self-management program :usual and customary care from their primary care physician, plus web-based face-to-face cognitive-behavioural	usual and customary care from their primary care physician	6 months Physical Functional Status(SF-36), chronic pain(The severity scale of the brief pain inventory), fatigue, sleep, mood	(i) WEB-SM group demonstrated statistically significant improvement in physical functional status compared to standard care only (F(1,115)=5.08, p<.03). (ii) General	(i) WEB-SM vs only standard care patients significantly improved average pain intensity (F(1,115)=5.67, p<.01). (ii) proportion of patients reporting a 30% decrease in mean pain score was significantly greater in the WEB-SM group vs	NR	A no-contact web-based educational self-management programme signi-ficantly reduced pain and improved physical functioning in individuals with FM compared to a standard care control group.

Reference, country, N of sites	Type of chronic disease	Population and participants	Intervention	Control	Time of follow up and main study measure	Results-self-efficacy/self-care/knowledge	Results-clinical and QoL	Results-health care use	Interpretation of value of RCT for decision making
		Aged 18 years of age, fulfilled the American College of Rheumatology (ACR) research classification criteria for FM; under the standard medical care of a physician for at least 3 months prior to enrolment	therapy via educational self-help format. The website contained 13 modules – education about fibromyalgia, , how to manage disease, how to adapt life style changes.			satisfaction and satisfaction with the amount of help was endorsed by 91% and 82% of the WEB-SM group respectively; vs. 73% and 57%, respectively, in standard care participants (p<.01, Fisher's exact test for both questions	standard care only (29% vs. 8%; p<.008)		However there is no evidence the effects will last post-intervention after 6 months. A no-contact intervention may not be sufficiently intense or structured to address the needs, complex sets of symptoms, and preferences of all patients

3.5.5. Search Strategy

The table below illustrated the search strategy for systematic reviews in Medline.

The search strategies in the other databases as the search strategies for RCTs are available upon request.

Date	2012-01-19
Database	Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>
Search Strategy	1 (patient adj education).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 70279 2 exp Self Care/ 33912 3 (patient adj2 (educatio* or reliance or efficacy or responsibilit*)).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 72573 4 (self adj2 care).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 24845 5 (self adj2 efficacy).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 14605 6 (self adj2 management).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 6319 7 (self adj2 reliance).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 719 8 ((self or patient) adj2 management adj2 programme).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 138 9 (self adj monitoring).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier 5856 10 or/1-9 120674 11 *Cardiovascular Diseases/ 54128 12 *Hypertension/ 125814 13 *Heart Failure/ 53494 14 *Myocardial Ischemia/or *Myocardial Infarction/ 113808 15 *Stroke/ 33028 16 *Neurodegenerative Diseases/ 5132 17 *Depression/ 35634 18 *Psychotic Disorders/ 20648 19 *Schizophrenia/ 57880 20 *Mental Disorders/ 81295 21 *Asthma/ 76769 22 *Pulmonary Disease, Chronic Obstructive/ 13515 23 *Arthritis/ 15279 24 *Emphysema/ 3064 25 *Fibromyalgia/ 4455 26 *Fatigue Syndrome, Chronic/ 3441 27 *Irritable Bowel Syndrome/ 2548

28	*Obesity/	69760
29	exp Rheumatic Diseases/	158483
30	long-term disease.mp.	1702
31	(chronic adj2 disease).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier	263298
32	(chronic adj2 care).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier	2901
33	or/11-32	1113546
34	((patient or self) adj2 empowerment).mp. mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier	604
35	10 or 34	121027
36	33 and 35	18988
37	Meta-Analysis as Topic/	11663
38	meta analy$.tw.	38958
39	metaanaly$.tw.	1081
40	Meta-Analysis/	30865
41	(systematic adj (review$1 or overview$1)).tw.	31958
42	exp Review Literature as Topic/	5925
43	or/37-42	80559
44	cochrane.ab.	19229
45	embase.ab.	16652
46	(psychlit or psyclit).ab.	831
47	(psychinfo or psycinfo).ab.	6172
48	(cinahl or cinhal).ab.	6333
49	science citation index.ab.	1406
50	bids.ab.	309
51	cancerlit.ab.	519
52	or/44-51	31005
53	reference list$.ab.	6810
54	bibliograph$.ab.	9582
55	hand-search$.ab.	2953
56	relevant journals.ab.	507
57	manual search$.ab.	1698
58	or/53-57	19276
59	selection criteria.ab.	14971
60	data extraction.ab.	7233
61	59 or 60	21054
62	Review/	1647579
63	61 and 62	13702
64	Comment/	483047
65	Letter/	743681
66	Editorial/	296404
67	43 or 52 or 58 or 63	103786
68	or/64-66	1140449
69	67 not 68	97596
70	36 and 69	574
71	exp Health Literacy/	562
72	*Diabetes Mellitus/	55644
73	33 or 72	1161782
74	35 or 71	121397
75	73 and 74	23212
76	75 and 69	638

77	limit 76 to yr="1999 -Current"	590

REFERENCES

1. Boren SA, Wakefield BJ, Gunlock TL, Wakefield DS. Heart failure self-management education: a systematic review of the evidence. Int J Evid Based Healthc. 2009;7(3):159-68.
2. Bravata DM, Gienger AL, Holty JEC, Sundaram V, Khazeni N, Wise PH, et al. Quality improvement strategies for children with asthma: A systematic review. Archives of Pediatrics and Adolescent Medicine. 2009;163 (6):572-81.
3. Gilbody S, Whitty P, Grimshaw J, Thomas R. Educational and organizational interventions to improve the management of depression in primary care: a systematic review. JAMA. 2003;289(23):3145-51.
4. Hill-Briggs F, Gemmell L. Problem solving in diabetes self-management and control: A systematic review of the literature. Diabetes Educator. 2007;33 (6):1032-50.
5. Benyon K, Hill S, Zadurian N, Mallen C. Coping strategies and self-efficacy as predictors of outcome in osteoarthritis: a systematic review. Musculoskeletal Care. 2010;8(4):224-36.
6. Boren SA. A review of health literacy and diabetes: opportunities for technology. Journal of Diabetes Science & Technology. 2009;3(1):202-9.
7. Battersby M, Von Korff M, Schaefer J, Davis C, Ludman E, Greene SM, et al. Twelve evidence-based principles for implementing self-management support in primary care. Joint Commission journal on quality and patient safety / Joint Commission Resources. 2010;36 (12):561-70.
8. Du S, Yuan C, Xiao X, Chu J, Qiu Y, Qian H. Self-management programs for chronic musculoskeletal pain conditions: A systematic review and meta-analysis. Patient Education and Counseling. 2011;85 (3):e299-e310.
9. Fischer E, Thorpe C, DeVellis B, DeVellis R. Healthy coping, negative emotions and diabetes management. A systematic review and appraisal. The Diabetes Educator. 2007;33(1080).
10. Wolf FM, Guevara JP, Grum CM, al. e. Educational interventions for asthma in children. The Cochrane Library. 2002(4).

11. Anker SD, Koehler F, Abraham WT. Telemedicine and remote management of patients with heart failure. The Lancet. 2011;378 (9792):731-9.
12. Bernardy K, Fuber N, Kollner V, Hauser W. Efficacy of cognitive-behavioral therapies in fibromyalgia syndrome - a systematic review and metaanalysis of randomized controlled trials. Journal of Rheumatology. 2010;37(10):1991-2005.
13. Lawrence R, Bradshaw T, Mairs H. Group cognitive behavioural therapy for schizophrenia: A systematic review of the literature. Journal of Psychiatric and Mental Health Nursing. 2006;13 (6):673-81.
14. Albano MG, Crozet C, d'Ivernois JF. Analysis of the 2004-2007 literature on therapeutic patient education in diabetes: results and trends. Acta Diabetologica. 2008;45(4):211-9.
15. Barlow JH, Ellard DR. Psycho-educational interventions for children with chronic disease, parents and siblings: An overview of the research evidence base. Child: Care, Health and Development. 2004;30 (6):637-45.
16. Boren SA, Gunlock TL, Peeples MM, Krishna S. Computerized learning technologies for diabetes: a systematic review. Journal of Diabetes Science & Technology. 2008;2(1):139-46.
17. Davis DW, Gordon MK, Burns BM. Educational interventions for childhood asthma: a review and integrative model for preschoolers from low-income families. Pediatric Nursing. 2011;37(1):31-8.
18. Iversen MD, Hammond A, Betteridge N. Self-management of rheumatic diseases: state of the art and future perspectives. Annals of the Rheumatic Diseases. 2010;69(6):955-63.
19. Merinder LB. Patient education in schizophrenia: a review. Acta Psychiatrica Scandinavica. 2000;102(2):98-106.
20. Solomon MR. Information technology to support self-management in chronic care: a systematic review. Disease Management & Health Outcomes. 2008;16(6):391-401.
21. Yehle KS, Plake KS. Self-efficacy and educational interventions in heart failure: a review of the literature. Journal of Cardiovascular Nursing. 2010;25(3):175-88.
22. Bailey EJ, Cates CJ, Kruske SG, Morris PS, Brown N, Chang AB. Culture-specific programs for children and adults from minority groups who have asthma. Cochrane Database of Systematic Reviews. 2009;(2)(CD006580).
23. Blackstock F, Webster K. Disease-specific health education for COPD: a systematic review of changes in health outcomes. Health Education Research. 2007;22(5):703-17.
24. Bussey-Smith KL, Rossen RD. A systematic review of randomized control trials evaluating the effectiveness of interactive computerized asthma patient education programs. Annals of Allergy, Asthma, & Immunology. 2007;98(6):507-16; quiz 16.
25. Boulware LE, Daumit GL, Frick KD, Minkovitz CS, Lawrence RS, Powe NR. An evidence-based review of patient-centered behavioral interventions for hypertension. American Journal of Preventive Medicine. 2001;21(3):221-32.
26. Boyde M, Turner C, Thompson DR, Stewart S. Educational interventions for patients with heart failure: a systematic review of randomized controlled trials. Journal of Cardiovascular Nursing. 2011;26(4):E27-35.
27. Coster S, Norman I. Cochrane reviews of educational and self-management interventions to guide nursing practice: a review. International Journal of Nursing Studies. 2009;46(4):508-28.
28. Deakin TA, McShane CE, Cade JE, Williams R. Group based training for self-management strategies in people with type 2 diabetes mellitus. In: Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd; 2005.
29. Dorn SD. Systematic review: self-management support interventions for irritable bowel syndrome. Alimentary Pharmacology & Therapeutics. 2010;32(4):513-21.
30. Ditewig JB, Blok H, Havers J, van Veenendaal H. Effectiveness of self-management interventions on mortality, hospital readmissions,

chronic heart failure hospitalization rate and quality of life in patients with chronic heart failure: a systematic review. Patient Education and Counseling. 2010;78(3):297-315.

31. Dennis S, Zwar N, Griffiths R, Roland M, Hasan I, Davies G, et al. Chronic disease management in primary care: from evidence to policy. Medical Journal Australia. 2008;188:S53-S6.
32. Duke SA, Colagiuri S, Colagiuri R. Individual patient education for people with type 2 diabetes mellitus. Cochrane database of systematic reviews (Online). 2009;(1):CD005268.
33. Effing T, Monninkhof EEM, Van Der Valk PPDLPM, Zielhuis GGA, Haydn Walters E, Van Der Palen JJ, et al. Self-management education for patients with chronic obstructive pulmonary disease. Cochrane Database of Systematic Reviews. 2009;(4)(CD002990).
34. Gibson PG, Coughlan J, Wilson AJ, Abramson M, Bauman A, Hensley MJ, et al. Self-management education and regular practitioner review for adults with asthma. Cochrane Database of Systematic Reviews. 2000(2):CD001117.
35. Guevara JP, Wolf FM, Grum CM, Clark NM. Effects of educational interventions for self management of asthma in children and adolescents: systematic review and meta-analysis. BMJ. 2003;326(7402):1308-9.
36. Hampson SE, Skinner TC, Hart J, Storey L, Gage H, Foxcroft D, et al. Effects of educational and psychosocial interventions for adolescents with diabetes mellitus: A systematic review. Health Technology Assessment. 2001;5 (10):i+iii-iv+1-69.
37. Hawthorne K, Robles Y, Cannings-John R, Edwards Adrian GK. Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups. In: Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd; 2008.
38. Jovicic A, Holroyd-Leduc JM, Straus SE. Effects of self-management intervention on health outcomes of patients with heart failure: a systematic review of randomized controlled trials. BMC Cardiovascular Disorders. 2006;6:43.
39. Jones F, Riazi A. Self-efficacy and self-management after stroke: a systematic review. Disability & Rehabilitation. 2011;33(10):797-810.
40. Korpershoek C, van der Bijl J, Hafsteinsdottir TB. Self-efficacy and its influence on recovery of patients with stroke: a systematic review. Journal of Advanced Nursing. 2011;67(9):1876-94.
41. McGillion M, Watt-Watson J, Kim J, Yamada J. A systematic review of psychoeducational intervention trials for the management of chronic stable angina. Journal of Nursing Management. 2004;12(3):174-82.
42. Mason J, Khunti K, Stone M, Farooqi A, Carr S. Educational interventions in kidney disease care: a systematic review of randomized trials. American Journal of Kidney Diseases. 2008;51(6):933-51.
43. Monninkhof E, van der Valk P, van der Palen J, van Herwaarden C, Partridge MR, Zielhuis G. Self-management education for patients with chronic obstructive pulmonary disease: a systematic review. Thorax. 2003;58(5):394-8.
44. Niedermann K, Fransen J, Knols R, Uebelhart D. Gap Between Short- and Long-Term Effects of Patient Education in Rheumatoid Arthritis Patients: A Systematic Review. Arthritis & Rheumatism (Arthritis Care & Research). 2004;51(3):388-98.
45. Riemsma RP, Kirwan JR, Taal E, Rasker JJ. Patient education for adults with rheumatoid arthritis. Cochrane Database of Systematic Reviews. 2003(2):CD003688.
46. Sarkisian CA, Brown AF, Norris KC, Wintz RL, Mangione CM. A systematic review of diabetes self-care interventions for older, African American, or Latino adults. Diabetes Educator. 2003;29(3):467-79.
47. Shin SY, Kolanowski AM. Best evidence of psychosocially focused nonpharmacologic therapies for symptom management in older adults with osteoarthritis. Pain Management Nursing. 2010;11(4):234-44.

48. Thomas PW, Thomas S, Hillier C, Galvin K, Baker R. Psychological interventions for multiple sclerosis. In: Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd; 2006.
49. Powell H, Gibson PG. Options for self-management education for adults with asthma. Cochrane Database of Systematic Reviews. 2003(1):CD004107.
50. Smith JR, Mugford M, Holland R, Noble M, Harrison B. Pyscho-educational interventions for adults with severe or difficult asthma:A systematic review. Journal of asthma. 2007;44:219-41.
51. Borras L, Boucherie M, Mohr S, Lecomte T, Perroud N, Huguelet P. Increasing self-esteem: efficacy of a group intervention for individuals with severe mental disorders. European Psychiatry: the Journal of the Association of European Psychiatrists. 2009;24(5):307-16.
52. Brennan T, Spettell C, Villagra V, Ofili E, McMahill-Walraven C, Lowy EJ, et al. Disease management to promote blood pressure control among african americans. Population Health Management. 2010;13 (2):65-72.
53. Stinson JN, McGrath PJ, Hodnett ED, Feldman BM, Duffy CM, Huber AM, et al. An internet-based self-management program with telephone support for adolescents with arthritis: a pilot randomized controlled trial. Journal of Rheumatology. 2010;37(9):1944-52.
54. Tummers M, Knoop H, Bleijenberg G. Effectiveness of stepped care for chronic fatigue syndrome: a randomized noninferiority trial. Journal of Consulting & Clinical Psychology. 2010;78(5):724-31.
55. Bosma H, Lamers F, Jonkers CCM, van Eijk JT. Disparities by education level in outcomes of a self-management intervention: the DELTA trial in The Netherlands. Psychiatric Services. 2011;62(7):793-5.
56. Lovisi Neto BE, Jennings F, Ohashi CB, Silva PG, Natour J. Evaluation of the efficacy of an educational program for rheumatoid arthritis patients. Clinical and Experimental Rheumatology. 2009;27 (1):28-34.
57. Copeland LA, Berg GD, Johnson DM, Bauer RL. An intervention for VA patients with congestive heart failure. American Journal of Managed Care. 2010;16(3):158-65.
58. Kiser K, Jonas D, Warner Z, Scanlon K, Bryant Shilliday B, Dewalt DA. A randomized controlled trial of a literacy-sensitive self-management intervention for chronic obstructive pulmonary disease patients. Journal of General Internal Medicine. 2012;27 (2):190-5.
59. Sahebalzamani M, Aliloo L, Shakibi A. The efficacy of self-care education on rehabilitation of stroke patients. Saudi Medical Journal. 2009;30(4):550-4.
60. Yoo HJ, Park MS, Kim TN, Yang SJ, Cho GJ, Hwang TG, et al. A Ubiquitous Chronic Disease Care system using cellular phones and the internet. Diabetic Medicine. 2009;26(6):628-35.
61. Hochhalter AK, Song J, Rush J, Sklar L, Stevens A. Making the Most of Your Healthcare intervention for older adults with multiple chronic illnesses. Patient Education and Counseling. 2010;81(2):207-13.
62. Jerant A, Moore-Hill M, Franks P. Home-based, peer-led chronic illness self-management training: findings from a 1-year randomized controlled trial. Ann Fam Med. 2009;7(4):319-27.
63. Mancuso CA, Peterson MGE, Gaeta TJ, Fernandez JL, Birkhahn RH, Melniker LA, et al. A randomized controlled trial of self-management education for asthma patients in the emergency department. Annals of Emergency Medicine. 2011;57(6):603-12.
64. Berman RLH, Iris MA, Bode R, Drengenberg C. The effectiveness of an online mind-body intervention for older adults with chronic pain. Journal of Pain. 2009;10(1):68-79.
65. Ghahari S, Leigh Packer T, Passmore AE. Effectiveness of an online fatigue self-management programme for people with chronic neurological conditions: a randomized controlled trial. Clinical Rehabilitation. 2010;24(8):727-44.
66. Wakabayashi R, Motegi T, Yamada K, Ishii T, Jones RC, Hyland ME, et al. Efficient integrated education for older patients with

chronic obstructive pulmonary disease using the Lung Information Needs Questionnaire. Geriatrics & gerontology international. 2011;11(4):422-30.

67. Wearden AJ, Dowrick C, Chew-Graham C, Bentall RP, Morriss RK, Peters S, et al. Nurse led, home based self help treatment for patients in primary care with chronic fatigue syndrome: randomised controlled trial. BMJ. 2010;340:c1777.

68. Bucknall CE, Miller G, Lloyd SM, Cleland J, McCluskey S, Cotton M, et al. Glasgow supported self-management trial (GSuST) for patients with moderate to severe COPD: randomised controlled trial. BMJ. 2012;344:e1060.

69. Rice KL, Dewan N, Bloomfield HE, Grill J, Schult TM, Nelson DB, et al. Disease management program for chronic obstructive pulmonary disease: a randomized controlled trial. American journal of respiratory and critical care medicine. 2010;182(7):890-6.

70. Sun HW, Wang JP, Wang SZ, Wang YY, Song YP, Yang ZH, et al. Effect of educational and psychological intervention on the quality of life of asthmatic patients. Respir Care. 2010;55(6):725-8.

71. Watson WT, Gillespie C, Thomas N, Filuk SE, McColm J, Piwniuk MP, et al. Small-group, interactive education and the effect on asthma control by children and their families. CMAJ. 2009;181(5):257-63.

72. Baker DW, Dewalt DA, Schillinger D, Hawk V, Ruo B, Bibbins-Domingo K, et al. The effect of progressive, reinforcing telephone education and counseling versus brief educational intervention on knowledge, self-care behaviors and heart failure symptoms. Journal of Cardiac Failure. 2011;17(10):789-96.

73. Bosworth HB, Olsen MK, Dudley T, Orr M, Goldstein MK, Datta SK, et al. Patient education and provider decision support to control blood pressure in primary care: a cluster randomized trial. American Heart Journal. 2009;157(3):450-6.

74. Bosworth HB, Olsen MK, Grubber JM, Neary AM, Orr MM, Powers BJ, et al. Two self-management interventions to improve hypertension control: a randomized trial. Annals of Internal Medicine. 2009;151(10):687-95.

75. Luciano JV, Martinez N, Penarrubia-Maria MT, Fernandez-Vergel R, Garcia-Campayo J, Verduras C, et al. Effectiveness of a psychoeducational treatment program implemented in general practice for fibromyalgia patients: a randomized controlled trial. Clinical Journal of Pain. 2011;27(5):383-91.

76. Oerlemans S, van Cranenburgh O, Herremans P-J, Spreeuwenberg P, van Dulmen S. Intervening on cognitions and behavior in irritable bowel syndrome: A feasibility trial using PDAs. Journal of Psychosomatic Research. 2011;70(3):267-77.

77. Rosal MC, Ockene IS, Restrepo A, White MJ, Borg A, Olendzki B, et al. Randomized trial of a literacy-sensitive, culturally tailored diabetes self-management intervention for low-income latinos: latinos en control. Diabetes care. 2011;34(4):838-44.

78. Powell LH, Calvin JE, Jr., Richardson D, Janssen I, Mendes de Leon CF, Flynn KJ, et al. Self-management counseling in patients with heart failure: the heart failure adherence and retention randomized behavioral trial. JAMA. 2010;304(12):1331-8.

79. Williams DA, Kuper D, Segar M, Mohan N, Sheth M, Clauw DJ. Internet-enhanced management of fibromyalgia: a randomized controlled trial. Pain. 2010;151(3):694-702.

80. Jarrett ME, Cain KC, Burr RL, Hertig VL, Rosen SN, Heitkemper MM. Comprehensive self-management for irritable bowel syndrome: randomized trial of in-person vs. combined in-person and telephone sessions. American Journal of Gastroenterology. 2009;104(12):3004-14.

81. Barlow J, Turner A, Edwards R, Gilchrist M. A randomised controlled trial of lay-led self-management for people with multiple sclerosis. Patient Education and Counseling. 2009;77(1):81-9.

82. Cadilhac DA, Hoffmann S, Kilkenny M, Lindley R, Lalor E, Osborne RH, et al. A phase II multicentered, single-blind, randomized, controlled trial of the stroke self-management program. Stroke. 2011;42(6):1673-9.

83. Chan SW-C, Yip B, Tso S, Cheng B-S, Tam W. Evaluation of a psychoeducation program for Chinese clients with schizophrenia

and their family caregivers. Patient Education and Counseling. 2009;75(1):67-76.

84. Chen SH, Tsai YF, Sun CY, Wu IW, Lee CC, Wu MS. The impact of self-management support on the progression of chronic kidney disease - A prospective randomized controlled trial. Nephrology Dialysis Transplantation. 2011;26 (11):3560-6.

85. Chow SKY, Wong FKY. Health-related quality of life in patients undergoing peritoneal dialysis: effects of a nurse-led case management programme. Journal of Advanced Nursing. 2010;66(8):1780-92.

86. Ringstrom G, Storsrud S, Posserud I, Lundqvist S, Westman B, Simren M. Structured patient education is superior to written information in the management of patients with irritable bowel syndrome: a randomized controlled study. European Journal of Gastroenterology & Hepatology. 2010;22(4):420-8.

87. Saksena A. Computer-based education for patients with hypertension: A systematic review. Health Education Journal. 2010;69(236).

4. ORGANISATION OF CHRONIC CARE IN BELGIUM: SWOT ANALYSIS AND COORDINATION STRUCTURES/PROGRAMMES

4.1. Stakeholders consulted during brainstorming sessions (micro and meso level)

Stakeholders micro and meso level Sessions Flanders, 17/04/2012 & 26/04/2012		
Micro/meso level	Name	Function
Patient and informal carers representatives	Lamers Hilde	Director Vlaamse Alzheimer Liga vzw, Turnhout
	Sofie De Mars	Staff Christelijke Mutualiteiten coördination Ziekenzorg CM, Informal Caregiver Organisation (Mantelzorg)
Pharmacists organisation	Haems Marleen	Koninklijke Oost-Vlaams Apothekersgild Director Departement Professioneel Management, KOVAG
	Marina Lermytte	De Volksmacht Turnhout Project leader “Medicatie op maat in de thuiszorg.”
Hospital Specialist	Frank Nobels	Endocrinologist OLV Ziekenhuis Aalst Vlaams Tijdschrift voor Diabetologie Vlaamse Diabetes Vereniging
	Paul van den Heuvel	Cardiologist Ziekenhuis Netwerk Antwerpen maker van klinisch pad hartfalen ZNA LOK verantwoordelijke cadiologie
Representatives of resting/nursing homes	Bart Coessens	Director Bewonerszorg St Bernardus nursinghome Bertem
	Johan Abrahams	Director St Elisabeth Woon- en zorgcentrum Hasselt.
Regional representatives of primary care nurses and independent nurses	Jannie Van Hespel	Nationaal Verbond van Socialistische Mutualiteiten Deputy director Department Gezondheid en Welzijn o.a. homecare (thuiszorg)
	Louis Paquay	Nurse coordinator Wit-Gele Kruis, homecare (thuiszorg)
	Tine De Vlieger	Coordinator Palliatieve Hulpverlening Antwerpen (netwerk voor palliatieve zorg region Antwerpen)
General Practice Nurse	Karin Van Sas	Nurse in GP group practice Baarle, and Diabetes educator
	Janneke Ronse	Nurse in GP group practice Deurne
Representative of regional care organisations	Leentje Cools	Coordinator Samenwerkingsinitiatieven Eerstelijnsgezondheidszorg(SEL) Amberes Antwerpen
	Ingrid Druyts	CoordinatorMultidisciplinary cooperation - Zorgtrajectpromotor Zuiderkempen Lokaal Multidisciplinair Netwerk

Stakeholders micro and meso level Sessions Flanders, 17/04/2012 & 26/04/2012		
		Zuiderkempen, Verenigde Huisartsenkringen Zuiderkempen
	Ilse Pynaert	Coordinator,zorgtrajectpromotor head of local multidisciplinary network Meetjesland
Hospital Manager	Geert Debbaut (not attending)	Director AZ Turnhout
GP organisation	Jos De Smedt	GP Booischot CRA RVT Heist-op-den-Berg Voorzitter Raad van Bestuur van VELO (Vlaams Eerstelijnsoverleg) lid Raad van Bestuur Wit Gele Kruis lid Raad van Bestuur GDT/SEL Thuiszorgoverleg Mechelen
	Patrick Verdonck	General practitioner CoordinatorSamenwerkingsinitiatieven Eerstelijnsgezondheidszorg (SEL) Gent
Hospital APN	Kristien Van Deyk	UZLeuven cardiology Nurse specialist

Stakeholders micro and meso level Francophone Sessions, 19/04/2012 & 23/04/2012		
Micro/meso level	**Name**	**Function**
Patient and informal carers representatives	Caroline Ducenne	Social worker, Coordinator ASBL Aidants proches
	Sabine Henry	President ASBL Ligue Alzheimer
	Marlène Cloës	Vice-president Ligue des Insuffisants rénaux
Pharmacists organisation	Anne Spinewine (Interviewed)	Professor, Clinical pharmacist, Cliniques Universitaires Saint Luc
GP organisations	Jean François Soupart	General practitioner, president Forum des Associations de Généralistes ASBL
	Corinne Boüüart	General practitioner Maison Médicale Seraing
	Guy Beuken	General practitionerCAMG, UCL
	Saphia Mokrane	General practitioner Maison Medicale solidarité Marolles
Hospital managers	Marius Laurent (not attending)	Ex-president of the association francophone des directeurs médicaux
	Myriam Seront	Nursing director Hôpital Saint Pierre
Hospital specialists	Emmanuel Leyder	Pneumologist (HENALUX)
	Emonts (Interviewed)	Cardiologist, director of clinique de l'insuffisance cardiaque (HENALUX)
Hospital APN	Marie-Claire Beaudelot	APN, coordinator of Auxad,transmural care, CliniquesUniversitaires Saint Luc
Representatives of regional care organisations	Mazlum Kara	Social worker, Coordinator ofSISD Conectar
	François Poncin	Social worker, Coordinator of the Hepatitis C network in Brussels (hôpital St-Pierre)
Regional representatives of primary care nurses and independent nurses	Christine Ori	Nurse coordinator, Fédération Aide et Soins à Domicile (FASD)
	Claudine Baudart	Independent nurse, president of the AIIB (association of independent nurses)
Nurse coordinator	Valentine Musette	Coordinator of RML-B

4.2. Stakeholders consulted during stakeholders group meetings (macro level)

Macro level Sessions 23/05/2012 & 31/05/2012	
Baeyens Jean-Pierre	Observatorium voor de Chronische ziekten + Stuurgroep National Conferentie Chronische Ziekten
Minne Marie-Claire	Stuurgroep National Conferentie Chronische Ziekten; DG Santé FWB
De Ridder Ri	Stuurgroep National Conferentie Chronische Ziekten, RIZIV
Decoster Christiaan	Observatorium voor de Chronische ziekten + Stuurgroep National Conferentie Chronische Ziekten; FOD VVVL, DG1
Borgermans Liesbeth	Stuurgroep National Conferentie Chronische Ziekten;FOD VVVL, DG1
Quoidbach Vinciane (remplace C. Leto)	Observatorium voor de Chronische ziekten + Stuurgroep National ConferentieChronische Ziekten+ Kabinet Minister Onkelinckx
Fierens Micky	Observatorium voor de Chronische ziekten + Stuurgroep National Conferentie Chronische Ziekten+ LUSS
Van Hul Christian	Observatorium voor de Chronische ziekten; Landsbond van de Onafhankelijke Ziekenfondsen
Isabelle Van der Brempt Quoidbach Vinciane (remplace C. Leto)	Observatorium voor de Chronische ziekten + Stuurgroep National Conferentie Chronische Ziekten; SPF Santé Publique, DG1
Grégoire Olivier	Stuurgroep National Conferentie Chronische Ziekte; SPF Santé Publique, DG2
Van Haute Omer	Universitair Ziekenhuis Gent
Loiseau Jean	Observatorium voor de Chronische ziekten; Santhea (MR/MRS)
Gillet Anne	Observatorium voor de Chronische ziekten Médecingénéraliste -
Chevalier Pierre	Observatorium voor de Chronische ziekten+ Médecingénéraliste
Boly Jacques	Observatorium voor de Chronische ziekten + Stuurgroep National

	Conferentie Chronische Ziekten+ ANMC/LCM
Pacquay Louis	Observatorium voor de Chronische ziekten; Wit-Gele Kruis
Weeghmans Ilse	Stuurgroep National Conferentie Chronische Ziekten+ VlaamsPatiënten Platform
Haucotte Geneviève	Stuurgroep National Conferentie Chronische Ziekten+ INAMI
Schreurs Fernand	Observatorium voor de Chronische ziekten

4.3. Overview of the data collected during the brainstorming sessions and de stakeholders group meetings

The themes identified during the qualitative analysis are reported using the SWOT matrix.

Subsequently the information was reported in the macro level meetings as reform proposals. The quotes are reported in the French and Dutch language.

Theme 1

Seamless care: Continuum of care across lines and within lines

Strength	Weakness
Working as a team for a patient "Het team moet versterkt worden, maar dit moet niet geleid worden door één persoon die daarvoor opgeleid wordt, dan valt en staat het met die ene persoon en dat werkt niet, in een palliatief team werkt het goed, we werken als een team rond één patiënt met de huisarts als centraal persoon."(B2VL)	**Shortened hospitalisation, unprepared in primary care** "Patiënten worden sneller naar huis gestuurd, ook allemaal op heel korte termijn, je kunt pas te laat thuiszorg beginnen organiseren, we weten het pas als de patiënt thuis is."(B1VL)
Local organizations who work closely together and so can guide each other in the care "Het kort bij elkaar zitten van de verschillende diensten (thuiszorg, maaltijdbedeling, rusthuis,…), om overleg te hebben, dit is zeer laagdrempelig, het zijn bekende gezichten. Lokaal netwerk dat gekend is. Dit is zeker belangrijk. Goede samenwerking met verpleegkundige, er is ook een referentieverpleegkundige wondzorg ingeschakeld aan huis (van Wit Gele Kruis)."(B2VL)	**No coordination for the follow up of medication across lines** "Wij hebben de patiënt gezien (in ziekenhuis) en vragen aan de huisarts om een bepaalde medicatie te veranderen, maar dat is dan bvb na een jaar nog niet gebeurd."(B1VL) "On voit régulièrement des patients qui sont hospitalisés pour un problème aigu pour qui, lorsqu'ils retransitent dans le milieu de soins chroniques, il va y avoir un problème dans la continuité, par exemple parce qu'ils n'ont pas été bien informés des changements de traitement qui ont été mis en place suite à leur épisode aigu."
Patient guider "Kleine ziekenhuizen hebben patiëntenbegeleiders, er is veel sneller contact met sociale diensten, ook naar de familie toe, algemene ziekenhuizen hebben dit niet."(B2VL)	
Structured hospital-based coordination to link with home-based coordinations "Ce qui nous aide bien, à l'hôpital, c'est une plateforme qu'on a appelé 'Enodios', qui est un lieu de concertation entre le service social et au moins les coordinations de soins et de services de Bxl. C'est un lieu où on échange et où on apprend à se connaître, où on peut aussi dire ce qui ne va pas. »	**Limitation to the GP Participation to coordination meetings (SISD and GDT) :** "C'est bien, mais pour un MG, c'est compliqué d'y aller, parce que je dois annuler une matinée de consultation pour y aller, parce qu'il faut compter les temps de trajet."
Coordination meetings (with SISD and LOGO-SEL) at the patient's life place	**Lack of synthesis function within the system** "Problème d'information, très liée à la fonction de synthèse. Beaucoup de ressources disponibles, d'où la difficulté pour ces personnes d'avoir l'information correcte. La

“La concertation SISD est un bel outil pour la coordination, avec le patient éventuellement.”

“On a également confié aux SISD la gestion d’un outil, la concertation MD. C’est surtout pour les intervenants du domicile, aussi bien les indépendants que les représentants de structures, qui discutent entre eux pour voir comment les choses s’organisent sur une zone déterminée, pour essayer d’articuler au mieux l’offre de soins. Mais donc, on n’est pas dans une relation directe avec le patient. ”

personne ne sait parfois plus elle-même à quels services elle fait appel (image du ‘hall de gare’).”

The difficulties to find your way in the health care system, not only for patients but also for health professionals

“Er moeten ‘wegwijzers’ komen in het bestaande zorgaanbod, dit kan een loket zijn, een cel, een OCMW, er zijn zoveel mogelijkheden, maar nu het is allemaal een beetje onduidelijk. De huisarts kan doorverwijzen naar dit loket. Ja zo’n wegwijzers zijn zeker nodig.”(B2VL)

Lack of recognizable contact person across and between lines

“Voor de huisarts is het niet gemakkelijk om te weten wie het contactpersoon is in het ziekenhuis om een plan te bespreken, een aanspreekpunt ontbreekt.”(B2VL)

“La communication et l’échange d’information, vu que ça se passe dans l’urgence et de manière non organisée – le MG n’a pas décidé d’organiser une hospitalisation-, le MG l’apprend souvent longtemps après.”

Disease-oriented coordination

“Je ne suis pas super-enthousiaste par rapport aux trajets de soins, ce qui me fait peur, c’est que c’est utilisé sur une pathologie et ça me fait penser à ces pseudopodes hospitaliers : le centre de la ménopause, le centre de ceci et cela. Si on multiplie les trajets de soins, comment va-t-on faire pour la personne qui est à la fois diabétique, insuffisant rénal et hypertendu ?”

The lack of proactive planning and working goal oriented, and lack of anticipation or avoiding of acute episodes

“De huisarts is vooral opgeleid om creatief, probleemoplossend te werken,minder om te structureren. We hebben pro actieve chronische zorg nodig in plaats van telkens te moeten reageren op acute situaties.”(B2Vl)

Guidelines and protocols are very biomedical oriented, lack of psychosocial issues

« Cette dame est très débrouillarde, mais elle ne choisit pas ce qu’elle mange. Elle ne mange pas tous les jours et elle mange ce qu’il y a au SAMU social. Ici, on oublie les

guidelines diététiques, dans ce cas, ça ne sert à rien. »

Carepaths are not initiated soon enough

“Er is niets is voorzien voor dergelijke patiënten met een beginnende chronische aandoening. Zorgtrajecten starten pas in een heel laattijdig stadium van chronische aandoening.(B1VL)

Too many healthcare professionals around a patient. Too many different types of “coordination structures” (fragmented coordination)

“Er ontstaat een spanningsveld doordat we met veel hulpverleners rond 1 patiënt werken: hiervoor is er een aangepaste attitude van een ploeg nodig: en ook grenzen kennen en herkennen. De vraag kan gesteld worden met hoeveel mensen mag je rond 1persoon samenwerken zonder de trappers te verliezen, ook voor de patiënt zelf. Teveel brengt een aantal gevaren met zich mee.”(B1VL)

“Pour Bruxelles, on a une vingtaine d’institutions compétentes pour faire de la coordination et la concertation autour du patient. Il y a plus d’intervenants faisant de la coordination que d’intervenants tout court autour d’un patient”.

Lack of a coordinator for the individual care of a chronic patient

“De zorg rond de patiënt zou toch gecoördineerd moeten worden door een persoon die daarvoor opgeleid wordt. Hij moet een overzicht hebben over het geheel en niet puur over het medische, maar ook over de psychosociale problematieken,.. de huisarts kan niet de spilfiguur zijn.(B2VL)

Threat

Pillarization of networks, cultural influence on organization, competition between different decision level (region, province, federal...)

“Il y a une multiplication de projets similaires : on fait de la prévention pour le diabète au niveau provincial, au niveau communautaire, au niveau régional, au niveau fédéral …. On gaspille beaucoup d’argent. Si les SISD deviennent l’organe qui va centraliser les finances, ce qui serait une bonne chose, au lieu d’avoir des coordinations rattachées à des organismes assureurs, il y aurait nettement moins d’injustice sociale.

Opportunities

Ce serait plus facile si les coordinations n'avaient pas d'étiquette, les rattachant à un organisme assureur. » (B1FR)

Lack of clear boundaries of health care organizations

"Il peut aussi y avoir un sentiment de concurrence qui s'établit, par une mauvaise répartition des tâches, avec des missions peu claires. » (B1FR)

Tension between the priorities of care givers or coordinators and the priorities and choices of the individual patient

" Dans cette situation, la dame a accepté le principe d'une aide familiale. Parce qu'au début, la dame ne voulait pas d'aide familiale. » (B1FR)

Lack of mutual knowledge between hospital and coordination centres

« Il y a parfois des hiatus entre les MG et les centres de coordination de soins parce qu'il y a encore l'idée que si on s'adresse à une coordination de soins, que tous les prestataires devront faire partie de cette coordination. Il y a encore de la méfiance par rapport à ça. »

4.3.1. Reform proposal 1: A polyvalent multidisciplinary primary care team is at the center of a system caring for people with chronic care needs

People with chronic care needs should be cared for by a team consisting of a range of care providers. This should be organized as a multidisciplinary primary care team, with the patient at the center, in close collaboration with the GP and helped by coordination and work of the "referent health care provider" (who will thereafter be named "case manager", see proposal 2), as a dyad. This team is vital to reinforce the first line of care and the dialogue between primary care (home-based) and teams from the institutional-hospital sector.In this view, not only biomedical needs will be taken into account, but also psychological, social and psychosocial needs and preferences.

- There is a need for a clear definition of chronic care as starting point and mainly defining chronic patient in relation to their needs (simple vs complex need)
  - Overconsumption: a lack of prioritization may lead to "Over-shooting" of care. This might be a financial burden
  - The question is not whether a multidisciplinary team should exist or not, depending of the type of need. That team should be near the people with chronic need but act accordingly to the needs.
  - The issue of the case manager should be more prioritized. In a stepped care approach, the case manager should focus in more complex cases. Otherwise, this may lead to the overshooting mentioned here above

"Wanneer beschouwen we nu eigenlijk dat een patiënt een chronische zorg patiënt is? Dit hebben we nodig om te weten wanneer er meerdere personen noodzakelijk zijn, want iemand die één pilletje per dag nodig heeft (bijv voor hoge bloeddruk), heeft geen nood aan een multidisciplinair team, dat zou 'overshooting' zijn. Dit zou geen efficiënt systeem zijn. Voor chronische zorg, moeten er meer dan één intervenanten nodig zijn."(SGM1)

"Je kan daar een antwoord op geven door 'stepped care' voor chronische patiënt, zorg op het laagst mogelijke en efficiënte manier,

… we hebben er alle belang bij voor chronische zieken dat in de eerste lijn een team optreedt en daar heb je nood aan een multidisciplinair team." (SGM1)

- There is also a need for a clear definition of some central concepts like "coordination", "referent health care manager"…

  "Il faut clarifier les mots 'coordination', leadership, personne de reference, ce n'est pas clair. Parle-t-on de la même chose ? Parle-t-on de la situation actuelle ou bien de ce qu'on souhaite ? » (SGM2)

- The issue of multidisciplinary team needs to be clarified: focused on specific health problem (for example, has been done in some area in Belgium for obesity) or as a generic primary care team

  "Voor mij is het niet belangrijk of de eerstelijn of het ziekenhuis in het centrum staat, maar het is belangrijk dat de organisatie in zijn geheel in het middelpunt staat, en hierin heeft de eerstelijn een belangrijke rol maar de globale organisatie is het allerbelangrijkst."(SGM1)

- The multidisciplinary team should not only be concerned by the care organization, but also by the diagnostic

  "L'aspect MD doit intervenir dès le diagnostic : le diagnostic infirmier est très complémentaire par rapport au diagnostic médical (…) et ça peut aussi être le diagnostic psychologique, le diagnostic MD » (SGM2).

- Patient should be at the center of this multidisciplinary team

  "Ik mis nog iets heel essentieels. Ik zou in die statement ook de patiënt willen zien en zijn onmiddellijke verzorgers, mantelzorgers, want dat is echt wel essentieel, als je een multidisciplinair team hebt zonder uw patiënt erbij , dan ben je verkeerd bezig."(SGM1)

  "De patiënt zou in het midden van het systeem moeten staan, en daarond een eerstelijnsteam" (SGM2)

- Patient should be clear about the fact that he is cared by a team, but also about who does what in the team

  "Er is gebrek aan synthese binnen een team. De patient is niet gekend als een teamspeler, als een patient die door een team verzrgd wordt. Patient moet een label krijgen, met daarbij het feit dat deze label een positieve connotative moet krijgen, moet ook helpen voor het 'marketen' van het teamaanpak. De patient moet weten dat het team werkt al seen team, die zorgt dat hij bij de juiste person terecht komt op het juiste moment, en moet hun advise kunnen geven rond wie de team kunnen ingeschakeld worden" (SGM2)

- It should be more emphasized that primary care multidisciplinary team play a leading role in structuring the dialogue between first and second line of care

  "Cette équipe doit renforcer le dialogue entre les soins de première ligne et le secteur de deuxième ligne, mais je ne vois pas comment la simple création de ces équipes va renforcer le dialogue. Je pense qu'il faut plus que mettre les équipes en place" (SGM2)

- However working on a primary care multidisciplinary team should be done by looking at the best equilibrium between institutionalized care and primary care (not falling in primary care- centrism after hospital-centrism)

  "Mijn belangrijkste opmerking is dat we lang van uit hospitaal centrisme hebben gewerkt dat was fout maar we moeten nu ook niet gaan vervallen in het andere en louter eerstelijn werken maar voor mij is het allerbelangrijkste de geïntegreerde samenwerking die heel belangrijk is. Maar wel met een belangrijke aansturing vanuit de eerstelijn."(SGM1)

  "Wat bedoel je met 'institutionalised care', dit moet verduidelijkt worden, het gaat niet enkel om ziekenhuizen, maar dit kunnen ook kortverblijven zijn". (SGM1)

- Chronic care comes in a diverse health landscape (threat)

  "Er is enorm veel te doen rond 'lokaliteit', ook al komen we met generieke voorstellen, het zal altijd afhankelijk zijn van de lokaliteit waarin het geïmplementeerd wordt."(SGM1)

- Information means about what does exist as services at the locallevelis often lacking (threat)

"Souvent, le médecin généraliste n'a pas une idée de toutes les aides qui sont disponibles au sein de sa région ou de sa commune. Celles-ci ne sont souvent pas mises en valeur. Il y a un souci d'information et de clarté sur ce qui est disponible" (SGM2)

"Il faut qu'il y ait des équipes sur le terrain en première ligne qui soutiennent le MG au niveau de l'information sur les possibilités qui existent sur le terrain" (SGM2).

- The role of the GP

"Le MG peut être la personne de référence, mais doit être accompagné de quelqu'un. C'est en équipe à deux qu'ils peuvent faire un travail efficace" (SGM2)

"Il faut quelqu'un qui coordonne la fonction de chacun, et le MG se dépensera moins et pourra se préoccuper plus de certaines choses essentielles qui lui seront rapportées par les gens du terrain" (SGM2)

"Il faut aussi un case manager pour aider le médecin généraliste, qui peut identifier les différents besoins, mais qui n'est pas nécessairement outillé ou qui n'a pas le temps" (SGM2)

"De huisarts deze taak niet kan opnemen, omdat hij zoveel andere taken heeft, en de organisatie hiervoor zo verscheiden is. Ons voorstel is vandaag een manager op die plaats te zetten, zou dit zinvol zijn" (SGM2)

" L'AR 78 ne dit rien du rôle du MG concernant la coordination" (SGM2)

- There are different visions and opinions on the task delegation between primary and secondary care in our country and who should have a central position. These views will have to be taken into account when posing this statement (threat)

"Je moet de stelling meenemen dat er ook andere opinies zijn die vertrekken vanuit het zorgcircuit die het ganse zorgsysteem overspant."(SGM1)

"J'entends des choses diférentes : vous parlez de médecins qui délèguent les tâches et de travailler en duo. Ce sont deux manièresde voir les choses différentes. Dans un duo, le médecin généraliste travaille avec quelqu'un, n'est pas au-dessus de tout le monde" (SGM2)

- A revision of the care tasks list by profession can lead to a more shared care

"Cela ne sert à rien d'envoyer 10 personnes à domicile l'une derrière l'autre, je crois que l'on doit revoir les sacro-saintes listes d'actes et voir s'il n'y a pas des rôles qui peuvent être partagés » (SGM2)

« Aujourd'hui, le MG fait parfois des tâches d'infirmier. Il faut restituer à chacun ses missions spécifiques. Il est dommage d'utiliser un pédiatre pour vacciner un enfant » (SGM2)

- We have new financial modalities that allow for networks organization (payment at network level?). This could be better used?

"Er is geen financiering voor een aantal van die deelnemers aan het multidisciplinair team zoals bijvoorbeeld voor cognitieve gedragstherapeuten of meer algemene psychologen of diëtisten,…."(SGM1)

- Existing multidisciplinary networks are a structure that can be easily used (strengths)

"Anderzijds een succes van lokale multidisciplinaire netwerken en waar ruim op ingespeeld is, wat een fenomeen is, dit is omarmd geworden terwijl er al een soort structuur bestond." (SGM1)

- The right of the patient to choice its care providers can be a threat against the model of a care delivered by a team

"Par rapport aux mentalités en Belgique concernant le choix du MG en MR, qui pose problème. C'est une faiblesse du système" (SGM2)

4.3.2. Reform proposal 2: A case manager for all patients with chronic condition(s)

Improved coordination of health and supportive care for chronic patients are necessary to cope with the increasing number of people with multiple co-morbidities. Strategies should be developed in order to tailor the care to people's needs and individual life-goals. The "reference health care provider"- a senior nurse for example – should, in close collaborationwith the GP, provide routine care. Moreover he/she would discuss with the patient and informal caregivers, at least (1) needs, preference, life-goals, (2) care plan and (3) how this will be evaluated and eventually improved. For that purpose, he/she should be able to deal with a well defined scope of chronic situations (e.g. cardiovascular and respiratory diseases, frail elderly people).In that process the reference health care provider uses a shared patient file accessible to all health professionals authorized by the patient.

- Reference persons are already in action in for instance psychiatric care, home care or in geriatric care (At the condition it is linked with the above multidisciplinary team…)

  "Ik wil hier ook refereren naar een 'referentie persoon' die ook aangesteld wordt in de geestelijke gezondheidszorg …. ik hoor daar ook grote tevredenheid over, het bestaat al een hele tijd. Geestelijke gezondheidszorg valt toch ook onder chronische ziektes?" (SGM1)

  "Les coordinations de l'aide à domicile, on les active régulièrement" (SGM2)

- In our system tasks are related to payment systems which inhibits new roles. For example, GPs might be afraid to lose work and income from task delegation, because of the payment system

  "Wat betreft de belemmeringen waarom het nu nog niet zo is in de realiteit, wel het is heel simpel omdat de taken die hier geformuleerd worden nu vandaag door anderen gedaan worden en dus die taken uitvoeren omdat ze er financieel afhankelijk van zijn. En het zelfde voor de verpleegkundigen, is dat betaalbaar, neen zolang ze iedereen blijven wassen is dat niet betaalbaar."(SGM1)

- Early detection of acute situations or complications by highly skilled trained nurses

  '… de huisarts moet niet vrezen om zijn job te verliezen, integendeel als er inderdaad een 'casemanager' aangesteld wordt die bijvoorbeeld bij een COPD patiënt om de twee dagen een telefonische enquete afneemt bij die patiënt, zal de huisarts er naar toe gaan wanneer er een interventie noodzakelijk is. Terwijl hij er misschien anders 14 dagen later naar toe zou gaan wanneer het al te laat is en de patiënt drie weken gehospitaliseerd moet worden en dan ziet hij die patiënt ook niet meer in die tijd. Op die manier zou je dus efficiënter en goedkoper kunnen werken als er een persoon tussenzit die de patiënt van nabij opvolgt."(SGM1)

- Some nurses are not ideally educated to coordinate. Need to specific formation in care / support management

  "Ik stel me wat vragen over de opleiding en de invulling van die CM. Omdat het niet alleen om de geneeskundige zorg gaat, maar de zorg in het algemeen.(…) Als we spreken over zorg, zou die person dan een heel brede kijk moeten hebben over al wat mogelijk is, niet alleen over de medische en verpleegkundige zorg, maar ook, social, school – en werkreïntegratie… Binnen onze opleidingen zijn er maar weinig profielen die hiervoor in aanmerking komen. Sociaal assistenten, social verpleegkundigen ?" (SGM2)

  "On sait que 60 % des infirmières travaillant à domicile pour l'instant sont des infirmières brevetées. Cela pose la question de savoir si ces personnes ont le niveau adéquat pour coordonner l'aide dans le futur" (SGM2).

- Social aspect should also be included in routine care for chronic conditions

"De vraag is inderdaad terecht is dat een verpleegkundige die die rol op zich neemt of is dat een persoon die diverse aspecten op volgt, ook het sociale? Is het eerder een type 'coach', iemand die overal contacten gaat leggen, die mensen bijeenbreng. Het is heel belangrijk om te definiëren wat we verstaan onder 'referentie persoon'"(SGM1)

- One should be very clear of the definition of this role: more focused on disease, on patient, or on a person (not necessarily sick person), on the services available in the local system ?

  "Le réfèrent ou le casemanager? Le casemanager, pour moi, c'est celui qui gère tout ce qui est disease management. S'il avait un autre rôle, il faudrait des aspect sociaux, ce qui n'est pas nécessairement le cas du rôle du case manger" (SGM1)

  "Case manager, n'est-ce pas un nouveau rôle, qui suppose qu'on soit bien au courant de de qui existe, mais qui ne nécessite pas qu'on sache faire une intraveineuse, prendre la tension…" (SGM2)

- This role should only target some patients (see stepped care). Furthermore they should play their role at the level of individual patient and encompass health promotion

  "De lokale multidisciplinaire netwerken hebben een gezondheidspromotor, die heeft geen rechtstreeks contact met de patiënten. Dus dat zou complementair erbij kunnen zijn, dat die persoon wel rechtstreeks contact heeft met de patiënten en die toch ook wat meer zou kunnen, bijvoorbeeld enkele aspecten van disease management gebruiken. Ze hoeft niet per ziekte te kunnen werken, maar zou toch wel wat 'coaching' op afstand kunnen doen."(SGM1)

- This role may overcome the difficulty of GP to play a role as "health care plan manager"

  "Dit kan evengoed ingebed worden als praktijkondersteuner bij de huisarts. Daar is ook nood aan, maar het kan evengoed op een hoger niveau zijn, wat meer coördinerende taken tussen eerstelijn en tweedelijn bijvoorbeeld dan is dat een andere rol, dus daar moet klaarheid over komen. Er zijn eigenlijk 'referenten' op verschillende niveaus."(SGM1)

  "Le médecin généraliste doit garder le plan de traitement et faire appel à quelqu'un en qui il peut avoir confiance pour évaluer les besoins globaux du patient" (SGM2)

  "MG coordinateur de soins, il lui faut un coordinateur de l'aide, c'est ce duo là qu'il faut favoriser" (SGM2)

  "La coordination du soin et de l'aide, ce n'est pas la même chose, c'est un autre rôle" (SGM2)

- CM should play a key role in the anticipation of future needs of the patient

  "C'est peut-être un rôle supplémentaire pour le Case Manager. Lorsque le patient a besoin d'être placé, que ce soit en MR ou en MRS, les démarches (sont) laborieuses, cela demande une planification, y compris avec la famille, surtout pour les patients déments" (SGM2)

  "La planification des soins est nécessaire, comme on le fait dans les soins palliatifs (Advanced care planning)" (SGM2)

4.3.3. Reform proposal 3: mid-level scale initiatives to improve seamless care between hospital and home care are needed

Forms of coordination at a lower scale than "Services integré de soins à domicile" (SISD) – Samenwerkingsinitiatieveneerstelijnsgezondheidszorg (SEL) but larger than primary care coordination structures need to be created to strengthen seamless care between hospital and specialist care and primary care. Other networks between home and hospitals play a leading role in that respect.

- It is very important to look at the scale dimension in coordination. We can at least distinguish coordination at patient level, at practice (or group of practices level) and at regional level (SISD, SEL, …)

  "Il ne faut pas multiplier les niveaux, sinon risque que le patient tombe dans les trous…" (SGM2)

- Coordination at the midlevel can best be performed at the level of 6000 patient in general practices. That would mean that actual GP practices are too small. We should aim at bigger primary care group-practices (around 6000 people) or networks that would make such coordination possible

  "Ook belangrijk binnen de eerstelijn, de huisartspraktijken en zelfs een aantal groepspraktijken zijn van schaalgrootte te klein om zo'n model te kunnen toepassen. Dus of moet je naar grotere groepspraktijken evolueren of naar netwerken, ik heb daar geen cijfers over, maar ik denk dat je toch aan een minimum van 6000 patiënten moet gaan om een zekere economische return te kunnen garanderen"(SGM1)

- From regional networks (ie CAW) referent persons can be supplied without too much difficulty

  "Dit kan perfect voor een netwerk van huisartsen, er kunnen zorgcoördinatie teams ter beschikking gesteld worden voor een groep van huisartsen die daar beroep op doen, CAWs; dit kan allemaal."(SGM1)

- At this level, innovative reimbursement systems might be possible to adjust locally (ie group practice, network teams etc)

- We need health-plans that go further than the institutionalized care. We have tocreate "care pathways" helpingpeopletouse the most appropriated setting

  "Er zijn verschillende meningen/visies over de rolverdeling eerstelijn en tweedelijn in ons land en over de centrale positie van de eerstelijn in de chronische zorg. De zorgtrajecten zijn niet altijd even goed onthaald geweest. Niet iedereen kan zich vinden in dit statement en sommigen vinden dat de eerstelijn versterkt moet worden maar niet ten koste van de tweede lijn. Ons centrale zorgsysteem moet een duidelijkere positie krijgen vertrekkende vanuit de zorgcircuits in zijn geheel en dan de positie bekijken van de eerstelijn of tweede lijn.

- 'Institutionalized care' is not only hospital care, but also care in resting homes and other services

  "… dat er in ons land ook andere institutionele zorgkaders zijn dan het ziekenhuis."

  "Ja, er zijn niet alleen ziekenhuizen, er zijn ook mensen die heel lang ziek zijn en niet in ziekenhuizen zullen verblijven." (SGM1)

  "Il faut de la flexibilité. On a des équipes de soins palliatifs à domicile : il y a des patients qui ne viennent jamais à l'hôpital, il y a des équipes hospitalières qui descendent vers le domicile. Il ne faut pas tout centrer sur l'hôpital, car il est très clair qu'il y a des malades chroniques qui ne vont jamais à l'hôpital. Il faut l'organisation de l'ambulatoire, sans compter sur l'hôpital" (SGM2)

- We may also think about special functions or teams that focus on transversal coordination between lines of care

  "Als we blijven in functie van de eerste, tweede en derde lijn en proberen structuren aft e stemmen op elkaar, blijven we in hokjes werken. (…) Misschien moeten er ad hoc teams zijn. Dit gaat natuurlijk heel ver en zou heel onze denkwijze en zorgsysteem op zijn kop zetten. In chronische zorg is dit echt een system waar de patient echt central gezet wordt. In een degerlijk system denk je niet meer in de zin van, het is mijn patient en il wil hem terugkrijgen als ik hem doorverwijs, enz." (SGM2)

"A quelle échelle se trouve le Case Manager ? Par qui sont-ils payés ? Actuellement, les RML sont centrés 'médecin généraliste', et les SEL / SISD sont centrés 'services'. Il faut les intégrer, car la prise en charge doit être intégrée" (SGM2)

- Belgian "reform" must always look at the balance between local adaptation (to local context) and general policies

  "Het is ook belangrijk dat die verschillende modellen op zich naast elkaar moeten kunnen bestaan. Dit is ook het aspect 'localiteit' op zich, er zijn veel vertaalslagen op zich mogelijk maar die dan lokaal gebonden zijn."(SGM1)

- We do not have to create new structures of coordination, but use otherwise what already exist

  "J'ai des doutes par rapport à la création d'une nouvelle structure. Il faut partir de l'existant.Les SISD ne font pas de la coordination, ils font de la concertation. Dans la pratique, c'est mille concertations par an, ce qui est absolument insignifiant. (…) Beaucoup d'infirmières travaillent à l'hôpital, en plus du domicile…"(SGM2)

  "Il ne faut pas créer de nouvelles structures, oui pour de nouvelles fonctions avec des profils bien définis et redéfinir les rôles de tout un chacun, de manière à ce que, quand le patient sort de l'hôpital, que l'on sache à qui l'adresser…" (SGM2)

- Using "impulseo" at a larger scale as it is now may help in … (looking for resources to organize such a coördination?)

  "Een heel praktisch aspect van deze gedachte, we hebben een model ter ondersteuning van huisartsen 'Impulseo', dat werkt met criteria van een aantal GMDs, maar dan kom je niet op die schaalgroep, het is veel lager. Maar het is wel al een model dat bestaat om dingen in te voegen… We hebben een financieel systeem nu dat ook wel opgevat is die toelaat om op netwerken te werken. Er bestaat een nieuw financieringsmodel."(SGM1)

- The existing palliative team / network may also be an entry-point but it is now at a too large scale (around 250 000 people)

4.3.4. Reform proposal 4: the right environment according to the needs of people with chronic health problem

The support of people with limited or high need for chronic care is a challenge for the following decades in Belgium. On the one hand the care in institutions should be reserved for people with high care/supportive needs. On the other hand specific support is required for persons with limited care/social needs, outside institutions. Increasing the offer of care/support at home as well as adapted accommodations for relieve are possible solutions to avoid institutionalizations.

- There is a need for more 'respite' care organisation, as well as a need for information about the existing formula, in order to avoid some hospitalisations…

  "En anderzijds een aantal 'respite' formules, ofwel dat de patiënt eens ergens naar toe kan gaan, ofwel dat de mantelzorger es ergens tussen uit kan, dat er thuis oplossingen zijn voor mantelzorgers."(SGM1)

  "Souvent, il y a hospitalisation par épuisement du réseau, alors qu'ils n'ont rien à faire à l'hôpital" (SGM2)

  "Qui doit organiser ces structures de répit ? Les ligues en organisent, on peut les soutenir pour qu'elles en organisent plus. Ce n'est peut-être pas aux SISD de devoir organiser un truc médicalisé"(SGM2)

  "Il existe des possibilités pour soulager l'aidant proche en court séjour, mais c'est trop peu exploité. Ce serait un plus pour tout le monde. Il y a une certaine méconnaissance, ou bien c'est difficile à organiser" (SGM2)

  "Dans mon expérience, la première chose qui pose problème, se situe au niveau du soutien de l'aide informelle, motif d'hospitalisation le plus fréquent. On finit par hospitaliser pour pallier à l'épuisement de l'aidant proche. C'est toute cette organisation de soutien de la famille qui pourrait être présent et permettre aux gens de rester à la maison. Les centres de répit, les centres de jour, il manque de places…" (SGM2)

- …And a need for day centres in rural area, as well as a need for information about the existing day centre…

  "Et aussi le soutien d'activités intergénérationnelles au niveau local, pour que justement la personne âgée qui peut rester chez elle, sorte de sa solitude parce que ça fait partie de la qualité de vie."(SGM1)

  "Un autre problème est l'isolement de la personne âgée, qui quitte la ville pour aller vivre dans un village, où l'infrastructure n'est pas aussi développée…."(SGM1)

  "Les centres de jour existent, (mais) il s'agit effectivement de quelque chose de méconnu. Il y a trois éléments qui jouent en leur défaveur. Premièrement, le coût : si on y va régulièrement, c'est de 300 à 400 €/mois, ce qui veut dire que ce n'est pas accessible à tous. Deuxièmement, ces centres de jour sont perçus comme un détournement de clientèle par les services de soins à domicile, alors qu'ils sont complémentaires. Troisièmement, il n'y a que 200 places en RW. C'est une faiblesse du système…" (SGM2)

- Social security and financial incentives to alleviate the burden of the informal caregivers and formal recognition for informal caregivers

  "Eén van de zwaktes zijn de lacunes van de mantelzorg, bijvoorbeeld het ontbreken van een statuut, ik zeg niet dat ze moeten betaald worden, maar wel dat er bijvoorbeeld een bepaald aantal garanties moeten zijn ivm hun sociaal statuut bijvoorbeeld."(SGM1)

- The division in our national and regional system between medical care and social care need to be dealt with at the work floor. The actual state reforms have overlooked that issue. Municipalities could play a role in that aspect

  "Hier moet er vooral rekening mee gehouden worden: ook na onze staatshervorming is dat een grote zwakte: de split tussen medische zorg versus welzijnszorg. Met de staatshervorming is dat niet vergemakkelijkt. Dat is beleidsmatig gezien toch een heel belangrijk signaal, we zullen toch moeten zoeken naar systemen die deze twee bij elkaar brengen."(SGM1)

  "Inderdaad en daarom moet er gewerkt worden aan een formule die deze structuren structureert ook al zijn er andere bevoegdheden, en deze meer op elkaar gaat afstemt. Met verbeelding en creativiteit kan dit. Het moet wel op de werkvloer georganiseerd worden. We moeten formules vinden die de welzijns- en de niet welzijnssector met elkaar te doen samenwerken. "(SGM1)

- Chronic patients should be stimulated to be and remain active producers in our society

  "Met 'environment' gaan we ver: het is een integratie in diverse vormen, niet alleen materieel maar ook werk bijvoorbeeld. Niet alleen om de mensen terug aan het werk te krijgen maar ook om ze aan het werk te houden, dat is zeker niet onbelangrijk.Of om ze toe te laten om te werken."(SGM1)

Theme 2

(Re) defining the roles of health professionals and their training

Strength

Professionals are willing to take the role as coordinator

"De verpleegkundige (in groepspraktijk) krijgt eigenlijk een centrale rol, de huisarts behoudt wel zicht over het medische luik, maar het hoeft niet altijd de huisarts te zijn die de coördinerende rol op zich neemt. Wij merken zelf wel dat we onszelf ook goed moeten bijscholen en je moet mensen helpen en ondersteunen die dat willen op zich nemen. Een verpleegkundige kan dit evengoed. De huisarts beslist dan dat hij een deel van zijn coördinerende rol delegeert. Soms beslist ook de patiënt dat de verpleegkundige die rol op zich kan nemen doordat hij/zij laagdrempelig is. Tenzij de huisarts zegt : nee, het is te complex, dan moet je dat bijsturen.(B1VL)"

«La place à donner à l'aidant est très compliquée dans une relation MG-patient. Notamment pour donner à chacun une place qui lui convient et la fameuse question de 'qui coordonne?'. L'aidant a parfois aussi envie de coordonner. Et pourtant, les professionnels s'attribuent ce rôle-là de plein droit, ce qui est logique aussi, parce que ça fait partie de leur formation. Mais c'est parfois un tel nœud à défaire, ce qui décourage parfois les familles à faire appel à ces services aussi. »

The strength of interdisciplinary team in organizing the communication between professions and tasks

"Dans une MM, c'est plus facile d'organiser les choses. Dans les autres cas, il y a peu d'échanges inter-métiers, sauf quand on se voit en coordination. On ne s'écrit pas."

Weakness

Lack of inter-professionals communication tools

"La difficulté aussi, c'est qu'on a des tas de moyens de communication, mais toujours intra-métiers. On a le dossier infirmier, le dossier médical"" Pour les guidelines aussi, c'est vraiment cloisonné par métier. »

Lack on agreement about who have to play the role of care coordinator in primary care and beyond the medical needs

"De zorg rond de patiënt zou toch gecoördineerd worden door een coördinerend persoon die daarvoor opgeleid wordt. Hij moet een overzicht hebben over het geheel en niet puur over het medische, maar ook over de psychosociale problematieken,… de huisarts kan niet de spilfiguur zijn. Die rol wordt nu niet opgenomen, de groep die de rol zou moeten opnemen doet dit nu niet, er is weinig opleiding, onvoldoende vaardigheden, geen kennis, tijd, geen voorzieningen. Het bestaat wel maar het wordt niet opgenomen."(B2VL)

GPs have not enough support. Group practices should also be stimulated

"Rigiditeit van planning en wie de planning moet opmaken is ook een probleem. Huisartsen zijn ook niet op de hoogte van wie die planning zou kunnen opmaken op hun initiatief, ze hebben geen kennis van de verschillende systemen die mogelijk zijn. Het is dus enerzijds een attitude probleem maar anderszijds ook een kennis tekort over de verschillende mogelijkheden. Jongere huisartsen willen dit wel op zich nemen maar er moet een omkadering komen, en er moet een vlot systeem zijn, haalbaar en goed uitvoerbaar. Financiële incentives zijn niet zo belangrijk, er is nu een financiële vergoeding voor huisartsen voorzien die een zorgplanning opmaken, maar dit is niet zo belangrijk. De zorg moet vooruitgaan, en de zorg gaat beter."(B2VL)

GP has too many tasks + there is a lack of clear task delegation

"De huisarts wil de centrale zorg behouden en een aanspreekpunt zijn, maar ze kunnen niet alles, ze hebben ondersteuning nodig."(B2VL)

« Pour ce qui est de la réponse aigüe aux situations, on voit que le médecin est surchargé, il devient moins accessible, mais on lui donne toujours le rôle central et il n'est pas très bien au

centre de l'information quand il y a une situation complexe. »

"'manager' – (GP manager = afstemmen van de zorg binnen een huisartsensetting.)- is een geladen woord. Alle hulpverleners moeten op elkaar afgestemd worden, het managen van het hogere niveau en ook het lagere niveau: ook de patiënt moet er bij betrokken worden. Wie kan dit op zich nemen, iemand met een brede basis opleiding, kennis hebben over wat de eerste lijn te bieden heeft, hoe het aanbod kan terecht komen bij de juiste persoon, afspraken maken op basis van protocollen, procedures- en werken binnen de eerstelijns praktijk De specifieke taak: alleen management, zal de handen hiermee vol hebben, 'zorgmanager'. Ik denk niet dat de Lokale multidisciplinaire netwerken die taak aan kunnen.(B1VL)

Pharmacists are not enough involved in chronic care

"De rol van de apotheker in de chronische zorg is nog niet sterk genoeg. De apotheker moet op de kaart gezet worden. De apotheker is zeer laagdrempelig maar ze worden niet betrokken"(B2VL)

"Peu de pharmaciens d'officine ont une collaboration fructueuse avec les médecins généralistes, mais ce n'est pas du tout la majorité, pourquoi, parce que les pharmaciens d'officine sont tendance à se sentir hiérarchiquement inférieurs aux médecins généralistes, et que les MG ne sont pas du tout ouverts à recevoir des informations ou des conseils de la part de pharmaciens. »

Manpowerplanning is not ad hoc

"In de opleiding zit weinig sturing naar wat we effectief nodig hebben - vb numeros clausus in de geneeskunde, maar eens je het bent kan je je specialisatie kiezen, vb teveel cardiologen, te weinig endocrinologen bvb. Ik denk ook aan de eerstelijn. Daar is er ook te weinig gestuurd naar wat er effectief nodig is." (B1VL)

"Il y a beaucoup d'AS disponibles. Il y en a dans les MM, des CPAS, des coordinations de soins, des centres d'action globale, les services d'aide aux familles. Il y a pléthore, mais on ne les utilise pas suffisamment." (B1FR)

Legal framework and legislation make task delegation difficult

"Wettelijk blijft de arts verantwoordelijk, ook al werk je met protocollen en zo. (eerstelijnsverpleegkundige): het speelt ook een rol in hoeverre artsen willen gaan in taakdelegatie: zij blijven wel wettelijk verantwoordelijk. Ze willen wel en vertrouwen ook op de verpleegkundigen maar blijven zelf verantwoordelijk.
Het gekke is dat we patiënten leren om taken zelf te doen (insuline spuiten, optrekken, ..) wat

verpleegkundigen dan weer niet mogen doen! “(B2VL)

“Oui, les aides-familiales ne peuvent pas pour des raisons médico-légales. Elles ne peuvent pas préparer les semainiers.

A lack of coaching to overcome stress of professionals

“Stress onder hulpverleners is een probleem - Het heeft ook te maken met hoe je een groep kan coachen. Werkstress is hetzelfde, hangt van je mensen op de bepaalde diensten af, bv andere hoofdverpleegkundige. - Er is nood aan coaching van hulpverleners.”(B2VL)

Not enough interdisciplinary education

“Er is echt nood aan een interdisciplinaire opleiding, dit ontbreekt echt op dit moment, of is juist aanwezig bij enkele opleidingen. Zo kan je de verschillende disciplines leren kennen met hun mogelijkheden, en beperkingen. Tools voor levenslang leren zijn zeker noodzakelijk en bepaalde competenties moeten uitgebouwd worden zoals planning,…”(B2VL)

Threats

Opportunities

Creation of new professions (generic primary health care professionals, specialised primary care nurses, generic educators,...)

“generieke educator:psycholoog, kunnen educeren, noties diethiek want is een probleem bij heel veel chronische aandoeningen, ook wat verpleegkundige activiteiten kunnen uitvoeren- nood aan iemand die wat meer disciplines of competenties in zich heeft”(B2VL)

4.3.5. *Reform proposal 5: creation of new functions at primary care level*

At primary care level, new functions need to be created and officially recognized (legally and in the organisation of the health care system). In particular nurses with a higher education level (e.g. MSc) should receive new functions (e.g. case management). In parallel, basic care (e.g. washing) should be delegated to nurse aids with a lower education level.

The GP has been and is still a key actor in the coordination of chronic medical care but he/she has increasing difficulties to cope alone with this complex and time-consuming task. A better share of tasks is needed within the primary care team, i.e. between GP, case manager (see point 2) and community pharmacists. One solution is to set up a cascade of delegation of activities. "The right care provider at the right place" call for reformed legislation, specific training (e.g. highly skilled primary care nurses, clinical pharmacists) and incentives for the implementation of these new roles.

- Professional organisationstend to protect their role. For instance the role of the practice assistant (In Flanders) is still an open discussion

  "Je voegt nieuwe hoger gespecialiseerde niet-artsen toe, verpleegkundigen of paramedici, en dat maakt dan tijd vrij, dan kan je gaan verschuiven. Waarschijnlijk zal het in de andere richting moeten werken: dat het werk dat vandaag gedaan wordt tegen een hoge prijs, overgenomen wordt door anderen en dat je tegelijk iets anders aanbiedt. Het moet strategisch lopen."(SGM1)

  "Er gaan zeker territoriumgevechten zijn maar anderzijds gaan we ook de verdediging van het beroep zien. Zoals we hebben gezien bij de zorgtrajecten, dat de dietiste die educatrice is, niet mag leren om in te spuiten, dan vrees ik het ergste."(SGM1)

  "Het invoeren van nieuwe beroepen in ons systeem komt als bedreigend over voor de bestaande beroepen omdat het niet als complementair wordt beschouwd."(SGM1)

- New roles require new curricula, to begin with GP, in order to shift their working paradigm

  "Heel veel oorzaken daarvan zitten in de opleiding en niet alleen met betrekking tot nieuwe functies die je zou wensen, maar ook waarom er zoveel zaken fout lopen. Als artsen vandaag niet zo'n goede managers zijn, of niet zo goed kunnen multidisciplinair werken, ligt ook voor een deel aan het feit dat ze daar te weinig of geen aandacht voor krijgen in hun opleiding."(SGM1)

- New roles require optimal workforce planning

  "…Et le planning, la programmation des ressources humaines qui est important aussi"(SGM1)

- Need to (new) specific training for primary care nurses working in MD team

  "Est-ce que c'est quelque chose de diffèrent, coordinateur de soins et infirmière soignante ? S'il y a des équipes qui sont organisées sur le terrain, et qu'au sein de ces équipes il y a un infirmier, moyennant une formation spécifique par rapport à la gestion de la maladie chronique, c'est mieux. Ça veut dire que cette infirmière va aussi continuer à faire des tâches de soins à proprement parler" (SGM2)

- New roles can go beyond the role of nurses, for instance pharmacists and nurse assistants, but also other profession not included in the current AR 78

  "Een opportuniteit op dit moment is dat het debat over het inschakelen van de zorgverpleegkundigen in de thuiszorg, op dit moment volledig open ligt, moet gevoerd worden. Er is een studie geweest over zorgkundigen in de thuisverpleging, die is opgeleverd, die ligt bij de minister. Dus er is op dit moment een enorme opportuniteit om van onderuit door het creeren van zorgkundigen in de thuisverpleging kan je daar ruimte vrij te kunnen maken voor andere opdrachten voor verpleegkundigen"(SGM1)

  "On doit faire évoluer le rôle de l'infirmière, ce qui n'empêche pas que l'on revoie la liste d'actes… Il y a tous ceux qui ne sont pas dans l'AR

78: les éducateurs, les psychologues, mais aussi les autres professions… Il faut faire plus simple" (SGM2)

- Which new role for the community / clinical pharmacist in the chronic care system ?

  "Le rôle possible du pharmacien d'officine, ce serait nécessaire de le détailler" (SGM2)

  "Dans d'autres pays, dont la Hollande, le patient a un pharmacien attitré. En Belgique, c'est plus difficile, il y a rarement une coordination entre le pharmacien hospitalier, le pharmacien d'officine et le médecin généraliste" (SGM2)

  "A la base, il y a un problème de communication entre pharmacien et soignant. Même si le pharmacien a un rôle et qu'il a la responsabilité de ce qu'il délivre, il est parfois mal accueilli par le médecin. Il y a une habitude de mise en commun des compétences qui n'existe pas sur le terrain" (SGM2)

- Because of cascade is a risk for deterioration or loss of Quality
- Some practices can be delegated to the caregiver, andrequire may be not new roles

  "Een van de bedreigingen van ons system, is dat we verder professionaliseren van wat de mantelzorg zou kunnen doen. In de toekomst gaat di tons onnoemelijk veel geld kosten, als wij blijven niewe functions, niewe opdrachten professionaliseren. Dit is de tendens van onze maatschappij" (SGM2)

4.3.6. Reform proposal 6: Specialized hospital functions

Specialized hospital functions (clinical MD specialists and allied professions) should focus on specific problems in acute contexts. They should also invest in patient autonomy before the return at home to ensure the transition with self-management in primary care. A discharge specialized nurse should ensure a seamless transition through arrangements with the primary care team. Finally, they should coach and support the primary care level for specialized and technical issues.

Some suggestions from the analysis of other chronic care systems are the appointment of a contact person in the hospital to support the discharge process, (e.g. to contact the primary care team), the self-management of the patient about his/her condition(s) by a specialized nurse/allied professional, and care plan oriented exchanges between clinical specialists and primary care providers.

- Telemonitoring can help to observe patients that can be discharged earlier from hospitals, but evidence of efficacy is lacking at present

  "Een studie in Denemarken toont dat men er in geslaagd is om het aantal hospitalisaties voor COPD manifest te verminderen door telemonitoring van de patiënten als ze het hospitaal verlaten.De patiënt kan sneller het hospitaal verlaten, hij wordt opgevolgd voor een telemonitoring door nurse die een probleem snel kan detecteren, dat meldt aan de huisarts, de huisarts start een corticoide op, waardoor hij problemen kan vermijden."(SGM1)

  "Die dimensie zou er zeker moeten inzitten, het is een brug tussen de eerste en de tweede lijn, door wie het ook georganiseerd wordt."(SGM1)

- At present there are 5 experiments for better coordination between primary care and the hospital sector
- In hospitals we have extern liaison nurses (for instance for end stage kidneydisease) , and within shortly there will be a list of these functions

  "Er wordt al geïnvesteerd in een ontslagmanager in het ziekenhuis, en in sommige diensten in outreaching nurses, die de zorg gaan doen aan huis, denk aan dialyse. En 'liaison-nurses' Er bestaan wel modellen."(SGM1)

  'Die rol moet beter gedefinieerd worden. Er zijn 2 aspecten: er is het aspect zorg dat moet overgedragen worden, maar er is ook de voorbereiding van het ontslag, nl. nakijken met de eerste lijn of de voorwaarden vervuld zijn om uit het ziekenhuis te kunnen vertrekken. Alle voorwaarden: dat kunnen huisproblemen zijn, zoals trappen, enzovoort. " (SGM1)

- Need to clarify the concept of empowerment, as it is more than education…

  "C'est surtout là qu'il faut investir pour que le patient devienne aussi autonome que possible"(SGM1)

- In protocol 3 projects we have many examples of coordination
- Think about the KCE seamless care study
- Maybe the wording of coaching is wrong in this respect and supporting is more appropriate

  "Maar waar ik me zorgen over maak is dat dit heel dikwijls als zeer bedreigend wordt ervaren vanuit eerste lijn. Zoals je ook in de zorgtrajecten ziet, daar zit een expliciet model van coaching van de tweede lijn naar de eerste lijn in, van de specialist naar huisarts, van educator ziekenhuis naar educator eerste lijn, en dat is voor het ogenblik voor ons 'een blanco', we weten daar niks over. Werkt dat of werkt dat niet? We betalen dat maar…?"(SGM1)

Theme 3
Empowerment and support of patient and informal caregiver

Strength

Patient education by specialised nurses

“Ons zorgprogramma is zo georganiseerd dat elke patiënt die op raadpleging komt eerst de verpleegkundige ziet, ze gaat het gezondheidsgedrag bevragen met daaraan gekoppeld ook educatie .”(B1VL)

“Ici dans notre structure, on n’a pas de diététicienne, mais on met toujours nos patients en contact avec des diététiciennes, et je me rends compte que mon infirmière connaît beaucoup mieux la diététique de l’insuffisance cardiaque que la diététicienne… elle a de nombreux petits trucs, on les lui a appris à Paris. Il y a comme ça quelques critères, mais la gestion psychique de la maladie en elle-même, on voit tout de suite si le patient gère sa maladie ou pas, et on pourrait… » (interview)

Patient organisations are an added value next to the educator

“Er wordt geregeld contact opgenomen met patiëntenorganisaties , o.a.-platform, -liga, 0800 lijnen, expertisecentra, referentiepersonen,dit zijn allemaal aanvullende opties , ook sommige artsen proberen een zekere samenwerking te krijgen met deze organisaties.
(ziekenhuisspecialist) Ik geloof daar sterk in, aanvullend.”(B1VL)

“Si on veut que le patient puisse décider pour lui-même, il faut qu’il comprenne les choix. Les choix sont difficiles lorsqu’ils viennent des professionnels qui sont experts. On devrait lui donner l’occasion de rencontrer des pairs. Il est important de donner l’information par rapport à un groupe d’entraide, car ce n’est pas proposé systématiquement par les professionnels. Ceci est important pour combattre l’isolement et pratiquer le self-help. Il ne s’agit pas seulement de donner l’accès aux aides financières, … mais aussi aux relations, qui peuvent soutenir la personne, sans rien attendre en contrepartie » (B1FR).

Support for informal caregivers

“Communicatie met en informeren van de mantelzorg is heel belangrijk. De draagkracht van de mantelzorger zo hoog mogelijk houden en hen mogelijkheden bieden. Er worden info momenten georganiseerd, dit is niet ziekte specifiek. Lotgenoten momenten om ervaringen te kunnen delen. Aanbieden van ‘adempauzes’ voor deze mantelzorgers.”(B2VL)

“Pour ce point de vue-là, l’aidant n’est pas entouré. On a besoin de plus qu’un support technique, on a besoin d’un soutien. Moi-même j’ai pris l’initiative d’organiser une association avec des proches de personnes souffrant d’insuffisance rénale, avec un psychologue. Parce qu’il n’y a pas de psychologue rattachée à l’équipe interdisciplinaire adulte, alors que c’est vraiment une nécessité. » (B1FR)

Working with volunteers to support and strengthen the informal caregivers

“Inzetten van vrijwilligers naast mantelzorgers, trainen van hulpverleners in een goed inschattingsvermogen, overschat de mantelzorger niet (vermoeidheid,…). Ze moeten getraind worden om nabij te zijn maar geen vrienden te worden, empatisch te zijn, en een signaalfunctie te hebben naar de hulpverlening toe.”(B2VL)

Weakness

Financial barrier for patient empowerment

“(Thuiszorg): Ja,het is alleen in de diabetes setting waar je betaald wordt om de patiënt onafhankelijk te maken, in alle andere settings word je betaald omde patiënt afhankelijk te houden.”(B2VL)

There is a lack of a generic patient educator, there is a lot of fragmented education, but with the rising co-morbidity there is a need for more generic education

“Er is nood aan een eerstelijns: generische educator. Het probleem nu is dat te vaak in vakjes geredeneerd wordt bij de zorgtrajecten, terwijl veel van deze mensen multi-morbiditeit hebben en voor verschillende zaken tegelijk moeten geholpen worden.”(B1VL)

Limited access to information to allow for patient empowerment

"Pour pouvoir faire des choix, le patient doit être informé quant aux possibilités qu’offre le système, outre une information sur la maladie. Le patient ne peut pas prendre des décisions s’il n’est pas réellement au centre du système (importance de l’empowerment). Il se trouve comme dans une forteresse dont il ne peut pas sortir et toutes ces volontés sont un peu vaines. Qui peut s’en charger ? Le MG (a-t-il assez de temps pour l’exprimer et faire cette information indispensable ?). Pour qu’il y ait autonomie, il faut qu’il y ait un choix possible."

Informal caregiver is isolated

“Toch bereiken we onvoldoende alle mantelzorgers, want dit blijft toch nog iets van thuis, mensen beseffen niet altijd dat ze mantelzorgers zijn, en dus op deze manier heel veel ondersteuning en informatie mislopen. “(B2VL)

“ Lors des réunions avec des aidants, on s’est rendu compte à quel point on est isolé chez soi lorsqu’on fait la dialyse à domicile (B1FR).

Legal framework for patient rights and protection is difficult to understand

“Mensen zijn niet vertrouwd met de rechten van de patiënt en de mantelzorger en wat de juiste rol van de mantelzorger kan zijn. Er is weinig openheid. Het is een zeer moeilijk wettelijk kader. We moeten ook opletten omde mantelzorger niet te sterk gaan regulieren, het is een valkuil om mantelzorgers in regels te laten lopen.” (B2VL)

Threat

Opportunities

4.3.7. Reform proposal 7: need to clarify the role of patient associations and to offer respite care possibilities for informal caregivers.

One cornerstone of any health system is the informal caregivers` role. Support and coaching of patients and care givers should be delivered at the local (i.e. practice) and regional (i.e. hospital, municipality, sickness fund) levels. A lack of caregiver support may cause psychological or health problems, as well as inappropriate hospital admissions/institutionalization for the patient. Respite care should be offered (in terms of adequate information, availability and (financial) accessibility) at the local and regional level. Illustrations are day care centres, respite at home.

- Informational care and support can be given at different levels: patient clubs, mutualities and also municipalities. This should target both patients an informal caregivers (opportunity)

  "Le rôle des mutuelles devrait être de fournir des informations aux aidants, de manière à ce que ces derniers aient un point de contact où s'adresser" (SGM1)

  "Quand on a réussi à mettre toute une structure en place, au dernier moment, l'aidant proche fait marche arrière, par manque d'encadrement" (SGM2)

- Informal caregivers complain that they are not often seen as an important partner (threat)

  "Mantelzorgers klagen er dikwijls over dat ze niet voldoende au sérieux worden genomen en de hulpverleners leggen het niet voldoende uit aan de mantelzorgers."(SGM1)

  "Au même titre que les associations de patients sont une aide pour l'échange d'expérience entre patients, les assocations d'aidants proches peuvent être une aide précieuse pour l'identification des besoins de cette population, notamment pour ce qui touche au répit" (SGM1)

- There are already financial incentives (in the Flemish region / community) for informal caregivers and patients. However, the current political climate is a threat to this (threat)
- The role of patient association is much more than the issue of respite care, it is firstly about helping each other, facilitating the sharing of experiences

  "Il y a également des groupes de parole qui existent, il y a des projets pilote à ce niveau-là" (SGM1)

  "De rol van de patiëntenorganisaties en mantelzorgers op zich moeten meer beklemtoond worden, is veel meer en op veel meer niveaus, is in ieder geval veel ruimer dan 'respite care'. We moeten de rol van de patiëntenorganisatie veel meer opnemen in het gehele plaatje."(SGM1)

Theme 4

Payment systems and influence on care

Strength	Weakness
Capitation system “Forfaitaire systemen geven veel meer flexibiliteit,forfait voor educatie, zo kun je dat flexibeler toepassen”(B1VL)	**Interaction between financial incentives and interdisciplinary collaboration – difficulties for some professionals (i.e. nurse) to provide care** ‘’Pour l’instant, il n’y a pas de financement prévu pour l’infirmière à domicile, lorsqu’elle ne fait pas partie d’une équipe multidisciplinaire hospitalière (pas dans la nomenclature). Ce qui se fait parfois, c’est une rétrocession du montant, par l’équipe hospitalière, à l’infirmière indépendante. Il n’existe pas d’équipe mobile qui pourrait organiser ce genre de choses en milieu rural.’’
Episode and or health problem – based payment system “Dans les trajets de soins, on voit une tendance à vouloir financer des épisodes, à vouloir dépasser le paiement à l’acte. Un financement au problème.’’ ‘’Un épisode de maladie, dans notre jargon de GP, ça a un début et une fin. Un financement au problème, ça peut être un problème chronique. C’est plutôt un mieux.’’	**Different type of payment system implemented by different primary care providers in the same area leading to administrative difficulties** "Passer au forfait? Dans notre système, où les deux systèmes cohabitent, je pense qu’aucun des deux ne marche. Dans notre quartier, il y a deux maisons médicales au forfait, nous on est à l’acte et on a tout le temps des problèmes, parce qu’ils sont soignés dans l'autre maison médicale, mais ils aiment bien notre kiné. Quand on a facturé et que la mutuelle nous envoie la facture, on se rend compte que le patient était au forfait dans l'autre maison médicale…" **Fee for services is a push for quantity and may lead to patient selection** ‘’Le problème du paiement à l’acte c’est qu’elles (infirmières) doivent voir 20 patients pour que ce soit rentable sur une matinée. Les indépendants choisissent alors leurs soins. Les infirmières consciencieuses vont passer beaucoup de temps, mais ce n’est pas vraiment payé. On dépend alors du coût de la conscience professionnelle des prestataires. Si ce sont des services intégrés, elles n’ont même pas le choix, elles doivent aller vite. Il faudrait que la personne soit déjà à moitié déshabillée devant son lavabo pour que l’infirmière accepte (et arrive) à le laver. Le paiement à l’acte incite les gens à produire beaucoup.’’ **Payment system disease oriented rather than patient oriented** ’’Avec un DMG par an, je ne vois pas dans le financement ce que ça change. Notre rémunération à l’acte est axée sur les maladies, pas sur les patients. Passer au forfait ? Dans notre système, où les deux systèmes cohabitent, je pense qu’aucun des deux ne marche. Dans notre quartier, il y a deux MM au forfait, nous on est à l’acte et on a tout le temps des problèmes, parce qu’ils sont soignés à côté, mais ils aiment bien notre kiné. Quand on a facturé et que la mutuelle nous envoie la facture, on se rend compte que le patient était au forfait dans une autre MM… Puis, le système nous forme à soigner des maladies, pas des patients. Ce n’est qu’en médecine générale qu’on se rend compte qu’il y a un peu plus que la maladie, il y l’habitat et les familles dont on doit tenir compte, mais ce n’est pas dans nos études. Toute la journée moi, je suis dans

le paradoxe."

''On a un système de sécurité sociale qui couvre pas mal de choses mais j'ai l'impression qu'il y a un fossé qui va se creuser par rapport aux inégalités sociales. Par rapport au soutien psychosocial où tant le médecin que d'autres pourraient consacrer du temps, mais existe-t-il une nomenclature pour la prise en charge des patients de longue durée ?''

Criteria are ill adapted to some situations

'' Pour les insuffisants rénaux, il y a des limites, qui sont absurdes. Les personnes qui sont dans une MRS ne peuvent pas être dans ces trajets de soins, parce que le remboursement est lié au fait que le MG puisse se rendre au domicile. Le fait que les trajets de soins soient liés à la notion de mobilité, lorsque la personne est en MRS, elle ne peut pas bénéficier du trajet de soins ''.

Control of the payment system

« Concernant les forfaits, les mutuelles font leur travail mais, très souvent les patients qui bénéficient du forfait sont visitées par l'infirmière de la mutuelle. Les patients trouvent ça très envahissant et dégradant. Très souvent, le forfait est rabaissé de manière inopportune. C'est à nous, GP à recontacter le médecin conseil, en disant, c'est quoi ces histoires, le patient ne sait plus marcher. « Oui, elle ne m'a pas ouvert ». Forcément, elle ne vous a pas ouvert, elle ne peut pas ouvrir la porte. Ce sont des situations invraisemblables. »

Social worker out of reimbursement system

'' Moi je n'ai pas la chance de travailler au forfait et je ne travaille pas dans un endroit où les AS sont accessibles. C'est quelque chose qui me manque cruellement. J'aurais envie d'avoir accès à l'AS comme j'ai accès à l'infirmière, au kiné. Qui fait ce travail-là chez nous ? On travaille à 4 plus un assistant, c'est l'accueil, qui essaie …,''

Threat	Opportunities

4.3.8. Reform proposal 8: moving froma individual provider and service-based to a team and patient-based payment system

At present, the larger share of payments in primary care are provider fees for specific services. This system provides de facto incentives for (over)production, and against delegation of tasks.

New payment systems based on capitation can help to improve the quality of chronic care, focusing more on the patient than on the service. A shift from a provider and service-based to a team and patient-based system requires a parallel shift in the organization of care around the patient.

- In general practice there is already 20 percent of lump sums, but not allocated to a team

  "Ce n'est pas encore un forfait par équipe"(SGM2)

- It already exist some examples of good practices of capitation in the current system

  "Ik denk dat we een excellent voorbeeld in art 107 hebben bij de psychiaters. Ze hebben dat zelf gevraagd" (SGM1)

  "Quand on parle de forfait, il y a dans la nomenclature des actes qui représentent un diagnostic d'équipe. Je pense au diagnostic de démence, tel qu'il a été conçu l'année dernière. C'est une équipe qui pose le diagnostic, et qui est financée. On pourrait imaginer, par extension, le faire vers d'autres organisations" (SGM2)

- But lump sums allocated to a team can create tensions between participants

  "La concertation en psychiatrie, ça a démarré avec les projets thérapeutiques, mais ce n'était pas spécialement facile à exploiter. Comment répartir entre les différents participants de l'équipe. Ça doit être bien défini, c'est très difficile" (SGM2)

  "Payer au niveau d'une équipe qui soit structurellement soudée, si c'est une équipe ad hoc, comme en consultation oncologique MD, risque de dispute sur le partage" (SGM2)

- However, these lump sums are not precisely targeted to tasks

  "We zijn vandaag, op 10 jaar tijd in de huisartsgeneeskunde van quasi nul naar 20% lump sums gekomen. De zwakte is dat ze niet altijd goed getarget zijn, niet altijd duidelijk gebonden aan wat de achterliggende opdrachten zijn"(SGM1)

- Actual payment system by fees generates professional stress

  "Les soins palliatifs ne sont pas payés à l'acte. C'est un rêve pour le MG de travailler avec ces infirmières, elles prennent le temps. Travailler avec des infirmières payées à l'acte, c'est insupportable, parce qu'elles sont tout le temps stressées. On pourrait le faire avec d'autres professionnels aussi"(SGM2)

  "Ik kan daar bijtreden. De forfaitairen system die we kennen in de thuisverpleging zijn forfaits per dat. Wij pleiten daarvoor om verder te forfaitariseren"(SGM2)

- Payment systems based on capitation present a risk of under-consumption of health care services

  "Le paiement à l'acte règle mal la problématique de la maladie chronique. Les MM au forfait, c'est une superbe organisation, mais on commence à voir poindre, puisque ce ne sont plus que des idéalistes qui y travaillent, une sous-consommation de soins dans certaines MM"(SGM2)

  "Il faut définir un certain nombre d'éléments objectifs de qualité à atteindre, ce qui est aussi un élément de réponse au problème de la sous-consommation"(SGM2)

- Professional bodies are often contrary to pay for quality
- There is possibility for patient selection when pay for quality would be introduced

  "Een ander gevaar is patiëntenselectie. Als je werkt naar een systeem van fee for service dan heb je graag zeer zieke patiënten, als je forfaitair werkt dan heb je ze misschien liever gezonder. We hebben wel heel wat ervaring binnen het revalidatiesysteem met forfaitaire betalingen. Voor sommige pathologieën is zo'n 'all in' de goede oplossing. Behalve dat we keer op keer de fout gemaakt hebben, en dat is ook wat P7 zegt: 'Wat doen jullie nu voor ons harde geld?'. We

hebben dus te weinig datacollectie. Die ook nog dikwijls niet verplicht is, die verloren gaat in de lades, waar mutualiteiten ook niet veel mee doen, … en we volgen de outcome niet op van wat er uiteindelijk met onze patiënten gebeurt. Hoe vaak ziet een aidscentrum voor onze 870 euro per jaar de mensen? Is dat 2x per jaar, of is dat 27x per jaar? We weten het niet. En men verwijst naar de jaarverslagen maar daar blijkt helemaal niks uit."(SGM1)

- There is a need for transparent quality assessment system for this (for instance we do not know what happens to the lump sums per patient in HIV reference centres)

  "Ik vind die link naar kwaliteit heel belangrijk. Maar dan echt kwaliteit gelinkt onder de vorm van inidicatoren, niet alleen kwaliteitsevaluatie maar het moet meetbaar zijn. Want eigenlijk er zou geen enkel financieringssysteem nog los mogen staan van evaluatie. Dat mis ik een beetje. Die link zou ik zeker proberen te integreren."(SGM1)

  "Il faut aller vers un système de paiement mixte, en partie à l'acte, en partie au forfait, mais aussi définir un certain nombre d'éléments objectifs de qualité à atteindre" (SGM2)

Important note: the document "Priorité aux maladies chroniques" suggested and evaluated many measures for the persons with a chronic disease (simplified administration, integration in the social/work environment, financial accessibility measures, reimbursements). This position paper does not come back to these important measures but adds a proposal in relation to new ways of payment.

Theme 5

Clinical information system(s), including E-data

Strength

Electronic file enables personalized care

"Ook het elektronisch dossier zorgt dat we de patiënt persoonlijk kunnen helpen, de verpleegkundige kan de patiënt heel gepersonaliseerd benaderen"(B1VL)

"Als cel in Brabant werken we met een e-zorg plan, een elektronisch dossier over de verschillende disciplines heen (ontwikkeld in Brabant, dus lokaal per provincie). Alle hulpverleners kunnen mits een toegangssleutel daar op in kijken, huisartsen, thuisverpleegkundigen, kinesisten, diëtisten,… Het wordt veel gebruikt, de webapplicatie en is sterk beveiligd. Het krijgt meer en meer bekendheid."

"Il serait bon, si on parle de dossier médical partagé, un dossier dans lequel il y aurait une place pour le social, pour le psychologique. Avec un accès sécurisé, du type de mycarenet, avec une carte d'identité. »

Electronic file enables smooth communication flow

"Elk uur van de dag kan er gekeken worden naar de stand van zaken van zorg met betrekking tot die ene patiënt. Zo kan er snel rond de tafel gezeten worden met de verschillende partners of kan er een nieuw stappenplan opgemaakt worden indien nodig. Er kan gemaild worden vanuit deze webapplicatie naar de verschillende zorgverleners, maar het is allemaal sterk beveiligd. Je moet sowieso aanloggen in het systeem. Dit e -zorg dossier of plan wordt aangeboden als extra aan de verschillende disciplines, dus het komt als extra op hun eigen systeem en ze kunnen kiezen om hiervoor in te teken en daarmee te werken. Voor sommigen is dit wel extra werk. Maar de woon zorg centrum en de ziekenhuizen zijn wel sterk vragende partij om hiervan gebruik te maken, om de stand van zaken in de thuiszorg te kunnen opvolgen."(B2VL)

'' La chance est que cette dame est connue dans le système de l'hôpital, je suis référée comme son GP. J'ai pu avoir l'information. L'hôpital a mis sur pied un système où je peux avoir l'information sur mes patients, moyennant leur accord. Cela me permet de voir une série de rapports que je n'ai jamais reçus ''

Weakness

A uniform care language is lacking

"Technische protocols zijn nog simpel, maar protocols in verband met omgangsvormen (zeker bij dementie of andere psychopathologieën) zijn zeker niet zo evident (…)Dingen formuleren aan familieleden, iedereen heeft z'n manier en dikwijls lijnrecht tegenoverelkaar.Hulpverleners spreken dikwijls een 'verschillende taal' wat de draagkracht van de familie en de patiënt echt wel verzwakt."

Communication between lines can be improved

"Communicatie verloopt via een schriftje (heen en weer schriftje is echt ondermaats), moeilijk om contact te houden, verpleegkundigen wisselen elkaar vaak af. Dus zeer moeilijk voor de huisarts om te weten met wie hij nu contact moest opnemen in verband met bijvoorbeeld wondzorg.(B2VL)

Communication across line can be improved

"De overdracht van informatie tussen de verschillende hulpverleners is echt ondermaats. De ernst van de anamnese in het ziekenhuis werd ons niet meegedeeld, zo is het ook het gevolg van de problematiek ontstaan, en zo heeft dit geleid tot verschillende ziekenhuisopnames die eigenlijk vermeden had kunnen worden."(B2VL)

''Optimaliser l'outil dossier médical du patient pour systématiser l'information médicamenteuse du patient à la sortie… Un exemple tout bête serait d'ajouter une case pour les médicaments arrêtés, pour les raisons suivantes… parce qu'on ne pense pas automatiquement à les informer, alors que cela peut poser des problèmes.'' (interview)

Telemonitoring

"Telemonitoring voor hartfalen loopt al enkele jaren, het blijkt wel niet dat er daardoor minder ziekenhuisopnames zijn, en het is financieel heel erg duur, het brengt dus niet echt op of het rendeert niet. Het vergt meer inzet van verschillende figuren. Het totale kostenplaatje brengt niet op."(B2VL)

"Oui pour tout ce que l'on appelle le télémonitoring à domicile, tous ces paramètres que le patient prend à domicile, on peut raccorder le patient à un système qui peut enregistrer directement ses paramètres, ce qui peut être important pour les insuffisants cardiaques en raison des indices précurseurs qui jouent un rôle important dans la prévention de grosses aggravation. Le

	télémonitoring mériterait d'être remboursé, mais en CIC, il n'y a rien de spécifique qui est subsidié… qu'il y ait une convention pour le suivi du patient en CIC… » (interview) **Lack of compatibility of information systems** "(thuiszorg) Wij hebben elektronisch patiëntendossiers maar die staan niet met elkaar in verbinding, dus de huisarts en thuiszorg kunnen niet elektronisch met elkaar communiceren over die patiënt."(B2VL) "Men zou wel moeten opteren om te vertrekken vanuit het medisch dossier van de huisarts zoals bij het 'vitalink project' (medicatie schema's).(apotheker) Inderdaad systeem naast systeem is niet gebruikersvriendelijk en werkt niet op lange termijn, systemen moeten op elkaar afgestemd worden."(B2VL) "Il y a tout le temps des nouvelles initiatives, peut-être les Wallons n'aiment-ils pas qu'on leur impose quelque chose mais, pour les TIC, c'est vraiment un magnifique exemple. J'apprends maintenant qu'il y a le réseau Santé Wallon, mais depuis quelques années on parle de la plateforme eHealth et, par ailleurs, beaucoup d'hôpitaux proposent au GP d'avoir accès au dossier patient. » (B1FR)
Threat **Unsafe data transport and privacy** "Privacy van zo'n dossier is ook een probleem"(B2VL) ''C'est très positif, mais ça posera beaucoup de questions éthiques. Parce que le patient n'aura peut-être pas envie que ses données soient partagées.'' ''Il y a des balises importantes à mettre''. **Fear for control (GPs)** ''Vanuit de huisartsen kijken we met argwaan naar kwaliteitscontrole, we zien dat wel een beetje als 'big brother'' **Ethical problems** « C'est très positif, mais ça posera beaucoup de questions éthiques. Parce que le patient n'aura peut-être pas envie que ses données soient partagées. « Il y a des balises importantes à mettre. » (B2FR)	**Opportunities** **Utilisation of algorithms to assess the quality/safety/adequacy of drug prescription** '' Ce n'est pas toujours tous les mois qu'il faudrait revoir la médication d'un patient, cela dépend un peu du traitement et de la maladie… Si on prend un patient diabétique, il est fréquent qu'il ait déjà trois ou quatre médicaments rien que pour son diabète, d'autres pour les pathologies associées, si on a pas demandé l'avis du patient sur les mesures à mettre en place… mais maintenant, il existe quand même beaucoup d'outils qui existent et qui sont à la disposition du patient…''

4.3.9. Reform proposal 9: shared medical file across lines and across disciplines

Patient medical records (at least the most important data such as care goals, lab data, medication, care plans) should be accessible for the health professionals involved at the different levels of care. This means an obligation to use compatible software systems and a well protected data exchange provision.

- Central files can be in a cloud which makes accessibility among different professional groups more easy (opportunity)

  "... dat kun je toch opvangen door een dataregister op te bouwen, dan moeten data, als die van algemeen belang zijn in een register kunnen opgeslagen worden."(SGM1)

  "Ik zou zeggen: dit zou een wettelijke verplichting moeten zijn die binnen een periode van maximum 5 jaar moet kunnen behaald worden." (SGM1) "Absoluut.""(SGM1) (observatienotitie: ook instemming van anderen)

- Such a system gathering the medical patient data is a threat for the professional secret

  " - Dat is misschien de Achilleshield van het systeem. Het is zeker niet een zwakte… - Angst voor Big Brother ? - Secret professionnel… - C'est souvent un alibi, mais il faut parfois faire confiance à la profession qui veut preserver un secret professionnel" (SGM2)

- Some stakeholder groups oppose the exchange and storage of information of patient data which are needed for working multi disciplinary, complementary and for quality issues

  "Il faut peut-être mieux cibler ce qui doit être accessible comme données, ce qui est important et pas simplement des infos qui ne sont pas intéressantes pour continuer les soins. Et je pense que autour de quelque chose comme ça, tout le monde peut se mettre d'accord. Y compris les patients. Parce que les patients aussi ont des résistances par rapport au problème qu'on touche à leur vie privée" (SGM1).

- RAI data (like in protocole 3) are an example of this (opportunity)

  "Avec le RAI, ils sont enthousiastes"(SGM1)

  "En omdat de RAI ook vanuit een geintegreerd concept denkt. Ik zou RAI durven als voorbeeld geven"(SGM1)

- Patients need access to open rights in the health system

  "Het zou voor de patiënten ook mogelijk moeten zijn om aan hun data te geraken om bij verschillende instanties rechten te openen. Parkeerkaarten, kindergeld, en zo."(SGM1)

4.3.10. Reform proposal 10: aggregated patient data at health facility and local system levels for quality management purpose

The availability of data on the care provided is a condition for quality improvement initiatives at the local (practice) and intermediate levels (local or regional). Conditions for implementation are the accurate registration at practice level, user-friendly and safe upload procedures, the appointment of a third party to collect the data anonymously, competences within the primary care team and/or the appointment of organisations with competencies to analyze the data and to provide feedback.

- At present we lack good quality aggregated data for management purposes
- We should much more focus on process indicators

  "In België hebben we een probleem dat daar nog voor komt en dat is dat we geen kijk hebben op de prevalentie, de incidentie van ziekten op zich, laat staan naar multi-morbiditeit. Dus procesindicatoren. Ik zou ook wat explicieter zijn, dat we ook behoefte hebben aan: hoe vaak komt nu een pathologie in ons land voor? En ook het aspect daarbij: instrumenten rond patiëntenregisters. Dat we moeten evolueren naar systemen dat zorgverstrekkers, of dat nu de huisarts is of iemand anders, dat zij echt inventarissen beginnen maken van: wie zijn mijn patiënten.

  "En ook hier weer vind ik een beetje te eng als men hier enkel neemt primary care, het gaat over de kwaliteitsbewaking in het circuit ook,

waarin natuurlijk primary care heel belangrijk is. Patiëntcentred over heel het circuit."(SGM1)

Theme 6
Accessibility of care

Strength

Easy hospitalisation is often a solution to "crisis situation at home"

"Binnen ons zorgsysteem wordt er wel heel snel een oplossing bedacht. Het is een evidentie om direct naar een ziekenhuis te kunnen gaan (dit in tegenstelling tot in Nederland, dit gaat niet zo snel). Kinderen kunnen het probleem van één van de ouders niet aan, en in ons systeem kan een ziekenhuisopname zeer snel plaatsvinden."(B2VL)

Emergency line within primary care practice

"Een huisartspraktijk waar er een assistente aan de telefoon zit-(ze hebben daar opleiding voor genoten), er is ook een spoedlijn binnen de huisartsenpraktijk : die activeert alle telefoontoestellen in het hele gebouw, - de huisarts kan onmiddellijk ter plaatse gaan,dit kan doordat er meerdere huisartsen zijn in de groepspraktijkaanwezig zijn: op die manier kan er meer ruimte en ondersteuning gegeven wordendan bijvoorbeeld een soloarts die met een volle wachtzaal zit"(B1VL)

Facilitator to improve access to care

"Un service d'accompagnement a été mis en place pour aider le patient à réaliser toutes les démarches. Pour nos patients (souffrant d'hépatite C), il est très rare qu'il y ait un aidant. Le MG n'est pas en mesure d'aider le patient à avoir accès au spécialiste hospitalier. Le patient va arriver, ne va pas se faire comprendre, va devoir sortir de l'hôpital (SDF, psychiatrique). L'idée d'avoir un accompagnateur psychosocial, qui puisse faire le relais entre le milieu hospitalier et les MM est important. Au début, on ne devait accompagner que les patients souffrant d'hépatite C et très vite, on est devenu des accompagnateurs de santé globale. "

Weakness

Waiting lists for nursing homes

"Er is een tekort aan chronische zorgopvangmogelijkheden - tekort aan woongelegenheid ,we krijgen regelmatig vragen van mensen die we zelfs niet op wachtlijst kunnen plaatsen – er ontbreekt maatschappelijk iets om die mensen op te vangen- er is echt een aanbod tekort.(B2VL)"

Financial Aspects have an impact on the access and delivery of care

''C'est l'aspect financier qui est dramatiquement important. On a parlé de précarité ; lorsqu'on vit une situation très précaire, on a accès à certaines aides. Mais le commun du petit VIPO qui constitue une grosse partie de la population qui a besoin de soins chroniques, n'ont pas accès financièrement à toutes ces aides. Ils ne sont pas assez pauvres pour pouvoir faire appel à l'aide et pas assez riches pour pouvoir le payer eux-mêmes. ''

Access to specialized care

''Par rapport à la question de l'accès aux soins spécialisés, en région bruxelloise, nous sommes confrontés à un gros problème de délais de rendez-vous, l'accessibilité des médecins spécialistes en termes de communication avec les autres professionnels, des médecins spécialistes hyperspécialisés. Ce que je sens, c'est des médecins spécialistes qui sortent de l'hôpital, lié au mode de financement du système hospitalier et qui se mettent en cabinet privé, avec un problème d'accès financier. Moi je sens beaucoup de médecins spécialistes qui s'installent à leur compte.''

The specificity of rural area in accessing i.e. nursing care

" L'accès aux soins (médecins spécialistes, le maintien d'une activité professionnelle en étant dialysé) n'est pas si simple en milieu rural (Luxembourg). Pour l'instant, il n'y a pas de financement prévu pour l'infirmière à domicile, lorsqu'elle ne fait pas partie d'une équipe multidisciplinaire hospitalière (pas dans la nomenclature). Ce qui se fait parfois, c'est une rétrocession du montant, par l'équipe hospitalière, à l'infirmière indépendante. Il n'existe pas d'équipe mobile qui pourrait organiser ce genre de choses en milieu rural.''

Access to coordination activities (i.e. done by case manager) for people outside capitation system

''Quand on n'a pas la chance d'être dans un forfait de MM et qu'on doit bénéficier de soins infirmiers à domicile, il y a une série de choses qui ne sont pas prises en charge. Avec nos patients chroniques, avec des troubles cognitifs, nos patients psychiatriques (sauf ceux qui sont schizophrènes bipolaires chroniques), … on est vraiment freinés parce que les coordinations vont demander 10€ pour le passage pour la préparation des médicaments. Ça ne paraît pas grand-chose, mais le problème est de convaincre ces personnes, qui ont déjà du mal à accepter qu'ils ont besoin d'aide, de devoir payer en plus, parce que l'INAMI ne l'a pas prévu. Une autre dame, qui avait besoin de collyre, ne pouvait pas le faire (Parkinson, malvoyant, …). Lorsqu'il n'y a pas de référent, c'est difficile. Certains disent, on peut le demander à un voisin, mais qui est le voisin qui va passer deux fois par jour à heure fixe, … La liste est longue. Ce sont souvent des problèmes de nomenclature .''

Different access criteria depending on the pathology

''Pour les insuffisants rénaux, il y a des limites, qui sont absurdes. Les personnes qui sont dans une MRS ne peuvent pas être dans ces trajets de soins, parce que le remboursement est lié au fait que le MG puisse se rendre au domicile. Le fait que les trajets de soins soient liés à la notion de mobilité, lorsque la personne est en MRS, elle ne peut pas bénéficier du trajet de soins.''

Access to « family aids»

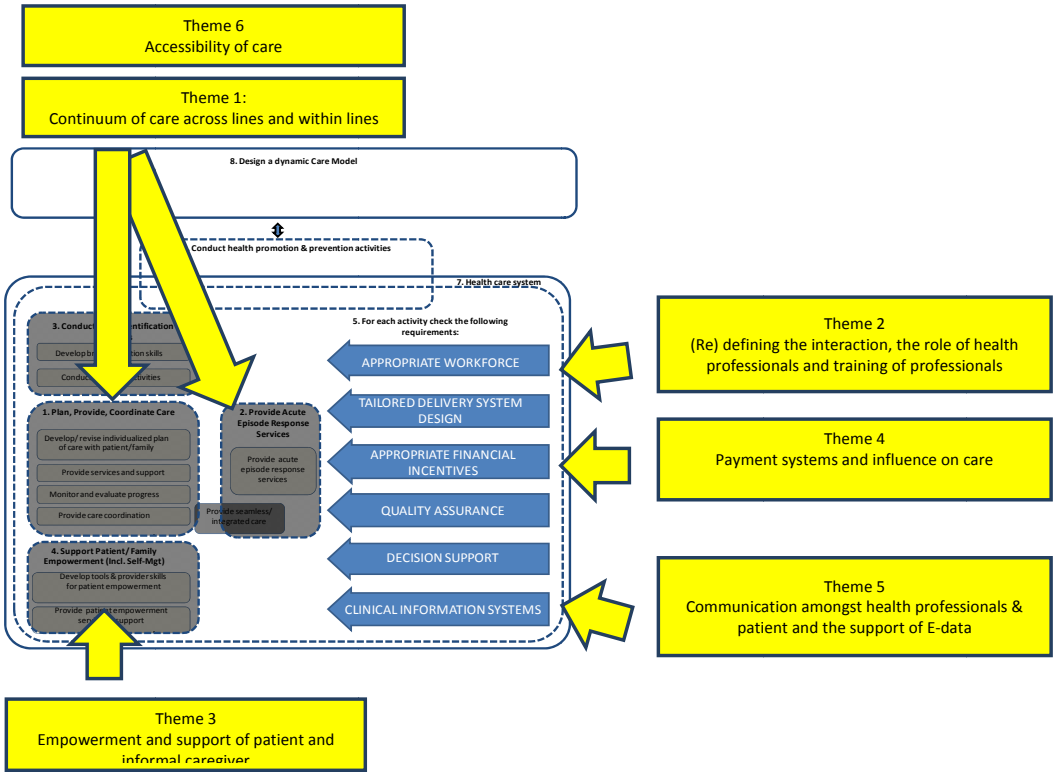
''Pour ce qui est de l'accessibilité aux soins, hormis les soins infirmiers qui peuvent être prescrits par la nomenclature, tout le reste est assez cher. Une aide familiale tous les matins, c'est tout de suite un coût énorme. Lorsqu'on est très précarisé, le coût est très bas. Mais dès qu'il s'agit d'autres personnes, avec un début de démence, on nous dit qu'il faudrait passer pour surveiller la prise de médicaments, il n'y a aucun remboursement prévu : les gouttes oculaires, les aérosols, la surveillance des paramètres : prendre le poids, …''

Contradiction between GP working in solo practice and importance of tasks requested to himorher

''Pour ce qui est de la réponse aigüe aux situations, on voit que le médecin est surchargé, il devient moins accessible, mais on lui donne toujours le rôle central et il n'est pas très bien au centre de l'information quand il y a une situation complexe.''

Threat	Opportunities

4.4. The adapted chronic Care Model and the relation with the themes from the brainstorming sessions



4.5. Belgian coordination structures and programmes

4.5.1. Belgian coordination structures

Structure initials	Size	Main function	Main characteristics	Financing or legislative framework
SISD (Services Intégrés de Soins à Domicile)	Geographically delimited according to 13 care zones: maximum one per care zone in Wallonia[f] — 2 in Brussels[g].	- Ensure a continuity of information and support throughout the care process, both at the level of the patient and of care providers; - Enhance the collaboration between S.I.S.D. members; _ Promote multidisciplinary concertation; - Develop collaboration between first and the second line of care delivery; - Support new initiatives.	Platforms for information, support, collaboration and exchange between care and services providers, at the level of the health zones.	ASBL Financed by the NIHDI (federal level) and recognized by the regional government
SEL (Samenwerkingsinitiatief EersteLijns gezondheidszorg)	Geographically delimited according 14 regional care zones Average 1/500.000	Coordination of healthcare + social care organizations social map of providers	Task definition by programme from Flemish Community 2009	Financed by the NIHDI Recognised by Flemish Community
GDT Geintegreerde Dienst Thuiszorg	Geographically delimited. Taken in Wallonia by SISD, in Flanders by SEL	-defines need of care within population -organise and finance MDO meetings around complex patients care	Integrated in appropriate organizations	ASBL Financed by the NIHDI
CCSSD: Centre de Coordination de Soins et de Services à Domicile (SIT)	Geographically delimited according to care zones: several CCSSD per care zone, each of them being affiliated to a particular "pillar" (catholic,	- Coordinate the provision of care and services around chronically ill patients, so that they are able to stay longer at home and with a better quality of life.	Structured by health insurance companies ("mutualités" in French) or independent structures. Formal recognition of coordination as a specific role (one person ensures that providers' interventions are coordinated around the patient). These structures are positioned at the second line. Their	ASBL Recognized and financed by the regional government.

f There are 13 health zones in Wallonia. Two S.I.S.D. (GLS and S.I.S.D. Luxembourg) cover two health zones, while 4 health zones are covered by no S.I.S.D. (see annex).

g One for the French-speaking community, one "bicommunautaire" (for both French-speaking and Dutch-speaking communities).

	socialist, liberal, neutral, pluralist…).		intervention is free for the patient.	
SIT: Samenwerkings Intiatief voor Thuisverzorging (CCSSD)	At beginning >25.000 inhabitants, Later taken over by SEL	-care coordinator -care plan per patient	Umbrella function of bringing organizations together and + care coordinating function for high care needing complex patients	Taken over in 2009 by SEL
SEL (Samenwerkingsinitiatief EersteLijns gezondheidszorg)	Geographically delimited at 14 regional care zones Average 1/500.000	Coordination of healthcare + social care organizations social map of providers Tasks from SIT + GDT	Task definition by programme from Flemish Community 2009	Recognised by Flemish Community
Local GP Organisations (Huisartsenkringen / Cercles de médecins generalistes)	Geographically delimited at local level: they cover the area of one or several municipalities.	They organize after-hours services and represent GPs at various levels.	Corporate group of GPs working in a given area : 90 huisartsenkringen in Flanders, 35 Cercles des Médecins Généralistes in Wallonia	ASBL Recognized and financed by the NIHDI
ASI	Locally based: they cover several thousands of people.	They provide comprehensive care.	In every “organized group practice”, one finds a multidisciplinary team with minimum two GPs, administrative staff, and other care providers (paramedical, social…). The structure must also collaborate with social workers and mental health professionals. It follows a perspective of integrated care.	Financed by Region Wallonne and CoCof

4.5.2. Belgian coordination programmes financed by the NIHDI

Structure initials	Size	Main function	Main characteristics	Financing or legislative framework
Care pathways	Delimited by the RLM/LMN (the relevant area corresponds to a subarea of the previously mentioned health zone). Recommended 75.000<<170.000	Integrate care for chronic disease across disciplines and levels of care (at home, in hospital, etc.)	Care trajectories are strongly intertwined with RLM/LMN. Their main characteristic is the central role the GP plays in their organization (RLM are initiated by CMG).	Financed by the NIHDI
Innovative forms of care (P3)	Variable	Allows the frail elderly to stay at home with a good quality of life.	P3 projects are diverse. They are usually initiated by SISD/GDT or MRS (nursing homes for the elderly). A strong characteristic of many P3 projects is the organization of a case management function.	Financed by the NIHDI
Palliative care platforms	Each platform covers a geographic area of 200.000 to 1.000.000 inhabitants. 15 in Flanders, 8 in Wallonia, 2 Brussel, 1 Germanophone,	Positioned as collaboration over three lines. Platforms provide support to care providers in terms of information, sensitization, and training of formal care providers as well as volunteers.	Each platform's staff is compound with one or several coordinator/s and a psychologist. Coordination tasks are determined by the needs of the field. As for the psychologists, their work consists in providing a space where first line care providers can find support. They also contribute to projects developed by the platform in response to local needs.	Financed by the NIHDI