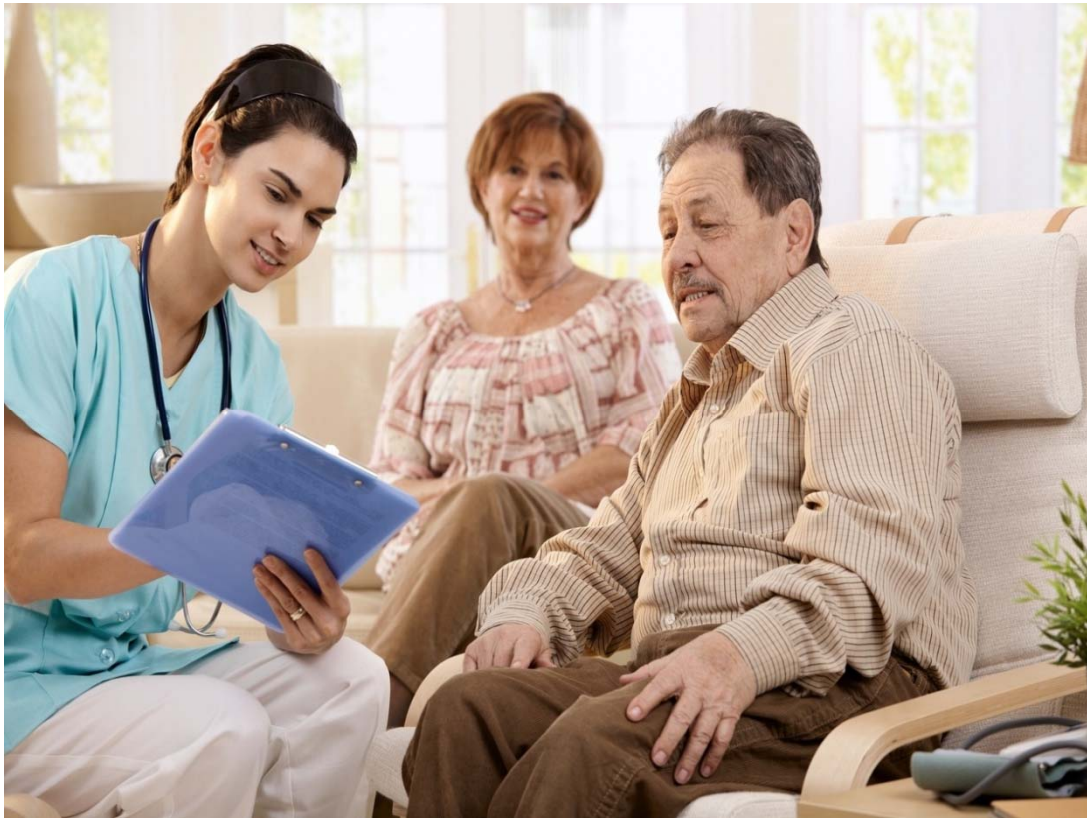
KCE REPORT 190A

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

ORGANISATIE VAN ZORG VOOR CHRONISCH ZIEKEN IN BELGIË: ONTWIKKELING VAN EEN POSITION PAPER





Het Federaal Kenniscentrum voor de Gezondheidszorg

Het Federaal Kenniscentrum voor de Gezondheidszorg is een parastatale, opgericht door de programmawet (1) van 24 december 2002 (artikelen 259 tot 281) die onder de bevoegdheid valt van de Minister van Volksgezondheid en Sociale Zaken. Het Centrum is belast met het realiseren van beleidsondersteunende studies binnen de sector van de gezondheidszorg en de ziekteverzekering.

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HEALTH SERVICES RESEARCH

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ORGANISATIE VAN ZORG VOOR CHRONISCH ZIEKEN IN BELGIË: ONTWIKKELING VAN EEN POSITION PAPER

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VOORWOORD

Toen de Minister van Volksgezondheid ons in juli 2011 opdroeg om samen met de FOD Volksgezondheid en het RIZIV een 'Position Paper' te schrijven rond de toekomstige zorg voor chronisch zieken, waren twee uitdagingen van meet af aan duidelijk. Ten eerste, dat het een ontzettend ambitieuze uitdaging was om de opdracht binnen de gestelde periode – minder dan 18 maanden – tot een goed einde te brengen. En, ten tweede, dat het ook een ontzettend boeiende uitdaging was: de zorg voor chronisch zieken is tenslotte een kernopdracht voor de gezondheidszorg, en dit zal in de toekomst nog meer het geval zijn dan nu.

Wij hebben vrij snel de keuze gemaakt voor een dubbele aanpak. Om te beginnen had het niet veel zin om van een onbeschreven blad te vertrekken. Over chronische zorg was reeds lang, op vele niveaus, ook op het hoogste internationale niveau, nagedacht. Wereldgezondheidsorganisatie, VN, EU boden ons een denkkader waarin een aantal fundamentele concepten werden aangereikt die absoluut pertinent zijn, ook voor ons land. Onze position paper schrijft zich dan ook resoluut in dit internationaal denkkader in.

Maar deze deductieve aanpak had ook zijn grenzen. De aangereikte concepten moesten aangepast worden aan de Belgische situatie. We moesten dus duidelijk ook vertrekken van een meer empirische, op feiten gebaseerde aanpak.

Voor een aantal innoverende concepten was er nood aan recent onderzoeksmateriaal: wij doorzochten de wetenschappelijke literatuur rond de thema's van "patient empowerment" en rond de nieuwe rollen in de eerste lijn. Ook de resultaten van vorige KCE rapporten in verband met de zorg voor chronische patiënten werden meegenomen. Daarnaast was het ook zaak om alle stellingen van deze Position Paper grondig te toetsen aan de Belgische realiteit. Er werd dan ook zwaar ingezet op het betrekken van de stakeholders: mensen van het 'terrein', maar ook stakeholders op beleidsniveau. Een speciale plaats hierin bekleden de stuurgroep van dit project en het Wetenschappelijk en het Raadgevend Comité van het Observatorium voor Chronische Ziekten. Wij danken hun voor hun vele constructieve commentaren.

Wij willen ook onze oprechte dank betuigen aan de verschillende onderzoeksequipes die mee de wetenschappelijke basis van deze position paper hebben gelegd : Abacus International, de universitaire equipes van Tilburg, Antwerpen et de Université Catholique de Louvain. Ook onze collega's van het RIZIV en van de FOD Volksgezondheid hebben een waardevolle bijdrage geleverd bij het beschrijven van de in ons land reeds bestaande initiatieven.

Vandaag zijn we blij om u deze Position Paper aan te bieden, de vrucht van een intense samenwerking . Niet alle stakeholders van het gezondheidszorgsysteem zullen er zich onverdeeld in terugvinden – daarvoor zijn de voorgestelde hervormingen te fundamenteel gebleken – maar wij hopen minstens dat de centrale stakeholders, de chronisch zieken met hun mantelzorgers, hier op termijn de vruchten zullen van plukken. Wij durven zelfs hopen dat onze gezondheidszorg in haar geheel door deze impulsen verder kan groeien naar meer kwaliteit en effectiviteit.

Raf Mertens

Algemeen directeur

SAMENVATTING

CHRONISCHE ZIEKTEN: EEN TOENEMEND FENOMEEN

Chronische ziekten nemen een steeds prominentere plaats in onze maatschappij in. De stijging van de levensverwachting gaat hand in hand met een stijging van de prevalentie van chronische ziekten. Deze worden door de WGO gedefinieerd als "langdurige aandoeningen die over het algemeen langzaam evolueren". In Europa zijn cardiovasculaire aandoeningen de eerste doodsoorzaak (33%), gevolgd door kanker (27%). In België zegt meer dan een vierde van de bevolking (27,2%) dat hij/zij aan een chronische aandoening lijdt: rugpijn (17,7%), allergieën (13%), gewrichtsaandoeningen (12,7%), hypertensie (12,7%), nekpijn (9,4%), migraine (8,1%) en ademhalingsaandoeningen (7,9%) voeren de lijst aan. Bovendien verklaart een vierde van de Belgische bevolking dat ze lijdt aan een geestelijk gezondheidsprobleem.

Jammer genoeg komt een chronische aandoening zelden geïsoleerd voor. Personen die eraan lijden hebben vaak meerdere problemen: 50 à 70% van personen boven 70 jaar lijdt aan minstens twee aandoeningen.

KAN ONZE GEZONDHEIDSZORG DEZE UITDAGING AAN?

Tijdens de laatste decennia was in Europa de ontwikkeling van de gezondheidszorg vooral gericht op de genezing van acute ziekten, vooral in een ziekenhuisomgeving. Een kentering naar een zorgverlening die de persoon, die aan de chronische aandoening(en) lijdt, centraal stelt is noodzakelijk. Indien mogelijk, vindt deze zorgverlening plaats in de levensomgeving van de chronisch zieke.

In 2008 werd in ons land een eerste stap in die richting gezet met de publicatie van een nationaal programma “Prioriteit aan de chronisch zieken!". Dit programma voert talrijke maatregelen in die de positie van de chronisch zieken in het zorgsysteem versterken, de financiële toegankelijkheid verbeteren en het ter beschikking stellen van informatie voor de patiënt en zijn/haar mantelzorgers vergemakkelijken. Een volgende stap werd bereikt met de publicatie van deze "position paper" die voornamelijk gericht is op de hervormingen met betrekking tot de organisatie van de zorg.

Deze "position paper" behandelt niet de aspecten van gezondheidspromotie en evenmin de maatregelen binnen primaire gezondheidspreventie in de strijd tegen risicofactoren (roken, voeding, lichaamsbeweging). Hiervoor is een benadering nodig die veel meer omvat dan alleen maar de gezondheidszorg. Het heeft ook raakvlakken met andere domeinen, zoals werkgelegenheid of milieu. Bovendien is het de ambitie van deze "position paper" om concrete acties voor te stellen aan de specifieke actoren van het domein van de gezondheidszorg.

DEZE "POSITION PAPER" IS GEÏNSPIREERD OP VERSCHILLENDE BRONNEN

Dit document werd opgesteld op basis van talrijke bronnen. Enerzijds analyseerden de auteurs de internationale literatuur:

- de relevante publicaties van de WGO, de Europese Commissie, de Verenigde Naties over het onderwerp;
- de nationale plannen voor "chronische ziekten" van andere landen/regio's die zich in dit domein in de voorhoede bevinden: Denemarken, Nederland, Quebec, Pennsylvanië;
- de wetenschappelijke studies met betrekking tot (1) de beste technieken om de patiënt te helpen zich zo autonoom mogelijk te verzorgen ("empowerment") en (2) de nieuwe taken en functies van de zorgverleners.

Ook talrijke Belgische bronnen werden geconsulteerd. Dit omvatte: een analyse van de initiatieven van het RIZIV en de Federale Overheidsdienst (FOD) Volksgezondheid, een analyse van eerdere KCE-rapporten en een sterkte-zwakte analyse met betrekking tot de huidige aanpak van chronische aandoeningen.

Bij het opstellen van deze ‘position paper’, die gerealiseerd werd in nauwe samenwerking met het RIZIV en de FOD Volksgezondheid, werd veel overleg gepleegd met talrijke actoren uit het werkveld en met vertegenwoordigers van de organisaties die betrokken zijn bij de gezondheidszorg (of zorgorganisatie) voor chronisch zieken: zorgverleners, ziekenhuizen, overheden, verzekeringsinstellingen, e-Health.

WAT ZIJN DE BEHOEFTEN VAN CHRONISCH ZIEKEN?

De initiatieven die tot doel hebben de situatie van chronisch zieken te verbeteren, hanteren meestal een benadering die gericht is op één pathologie. Dit wordt duidelijk geïllustreerd door sommige nationale plannen ("het diabetesplan", "het dementieplan"), evenals door de criteria waaraan moet worden beantwoord om van bepaalde voordelen of diensten te kunnen genieten (bijvoorbeeld de lijst van aandoeningen die toegang heeft tot kinesitherapie). Deze pathologiegerichte benadering heeft twee grote nadelen. Ten eerste worden sommige patiënten die vergelijkbare behoeften hebben op het vlak van zorg uitgesloten omwille van het etiket dat op hun ziekte wordt geplakt (zoals tot voor kort het geval was voor de zeldzame ziekten). Ten tweede, komen patiënten die meer dan één pathologie hebben (Bijv. een diabetespatiënt die aan schizofrenie lijdt) in aanmerking voor parallelle zorgcircuits die zelden met elkaar verbonden zijn.

Deze "position paper" stelt dus een benadering voor die gericht is op de persoon die (continu of met tussenpozen) behoefte heeft aan specifieke zorgen die verband houden met zijn/haar chronische aandoening. Deze behoeften zijn van medische aard: pijncontrole, voorkomen van complicaties.... Ze zijn ook van psychologische aard (nood aan informatie, emotionele steun), van sociale aard (hulp in het dagelijks leven, integratie in de maatschappij), van spirituele aard (zoektocht naar zingeving) en hebben ook betrekking op de organisatie van de zorgverlening (vooral de toegankelijkheid van de diensten, de coördinatie tussen zorgniveaus).

IN EEN IDEALE WERELD...

Dit onderzoek liet toe om een beeld te schetsen van een conceptueel - geïdealiseerd - systeem dat de kenmerken beschrijft van een optimale aanpak van de patiënt met chronische aandoeningen: "het gezondheidszorgsysteem dat zich richt op chronische zorg, biedt personen, die lijden aan chronische aandoeningen en die hulp nodig hebben gedurende enkele (tientallen) jaren, een gecoördineerd geheel van diensten aan die beantwoorden aan volgende kenmerken: gepersonaliseerde zorgverlening, gebaseerd op de behoeften van de patiënt, doelgericht, gepland en professioneel ondersteund. Ze omvatten zowel de routinezorg voor chronische aandoeningen als de zorg voor acute episoden. Deze dienstverlening gebeurt op een kwaliteitsvolle, evidence-based, efficiënte, duurzame, toegankelijke, cultureel competente en “patiënt empowering” manier in de minst complexe omgeving die klinisch aanvaardbaar is. Het doel is de levenskwaliteit van de begunstigden te verbeteren en hen te helpen beter te functioneren, zowel thuis, op school/werk, in de gemeenschap.”

HOE KUNNEN WE DIT TOEPASSEN OP ONS GEZONDHEIDSZORGSYSTEEM?

Deze "position paper" stelt een twintigtal aanbevelingen voor die onderverdeeld zijn in concrete actiepunten. Ze bestrijken de belangrijkste domeinen die betrekking hebben op de aanpak van chronische aandoeningen: zorgen in een eerstelijnszorg/thuiszorg omgeving, in een gespecialiseerd omgeving, opsporing van de aandoeningen en hun complicaties, ondersteuning van de patiënt en van zijn omgeving, invoering van een dynamisch evoluerend model voor zorgorganisatie.

Het uitgangspunt: kwaliteitsvolle routinezorg in een ambulante omgeving organiseren

Uitwerken van een plan van individuele zorg, gericht op de patiënt

De persoon die aan een chronische aandoening lijdt heeft in de eerste plaats een levensproject. Op dit project moet een zorgplan worden geënt, uitgewerkt in samenspraak met de behandelende arts en andere partijen betrokken in de eerstelijnszorg. Het verlenen van chronische zorg moet in teamverband gebeuren en gericht zijn op de patiënt. Werken in een multidisciplinair team dat een gemeenschappelijk zorgplan deelt is noodzakelijk omwille van de complexiteit en de aard van chronisch zorgverlening. Een bijkomend argument voor teamwerking is de steeds sterker dalende beschikbaarheid van huisartsen. Dit houdt ook in dat de zorgverleners toegang moeten hebben tot het elektronisch medisch dossier dat een specifieke module "chronische zorg" bevat met alle onmisbare informatie (zorgplan en opvolgingsplan, evaluatie van de behoeften van de patiënt op basis van gestandaardiseerde instrumenten). Het respecteren van de privacy en van de selectieve toegangsrechten (met inbegrip van die van de patiënt) zijn problemen die in deze context van het allergrootste belang zijn.

Deze manier van werken (multidisciplinair, gericht op de behoeften van de patiënt) zal door heel wat zorgverleners als revolutionair worden beschouwd omdat hun opleiding hen daarvoor niet (of slechts weinig) heeft op voorbereid. Opleidingsmodules gericht op multidisciplinair teamwerk rond de patiënt moeten dus worden voorzien in de basisopleiding en de permanente vorming van het (para-)medisch personeel.

Zorgverlening in een ambulante omgeving

- "Zorgkwaliteit": een synoniem van "gekwalificeerd personeel".

Dit houdt, ondermeer, in dat het beroep van huisarts (opnieuw) gewaardeerd wordt. Een opgewaardeerde academische opleiding en aantrekkelijke arbeidsomstandigheden zijn hierbij de twee sleutelfactoren. De aantrekkelijkheid van het beroep van verpleegkundige, en vooral dat van de verpleegkundige die werkzaam is binnen de eerstelijnszorg, is een ander belangrijk werkterrein om kwaliteitsvolle thuiszorg te garanderen. Gezien de evolutie van het aantal huisartsen wordt een scenario waarin huisartsen en andere professionele zorgverleners steeds meer elkaars taken delen, al maar waarschijnlijker. Ook verpleegkundigen zullen in toenemende mate bepaalde taken moeten delegeren naar minder gekwalificeerd personeel. Deze waterval van taakdelegatie vereist toezicht door de personen die sommige van hun taken delegeren, evenals een kwaliteitscontrole van de zorgen die *in fine* aan de patiënt worden verstrekt. Een logisch gevolg hiervan is dat een specifieke opleiding voor verpleegkundigen (bijv. "advanced practice nurse") moeten worden uitgewerkt om gespecialiseerde thuiszorg te kunnen verstrekken aan patiënten met chronische aandoeningen.

- In de omgeving die het best aangepast is aan de situatie van de patiënt

De meeste personen koesteren heel sterk de wens om thuis te kunnen blijven wonen, ook wanneer ze chronische behoeften hebben (medisch, sociaal of andere). Wanneer de gezondheidstoestand verergert, moet de aanpak dus ook tot doel hebben de leefomgeving in stand te houden: financiële steun, respijtstructuren, aanpassing van de woongelegenheid. De omgeving moet eveneens kunnen genieten van psychologische en materiële steun om het thuis houden van het familielid te vergemakkelijken. Wanneer zijn/haar gezondheidstoestand het niet langer toelaat om thuis te blijven (erg verzwakte personen of personen die lijden aan een ernstige geestesziekte) moeten alternatieve structuren een andere oplossing bieden voor hospitalisatie. Tevens kunnen innoverende oplossingen (zoals intergenerationeel wonen) aan oudere personen toelaten om zo lang mogelijk in hun omgeving te blijven

Zorgkwaliteit bevorderen en meten

De evolutie van de chronische zorgorganisatie moet samengaan met het invoeren van een systeem dat de kwaliteit van de verstrekte zorgen evalueert. Een eerste fase is de definitie van de doelstellingen van dit evaluatiesysteem en de mogelijke gevolgen voor de zorgverleners. In andere landen kunnen de resultaten van de kwaliteitsmeting bijvoorbeeld financiële gevolgen hebben of worden de resultaten publiek toegankelijk gemaakt. Terugkoppeling naar de betrokken professionele zorgverleners is een kernfactor die de performantie van dit systeem garandeert.

De daaropvolgende fasen omvatten de selectie van geschikte kwaliteitsindicatoren en het invoeren van een systeem voor gegevensregistratie dat, waar mogelijk, gebruik zal maken van de bestaande databanken. Deze systemen moeten de noodzakelijke garanties voor confidentialiteit en ethische praktijkvoering waarborgen.

Coördineren van zorg

Voor patiënten die meervoudige en complexe behoeften hebben, is coördinatie noodzakelijk om gezamenlijke acties tussen de verschillende zorgverleners te verzekeren. Huisartsen namen deze taak sinds lange tijd op zich. Het is echter niet zeker dat ze deze rol in alle situaties zullen kunnen blijven uitvoeren. De situaties worden steeds complexer, met interacties tussen medische en sociale probleemgebieden. De interventie (gericht of continu) van een derde persoon uit het zorgteam, de "casemanager" genoemd, zou kunnen helpen bij het optimaliseren van het geheel van de interventies, in samenspraak met de patiënt en zijn/haar zorgteam.

Coördinerende structuren zijn ook onmisbaar op hoger niveau, om de zorgverleners en de "casemanagers" lokale netwerken te bieden waarop ze een beroep kunnen doen om op een zo geïntegreerd mogelijke manier medische en sociale diensten aan te bieden.

De eerstelijnszorg en de gespecialiseerde zorg met elkaar verbinden

Ziekenhuisdiensten en gespecialiseerde artsen spelen ook een belangrijke rol. Zij volgen de bijzonder complexe situaties op, komen tussenbeide bij het op punt stellen van de behandeling of in het geval van exacerbaties of complicaties en helpen het eerstelijnszorgteam in geval van vragen met betrekking tot de pathologie / behandeling. De doeltreffendheid van hun actie wordt bepaald door het delen van informatie met de eerstelijnszorgverstrekkers.

De overgang van de patiënt tussen de zorgniveaus is een erg delicaat moment. Het vormt een mogelijke bron van complicaties die bijvoorbeeld samenhangen met nieuwe medicatieschema's of onwetendheid over de voorgeschiedenis van de patiënt. Bepaalde interventies kunnen deze moeilijkheden helpen vermijden. Het delen van elementen uit het hierboven vermelde elektronisch dossier en de doelgerichte actie van een persoon die zorgt voor goede afspraken met de thuisverpleging ("discharge manager") zijn waarborgen voor een succesvolle overstap tussen ziekenhuis en thuisomgeving.

Vroegtijdig opsporen van de chronische ziekte en zijn complicaties

Het opsporen van de eerste symptomen van de ziekte en het anticiperen op de complicaties zijn essentiële taken die afhangen van de opleiding en de competentie van de eerstelijnszorgverleners. Hierbij moet er echter op worden gelet dat men niet verzeild raakt in een vaak voorkomende situatie, nl. overdiagnosticering met aanvullende onderzoeken en overbodige behandelingen die de patiënt kunnen schaden.

De patiënt en zijn omgeving steun bieden

In de eerste paragrafen werd de centrale rol van de patiënt en van de mantelzorgers bij de zorgorganisatie besproken. Om deze taak optimaal te kunnen uitvoeren, hebben de patiënt en zijn/haar verwanten nood aan relevante informatie met betrekking tot de ziekte, de verschillende therapeutische opties, en de beschikbare steun (materieel of financieel). Wanneer deze informatie op het juiste moment wordt gegeven, kunnen de patiënt en zijn mantelzorgers ten volle deelnemen aan beslissingen met betrekking tot de zorgdoelstellingen, het invoeren ervan en aan de dagelijkse praktijkvoering. Deze "empowerment" van de patiënt vereist echter dat de zorgverleners worden opgeleid en gesensibiliseerd zodat ze het belang inzien van een partnerschap met de patiënt en zijn/haar omgeving.

Invoeren en opvolgen van dit dynamisch zorgmodel

Het voorgestelde zorgmodel, gericht op patiënten met chronische behoeften, vereist opvolging waarbij rekening wordt gehouden met de voortdurende evolutie van het zorgsysteem, met de maatschappelijke waarden waarin het verankerd is, met de variaties in de behoeften van de patiënten, met de budgettaire middelen en met de evolutie van de wetenschappelijke kennis. Dit laatste vereist de ontwikkeling en het onderhoud van "knowhow" op macroniveau. In het bijzonder dienen multidisciplinaire praktijkrichtlijnen ontwikkeld te worden die rekening houden met de complexiteit en het gelijktijdig voorkomen van chronische ziekten. Het nieuwe Observatorium voor chronische ziekten speelt een grote rol bij het invoeren en opvolgen van dit dynamisch zorgmodel.

Coördinatie op het niveau van de bestaande structuren

Het invoeren of rationaliseren van coördinerende structuren en uitwisselingsplatformen tussen professionele zorgverleners op "meso"niveau (klein stedelijk niveau) zal toelaten om de aangeboden diensten te harmoniseren, de uitwisseling tussen zorgverleners te bevorderen en de bestaande sociale en medische structuren te coördineren. De huidige platformen voor palliatieve zorg zijn hiervan een voorbeeld. Deze structuren moeten verschillende terreinen bestrijken om nodeloze herhaling van diensten te voorkomen. Ze zullen zelf ook weer overkoepeld moeten worden op meso-superieur niveau (grootstedelijk niveau of niveau van de provincies). Op macroniveau zal een coördinatiecel de coherentie tussen alle initiatieven dienen te verzekeren. Het nieuwe "Instituut dat tot taak krijgt overlegde antwoorden te geven op de grote uitdagingen inzake gezondheidszorg" zou een rol in dit opzicht kunnen spelen.

Toegankelijkheid en billijkheid als doelwit

De toegankelijkheid van de zorg is één van de troeven van de Belgische gezondheidszorg en het recente programma 'Prioriteit aan de chronisch zieken! " legde hierop de nadruk. Binnen sommige domeinen moeten nog inspanningen worden geleverd: wachtlijsten voor bepaalde instellingen, respijtzorgen, geografische toegankelijkheid of toegankelijkheid voor bepaalde pathologieën zoals bijvoorbeeld voor hartrevalidatie.

Wie toegankelijkheid zegt, zegt ook beschikbaarheid van zorgverleners. Toezicht houden op het beschikbare personeel is onontbeerlijk voor het oriënteren van het beleid met betrekking tot de aantrekkelijkheid en de planning van de (para-)medische beroepen.

Een betalingssysteem dat zorgkwaliteit bevordert

Bepaalde kwaliteitsaspecten zijn moeilijk te verenigen met een systeem dat voornamelijk gebaseerd is op de betaling per prestatie. Voor het delegeren en delen van taken, multidisciplinaire samenwerking en coördinatie zijn andere stimuli nodig. Deze "position paper" stelt pistes voor die financiering en zorgkwaliteit met elkaar verbinden, vooral door het combineren van verschillende betalingssystemen voor chronisch zieken die complexe zorg nodig hebben. Bovendien is het belonen van zorgkwaliteit een optie die ook ernstig moet worden overwogen. Men moet echter wel vermijden om het financieringssysteem nog complexer te maken dan het nu al is.

Dit plan omzetten in concrete acties en de evolutie ervan opvolgen

In deze "position paper" worden talrijke pistes voorgesteld. Deze pistes omzetten in concrete acties vereist overleg met de belangrijkste betrokken actoren, in de eerste plaats met de vertegenwoordigers van patiënten en zorgverleners. De evaluatie en de opvolging van de initiatieven die op het terrein worden ingevoerd, zullen afhangen van de bepaling van de relevante indicatoren. Het Observatorium voor chronische ziekten en andere partners (RIZIV, FOD, patiëntenverenigingen en ziekenfondsen om er slechts enkele te noemen) moeten het voortouw nemen om het werk dat werd uitgevoerd te meten en vast te stellen.

TABLE OF CONTENTS

LIST OF FIGURES **7**
LIST OF TABLES **7**
LIST OF ABBREVIATIONS **8**

■ **SCIENTIFIC REPORT** **11**
1. THE CHALLENGE OF CHRONIC CARE **11**
1.1. CHRONIC CARE: A GROWING BURDEN FOR THE HEALTH CARE SYSTEMS 11
1.2. OBJECTIVE: DEVELOPMENT OF A POSITION PAPER FOR CHRONIC CARE IN BELGIUM 11
1.3. SCOPE: FROM “CHRONIC DISEASE” TO “CHRONIC CARE BASED ON THE PATIENT’S NEEDS” 13
1.3.1. Chronic disease: official definitions based on a listing of diseases 13
1.3.2. The patient with “chronic disease”: frequently in the plural 13
1.3.3. Chronic care as an answer to the patient’s needs 13
1.3.4. on care (versus primary prevention and “health in all policies”) 15
1.4. EPIDEMIOLOGY AND COSTS OF CHRONIC DISEASES 15
1.4.1. Epidemiology 15
1.4.2. Costs 16
2. HIGHLIGHTS FROM THE INTERNATIONAL PERSPECTIVE **18**
2.1. VIEWPOINTS OF THE EUROPEAN UNION, THE UNITED NATIONS AND THE WORLD HEALTH ORGANIZATION 18
2.1.1. Data sources 18
2.1.2. International frameworks: calls for integrated care 18
2.1.3. Shift towards integrated care: advocacy for organizational changes 21
2.1.4. Role of primary care: hub of coordination 22
2.1.5. Summary and conclusions 24
2.2. CHRONIC CARE MODEL 26
2.2.1. Elements of the chronic care model 26
2.2.2. Evidence underlying the chronic care model 27

2.3. HIGHLIGHTS FROM 4 COUNTRIES ... 28
2.3.1. Methods ... 28
2.3.2. Stakeholder collaboration: shared vision and leadership ... 29
2.3.3. Information technologies and performance measurement ... 31
2.3.4. Engaging consumers ... 31
2.3.5. Improving Health Care delivery: translation of the national/regional strategy at local level ... 32
2.3.6. Aligning finance /insurance: incentives ... 32
2.3.7. Outcomes ... 33
2.3.8. Barriers in redesigning chronic care management ... 33
2.3.9. Key points: lessons learned ... 33
3. REASONING FRAMEWORK FOR A HEALTH SYSTEM ORIENTED TOWARDS CHRONIC CARE ... 34
3.1. OBJECTIVE OF THIS CHAPTER ... 34
3.2. DEVELOPMENT OF A VISION FOR A REFORM OF CHRONIC CARE IN BELGIUM ... 35
3.2.1. General shape of the vision or root definition ... 35
3.2.2. Core purpose ... 36
3.2.3. Additional qualifications ... 36
3.2.4. Expanded vision/root definition ... 38
3.3. CONCEPTUAL MODEL: FUNCTIONAL ACTIVITIES REQUIRED FOR A CHRONIC CARE SYSTEM ... 39
3.3.1. Plan, provide and co-ordinate routine care ... 40
3.3.2. Provide acute episode response and specialized services ... 41
3.3.3. Conduct early identification ... 42
3.3.4. Support patient/informal caregiver empowerment (including self-management) ... 43
3.3.5. Conduct health promotion and prevention activities ... 44
3.3.6. Implement and follow-up a dynamic care model ... 45
3.3.7. Six requirements for each activity ... 45
3.4. CONCLUDING REMARKS ... 47
4. CHRONIC CARE INITIATIVES IN BELGIUM ... 48
4.1. OBJECTIVE OF THIS CHAPTER ... 48
4.2. METHODS ... 48

4.2.1. Data sources 48
4.2.2. Data collection 48
4.2.3. Inclusion and exclusion criteria 48
4.3. NATIONAL PLAN: “PRIORITY TO CHRONIC PATIENTS!” 49
4.4. DESCRIPTION OF THE INITIATIVES FROM THE FEDERAL PUBLIC SERVICE HEALTH, FOOD CHAIN SAFETY AND ENVIRONMENT AND FROM THE SICKNESS FUNDS 49
4.4.1. Inventory of initiatives that target patients with a chronic illness 49
4.4.2. Discussion: initiatives from the Federal Public Service Health, Food Chain Safety and environment and from the Sickness Funds 55
4.5. DESCRIPTION OF INITIATIVES FROM THE NATIONAL INSTITUTE FOR HEALTH AND DISABILITY INSURANCE 56
4.5.1. Health care system level 56
4.5.2. Plan, provide and coordinate care in the primary care setting 57
4.5.3. Self-empowerment of the patients 63
4.6. KEY POINTS: CHRONIC CARE INITIATIVES IN BELGIUM 64
5. RECOMMENDATIONS IN RELATION TO CHRONIC CARE: ANALYSIS OF KCE REPORTS 65
5.1. OBJECTIVE OF THIS CHAPTER 65
5.2. METHODS 65
5.3. TAILORED DELIVERY SYSTEM DESIGN 65
5.3.1. Strengthening primary care: illustration of type 2 diabetes care 66
5.3.2. Organizational models that streamline transition between primary, secondary and tertiary care 67
5.3.3. Organization of services for the older persons 67
5.3.4. Organization of Palliative care services 69
5.3.5. Organization of Mental Health Care Services 70
5.3.6. Organization of rehabilitation services 70
5.4. APPROPRIATE WORKFORCE 71
5.4.1. Physician workforce planning 71
5.4.2. Attractiveness, recruitment and retention of the GP profession 71
5.4.3. Differentiated Nursing Practice 72

5.4.4. The right function for the right health professional: physiotherapists and pharmacists 72
5.4.5. Important role for the occupational physician and the advisory physician from the sickness funds 73
5.4.6. Role for informal caregivers 73
5.4.7. Curricula and continuous education based on needs 73
5.5. APPROPRIATE FINANCING 74
5.5.1. Financial accessibility 74
5.5.2. Financing system for home care nursing 75
5.5.3. Comparison of two financing systems for primary health care 76
5.5.4. Financial initiatives for quality 76
5.6. QUALITY PROCESSES 77
5.7. DECISION SUPPORT 78
5.7.1. Seamless care with regard to medications 79
5.7.2. Self-empowerment in chronic dialysis 79
5.8. CLINICAL INFORMATION SYSTEMS 79
5.9. KEY POINTS: EVIDENCE AND RECOMMENDATIONS FROM KCE REPORTS 80
6. FOCUS ON PATIENT EMPOWERMENT AND NEW PROFILES/ FUNCTIONS IN THE FIRST LINE OF CARE 82
6.1. OBJECTIVE OF THIS CHAPTER 82
6.2. METHODS 82
6.3. HOW TO FOSTER THE PATIENT SELF-EMPOWERMENT ? INSIGHTS FROM A SYSTEMATIC REVIEW OF THE LITERATURE 82
6.3.1. Scope of the literature review 83
6.3.2. Methods 84
6.3.3. Results of the search strategy 84
6.3.4. Effectiveness of the interventions: results by disease 88
6.3.5. Summary of the findings: analysis by type of intervention 94
6.3.6. Conclusion: what elements make up successful interventions? 97
6.3.7. Strengths of this review 98
6.3.8. Caveats in the interpretation of results 98
6.3.9. Key points: interventions to foster patient empowerment 99

6.4. NEW PROFILES AND FUNCTIONS IN THE HEALTH CARE SYSTEM 99
6.4.1. Objective: analysis of the possible changes within the workforce to tackle the future challenges of chronic care 99
6.4.2. Methods 100
6.4.3. New roles in health care: examples from the UK, Canada and The Netherlands 100
6.4.4. Situation in Belgium 110
6.4.5. Discussion: implementation of new functions and professions in the Belgian health care system 114
6.4.6. Key points: new functions and roles in primary health care 115
7. ORGANIZATION OF CHRONIC CARE IN BELGIUM: STAKEHOLDERS' ANALYSIS 116
7.1. OBJECTIVE OF THIS CHAPTER 116
7.2. METHODS: CONSULTATION OF STAKEHOLDERS FROM DIFFERENT LEVELS 116
7.2.1. Micro and meso levels: four brainstorming sessions and semi-structured interviews 116
7.2.2. Macro level: two meetings with stakeholders 117
7.3. RESULTS: STAKEHOLDERS' VIEWS ON THE ORGANIZATION OF CHRONIC CARE IN BELGIUM 118
7.3.1. Theme 1: continuum of care within lines of care and between lines of care calls for coordination 118
7.3.2. Theme 2: Redefining the roles of health professionals and training 121
7.3.3. Theme 3: Empowerment and support of the patient and his/her informal caregiver 124
7.3.4. Theme 4: Payment system influences care 125
7.3.5. Theme 5: Clinical information systems and e-Data 127
7.3.6. Theme 6: Accessibility of care 129
7.3.7. Strengths and limitations of this SWOT analysis 130
7.4. KEY POINTS: HIGHLIGHTS FROM THE SWOT ANALYSIS WITH STAKEHOLDERS 131
7.4.1. Lack of efficiency 131
7.4.2. Coordination at micro level: a multidisciplinary primary care team is at the centre of a system designed for people with chronic care needs 131
7.4.3. Coordination at the meso level: mid-level scale initiatives to improve seamless care between hospital and home care 131
7.4.4. Task delegation and new functions in the health care system: the added value of medical

assistants and qualified nurses 131
7.4.5. Preventing institutionalization: importance of respite care and coaching the informal caregivers 132
7.4.6. Patients and Informal care givers. Roles of their organizations 132
7.4.7. Balancing payment systems 132
7.4.8. Information systems 132
7.4.9. Accessible care 133
8. ANALYSIS OF COORDINATION STRUCTURES AND PROGRAMMES IN BELGIUM 134
8.1. OBJECTIVE OF THIS CHAPTER 134
8.2. BACKGROUND: HEALTH CARE SYSTEM, A COMPLEX ADAPTIVE SYSTEM 135
8.3. COORDINATION STRUCTURES AND PROGRAMMES IN HEALTH CARE 135
8.3.1. Coordination structures 135
8.3.2. Coordination programmes 136
8.4. KEY FEATURES OF COORDINATION STRUCTURES AND PROGRAMMES 136
8.4.1. Coordination structures at micro level 136
8.4.2. Need for a geographically integrated system at meso level 138
8.4.3. Towards a uniform vision at macro level 138
8.5. EVOLUTION OF COORDINATION STRUCTURES IN BELGIUM 139
8.5.1. Micro level: from single-handed practices towards more collaboration 139
8.5.2. Meso level: from home care coordinating centres (SIT/CCSSD) to Integrated Primary Care Systems (GDT/SISD) 140
8.6. CARE PROGRAMMES: FIT WITHIN “MICRO” OR “MESO” HORIZONTAL STRUCTURES 142
8.6.1. Local multidisciplinary Networks 143
8.6.2. Alternative forms of care for older persons 143
8.6.3. Palliative care platforms and teams 143
8.7. FROM LESSONS LEARNED TO FUTURE PERSPECTIVES 144

■ **REFERENCES 146**

LIST OF FIGURES

Figure 1 – Study approach 12
Figure 2 – Primary care as a hub of coordination: networking with community and extern health care services[34] 23
Figure 3 – Innovative approaches for chronic diseases in Public Health and Health Care systems[29] 25
Figure 4 – Chronic Care Model[43] 27
Figure 5 – Framework for creating a regional healthcare system 29
Figure 6 – Functional Modules of the Conceptual Model 39
Figure 7 – Plan, provide and coordinate routine care module 40
Figure 8 – Acute Episode Response and Specialized Services module 41
Figure 9 – Early identification activities module 42
Figure 10 – Support patient/informal caregiver empowerment module 43
Figure 11 – Conduct health promotion and prevention activities 44
Figure 12 – The full conceptual model for a chronic care system 46
Figure 13 – Primary care care giving traditions 137
Figure 14 – Vertical organization, horizontal integration 142

LIST OF TABLES

Table 1 – Key findings international papers on chronic care 24
Table 2 – Initiatives from the Sickness Funds 50
Table 3 – Initiatives from the Federal Public Service Health, Food Chain Safety and environment 51
Table 4 – List of functional rehabilitation “conventions” (and expenditures 2010) 60
Table 5 –Summary of included patient empowerment systematic reviews 85
Table 6 – Summary of included patient empowerment RCT’s 87
Table 7 – Overview of results of systematic reviews (and related RCTs) of self-management interventions in chronic diseases 89
Table 8 – Simplified backbone structure for organization primary care 144

LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
APN	Advanced Practice Nurse
ASI	Association de Soins Intégrés
BS	Brainstorming Session
CAS	Complex Adaptive System
CAW	Centrum voor Algemeen Welzijn
CBT	Cognitive behavioural therapy
CFS/ME	Chronic fatigue syndrome/myalgic encephalomyelitis
CCM	Chronic Care Model
CCSSD	Centre de Coordination de Soins et de Services à Domicile
CMG	Cercles de Médecine Générale
COCOF	Commission Communautaire Francophone
COPD	Chronic Obstructive Pulmonary Disease
CPAS / OCMW	Centre Public d'Aide Sociale/Openbaar Centrum voor Maatschappelijk Welzijn
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
CTP	Care Traject Promotor
eGFR	Estimated glomerular filtration rate
CSSS	Health and social services centers
DH	Department of health
DIEP	Diabetes interactive education programme
EBM	Evidence Based Medicine
ED	Emergency Department
EMR	Electronic Medical Record
EU	European Union
FPS	Federal Public Service Health, Food Chain Safety and environment (FOD/SPF)
GDT	Geintegreerde Dienst Thuiszorg (SISD – Services Intégrés de Soins à Domicile)

GP	General Practitioner
HAK	(erkende) Huisartsenkring
HBO	Hoger beroepsonderwijs (high professional school)
HiT	Health Systems in Transition
HRQoL	Health-related quality of life
IBS	Irritable bowel syndrome
ICT	Information and Communication Technologies
IELP/ICPC	Interdisciplinaire Eerstelijns Praktijk/ Interdisciplinary Primary Care Practice
IOM	Institute of Medicine
K&G / ONE	Kinde en Gezin / Office de la Naissance et de l'Enfance
LGPO	Local GP Organization
LINQ	Lung Information Needs Questionnaire
LISTEL	Limburgs Samenwerkingsinitiatief Eerste Lijn
LMN/RML	Lokale Multidisciplinaire Netwerken- Réseaux Multidisciplinaires locaux
LOGO	Locaal Gezondheidsoverleg
MAB	Maximum Billing system
MDO	Multi Disciplinair Overleg
MPG/RPM	Minimal psychiatric data / Minimale psychiatrische gegevens / Résumé psychiatrique minimum
MS	Multiple sclerosis
NCD	Non-communicable diseases
NIHDI	National Institute for Health and Disability Insurance (INAMI/RIZIV)
NP	Nurse practitioner
OECD	Organization for Economic Cooperation and Development
P4Q	Pay-for-Quality
PA	Physician Assistant
PAMVR	Physician Assistant Managed Voluntary Register
PGD	Patient Group Direction
PSC	Pain catastrophising scale

QoL	Quality of life
RA	Rheumatoid Arthritis
RAI	Resident Assessment Instrument
RCT	randomised controlled trial
SEN	Steunpunt Expertise Netwerken (Flemish point of contact for expertise centres in the handicapped sector)
SEL	Samenwerkingsinitiatief EersteLijns gezondheidszorg (replaces the SIT)
SGM	Stakeholders Group Meeting
SIGN	Scottish Intercollegiate Guidelines Network
SISD	Services Intégrés de Soins à Domicile (GDT - Geintegreerde Dienst Thuiszorg)
SIT	Samenwerkings Intiatief voor Thuisverzorging (SIT) – replaced today by SEL
SMS	Self-management support
SMD	Standardised mean difference
SR	Systematic review
SGRQ	St George's Respiratory Questionnaire
UN	United Nations
VINO	Vlaams Initiatief Netwerk Ondersteuning
WHO	World Health Organization
WIV / ISSP	Scientific Institute of Public Health
WZC/RMS	Woon-zorgcentrum/Maison de repos et de soins

SCIENTIFIC REPORT

1. THE CHALLENGE OF CHRONIC CARE

Authors: Dominique Paulus, Koen Van den Heede

1.1. Chronic care: a growing burden for the health care systems

The European population older than 65 years rapidly expand: they represent now 17.4% of the EU-27's population (2010) but will account for 29.5 % by 2060[1]. This higher life expectancy is coupled with major scientific breakthroughs in medicine, bringing significantly improved chances of surviving disease and living with a chronic condition[2].

This phenomenon has an increasing impact on healthcare systems and on the society as a whole. Chronic conditions are not just a health issue – they impact on the workplace, the home environment, social support services and family networks. Vulnerable and socially disadvantaged groups carry a greater chronic disease burden: dimensions of inequity overlap and reinforce each other. Governments are being challenged to integrate policies, inter-departmental budgets and service provision to suit the needs of the persons with a chronic condition[3,4].

1.2. Objective: development of a position paper for chronic care in Belgium

In follow-up of the Ministerial Conference on Innovative Approaches for Chronic Illnesses in Public Health and Healthcare Systems (Brussels, 20/10/2010) and the conclusions of the European Council in December 2010[5], the Minister of Health & Social Affairs asked for the development of a position paper on chronic care in Belgium.

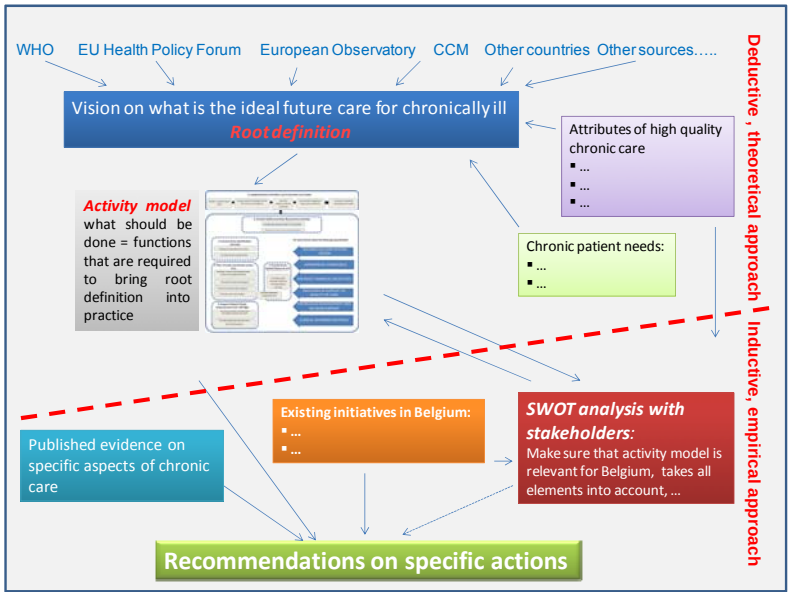
In a first step researchers have developed a scientific paper to lay a basis for the position paper. In a second step the editors have drafted a first version of position paper, based on the scientific report. This draft has been submitted to several groups of stakeholders with different backgrounds: the project steering committee (mainly representatives from authorities and patient associations), two groups of experts with relevant experience fielding this domain and the scientific and the consultative committees of the newly installed "Observatory for Chronic Diseases".

The final position paper (see synthesis at the front of the publication) is the results of numerous amendments proposed by all stakeholders consulted during this process (cf. list of experts and stakeholders in colophon).

The scientific report (see following sections) relies on two parallel approaches[6] (Figure 1):

- A theoretical, deductive approach (starts from general proposals and applies them to a specific situation):
  - A review of the main international papers that advocate for national policies for chronic care;
  - A review of the policies for chronic care in four selected countries;
  - These reviews contributed to the development of a conceptual framework that defines the vision on the ideal Belgian health care system oriented towards chronic care and the activities required to bring that vision into practice.
- A second approach that adds concrete elements, based on an analysis of specific situations (inductive approach: from facts to more general conclusions):
  - Data from the literature on chronic care: evidence found in the KCE reports, in the indexed literature on patient empowerment, in the grey literature on new professional roles in primary care;
  - The current situation in Belgium: review of the current initiatives, analysis of the existing coordination structures and SWOT analysis by stakeholders on the strengths and weaknesses of the Belgian health care system for the patients who need chronic care.

Figure 1 – Study approach



1.3. Scope: from "chronic disease" to "chronic care based on the patient's needs"

1.3.1. Chronic disease: official definitions based on a listing of diseases

Most international papers (see 2.1) emphasize the care for patients with chronic disease / non communicable disease. According to the definition of the "Medical Subject headings – MESH", chronic diseases have one or more of the following characteristics: they are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation, or care.

The WHO defines chronic diseases as "diseases of long duration and generally slow progression"[7]. This definition covers a wide range of health problems, mostly non-communicable diseases e.g. diabetes, cancer, musculoskeletal, respiratory neurodegenerative, oral and cardiovascular diseases. Mental diseases (e.g. depression, schizophrenia) and some communicable diseases such as the acquired immunodeficiency syndrome (HIV/AIDS) are also included[8]. The WHO also adds impairments, blindness for example.

The recent paper from the European Union Health Policy Forum[9] endorses this definition based on a listing of diseases.

1.3.2. The patient with "chronic disease": frequently in the plural

1.3.2.1. Comorbidity - multimorbidity

The organization of care for patients with chronic disease is often complex, due to the coexistence of several diseases. Two terms describe this coexistence[10] :

- Comorbidity: any distinct additional entity that has existed or may occur during the course of an index disease. The causal relationship between diseases or their common pathophysiological cause is (or not) present;
- Multimorbidity: the co-occurrence of multiple diseases and medical conditions within one person.

This last term will be preferably used in this report that does not focus on a specific disease category.

1.3.2.2. Prevalence of multimorbidity

Some authors assessed the prevalence of multimorbidity in primary care settings and general populations[11]. Globally the prevalence increases with age: the prevalence is low before 40 years, then increases till 70 years with a plateau afterwards. Factors associated with a higher risk of multimorbidity are a low level of education, obesity, tobacco and alcohol consumption[12,13]. The lack of comparability between studies precludes from giving a unique estimate of the prevalence as the figures vary according to [11]:

- The setting: figures are higher in the primary care setting than in the general population [14];
- The data collection method: the review of medical records gives lower estimates than the collection of data from consultations;
- The minimum number of diseases considered (2 or 3);
- The list of diagnoses considered for the definition of the multimorbidity;
- The cut-off used to define the presence of the diagnosis.

However, in most studies, the prevalence of at least 2 conditions in the general population is between 10% and 20% around 40 years and increases to 50-70 % in the population aged 70 years or more[14].

1.3.3. Chronic care as an answer to the patient's needs

The WHO definition above ("diseases of long duration and generally slow progression")[7] is close to the definition proposed in a KCE report[15] that concludes that the care of those patients with long-term illness should mainly rely on their needs, instead of definitions based on diseases.

1.3.3.1. Needs of the patients with a long-term condition

These needs may be grouped by five main dimensions[15]: biological needs, psychological needs, health care services needs, social needs and spiritual needs.

Biological needs

These needs depend on the underlying disease, but the common demand of the patients is the relief of their physical symptoms thanks to the optimal management of the underlying cause. Pain, fatigue, dyspnea, gastro-intestinal symptoms (lack of appetite, constipation) are common illustrations.

Psychological needs

- Need for Information

The need for tailored information is common, in particular for the treatment options and the possible evolution of the disease. The information needs to be adapted to the patient but also to the evolution of the illness. Many patients ask for the involvement of a relative or friend when receiving the information. The information of the relatives is even more important for caregivers in case of a specific disease as dementia. Information is crucial in particular for non native and lower educated patients who are usually less informed about their diagnosis.

- Need for psychological support

Patients (in particular when isolated) and informal caregivers need support to deal with emotions related to the chronic condition (fear, frustration, depression, distress).

Health care services needs

Patients usually request a single, well known and trustful caregiver (mostly their GP) but they are very sensitive to collaboration and shared expertise between caregivers, irrespective of the care setting (hospital, nursing home). Health care provision needs to be coordinated and integrated between the different settings.

Social needs

Social needs are a major concern for people living with a long term disabling condition, in particular to keep their independency. The main examples are people who live for years with heart failure or dementia. Activities of daily living in particular need assistance: housekeeping, shopping, transport. Another field of concern relates to the prevention of social isolation. Financial and administrative support are also mentioned.

Spiritual needs

Spirituality goes beyond the concept of religion and is more related towards a search for meaning, moral or biographical contexts besides religious beliefs.

1.3.3.2. The provision of chronic care in relation to needs

The care provided to meet the needs detailed above is an example of holistic (bio- psycho- social, ecological, spiritual) and comprehensive (hospital, community, home, respite) care. The patients suffering from progressive chronic diseases require coordinated, multidisciplinary care, provided by competent health professionals. Moreover the joint medical and social needs entail collaboration and ongoing communication between health and social care professionals.

One major characteristic of chronic care is that the evolution of the disease requires adapted interventions to answer to the changing biological, medical and social needs.

Each episode of the disease requires a different approach. Home care services play a major role most of the time. Patients ask for the continuity of home care workers, who know them and their family. In case of acute episodes the patient will require accessible acute care services whereas end-stage diseases call for accessible palliative care services.

Finally, the KCE report concludes that:

- Meeting a need depends on the individual perspective: a patient may assert that his/her need was met whilst (informal) caregivers report that this element was missing in the care delivery;
- Not all needs imply a professional intervention: the informal caregivers and the social network are often sufficient for assisting the patient. This statement emphasizes the importance to support the informal caregivers.

1.3.4. On care (versus primary prevention and "health in all policies")

Primary prevention and "health in all policies" are of utmost importance to tackle the problem of chronic diseases.

The MESH thesaurus gives the following definitions of prevention (http://www.ncbi.nlm.nih.gov/mesh). Primary prevention refers to practices for the prevention of disease in susceptible individuals or populations. Examples include breast feeding, communicable disease control measures, immunization. Secondary prevention includes interventions for patients who have a diagnosis of chronic disease, to diminish the recurrences or exacerbations or complications. Examples are statins and physical activity in patients with cardiovascular disease. Tertiary prevention encompasses supportive and rehabilitative services to minimize morbidity and maximize quality of life of people with a long-term disease, as for example rehabilitation after stroke.

"Health in all policies" relates to the social determinants of health. The Commission on Social Determinants of health set up by the WHO[16] expressed specific recommendations on this topic in three main areas:

- Improving daily living conditions: education, nutrition, healthy places for living, working conditions, social protection; universal health care;
- Tackling the inequitable distribution of power, money and resources e.g. health equity in all policies, fair financing, gender equity, political empowerment of all groups in society;
- Measuring the problem and assessing the impact of action by monitoring and research on determinants of health.

Regardless of the importance of primary prevention and "health in all policies" mentioned above, this report focuses on the care of the patients who experience chronic disease and related care needs.

First, the scope of this mission was defined by the stakeholders who entrusted this mission to the KCE, The NIHDI and the FPS Public Health. Second, addressing all dimensions of chronic care, including (primary) prevention and 'health in all policies' was impossible within the timeframe imposed on this project but also went far beyond the competency domains of KCE. At last, this "limited" scope still offers a meaningful framework to develop a coherent set of recommendations addressing a finite and well-identified target group of actors.

1.4. Epidemiology and costs of chronic diseases

1.4.1. Epidemiology

1.4.1.1. International figures

Chronic diseases are nowadays the major causes of morbidity and mortality across the globe, accounting for 63% of deaths. Cardiovascular diseases (48% of NCD deaths), cancers (21% of NCD deaths), diabetes and chronic respiratory diseases are the first causes[17].

The recent paper from the European Union Policy Forum[9] summarizes the burden of chronic diseases:

- 40% of the population in Europe above the age of 15 is reported to have a chronic disease[5]: these are responsible for 86% of deaths;
- Cardiovascular diseases cause nearly half of all deaths in the WHO European region;
- Differences are noted between genders. Men are more likely to suffer and to die earlier in life from the most common diseases e.g. cardiovascular disease and cancer.

1.4.1.2. Risk factors and burden of chronic diseases in Belgium

Leading causes of death in Belgium are similar to the causes mentioned for the European region i.e. diseases of the circulatory system (32.9%) and tumors (27%)(2006)[18].

The most recent figures from the health interview survey[19] give an estimate of the prevalence of risk factors and self-reported chronic diseases in Belgium. The World Health Organization (WHO) also published recent figures that allow between-country comparisons[20]. One limitation is that most data rely on self-reports.

- 27,2 % of the adult population reports at least one chronic disease:
  - Low back pain (17.7%), allergy (13%), arthrosis (12.7%), hypertension (12.7%), neck pain (9.4%), chronic headaches (8.1%) have the highest percentages;
  - 4.2% and 3.7% of the interviewees report asthma and chronic pulmonary disease respectively;
  - 3.4% of the adults report diabetes;
  - Chronic anxiety (4.6%), depression (4.9%) and serious psychological problems (14%) are frequent in the population;
  - Pain: 39% of the population experience light to moderate pain and 12% report severe pain.
- 17.1% of the population have functional limitations as a result of chronic diseases;
- Risk factors for chronic diseases are common and more frequently reported among persons with a lower socio-economic status:
  - Overweight is the most common one: 47 % of the population have overweight (BMI ≥ 25) and 14% suffer from obesity (BMI ≥ 30). These figures were respectively 41% and 11% in 1997;
  - 38% of the population exercises at least 30 minutes per day (29% of the women, 49% of the men). A quarter (26%) has no activity.
  - 35% of the population eats at least 2 portions of fruits per day, 62% at least 200g vegetables;
  - 25% of the population are smokers (21% daily). The proportions decreased between 1997 and 2008 (30% and 26% in 1997);
  - 12% of the population are daily drinkers. The proportion of "overconsumption" is 10% for men (> 21 drinks/weeks) and 6% for women (> 14% drinks / week).

1.4.2. Costs

1.4.2.1. Escalating global health care expenditures

Healthcare expenditures are escalating: in 2009, OECD countries devoted 9.6% of their GDP on average to health, a sharp increase from 8.8% in 2008[21]. The increasing prevalence of chronic diseases plays a role in the rising of health care expenditures.

Bartozs Przywara[22] summarizes the driving forces of health expenditures in Europe. The determinants of health expenditures usually cited in the literature encompass:

- Demographic and health factors (e.g. health status of the ageing population);
- Economic factors (e.g. income elasticity, development of new technologies and medical progress, relative prices for health care inputs, organization and financing of health care systems);
- Social factors (e.g. determinants of health and health-related behaviour, increasing expectations of populations).

A recent review of the literature on this topic points out that there is uncertainty regarding to what extent these factors contribute to increase health expenditures. Still a focus on promoting healthy ageing may reduce health care costs relating to a large elderly population. Moreover, making use of health technology assessment and increasing patient participation in decision process may improve efficient use of health resources[23].

1.4.2.2. Key figures on the cost of chronic diseases in Europe

The 2012 paper from the European Union Policy Forum[9] includes key figures on the costs of chronic diseases mainly based on reports from the WHO and from the Organization for Economic Cooperation and Development (OECD).

- Cardiovascular diseases cause nearly half of all deaths in the WHO European region. They cost the EU economy in excess of € 192 billion a year[17];
- The financial implications of cancer treatment and recovery are starting to be assessed across Europe. Findings point to increased

costs for individual patients and families due to increased household costs, loss of income, lack of disability/illness allowances, use of savings for treatment and drugs (especially amongst young patients) and severe psychosocial effects such as fatigue and loss of self-confidence. Losses in productivity to cancer in the UK alone in 2008 were estimated at € 6.6 billion related to cancer survivors and € 8.81 billon related to cancer deaths;

- Respiratory diseases: the 5 major respiratory diseases (asthma, lung cancer, chronic obstructive pulmonary disease, pneumonia and tuberculosis) cause a financial burden of over € 100 billion in Europe due to health care costs and lost working days;
- Diabetes affects nearly 10% (52.8 million) of the adult population in the WHO Europe region and cost € 131 billion. There is a wide variation in the prevalence of diabetes in the region, and in the mean diabetes-related expenditures per person with diabetes. Worldwide, in 2011, 366 million people were reported to have diabetes and this is predicted to rise to 552 million by 2030.

About 70% to 80% of healthcare costs would be spent on chronic diseases. This corresponds to € 700 billion in the European Union and this number is expected to rise in the coming years. Still the authors conclude to a lack of reliable data for assessing the real burden and costs of chronic diseases as well as the impact of policies, programmes and treatment.

1.4.2.3. Cost-of-illness studies in Belgium

Data for Belgium are scarce. The authors of this report identified three cost-of-illness analyses:

- A KCE study on chronic low back pain (2006) [24] concluded that the direct medical cost of this disease amounts between 81 and 167 million Euros per year, with the largest part devoted to physiotherapy. The global budget (including the patient's and society's investment) would amount between € 270 million and € 1.6 billion. Over one year, 40 000 classical hospital stays and 46 000 day hospital stays had low back pain as main reason for hospitalization. Over a period of 10 years, a quarter of the adult population had consulted their GP for low back pain.
- A study quantified the costs of atherosclerosis in Belgium (2004) [25]. The estimation for the year 2004 amounted to € 3.5 billion: € 80 million for prevention, € 1.3 billion for pre-clinical disease and € 2.2 billion related to established disease. The largest part of the costs (59%) was incurred by the National Institute for Health and Disability Insurance. Patients invested 10% of the sum and third parties (employers and complementary health insurance) bore the last 32%.
- The third study quantified the costs associated with breast cancer[26]. Total average costs attributable to breast cancer amounted to € 107 456 over a period of 6 years (from 1 year before diagnosis to 5 years at follow-up). Productivity losses represented the major part (89%) and health care costs represented 11% of the total amount.

1.4.2.4. Human costs

As illustrated in the previous section, chronic diseases carry in parallel significant human costs for the patients, their families and caregivers[17]. The impact of the illness can be physical, psychological, emotional, economic and social. Chronic diseases also create vulnerabilities e.g. due to reduced or non ability to work and the resulting loss of income and risk of poverty.

The economic impact of chronic diseases extends well beyond the health care system[22] as illustrated by the Belgian studies mentioned above:

- costs of productivity losses for employers;
- indirect costs for patients and families.

2. HIGHLIGHTS FROM THE INTERNATIONAL PERSPECTIVE

Authors: Vinciane Quoidbach (international organizations), Hilde Spitters and Bert Vrijhoef (review of four countries), Dominique Paulus

This chapter describes the highlights of international papers (see 2.1), the widely cited Chronic Care Model – CCM (see 2.2) and a review of policies in a selection of countries (see 2.3).

2.1. Viewpoints of the European Union, the United Nations and the World Health Organization

This section is a review of the main papers published at international level about the future of chronic care. The development of a position paper for Belgium goes indeed with the stream of international organizations that draw attention to the increasing burden of chronic diseases around the world and in Europe in particular. Problems are country-specific but the epidemiologic burden as well as the need for implementing new organizational care models are common to all regions.

2.1.1. Data sources

The main researcher (VQ) scrutinized the main avenues proposed in the international reports from the United Nations (UN), the European Union (EU) and the World Health Organization (WHO).

Reports exclusively dealing with health promotion and primary prevention were excluded from our analysis given the scope of this report on care.

2.1.2. International frameworks: calls for integrated care

2.1.2.1. United Nations

The UN General Assembly adopted a political declaration on the Prevention and control of Non-communicable diseases in September 2010[27]. This declaration:

- Recognizes the burden of non-communicable diseases in terms of deaths and morbidity;
- Emphasizes the role of lifestyle and social determinants;
- Calls on member states and other relevant stakeholders for taking collective and multisectoral actions;
- Advocates for the implementation of cost-effective, population-wide interventions to reduce the prevalence of risk factors (e.g. through education, legal, fiscal measures);
- Recommends the strengthening of the health system e.g. development of non-communicable disease programmes, adequate well trained workforce, information systems, reduction of health disparities, universal health coverage, implementation of cost-effective interventions;
- Encourages international cooperation and partnerships for the prevention and control of non-communicable diseases;
- Calls for a comprehensive monitoring framework, including a set of indicators, suitable for application across regional and country settings to monitor trends and to assess progress made in implementing national strategies and plans on non-communicable diseases.

2.1.2.2. European Union

The EU published several recent papers among others in response to the declaration of the United Nations mentioned above.

- White paper on the principles for EU action on health. This paper, published by the commission of the European communities in 2007, sets up the fundamental principles for EU action on health[3]:
  - A strategy based on shared health values: universality, access to good quality care, equity and solidarity. Citizens' empowerment (see 6.3) and a health policy based on scientific evidence are central;
  - Health is the greatest wealth: health expenditure is not just a cost but also an investment, to decrease the direct and indirect costs linked to illness;
  - "Health in all policies" is a corner stone of the population's health: tobacco taxation, animal health and environment policy are some illustrations;

- The EU should contribute to global health, in particular by taking concrete steps to improve health.

- European Innovation Partnership on Active and Healthy Ageing. This EU initiative sets a target of increasing the healthy lifespan of EU citizens by 2 years by 2020. The Partnership behind this initiative is a consortium of private and public stakeholders committed to accelerate the development of innovations with a triple aim:
  - Improving health and quality of life of older people;
  - Improving the sustainability and efficiency of care systems;
  - Creating growth and market opportunities for businesses.

  They propose a strategic implementation plan structured according to 3 pillars, each of them having 3 priority action areas:
  - Prevention, screening and early diagnosis with these priority actions areas:
    - Patient health literacy, patient empowerment, ethics and adherence programmes;
    - Personalised health management;
    - Prevention and early detection of functional decline.
  - Care and cure with priority actions areas:
    - Education, protocols for health professionals and other caregivers, with an emphasis on comprehensive care management;
    - New models of care for chronic conditions, with a focus on multimorbidity case management, e.g. individualised care plans;
    - Organization of integrated health care based on innovative tools and services.
  - Active ageing and independent living with priority actions areas:
    - Assistance of people with cognitive impairment;
    - ICT solutions to foster independent living;
    - Increase social inclusion of older people.

  Some EU issues are relevant for the successful implementation of the strategic plan: regulatory issues, shared and robust evidence base, effective funding, exchange and transfer of good practices between stakeholders.

- E-Health: the European Commission in May 2010 [28] and the Directive of the European Parliament and of the Council on the application of patients' rights adopted the Digital Agenda for Europe. Specific objectives are "to create an electronic health record architecture by supporting the exchange of information and standardization; to set up health information networks between points of care to coordinate reactions to health threats; to ensure online health services such as information on healthy living and illness prevention; and to develop teleconsultation, ePrescribing, eReferral and eReimbursement capabilities".

- "Innovative approaches for chronic diseases in public health and healthcare systems". The Council of the European Union invited member states to initiate a reflection with all stakeholders to identify options to optimize the response to the challenges of chronic diseases[29]. Their conclusions focus on the following areas:
  - Action for health promotion (e.g. health in all policies) and prevention of chronic diseases;
  - Identification and sharing of good practices in chronic care (e.g. innovative chronic care models);
  - Research into chronic diseases e.g. to base implementation of prevention, early interventions and care on scientific knowledge;
  - Data collection on chronic diseases (incidence, prevalence, risk factors, outcomes).

- European Union position and commitment to the UN high-level meeting on the prevention and control of non-communicable diseases

  The European Parliament resolution of 15 September 2011[30] advocates for a shift from care to early prevention of chronic diseases and among others:
  - Emphasizes the importance of policies addressing behavioural, social, economic and environmental factors associated with NCDs;

- Acknowledges the burden of chronic diseases and the importance of related risk factors (e.g. tobacco, diet, alcohol, physical activity);
- Mentions the “need for an integrated and holistic patient-centred approach to long-term conditions, encompassing disease prevention and health promotion”;
- Includes e.g. a reference to "chronic care models”: “the focus of chronic care models on advanced chronic conditions needs to be shifted toward addressing people in the early stages of non-communicable disorders, with the ultimate goal of not merely managing diseases, but also improving the prognosis for sufferers from chronic disorders”.

2.1.2.3. World Health Organization

Non-communicable diseases are a focus of interest for the World Health Organization[7]. Two recent papers discuss the burden of non-communicable diseases as well as an action plan 2012-2016 to tackle the problem[17,31]. This action plan, proposed by the regional committee of the WHO for Europe[31], focuses more specifically on diabetes, cancer, cardiovascular and respiratory diseases but other disorders are also mentioned (mental disorders, consequences of violence and injury, infectious and environmental diseases). The most recent publication proposes a European policy framework for supporting action for health and well-being in all countries [32].

- General principles and priority areas:

  The above mentioned papers [31-33] stress some principles: focus on equity, stregthening health systems, health in all policies, a life course approach, individual empowerment, population-based and individual approaches, integrated programmes, approach at the level of the society by a collaboration between all actors.

The 2011 action plan[31] suggests four priority action areas:

- Governance for NCDs, fostering on citizen empowerment;
- Strengthening surveillance and monitoring;
- Promoting health and preventing disease;
- Reorienting health services towards prevention and care of chronic diseases.

- Importance of risk factors and proposed actions:

  Both reports[17,31] emphasize the importance of specific risk factors: tobacco, alcohol, physical inactivity, diet, obesity, blood pressure, cholesterol, cancer-associated infections. They also stress the social and economic impact of non-communicable diseases, in particular among the most vulnerable and socially disadvantaged people.

  The Global status report on non-communicable diseases[17] advocates for “best buys”, actions that should be undertaken at population level to save lives, prevent diseases and avoid costs:

  - Tobacco: protecting people from tobacco smoke, banning smoking in public places, warning about the dangers of tobacco use, enforcing bans on tobacco advertising, promotion and sponsorship, raising taxes on tobacco;
  - Alcohol: restricting access to retailed alcohol, enforcing bans on alcohol advertising, raising taxes on alcohol;
  - Salt: reduce intake and salt content of food;
  - Fats: replace trans-fat in food with polyunsaturated fat;
  - Promotion of healthy diet and physical activity.

  “Best buys” are also proposed for specific groups of patients as for example:

  - Cardiovascular diseases: low-cost generic medicines (aspirin, statin, blood pressure control);
  - Early diagnosis of cancer;
  - Diabetes: blood pressure and glycemic control, foot care;
  - Treatment of asthma with inhaled steroids and beta-2 agonists.

- Need for a strong primary health care system to tackle the challenges of the future:

  The World Health Organization advocates for the reform and growing role of primary care in the health care system[34]. Future challenges for health care systems are the ageing of the populations and the burden

of chronic diseases, the equal distribution of health and the place of health systems in changing economic and political environments.

WHO suggests four sets of reforms:

- Universal coverage reforms, primarily by moving towards universal access and social health protection;
- Service delivery reforms, to reorganize health services around people's needs and expectations;
- Public policy reforms, that secure healthier communities e.g. through public health policies across sectors;
- Leadership reforms, required by the complexity of contemporary health systems.

Health care organized as people centred primary care has the following characteristics: person-centeredness, comprehensiveness, integration, continuity, participation of patients, families and communities. Health services need to be organized accordingly: a collaboration and integration of primary care and hospital care is the corner stone of the system, in collaboration with social and other community services.

2.1.3. Shift towards integrated care: advocacy for organizational changes

The documents described above focus on common diseases (cancer, diabetes, respiratory, cardiovascular) and emphasize the need for primary prevention and national plans to decrease the incidence of these conditions.

Another common theme related to the chronic care of people with multi-morbidities is the shift towards an approach involving multiple providers, across settings of care[35]. The prevailing models for financing and delivering healthcare as well as the medical education are oriented towards acute care, in-hospital settings, based on the assumption that people have (a sum of) single disease(s). However, a new perspective on transformative learning and interdependence emerges in the literature.[36]

2.1.3.1. What is integrated care?

WHO defines integrated Care as "a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve the services in relation to access, quality, user satisfaction and efficiency"[35].

There is a substantial consensus for implementing new ways of delivering high-quality healthcare, that imply integration (as opposed to fragmentation) of care providers and much closer coordination of their activities across levels of care and multiple sites, all of which need to be optimally embedded within a system that promotes patient empowerment.[34,37]

"Shared care", "transmural care", "seamless care", "continuous care", "integrated care pathways", "integrated delivery networks" are strategies that refer to the concepts of coordination and integration of services. Some aim towards the development of multi-professional teams (horizontal integration that brings together services that operate at the same level). Others aim to integrate different levels of care (vertical integration).

2.1.3.2. How to foster integrated care?

A policy brief published by the WHO[37] suggests a number of conditions for the successful implementation of chronic disease management:

- Strong leadership and vision at the national, regional or organizational level;
- Data collection and data-sharing among stakeholders;
- Patient-centered care based on people's needs;
- Prevention to target key risk factors;
- Supporting self-management and empowering people with chronic diseases;
- Involvement of a wide range of stakeholders such as individuals, the voluntary and community sector, clinicians, private industry and public services.

2.1.3.3. *Integrated care: a major component of the future health care systems*

Integrated care is one of the 8 essential building blocks proposed by the WHO for taking action in the field of chronic diseases[38]. This concept is variously used but provides a useful way of thinking about a range of approaches that are deployed to increase coordination, continuity, collaboration and networking across different components of the health services delivery[39]. A first illustration is the Østebro health care centre in Denmark (see description in appendix) with different facilities and therapies for patients with chronic conditions. Another illustration is the implementation of a model of integrated home care for elderly persons that has been shown to reduce the number and duration of hospitalizations in Italy[40,41]. Similar positive results were obtained with integrated care projects in Québec (see 2.3.2.3).

The analysis of the organization of mental care shows that the concept of "Integrated care" can be interpreted and implemented in different ways[42]:

- Integrated care around the patient versus organization of integrated care for a group of patients;
- From a loose cooperation between providers to a high level of integration;
- Formal processes (e.g. written processes) or informal (e.g. verbal) agreements.

The importance of the integration of primary care and hospital care has been underlined above (see 2.1.2.3)[34].

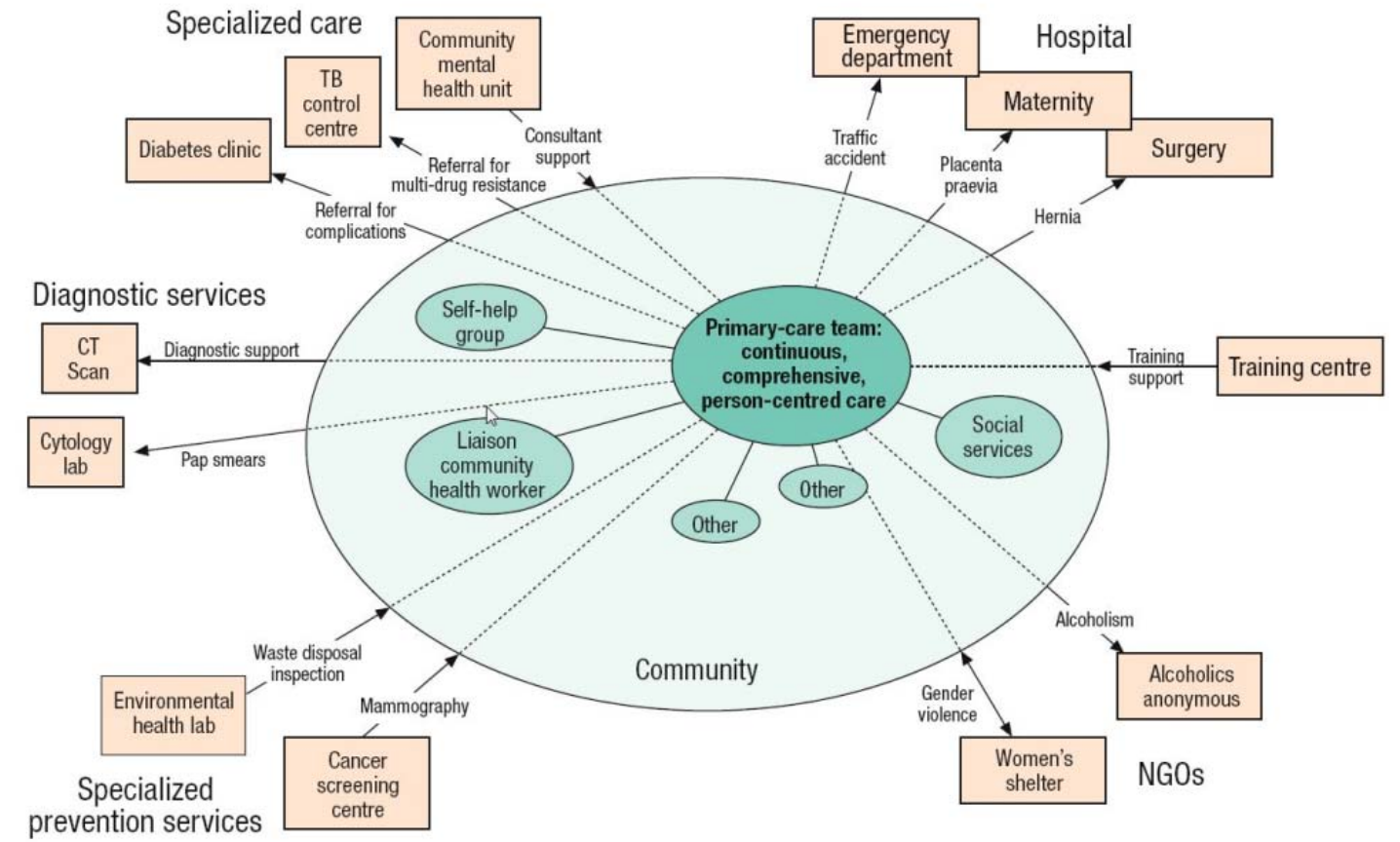
Information and communication technologies (ICT) are facilitators for the implementation of integrated care for the follow-up of the patient care. More user-friendly and efficient ICT platforms are needed e.g. for shared decision making, the process by which a healthcare choice is made jointly by the practitioner and the patient. The results of a Cochrane review on the best interventions to improve shared decision-making are however inconclusive: the implementation of patient-mediated interventions (e.g. decision aids) and healthcare professional training may be effective.

2.1.4. *Role of primary care: hub of coordination*

The quality and in particular the continuity and efficiency of health care services provided to a population depend upon the quality of the primary care teams supported by a network of specialized services, prevention services, diagnostic services, local hospitals[34].

The diagram below illustrates the central role of primary care is this array of services. The primary care team is at the centre of the care, embedded and in relation with other services provided by the community (a.o. social support, self-help groups). The primary care team is a bridge between this community and the other actors of the health system, helping people navigate in this system in the most appropriate way. The effect would be to optimize the use of the health services through an appropriate referral to the service that will best answer to the patient's needs. The implementation of this dynamics requires organization, administrative and financial support and recognition of the major role of primary care by the other institutions.

Figure 2 – Primary care as a hub of coordination: networking with community and extern health care services[34]



2.1.5. Summary and conclusions

2.1.5.1. Key findings based on the WHO report and action plan for non-communicable diseases[17, 31], UN declaration[27], OECD health data[21] and EU documents[5, 9, 21, 30]

The international papers share common priority areas for action. Table 1 below summarizes some of these common priorities and further defines to which part of the chronic care model each of them refers.

Table 1 – Key findings international papers on chronic care

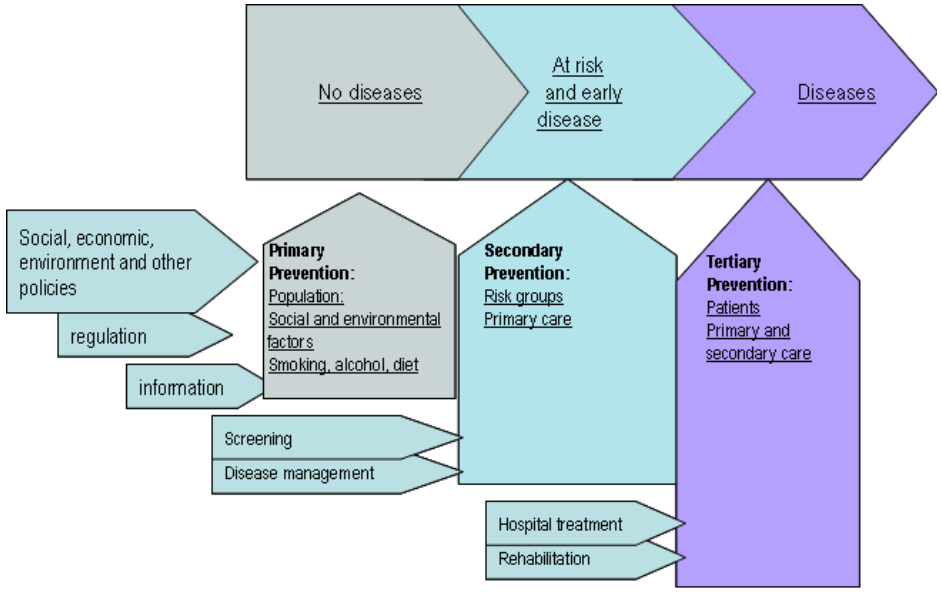
Priorities	HS	C	SM	DS	HSD	CIS
A shifted approach to tackle non-communicable diseases: integrated primary health care with a focus on horizontal approaches (multimorbidity and long term care) – ensuring early detection and timely treatment using cost effective and sustainable health care interventions	x		x		x	
Strengthening primary healthcare: integration of hospitals within the first line of care with a gate keeping function fully effective.	x				x	x
Tackling health inequalities with a focus on ageing and vulnerable groups	x	x	x			
NCDs national plans (cancer, …) and guidelines	x			x		
Surveillance and monitoring: need for reliable, appropriate and comparable data to inform local and national policies.	x					x
Package of essential services delivery to be expanded in primary health care.	x	x			x	
Health systems financing: • Financing and strengthening health systems to deliver cost effective individual interventions through a primary health care approach; • Innovative financing mechanisms to complement national health budgets, expanding health insurance services at the primary healthcare level	x				x	
Strengthened ICT and health records between the first and the second line (e-health) with a focus on data exchange. Initiatives from various authorities to enable health care providers (and patients) to better manage patient records. The European Council of Ministers (2009) recalled that eHealth must not only be a technical application for service providers but also a tool to develop health policy.	x			x		x
Workforce: assessing needs (GPs) and clear mapping of roles and responsibilities of individuals and groups involved.	x				x	
Major role of prevention: cf. the existing WHO global strategies to be implemented at country level	x					

Abbreviations: HS: "Health system", C: "Community", SM "Self management", DS "Decision support", HSD "Health system design", CIS "Clinical information systems".

2.1.5.2. *Conclusion: innovative approaches for chronic care*

The illustration below has been proposed by the EU for innovative approaches for chronic diseases in Public Health and Health Care systems[29]:

Figure 3 – Innovative approaches for chronic diseases in Public Health and Health Care systems[29]



This position paper focuses on the second and third groups i.e. the persons at risk for or with early/established disease (secondary and tertiary prevention, primary and secondary care). The international papers state that the challenge of chronic diseases for health care systems urges for:

- Health care delivery changes e.g. integration of care at hospital and primary care level;
- A growing role of primary health care including cost effective, affordable and sustainable services that are accessible, integrated and uninterrupted across the continuum of care and delivered by the most appropriate provider at the right place and time;
- A network of health care services where primary care is at the centre of the community, offering a bridge to the most appropriate specialized care services;
- A shift from problem-oriented to goal-oriented care with definitions of activities to reach desired outcomes (results-based management approach). This needs to be done by introducing innovative patient management programmes including shared decision making and interventions for the empowerment of the patient;
- Integrated care models are a priority for efficient health care systems and better patient care outcomes;
- Secondary prevention interventions need to be strengthened and more targeted;
- Evaluations of the present integrated care initiatives implemented at country level need to be carried out for policy purposes.

The international papers published by the United Nations, European Union and World Health Organization mostly focus on the prevention of chronic diseases at population level. They emphasize:

- **The burden of chronic diseases in terms of deaths and morbidity;**
- **The major role of social determinants and lifestyle factors, in particular tobacco, diet, alcohol and physical activity;**
- **The importance of actions that are multisectoral and cost effective in the fields of health promotion and prevention;**
- **The need for strengthening health systems (national programmes, appropriate workforce, evidence-based actions);**

- **The major role of the first line of care, embedded in the community, offering a necessary link to more specialized health care services according to the patient's needs;**
- **The importance of data exchange systems.**

They suggest to develop new, integrated care models centred on the patient.

2.2. Chronic care model

The aim of the Chronic Care Model (CCM) is to transform the daily care for patients with chronic illnesses from acute and reactive to a proactive, planned approach. It is designed to accomplish these goals through a combination of effective team care and planned interactions; self-management support; and patient registries and other supportive information technology. These elements are designed to work together to strengthen the provider patient relationship and improve health outcomes[43].

The chronic care model has been proposed since more than a decade to foster high-quality chronic disease care [44]. Researchers from the MacColl Institute for Healthcare Innovation identified in the literature promising strategies for increasing the quality of chronic care and organizing it in a more efficient way. This model can be applied to a variety of chronic illnesses, health care settings and target populations.

The chronic care model has been implemented in different health care environments e.g. the United States, Denmark, The Netherlands, Australia, the United Kingdom[45,46]. France is also implementing some components of the model e.g. patient empowerment, decision support, clinical information systems. Section 2.2 provides further details on four countries/regions: Pennsylvania, Québec, The Netherlands and Denmark.

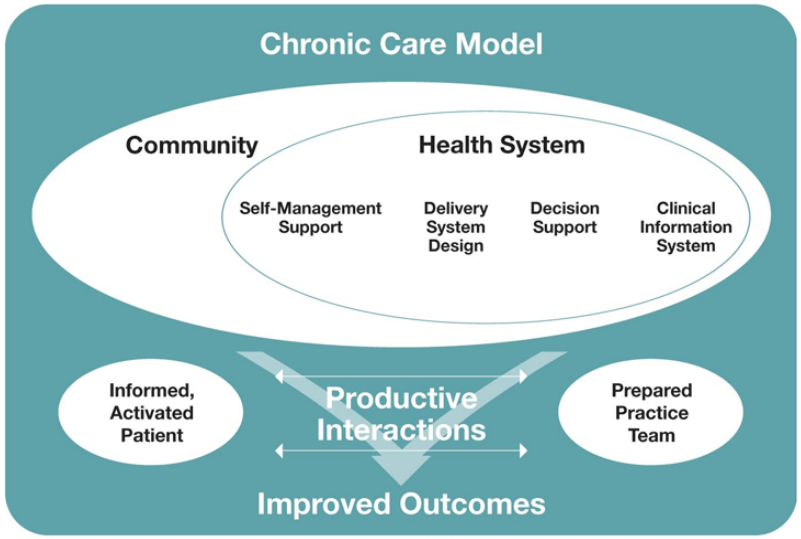
2.2.1. Elements of the chronic care model

The chronic care model (Figure 1) lists the following elements as key features that determine high-quality chronic disease:

- Self-management support e.g. patient information, collaborative decision, guidelines for patients;
- Decision support e.g. guidelines for health providers;
- Delivery system design e.g. team practice, coordination of care;
- Clinical information systems e.g. computerized information, registries,
- Community resources and policies as for example physical activity programmes;
- Health care organization e.g. leadership and definition of organization's goals.

The authors state that improvement in the care of patients with chronic illness requires a support by an effective leadership, incentives and adequate resources for improvement[47]. The productive interactions between informed patients who take an active part in their care and providers with resources and expertise are the conditions for effective and accessible care services for chronic patients.

Figure 4 – Chronic Care Model[43]



The 2003 update of the CCM aimed to reflect advances in the field of chronic care both from the research literature and from the scores of health care systems that implemented the Model in their improvement efforts. We list more specific concepts under each of the six elements. Based on more recent evidence, five additional themes were incorporated into the CCM:

- Patient Safety (in Health System);
- Cultural competency (in Delivery System Design);
- Care coordination (in Health System and Clinical Information Systems)
- Community policies (in Community Resources and Policies);
- Case management (in Delivery System Design).

The CCM has been used as a basis for other frameworks as for example the 'Innovative Care for Chronic Conditions'[38] framework developed by the WHO and the Canadian expanded chronic care model[48].

2.2.2. Evidence underlying the chronic care model

Randomized controlled trials, studies that evaluate the implementation and distinct components of the model provide evidence of an impact on health care process and outcomes across a variety of diseases[49,50].

The body of research mainly focused on diabetes. Some other studies analyzed e.g. patients with asthma, depression, hypertension, heart failure and geriatric care. One limitation is the difficulty to conduct studies on all components of the CCM:

- In trials about the care of chronic patients, some components might be already present before the trial that can only measure the effect of an additional component;
- In studies about organizational changes in health care delivery, not all components will be implemented at once. Evaluations are therefore usually limited to one or to a few components.

A few studies also analyzed how the implementation of the chronic care model can reduce health care use and costs. The results were usually positive or mixed but the investment for the implementation of the model is not often taken into account[51].

2.3. Highlights from 4 countries

This section describes the policies for improving the quality of chronic care in countries that implemented policies at national/regional scale for the care of patients with chronic disease. A full description by country can be found in the first chapter of the supplement.

The analysis aims to understand and explain the ways in which these frontrunner countries act upon the challenge of redesigning healthcare systems to meet the needs of people with chronic conditions:

- What policies for improving the quality of care for people with chronic diseases are being implemented in the Netherlands, Denmark, Pennsylvania and Quebec?
- Is there an impact of these policies on outcomes?

2.3.1. Methods

2.3.1.1. Selection of the countries

The selection of four regions/countries (for feasibility reasons) was decided in collaboration with Dr. Ed Wagner (MacColl Institute, Seattle) and Dr. Ellen Nolte (RAND Cambridge). Criteria for defining a country with large scale changes were:

- the presence of a country of state wide policy plan,
- the allocation of financial resources for executing the policy plan,
- the presence of reports (in English, French or Dutch) regarding the progress in redesigning chronic care.

Both experts recommended including Denmark, The Netherlands, the province of Quebec in Canada and the state of Pennsylvania in the United States as being frontrunner countries or regions where large scale changes took place regarding the care for people with chronic conditions. This choice was endorsed by the literature, by the research team and by the steering committee of this project.[45]

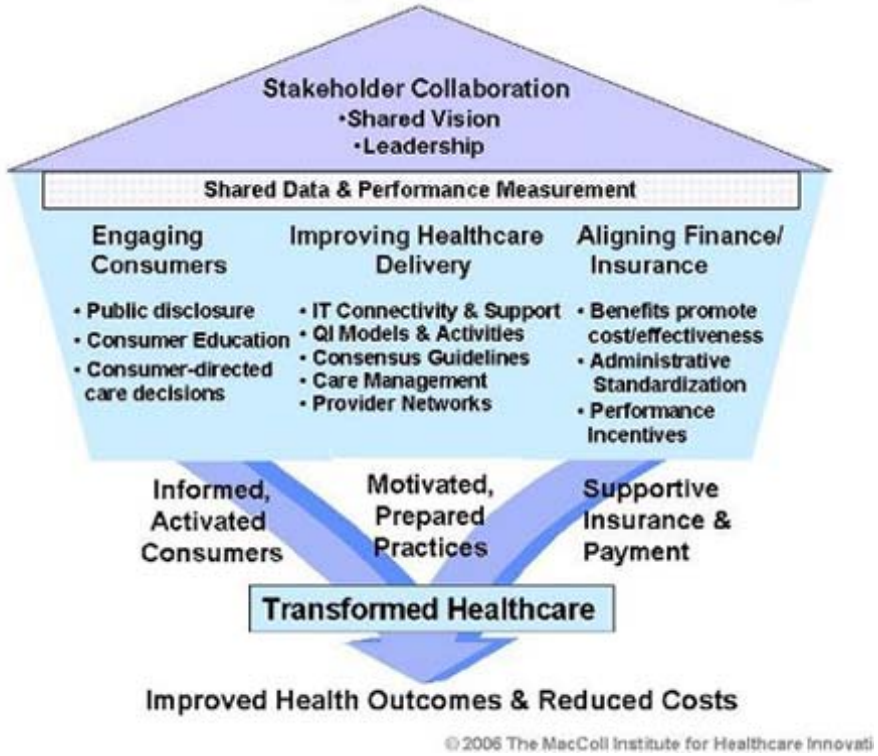
2.3.1.2. Data sources

This analysis is a scoping study based on a combination of methods and sources including the indexed literature (Medline), government documents and personal communications about disease management programmes (DMPs). The first chapter of the supplement provides details on the methodology (section 1.2) and on the health care systems of the 4 countries/regions (section 1.3).

2.3.1.3. Data validation and structure of the analysis

Interviews with experts from each region/country validated the results. These were structured according to the analytic framework displayed below (Figure 3)[52,53]. This framework describes that improvement strategies regarding chronic care need to rely on stakeholder collaboration (shared vision and leadership) with coordinated actions: data-sharing for performance measurement, engaging consumers, improving health care delivery, and aligning benefits and finances.

Figure 5 – Framework for creating a regional healthcare system



2.3.2. Stakeholder collaboration: shared vision and leadership

2.3.2.1. Common objectives and elements of country/region policy plans that aim to provide chronic care of high quality

The four countries/regions launched a country/region-wide policy plan, to provide chronic care of high quality[54,45,55-65]. The countries/regions adapted their legislation and adopted new policies to implement the reforms proposed in the plans. The common goal is the provision of care that answers to quality criteria (safety, timeliness, effectiveness, appropriateness, efficiency, comprehensiveness, continuity, equitability, patient centeredness) in order to achieve positive patient outcomes. These programmes provide the individual with chronic disease knowledge and tools to enable him/her to improve his/her own health status and functional abilities.

Common elements of the plans for chronic care are:

- The development of a national/regional framework as the basis of chronic care organization;
- Integrated health care system: the MESH definition refers to “a health care system which combines physicians, hospitals, and other medical services with a health plan to provide the complete spectrum of medical care for its customers. All countries implemented models of collaboration/integration between existing services [66]. Municipalities’, social, occupational health services and usual care services are integrated at local level[67,68]. Québec is one outstanding example: regional community centers coordinate, improve and integrate health and social services as well as multidisciplinary team-based practices in primary care[45,60,61]. Further organizational expansion took place when local community centers, acute hospitals and long-term hospitals merged into health and social services centers or local health networks which nowadays also include family medicine groups;

- Implementation of "disease management": the MESH definition is "a broad approach to appropriate coordination of the entire disease treatment process that often involves shifting away from more expensive inpatient and acute care to areas such as preventive medicine, patient counseling and education, and outpatient care...";
- Personal (health) care plans with the patient's needs at the centre. The management of the disease implies the coordination by a care provider as well as the involvement of a multidisciplinary team.

2.3.2.2. Specificities of chronic care plans in each country

- The Netherlands: programmatic approach for chronic care.

  The programmatic approach offers an integrated care package (prevention, self-management, evidence-based cure and care) i.e. a continuum of care for the patient with a chronic disease. The patient would benefit from an individual treatment plan provided by a multidisciplinary team[55,69,70].
- Denmark: national disease management with implementation at local level according to local specifications.

  The Danish Ministry of Interior and Health has laid down its policy aims regarding chronic care in multiple documents e.g. the "Health Act" and the "Health Throughout Life" (targets and strategies for public health policy 2002-2010)[57]. Important policy objectives are:
  - Strengthening the role of healthcare providers and their collaboration;
  - Coherence regarding chronic care on regional level;
  - Strengthening the patients' self-empowerment i.e. their ability to promote their own health within the healthcare and social context.
- Québec: multidisciplinarity and accessibility of primary care services.

  Integrated delivery systems exist in Canada since the 1970s but disease management programmes and multidisciplinary primary care practices were recently introduced in order to diminish the fragmentation and to increase the accessibility of chronic care. Further organizational expansion took place when local community centers, acute hospitals and long-term hospitals merged into health and social services centers or local health networks which nowadays also include family medicine groups[59-61].
- 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 [62]. 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 to achieve the objectives.

2.3.2.3. Major limitation: a disease-oriented approach

The countries that set up new models for chronic care first focused on specific groups of patients. The advantage of this approach is the progressive implementation of changes, with possible evaluation. The diabetes population is a frequent target group [71-74]. Other target diseases include cancer, cardiovascular, osteoarticular, respiratory diseases. The major drawbacks are the absence of holistic vision on a patient with multiple co-morbidities and the focus on a disease rather than on the patient's needs.

One interesting counterexample is SIPA ("Services Intégrés pour la Personne Agée") in Québec [75]. This community based programme focuses on older persons with disabilities and offers a full range of coordinated health and social services. This programme appeared to reduce hospital and nursing home utilization without increasing costs[76].

2.3.3. Information technologies and performance measurement

2.3.3.1. Communication technologies

The countries/regions under study have developed information systems to exchange data between providers and sometimes also with patients. This implementation is far from being successful till now in all regions/countries.

The Netherlands lack a national electronic patient record: on the one hand there were problems with digitalizing the information, on the other hand there was ethical resistance for ethical reasons[66].

The Danish healthcare system uses a health information technology tool that allows general practitioners (GPs) to coordinate with other healthcare professionals [77]. The evaluation shows that this tool is neither widespread nor used outside the GP practices.

Two initiatives in Québec relate to the implementation of an interactive system of electronic prescribing and integrated drug and disease management [60] and to the development of telehealth services[78]:

The Department of Veteran Affairs in Pennsylvania is a good example of effective large-scale implementation of IT and registries in chronic care [79]. The electronic medical registry system is particularly effective.

2.3.3.2. Performance measurement

In all countries studied attempts are made to collect data in a standardized way in order to measure performance. However this measurement is limited to specific conditions, usually with only measurement at local level. In addition, most of the data collected is orientated towards biomedical indicators ("medical evidence"), not towards achievement of "patient goals" (contextual evidence).The Netherlands developed a set of quality indicators (Zichtbare zorg). However, performance measurements only takes place regarding specific diseases (diabetes), on an experimental base at local level [80]. In Denmark, performance measurement takes place at national level for eight diseases including COPD, diabetes, and heart failure [81]. Likewise in Quebec performance measurement and data collection regarding chronic care management takes place on a project base, sometimes as a part of telehealth experiments [78,82]. In Pennsylvania there is the Improvement of "Performance Initiative Program"[62] that provides support services to the Pennsylvania Chronic Care Initiative including data management for all practices, interventional coaching services for low-performing practices, education for health professionals and improvements in collaborative data sharing.

2.3.4. Engaging consumers

Self management and individual care plans are leitmotivs of the countries with a chronic plan [66, 83-85]. The implementation has different faces but most initiatives target one or a few diseases, most frequently diabetes. Illustrations of consumers' involvement are:

- The diabetes interactive education programme (DIEP) in The Netherlands is one of the best known projects focusing on self-management[72,73].
- The Stanford Chronic Disease Self-Management Programme in Denmark: it focuses on the disease specific patient education and on the active involvement of patients in monitoring and treatment [86]. A six week workshop in a community center is facilitated by two trainers, one or both without a health professional background and with a chronic disease. The workshop includes e.g. coping strategies, possible exercises and nutrition, medication, communication with the surrounding and evaluation of new treatments. The process has been found effective. Moreover Denmark pays attention to the role of health professionals for lifestyle changes as well as their interaction with patients: this resulted in the introduction of shared decision making;
- Disease self- management programmes in Québec are for example:
  - Priisme ("Programmes Régionaux Intégrés d'Information, de Suivi Médical et d'Enseignement")[60] for the management of chronic pulmonary diseases and diabetes;
  - My Tool Box[87]: the assumption of this effective strategy is that providing patients with access to their own health information enables their better understanding of disease risk and concomitant therapeutic benefits.
- A diabetes programme in Pennsylvania includes the provision of intensive education by culturally competent health educators.

The situation on the field might differ from the theory: for example in the Netherlands only a minority of the patients benefit from an individual treatment plan.

2.3.5. *Improving Health Care delivery: translation of the national/regional strategy at local level*

National plans are translated and implemented at local level by the competent authorities: existing services were often redesigned to achieve a better integration.

In particular, disease management programmes aim to better integrate the first and second lines of care. The role of primary care receives specific attention in order to strengthen its activities regarding the organization of chronic care. Initiatives have been launched to redesign primary care, to create multidisciplinary teams or network organizations in order to provide accessible, comprehensive, ongoing and personalized care. The emphasis lies on the coordination of care by a GP or another professional[61,63,67].

- In The Netherlands, care groups, standards of care and practice supporters in general medical practices have been started:
  - 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. The care group is a collaboration of general practitioners, practice supporters, nurses trained in a specific disease area and other health care providers. This group is responsible for the quality of care of a patient group. A process is negotiated for the delivery of chronic care for patients with diabetes, COPD or vascular risk [88-92] ;
  - Standards of care are now the basis for the bundled payment of integrated care[66,90,93];
  - One care provider is the contact person for a patient: he/she coordinates the individual care of the patient. It is often the GP or the practice supporter.
- In Denmark disease management programmes are mainly implemented by health professionals working at hospitals, general practitioners, and health professionals employed in the municipalities[56]. The GPs are functioning as a gate to other healthcare professionals[67]. It is expected that greater integration between the primary and secondary healthcare sectors will occur from disease management programmes, whilst primary healthcare is already integrated within the social services[68];
- The Health and social services centers (CSSS) in Québec 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 centers, residential and long-term care centers and the community hospitals within a given territory[45]. The regional authorities are mainly responsible for supporting and coordinating their local networks and monitoring network and service performance in their territory.

2.3.6. *Aligning finance /insurance: incentives*

All countries under study have linked the launching of chronic care plan with different incentives for the providers. Examples are e.g.:

- Quality measures and bundled payments of integrated care for diabetes, COPD and vascular risk management (Netherlands)[69,93];
- Financial incentives for GPs and municipalities, quality improvement incentives through benchmarking, incentives in disease management programmes where GP's have to report data on chronic patients (Denmark)[45,56,68];
- Financial incentives for initiatives to redesign primary care and to create multidisciplinary teams or network organizations in order to provide accessible, comprehensive, ongoing and personalized care (Québec)[61,94];
- The implementation of the chronic care model in the South East Pennsylvania programme[95] included e.g. monthly reporting of quality indicators, help from practice coaches and multi-payer financial reimbursement.

2.3.7. Outcomes

In all four countries/regions only preliminary results have been presented until now. They usually show improvements in the process and limited changes in the patient outcomes:

- The Netherlands: the results regarding the impact of integrated care for chronic patients show modest improvements in care process and outcomes[88,89,96];
- Denmark: an evaluation concluded that health care centers have succeeded in implementing activities e.g. health promotion and/or disease prevention. Collaboration has taken place with several stakeholders, especially general practitioners, hospitals, other municipal institutions, patients and voluntary organizations. There is a modest impact of healthcare centers on health outcomes[45,97,98].
- In Quebec reforms are still in an implementation phase but the first results show room for improvement;
- In Pennsylvania preliminary results are positive in particular for the patients with diabetes[95,99-102]: improved patient's attitude regarding and performance of self-management, professionals' readiness to change, teamwork, communication between professionals and patients, clinical outcomes and cost savings for the highest risk group.

2.3.8. Barriers in redesigning chronic care management

Barriers for implementing integrated chronic care have been analyzed in the Netherlands[66] in Denmark[56,68] and in Québec[61]:

- Lack of incentives;
- Lack of collaboration between providers (fragmented primary care);
- Components of the Chronic Care Model are underdeveloped (ICT, coordination of care, proactive patients);
- Challenges to set up an overall strategy on a wider scale: more practices, management of the whole patient population, inclusion of more diseases;
- Lack of organizational readiness regarding actual change;
- IT and data collection: structural problems are coupled with a reluctance of the providers to use new technologies to share data. Opinions on what should be shared is also a matter of debate. In all regions the systematic collection of meaningful data seems to be troublesome. Currently, aggregate measures of quality or efficiency are generally missing or get collected for research purposes only. The clinical data on individual patients are in disconnected provider record systems. Given that performance measurement is a crucial tool for quality improvement and is linked with the other strategies (e.g. financial incentives), regions need to strengthen the data collection to be able to monitor and to improve the quality of care[53].

2.3.9. Key points: lessons learned

In all four regions multiple policy measures are introduced regarding the three stakeholders' groups: the patient, the provider and the insurer.

- There is a general shift towards consumer involvement: self-management is part of chronic care to ensure an informed and activated patient. The literature[83] found effects on clinical and patient related measures and health services utilization. Education by health professionals is usually effective. Patient-led-education has an effect on patient-related measures.
- Key factors 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. networks);
  - Communication and knowledge sharing between providers;
  - 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 Quality and Outcomes Framework introduced in 2004 in the United Kingdom illustrated, for example, that payment incentives are appropriate to achieve a change in behaviour of providers at a short term but the impact on costs, professional behaviour and patient experience remains uncertain.[103]

In all 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 specific practice change associated with a particular element of the chronic care model vary from organization to organization and from country to country. Furthermore, practices redesigning chronic care management make changes across multiple elements of the chronic care model and its impact is therefore difficult to measure[104].

In all four regions, chronic care management remains work in progress. Authors state that the four strategies (i.e. performance measurement, engaging consumers, supporting delivery system improvement, and aligning benefits and payment) are synergistic and need to be combined to produce effective results [53].

3. REASONING FRAMEWORK FOR A HEALTH SYSTEM ORIENTED TOWARDS CHRONIC CARE

Authors: Koen Van den Heede, Raf Mertens

3.1. Objective of this chapter

This section describes the development of a vision ("Root definition") for a systemic reform of chronic care in Belgium as well as the required functional activities to reach achieve this objective ("Conceptual Model").

Both elements are drawn from "Soft Systems Methodology"[105], a methodology that offers tools that are useful for systemic reforms.

The vision (term used in this chapter, same concept as the "root definition" used in the soft systems methodology) is a description of the unique contribution (the 'purpose') that the system is meant to deliver:

A root definition is a precise statement that takes the following generic form: "A system owned by O and operated by A, to do X by Y to customers C in order to achieve Z within constraints E"[105].

Based on this vision a 'conceptual model' is developed to show how the system will realize its purpose.

A conceptual model does not represent an actual, existing system but represents an idealized system that is able to deliver that unique contribution as summarized by the vision. It consists of a set of 'functional activities'.

The vision and conceptual model are based on the insights that emerge from the analysis of:

- The chronic care model (see scientific report section 2.2);
- The reports from international organizations (see scientific report section 2.2);
- Policies for patients with chronic conditions in 4 countries (see scientific report section 2.2);
- Attributes of high quality chronic care[106,107];

- Discussions with stakeholders and within the research team;
- A previous similar exercise for child and adolescent mental health care (KCE-study HSR-025-02).[108]

The vision and corresponding conceptual model described in this chapter represent an idealized system without recognized boundary, legal status, resources, power and so on. In a further step (see chapter 7) Belgian stakeholders will compare this idealized system with the current Belgian system to identify priority areas for reform.

Recommendations and related actions are formulated at the end of this research, based on the inputs mentioned above with additional information from:

- An analysis of existing KCE-reports (see scientific report chapter 5);
- A systematic review on patient empowerment interventions (see chapter 6.3);
- A scoping review of new roles for health professionals to reinforce the first line of care (see scientific report 6.4).

It should be stressed that chronic care of high quality is an integral part of the global health care system, not an apart system. The purpose is that the overall health care system would provide care that specifically answers to the needs of the chronic patient.

3.2. Development of a vision for a reform of chronic care in Belgium

Policies oriented towards chronic care of high quality have four macro-goals:

- Preventing the onset of chronic illnesses;
- Postponing the age on which chronic illnesses appear;
- Preventing or delaying complications;
- Achieving the highest quality of life by supporting people with chronic illnesses to manage their illness to the best extent possible.

The vision described in this report entails those 4 macro-goals. However, the partners involved in this project agreed to limit the scope of the next parts of the document for feasibility reasons on the two last macro-goals with a limitation to the health care system. The first two goals (parallel to health promotion, health in all policies) call for the active contribution of stakeholders involved in other domains than the health care system. Also for the latter two macro-goals the involvement of stakeholders outside the healthcare system is relevant. However, this was not possible within the scope and timing of this project.

3.2.1. General shape of the vision or root definition

The vision/root definition for a future system oriented towards chronic care is a synthetic expression of the fundamental contribution (or 'purpose') of this care system. In other words, it expresses the purpose of an idealized system using a statement that takes the following generic form: "The envisaged Belgian chronic care system is a system owned by O and operated by A, to do X in a Y way to customers C in order to achieve Z within constraints E."

- Core assertion: "The envisaged Belgian chronic care system is a system to do X to clients C in order to achieve Z."
- Y way specifies how this purpose is realized.

Additional qualifications provide a richer framing of the basic purpose:

- Actors A: people and organizations that are involved in actually implementing the system's purpose;

- Owner O: actor(s) who are able to change or stop the system and therefore can be regarded to own it;
- Environmental constraints E: external circumstances that influence the system's operations.

3.2.2. Core purpose

We will now proceed by proposing a formulation for the core purpose of the envisaged chronic care system in Belgium:

"The chronic care system offers an array of services (X) for people with conditions requiring ongoing management over a period of years or decades (C), to help these people to improve their quality of life and to function better at home, at work/school, in the community and throughout life (Z)."

Delivering services (X)

The chronic care system is basically there to deliver 'services'. These services cut across the primary, secondary and tertiary levels of care and extends beyond the boundaries of the healthcare system to cover issues such as population health promotion, prevention, screening and early detection, diagnosis, management of diagnosed cases, rehabilitation and palliative care'.

As noted above, the scope of this paper is the chronic care from the health care system perspective. Health in all policies, population health promotion and primary prevention (although part of the larger chronic care system) are beyond the scope of this study.

Beneficiaries (C)

The 'clients' of the system are people with chronic conditions requiring ongoing management over a period of years or decades and their families/informal caregivers (see scientific report 1.3). The system delivers services to all people with chronic conditions during the continuum of their disease i.e. the routine management, the management of acute episodes and supportive care.

Outcomes (Z)

The long-term management of chronic conditions requires more than the improvement of the person's situation in a merely technical sense. The ultimate aim of the services is to help people to improve their quality of life and to function better in society - at home, at school, at work and in their communities. This requires a shift of paradigm, from problem-oriented to goal-oriented care[109]. This vision of ideal outcomes is in line with the vision of the International Classification of Functioning, Disability and Health (ICF) [110]. As a matter of fact this classification based on a biopsychosocial model integrates the medical but also the social consequences of disability.

3.2.3. Additional qualifications

The core of the vision is now supplemented with additional qualifications: how is the purpose realized (Y)? who are the actors involved (A)? who 'owns' the system (O)? And what are crucial constraints in which the system has to operate (E)?

Modus operandi (Y)

The envisaged chronic care system delivers services. We propose to include 8 qualifiers that specify how this system should function.

1. Co-ordinated

The current healthcare system has difficulties to deal with the increasing number of persons with (mostly multiple) chronic conditions [39]. Patients receive fragmented care from many different providers, in different settings and institutions. In addition, isolated initiatives (e.g. patient education classes organized locally by health insurers, follow-up of heart failure patients in university hospitals) are often not coordinated with other services.

Coordination' is one of key requirements for the envisaged chronic care system. Coordination is also one of the main objectives of the CCM[51]. The review of policies in four countries has indeed shown a move towards a higher level of co-ordination between health services and also between health and social services. The set up of care networks is one way to enhance the co-ordination between services. The Montréal stroke network is one illustration[111] (see appendix 1.6).

2. Integrated

Integrated care is closely related to the former concept. The WHO defines it as "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system"[112]. In this document integrated care more specifically refers to a vertical integration between lines of care whilst the word "coordination" mentioned in the former point refers to multi-professional teams that work within the same level of care.

3. Person- and Goal-oriented

The increasing prevalence of multi-morbidity stresses the need for a shift from "chronic disease management" towards "participatory patient management", with the patient at the centre of the process. The goal of chronic care is to assist individuals in achieving their maximum individual health potential in line with their individually defined and goals in a planned way[39,113]. One important determinant is the complexity of care and social problems that determine the complexity and coordination of the solutions.

4. Sustainable

Sustainability is the system's capacity to provide and maintain infrastructure such as workforce (e.g. through education and training), facilities and equipment, and be innovative and responsive to emerging needs[106].

5. Professionally supported

A human resource continuum, able to meet the range of needs of people with chronic conditions (from minimal personal assistance to daily total care), is essential to ensure that the right patients get the right type of care at the right time. This involves many different professionals and specialists working as teams. Existing roles will have to be refined (i.e. enhancement, substitution, delegation and innovation) to make optimal use of this diversified workforce and to ensure adequate supplies of the right type and mix of workers[8,39]. It is important that health professionals would spend most of their time on tasks that do require their expertise. This entails the shifting some tasks from more specialized professionals to less-qualified, lower-cost workers[114].

6. Care of high quality based on the best available evidence

This document adopts the definition and dimensions of quality of care proposed by previous KCE-reports[106,107,115,116]. They selected the most used and comprehensive one, from the Institute of Medicine (IOM): " the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge". This definition focuses on a goal-oriented care i.e. to achieve the highest possible level of health as defined by the individual.

The dimensions of quality of care match the ones recently published by the Flemish advisory body well-being, health and family in 2011 [117]. They include:

- Safety ('the degree to which the system has the right structures, renders services, and attains results in ways that prevent harm to the user, provider, or environment');
- Effectiveness (services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit);
- The closely related concept of appropriateness (the degree to which provided healthcare is relevant to the clinical needs, given the current best evidence);
- Patient centeredness: care that is respectful of and responsive to individual patient preferences, needs, and values;
- Timeliness: reducing waits and sometimes harmful delays;
- Efficiency: the degree to which the right level of resources (i.e. money, time and personnel) is found for the system (macro-level) and ensuring that these resources are used to yield maximum benefits or results (i.e. allocative efficiency);
- Equity: the level of care does not vary in quality because of personal characteristics. This term covers physical access (geographical distribution), costs, time, cultural access (e.g. religion), psychological access and availability of qualified personnel[106];
- Comprehensiveness: defined by the WHO[118] as "health services that are managed so as to ensure that people receive a continuum of health promotion, disease prevention, diagnosis, treatment and

management, rehabilitation and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course".

- range of services and care broad enough to meet all common needs as they occur;
- Continuity: 'the extent to which healthcare for specified users, over time, is smoothly organised within and across providers, institutions and regions'. This means that 'coordination' (i.e. smooth organization across providers, institutions and regions) is considered to be part of continuity[106]. The concept of integration is closely related to the concept of continuity of care and further detailed in the section on international papers (see scientific report section 3.1).

7. Patient empowerment:

'Patient-centeredness' implicitly keeps the active role at the side of the provider, whilst "self-empowerment" places the patient in the centre of his/her care. This concept entails a re-distribution of power between patients and physicians: empowered patients are more able to care for their health and for the interactions with health care professionals.

Patient empowerment is related to a range of interventions to achieve various outcomes (e.g. patient satisfaction, self efficacy, clinical outcomes) [51,119]. The evidence for the techniques that support self-empowerment is described in the literature review (see chapter 6.1).

8. Provided in the least complex environment that is clinically appropriate to the patient's situation

The Chronic Care Model stresses the role of the community for delivering care in the least complex environment that is clinically appropriate (relates also to accessibility). This principle of 'subsidiarity' means that, whenever possible, 'lower level' (less complex) home-based or outpatient services are used instead of costly residential services. This requires a primary health care system more closely oriented to the needs of patients: multidisciplinary, well coordinated and accessible 24 hours a day (e.g. multidisciplinary group practices; nurse-led clinics). One illustration is the "SIPA", system of integrated services for the frail older persons, in Québec (see 2.2).

Actors (A)

The vision articulates a purpose and a general modus operandi of a conceptual, idealized system. The general purpose encapsulated by the vision will be realized by the contribution of different actors, health professionals and other parties (e.g. GPs and primary care practices, nursing homes, community nurses, nurse practitioners, specialists, family caregivers, physiotherapists, speech and language therapists, acute care hospitals, social services). At a later stage this report will investigate how actors in the existing care system can contribute to the envisaged system.

Owner (O)

The Belgian (chronic) care system is for the largest part funded by public money, but private for profit and not-for-profit actors play a big role in the actual provision of care. Successful reforms will need a shared ownership of both the providers and the authorities. .

Constraints (E)

The available limited budget will exert an important influence on the chronic care system's operations. Moreover, the current institutional, professional and sectional fragmentation might continue to influence the implementation of the ideal chronic care system.

3.2.4. Expanded vision/root definition

In light of the qualifications defined above, the vision can be set out as follows:

The chronic care system offers a co-ordinated array of needs-based, personalized, goal-oriented, planned, professionally supported services for and with persons with chronic conditions requiring assistance over years or decades with the routine management of their condition as well as the management of acute care episodes. These services are provided in a high quality, efficient, sustainable, accessible, culturally competent and patient empowering manner in the least complex environment that is clinically appropriate. The objective is to improve the beneficiaries' quality of life and to help them to function better at home, at school/work, in the community.

3.3. Conceptual model: functional activities required for a chronic care system

The vision is the basis for the development of a conceptual model. This is a synthetic representation of a work system that exists to achieve a particular purpose. It shows the activities to be carried out to realize the system's purpose.

It is very likely that people belonging to a range of different organizations and services will contribute to those activities. So the boundary delimiting the conceptual model is not an organizational boundary.

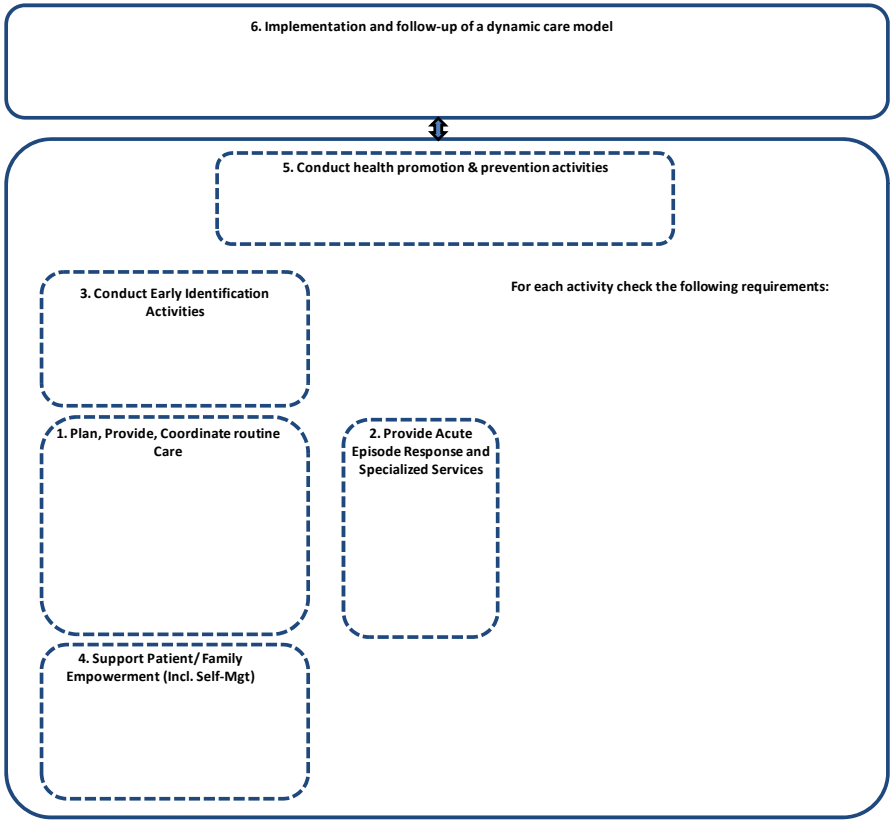
The model developed for the chronic care system is composed of 17 different activities, grouped into 6 functional modules:

1. Plan, provide and coordinate routine care;
2. Provide acute episode response and specialized services;
3. Conduct early identification activities;
4. Support patient/family empowerment (including self-management);
5. Conduct health promotion and (primary) prevention activities;
6. Implementation and follow-up of a dynamic care model.

For each of these activities 6 requirements need to be checked (in order that each module functions appropriately);

The relationships between the different modules are illustrated in Figure 6. We will gradually build up the conceptual model by describing each module briefly, together with the constituent activities.

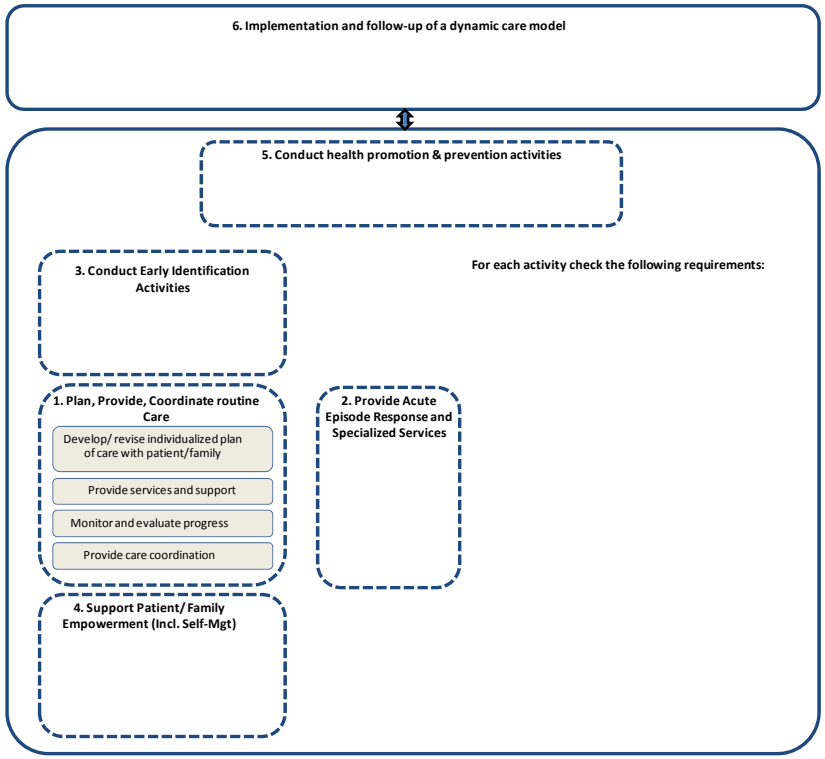
Figure 6 – Functional Modules of the Conceptual Model



3.3.1. Plan, provide and co-ordinate routine care

According to the vision/root definition, the chronic care system is a system that delivers services. The actual care by the individual provider(s) to the individual patients is At the heart of the system. Hence, there is a core module in which routine and supportive care services are delivered.

Figure 7 – Plan, provide and coordinate routine care module



The provision of routine care has 4 constituent activities:

- Develop/revise individualized plan of care with patient/family: as indicated above, a care plan for people with chronic conditions is individualized, based on the goals that the patients want to achieve. This activity will require few resources when patients are in a steady stage of a single chronic condition. In more complex cases with multimorbidity and/or regular acute episodes, this will take more effort;
- Provide services and support: this is the actual delivery of services (including supportive care, secondary and tertiary prevention). In Belgium these services are typically delivered by the GP and the home nurse, but they can also be delivered at primary care centres, at school/work, at social care centres, or in facilities as nursing homes;
- Monitor and evaluate progress: the provision of care services to people with chronic conditions and their families has to be monitored for effectiveness. The monitoring generates a feedback that gives professionals and patients/family a basis to decide on the nature and extent of the care pathway;
- Provide care coordination: the vision puts forward the requirement that service provision is coordinated within and beyond the chronic care sector. This requires dedicated resources. This activity focuses on the coordination of routine care. A separate activity (see below) is foreseen to link modules 1 (plan, provide, coordinate care) and 2 (provide acute episode response services);

3.3.2. *Provide acute episode response and specialized services*

Acute episode response and specialized services are in a second module of the conceptual model (Figure 8). It is the care in response to acute exacerbations, complications, decompression, … of the chronic condition and, on the other hand, also the specialist services for diagnostic work-up, initial treatment elaboration and regular follow-up. It also includes coaching of the GP and other primary care actors. The related activity is:

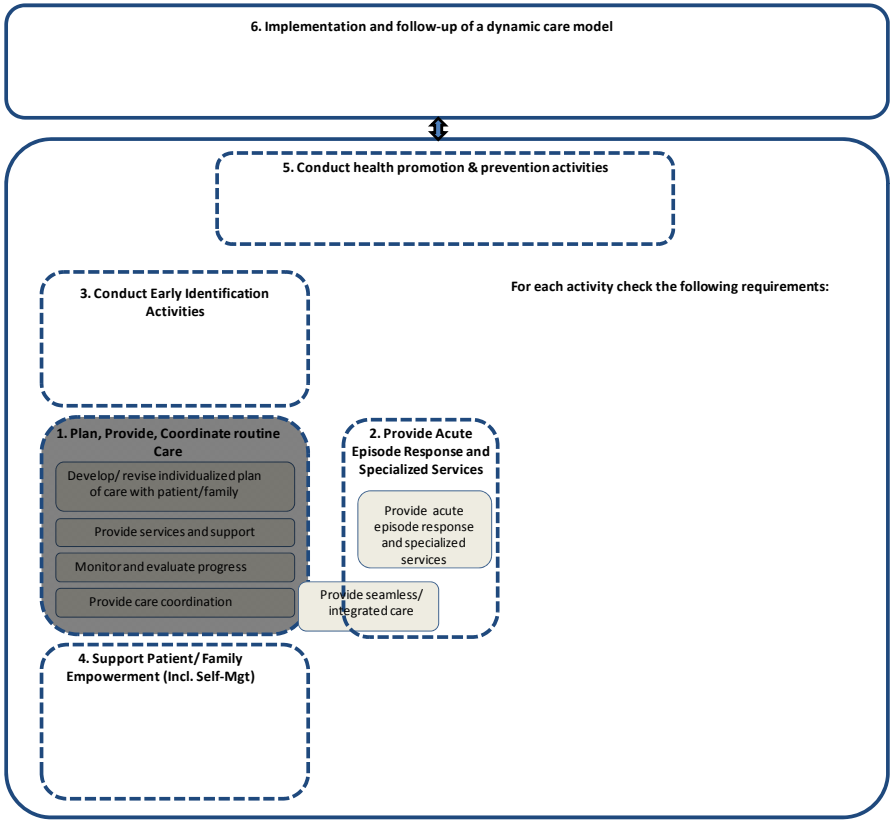
- Provision of acute episode response and specialized services: The conceptual model does, however, not specify how this has to happen (e.g. specialized units in acute hospitals, day hospitals, outpatient specialized care).

An activity has been placed on the interface between modules 1 (plan, provide, coordinate routine care) and 2 (provide acute episode response and specialized services) with the aim to connect both modules:

- Provide seamless/ integrated care: there is need to dedicated activities, tools, infrastructure and resources to provide a seamless transition between routine care and acute episodes or specialized care (and vice versa).

This module stresses the importance of integrating chronic care in the general health care system. The concept of integrated care has been detailed in section 3.2.3.

Figure 8 – Acute Episode Response and Specialized Services module



3.3.3. *Conduct early identification*

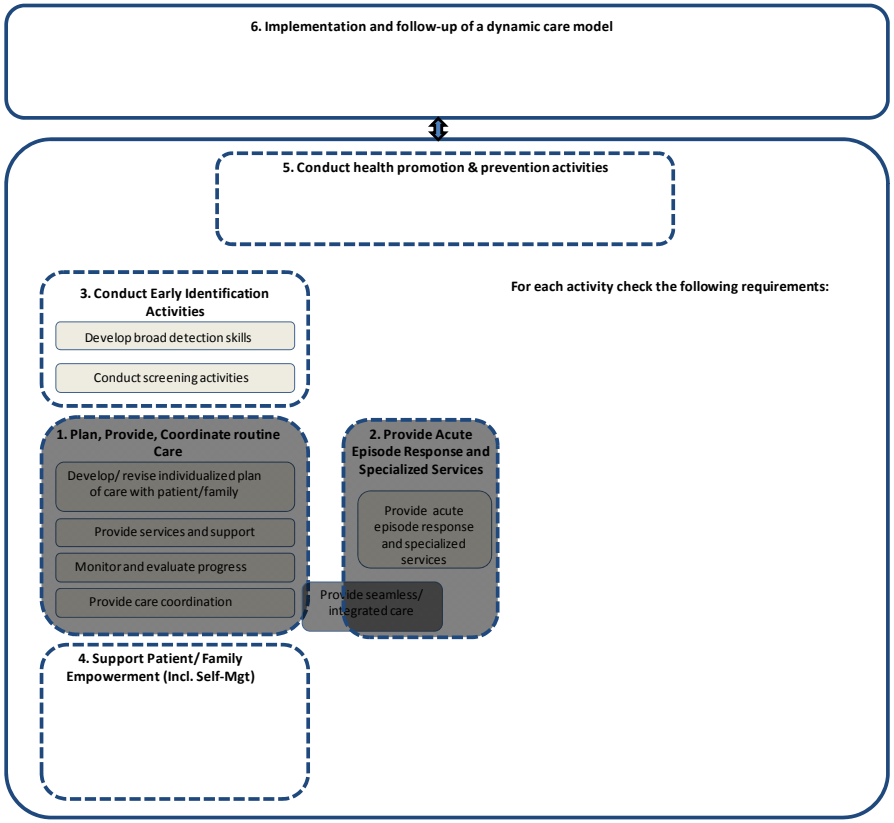
There is broad agreement that early identification of chronic conditions is particularly important[8].

This module (Figure 9) connects with the 'plan, provide, coordinate routine care' module. There are 2 related activities:

- Develop broad detection skills: these skills have to be developed in primary care workers (e.g. GPs) in the first place but also in occupational healthcare workers.
- Conduct screening of the target populations when appropriate. The validity of a screening programme can be assessed according to the criteria specified by Wilson and Junger (1968)[120]:

1. the condition should be an important health problem;
2. the natural history of the condition should be understood;
3. there should be a recognisable latent or early symptomatic stage;
4. there should be a test that is easy to perform and interpret, acceptable, accurate, reliable, sensitive and specific;
5. there should be an accepted treatment recognised for the disease;
6. treatment should be more effective if started early;
7. there should be a policy on who should be treated;
8. diagnosis and treatment should be cost-effective;
9. case-finding should be a continuous process.

Figure 9 – Early identification activities module



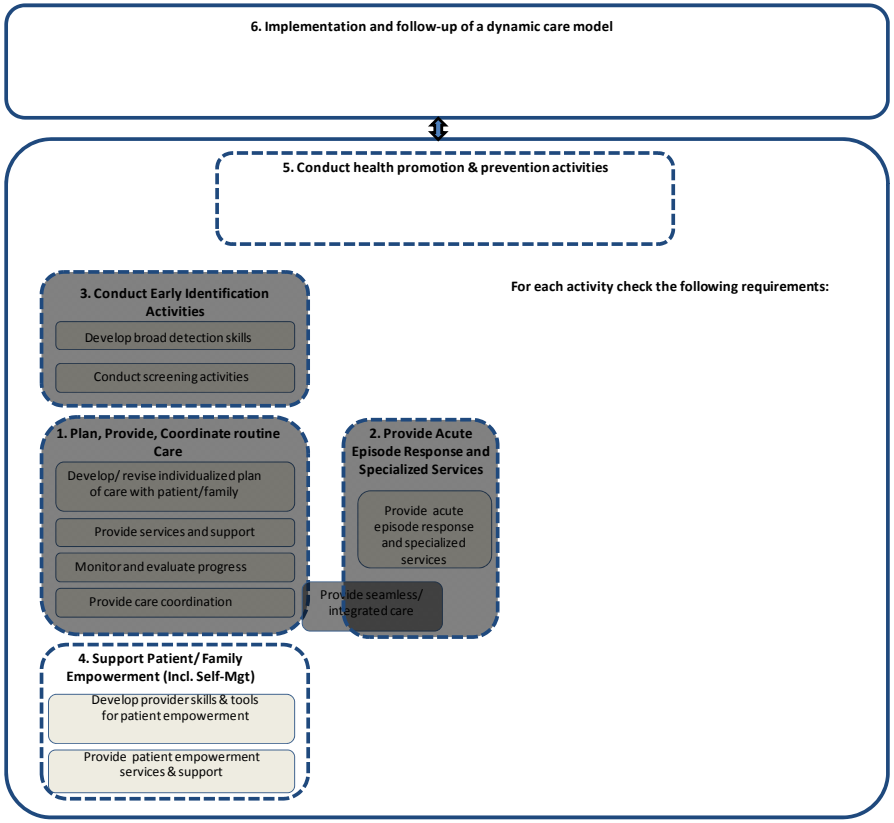
3.3.4. *Support patient/informal caregiver empowerment (including self-management)*

As described above patient empowerment is an essential element of chronic care[51]. Self-management and the support of informal caregivers are two major pillars. Illustrations of self-empowerment are instruction and help for lifestyle changes, medication use or self-measurement (e.g. glucometers or bathroom scales)[51]. An illustration of the effectiveness of support to caregivers is found in the KCE report 160 on interventions for dementia[121].

This module (Figure 10) consists of 2 activities:

- Develop provider skills & tools for patient/caregiver empowerment: a set of new provider skills (e.g. behaviour management) and tools (e.g. patient diaries; guidelines/educational materials) need to be developed.
- Provide empowerment services & support: by putting in practice the above-mentioned skills and tools, the patients and families will be be supported with information, coaching, peer support, training by formal and informal services.

Figure 10 – Support patient/informal caregiver empowerment module



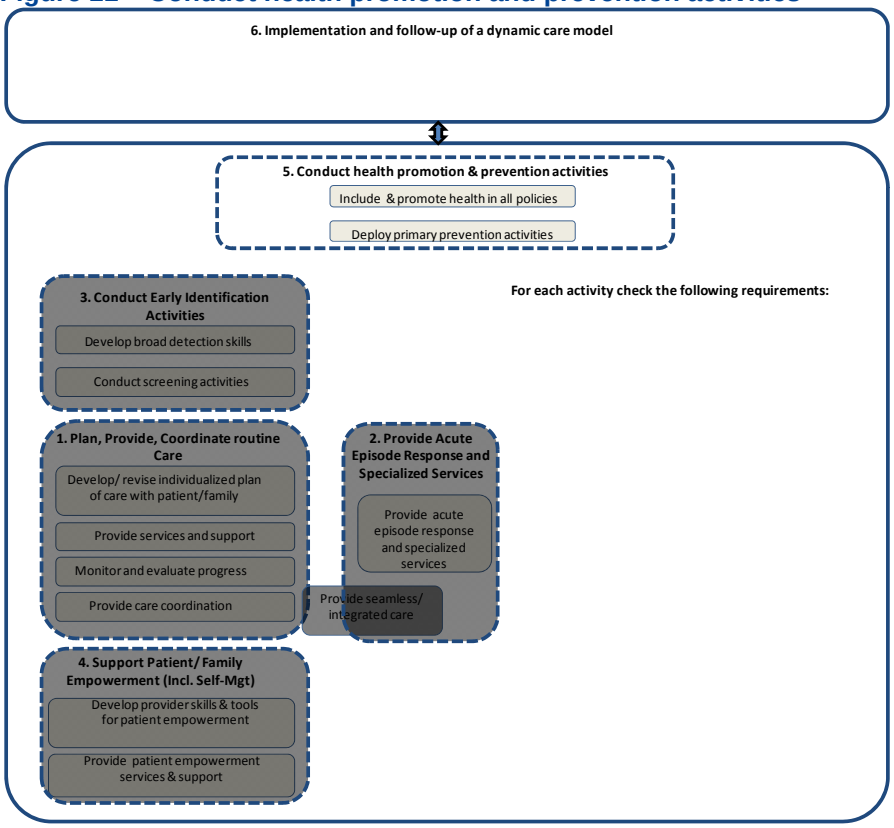
3.3.5. *Conduct health promotion and prevention activities*

This module aims to prevent the onset of chronic illnesses and to postpone the age of onset. Despite being part of the system, this module will, due to feasibility reasons, not be operationally defined in the next study phase.

The prevention and health promotion module consists of 2 activities:

- Include and promote health in all policies: "Health in All Policies" is an approach which goes beyond the boundaries of the health sector. It addresses all policies such as transport, housing, the environment, education, fiscal policies, tax policies and economic policies. This activity requires multisectoral action for health, by the entire government. It may help to make policies more consistent overall and contribute to better regulation[122];
- Deploy primary prevention activities: this is the core prevention activity that targets all common risk factors to chronic diseases (see international papers chapter 3). Different kinds of interventions take place in various settings.

Figure 11 – Conduct health promotion and prevention activities



3.3.6. Implement and follow-up a dynamic care model

The system needs to have the capacity to adapt itself and to refine the care model in the light of developments in society, in science, in the expectations of people with chronic conditions and in the economic reality. Five activities are included in this last module:

- Develop/update care model: this central activity of the module is a reflexive questioning and subsequent adaptation of the model for people with chronic conditions;

  The development and updating of the care model originates from the combination of four activities:
- Base the model on societal values to reflect and respond to dominant trends in society. A care system reflects a particular value base (as does the present exercise). There has to be a regular assessment of the relevance of these guiding values and their capacity to inspire health professionals and policy makers;
- Assess the needs of people/ family with chronic conditions: the problems of people with chronic conditions are a dynamic datum. Society evolves: keeping abreast of these developments requires dedicated resources;
- Identify state-of-the-art practices: research is needed to assess novel developments and techniques (e.g. the development of evidence based guidelines for the chronic care target population taking into account the complexity of multimorbidity). The knowledge base should include 'medical', 'contextual' and 'policy' evidence. 'Medical evidence informs us about 'efficacy' (what works in isolation, in an ideal setting). Contextual evidence contributes to make medical research work in daily practice (i.e. effectiveness: what works in routine practice), while policy evidence contributes to efficiency and equity on an (inter)national scale.[123]
- Incorporate budgetary/ resource constraints.

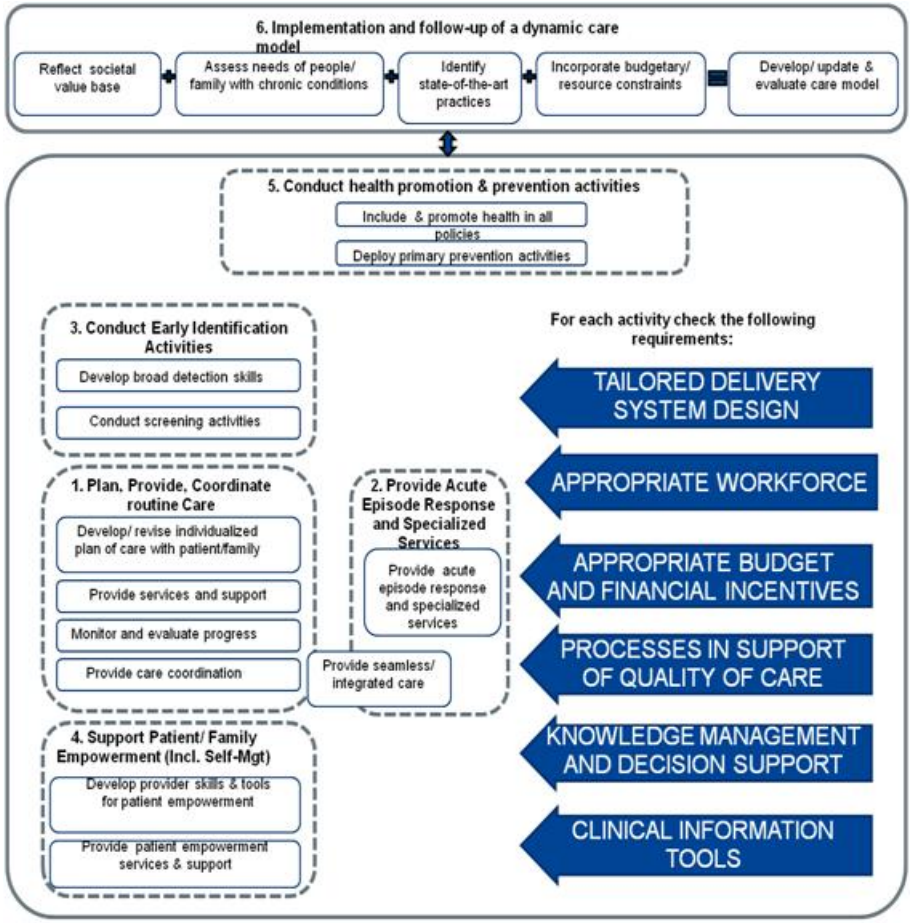
3.3.7. Six requirements for each activity

Services can only be provided when they are developed, supported and organized. This transversal module consists of a set of 6 requirements that need to be fulfilled for the successful implementation of each of the activities of the conceptual model. This checklist will have to be applied in a specific (and different) way for each module.

- Tailored service design and organization: a synthesis from the European Observatory for health care systems shows that in most western countries the current service array for people with chronic conditions is too hospital-centred[8,39]. Many countries are therefore reinforcing services in the primary care setting (see the review of 4 countries: paragraph 2.2). The development of alternative services, however, rests on a gap analysis between the nature and quality of services and infrastructures already in place and the actual demand for services;
- An appropriate workforce is a key for chronic care provision. This requirement includes the provision of a sufficient number of healthcare workers with the right qualifications to carry out the professional roles that are required to meet the system's goals. The review on health professionals (see paragraph 6.4) highlight the new functions in evolution (i.e. enhancement, substitution, delegation and innovation);
- The right financial incentives: There is no single 'best' way to pay for services for people with chronic illnesses, but there is little doubt that payment methods have important implications for the nature and quality of the services provided[39]. This requirement is part of the model to assure that a coherent package of financial incentives is put in place to nurture the other functional modules;
- Processes in support of quality of care: this requirement includes procedures (e.g. audit and feedbacks) that are developed and implemented into the entire system so that quality requirements for services will be fulfilled;

- Knowledge management and decision support: This component of the Chronic Care Model refers to evidence-based clinical practice guidelines that should be integrated into daily practice (e.g. use of proven provider education tools; sharing of evidence-based guidelines and information with patients to encourage their participation). [51] In addition to 'medical evidence' there is a need for a better understanding of the context and the policy level (see above).[123]
- Clinical information tools: coordination, decision support, self-management, etc. depend on at least some information management. There is growing international agreement that introducing modern ICT at different levels into the care process may lead to more effective use of resources, an improvement in quality of care and greater attention paid to the needs and wishes of patients[8]. Technical and organizational infrastructure to support these activities will be discussed later in the report.

Figure 12 – The full conceptual model for a chronic care system



3.4. Concluding remarks

The sections above formulated a vision and conceptual model including the generic activities that are needed to realize the vision. The conceptual model should not be dissociated from the vision with which it is narrowly connected and which provides necessary framing.

The reasoning framework for a reform of the Belgian chronic care system relies heavily on the international evolutions within this field and as such reflects the distinctive features of a newly emerging care philosophy.

The conceptual model which is inspired by the CCM differs in several ways from this original model.

Firstly, our conceptual model uses a functional logic. In contrast, the CCM mixes a functional logic with an organizational logic. Our conceptual model, for instance, provides a 'care coordination' activity. This activity is generic and could be implemented in different ways as long as it complies with the 'vision'. The CCM stipulates already some specific organization types of services (e.g. case management for complex cases).

Secondly, our conceptual model includes 'plan, provide, coordinate routine care' and 'provide acute episode response and specialized services' as the atomic activity at the heart of the care for the chronically ill, therefore constituting the service backbone of the system. In addition the modules 'conduct early identification activities', 'support patient family empowerment' and 'conduct health promotion and prevention activities' are foreseen. The module that concerns 'health promotion and prevention' is out of the scope of this study.

To realize each of these modules according to the specified vision several requirements are needed. As a matter of fact, whatever activity one is envisaging, one will always need adequate people, appropriate structures, money, well designed procedures, access to relevant knowledge and effective information and communication tools.

These requirements resemble (partly) the CCM-dimensions. The Clinical information tools and knowledge management & decision support overlap largely. The CCM dimension delivery system design is specified as 'tailored delivery system design' and 'appropriate workforce, the CCM module 'Health system' is specified as 'the right financial incentives' and 'processes in support of quality of care'. The CCM dimension 'self-management' is not specified as a requirement. We included 'patient empowerment and self-management' as a separate module. After all, the future care system calls for participatory patient management, with the patient at the center of the care provision process. This does not mean that the patient is passively put at the center but is in control of his/her health and interactions with health care professionals. This requires a substantial reconfiguration of the relationship between provider and patient compared to the existing system which is still quite often paternalistic in spirit. We think that interventions on each of the requirements (i.e. workforce, organizational designs, financing mechanisms, quality processes, decision support and clinical information systems) are needed to realize this.

Thirdly, another added value of our 'conceptual model' compared to the CCM is the inclusion of 'implement and follow-up a dynamic care model' module. This is a strategic module that on a regular basis reassesses the purpose of the system against evolving values, needs and available resources.

4. CHRONIC CARE INITIATIVES IN BELGIUM

Authors: Liesbeth Borgermans (initiatives from Federal Public Health Services), Geneviève Haucotte and Sophie Gerkens (initiatives from National Institute for Health and Disability Insurance), Dominique Paulus

4.1. Objective of this chapter

This chapter describes the existing initiatives in Belgium with the following research question: “What initiatives on chronic care are implemented in Belgium that target patients in a direct and indirect way?"

A chronic care initiative is defined in this study as:

'An initiative or intervention for which there is a payment and/or legislation in Belgium and that focuses on the provision of information, support or care to patients with chronic illnesses in a direct and indirect way with the aim to improve the quality of care'.

A definition of a chronic illness is defined in section 1.3.1 of this report. The definition of quality and its related dimensions can be found in section 3.2.3.

4.2. Methods

4.2.1. Data sources

The first data source is the analysis of the national programme “Priority to chronic patients !” [124] published by the Minister of Public Health and Social Affairs in 2008 with a first evaluation published in 2012[125].

The initiatives for chronic care patients were identified through three other sources at federal level:

- The Federal Public Service Health, Food Chain Safety and environment;
- Sickness funds: Christian, Socialist and Independent sickness funds;
- The National Institute for Health and Disability Insurance (NIHDI/INAMI/RIZIV).

Initiatives at the Region and Community level are also multiple. The scope was however limited to initiatives that relate to the care of patients at national level as the competences of the Communities and Regions mostly cover the health promotion and prevention and help related to personal matters.

4.2.2. Data collection

- Data from the Federal Public Service

One author of this report (LB) drafted a standardized form to collect the information from the FPS departments involved in the organization of care for chronic patients. For every initiative an analysis was made of the following items: short description of the initiative, target population and setting, type of services (e.g. information, support, type of care) and costs (if available).

- Data from the NIHDI

Staff members from the NIHDI under the coordination of a colleague (GH) compiled an extensive description of the initiatives oriented towards the patients with chronic disease (perhaps soon available on NIHDI website). One author of this report (SG) wrote up a summary of this overview (see 4.5).

4.2.3. Inclusion and exclusion criteria

Initiatives (policies) were included if they answered to the definition of a chronic care initiative (cf. 4.1). Two domains were excluded from this analysis:

- Primary prevention

Initiatives were excluded if they dealt with primary prevention (e.g. screening, immunization, counselling and population-based awareness campaigns).

- Long-term residential care

Long-term residential care refers to nursing homes and facilities for patients with neuropsychiatric diseases (forensic and non-forensic), sensory disorders (e.g. blindness, deafness), musculoskeletal disorders (e.g. multiple sclerosis, amyotrophic lateral sclerosis) and a broad range of

physical disabilities (e.g. paraplegia, quadriplegia). A recent list of the rest and nursing homes has been recently published on the NIHDI website[126].

4.3. National plan: "Priority to chronic patients!"

This national programme published in 2008[124,125] covers the following domains:

- Information to the patient;
- Measures to improve the accessibility to care for chronic patients:
  - better access to the patient's status that gives right to higher reimbursement (OMNIO – BIM);
  - easier entitlement to free access to care via an online application (MyCareNet);
  - connections between health administrations to offer a unique counter for the patient who needs administrative services;
  - easier administration for receiving help in case of incurable disease.
- Integration of chronic patients in the society:
  - minimum wage for patients with a chronic disease;
  - standard criteria for the advisory physician's decisions;
  - help to go back to work;
  - financial support for the informal caregiver who gives up his/her job to help the chronic patient.
- Improved financial accessibility e.g. adaptation of the "MAF" for chronic patients; transport, physiotherapy, respite care, reimbursement of specific medications;.
- Development of a new action plan for rare diseases;
- Set-up of an observatory for chronic diseases within the NIHDI with two sections (scientific and consultative sections). Patients' organizations and sickness funds play a major role.

4.4. Description of the initiatives from the Federal Public Service Health, Food Chain Safety and environment and from the Sickness Funds

4.4.1. Inventory of initiatives that target patients with a chronic illness

A total of 40 initiatives that target patients with chronic illnesses were identified: 35 of these initiatives directly and 5 indirectly impacted on patients (sickness funds related care services, scientific studies, financing of data-managers, reinforcement of the cancer register and electronic data registration by community nurses).

Table 2 – Initiatives from the Sickness Funds

	Type	Population	Information	Support	Cure	Rehabilitation	Palliative care	Home care	Hospital care
1.	Social services centres	NS	X	X				X	
2.	Member organizations	NS	X	X				X	
3.	Information centres	NS	X	X				X	
4.	Home care centres/shop	NS	X	X				X	
5	Phone centres	NS	X	X				X	
6.	Internet services	NS	X					X	
7.	Information sessions	NS	X					X	
8.	Transport services	NS		X				X	
9.	Surveillance services	NS		X				X	
10.	Sickness funds related organizations	Older and younger people	X	X				X	
11.	Sickness funds related care services	NS							
12.	Interest groups	NS	X						
13.	Insurance services for specific populations	Cancer, MS, ALS, Parkinson, AIDS, hepatitis, type 1 diabetes, kidney disease, cystic fibrosis, Crohn disease…		**X**	**X**	**X**		**X**	**X**

Table 3 – Initiatives from the Federal Public Service Health, Food Chain Safety and environment

	Title	Population	Information	Support	Cure	Rehabilitation	Palliative care	Home care	Hospital care
14.	Pain function	Patients with chronic pain			X				X
15.	Pain networks (= multidisciplinary networks hospital and home care)	Patients with chronic pain	X	X	X	X		X	X
16.	Oncological centres for children	Children with cancer	X	X	X	X			X
17.	Multidisciplinary teams in support of children with cancer	Children with cancer							X
18.	Paramedics operating in hemato-oncological centre	Patients with cancer		X	X				X
19.	Post-graduate training of tabaccologists	Patients with cancer		X				X	X
20.	Post-graduate training of psycho-oncologists	Patients with cancer		X					X
21.	Peer support groups	Patients with cancer	X	X					X
22.	Psycho-social support of patients	Patients with cancer		X					X
23.	Psycho-social support of families	Patients with cancer		X					X
24.	Recognition of the title oncological nurse	Patients with cancer			X				X
25.	Scientific study on rare cancers, cancers that need a complex treatment and organizational models	Patients with cancer	NA	NA	NA	NA	NA	NA	NA
26.	Financing of data-managers	Patients with cancer							X

	Title	Population	Information	Support	Cure	Rehabilitation	Palliative care	Home care	Hospital care
	(= follow-up on number of patients with cancer, treatment results, ...)								
27.	Reinforcement of the cancer register	Patients with cancer	NA	NA	NA	NA	NA	NA	NA
28.	Electronic data registration by community nurses	Mainly geriatric patients						X	
29.	Internal and external liaison (care programmes)	Geriatric/ oncological patients		X	X				X
30.	Geriatric reference nurses	Geriatric patients			X				X
31.	Discharge manager	Geriatric patients		X					X
32.	Day care centres	Geriatric patients			X				X
33.	Day care centres	Parkinson disease							X
34.	Diabetes education (hospital-based)	Patients with type 2 diabetes	X	X	X				X
35.	Recognition of the title diabetes educator	Patients with diabetes							X
36.	Internet site with info on chronic diseases	Not specified	X						
37.	Care circuits and networks (art. 107)	Psychiatric patients				X		X	
38.	Co-ordinator platform palliative care	Patients who need palliative care					X	X	X

	Title	Population	Information	Support	Cure	Rehabilitation	Palliative care	Home care	Hospital care
39.	Psychologist platform palliative care	Patients who need palliative care					X	X	X
40	Palliative care function (mobile multidisciplinary teams)	Patients who need palliative care					X	X	X

4.4.1.1. Population

The populations that were most often mentioned were patients suffering from cancer (n=12), from psychiatric illnesses (n=6) and patients who need palliative care (n=3). Patients with chronic pain (n= 2) and diabetes (n=2) were also mentioned. Very few initiatives were mentioned for people with Parkinson disease, multiple sclerosis, AIDS, hepatitis, cystic fibrosis, Crohn disease and colitis ulcerosa (n= 1).

For 14 initiatives the population was not mentioned or focused on frail older or younger people with complex care needs.

No initiative was identified that explicitly focused on patients with multimorbidity (see 1.3.2.1).

Family and informal caregivers are explicitly mentioned in only 2 (5%) of the initiatives. Some sickness funds provide support services for family caregivers through their related organizations. These include member organizations (e.g. defence of interests) and non-profit organizations (e.g. home care organizations). Another example is the national cancer plan that includes measures to improve the psycho-social support of family and informal caregivers.

4.4.1.2. Information services

Information to patients is provided in 35% (n=14) of the initiatives. Sickness funds provide most information to patients e.g. prevention, financial (reimbursement) information, home care services. A range of sickness fund related organizations also provide information to patients. Particular channels of information services include internet services and phone centres. These services offer e.g. applications to simulate hospital costs, calculations of cost-savings when using generics and the comparison of costs between hospitals.

4.4.1.3. Support services

More than half of the initiatives (n=23) provide support to patients. The extent and number of support services provided by the different sickness funds substantially differ.

Sickness funds offer a variety of social services in terms of home care services, transport and surveillance services. Their wide range of psycho-social support services are provided through social service organizations, local initiatives and volunteers.

A range of services is also included in the complementary insurance scheme or organised on a local basis for targeted populations including cancer, dementia, multiple sclerosis, ALS, Parkinson disease, AIDS, hepatitis, diabetes type 2, kidney disease, cystic fibrosis, Crohn disease and colitis ulcerosa.

Support services for family members and informal caregivers are provided through sickness funds related organizations.

Support services that are hospital-based (but liaise with primary care) are provided by pain and cancer networks (multidisciplinary teams that support patients with cancer and patients who need palliative care). Support is also provided by specialized nurses (e.g. diabetes educator, oncological nurse) and specialists (tabaccologists, psycho-oncologists).

The costs for the patient were not obtained in this analysis.

4.4.1.4. Care (cure, rehabilitation and palliative) services

Initiatives that focus on curative aspects of care are provided in 25% (n=10) of the initiatives, rehabilitation in 10% (n=4) and palliative care in 7.5% (n=3) of the initiatives. Examples are:

- the pain networks (mobile multidisciplinary teams) embedded in hospitals;
- rehabilitation provided by e.g. oncological centres for children and the care networks (=multidisciplinary teams for patients with psychiatric conditions);
- multidisciplinary networks for patients who need palliative care.

4.4.1.5. Home care versus hospital care

Eleven (n=11) initiatives were developed for home care settings, 19 for hospital settings, 5 for both home and hospital settings and for 5 initiatives this was not applicable.

4.4.1.6. Costs

Valid data on the budget of the respective initiatives could not be obtained for the majority of the initiatives: they are not included in the analysis.

4.4.2. Discussion: initiatives from the Federal Public Service Health, Food Chain Safety and environment and from the Sickness Funds

Common points emerge from this analysis focused on initiatives (policies) that directly and indirectly target patients with chronic illnesses.

4.4.2.1. Stand-alone initiatives

An overall finding is that a range of noteworthy services exists for patients with chronic illnesses in Belgium. However, the majority of initiatives can be regarded as stand-alone initiatives developed and provided within the boundaries of single organizations or care entities.

In the same way, this inventory could not analyse to what extent these initiatives are implemented within the usual care environment of the patient i.e. the communication between the initiative's stakeholders and the usual patient's caregivers.

4.4.2.2. Emphasis on reimbursement, workforce, structures

Data show that the emphasis is mainly put on:

- the reimbursement of individual medical acts;
- the creation of new functions (e.g. oncological and diabetes educator) and medical facilities (e.g. oncological and geriatric centres);

A minority of initiatives:

- develop new care processes that foster integrated care and consider individual needs of patients;
- aim to improve the communication between providers and quality assurance processes.

4.4.2.3. Many disease-oriented initiatives

With the exception of the national programme for chronic patients, the Belgian health care system focuses on vertical and disease-oriented programmes. Examples of populations are patients with cancer, patients with rare diseases.

4.4.2.4. Integrated care

The existing initiatives on chronic care do not reflect a consistent and global (political) vision on chronic care delivery. In particular, very few initiatives aim at the development of new models of integrated care (see definition in 3.2.3). Examples of integrated care are:

- the pilot projects on mobile multidisciplinary teams targeting patients with psychiatric disorders;
- the initiatives on transmural care that link hospital with primary and long-term care.

4.4.2.5. A wider target population than chronic patients

A majority of the chronic care initiatives presented in this study target other patient populations besides patients with chronic illnesses including e.g. older persons with complex care needs. There is an important 'grey zone' of services offered to both patients with chronic illnesses and (older and younger) patients with complex care needs.

This is especially the case when it comes to social care services that target both aforementioned patient groups. In this context it is important to note that family and informal caregivers are targeted in only a minority of the chronic care initiatives.

4.4.2.6. Role of sickness funds and accessibility

Sickness funds play an important role in the provision of services to patients with chronic illnesses and place special emphasis on the provision of information and support of their members (as it is defined by law). However, the extent and type of services provided by the different sickness funds substantially differ as well as the conditions to benefit from the services (patient's profile, budget if applicable): the result is that the accessibility of services depends on the patient's individual sickness fund.

Children with chronic illnesses equally benefit from initiatives that are provided to adults (especially when it comes to reimbursements).

4.4.2.7. Evaluation

A limited number of scientific initiatives only evaluate the effectiveness of new care models for patients with chronic illnesses. They mainly focus on diabetes, renal insufficiency, cancer, chronic heart failure and COPD.

4.4.2.8. Few data on costs

The questionnaire sent to representatives from the Federal Service of Health and the Sickness Funds included a search for data on costs. Unfortunately, the results did not provide sufficiently detailed information on that point. Their share within the global health care budget is therefore impossible to assess.

4.5. Description of initiatives from the National Institute for Health and Disability Insurance

The patient with chronic disease benefits the same reimbursement of care services and medicines within the health insurance as acute care patients. In addition to this reimbursement system, the NIHDI has set up several initiatives to answer to the needs of the patient with chronic disease. This chapter focuses on these chronic care initiatives. For the description of the initiatives the activity model is used as framework.

4.5.1. Health care system level

The NIHDI finances coordination structures in primary care. The description and reflection upon their future will be detailed in chapter 8. A table in appendix 4.5 summarizes their structure and objectives.

- For the French-speaking part of Belgium this chapter 8 focused on "Associations de Soins Intégrés" (ASI), on " Centres de Coordination de Soins et Services à Domicile » (CCSSD), on "Services Intégrés de Soins à Domicile" (SISD) ;
- For the Dutch-speaking part of Belgium, it focused on the existing "Community Health Centre" movement and the more recent trend to "Interdisciplinary Primary Care Practices", and the originally called "Samenwerkingsinitiatieven voor Thuisverzorging" (SIT), and the "Geintegreerde Diensten Thuiszorg" (GDT), which in Flanders both were gradually upgraded and integrated in the new "Samenwerkingsinitiatief Eerstelijnsgezondheidszorg" (SEL).

The paragraphs below give more details on the Services Intégrés de Soins à Domicile (SISD) / Samenwerkingsinitiatief EersteLijns gezondheidszorg (SEL) given their major role in the landscape of the Belgian health care system.

- Missions of the SISD/GDT

The SISD/GDT work following 3 main lines:

  - Stimulation of the collaboration between care providers (by the use of specific tools);
  - Development of a multidisciplinary work around the patient: evaluation of his/her health/dependency status, development / follow-up of a care plan, task sharing between care providers[127];
  - Collaboration with the care institutions from the same region.

The target population are persons with limited autonomy, who stay at home (including psychiatric patients and persons in a vegetative state).

- Payment: fees are provided for:
  - the care providers who take part in coordination meetings (from 1 to 4 times a year according to the patient's status);
  - the registration of the activities.

4.5.2. Plan, provide and coordinate care in the primary care setting

4.5.2.1. Primary and specialised care accessible to all patients, without geographical or financial barrier

- The national fee schedule

Services covered by compulsory health insurance as well as conditions for reimbursement are described in the national fee schedule, called "nomenclatuur/nomenclature" (article 35 of the Coordinated Health Care Act of July 14, 1994 and appendix of the Royal Decree of September 14, 1984). The fee schedule promotes preventive, curative, rehabilitative or palliative actions. It focuses on the organization of health care provision and health care access (as described in this section) but may also concern coordination (see section 4.5.2.2), care in the least complex environment that is clinically appropriate (see section 4.5.2.3), quality of care (see section 4.5.2.4), information systems (see section 4.5.2.5), patient empowerment (see section 4.5.3), or even the overall design of the health system (see section 4.5.1).

  - A wide range of services

The fee schedule lists a wide range of reimbursed services (more than 8000) [128]. It includes medical procedures performed by health care workers (as defined by the Royal Decree N°78 of 10 November 1967), as well as aid materials, medical devices and equipments (band aid materials, mobility aids, orthopaedics, opticians, hearing aids specialties). Those services are provided to all patients, either with an acute disease or with a chronic one. Nevertheless, a few services are specific for chronic patients, i.e. specific treatments, prevention of complications related to their disease or services addressing the compensation of their disability. For example, the fee schedule includes osteotomy equipment, therapeutic elastic stockings for venous disease, electronic carts, lower limb prostheses (see the full list at the following link: http://www.inami.be/insurer/fr/rate/).

  - Physiotherapy

The fee schedule also includes reimbursements specific to long term physiotherapy. The number of reimbursed sessions and the reimbursement rate are higher for patients with a chronic condition described in "the list Fb of serious diseases" [129]. This list includes a.o. extended peripheral paralysis, spina bifida, cystic fibrosis, obstructive or restrictive chronic irreversible lung diseases, severe lymphoedema, chronic motor polyneuropathy. The expenditures for these physical therapy treatments accounted for € 244 million in 2011.

  - Nursing home care

The fee schedule for nursing home care also focus on long term care. An example in nursing home care is the reimbursement of the education and monitoring of diabetic patients by a nurse. These expenditures accounted for € 1.6 million in 2011.

In order to protect people who can be expected to have high medical expenditure, such as chronically ill patients, specific measures have been introduced, accounting for € 628 million in 2011:

  - the system of preferential reimbursement,
  - the maximum billing,
  - fixed payments to patients,
  - the solidarity fund.

- System of preferential reimbursement

Socially and economically vulnerable groups are entitled to a higher reimbursement (BIM/RVV status). They are identified[130] on the basis of:

  - a granted social benefit (without income condition): persons entitled to a social integration revenue, to a support from the Public social welfare centre, to guaranteed income for the older persons, to an allowance for disabled persons, to increased child allowance;
  - their gross annual taxable income under a given threshold (varies according to the family size) AND a specific status (for example orphans, long term unemployment, retired people, disabled

people not entitled to a benefit for disabled, members of a religious community, residents over 65 years), single-parent families.

- their gross annual taxable income (known as the Omnio status): € 15 606.71 (+ € 2889.22 per dependent person) in 2012.

- Maximum billing

A maximum billing system (MAB-MAF) was introduced in 2002 alongside the existing preferential reimbursement levels [130]. Each household has an annual out-of-pocket maximum for all "necessary health care expenses". This maximum is set according to the family's net income. As soon as expenses reach a ceiling, any further health care costs are automatically covered in full by the sickness funds for the rest of the year.

There are three types of MAB:

- Social maximum billing system: a ceiling of € 450 is applied at the household level for households with at least one individual with preferential reimbursement. As soon as the limit of € 450 is exceeded, the co-payments are reimbursed;
- Maximum billing system for children: a ceiling of € 650 is applied for children under 19 years, without taking into account the family income (€ 550 when the child spent € 450 of annual out-of-pocket payments during the 2 preceding calendar years);
- Income maximum billing system: applied in a gradual way according to net family income (for example a ceiling of € 450 for incomes ≤ € 17 039, increasing to € 1800 for incomes ≥ € 44 125)

Since January 2009, the ceilings mentioned above are reduced by €100 if a member of the household has annually supported € 450 of out-of-pocket payments during the 2 preceding calendar years. This measure is known as "maximum billing system for the chronically ill".

- Fixed payments to patients

Fixed payments systems have been introduced In order to protect people who can be expected to have high medical expenditure ("forfaits/forfeiten") [131] as for example:

- patients with chronic illness (Royal Decree of 2 June 1998),
- incontinence material (Royal Decree of 2 June 1998),
- IgE-mediated allergy to gluten / gliadin or grain flour (Royal Decree of 8 November 1998),
- palliative treatment at home (Royal Decree of 2 December 1999),
- patients in a persistent vegetative state (Royal Decree of 18 November 2005),
- patients suffering from Sjögren's syndrome (Royal Decree of 3 June 2007);
- active bandages used for chronic wounds (Royal Decree of 3 June 2007);
- paracetamol-based or paracetamol/codeine-based analgesics used for chronic pain (Royal Decree of 3 June 2007),
- programmes against drugs or alcohol addictions (Royal Decree of 18 December 2008),
- special diet e.g. for patients with renal failure (Royal Decree of 4 May 2009),
- smoking cessation assistance (Royal Decree of 31 August 2009).

- Solidarity fund

The Special Solidarity Fund was established in 1990 at the NIHDI in order to grant additional reimbursement for patients with a rare illness or who need a very specific treatment [132]. Additional reimbursement is possible for: (a) a rare indication or (b) rare disorder, (c) a rare disorder which needs continuous and complex care, (d) the application of innovative medical aids or treatments (excluding pharmaceuticals), (e) chronically ill children and (f) some treatments abroad (NIHDI 2006). For each case, specific conditions must be fulfilled and the total reimbursement is set according to the availability of funds. In 2011, the expenditures for the solidarity fund were € 12 311 531, within the foreseen budget of € 17 643 000.

4.5.2.2. Care coordination within the first line of care and multidisciplinary teams

"Conventions" (agreement) for functional rehabilitation have been concluded to finance the holistic care of patients suffering from a chronic disease that has an impact on their psychic, social or work (or school) functioning. Services covered by these agreements are provided by a multidisciplinary team (physicians but also non-medical professionals). These conventions cover the labour cost of non medical professionals (e.g. social workers) for whom there is no fee schedule as well as activities related to the multidisciplinary work (time spent in multidisciplinary consultations, etc.). Usually, these services are part of a broader diagnostic or therapeutic programme provided for a specified period. Programmes can be organised in outpatient or in institution settings. These conventions have their legal basis in Articles 22, 6, and 23 § 3 of the Coordinated Health Care Act of 14 July 1994.

These conventions concern many chronic diseases[133].

Table 4 – List of functional rehabilitation "conventions" (and expenditures 2010)

- Diabetes (€ 98 354 965.69 for the convention on autoregulation of the diabetic patient, € 4 889 879.40 for the convention on insulin therapy with a portable insulin pump, € 5 358 842.61 for the convention on autoregulation of children and young adults, € 390 175.87 for the convention on diabetic foot)
- Rare inherited monogenic metabolic disorders (€ 2 299 218.25)
- Cystic fibrosis (€ 3 038 750.82)
- AIDS (€ 6 657 256.69)
- Haemophilia (in progress)
- Paediatric Nephrology (€ 624 769.13)
- Long term oxygen therapy at home (new convention from 1 July 2012 (€ 20 559 230.90)
- Long term mechanical ventilatory support at home (€ 5 210 329.33 for the convention on ventilatory support at home, € 294 678.45 for the convention for obesity-hypoventilation, € 34 138 009.23 for the convention for sleep apnoea)
- Severe chronic respiratory diseases (€ 1 031 865.03)
- Locomotor rehabilitation 771 (€ 17 157 037.89)
- Locomotor rehabilitation 950 (€ 17 921 806.80)
- Neuromuscular diseases (€ 4 156 872.88)
- Physical disability of cerebral origin (€ 1 388 558.35)
- Spina bifida (amendment to the convention (€ 376 624.73)
- Autism (€ 2 086 165)
- Psychosocial rehabilitation of adult psychiatric patients (€ 19 589.586)
- Functional rehabilitation of children with psychiatric disorders (€ 14 512 426)
- Functional outpatient rehabilitation centres of language, speech and voice, mental and behavioural disorders (€ 88 006 513)
- Neuropsychiatric disorders (€ 905 331)
- Mother-child dyads whose interaction is disrupted (€ 696 015)
- Functional rehabilitation centres for drug addicts (€ 41 957 701)
- Intractable epilepsy (€ 438 847.15)
- Dementia: Memory Clinics (no data)
- Chronic pain (€ 2 092 764)
- Vision rehabilitation (€ 1 633 875)
- Respiratory and neurological diseases (functional rehabilitation centre Pulderbos) (€ 10 150 496)
- Morbid Obesity (no data)
- Chronic Fatigue (€ 1.3 million)

There are also experimental conventions in process (Article 56) such as for special forms of foods, multi-drug-resistant tuberculosis, the free and anonymous screening of HIV/AIDS, the prophylactic treatment of persons accidentally exposed to HIV, and the project "Coached Aerobic Regular Exercise" for patients with multiple sclerosis (CARE-MS).

Finally, there are special forms of conventions for multiple sclerosis, amyotrophic lateral sclerosis, and Huntington.

- Multidisciplinary consultations

Some services (registered in the national fee schedule) target specific chronic diseases. Their aim is to promote the coordination and care centred on the patient, with specific care plan and multidisciplinary consultations. Illustrations are bariatric consultation before a surgical intervention, rheumatologic assessment of patients with a rheumatoid disease, the "diabetes passport", the specialized diagnostic procedure of dementia, multidisciplinary consultations (for (pedo)psychiatric patients, geriatric patients, in oncology) with a report sent to the GP.

In the mental health care sector, therapeutic projects were financed between April 1, 2007 and March 31, 2012 to increase inter-professional and inter-sector collaboration and to promote multidisciplinary consultations around the patient. Since April 2012, a new regulation replaces therapeutic projects. An allowance is provided for the participation in consultations around the psychiatric patient, for a reference person, and for the organization and coordination of the consultation. The reference person is the contact person (for the patient, his/her family and the health care professionals) and is a.o. responsible for a management plan and its coordination.

- Care trajectories

Care trajectories (zorgtraject/trajet de soins) for the treatment and follow-up of specific chronic diseases have been developed to enhance the collaboration in care between the patient, the GP, the specialist and other caregivers [134]. The collaboration between caregivers is described in a "care trajectory" contract (duration 4 years) defined according to evidence-based clinical practice. The GP plays a coordination role and the patient has an active role in the management of his/her disease. Financial incentives are given to the physicians (yearly lump sum of € 80 per patient) and to the patient (complete reimbursement of consultations, access to self-management material, education sessions e.g. on dietetics, etc.). Clinical data are collected in order to assess the quality and effectiveness of care and to provide feedback.

Two trajectories exist since 2009:

- one for patients with chronic kidney failure: 16 609 patients have signed the contract between the 1st June 2009 and end 2011. About 5000-6000 new patients were enrolled each year. Expenditures increased from € 957 134.18 in 2009 to € 2 381 125.43 in 2011.
- one for patients with diabetes type 2 who no longer respond to oral treatment. The number of new patients enrolled each year within this pathway increased from 3 412 in 2009 to 8 672 in 2011. The total expenditures increased from € 873 113.49 in 2009 to € 6 294 504.77 in 2011.

A pilot project on the definition of care trajectory for palliative care is in process[134].

- Local multidisciplinary networks

Local multidisciplinary networks were set up to enhance the collaboration between all caregivers (especially between the GP and the specialists) and to optimize the quality of care (see also chapter 8). The aim of operational plans, initiated by GPs and supervised by a care trajectory promoter, is to gather information about the caregivers and the local organizations, to support local initiatives, to inform caregivers and patients included in care trajectories, to facilitate the communication between caregivers implied in care trajectories and to evaluate the local network. The local networks receive a yearly sum depending of the number of inhabitants in the region, via conventions between the Insurance Committee of the NIHDI and GP circles. The budget for the local multidisciplinary networks increased from € 1 003 688 in 2009 to € 6 436 062 in 2012.

4.5.2.3. *Care in the least complex environment that is clinically appropriate*

The requirements for chronic care of high quality require that daily care should be provided in an environment that is least complex as possible but adapted to the clinical situation of the patient (see 3.2.3)

- Alternative forms of care for the frail older persons

A protocol between the federal authorities and the federated entities (regions and communities) was signed to meet the changing care needs of older persons (in institutions and at home) and to provide a global and concerted answers to their needs by implementing alternative forms of care ("Protocol n°3") [135]. The Insurance Committee of the NIHDI has made agreements with selected projects after an invitation to tender. Currently, 62 projects are ongoing. Their main mission is to provide services with a multidisciplinary approach, in order to delay institutionalisation whilst improving/maintaining the quality of life.

Overall, they combine:

- Management of chronically ill patients in primary care structures: occupational therapy at home, day care centres, psychological / psychosocial supports, nutritional care, night care at home, nights hotels in nursing homes, day care centres for specific population (e.g.; with dementia);
- Models of care delivery and services: organization of the care process (case-management, coordination of care) and support for self-management (respite care to support both the patient and the informal carer);
- A clinical information system and data registration through the main use of the patient assessment tool known as "BelRAI" [136].

These projects are developed on an experimental basis for a fixed period. A scientific evaluation of these projects will support the decision of the authorities to extend some of them (based on cost-effectiveness analysis, impact on quality of life, etc.).

The chapter 8 details the case management aspects in this context (see 8.6.2).

- Projects in the mental health care sector

Projects in the mental health care sector were also financed (cf. law article 107) with two objectives:

- organization of mental health care pathways for the patient, with collaboration between outpatient centres and residential institutions for mental health care, together with actors in primary care and bodies responsible for personal assistance;
- detection, as quickly as possible, of people with a mental problem and the provision of support in their living environment.

The reform gives priority to outpatient care in collaboration with the first line instead of psychiatric hospitalization.

4.5.2.4. *Quality of care*

E-learning programmes have been developed to support the clinical decision of physicians and nurses (dementia, urinary incontinence). For both programmes a budget of € 175 000 is provided during 3 years.

Operational plans on quality of care have also been developed:

- A convention has been concluded between partners involved in the implementation of evidence-based medicine (EBM). Partners include the CEBAM Digital Library for Health and EBMPracticeNet. The aim is to make EBM information available for free to all health professionals and therefore to promote quality of care. A yearly budget of € 1 715 000 is dedicated to both structures.
- The NIHDI also finance Minerva, a journal that comments international publications on evidence-based medicine. Target groups are GPs, pharmacists, medical specialists and other health professionals in primary care. They also organize training, conferences, consensus meetings and other activities as part of evidence-based medicine in primary care. They are also actively involved in the development of the EBM platform. A yearly budget of € 350 000 is provided to Minerva.
- The initiative for Quality Promotion and Epidemiology in Diabetes Care (IKED-IPQED) is a structured programme of evaluation and promotion of quality of care in Belgian diabetes centres. Each centre collects data of a representative sample of patients. The profile of the patient, his medical management, risk factors for microvascular and macrovascular diabetic complications, early markers of complications

and complication of the terminal phase are collected. Data are then anonymously analysed by the Scientific Institute of Public Health (WIV/ISSP), which produces feedback to the centres. Abnormal results call for a multidisciplinary approach within the centre, including the set up of quality circles. The data are used for the global evaluation of the quality of care of diabetes patients in Belgium and to have epidemiologic data used at the national and international level.

4.5.2.5. ICT development

- Registry and databases

The national fee schedule is involved in clinical information system, either directly because more and more services explicitly require participation in kind of registry (pacemakers, implantable defibrillators, stents, etc.), or indirectly with the database of reimbursed services providing individual health data (patient data recorded by sickness funds) or health data on the population (anonymous data transmitted to the NIHDI).

- Telemonitoring

A call for projects on telemonitoring was published on the website of the NIHDI on July 31, 2009. The NIHDI received 22 projects related to telemonitoring. The selected projects covered the following topics:

- Dementia;
- Measurement of blood pressure via telemonitoring for patients with hypertension risk;
- Chronic Obstructive Pulmonary disease (prematurely stopped),
- Heart failure (3 projects).

The projects last 2 years + 6 months for the report. Their designs differ but the common goal is to learn and to gather data useful for the future of remote monitoring and health care online in Belgium.

- Clinical data exchange system

The NIHDI invests in the promotion of the quality of the medical record (by setting quality criteria that these systems have to meet and by labelling officially systems that fulfil these criteria). Moreover it encourages the correct use of these systems by caregivers (by granting an annual premium to the registered users).

An eHealth digital platform has been set up to allow an electronic exchange of secured data between health actors. They encompass an infrastructure, technology standards and basic services such as identification and authentication of health care providers, encryption, secure communication, etc.

Moreover, the establishment of an eCare platform to share and exchange data is in process, accelerating the development of applications for data sharing, building trust and membership of health care providers. It is foreseen that eCare applications would use as much as possible the technological support provided by the eHealth platform. More information can be found in the 2011 annual report of the NIHDI[137].

4.5.3. Self-empowerment of the patients

4.5.3.1. Specific services included in the fee schedule

Some services included in the fee schedule imply active participation of patients: e.g. the opening of a global medical file and the prevention module.

The passport diabetes (fully reimbursed) is also a tool for involving patients in the management of their treatment[138]: the GP determines with the patient the objectives of the treatment. This passport also promotes the consultation of the dietician and the podiatrist. The patients with diabetes can also enter care trajectories (see section 4.5.2.2) or participate in an education and self-management programme (see section 4.5.3.2 below) but these systems are mutually exclusive.

4.5.3.2. Education and self-management programme for patients with diabetes

This programme consists in the monitoring and education of diabetic patients by the GP (no collaboration with a diabetes specialist or a diabetes educator). The patient has access to reimbursed self-management material (glucometer, lancets, test strips). These programmes concern patients with diabetes type 2 treated by injections of incretinomimetics or single daily injection of insulin. The patient opens a global medical file with the GP who notifies the sickness fund about the start of the patient's programme. The expenditures related to this programme increased from € 30 973.93 in 2009 to € 123 446.50 in 2011.

4.6. Key points: chronic care initiatives in Belgium

- **A range of noteworthy services exists for patients with chronic illnesses in Belgium.**
- **The existing initiatives on chronic care do not reflect a consistent and global (political) vision on chronic care delivery.**
- **Populations that are most often targeted are patients with cancer, psychiatric disorders and patients who need palliative care.**
- **Target populations are defined by diseases; no initiative was identified that explicitly focused on patients with multimorbidity.**
- **The majority of chronic care initiatives can be regarded as stand-alone initiatives developed and provided within the boundaries of single organizations and care entities.**
- **Emphasis is put on the reimbursement of medical services, the creation of new functions and medical facilities rather than on the development of new care processes that foster integrated care.**
- **National and vertical disease-oriented programmes are developed for patients as for example the cancer plan.**
- **The emphasis is put on cure, less on rehabilitation and palliative care.**
- **A substantial majority of the chronic care initiatives target other patient populations including e.g. older persons with complex care needs and younger patients.**
- **Family and informal caregivers are targeted in only a minority of the chronic care initiatives.**
- **Sickness funds play an important role in the provision of services to patients with chronic illnesses and place special emphasis on the provision of information and support.**
- **There are substantial differences between sickness funds for what concerns the extent of information and support services provided.**
- **There are only a limited number of initiatives that evaluate the effectiveness of new care models for patients with chronic illnesses.**

The main initiatives from the National Institute for Health and Disability Insurance for the patients with chronic disease include:

- **Measures to foster the accessibility of care for patients with chronic disease:**
  - **reimbursements for material, physiotherapy, nursing home care;**
  - **system of preferential reimbursement,**
  - **maximum billing;**
  - **fixed payments to patients;**
  - **the solidarity fund.**
- **Financing of coordination structures at primary care level (e.g. the SISD/GDT);**
- **Financing of coordination of care around the patient:**
  - **functional rehabilitation agreements (“conventions”): holistic care of patients suffering from a specific chronic disease by a multidisciplinary team;**
  - **multidisciplinary consultations (e.g. mental health care);**
  - **care trajectories (for kidney failure, diabetes);**
  - **multidisciplinary local networks.**
- **Support of projects to foster the care in the least complex environment that is clinically appropriate:**
  - **alternative forms of care for older persons;**

- projects in the mental health care sector.

- **Support of projects in relation to the quality of care: data registration, dissemination of evidence based material.**
- **Support of projects in relation to ICT developments: telemonitoring, eCare platform.**
- **Support of patient empowerment, in particular for patients with diabetes (for example passport for diabetes, diabetes educator).**

5. RECOMMENDATIONS IN RELATION TO CHRONIC CARE: ANALYSIS OF KCE REPORTS

Authors: Anja Desomer, Koen Van den Heede

5.1. Objective of this chapter

The objective of this chapter is to review the KCE reports to highlight the evidence and recommendations in relation to the care of chronic patients.

5.2. Methods

Four KCE researchers performed the selection of the KCE reports (published since 2006) in relation to the care of chronic patients. Inclusion criteria were:

- Relation to the care of patients with a chronic disease, and/or;
- Relation to the organization of chronic care, and/or;
- Proposed recommendations relevant for chronic care.

One researcher (AD) tabulated all recommendations relevant to chronic care (see chapter 2 in the supplement). She drafted a synthesis of the results structured according to the requirements of the conceptual model (see section 3.3.7)

5.3. Tailored Delivery System Design

The section is divided in two parts:

- The importance of strengthening primary care and the coordination between different levels of care (5.3.1-5.3.2);
- Health care services for specific populations as services for the older persons (5.3.3); palliative care services (5.3.4) and mental health care services (5.3.5).

5.3.1. Strengthening primary care: illustration of type 2 diabetes care

The analysis of the main international papers (Chapter 2.1) and the analysis of chronic care policies in 4 countries (Chapter 2.2) highlighted the importance of strengthening the role of primary care as a cornerstone in chronic care reforms. Ambulatory care in Belgium is mainly delivered by self-employed physicians, usually remunerated on a fee-for-service basis. General practitioners (GPs) work in single-handed or group practices, frequently without any staff except a medical secretary[139].

The role of primary care in Belgium is illustrated by the KCE report on the organization of care for type 2 diabetes patients[140].

5.3.1.1. Multidisciplinary teams coordinated by GP's

The KCE-report 27[140] concluded that the efficacy of diabetic care was not influenced by the setting where care is provided (hospital versus GP practice). A review of country policies showed that the GPs have a central coordinating role for type 2 diabetic patients. Specialists are mainly involved in case of complications. This corresponds to the conceptual model above where a distinction is made between:

- Planning, providing and monitoring routine chronic care on one hand;
- The management of acute episodes on the other hand.

In countries where GPs are gatekeepers (e.g. The Netherlands, UK, Denmark) group practices are often multidisciplinary staffed resulting in a more extended, more polyvalent service offer (e.g. group session regarding health promotion, telephone-follow up by nurses, diabetic registry) necessary for the care for patients with chronic conditions. Some GP practices only include clerical assistance and nurses whereas other group practices also include advanced practice nurses in diabetic care, dieticians and chiropodists[140]. They use shared care protocols to define the role and responsibilities of all professionals.

Several countries also set up structures (primary care organizations) at the local level to enhance the horizontal integration in chronic care. These primary care organizations offer a platform where local stakeholders are involved in the healthcare policy.

5.3.1.2. Role of nurses in primary care

The role of nurses in the care for diabetic patients is gradually increasing in primary as well as in secondary care. The chapter on professions described different categories i.e. advanced nurse practitioners, clinical nursing specialists (see 6.4.3). Their role can include patient education, clinical follow-up, education of other healthcare workers, liaison between first and second line of care, etc. Some studies where nurses substituted physicians showed a positive impact on patient outcomes (i.e. blood glucose level), but the evidence remains inconclusive[140].

5.3.1.3. KCE recommendations for the organization of care for type 2 diabetic patients:

The recommendations formulated by the KCE for type 2 diabetic patients are applicable to the care of chronic patients in general (KCE-report 27[140]):

- Chronic care to be provided by a multidisciplinary team at the primary care level (in collaboration with circles, local discussion platforms (LOKs/Glems) or diabetes networks;
- A central role for GP's in care coordination;
- crucial role of diabetes educators (for activities like healthy life style advice and education insulin injections);
- Clear role description for specialized physicians (i.e. endocrinologists) i.e. coaching of other health care providers and treating complex clinical situations;
- A proactive, patient-focused and integrated care with patient education, follow-up and secondary/tertiary prevention of complications.

5.3.2. Organizational models that streamline transition between primary, secondary and tertiary care

Smoothening transition between primary, secondary and tertiary care, has been regular addressed as one of the areas that needs attention in international papers and existing KCE-reports. As discussed above, the KCE recommended to strengthen the coordinating role of GP's and to clarify the role of specialists in the treatment of type 2 diabetic patients[140].

Two KCE reports illustrate the lack of care coordination between the first, second and third lines of care: the reference centres for patients with fatigue syndrome[141] and the care for persons with acquired brain injury aged 18 to 65 years[142]. The complex organization of health care services (e.g. by different authorities) and financing mechanisms are two major brakes on this coordination[141, 142].

The KCE reports 51 and 88 recommended[141, 142]:

- To develop collaboration initiatives between the different care levels for patients with the Fatigue syndrome[141];
- To enhance coordination between the different services for persons with acquired brain injury aged 18 to 65 years. Different options were offered:
  - Appoint specific expertise centres;
  - To appoint SEN (Flemish point of contact for expertise centres in the handicapped sector) as point of contact for persons with acquired brain injury who have difficulties with their search for appropriate care and start similar initiatives in the other regions[142].

5.3.3. Organization of services for the older persons

Three KCE reports 167[143], 73[144] and 99[145] studied important aspects of the routine care (module 1 of the conceptual model) and acute episodes (module 2 of the conceptual model):

- The organization of residential care for older persons in Belgium[143];
- The care programme for geriatric patients in acute hospitals[144];
- The geriatric day hospital[145].

5.3.3.1. Organization of residential care for older persons in Belgium

The Belgian long-term care system for the older persons offers different services according to their dependency and ability to stay at home:

- Home nursing is available for persons with ADL and/or cognitive limitations;
- Basic nursing care partly overlaps with care provided by family care services, which are subsidized by the regional governments;
- Day care centres and short stay centres for older persons who live at home but (temporarily) lack informal care or whose caregivers need respite time;
- Service flats combine individual living arrangements with collective facilities (e.g. meals, home help, …) for persons with no or low-care needs;
- Two types of residential care facilities are available:
  - Homes for older persons provide nursing and personal care as well as living facilities for dependent older people;
  - Nursing homes for persons who need continuous care[143].

On 1 January 2011, the total number of beds in residential settings equalled 129 732 (homes for the older persons, nursing homes and coma beds), 131 489 (adding short stays) or 133 370 (adding day care places) according to types of beds/places included. Inter-ministry conferences formulated common objectives i.e. the progressive replacement of beds in homes for older persons by nursing home beds. The aim is to guarantee a better financing of care-dependent residents within the margins set by a moratorium (max 140 049 residential beds in October 2011).

The current shift from residential care home care corresponds to the root definition of the envisaged chronic care system. During the past decade the number of home nursing care users has grown by more than 40% and the number of users of family care has grown by more than 20%, while the increase in residential care users amounts to less than 10% only.

The KCE developed a projection model to calculate the number of beds in residential structures over the next 15 years (2011-2025) and recommended (KCE-report 167[143]):

- To create between 27 000 and 45 000 (depending on scenario assumptions: evolution of the morbidity, availability of informal caregivers) extra beds in residential care facilities by 2025. This corresponds with a yearly increase of 1800 to 3000 beds;
- To plan 23 500 extra beds when it is assumed that home care is expanded by 50%;
- To anticipate the stronger need for residential care facilities after 2025;
- To take into account the unequal evolution in the geographical distribution of the oldest persons (85+) at the local level;
- To elaborate policies that encourage the older persons to stay as long as possible at home (e.g. more stringent access criteria residential facilities, administrative and financial status for informal care, home care initiatives for the older persons), to limit the increasing demand on residential facilities[143].

5.3.3.2. Persons with acquired brain injury in residences for older persons

Approximately 1000 chronic care persons with acquired brain injury aged 18 to 65 years live in residential facilities for the older persons. In principle this is the responsibility of the handicapped car sector but this sector has serious capacity problems which result in long waiting-lists[142]. This situation jeopardizes the principle of 'equity' that was put forward in the root definition of the chronic care system: there are differences in staffing, financial accessibility and service offer between the residential facilities for the older persons and the handicapped sector. The KCE recommended (KCE-report 51[142]):

- To the different authorities to find a solution for the persons with acquired brain injury younger than 65 years who are treated in residential facilities for the older persons on short-notice since caring for these persons in this setting is inappropriate;
- When a solution is to be found within the residential facilities for the older persons approximately 400 places in specific units should be provided with staffs that are competent to care for this specific population;
- A number of institutions (Sp-units and nursing homes) could specialize to provide residential facilities for highly care dependent persons with acquired brain injury or with a degenerative condition (e.g. MS, Huntington disease)[142].

5.3.3.3. Care programme for geriatric patients in acute hospitals

The main objective of the care programme for geriatric patients is the optimal recovery of functional abilities and highest possible level of self-management and quality of life. This is similar to the root definition of the chronic care system (see 3.2): the system should be person and goal-oriented and aims to improve the quality of life and functioning of persons with chronic conditions. The geriatric care programme specifies that every hospital has to organise:

- Inpatient geriatric care (G beds);
- Outpatient consultations;
- Geriatric day hospital: to avoid hospitalizations whenever possible;
- Internal liaison for geriatric patients hospitalized in non-geriatric nursing units;
- External liaison: a social worker or nurse that acts as a discharge manager to improve the continuity of care and formal arrangement with GP's, home care services, residential facilities and day centres are required.

A Royal Decree[146] defines the programme, the geriatric patient, the personnel and structure required. Furthermore, it specifies the need for a multidisciplinary geriatric file including care plans and the summary of the team meetings.

KCE made the following recommendations in relation to the financing of the care programme for geriatric patients (KCE reports 73 and 99[144, 145]):

- Internal liaison:

- To screen all patients aged 75 years or older admitted to an emergency department with a similar standard instrument in all hospitals;
- To consider all demented patients admitted from residential facilities and patients with a hip fracture as geriatric patients;
- To organize a consultation with the geriatric nurse of the internal liaison team for all hospitalized patients identified as geriatric patients, with a report to the geriatrician;
- To work with a decentralized geriatric care model;
- To include in the liaison team at least one geriatrician and one nurse. The composition of the multidisciplinary team (physiotherapist, speech & language therapist, occupational therapist, psychologist, social worker) should be further defined by the hospital.

- Financing of geriatric day hospitals: should be coupled with a research programme that guides and evaluates its development (limited scientific evidence).

5.3.4. Organization of Palliative care services

The objectives of palliative care mirror the objectives (e.g. networking, coordination, personalized care, adapted environment) specified in the idealized vision (root definition) of a health care system for chronic patients (cf. 3.2.1). Between 10 000 and 20 000 patients need palliative care in Belgium: the KCE report 115[147] analyzed the situation in Belgium.

5.3.4.1. Current organization

- In 1997 the palliative networks were created to develop a palliative care culture, to organize trainings for caregivers, to coordinate actions between organizations and services and to evaluate the palliative services.
- Several initiatives support the patients who wish to stay at home (see also financing of home care nursing in 5.5.2): palliative home care team, day care centres, lump sum during 2 months, abolition of out-of-pocket expenses for home care.
- Approximately 400 SP-palliative beds are clustered in small Palliative Care Units.
- The palliative function in hospitals (and nursing homes) provides specific support for palliative patients who stay in any care unit.

5.3.4.2. Main findings

Some findings of the report on palliative care[15]:

- The difficulty of physicians to discuss palliative care issues and advanced care planning with patients and families;
- The frequent fulfilment of patients' wishes (e.g. place of death) when the physicians are aware of them;
- The importance of communication between settings as many patients (one third from home, 10% in nursing homes) experience a hospitalization during their last weeks of life;
- The infrequent call of health professionals for specific palliative services for their patients[147].

5.3.4.3. KCE recommendations

The KCE recommended (KCE-report 115[15]):

- To recognize patients as "palliative" when they are in an advanced or terminal stage of severe, progressive and life threatening disease whatever their life expectancy (i.e. a definition similar to the definition of the chronic patient);
- To perform a needs (including need for information and social support) assessment at regular intervals by the main physician in collaboration with a palliative care team;
- To identify all palliative patients including patients with non-cancer disease, such as patients with dementia or an advanced chronic condition;
- To provide a care model that is multidisciplinary and tailored to the individual patient and relatives;
- To reinforce links between settings to offer a continuity of care;(see also 5.3.2);

- To encourage the intervention of palliative care mobile teams in hospitals (to answer to the patient's needs with lower costs).

5.3.5. Organization of Mental Health Care Services

Six KCE reports analyzed the organization of mental health care and its recent reforms: KCE-report 84 about long stay patients in psychiatry T-beds[148], KCE-report 135 on emergency psychiatric care for children and adolescents[149], KCE-report 146 on the evaluation of the 'therapeutic projects[150], KCE-report 144 about mental health care for persons with severe and persistent mental illness[42], KCE-reports 170 and 175 about mental health care for children and adolescents[108,151]. This section summarizes the main recommendations from these studies (see appendix 2 for all recommendations):

- Reforms should achieve a balanced care model i.e. care should be accessible and delivered as close as possible to the patient's living environment, in an institution only if necessary. This requires an expansion (and transformation of residential into ambulatory facilities) of services that allow care in the community when possible (e.g. respite care, multidisciplinary outreaching teams, day-care facilities);
- The integration of the primary care sector and specialized mental health care services should be strengthened, for instance, by increasing the competencies of non-specialized staff in mental health care or by handling the issues regarding aspects of professional secrecy and sharing of information;
- Cross-sectional forums at different institutional levels should activate and mobilize the collaboration and networking on an ongoing basis;
- Bottom-up innovation should be stimulated but also integrated into the wider care system;
- The data collection on the needs for services and their evaluation (processes and outcomes) should be improved. This includes a better use and reform of the current administrative database (MPG/RPM);
- Reforms in mental health care require collaboration and fine-tuning of policies between the different competence levels: The Interministry conference should mandate the planning and evaluations of these reforms.

5.3.6. Organization of rehabilitation services

The KCE report 140 on cardiac rehabilitation[152] confirmed the benefits of cardiac rehabilitation with exercises for cardiac patients at low to moderate risk. The data analyses revealed the small percentage of patients who undergo rehabilitation (especially multidisciplinary) following their discharge from hospital, as well as the socio-demographic factors influencing treatment adherence.

The KCE recommendations focus on the accessibility of the services. Any cardiac patient who has undergone a coronary intervention or who has been discharged after hospitalization for coronary disease or heart failure should benefit from:

- A medical check up to determine his/her cardiovascular risk profile (secondary prevention) and specific sessions to improve this profile (diet, smoking);
- An exercise programme geared to his/her specific needs (upon advice of a specialist physician).

The active involvement of GPs and cardiologists is a condition to raise the patients' awareness of the importance of exercise.

The billing codes for cardiac rehabilitation should allow cardiac rehabilitation sessions with physiotherapists, to enhance the accessibility of the services[152].

KCE-report 57 focuses on the organization of rehabilitation for musculoskeletal and neurological conditions [153]. The recommendations cover similar topics, mainly changes in the financing system and accessibility.

5.4. Appropriate workforce

Strengthening the role of primary care implies an appropriate work force, while the chapter on work force also suggested new roles (e.g. advanced practice nurses, clinical pharmacists) in the chronic care system. Many KCE-reports studied aspects of the healthcare workforce that are relevant to this report:

- Physician workforce supply: current situation and challenges (KCE-report 72[154])(see 5.4.1);
- Attractiveness and retention GP profession (KCE-report 90[155]) (see 5.4.2);
- Differentiated nursing practice (KCE -reports 86[156] and 122[157]) (see 5.4.3);
- The role of physiotherapists and pharmacists (KCE reports 47[158], 87[159], 140[152]) (see also 6.4);
- Role of occupational physicians and advisory physicians from the sickness Funds. (KCE-report 48[24])
- Role of informal caregivers (report 160[121]).

5.4.1. Physician workforce planning

Healthcare workforce planning is the process of estimating the required healthcare workforce to meet future health service requirements and the development of strategies to meet those requirements. The aim is to ensure that practitioners are in the right place at the right time with the right skills.

The KCE report 72 on physician workforce supply[154] highlighted three main issues that are important when considering the evolution of the chronic care system.

- Absence of a valid framework for planning the physician workforce: a system of restricted intake ("numerus clausus") is in force for medicine studies. The quotas are defined by the Committee of Medical Supply Planning. However the computation methods are based on rough data on supply. Elements like working time, skill-mix, technological advancements, financial arrangements and workforce in other health professional groups are not considered[154];
- Decreasing number of general practitioners: an issue for the care of chronic patients. The GP density decreased 7% between 2002 and 2005 and the pre-defined quota for GP's are not met (i.e. 26% not met in the period 2004-2006)[154]. The low attraction of the GP profession is coupled with a problem of retention: the inactivity rate of GP's who qualified 9 to 11 years before increased from 7.5% in 1999 to 14.6% in 2005[155];
- Limitations of the national registers: there is a difference between the head counts in the registers and the number of practicing physicians (e.g. in 2005 only 53.3% of the registered GPs were practicing)[154].

The KCE-recommended for the planning of the physician workforce (KCE-report 72):

- To improve the coordination and harmonization of routine data collection of the 'stock and flows' (e.g. data on head counts, actual level of activity, attrition or migration rate, complementary information on practice arrangements or workload);
- To identify and monitor indicators of health needs, such as disease trends or new clinical management (see also 5.8);
- To develop a national workforce planning framework which would be integrated, consistent and adapted to the changing health system)[154].

5.4.2. Attractiveness, recruitment and retention of the GP profession

The key role of the GP in the chronic care system has been emphasized before (see 5.3.1.1). Therefore, the KCE recommended (KCE-report 90[155]) the following actions to improve the attraction, recruitment and retention of GPs in the profession (see 5.4.1):

- Initiatives at the level of medical faculties (e.g. to position GP as a fully-fledged specialty within the medical faculties; to provide early in the curriculum an accurate information about this specialty; GP clerkships of high quality for all medical students; clerkships in various primary care settings to show the multiplicity of practices and activities);

- Initiatives to improve the working conditions: for instance work in team or within networks, well organized out-of-hours services (see also the KCE report 171[160]);
- Initiatives to improve the financial conditions: incentives for team work, for work in underserved areas, analysis of the income differences between the GPs and other specialists (and move towards a softening of these differences if they exist), diversification of payment mechanisms [155].

5.4.3. Differentiated Nursing Practice

Chronic reforms often include new roles for the nursing workforce. The Belgian education system levels and new functions of nurses have been detailed in 6.4.4. Besides these different educational levels there is room for differentiation in practice (KCE-reports 86[157] and 122[161]):

- Nurses carry out many activities (administrative, clerical task; support activities daily living) that can be carried out by lower educated (healthcare) professionals, in hospitals (KCE report 86[157]) as well as in home care (KCE-report 122[161]);
- There is a need for an upward differentiation for highly complex nursing activities (KCE reports 27[140] and 86[157]). An example is the substitution of physicians by advanced practice nurses (see 6.4.3.1);
- Patient education activities as well as improved patient follow-up maintain or improve the quality of care[157].

These new roles may improve the attractiveness of the nursing profession. No efficiency gains were found[157].

Most KCE-recommendations are relevant for a chronic care system (KCE-report 86[157]):

- To increase the delegation of clerical and administrative tasks to professionals with a lower educational level;
- To educate nurses to delegate tasks to healthcare workers with a lower education level;
- To conduct pilot-projects (with a monitoring of efficiency and quality) on the function differentiation to lower and higher levels;
- To develop the upward differentiation of the nursing profession to increase the attractiveness of the profession for the nurses with a Master diploma;
- To start a political reflection on the respective roles of different health services functions (hospitals, primary care, home nursing, home care, nursing homes, informal care) and on the interconnection of these functions within an overall vision on health services provision (report 122[161]).

5.4.4. The right function for the right health professional: physiotherapists and pharmacists

5.4.4.1. The role of the physiotherapist in rehabilitation

The KCE-report 140 on cardiac rehabilitation mentioned above[152] and KCE-report 87 on the use of billing codes in rehabilitation[159] underlined the need for care given by the most appropriate health professional according to the patient's health status. There are currently two types of billing codes for the rehabilitation of similar pathologies i.e. either billing codes in physical and rehabilitation medicine or physiotherapy billing codes. The KCE recommended that (KCE-report 87[159]):

- Billing codes of the specialist in physical and rehabilitation medicine should be used for intellectual activities as for example the medical diagnosis, the drawing up of the rehabilitation treatment, the follow-up and coordination of the care;
- Physiotherapy billing codes should be used for the routine treatment of the patients.

5.4.4.2. New role for the pharmacist

The section on health professionals described initiatives abroad to enhance the role of the pharmacist. KCE reports also underlined new roles, in the community and in the hospital settings. KCE report 47 on medications in nursing homes[158] concluded that clinical pharmacists should assist and participate more in all stages of the medication use process: prescription, purchase, packaging, distribution system and follow-up of the effectiveness and safety of pharmacotherapy.

5.4.5. *Important role for the occupational physician and the advisory physician from the sickness funds*

KCE-report 48 on low back pain[24] illustrates the important role of occupational physicians and physicians from the sickness funds for limiting the duration of sick leave in case of chronic condition that affects middle-aged, active population. The KCE recommended a close cooperation between occupational physicians and physicians working in curative sector to prevent a transition to chronicity[24]):

- Occupational physicians and advisory physicians from the sickness funds play a crucial role to reduce the consequences for the patient and for the society;
- Information of the workers about e.g. the risk linked to occupation, the need for staying active in spite of the pain;
- Promotion of prevention strategies to prevent chronicity (e.g. back schools at the workplace);
- Promotion of a multidisciplinary approach in collaboration with the general practitioner: combination of exercises and psychological and/or social care;
- Adaptation of the task when the worker returns to work (duration and load).

5.4.6. *Role for informal caregivers*

Informal caregivers play a major role in the context of chronic care. The KCE-report 160 on the effectiveness of non-pharmacological interventions for patients with dementia confirms this statement[121]. Multi-component interventions that aim to support informal caregivers are generally effective to reduce the risk of, or to delay the patient's institutionalisation on the patient's outcomes. They have also a positive impact on the caregiver (e.g. mood, well-being, quality of life). Their components include, for example: (telephone) counselling sessions, support groups, assessment of the patient's individual situation, referral to a psychiatrist, networking of families.

Based on these findings the KCE recommended to support and train informal caregivers, including multi-component interventions at home[121].

Reinforcing the role of informal caregivers is in accordance with the root definition of the chronic care system and with the module 'self empowerment' of the conceptual model (see chapter 2).

5.4.7. *Curricula and continuous education based on needs*

The analysis of KCE-reports revealed the importance of a meticulous analysis and planning of the education needs of (future) health care professionals (basic curricula and continuing education).

Some illustrations of KCE recommendations in the field of chronic diseases are:

- To include courses in palliative care ("basic training") in the curriculum of all health professionals and to organize continuing education in palliative care (KCE-report 115[147]);
- To include general practice in the core curriculum of all physicians (KCE-report 90[155]);
- The training of staff in nursing homes on how to look after residents with dementia (KCE-report 160[121]);
- The professional training of nurses in relation to their new role in medication management. A better training in pharmacology of the nursing staff and enhanced communication with the dispensing pharmacist and the prescribing physicians has the potential to improve the quality of pharmaceutical care in nursing homes (KCE-report 47[158]);
- The training of health professionals who work in any setting (ambulatory of hospital setting) should include aspects relating to seamless care (with regards to medication KCE-report 131[162]). (See also 5.7.1)

5.5. Appropriate financing

The analysis of the KCE-reports can be grouped in 3 themes that are relevant for a chronic care system:

- Financial accessibility; (see 5.5.1)
- Financing services required by the chronic care system; (see 5.5.2 and 5.5.3)
- Financial initiatives for quality; (see 5.5.4)

Other examples about financing mechanisms relevant for the chronic care system can be found in KCE-report 124 about chronic dialysis[163], KCE-report 73 on the geriatric care programme[144] and KCE-report 99 on geriatric day hospitals[145].

5.5.1. Financial accessibility

Financial accessibility is an important dimension of quality of care for the equity of the health care system. The Belgian Health care system is mainly based on a fee-for-service system[164]. Out-of-pocket payments may be high and endanger the financial accessibility. They include:

- Individual co-payments (i.e. the official tariff is higher than the reimbursement);
- Supplements: health care providers can charge more than this official tariff in some circumstances, some services not covered by the compulsory health insurance (e.g. some medical devices, cosmetic surgery.

Several financial mechanisms were introduced to maintain a health care system that is financial accessible. Examples are lump sums provided for incontinence material, palliative treatment at home or the Maximum Billing system (MAB).

5.5.1.1. Evaluation of the Maximum Billing System

This system limits the co-payments in relation to the income of households. The system restricts the co-payments for all income groups in a range between 3 and 4.5% of the net taxable income of the household. The Maximum Billing System is an elegant and flexible mechanism of social protection. Nevertheless, the evaluation by the KCE (KCE-report 80[164]) highlighted some sensitive areas:

- The administrative complexity caused by regulatory changes. The KCE recommends to simplify the system and to harmonize calculation methods with other systems like OMNIO;
- The system only considers the expenditures for one year, a short time period for chronic patients. The KCE recommends to integrate the persistence of high out-of-pocket expenses in the Maximum Billing System calculation;
- Institutionalized psychiatric patients have very high expenses that raises the sensitive question of the possible suppression of their co-payments;
- A significant number of families have very low incomes with a possible medical underconsumption. A solution could be the introduction of an additional lower MAB-ceiling (e.g. € 250) for these groups;
- The supplements are not covered by the MAB-protection but are a significant part of the out-of-pocket payments. The budgetary cost of including them in the MAB makes this prohibitive.

5.5.1.2. Impact of supplements

Another KCE report showed that chronically ill patients (e.g. kidney failure) pay higher amounts of supplements (KCE-report 50[165]). However, the individual financial impact depends on the personal supplementary private hospital insurance.

5.5.1.3. Entitlement to a hospital insurance

In Belgium the legislation protects the patients with chronic diseases: no insurance company can dismiss a patient with a chronic condition. KCE-report 166 [166] found that patients with a chronic disease did not experience any great difficulty when applying for private hospital insurance. For these reasons it is necessary to think carefully about how the MAB and supplementary hospital insurance have to be geared to one another.

5.5.1.4. *The reference price system*

The KCE also studied the impact of measures that aim to control the health care budget on the financial accessibility. An example is the reference price system for drugs: there is a maximum level of reimbursement for a given group of pharmaceutical products. The patient pays any difference between the reference price and the price of a more costly drug ("reference supplement"). The total amount of reference supplements in 2008 was € 60.45 million which corresponded to 10.2% of all out-of-pocket payments for reimbursed pharmaceuticals. Nevertheless, there is no evidence that the use of originator (more expensive) drugs differs between socioeconomic groups. The KCE recommended several measures to further reduce the amount of reference supplements (KCE-report 126[167]):

- To allow a substitution right (unless explicitly prohibited by the prescriber) to pharmacists;
- To increase the quota of low cost prescription with consultation of the National Commission Physicians-Sickness funds;
- To increase the patient's awareness of the reference supplement, by providing a clear information on the supplement paid;
- To set the reference price with respect to the price of all low cost drugs within a cluster (versus the price of the originator drug only).

5.5.2. *Financing system for home care nursing*

New organization models emerged or existing ones were re-designed to answer to the new challenges of chronic care. One illustration is home care nursing, that relies in Belgium relies on two main payment systems (KCE-report 122[156]):

- Per diem lump sum system: covers nursing interventions for patients with deficiencies in the activities of daily living (ADL). Medical prescription is not required;
- Fee-for-service system that covers technical nursing interventions: it requires a doctor's prescription, with a maximum day-limit.

The budget spent on home care nursing is expanding more rapidly than the overall healthcare expenditure. Several problems have been identified in the current financing system:

- The list of billing acts of nursing activities is obsolete and complex;
- The different educational levels of the nurse are not reflected in the financing scheme;
- The Belgian home care nursing financing system does not distinguish basic care (that might be delegated from specialized nursing care;
- There is a lack of incentives to stimulate the coordination of care between the first and the second line workers;

The KCE recommended to keep a mixed financing system for home care nursing but the system requires new payment mechanisms (KCE-report 122[156]):

- A distinction should be made between post-acute care and long term care. Specific post-acute care can, for instance, be financed via a parallel hospital financing system (DRG or case-mix) as in some neighbouring countries. This system could stimulate early discharge and enhance the collaboration between hospitals and home care;
- Long-term care payments need disentangle basic care and follow-up of chronic conditions from technical care. Payment for the follow-up of 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 (i.e. content and amount);
- The nurses' qualifications, level of expertise and experience should be taken into account. Explicit criteria used to justify different payments should be discussed.

5.5.3. Comparison of two financing systems for primary health care

In Belgium fee-for-service and capitation are two parallel financing systems in general practice. Only a minority of the GPs (approximately 400 in 2010) work in a capitation system: the payment is calculated as the average cost per beneficiary of the same category under the fee-for-services system. This amount is increased by 31% to compensate e.g. differences in socio-economic status of the patient population, possible savings in secondary care. The evaluation of the KCE found that (KCE-report 85[168]):

- Health care expenditures by the NIHDI (RIZIV/INAMI) are equivalent in both systems;
- Co-payments for the patients are higher in the fee-for-services system;
- The proportion of patients from lower socio-economic groups and from younger age groups are higher in the capitation system;
- Expenditure for secondary care is lower under the capitation system;
- Quality of care, in general, is similar in both systems. However, a better quality was observed for specific activities in the capitation system i.e. more preventive activities and prescription of antibiotics in accordance with EBM guidelines.;

The KCE recommended (KCE-report 85[168]):

- To monitor the quality using available quality indicators in administrative databases (to be completed by new studies on quality);
- To adjust the capitation payments according to the socio-demographic profile of the patients (e.g. low social class);
- To foster the accessibility, quality and efficiency for all in primary care (e.g. to avoid a patient selection if the financing is linked to savings in the second line of care);
- To monitor the evolution of the capitation payments in parallel with the expenses for the patients in the fee-for-service system.

5.5.4. Financial initiatives for quality

Some KCE reports suggested introducing financial incentives to improve the quality of care as for instance: financing home care nursing (KCE-report 122[156]); organization of care for diabetes 2 patients (KCE-report 27[140]); seamless care (KCE-report 47[162]). This mechanism is called Pay for Performance (P4P) or Pay for Quality (P4Q), if the objective exclusively focuses on the quality component of performance.

The advantages, disadvantages and feasibility of the introduction of 'Pay for Quality' programmes in Belgium were the subject of a KCE-report 118 [169]. This report did not identify Belgian initiative that fits the definition of P4Q (i.e. financial incentive based on quality measurement). The main conclusion of the literature review is that of a strong variation in the results measured after the introduction of P4Q programmes: most of them had only a moderate effect. The KCE recommended (KCE-report 118[169]):

- To develop quality measures that are supported by evidence (see also KCE-reports 27, 85 and 41: diabetes[140], medical houses[168], clinical quality indicators[107];
- To reward the achievement of quality targets rather than the providers and organizations with the best results;
- To implement P4Q programmes gradually;
- To use accurate, validated and already available data;
- To set up, from the start, a monitor system of the overall impact, effectiveness, cost-effectiveness and potential unintended consequences;
- To provide a feedback to the health professionals.

5.6. Quality processes

Care of high-quality is one of the qualifiers of the activity model presented in 3. The different dimensions of quality of care are safety, effectiveness, appropriateness, patient centeredness, timeliness, efficiency, equity, comprehensiveness and continuity (see section 3.2.3).

5.6.1.1. Framework for the measurement of clinical quality indicators

The first KCE report (41) on quality of care focused on clinical quality indicators[107] and proposed a framework to develop sets of clinical indicators and to implement a system for the measurement of quality of care in Belgium. The development of this framework at policy level requires a national health policy with clear health care goals and priorities. It will take into account the impact on public health, the availability of data and the potential for improvement. Clinical quality indicator systems take into account the technical characteristics of the indicators as validity, reliability, sensitivity and specificity. Characteristics related to the use of the indicator, such as feasibility and interpretation are also important. Process indicators are more sensitive to differences in the quality of care whereas outcome indicators are indirect measures and reflect all aspects of the processes of care (even those which are not directly measurable).

The KCE-report 41[107] concluded that coordination is needed to harmonize the multiple quality initiatives and data collections in Belgium. Furthermore the KCE recommended the development of a system for the measurement of quality with a special attention to:

- The definition of clear objectives and consequences of the measurement;
- The set up of a valid data collection that takes into account the existing databases;
- The search for evidence-based clinical quality indicators;
- The improvement of the collection of hospital data to allow further analyses in relation to the quality of care.

5.6.1.2. Quality framework in general practice

Care of high quality in the first line of care is important for the chronic patient. The KCE report 76[170] on quality in general practice identified key elements for developing a successful quality system in general practice:

- The role of the authorities i.e. a leadership in the development of a national quality policy and a vision on implementation conditions;
- IT developments for the data collection and quality measurement, discussed within the Be-Health Programme;
- New budgets or reallocation of the current ones to support quality initiatives;
- A professional culture and the participation of the GP profession as driving forces for setting up quality initiatives in general practice;
- A the practice level: need for motivation, adapted organization, awareness of the consequences of the measurement, accurate data registration.

5.6.1.3. Quality indicators for specific diseases

Some KCE reports developed quality indicators, based on the evidence and in collaboration with clinical experts:

- Monitoring and evaluation of quality of care for type 2 diabetes patients (KCE report 27[140]);
- Testis cancer: 12 indicators were selected (9 process indicators and 3 outcomes indicators) covering the diagnosis, treatment and more general indicators, such as survival rate. Only 5 indicators were directly measurable. The measurability of the indicators depended on the data provision and the specificity of these data and the possibility of the linkage between the different databases (KCE-report 149[171]);
- Breast cancer: 32 indicators were selected (28 process indicators and 4 outcome indicators) for the diagnosis and staging, adjuvant treatment, histopathology and general indicators. Only 13 of the 32 indicators were measurable, for similar reasons as in the report on testis cancer (lack of specific data registration and collection, difficulties with linking different databases) (KCE-report 150[172]).

5.6.1.4. *Medication use in rest and nursing homes in Belgium*

The quality of prescribing and medication management is of utmost importance for older persons. Since 2000 each rest/nursing home has a medical coordinator (GP), who is responsible for the coordination of quality initiatives, for training of the staff and for the development and use of a formulary for the medication policy (legally regulated since 2004). However, the KCE-report 47 on medication use in rest/nursing homes[158] shows a large variation in the quality of the medication management systems. The quality of prescribing depends on the location of the rest/nursing home. A lower quality is found with a lower number of residents per GP. A higher quality is associated with greater activity of local pharmacist, higher activity of coordinating GP, a better implementation of the formulary and a higher ratio of nursing staff versus the number of residents.

The medication management system focuses more on the distribution process than on the quality of prescription, with a poor implementation of the formulary. Major problems are the poly-medication, the long term use of benzodiazepines, antidepressants and antipsychotics and the use of medications with a doubtful (cost)-effectiveness.

The KCE report 47[158] recommends:

- To improve the implementation of the formulary by giving a more important role to the coordinating physician;
- To adapt the training of nurses and pharmacists to the new roles within the medication management systems;
- To set up local agreements between institutions, physicians and pharmacists to promote the use of generic medications;
- To consider financing systems for medications (case-mix budgeting, reference prices), rather than a fee-for-service basis.

5.6.1.5. *Quality indicators to assess the performance of the Belgian Health care system*

An indicator set is now developed and pilot tested for the evaluation of the performance of the Belgian health care system (ongoing project). A former research defined conditions for the implementation of this system in Belgium in terms of data collection and conditions for implementation (KCE report 128[173]). Different components are gathered in the conceptual framework or performance evaluation:

- Health system (health promotion, preventive care, curative care, long term care and end-of-life care);
- Health status;
- Non-medical determinants of the health.

The performance of each component has 4 dimensions: quality, accessibility, efficiency and sustainability.

The major limitations of this study are a lack of data for all indicators and that not all dimensions are covered. In the second performance-report (ongoing project) a selection of indicators will be made for all components of the health system and health promotion.

5.7. Decision support

The KCE published a series of reports with evidence in relation to the care in oncology and many other conditions e.g. low back pain (KCE-report 48[24]), dementia (KCE-reports 111[174] and 160[121]), varicose veins (KCE-report 164[175]), osteoporosis (KCE-159[176]). Other Belgian institutions also publish guidelines and there is an effort today to rationalize this offer on the net (i.e. EBMPracticeNET) and to integrate this information into the medical file.

This section focuses on two KCE reports that provide insight in 2 modules of the conceptual model: seamless care (KCE-report 131[162]) and self-empowerment (KCE-report 124[163]). More detailed recommendations are in appendix 2.

5.7.1. Seamless care with regard to medications

An activity module of the conceptual model is the provision of "seamless care between routine care and acute care episodes". The KCE-report 131 was dedicated to the issue of seamless care with regard to medications, i.e. at admission and discharge from the hospital[162]. Problems affect between 20% and 60% of hospitalized patients and relate to:

- The communication at hospital admission (e.g. incomplete list of medications);
- The communication when returning home (e.g. lack of communication with GP);
- Health care professionals (e.g. lack of assistance to the patient with regard to medications management);
- Patients and families (e.g. non-compliance);

The KCE-report did not identify any scientific evidence on interventions to enhance seamless care but an analysis of the situation in other countries and in Belgium led to the following recommendations (KCE-report 131[162]):

- To compile, publish and circulate good practice guidelines on seamless care with regard to medication;
- To draw the attention of care providers and patients to the importance of the continuity of medications at the time of transition between care sites;
- To emphasize the shared responsibility of all in this matter;
- To formulate clear procedures for seamless care focusing on medications at the admission and discharge from hospital;
- To share the patient data in electronic form (medical data of interest, updated list of medications) while respecting the rules of safety and confidentiality (cf. 5.8 Clinical information systems).

5.7.2. Self-empowerment in chronic dialysis

KCE-report 124[163] on the organization of chronic dialysis illustrates the importance of self-empowerment in chronic patients. Chronic dialysis has a significant impact upon a patient's life, depending on the type of dialysis: hospital haemodialysis occurs typically three times a week in a hospital unit while peritoneal dialysis occurs daily at home. The patient preferences are therefore an important element in the choice of dialysis modality.

The KCE recommended that (KCE-report 124[163]):

- Every patient starting on dialysis should be informed timely, fully and objectively about the different dialysis modalities, conform the law on patient rights;
- Patient participation should be a key element in the process, in particular in final choice of dialysis modality;
- Patient counselling should be a requirement for all pre-dialysis patients in the existing ambulatory care trajectories (cf. 4.5.2.2) and for end-of life renal disease;
- The Belgian associations for nephrology should include in their current data registration protocols, a tool to assess the effect of introducing counselling services in dialysis centres.

5.8. Clinical information systems

Clinical information systems have not been studied as a topic sui generis by the KCE. Nevertheless, many KCE recommendations outlined in the previous sections require an IT investment:

- the reports on quality (clinical quality indicators (report 41[107]), performance of the health care system (report 128[173]), quality in general practice (report 76[170]), pay-for-quality (report 118 [169]);
- the measurement of quality of care for specific diseases also implies an accurate data registration to compute the indicators (e.g. quality in oncology (report 81[177]), testis cancer (report 149[171]), breast cancer (report 150[172]), mental health care (see reports in 5.3.5), palliative care (report 115 [147]), low back pain (report 48[24]), rehabilitation (report 57[153]).

The KCE report on the organization of care for diabetic-2 patients (report 27[140]) illustrates that investments in clinical information systems are needed for most requirements discussed above:

- Access to the medical record for all professionals involved in the multidisciplinary team require IT-systems compatible between organizations and between professionals;
- IT systems should also allow the extraction of data relevant to monitor the quality of patient care;
- IT systems could be used to set up pay-for-quality initiatives;
- Automated reminders (decision support) could improve the compliance with guidelines.

5.9. Key points: evidence and recommendations from KCE reports

This chapter summarizes the evidence and the recommendations from KCE reports on the organization of care for chronic patients. Common themes emerged from the recommendations in relation to the requirements of a system for chronic care:

- **Tailored delivery system design:**
  - **To perform an adequate screening and assessment of the patients with chronic disease(s) to plan their care according to their needs;**
  - **To inform the patient so that he can participate to the choice of his treatment and thereby optimize the compliance and quality of life.**
  - **To strengthen the organization of primary care i.e. the provision of care by a multidisciplinary team, coordinated by the GP (whilst specialists are involved in case of acute episodes);**
  - **To guarantee an efficient communication, coordination and collaboration between different professionals within the same setting and between the different levels of care;**
  - **To develop further policies that support a shift from residential care to home care for the persons who do not need continuous and/or high level of care: this requires an accurate planning of home care services and residential facilities based on the sociodemographic trends;**
  - **To collect standardized data to allow the planning of the services as well as their evaluation.**
- **Appropriate work force:**

The suggestions formulated in KCE reports have concrete illustrations in the chapter on new functions and roles for the health professionals.

  - **To take concrete measures to reinforce the profession of general practitioner: attraction (academic curriculum, training), improvement of working (e.g. out-of hours, career perspectives) and financial conditions;**
  - **To determine who is the most appropriate health professional (e.g. rehabilitation) according to the patient's situation;**
  - **To enhance the role of nurses (with a specific qualification) in chronic care: either to substitute the physician (e.g. patient follow-up) or to perform new tasks (e.g. patient self-education);**
  - **To consider the delegation of nurses' tasks to administrative staff and to professionals with a lower education level;**
  - **To consider new or increased roles of professionals (e.g. pharmacists, occupational physicians) for the follow-up and secondary prevention of patients with a chronic condition;**
  - **To support and acknowledge the major role of informal caregivers;**
  - **To keep up-to-date an accurate registry to monitor the work force in the health care sector.**
- **Adequate financing:**

Adequate financing is a major condition for the accessibility and sustainability of the chronic care system. Recommendations have been formulated for specific care (dialysis, geriatric care) but this analysis focused on issues common to most patients. Several avenues have been suggested:

- **To pay attention to the financial accessibility of all chronic patients: simplification of the current administration, attention for vulnerable groups (families with a very low income, chronic psychiatric patients), impact of supplements in the absence of private medical insurance;**
- **To review the current payment mechanisms in home care nursing: in particular the long-term care of chronic patients should benefit from a system parallel to the fee-for-service system and the financing system should stimulate the collaboration between the first and the second line of care;**
- **To monitor both financing systems in primary care in order to adapt the capitation payments according to the reality (sociodemographic profile of patients, efficiency);**
- **To develop a financing system linked to the quality of care: this requires e.g. the development of (evidence-based) quality indicators, the collection of valid data, a definition of possible consequences and a feedback to professionals.**

- **Quality processes:**

The link between quality and financing has been mentioned above. Other reports focused exclusively on quality, either in general (measurement of clinical quality indicators, quality framework for general practice) or for specific situations. Common recommendations are:

- **The major role of the authorities for launching and supporting quality initiatives (leadership, quality policy, definition of objectives and consequences);**
- **The development of quality indicators in collaboration with the professionals;**
- **The involvement of the profession (scientific associations and individuals);**
- **An accurate data collection of quality indicators that requires specific IT developments;**
- **A training of the professionals to take new roles in the quality system;**
- **An adequate financing (or reorientation of the current budget) to support the quality initiatives.**

- **Decision support:**

The KCE reports on good clinical practice provide tools to support the clinical decision. Other Belgian institutions also publish guidelines and there is an effort today to rationalize this offer on the net (i.e. EBMPracticeNET) and to integrate this information into the medical file.

- **Clinical information systems:**

Investments in clinical information systems are required to fulfil the requirements above i.e. to share information between professionals, to collect accurate data for financing and for the measurement of quality of care, to offer a decision-support for the clinicians.

6. FOCUS ON PATIENT EMPOWERMENT AND NEW PROFILES/ FUNCTIONS IN THE FIRST LINE OF CARE

Authors: Felicity Allen and George Osei-Assibey (systematic review on patient empowerment), Sophie Gerkens (new functions in the health care system), Dominique Paulus

6.1. Objective of this chapter

Advice to policy makers requires a review of the literature so that their decision would be based on the most recent available facts. A search for data underlying the whole position paper was impossible and the researchers decided to focus on two themes that emerged from the international papers (see 2.1): patient empowerment and new roles in the health care system.

The reasons of this choice were :

- Consensus of international organisations on the need to implement patient empowerment and new roles in primary care;
- Consensus of scientific and clinicians' worlds about:
  - the need to increase patient's involvement in the management of his/her disease. However little is known about the best way to achieve this objective concretely. This called for a synthesis of the scientific literature on how to implement patient empowerment in the practice for any chronic disease;
  - new primary care organization models that call for new roles in primary care. The report of the European Observatory on Health Systems and Policies[8] gave an overview of possible new roles in other countries (nurse practitioners, community nurses, liaison nurses, case managers). The researchers of this project decided to go deeper into this question to implement similar innovations in the Belgian health care system.

6.2. Methods

Both reviews used different methodologies given their respective scope:

- The search for optimal interventions for patients empowerment relies on a systematic review of the indexed literature: a great deal has been written on the subject and interventions for patient empowerment are universal. A systematic review helps to identify which interventions work best and how to generalise the results to most chronic diseases;
- Changes in workforce are very contextual and depend upon the health care context. In addition, there is hardly any available evidence, therefore the researchers took the option to describe some best-practices from selected countries that can inform policy changes in Belgium.

6.3. How to foster the patient self-empowerment ? Insights from a systematic review of the literature

Health care systems are transforming their approach to managing chronic care and are seeking ways to promote increased involvement of patients in their own management[178]. This involvement is in line with the ethics principle of patient autonomy where the patient's decision and actions have to be supported by his/her care providers[179, 180]

This systematic literature review conducted by a research team from Abacus International® aims to determine what interventions enhance a patients' self-empowerment in chronic care looking at which groups of patients would benefit from these interventions and more specifically what are the components of an effective intervention.

6.3.1. Scope of the literature review

6.3.1.1. Definitions

For the purposes of this project, patient empowerment is closely related to the terms patient self-efficacy, patient self-management and patient self-care. The terms self-efficacy and self-empowerment originated through the study of human psychology in the 1980s. The definitions used to guide this review are based on the work in this field by Bodenheimer et al. 2002[51] with additional definitions as outlined below:

- Patient empowerment – "patients accept responsibility to manage their own conditions and are encouraged to solve their own problems with information, not orders, from professionals"[51] and "to promote autonomous self-regulation so that the individual's potential for health and wellness is maximised. Patient empowerment begins with information and education and includes seeking out information about one's own illness or condition, and actively participating in treatment decisions"[181];
- Patient self-efficacy – "a person's belief that they can perform a specific behaviour or task in the future"[51, 182]. Enhanced self-efficacy is associated with "improved health and subsequently reduced health care costs when these specific tasks or behaviours are implemented" [183];
- Patient self-management – "an individual's ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition, to effect the cognitive behavioural and emotional responses necessary to maintain a satisfactory quality of life, so a dynamic and continuous process of self-regulation is established"[184]. Bodenheimer et al (2002) differentiate patient self-management from patient education in that self-management teaches problem-solving skills which allow patients to take actions to improve their health;
- Patient self-care – "activities that individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness and restoring health"[185].

6.3.1.2. Population, Intervention, Control Group and Outcomes

- Patient population:

  Chronic patients with chronic care needs. The focus was on diseases emphasised by the recent EU proposal (chronic cardiovascular, respiratory, mental illness, arthritis, diabetes) but not restricted to only these chronic diseases.

  Excluded: cancer patients because Belgium already has a national strategy plan.
- Interventions:

  Any intervention designed to enhance the patients' self-efficacy/self-empowerment/self-management as outlined in the definitions in section 6.3.1.1.

  The intervention may be designed to improve clinical outcomes but was included if one of the aims of the intervention was to improve a patient's self- efficacy/management/empowerment.
- Comparators:
  - Usual care;
  - Traditional patient education/information.
- Outcomes
  - Assessment of self-efficacy and assessment tool used;
  - Clinical outcomes (dependent upon chronic disease patient group);
  - Quality of life;
  - Health care use.

6.3.2. Methods

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).

The following databases were searched in January 2012 for publications in English, French, Dutch or German from the year 1999: The Cochrane Library, OVID Medline, OVID EMBASE, Psychinfo, CINAHL. The search for RCTs (February 2012) in the same databases was conducted 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.

The methodological quality of systematic reviews and RCTs was rated using the appropriate SIGN toolsa. The data from the selected 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 details and results of the quality appraisal and the data extraction tables are in the supplement of this report.

6.3.3. Results of the search strategy

6.3.3.1. Systematic reviews

A total of 4 465 citations on the topic of patient empowerment interventions for chronic diseases were identified in database searches (see Figure in the supplement). 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.

31 systematic reviews were included after quality appraisal[186-215].

Table 5 below summarizes the content of the 31 selected systematic reviews. The details are displayed in the evidence tables in the supplement.

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

Table 5 –Summary of included patient empowerment systematic reviews

Disease area	Number of SRs	Authors	Patient group	Intervention type
Chronic disease in general	2	Coster and Norman 2009	chronic diseases all ages	educational and self-management
		Dennis et al 2008	chronic disease	chronic disease management from delivery of health care perspective
Angina	1	McGillion et al 2004	class I, II or II angina	psycho-educational
Asthma	6	Bailey 2009	children and adults minority groups	culturally appropriate patient education
		Bussey Smith 2007	asthma any age	patient education via computer
		Gibson et al 2009	asthma >16 years	patient education for self-management
		Guevara et al.2003	children and adolescents with asthma	patient education for self-management
		Powell et al 2003	asthma	patient education for self-management
		Smith 2008	severe or difficult asthma	psycho-educational
COPD	3	Blackstock and Webster 2007	COPD patients	Self-management and didactical patient education
		Effing et al 2009	COPD patients	self-management education
		Monninkhof et al 2003	COPD patients	self-management education
Diabetes	5	Deakin et al 2009	diabetes type 2 adults	group based patient education
		Duke et al 2009	diabetes type 2 adults	individual patient education
		Hampson et al 2001	diabetes type 1; 9 -21 years	educational and psychosocial interventions for self-management
		Hawthorne et al 2008	diabetes type 2; ethnic minorities	culturally appropriate health education
		Sarkisian et al 2003	>55 years, African Americans and Latinos	self-management education
Heart failure	3	Boyde et al 2011	HF patients	patient education
		Ditewig et al 2010	HF patients - adults	self-management
		Jovicic et al 2006	HF patients - adults	self-management
Hypertension	2	Boulware 2001	hypertension patients	Patient-centred behavioural
		Saksena et al 2010	hypertension patients	Computer-based education
Irritable bowel	1	Dorn et al 2010	IBS adults	self-management

syndrome				
Kidney disease	1	Mason et al 2008	chronic kidney disease exclude transplant recipients	patient education
Painful musculoskeletal conditions	4	Du et al 2011	arthritis, back/shoulder/neck pain	self-management
		Riemsma et al 2003	rheumatoid arthritis	patient education
		Shin et al 2010	adults >65 years with OA	self-management education
		Niedermann et al 2004	RA	patient education
Multiple sclerosis	1	Thomas et al 2006	MS patients	psychological interventions
Stroke	2	Jones et al 2011	post-stroke patients	self-efficacy and self-management
		Korpershoek et al 2011	post-stroke patients	self-efficacy
Total no. of SRs	31			

6.3.3.2. Randomised controlled trials

A total of 1 675 citations of possible relevant RCTs were found from database searches (see flow chart in the appendix 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, 31 were included and 6 RCTs were excluded.

After quality appraisal 26 RCTs were included as summarized in Table 6 [216-241]. The details are displayed in the evidence tables in appendix 3.

Table 6 – Summary of included patient empowerment RCT's

Disease area	Number of RCTs	Authors	Patient group	Intervention type
Chronic disease in general	2	Hochalter 2010	chronic disease treated for 2 of 7 chronic diseases and >65 years	Patient engagement
		Jerant 2009	Patients >40 years with 1 or more chronic disease, plus functional impairment	Peer led self-management
Asthma	3	Mancuso 2011	Adult asthma patients admitted to ED	Self-management education
		Sun 2010	Adult asthma patients	Psycho-education
		Watson 2009	Asthma patients <16 years and their families	Small group interactive education
Chronic fatigue	1	Wearden 2010	CFS/ME patients	Pragmatic rehabilitation activity programme
Fatigue associated with chronic neurological condition	1	Ghahari 2010	Patients with fatigue secondary to MS, Parkinson's disease or post-polio syndrome	Online self-management
Chronic pain	1	Berman 2009	Patients with chronic pain due to arthritis, spinal problems, previous injuries or surgery and sciatica	Online mind-body self-care programme
COPD	3	Bucknall 2012	COPD patients admitted to hospital	Supported self-management
		Rice 2010	COPD	Group education
		Wakabayashi 2010	COPD	Individualised self-management
Diabetes	1	Rosal 2010	Low income Latinos with diabetes	Literacy–sensitive culturally tailored self-management
Fibromyalgia	2	Luciano 2011	Fibromyalgia patients	Psycho educational
		Williams 2010	Fibromyalgia patients	Internet-based behavioural self-management
Heart failure	2	Baker 2011	HF patients	Education and behavioural support
		Powell 2010	HF patients - adults	self-management
Hypertension	2	Bosworth 2009a	hypertension patients	Self-management
		Bosworth 2009b	hypertension patients	Tailored patient behavioural intervention

Irritable bowel syndrome	3	Jarrett 2009	IBS adults	Comprehensive self-management
		Oerlemans 2011	IBS adults	Cognitive behavioural therapy for self-management
		Ringström 2009	IBS adults	IBS school
Kidney disease	2	Chen 2011	Pre-dialysis chronic kidney disease	Self-management support
		Chow 2010	Peritoneal dialysis patients	Nurse –led case management
Multiple sclerosis	1	Barlow 2009	MS patients	Lay-led self-management
Schizophrenia	1	Chan 2009	Schizophrenia patients and their family care givers	Psycho education
Stroke	1	Cadilhac 2011	Stroke patients	Self-management
Total no. of RCTs	26			

6.3.4. Effectiveness of the interventions: results by disease

The supplement provides in 20 pages a detailed description of the systematic reviews and randomised controlled trials, categorised by disease. Table 7 below summarises the main evidence found per outcome for the chronic diseases where systematic reviews were available (31 systematic reviews completed by 22 RCTs). For each disease, the different interventions are displayed with their impact (or absence of impact) on the five main categories of outcomes i.e. self-efficacy, health care use, quality of life (QoL), clinical status/symptoms and others.

Six RCTs with low risk of bias provided additional evidence for five conditions where no systematic review was available:

- Some benefits of pragmatic rehabilitation programme in chronic fatigue syndrome (Wearden et al 2010)[222];
- Little benefit for a self-management programme for fatigue in patients with a chronic neurological conditions (Ghahari et al 2010)[220];
- No benefit of an online mind body self care technique in chronic pain (Berman et al 2009)[219];
- A short-term benefit of psycho education for schizophrenia patients and their caregivers in a Chinese setting (Chan et al 2009)[238].
- Fibromyalgia:
  - Moderate benefit of a psycho educational treatment programme from one RCT[230];
  - Moderate benefit of an internet-based self-help intervention from one RCT[234].

The grading for the systematic reviews was assigned according to the following criteria (adapted from SIGN evidence checklist (http://www.sign.ac.uk/methodology/checklists.html):

- Strong evidence: statistically significant improvement in >1 well conducted RCT or from meta-analysis;
- Moderate evidence: findings from 1 well conducted RCT;
- Weak evidence: findings from non RCTs or RCTs with methodological flaws (design or follow-up);
- Not reported: outcomes not reported in systematic reviews, so no conclusions can be made.

Table 7 – Overview of results of systematic reviews (and related RCTs) of self-management interventions in chronic diseases

Disease area	Results				
	Self-efficacy	Health-care use	QoL	Clinical/Symptoms	Other/general
Chronic disease in general	One RCT: Self management training sessions showed some improvement: RCT (Hochhalter et al 2010) One RCT: Peer-led self-management training limited short-term evidence (Jerant 2009)	Moderate evidence for self-management education in asthma: SR (Coster and Norman 2009).	Strong evidence for self-management support (Dennis et al 2008).	Strong evidence for self-management in diabetes and hypertension (Dennis et al 2008) and moderate evidence in diabetes and epilepsy (Coster and Norman 2009).	Self-management support patient education sessions, and patient motivational counselling (Dennis et al 2008)
Asthma	Strong evidence for self-management SR: (Guevara et al 2003). Moderate evidence for self-management in patient outcomes (Dennis et al 2008).	Strong evidence for self-management education SRs: (Guevara et al 2003, Gibson et al 2009). RCT (Watson 2009) on small group interactive education. Moderate evidence for educational interventions (Coster and Norman 2009). Weak evidence (short term) for psycho-educational interventions (Smith et al 2007).	Weak evidence (short term) for psycho-educational interventions: SR (Smith et al 2007). Weak evidence for culture specific patient education SR (Bailey et al 2009). Moderate evidence for small group education for children and their families RCT (Watson et al 2009). Moderate evidence for educational and psychological counselling RCT (Sun et al 2010) No evidence for self-management education RCT (Mancuso 2011)	Weak evidence for culture specific patient education SR (Bailey et al 2009). Moderate evidence for computerised interventions: SR (Bussey-Smith 2007). Strong evidence for self-management SR (Guevara et al 2003, Gibson et al 2009). Weak evidence for psycho-educational interventions SR (Smith et al 2007).	Most effective interventions difficult to determine but combination (self-monitoring, regular reviews) including written action plan seems most effective. The effect is also related to the intensity of interventions Improvement in asthma knowledge: Strong evidence for computerised interventions SR (Bussey-Smith 2007).

Disease area	Results				
	Self-efficacy	Health-care use	QoL	Clinical/Symptoms	Other/general
COPD	One RCT: Individualised self-management programme improved patients' information needs and activities of daily living:(Wakabayashi et al 2010)	Weak evidence (but promising results) of no significant effect for self-management SR (Blackstock 2007) Moderate evidence for self-management: SR s (Blackstock and Webster 2007, Effing et al 2007, Monninkhof et al 2003). One RCT (Bucknall 2012):combination of interventions at home has no effect on admission or any other outcome (QOL, symptoms) RCT: group education with telephone support reduced hospital admissions and ED visits at 12 months (Rice et al 2010)	Strong evidence for self-management in reducing total score on the St George's Respiratory Questionnaire (SGRQ) (Effing et al 2007). Weak evidence (but promising results) of no significant effect for self-management SR (Blackstock 2007).	Moderate evidence for self-management SR (Effing et al 2007). One RCT: Individualised self-management programme improved symptoms (Wakabayashi et al 2010)	Weak evidence of no effect for didactic education SR on any outcome (Blackstock 2007)
Diabetes	Strong evidence for self-management in patient outcomes: SR (Dennis et al 2008).	Moderate evidence for group-based education to reduce diabetes	Weak evidence for self-management SR (Sarkisian et al 2003).	Better glycaemia control: culture/age-specific self-management SR: (Sarkisian et al 2003) interventions.	Strong evidence for no effect of individual patient education on any outcome SR (Duke

Disease area	Results				
	Self-efficacy	Health-care use	QoL	Clinical/Symptoms	Other/general
	Moderate evidence for group based patient education to improve patient empowerment score: SR (Deakin et al 2009). One RCT: impact of a literacy- and culture tailored programme from one RCT (Rosal et al 2011).	medication SR (Deakin et al 2009).		Strong evidence (meta-analysis) for reduction in glycated haemoglobin, fasting blood glucose, body weight and systolic blood pressure with group-based education SR (Deakin et al 2009). Strong evidence: Small to moderate improvements in various outcomes with educational and psychosocial interventions (adolescents) (Hampson et al 2001). Strong evidence for short-term better glycaemia control with culture-specific education SR (Hawthorne et al 2008).	2009) Effects recorded among patients with the worse glycaemia control: 2 SRs (Duke 2009 and (Sarkisian et al 2003) Long-term effects on glycolic control (12 months) unclear in some trials (Hawthorn 2008,Rosal 2011), Strong evidence for improvement in patient knowledge for group-based patient education SR (Deakin et al 2009). Strong evidence for literacy- and culture tailored programme from one RCT (Rosal et al 2011) for diabetes knowledge, blood glucose monitoring
Heart failure	Moderate evidence for some improvement in self-efficacy and self-care from patient education SR (Boyde et al 2011) (Baker 2011) No effect in one well-conducted RCT (Powell,	Strong evidence for self-management interventions 2 SRs: (Jovicic et al 2006, Ditewig et al 2010) No effect in one well-conducted	Moderate evidence (6 out of 14 RCTs) for self-management SR (Ditewig et al 2010).	Not reported	Knowledge levels showed a statistically significant improvement in the 8 studies that evaluated patient knowledge (Boyde et al 2011). One RCT reported

Disease area	Results				
	Self-efficacy	Health-care use	QoL	Clinical/Symptoms	Other/general
	2010)	RCT (Powell, 2010)			short term improvement for all outcomes after educational and behavioural programme (Baker 2011)
Hypertension	Strong evidence for self-management in patient outcomes: SR (Dennis et al 2008)	Not reported	Not reported	Weak evidence for behavioural interventions combining counselling and training courses (improvement in blood pressure, hypertension control) SR (Boulware et al 2000) One RCT showed reduction in blood pressure through combination of behavioural and home monitoring (Bosworth et al 2009b)	Strong evidence that a computer-based intervention does not change health behaviours: SR (Saksena 2010) and RCT (Bosworth, 2009)
Angina	Not reported	Not reported	Not reported	Weak evidence for improved symptoms, symptom-related stress and physical functioning in psycho-educational interventions SR (McGillion et al 2004)	Not reported
Stroke	Weak evidence SR: (Korpershoek et al 2011) One RCT found no evidence to support a self-management programme (Cadilhac 2011)	Not reported	Not reported	Not reported	Not reported
Irritable bowel syndrome	Not reported	Not reported	RCT: comprehensive self-management has an effect on QOL (Jarrett et al 2009)	One RCT supports the use of structured education (IBS School) (Ringström et al 2010) 2 RCTs: cognitive behavioural	Weak evidence for any outcome for self-management SR (Dorn 2010)

Disease area	Results				
	Self-efficacy	Health-care use	QoL	Clinical/Symptoms	Other/general
			RCT: cognitive behavioural therapy improves QOL at 1 month, not at 3 months (Oerlemans 2011)	therapy improves pain at 1 month (Oerlemans 2011), at 12 months (Jarrett 2009)	
Kidney disease	Not reported	Weak evidence for some benefit of multicomponent educational interventions, especially for patients in the early stages of kidney disease SR:(Mason et al 2008)	One RCT: no benefit of nurse-led case management on HRQOL (Chow et al 2010)	One small RCT: self-management support (combination of interventions) could slow the CKD progression and reduce morbidity)(Chen et al 2011)	
Painful musculoskeletal conditions	Strong evidence of some effects for educational interventions (Niedermann et al 2004). Moderate evidence for self-management in patient outcomes in arthritis (Dennis et al 2008).	Not reported	Not reported	Strong evidence of no effects for educational interventions (Niedermann et al 2004) Strong evidence with self-management programmes for reduction in pain and disability for arthritis patients – Moderate evidence of no effect for low back pain SR (Du et al 2011). Short term significant benefits of self-management in disability, joint counts, patient global assessment, as well as a positive trend regarding pain (Riemsma et al 2003). Moderate evidence that psychosocially focused interventions have a moderate	Psycho-educational interventions improved coping in the short-term, with some indications for long-term psychological benefits SR: (Niedermann et al 2004). Short term significant benefits of self-management in psychological status and depression (Riemsma et al 2003)

Disease area	Results				
	Self-efficacy	Health-care use	QoL	Clinical/Symptoms	Other/general
				effect on pain and function improvement SR (Shin, 2010)	
Multiple sclerosis	One RCT found small improvement after self-management course (Barlow et al 2009).	Not reported	No evidence	Strong evidence of little or no impact of psychological interventions on cognitive outcomes and mood SR (Thomas et al 2006).	Not reported

6.3.5. Summary of the findings: analysis by type of intervention

Evidence in this report was obtained from sources including a review of systematic reviews and many Cochrane reviews. This means very high quality reviews were utilised to condense the evidence. However across the included SRs and RCTs, study outcomes and method of assessments differed considerably both across all disease areas and even within similar intervention types of the same disease. This made it difficult to directly compare across studies and gave rise to some inconsistent results.

This section summarises:

- The types of interventions found in the patient empowerment literature;
- Which interventions are best suited to particular diseases.

6.3.5.1. Self-management

Self-management programmes were the most commonly found patient self-empowerment interventions across the disease groups with 15 SRs and nine RCTs evaluating an intervention under this definition.

The self-management interventions were studied in nine chronic disease groups: general disease (2 SRs[191, 196], 1 RCT[217]), asthma (3 SRs[199, 200, 214], 1 RCT[218]), COPD (3 SR[187, 198, 208], 2 RCTs[221, 223]), heart failure (2 SRs[194, 203], 1 RCT[233]), IBS (1 SR[193], 1 RCT[235]), kidney disease (1 RCT[239]), painful musculoskeletal (2 SR[195, 212]), MS (1 RCT[236]) and stroke (2 SR[204, 205], 1 RCT[237]).

Successful interventions were demonstrated for:

- General chronic diseases: Two SRs showed evidence for asthma, diabetes, epilepsy, mental health, hypertension, arthritis [191, 196];
- Asthma: Three SRs showed positive outcomes and found successful self-intervention programmes for asthma patients consist of multiple components: patient education, self-monitoring, regular medical review and a written asthma plan[199, 200, 214];
- COPD: One RCT showed a COPD self-management programme that was individually tailored to each patient according to the six domain scores on the Lung Information Needs Questionnaire (LINQ) gained improvements in the LINQ, BODE index and dyspnoea. 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[221];
- IBS: comprehensive self-management intervention delivered face to face or telephone with three face to face sessions showed improvement in IBS symptoms and QoL at 12 months[235];
- painful musculoskeletal: self-management programmes (most commonly face to face group sessions) were successful in managing pain and disability and improving self-efficacy[195, 212].

Inconclusive or no evidence:

- COPD: Self-management programmes for COPD showed weak or inconclusive evidence[187, 198, 208], in particular a home based self-management intervention led by a nurse showed no improvements compared to control[223];
- Heart failure: Inconclusive evidence for self-management interventions for heart failure with the exception of decreasing hospital readmissions[194, 203, 233];
- Kidney disease: inconclusive evidence that self-management improves CKD (slowing disease progression and reducing morbidity)[239];
- MS: inconclusive evidence that a chronic disease self-management course(consisted of six weekly 2-hour group sessions, delivered by pairs of trained lay tutors[236];
- Stroke: self-management programmes after a stroke showed inconclusive evidence for improving self-efficacy[204, 205, 237].

6.3.5.2. Patient education with self-efficacy elements

Patient education had to be based on self-empowerment/self-efficacy elements to be included. This was the second most commonly reported intervention being reported across seven disease areas. These included asthma (1 RCT[226]), COPD (1RCT [224]), diabetes (3 SR[192, 197, 201], heart failure (1 SR[190],1 RCT[227]), IBS (1 RCT[241]), kidney disease (1 SR[207])painful musculoskeletal conditions (2 SR[209, 210]).

- Successful interventions were demonstrated for:
  - Asthma: A small group, interactive programme of education about asthma, and targeted to either the parent or the child, or both, resulted in decreased use of health care resources [226];
  - Diabetes: Education programmes that address a wide-range of self-management aspects of diabetes show some benefit in decreasing blood glucose and patient empowerment score. There is not enough evidence to determine which format works best: group or individual education[192, 197, 201];
  - COPD: A group education intervention with telephone support reduced hospital admissions and ED visits at 12 months[224];
  - Heart failure: Short-term benefits in self-efficacy, self-care and quality of life outcomes were seen in an educational and behavioural support program which included specific instructions to guide diuretic self-adjustment, as well as an individualised plan developed with the patient's clinician[190, 227];
  - IBS: A structured patient education (“IBS school”) based on the self-efficacy theory, the general theory of nursing and a biopsychosocial model showed significant benefits for symptom severity, anxiety, knowledge and several aspects of HRQoL at 6 months[241];
  - Kidney disease: Educational interventions (multicomponent, with psychological elements) showed modest improvements in knowledge retention and delay in the onset of dialysis therapy[207];
  - Painful musculoskeletal conditions: Short –term benefits of educational interventions to improve disability, joint counts, patient global assessment, psychological status, and depression[210].
- Inconclusive or no evidence:
  - Painful musculoskeletal conditions: inconclusive evidence for educational programmes in RA[209] and individual education in diabetes (Duke).

6.3.5.3. *Psycho-educational*

Psycho-educational interventions were identified for angina (1 SR[206]), asthma (1 SR[215], 2 RCT[225,226]), fibromyalgia (1 RCT[230]) and schizophrenia (1 RCT[238]).

- Successful interventions were demonstrated for:
  - Fibromyalgia: a 2-month psycho-educational intervention that consisted of nine weekly 2-hour sessions, led to short-term improvements in the functional status of FM patients[230];
  - Schizophrenia: a psycho-educational programme for Chinese schizophrenic patients consisted of 10 sessions that were conducted over 3 months on a weekly basis and included the patient as well as a caregiver showed short-term positive effects on both patients and carers[238].
- Inconclusive or no evidence:
  - Angina: inconclusive evidence for effectiveness of psycho-educational intervention[206];
  - Asthma: inconclusive evidence as positive benefits were seen for a short duration[215,225].

6.3.5.4. *Culturally appropriate*

Interventions that were designed to meet the needs of specific cultural groups were found for asthma (1SR[186]) and diabetes (2 SRs[202,211]), (1 RCT[232]).

- Successful interventions were demonstrated for:
  - Asthma- Culture specific asthma self-management programmes (identifying and monitoring asthma symptoms, understanding medications, barriers to care, use of action plans) delivered through home visits with follow up telephone calls were found to have some positive effects[186];
  - diabetes- Culture specific interventions that are tailored toward the cultural or religious beliefs, taking into account the target group's literacy skills can improve a diabetic patient's knowledge, self-efficacy and blood glucose self-monitoring[202,232,211].

6.3.5.5. *Computer-based interventions*

Computer or online patient self-empowerment interventions were found for asthma (1SR[188]), chronic pain (1 RCT[219]) fatigue associated with neurological disease (1 RCT[220], hypertension (1SR[242]) and fibromyalgia (1RCT[234]).

- Successful interventions were demonstrated for:
  - Asthma- computerised asthma patient education programmes particularly computer game interventions for children were effective for improving knowledge and symptoms with inconclusive results on reduction of health-care use[188];
  - Fibromyalgia: A website delivering 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) showed modest improvement in pain intensity and physical functioning, as well as PGIC[234];
- Inconclusive or no evidence:
  - Hypertension: computer-based interventions for subjects with hypertension showed inconclusive evidence of effectiveness[242];
  - Fatigue associated with neurological disease: An active online intervention that included blogs, group experience and facilitators showed no positive benefit compared with usual care[220];
  - Chronic pain: An online mind-body self-care website described a problem-solving approach to planning for change, based on a 6-stage model. No differences were found between the intervention and the control group[219].

6.3.5.6. *Other interventions found for one specific condition*

- Behavioural interventions for hypertension:

  Behavioural interventions were only found for hypertension and were broadly defined to include counselling, structured training courses and patient self-BP monitoring interventions. This included one systematic review[189]) and RCTs from Bosworth et al. that are telephone-based[228,229]:

  - One RCT concluded to a successful intervention, for the combination of a behavioural intervention with home BP monitoring: positive results on BP (for ≥2 years)[229];
  - Inconclusive or no evidence: combination of counselling and training courses lead to better results than counselling or training on their own but evidence overall from a systematic review is inconclusive[189].

- Cognitive behavioural therapy for self-management in irritable bowel syndrome:

  One RCT on cognitive-behavioural therapy (CBT) studied in IBS patients[231] had no benefit at 3 months follow-up. A cognitive behaviour therapy intervention involved the treatment group receiving situational feedback from a psychologist on their personal electronic diaries over the course of three weeks for IBS. The overall QOL and pain improvement recorded after one month was no longer significant at 3 months follow-up[231].

- Psychological interventions for multiple sclerosis:

  Psychological interventions broadly defined as those that address mood and cognition were studied in one systematic review[213]). Overall it concluded that the evidence for psychological interventions for this patient group is inconclusive[213]. Only a few positive outcomes were reported across all trials[213].

- Patient engagement for chronic disease in general:

  The definition of "patient engagement" was used in one RCT to describe a complex intervention that included workshops and phone calls, with the aim of training patients to make the most of the healthcare they received. The sample was adults with at least two chronic conditions. The results were only positive for self-efficacy outcomes[216].

- Self-help programme in chronic fatigue syndrome:

  A self-help intervention for patients with chronic fatigue syndrome has been analysed in one RCT[222]. This pragmatic rehabilitation intervention showed some benefit on improving fatigue, sleep and depression.

6.3.6. *Conclusion: what elements make up successful interventions?*

Defining the elements that make up a successful intervention is difficult due to the many different chronic disease groups and the diversity of interventions studied. Taking this into consideration, common aspects of the identified successful interventions are outlined below.

- Tailored to the patient:

Interventions that modified their content to meet the differing needs of their patients [221] were more successful than those who did not[236,237]. This was evident in the group of asthma and diabetes interventions adapted to meet differing needs of certain cultural groups[186,202,211,232].

- Comprehensive programmes:

Interventions that used a wide range of self-management aspects[235] were more successful than simple programmes[216]. Strong evidence for asthma shows that successful interventions consist of multiple components: patient education, self-monitoring, regular medical review and a written asthma plan[199,200,214].

- Use of multiple delivery mediums:

  Interventions that used multiple delivery strategies such as face to face sessions with follow-up phone calls or additional educational materials[199,200,214,224] were more successful overall than those that relied on one medium such as telephone contact only[222,228].

- Involvement of patient's caregivers:

  Although the majority of the included interventions were focussed on the individual patient, those that included caregivers and family were

often successful. The evidence was particularly strong for parental involvement in their children's asthma interventions[200,226].

- Intensive interventions:

  Self-management interventions combined with more intensive education or skills training were more likely to significantly improve self-efficacy and clinical outcomes compared with intensive management alone[201,203,232].

6.3.7. Strengths of this review

The strict methodology of this review included a priori-defined inclusion criteria and quality appraisal tools that contributed to the robustness of the conclusions. The inclusion of a review of systematic reviews meant that many Cochrane reviews were included enabling a summary of high level evidence across many chronic disease areas. Additionally many Cochrane reviews have been published in this research field, condensing the evidence.

A major strength of this review is the transversal analysis of the techniques proposed for patient empowerment, for any chronic disease. The results show that the most current techniques (self-management, education) may be applied for many conditions: the results do not depend upon the disease under study but rather upon the design of the intervention.

Common features for successful interventions could be identified, independently of the target group of patients. However, it was not possible to identify groups of patients for whom interventions could have more chance to be successful.

6.3.8. Caveats in the interpretation of results

- Difficult to change health behaviours at long term.

  It could not be demonstrated in any of the included studies that the intervention was effective in changing a patient's health behaviour at long term. Changes were evident whilst an intervention was in progress but the effects measured were often not sustained once the intervention was over. Sustaining health changes in chronic care patients is a challenge.

- Methodological limitations of the included studies.

  o Trial designs:

  Many of the included trials had short term follow up of study outcomes making it difficult to predict the long lasting effects of the intervention. This has major implications for the implementation of interventions in estimating the duration of effect. Other limitations of the included RCTs were the lack of applying blinding to researchers and the variability of study outcomes. The definitions of self-efficacy varied with some authors linking an improvement in self-efficacy with an improvement in disease knowledge. The tools used to measure this outcome varied making it difficult to compare effects between studies.

  Recruitment of study participants in many of the included trials was commonly through advertisement or existing patients. These patients may be more motivated to succeed and not be a true representation of the general population. This limits the transferability of these studies to the general population or 'real world' setting.

  o Heterogeneity of study outcomes:

  The study outcomes and the way they were measured differed considerably both across all disease areas and even within similar intervention types of the same disease. This made it difficult to directly compare across studies and gave rise to some inconsistent results. For example, two SRs [209,210] evaluating patient education in rheumatoid arthritis gave conflicting conclusions as they did not report the same outcomes even though they had identified similar studies.

- No consideration of cost-effectiveness.

The benefit of health gain compared to the cost of the included interventions was not considered and is out of the scope of this review; however the cost of an intervention would be a major consideration for policy makers for implementation of any intervention. The wide availability of the internet and an ever-increasing computer-literate population means the internet and computerised games may be a cost effective way of delivering patient education and self-management. One included review demonstrated the benefit of computerised games for children helping to manage their asthma[188].

6.3.9. *Key points: interventions to foster patient empowerment*

- **This systematic review identified and analyzed a large body of evidence: 31 systematic reviews and 26 RCTs were selected after quality appraisal.**
- **Patient groups, interventions and outcomes were heterogeneous but can be categorised as follows:**
  - **The most frequent conditions were asthma, chronic obstructive pulmonary disease, diabetes, chronic pain, cardiovascular diseases (heart failure, hypertension);**
  - **Interventions included self-management interventions, education based on self-efficacy/self-empowerment, psycho educational sessions, interventions designed for specific cultural groups, computer-based interventions, behavioural interventions. A similar label could cover very different concepts, for example individual tailored interventions or group sessions;**
  - **Outcomes related to self-efficacy, health care use (hospitalizations), quality of life, clinical improvement. The measurement differed not only according to the disease but the measurement instruments also differed between the studies;**
- **It was not possible to identify neither the most effective interventions nor groups of patients who would most benefit from self-empowerment interventions. However, elements of successful interventions are:**
  - **Interventions tailored to the patient (meeting specific clinical needs or being culturally appropriate);**
  - **Comprehensive programmes that combine a range of interventions;**
  - **Use of different delivery mediums (face-to-face, telephone, video);**
  - **Involvement of the patient with his/her informal caregivers;**
  - **Spreading over time (months) with frequent contacts.**
- **Changes in health behaviours were usually not sustained at long term.**

6.4. New profiles and functions in the health care system

The increasing prevalence of chronic disease, the shortage of human resources and the specific needs of patients with chronic disease implied the redefinition of some existing functions and the creation of new profiles of providers[39]. The general practitioner keeps a central role but needs further support to face the complexity of the care for people with (multiple) chronic conditions. An exhaustive report of the European Observatory for health care systems and policies concludes to the emergence of new providers, new settings and new qualifications to face the new challenges of caring for an increasing population of chronic patients [8].

6.4.1. *Objective: analysis of the possible changes within the workforce to tackle the future challenges of chronic care*

The aim of this chapter is to analyse the possible changes within the workforce to tackle the future challenges of chronic care. The scope is the analysis of the health professionals (non-physician workforce, including informal caregivers) involved in the coordination and/or care of the chronic patient.

Functions that are not specifically related to the care of patients (e.g. administration) are out of scope. Organizational care models will neither be analysed.

This inventory is not exhaustive but describes the most interesting initiatives that could be food for thought for the Belgian health care system.

6.4.2. Methods

The main researcher responsible for this part (SG) used the report mentioned above as a starting point[8]. Contacts with experts permitted to identify a second report on the future of the workforce in primary care[243].

These two reports were used to define the framework of this research and to analyse more precisely experiences from three countries i.e. the UK, The Netherlands and Canada. The following method was used to identify relevant information on each country:

- A search on national official websites related to health care and personal contacts;
- An analysis of Health Systems in Transition (HiT) profiles for each country, available on the website of the European Observatory on health systems and policies;
- A search for other relevant articles using the reference lists of the reports identified above.

6.4.3. New roles in health care: examples from the UK, Canada and The Netherlands

Changes observed in health care workforce are complex. It was decided to classify them in three categories according to their main objective:

- Physician's substitution/supplementation: to create new types of providers or to enhance existing roles to perform tasks previously restricted to physicians and/or to extend the range of services currently provided by physicians (provision of new services);
- Delegation: to assign tasks of health care professionals (e.g. registered nurses) to less qualified or non health care professionals;
- Coordination: to improve the coordination between the different health professionals and/or the different settings (either new types of professionals or new roles of existing professions).

The limits between these categories may be somewhat unclear and specific changes often fall into more than one category.

6.4.3.1. Physician substitution/supplementation by advanced practice nurse

Advanced Practice Nurses and physician assistants are two new types of professionals who can substitute for physicians or supplement them. Third, community pharmacists may have their role extended, so as to perform tasks previously performed by physicians.

According to the International Council of Nurses (ICN), an Advanced Practice Nurse (APN) is "a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. A master's degree is recommended for entry level"[244]. "Expanded clinical practice" refers to the capacity of nurses to take responsibilities traditionally attributed to physicians (such as clinical assessment, diagnosis and treatment). It also refers to new care models where nurses take the lead e.g. in nurse-led centres but as specified in the method section, organizational models were not analysed in this chapter[245].

A variety of titles are found internationally: nurse practitioner, advanced practice nurse, nurse specialist, nurse consultant, advanced nurse practitioner, clinical nurse specialist, etc[246]. The two main categories are[245,246]:

- Nurse practitioners: in charge of some physicians' activities (substitution) including drug and medical tests prescription, diagnosis, screening, health promotion and prevention, monitoring of patients with chronic diseases, care coordination, etc[246];
- Clinical nurse specialists: their main function is to support and to improve the quality of nursing care. The roles of CNS usually include the clinical practice, the training, the research and the leadership. They are clinician experts in a specialised area of practice defined according to the patients' age (e.g. paediatrics), the setting (e.g. emergency room), the disease (e.g. diabetes or cardiovascular disease), the type of care (e.g. psychiatric or palliative care) or the health need (e.g. pain management)[246, 247].

The scope of the legislation that confers and protects those titles, the scope of activities and the required education level differ between countries[246].

The Canadian example:

Nurse practitioners

- Legislation:

  In Canada, NP are legislated and regulated at the provincial/territorial level. A legislation protects the NP title and enables NPs to practice in 11 of the 12 provinces and territories; some of them recognize both primary health care NPs and acute care (or specialised) NPs whilst others do not make any distinction[248].

- Scope of activities:

  They autonomously perform the following functions:

  - To diagnose a disease, a disorder or a condition;
  - To order and interpret screening and diagnostic tests; and
  - To prescribe medication.

  In some provinces and territories, additional functions are added, such as referring to a physician/specialist or providing emergency care.

- Education level:

  A master's degree is required for acute care NPs. For primary care NPs or NPs (without distinction), a master's degree will also be required in all provinces/territories from 2015 onwards (currently not mandatory in all provinces/territories having NPs)[246].

Clinical nurse specialists

- Legislation:

  There is no legislation to protect the title of CNS in Canada[247, 249]. Anyone can identify him/herself as CNS.

- Scope of activities:

  The function of clinical nurse specialists (CNS) in Canada may involve consulting patients, elaborating specific care programmes, teaching, advising other health care professionals to improve care, facilitating system change, and producing nursing knowledge and clinical guidelines which integrate research and practice[246, 250]. However, a recent study showed the absence of a common vision for the CNS role in Canada, making it difficult to distinguish CNSs from other types of nurses[247].

- Education level:

  A master degree is recommended but some nurses identify themselves as CNS without having the recommended education level[247]. However, there is limited access to CNS-specific education in Canada[251].

The UK example:

Advanced nurse practitioner

- Legislation:

  There is no UK regulation to protect the title of (advanced) NP. Anyone can call him/herself a NP and negotiate with an employer to be considered as a NP.

- Scope of practice:

  The Royal College of Nursing defines advanced nursing practice as a level of practice rather than a role or job title. They define the level of practice with which ANPs work as encompassing the followings:

  - "Makes professionally autonomous decisions, for which he or she is accountable;
  - Receives patients with undifferentiated and undiagnosed problems and makes an assessment of their health care needs, based on highly developed nursing knowledge and skills, including skills not usually exercised by nurses, such as physical examination;
  - Screens patients for disease risk factors and early signs of illness;
  - Makes differential diagnosis using decision-making and problem-solving skills;
  - Develops with the patient an ongoing nursing care plan for health, with an emphasis on preventive measures;

- Orders necessary investigations, and provides treatment and care both individually, as part of a team, and through referral to other agencies;
- Has a supportive role in helping people to manage and live with illness;
- Provides counselling and health education;
- Has the authority to admit or discharge patients from their caseload, and refer patients to other health care providers as appropriate;
- Works collaboratively with other health care professionals and disciplines;
- Provides a leadership and consultancy function as required"[252].

- Education level:

  A master degree is not mandatory to be employed as an advanced NP but they must have an adequate level of experience and follow a continuous education. The focus is more on the experience than on the education level[246, 253].

Clinical Nurse Specialist

- Legislation:

  There is no regulation to protect the title of CNS.

- Scope of practice:

  In UK, this term is used to describe some specific clinical roles such as CNS in rheumatology or in diabetes. Compared to NPs, CNSs act more as expert clinicians in a specific area of practice. Competences of CNS are[246]:

  - "Advanced nurse consultation and diagnosis (advanced physiological and psychological assessment), dependent on training and competency level;
  - Ordering and interpretation of diagnostic tests (including X-ray prescription, diagnostic ultrasound prescription and echography, laboratory test prescription), dependent on training and competency level;
  - Prescription of drugs with or without supervision of doctors (if the nurse is registered as a non-medical prescriber);
  - Management of a range of chronic diseases (follow-up, monitoring, health education and lifestyle advice for non-acute cases), dependent on role and training;
  - Triage activity to prioritise patients (dependent on training and competency level);
  - Referral of patients to specialists (dependent on training and competency level) / discharge management of a caseload development."

- Education level:

  A master degree is not mandatory to be employed as a CNS but they must have an adequate level of experience in their area of practice and follow a continuous education. The focus is more on the experience than on the education level[246, 253]. This has mainly to do with the UK-model of post-graduate training, organised by colleges and more orientated towards experience (versus academic degrees as in the Belgian context).

Modern matrons

- Legislation:

  There is no regulation to protect the title of Modern matrons.

- Scope of practice:

  The introduction of modern matron in the NHS system and the definition of guidance on their role were implemented in 2001 by the NHS Plan to strengthen the role of ward sisters and introduce senior sisters [254]. Modern matron is an agreed and approved national job profiles. Modern matrons are senior nurses providing clinical leadership who deal with the patient all the way through his/her clinical journey. They can be found in a range of specialties such as medical and surgical inpatients, accident and emergency (A&E), gynaecology, oncology, or mental health. The department of health defined 10 key responsibilities:

  - "Leading by example;

- Making sure patients get quality care;
- Ensuring staffing is appropriate to patient needs;
- Empowering nurses to take on a wider range of clinical tasks;
- Improving hospital cleanliness;
- Ensuring patients nutritional needs are met;
- Improving wards for patients;
- Making sure patients are treated with respect;
- Preventing hospital-acquired infection;
- Resolving problems for patients and their relatives by building closer relationships"[254].

Note 1: Advanced and specialist job titles in UK

Because the limited understanding of the meaning of advanced and specialist job titles in UK, the department of health (DH) performed in 2010 a position paper describing the elements corresponding to a practice at an advanced level. They proposed 28 elements around four themes: clinical/direct patient care; leadership and collaborative practice; improving quality and developing practice; and developing self and others (see http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121738.pdf)[255, 256]. This position paper insists on the fact that nurses with an advanced level of practice would have extensive clinical and practice experience and have completed a master's level of education (or equivalent)[256].

Note 2: Prescription of pharmaceuticals by nurses in UK

In the UK, Nurses can supply and/or administer medicines to patient without the need for a prescription using a Patient Group Direction (PGDs). PGDs are specific written instructions for the supply or administration of a licensed named medicine including vaccines to specific groups of patients who may not be individually identified before presenting for treatment [246, 253, 257, 258].

Moreover, registered nurses (and not only APN) are allowed to prescribe from the British National Formulary without the supervision of a physician if they follow a specific short term programme and if they are registered at the Nursing and Midwifery Council as nurse independent prescribers.

It should be noted that in the UK, not only nurses have access to independent prescribing rights but also pharmacists, podiatrists, physiotherapists, and radiographers[259].

The Dutch example: nurse specialists

- Legislation:

  The Netherlands have experience with advanced practice nurses since 1999 and the title of nurse specialist is now recognized by the Individual Health Care Professions Law (Wet Beroepen Individuele Gezondheidszorg).

- Scope of practice:

  They are mainly involved in the management of specific groups of chronic patients i.e. with diabetes, COPD or cardiovascular diseases. They work under supervision of a physician for medical tasks but are highly independent for nursing tasks. They can register as specialised nurses and have then to meet training requirements[260].

  Since January 2012, nurse specialists (with a Master of Advanced Nursing Practice) are allowed to prescribe medicines[261].

- Education level:

  Four specialisations are currently recognized, i.e. in preventive care; acute care and chronic care with somatic disorders; intensive care; and mental health care. Nurse specialists must have a Master's degree from a recognized education programme, accessible for nurses with a professional experience of at least 2 years. Nurses without this recognized educational qualification need to pass an assessment to prove that they have attained an equivalent professional level[260, 262].

6.4.3.2. Physician substitution/supplementation by a physician assistant

The Physician assistant is the second type of professionals who can substitute for physicians or supplement them. He/she provides medical care under the supervision of a physician. This health worker may be positioned between the doctor and the nurse.

The Canadian example

- Legislation:

  Only four provinces/territories have legislation protecting the PA title and enabling them to practice, i.e. Alberta, Manitoba, Ontario, and New Brunswick[263].

- Scope of practice:

  The Canadian Association of Physician Assistants defines the physician assistant as "a health care provider with the knowledge, skills and attitude to undertake delegated medical services. Physician Assistants are highly skilled health care professionals educated in the medical model who work under the supervision of a registered physician in a variety of clinical team structures and settings, in accordance with the delegated medical act"[263]. They can perform patient interviews, histories, and physical examinations; selected diagnostic and therapeutic interventions (including prescriptions and medical orders); and counselling on preventive health care.

- Education level:

  Four accredited PA programmes are available in Canada and the requirements to have access to these programmes differ. For instance the PA programme of the university of Toronto requires a minimum of two years of university study (10 university credits) and an experience in health care (1680 hours)[263].

The UK example

- Legislation:

  Registration is currently not mandatory but the UK Physician Assistant Association recommends that the registration on the PA Managed Voluntary Register (PAMVR) would become a compulsory criterion for employment.

- Scope of practice:

  The PA in the UK (previously "medical care practitioner") is defined as "a new health care professional who, while not a doctor, works to the medical model, with the attitudes, skills and knowledge base to deliver holistic care and treatment within the general medical and/or general practice team under defined levels of supervision"[264]. They work in general practice, walk-in centres, out-of-hours clinics, emergency medicine, cardiology, general surgery and orthopaedic surgery.

  Physician assistants are allowed to[264]:

  - "Formulate and document a detailed differential diagnosis, having taken a history and completed a physical examination;
  - Develop a comprehensive patient management plan in light of the individual characteristics, background and circumstances of the patient;
  - Maintain and deliver the clinical management of the patient on behalf of the supervising physician while the patient travels through a complete episode of care;
  - Perform diagnostic and therapeutic procedures and prescribe medications (subject to the necessary legislation); and
  - Request and interpret diagnostic studies and undertake patient education, counselling and health promotion."

- Education level

  Nationally approved postgraduate programmes of 2-year full-time are required. To have access to these programmes, applicants must have a first degree diploma in science or be a health care staff with a first level of qualification in nursing, physiotherapy, or others[265, 266].

The Dutch example

- Legislation:

  The profession exists for about 10 years but the related legislation is recent: a temporary law defining their competencies entered into force on January 1, 2012 (for a 5-year period). Physician assistants are now authorised to perform specific medical procedures and to prescribe "UR drugs" (= drugs only available under prescription) [267, 268]. The Netherlands' Association of PAs is the national organization and governing body for physician assistants.

- Scope of practice:

The PA works under the supervision of a physician within a specialised medical area and follows the directives and protocols of the concerned medical area. They are allowed to[267]:

- Investigate, treat and manage patients with common conditions within a particular area of medicine;
- Examine and assess the patient, make a diagnosis and establish a treatment plan;
- Carry out the treatment plan and carry out, on that purpose, common medical procedures;
- Determine indications and recognize complications of medical procedures and operations, and anticipate them;
- Provide emergency assistance, monitor vital signs and where necessary, take action to restore them;
- Refer to, consult and collaborate with physicians and other health workers;
- Provide advice, information, and preventive care;
- Perform surgical procedures, endoscopies, catheterisation, injections, punctures, elective cardio version, apply defibrillation, and prescribe UR drugs (as defined in article 1, first paragraph, part S of the Act on pharmaceuticals); only for acts in their field of expertise, acts with a limited complexity; routine operations; acts with incalculable risk, or acts carry out according to national guidelines, standards and protocols.

- Education level:

  To become a PA, candidates must follow an accredited master PA training based on the professional profile defined by the Netherlands Association of PA. This training covers the areas of medical expertise, communication, organization, cooperation, knowledge and science, social action and professionalism. To have access to such a training in the Netherlands, candidates must have a bachelor level of higher professional education (HBO- Hoger beroepsonderwijs) in health care (nursing or physiotherapy) and have at least two years of relevant work experience[267, 268].

6.4.3.3. Substitution for some tasks: role of community pharmacists

In some countries, the role of pharmacists enhanced to substitute for the GP for some areas of the medical practice.

The Canadian example

The trend of expanding the scope of pharmacists' practice in Canada was predominant in the hospital setting but it also involved community pharmacists.

According to the region/territory, pharmacists can be allowed to[269]:

- Manage medication dosages of anticoagulant drugs;
- Screen and manage patients on cholesterol medication;
- Perform a triage role e.g. assessing patients who purchase acid-reducers to refer them to physicians in case of "alarm symptoms";
- Providing health education and promotion;
- Take over new prescriptions and explain their usage, complete medication review, examine storage of medication in the patient home (during home visits) and assess medication interaction;
- Work in a primary health care team.

The UK example: new community pharmacist contract

The role of the community pharmacist has been enhanced in the UK by the development of a new community pharmacist contract in 2004.

Three levels of services have been defined:

- Essential: dispensing and disposal of medicines, providing health promotion and lifestyle advices, supporting self-care, orienting to other services;
- Advanced (if the pharmacist is accredited): providing medicines use review services, i.e. reviewing the patient's use of their medicines, offering advice on appropriate use to promote adherence and if needed, recommending changes in medicine to the patient's GP;
- Local enhanced: providing smoking cessation schemes, supervising administration of drugs like methadone and providing minor ailment

schemes (e.g. providing NHS treatment for person with a cough or cold who would otherwise consult a GP).

Community pharmacists in the UK are increasingly a first point-of-call resource for many people, providing advice as well as dispensing prescription drugs[270].

The pharmacists must follow a programme accredited by the General Pharmaceutical Council to receive a practice certificate in independent prescribing. This certificate allows them to prescribe for any condition within their clinical competence (except controlled drugs) and to be qualified as independent prescriber. Only registered pharmacists with at least 2 years of experience have access to this programme. It encompasses a minimum of 26 days of teaching and learning activity and a minimum of 12 days of practice with a medical practitioner[270].

6.4.3.4. Delegation to less qualified or non health care professionals

Some roles have been created to assign tasks previously performed by qualified personnel (e.g. registered nurses or allied health workers) to less qualified personnel or non health care professionals, such as health care assistants (including auxiliary nurses), health coaches and informal carers.

Health care assistants

The health care assistants work usually under the supervision of a regulated health care provider. They assist nurses, hospital staff and physicians in the basic care of patients. They provide homemaking, clearly identified personal care (such as mobility assistance) and routine activities of daily living (such as preparing food) according to predefined care plans[271, 272].

The Canadian example: Personal support workers

In Canada, the title of unregulated health care assistants differs according to the region/territory, e.g. Personal Support Workers in Ontario, Nurse Aid in Saskatchewan, Health Care Assistant in British Columbia, etc.

A series of measures guarantee that these professionals focus on activities that they are authorized to perform alone. In a near future they will be able to perform tasks not allowed previously (e.g. giving medication, performing rectal touches and inserting suppositories)[273].

The required level of education for health care assistant is:

- A secondary school education level and an on-the-job training; or
- A "health care assistant" programme (1 year) and a supervised practical training.

Some facilities also ask for the completion of specialized courses such as in cardiopulmonary resuscitation, first aid and food handling/sterile processing.

This occupation has currently no professional association[273, 274].

The UK example: Health care assistants

Unqualified people may enter in the NHS as health care assistant: through an apprenticeship, they have the opportunity to increase their qualification and to take responsibilities[272].

- Nursing health care assistants, also known as auxiliary nurses or nursing auxiliaries work alongside registered nurses and help for nursing tasks;
- Clinical support workers work alongside allied health professionals (e.g. physiotherapy assistants, podiatry assistants, or speech and language therapy assistants). Their role depends upon the area of therapy[272].

The Dutch example: Nurse assistants, nurse aides and nurse attendants

These professions work at the patient's home or in long-term facilities (nursing homes, homes for the older persons, or in facilities for people mentally or physically disabled).under a predefined care plan.

- Nurse assistants ("zorghulp") assist people in daily activities. They follow a one-year training programme;
- Nurse aids ("helpende zorg en welzijn") are in charge not only of household tasks but also of personal care (e.g. bath), under supervision. They follow a two-year training programme;

- Nurse attendants (“verzorgende”) perform similar tasks but mostly without supervision. They follow a three-year training programme [260, 275].

- Health coaches

The aim of health coaching is to help patients to get the knowledge, skills, tools and confidence to self-identify and reach their health goals and to become active participants in their care. Everyone can become health coach if appropriate training is given, i.e. health professionals such as nurses as well as a non health professional (e.g. patients)[276].

In Canada, some programmes use non health care professionals to support the patient in the self-management of their disease. The aim is to complete and reinforce the education given by professionals i.e. by new information, by learning new skills and abilities, developing new ways to manage their chronic condition. For instance, self-management programmes in British Columbia are given by “lay leaders” or “coaches” who successfully completed a four-day training workshop on self-management[277, 278].

- Informal carers

Informal carers are people who provide usually unpaid (except benefits described below) care-giving activities to an individual who requires help with basic activities of daily living. They are typically family members[279]. Support services and financial entitlements are often provided to help informal carers.

The Canadian example

Policies on informal carers depend upon the province or territory. Services for informal carers are mostly related to the package of public home care services. Some measures have been also taken by the federal government to support informal carers[280, 281]:

- Tax credits, i.e. a sum deducted from the total amount a taxpayer owes;
- The right to take a paid absence from work to provide home or end-of-life care in defined circumstances;
- A change of medical expense tax credit to allow carers to claim more than had been allowable to assist in the caring of children and dependent relatives;
- A compassionate family care benefit to support those who leave their job temporarily to care for a gravely ill or dying child, parent or spouse;
- Publicly-funded home care programmes for respite care (in-home services; facility-based respite; day programmes).

The UK example

Measures have been implemented in the UK to support informal carers[270]:

- A carer’s allowance, i.e. £ 53.90 per week in 2010-2011 for people over 16 years who look after someone quite disabled (i.e. receiving an allowance for his/her disability) for at least 35 hours a week. They must neither be in full-time education, nor earn more than £ 100 a week (in 2010-2011) nor receive a range of benefits superior to the carer’s allowance;
- National insurance carer’s credits for carers who care for someone for at least 20 hours a week;
- A carer’s premium of £ 30.05 per week for carers receiving means-tested benefits (income support, housing benefit, pension credit);
- A break of caring, up to 4 weeks every 26 weeks, without losing the right to the carer’s allowance;
- An assessment of carer’s needs;
- A support for carers who wanted to combine caring and paid employment;
- The provision of home care or district nursing;
- Other specific services for carers such as carer support groups, driving lessons, etc.

The Dutch example

The support of informal carers has increased in the Netherlands in the recent years. Major measures include [260]:

- The fact that patient can choose to use (a part of) their personal care budget to pay informal carers;

- The provision of a yearly allowance ("mantelzorgcomplement") with a maximum of € 250; allowed if the Centrum Indicatiestelling Zorg indicates that at least six months of extramural care is required.

6.4.3.5. Coordination

New types of functions have been developed to improve the coordination between the different health professionals and/or the different settings, such as case managers and liaison nurses.

- Case managers

The main aim of the case manager is to coordinate services for people with long-term conditions. They are also in charge of developing care plans, to control the quality of care and to maintain contact with the patient and his/her family[8].

The Canadian example

In Canada, the Parliament of Health funded the National Case Management Network (NCMN) to develop a standardised set of skills, knowledge and techniques for case management and to identify a process for the recognition of case managers. The aim of case managers is to provide, in collaboration with the "client", quality health and support services through an effective and efficient use of resources. They support and advocate people and their family and coordinate the care and services to achieve better health outcomes in a complex environment [282, 283].

The UK example

In UK, case management for people with long term conditions can be performed by "community matrons" or by case managers. The difference is that:

- "community matrons" also provide advanced clinical nursing care: they preferably care for patients with serious and/or multiple long term conditions, at risk for unplanned hospital admission and who combine pharmacy, social, medical and nursing needs.
- Case managers care for persons with a complex single condition or a complex social need requiring care coordination[284].

There is no regulation to protect these titles.

- Community matrons

Community matrons are highly skilled and experienced senior nurses providing nursing care, but also planning and coordinating health and social care needs. They are a single point of contact for care, support or advice. They also care patients at home in acute phase in order to avoid their hospitalization. Their skills are the following:

  - "Take a comprehensive patient history;
  - Carry out physical examinations;
  - Use their expert knowledge and clinical judgement to identify the potential diagnosis;
  - Refer patients for investigations;
  - Where appropriate make a final diagnosis;
  - Decide on and carry out treatment, including the prescribing medicines, or refer patients to an appropriate specialist;
  - Use their extensive practice experience to plan and provide skilled and competent care that meets patients' health and social care needs, involving other members of the health care team as appropriate;
  - Ensure the provision of continuity of care, including follow-up visits;
  - Assess and evaluate, with patients, the effectiveness of the treatment and care provided and make changes as needed;
  - Work independently, although often as part of a health care team;
  - Provide leadership;
  - Make sure that each patient's treatment and care is based on best practice"[285].

A master degree is usually required but is not mandatory to be employed as a community matron. They must also have an adequate level of experience [285].

- Case managers

The case manager in the UK is most likely a registered nurse, a social worker or allied health professional working with individuals with a dominant complex single condition, implying intensive needs requiring (social) care coordination. The case manager develops a personalised plan of care, proactively monitors and anticipates the change in needs, coordinates the care across all parts of the health and social care system[284].

The Dutch example

In the Netherlands, the Minister of Health Welfare and Sport decided to further strengthen primary care and to increase the multidisciplinary cooperation between primary health care professionals in order to offer a coordinated provision of primary care services. For chronically ill persons, they decided to develop disease management programmes organised around the patient, with one care provider, usually the GP, being the contact person for the patient and coordinating his/her individual care. The regulation to facilitate this tasks coordination is in process[286].

- Liaison nurses

Liaison nursing has been developed to improve the continuity of care between different settings (hospitals, rehabilitation centres, community settings, etc.). The use of this term in other countries is in contrast with the use of this term in Belgium, who makes a link between services within the hospital (a clear example of hospital-centrism).

Liaison nurses assess the patient's needs and plan the care, mainly at the admission or discharge. They also provide support and patient education.

The Canadian example

Canada has some experience of liaison nurses as for instance in Québec. They work within an interdisciplinary team, plan care and services after the patient's discharge, teach the patient for self-education. In serious cases, they plan the transfer of the patient from home to an institution[287].

The UK example

All registered nurses have access to this function, even if a specialisation and/or work experience is usually required by the employer. Many types of liaison nurses can be found in UK, such as the psychiatric liaison nurse, the respiratory liaison nurse or the paediatric cardiac liaison nurse.

Some emergency department in UK employed psychiatric liaison nurses to address specific needs of patients requiring psychiatric services. Their role usually consists in assessing the patient in need of psychiatric services, determining the nature and possible cause of mental illness as well as their related risk, providing, where possible, a brief treatment intervention and referring them to appropriate services[288].

Respiratory liaison nurses help people with COPD or asthma. They advise the patients on the use of inhalers, nebuliser or oxygen, plan their discharge, refer them to a pulmonary rehabilitation programme, provide education and advice on stopping smoking, on diet and nutrition and on ways of managing their breathlessness and/or anxiety[289, 290].

Paediatric cardiac liaison nurses support children (and families) who need cardiac care. They assess their needs, negotiate, implement and evaluate an agreed plan centred on the patient, coordinate the care and ensure an effective communication between home, community and hospital settings[291].

The Dutch example

The function of discharge professional has been developed to improve the transition of care from hospital to the home. Most of them are nurses, known as discharge liaison nurses. They organize the discharge of the patient, assess the patient's needs for and plan the community care. Some of them have more a role of consultant and give advice on matters concerning the discharge process[292].

6.4.4. Situation in Belgium

Roles and competences of the health care professions in Belgium are mostly regulated by the Royal Decree n°78 of November 10, 1967 on the practice of the health care professionals[293]. At the European level, the recognition of professional qualifications is addressed by the directive 2005/36.

6.4.4.1. Nurses

- Competences

The article 21quinquies of the Royal Decree n°78 of November 10, 1967 defines the competences of nurses in Belgium. They are listed in the annexes of the Royal Decree of June 18, 1990[293, 294]:

- To observe, identify and establish the health status of the patient on a psychological, physical and social plan; define the problems in nursing care; cooperate in the establishment of medical diagnosis by the doctor and in the execution of the prescribed treatment; inform and advise the patient and family; ensure a continued assistance, perform acts or assist in their accomplishment in order to maintain, improve and restore the health of individuals and groups of individuals, weather sick or healthy; support dying people and their family;
- To perform some technical acts (some of them requiring a prescription while for some others, a prescription is not necessary) (listed in the royal decree of June 18, 1990). They may be related to the establishment of the diagnosis done by the doctor, to the execution of a treatment prescribed by the doctor or to preventive measures;
- To perform some medical acts delegated by a physician (listed in the royal decree of June 18, 1990). These acts must always be prescribed by a physician and performed under well defined conditions.

In Belgium, there is no official title of “advanced practice nurse”. Nurses with a bachelor degree can further study for a Master, for example in health care management but this title has no official recognition for the nurse practice.

- European directive on professional qualifications

It should be noted that a European directive on the recognition of professional qualifications (Dir 2005/36) focuses on general care nursing. For specialised nurses, the recognition of their qualifications requires either an aptitude test to assess the nurse’s skills or the completion of an adaptation period[295]. The European recognition of additional education for nursing specialties and the valorisation of advanced competences need to be addressed in the future.

- Additional qualifications

The Belgian system has no legislation to confer and protect the title of advanced practice nurse. Nurses are never authorized to prescribe pharmaceuticals or to make diagnoses. Nevertheless, they can obtain extra qualifications/specific titles, sometimes allowing them to perform specific tasks:

- Specialist nurse in diabetes and specialist nurse in wound care.

These nursing specialties in home care are recognized by INAMI/RIZIV after completion of a 40-hours post-graduate course. They may perform all nursing interventions and some specific interventions related to diabetes education and visits for wound care advice[161].

- Nurses with a specific qualification

Nurses with a diploma or a bachelor level of qualification may also obtain an additional qualification after completion of a complementary training of 150 hours:

  - Specific qualification in mental health and psychiatry;
  - Specific qualification in geriatrics;
  - Specific qualification in wound care;
  - Specific qualification in palliative care;
  - Specific qualification in diabetes;
  - Specific qualification in pain assessment and treatment.

o However, only the qualifications in geriatrics and in diabetes currently have specific recognition criteria defined by a ministerial decree[296, 297].

- Nurses with a specific professional title

Nurses with a bachelor level of qualification may obtain a specific professional title after completion of a complementary training of 900 hours.

These specific professional titles are[128, 298]:

- Nurse specialised in paediatrics and neonatology;
- Nurse specialised in mental health and psychiatry;
- Nurse specialised in public health;
- Nurse specialised in geriatrics;
- Nurse specialised in intensive care and emergency;
- Nurse specialised in oncology;
- Nurse specialised in medical imaging;
- Nurse specialised in stomatherapy and wound care;
- Nurse specialised in instrumentation and surgical assistance;
- Nurse specialised as perfusionist;
- Nurse specialised in anaesthesia.

Currently, recognition criteria have currently only been defined for the nurse specialised in geriatrics (ministerial decree of April 19, 2007)[299], in intensive care and emergency (ministerial decree of April 19, 2007)[300], in oncology (ministerial decree of January 28, 2009)[301], and in paediatrics and neonatology (ministerial decree of 16 February 2012)[302].

To preserve these titles and qualifications, nurses have to follow an ongoing education programme and to work in the corresponding sector. It is advisable to link this development to the requirements of the Bologna Declaration on Higher education and Dublin-descriptors in order to harmonise developments in education and health care delivery (http://www.jointquality.org/) .

6.4.4.2. Pharmacists

The role of pharmacists is described in article 4 §2bis of the Royal Decree n°78 of November 10, 1967[293], the Royal Decree of May 31, 1985[303] and in the Royal Decree of January 21, 2009[304] describing, among others, the principles and guidelines of good pharmaceutical practices. Pharmacists issue, in a responsible way, prescribed drugs or medicines deliverable without prescription to achieve, in consultation with other health professionals and patients, general health objectives such as prevention, identification and solving of problems related to drug use. Pharmaceutical care aims to continually improve medication use and to maintain or improve the quality of life of the patient. Interprofessional dialogue includes the eventual referral to a physician and the information of the physician.

Even if the pharmacist in Belgium is already implied in some tasks described in section 6.4.3.3, such as health promotion, he cannot substitute for the physician, e.g. for such tasks as medication review.

At the European level, the role of pharmacist is described in article 45 of the directive on the recognition of professional qualifications (Dir 2005/36)[295]. However, this description does not include the changes observed in some countries (e.g. the right to perform a medication review). Several interested parties therefore suggested to expand in the European directive the list of activities that a pharmacist is allowed to perform[305].

6.4.4.3. Physician assistant

There is no legislation in place to confer and protect the title of physician assistant in Belgium. This function is also not addressed in the European directive 2005/36 (meaning that the country decides itself to recognize this profession).

6.4.4.4. Care assistant

In Belgium, care assistants may perform a limited list of nursing interventions under specific conditions and under supervision of a nurse (royal decree of January 12, 2006 and articles 21quinquiesdecies and 21sexiesdecies of the Royal Decree n°78 of November 10, 1967)[293, 306]. Modalities to be recognized as a care assistant are described in the Royal Decree of January 12, 2006[307], lastly modified in 2011[308].

To be recognized as a care assistant, the candidate must have:

- A certificate issued after the completion of a care assistant training (one year in full-time education) or equivalent in social promotion or;
- Z certificate of social promotion or professional training that is considered by the competent bodies as equivalent to the training of care assistant as specified above or;

- A certificate attesting the completion of a first year of training in Nursing (bachelor or diploma level) or;
- A document attesting that the candidate satisfies to specific conditions, for example having been employed as a caregiver in a health care facility before the Royal Decree (i.e. transitory measure).

6.4.4.5. Coaches

Coaches as described abroad are not health professionals: they could not be addressed by the Royal Decree n°78 of November 10, 1967[293]. This function is also not addressed by the European directive 2005/36[295].

6.4.4.6. Informal carer

There is no national strategy for the protection of informal caregivers in Belgium. However, an increasing number of services, including respite care, are available at a local level. More recently, planning of new alternatives for home care at a national level aimed to take into account caregivers' needs in terms of respite care. A total of 67 pilot programmes were accepted in 2010 (http://www.inami.be/care/fr/residential-care/alternative_forms/projects.html). An evaluation of these programmes and their impact on informal carers is currently being carried out.

They are no direct social protection provisions to support the carers but indirect help is available.

Two allowances can be used indirectly by the carer:

- The dependence allowance (i.e. Vlaamse Zorgverzekering) in the Flemish community, i.e. a monthly sum (€ 130 per month in 2009) granted to dependent individuals living in the community who receive informal or formal care[309];
- The "Personal Assistance Budget (PAB)" for people with disability ("Persoonlijke-assistentiebudget" in Flanders/ "budget d'assistance personnel" in Wallonia), i.e. a fixed amount (depending of the person's disabilities and the help used) granted to a disabled person to employ a "home-helper". The PAB cannot be used to pay for services from an informal caregiver except if a legal work contract is established between the disabled person and the carer. For 2009, the PAB in Wallonia varied from € 5000 to € 35 000 and in Flanders from € 8850 to € 41 280[310, 311].

In addition, specific leaves allow the carers to stop working or to reduce their working hours for some time[312, 313]:

- The palliative leave (for all individuals working full-time or part time) to care for a person at the end of life. Labour force participants are entitled to a full month of leave, renewable once;
- The extended parental leave. If the child is handicapped, the usual parental leave is extended until the child is 21 years old (instead of 12 for non-handicapped children). This new age limit was implemented since May 20, 2011. The leave can be taken as a 3-months full-time leave or can be taken as a part-time leave (reducing the number of working hours) for up to 12 month (e.g. one day per week);
- A leave to care for a household or family member with a serious illness. The leave can be taken as a 3-months full-time leave or can be taken as a part-time leave (reducing the number of working hours) for up to 12 month (e.g., one day per week).

For the three types of leaves, the worker can receive up to € 726.85 (for a month of full-time leave).

Training and information (seminars, panel discussion, etc.) for caregivers are mostly provided by non-profit-making organizations (patient education centres, etc.). There is no specific policy coordination at a central level [128].

6.4.4.7. Case managers and liaison nurses

There have been a number of initiatives in Belgium to increase the coordination of care, sometimes implying the creation of management/coordination functions:

- The development of care trajectories (zorgtraject/trajet de soins) for diabetes (since 1 June 2009) and renal failure (since 1 September 2009). The aim is to enhance the collaboration between the patient, the GP, the specialist and other caregivers[128] (see also 4.5.2.2);
- The creation of coordinated services for home care (Services Intégrés de Soins à Domicile-SISD/Geïntegreerde Diensten voor Thuisverzorging-GDT) to support a multidisciplinary approach within primary care (see also sections 4.5.1 and chapter 8).[128];
- Local multidisciplinary networks were set up to enhance the collaboration between all caregivers (see also 4.5.2.2). An operational plan is set up by local GP circles in collaboration with the local SISD/GDT. The aim of this operational plan (under the supervision of a care pathway promoter) is to gather information about the caregivers and local organizations, mainly to facilitate the communication[128];
- Care programmes are the organization of several hospital activities around specific pathologies or patients groups (e.g. reproductive medicine, cardiac pathology, oncology, geriatrics, paediatrics)[128]. The care programme for geriatric patients for example integrates a.o the principles of internal and external liaison teams[144]: the transmural approach includes care pathways and a discharge manager in charge of the continuity of care[162, 314];
- Palliative support networks provide support for the usual health professionals when the patient comes into a phase of palliative care[147];
- Innovative projects have been launched for older people to allow them to stay at home as long as possible by receiving appropriate care, guaranteeing the continuity and coordination of care, promoting the collaboration between caregivers (see also 4.5.2.3)[128].
- Initiatives in the mental health care sector (see also 4.5.2.3):
  - A more integrated approach to chronic psychiatric patients is the objective of the “care circuits” (care programmes and care services) and of networks of services (between caregivers, institutions and services; coordination of one or more pathways for a specific target group) through different care arrangements[128];
  - Another illustration is the development of consultation platforms to improve the continuity of care and the collaboration between different mental health services[128];
  - A new regulation (since 1 April 2012) provides allowance for the participation in consultation around the patient, for a reference person, and for the organization and coordination of the consultation. The reference person is the contact person for both the patient, his family and the health care professionals and is a.o. responsible for the establishment of a support plan and its coordination[315, 316].
- Pilot projects have also been developed for the management of substance abusers, including a pilot project on the function of case managers in hospitals to ensure the continuity of care of patients with disorders related to psychoactive substances. The case manager assesses the patients’ needs, plans their short- and long-term objectives; informs, advises and motivates; defends their interests; refers them to other services; ensures the implementation of support, controls the process and assesses the achievement of the objectives (http://www.sante.belgique.be/eportal/Myhealth/Healthylife/drugs/Pilot project/index.htm?ie2Term=drogues?&&fodnlang=fr)[317].

6.4.5. Discussion: implementation of new functions and professions in the Belgian health care system

6.4.5.1. Potential barriers to the implementation in Belgium

Potential barriers to the implementation of new functions in Belgium might be resistance of (other) health professionals, the characteristics of the Belgian health system, the difficulty to adapt the legislation, the lack of adequate training and the nurse shortage.

Barriers from health professionals

The principal reasons of health professionals to be opposed to these initiatives identified in the literature are[246]:

- The potential overlap of competences;
- Worries about the loss of some area of practice;
- Worries about the legal responsibility in case of medical error (especially in case of delegation and/or substitution);
- Worries about the lack of competences (due to inadequate training).

Characteristics of the Belgian health system

The following characteristics of the Belgian health system are also potential barriers to the implementation of these initiatives in Belgium:

- The predominance of single-handed practice instead of group practice in primary health care;
- The predominance of fee for service system of payment;
- The freedom of choice of the patient (no gate keeping);
- The dominant role of physicians in the health care decision making system

Legislation

The Belgian legislation precisely describes tasks that can be performed by health professionals. A change of their competences therefore would require a change of the legislations.

Training

The implementation of any initiative described above requires the design and recognition of training programmes.

Impact on attraction and work force in the nurse profession

New career pathways might increase the attraction and retention in the nurse profession, a conclusion from the KCE report on the differentiation of the nurse profession [157]. However, the substitution of the physician by an advanced practice nurse could also worsen the shortage of nurses at home, in hospitals and in other facilities for functions that do not require an advanced level of practice.

6.4.5.2. Critical points for the implementation

The analysis above highlights critical points that should be considered before the implementation of any new function in Belgium:

- Adaptation of the legislation;
- Definition of responsibility, supervision and other regulatory arrangements;
- Agreement with the health professionals on the shift of their competences to other professionals.
- Financial arrangements (e.g. financing system);
- Provision of recognized training programmes in accordance with the Bologna Declarationb;
- Definition of competences and tasks;
- Introduction of the new functions within the existing networks of health professionals;
- Monitoring of the number of health professionals with special attention for the nurse shortage;

[b] http://ec.europa.eu/education/higher-education/bologna_en.htm

6.4.6. *Key points: new functions and roles in primary health care*

New functions and roles in health care identified abroad can be classified according to three objectives:

- **GP substitution/supplementation:**
  - **Advanced practice nurses: Nurses with an advanced level of practice. The legislation in place (not always protected), the scope of practice (not always clearly defined; with or without supervision) and the required education level (master degree recommended but not always required) differ between countries. Overall, advanced practice nurses perform tasks previously attributed to physicians such as medication prescription and they also supplement them (e.g. patient education, support to self-management …);**
  - **Physician assistant: health care professionals working under the supervision of a physician and providing medical care such as patient histories or selected diagnostic and therapeutic interventions (including prescriptions and medical orders);**
  - **Pharmacists with extended roles such as managing medication dosages; completing medication review; prescribing medication, supporting self-care; performing triage / referral; providing health education and promotion services; or working in a primary health care team.**
- **Delegation of care to less qualified or non health professionals:**
  - **Health care assistants: "Less qualified" health professionals working under the supervision of a regulated health care provider and assisting them in the basic care of patients;**
  - **Coaches: (Non) health care professionals supporting patients mainly for self-management;**
  - **Informal carers: People, usually relatives or friends, providing "unpaid" care giving basic activities of daily living.**
- **Coordination of care between the different health professionals and/or the different settings:**
  - **Case managers and liaison professionals: (Non) health care professionals whose aim is to improve the coordination and continuity of care by developing care plans; but also to support the patient and his family.**

Before the implementation of these new functions in Belgium, the following points require attention:

- **Adaptation of the legislation;**
- **Definition of responsibility, supervision and other regulatory arrangements;**
- **Agreement with the health professionals on the shift of their competences to other professionals.**
- **Financial arrangements (e.g. payment system);**
- **Provision of recognized training programmes;**
- **Definition of competences and tasks;**
- **Introduction of the new functions within the existing networks of health professionals;**
- **Monitoring of the number of health professionals with special attention for the nurse shortage.**

7. ORGANIZATION OF CHRONIC CARE IN BELGIUM: STAKEHOLDERS' ANALYSIS

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The two following chapters describe the vision of the stakeholders on the organization in Belgium. This chapter describes a SWOT analysis (Strength – Weakness – Opportunities – Threats) of the organization of chronic care in Belgium from the stakeholders` point of view. The next one (chapter 8) displays an analysis of the coordination structures made by experts in the domain.

7.1. Objective of this chapter

The objective of this chapter is to present this SWOT analysis as seen on the stakeholders' point of view:

- Strengths: positive internal dimensions of the health system that can be controlled, and on which we can build the future;
- Weaknesses: negative internal dimensions of the health system that can also be controlled and improved;
- Opportunities: positive external possibilities from which the health system can eventually benefit. They develop outside of the field or in its margins;
- Threats: external constraints or limitations that threaten the improvement of health system.

The starting point of the SWOT analysis of the chronic care system in Belgium is the 'root definition' (the vision) and the 'activity model' (the conceptual model) described in chapter 2.2. These are based upon the chronic care model and encompass the cornerstones of effective chronic care.

7.2. Methods: consultation of stakeholders from different levels

Research teams from two universities (RR, LS, SA, JM, OS, TV) obtained data about the strengths and weaknesses of the current Belgian chronic care system from relevant key informants in the French and Dutch speaking communities. These were consulted in three steps:

- Brainstorming sessions (BS) with stakeholders from the micro and meso levels of chronic care;
- Completed with additional semi-structured individual interviews;
- Discussion sessions with stakeholders from the macro level who have an overview that can inform on the feasibility of the ideas that emerged from the stakeholders at micro and meso levels.

7.2.1. Micro and meso levels: four brainstorming sessions and semi-structured interviews

Four brainstorming sessions collected original ideas anchored in the experience of participants. At least four researchers were involved in each session: a group leader (moderator), a facilitator (who wrote down the information on flipcharts and shared the brainstorming elements and asked for clarification when necessary), and two observers (who took field notes).

7.2.1.1. Participants

Each session included maximum 12 relevant key participants with a sound knowledge of the Belgian chronic care system through their daily work in the field (see 4.1 in the supplement). Persons were selected in agreement with KCE researchers and were representatives for their stakeholders group:

- Health professionals working in the field of chronic care (i.e. nurses, GPs, medical specialists,…);
- Representatives of patients and informal caregivers;
- Representatives of regional organizations (i.e. home nursing) and facilities (nursing homes).

The research team contacted personally these key informants. A confirmatory email was sent with some explanation e.g. the characteristics of the conceptual model. The participants received a preparatory work before the meeting: they had to reflect on one of their chronic patients and indicate the points that went well and which aspects did not go well.

7.2.1.2. Brainstorming sessions and interviews

Four brainstorming sessions of three hours were held (two in each language, script available upon request). The sessions focused on the domains of the adapted chronic care model, using in depth probing and asking for clarification by the facilitator and group leader if necessary. These sessions were audio-taped and supplemented by field notes of two observers.

After the brainstorming sessions, two individual interviews with stakeholders involved in the field were conducted with participants who could not attend the brainstorming sessions and were not yet represented in any of the groups. These interviews followed the same logic as the brainstorming sessions, but were adapted to the stakeholder encountered.

7.2.1.3. Analysis

Concepts of thematic analysis were applied to the data from the brainstorming sessions. Two researchers in each team coded the data independently and a meeting was held to discuss the final themes with the entire research team. A SWOT analysis was performed on these emerging inductive themes, linked to the conceptual model described in chapter 2.2, emphasizing the six requirements per activity, whenever relevant.

7.2.1.4. Translation of the results into ten statements

In a next step, ten reform proposals for a future chronic care system were written, amended and approved by the entire research team. The proposals were inductive (bottom-up): they were built from data available from the previous brainstorming sessions (SWOT analysis) and from the findings of the previous chapters.

These reform proposals were challenging issues for discussion with the macro level stakeholders.

7.2.2. Macro level: two meetings with stakeholders

7.2.2.1. Participants

The researchers first contacted all members from the steering group of this project i.e. civil servants from ministries or public services from the various levels of decision making in Belgium (Federal, Community and Regions) and representatives of the major institutions involved with the organization of chronic care.

Representatives of all groups from the Observatory for chronic diseases were also invited. Additionally, people in charge of training of health professionals were invited. In total, 22 people attended these discussions (see supplement 4.2). The participants received in advance the reform proposals mentioned above (see supplement 4.3).

7.2.2.2. Procedure

Concrete reform proposals were used as guidance through the discussions (2 hours). The sessions were audio-taped. One moderator led the discussion and two facilitators gave additional information when necessary. The ten reform proposals were presented to trigger discussion on each idea or concept. This discussion led to new insights in the opportunities and threats involved.

7.2.2.3. Analysis:

A synthesis of the two meetings was made in pairs of researchers. Audiotapes were complemented with observations made during both sessions. Finally, the SWOT analysis from the brainstorming sessions was complemented with data coming from these stakeholder meetings.

7.3. Results: stakeholders' views on the organization of chronic care in Belgium

The initial framework of the brainstorming sessions (BS) was structured according to the model developed in chapter 0, with the activities grouped in 7 functional modules: the following modules were within the scope of this report (health care system):

- Plan, provide and coordinate care;
- Provide acute episode response services;
- Support patient/family empowerment (including self-management);
- Design a dynamic care model.
- Requirements to be checked for each activity that is part of the modules:
  - appropriate workforce;
  - tailored service design and organization;
  - appropriate financial incentives;
  - quality assurance;
  - decision support;
  - clinical information systems.

Key results of the brainstorming sessions and the group discussions were grouped into six themes summarised in the following sections. For each theme, the participants mainly identified weaknesses and strengths. Few threats and opportunities were discussed.

The analysis of the brainstorming sessions was subsequently complemented with the data collected from the stakeholders at macro level. A more detailed report of participants' views is available in supplement 4.3).

7.3.1. Theme 1: continuum of care within lines of care and between lines of care calls for coordination

Chronic patients often "navigate" between various health and social care providers, or between home and health care institutions. This calls for the organization of seamless care.

7.3.1.1. Strengths of the Belgian health care system

- Teams or care network around the chronic patient

Various processes at hospital or home care level tend to structure professionals as a team around the chronic patient: the "maisons médicales" and "groepspraktijk" at primary care level, the platform for palliative care (for home care), etc. (BS 1 & 4). Additionally, the organization of professionals into formal structures (as opposed to a work in a single-handed practice) and care networks are increasingly promoted as shown for example by the care trajectories for diabetes and chronic renal failure. These "teams" and these "networks" do not always follow the same logic in health care provision (disease oriented, patient centred, goal oriented, etc) (BS 1 & 2).

> *Palliative team: "Samenwerking kan leiden tot mogelijke oplossingen, veel meer dan het verbeteren van de communicatie. Het intenser samenwerken van de verschillende disciplines zal al sneller leiden tot het gebruiken van één taal, dan komt dit wel vanzelf. Puur communicatie verbeteren zal niet tot betere zorg leiden, wel het intenser samenwerken. De rest zijn mogelijke ondersteunende tools, maar samenwerken is uiterst belangrijk en daar zijn geen protocollen voor nodig."(BS 2)*

- Seamless care at discharge

At hospital and care institution level, strategies are developed to organise smooth discharge of (chronic) patients: it can take the form of a liaison nurse, a social worker, a coordination structure or hospital protocols (including build-in electronic prescriptions for health care providers, drugs or structured discharge mails for primary care providers (BS 1& 2).

> *Liaison team in hospital: "A l'hôpital XX, ils ont créé un service, indépendant de l'hôpital, où il y a un médecin, un psychologue, une*

infirmière de liaison… Dès qu'un patient arrive à l'hôpital, eux se chargent de faire le lien entre l'intra et l'extra muros…Ce n'est que pour les patients souffrant d'un certain type, mais ça pourrait être utile pour beaucoup d'autres pathologies... " (BS 2).

- Coordination initiatives

Coordination meetings are organised around the patient, even at home with care providers, through the "Services de Soins Intégrés à Domicile (SISD) / Geintegreerde Dienst Thuiszorg (GDT) (BS 1 & 2).

7.3.1.2. Weaknesses of the Belgian health care system

- Lack of GPs' availability for the coordination meetings

The GP should play a central role in the coordination of the patient care and support. However he/she encounters difficulties for instance to attend coordination meetings. Reasons mentioned are the low financial incentives or short notice when a meeting is organized (all BS).

- Care coordinator at the patient's level is not clearly identified

GPs are not always available and there is a lack of other well-trained professionals to act as coordinators. It is difficult to identify a coordinator for the care of a chronic patient, to identify one contact person responsible for daily care and if needed, the person who makes the link between lines of care (the "reference person" or "case manager") (BS 1 &2).

- Lack of synthesis of information for the patient

It is complicated for the patient to access useful information when they need it, for example information on services. Information is too dispersed (BS 2 &3).

- Lack of information for the care providers

The care providers experience a similar problem: they are aware of the existence of structures but this information is not readily available when needed.

- Fragmented and/or overlapping coordination structures

The lack of synthesis role and the lack of an identified coordinator are even more of a problem for people with complex chronic health problems and needs. There are often too many healthcare professionals and "coordination structures" around the patient (fragmented and/or overlapping coordination) (BS 1& 2).

GP:"Er ontstaat een spanningsveld doordat we met veel hulpverleners rond één patiënt werken: er is een attitude van een ploeg nodig: je moet je grenzen kennen van je werk. Met hoeveel mensen mag je rond één persoon samenwerken zonder de trappers te verliezen. Teveel hulpverleners geeft ook een aantal gevaren" (BS 1).

- Patient choice of care provider

The right of the patient to choose his/her care providers can be a threat in a care model delivered by a team

GP:"Par rapport aux mentalités en Belgique le choix du MG en maison de repos pose problème. C'est une faiblesse du système" (SGM 2)

- Disease-oriented care

There is a tendency to coordinate care in a disease-oriented way (see care trajectories for diabetes or chronic renal failure). This vertical approach is not efficient and a threat for the safety of the patient in case of multimorbidity (e.g. redundancy of tests, conflicting prescriptions). Similarly, most guidelines and protocols are single-disease and biomedically oriented with little attention to psychosocial, psychological and social issues (all BS).

GP: "Par rapport aux trajets de soins, ce qui me fait peur, c'est que c'est utilisé sur une pathologie. Si on multiplie les trajets de soins, comment on va faire pour la personne qui est à la fois diabétique, insuffisant rénal et hypertendu ? C'est mieux d'imaginer un trajet de soins polyvalent que quelque chose centré sur une pathologie" (BS 3).

- Transitional periods e.g. at hospital discharge, require high-level coordination

Admissions in case of emergencies and discharge at home after hospitalization are often a problem, in the absence of communication between lines of care. Planning care trajectories from the start of the chronic condition would allow anticipating acute events or hospitalizations (BS 2 & 3).

- Medication management

The prescriptions of medications by different physicians (GPs, specialists) are difficult to manage adequately (BS 1 & 2).

> *Medical specialist: "Continuïteit rond medicatie is zwak, tussen de lijnen kan nog heel veel gebeuren op vlak van communicatie qua medicatie. Er is een gebrek aan communicatie over medicatiebeleid tussen huisartsen, specialisten, apotheker en patiënt. Er is een gebrek aan een eenduidige visie. Patiënt komt buiten, hij/zij heeft ook eigen gedacht, apotheker weet niet wat arts gezegd heeft, en zo beginnen de problemen.."(BS 1)*

- Tension between the priorities of caregivers or coordinators and the priorities and choices of the individual patient
- Lack of mutual knowledge between health professionals and coordination centres

> *Social worker: "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. " (BS 3)*

7.3.1.3. Threats for good chronic care in the Belgian health care system

Main issues are the "pillarizationc" of our health care system and the complexity of distribution of competences between different decision levels (region, province, federal...).

[c] i.e.partitioning between public versus private organizations/institutions, primary care versus specialized care, between sickness funds etc.

7.3.1.4. Comments of the stakeholders in reaction to the statements proposed for a future organization of care (in relation to coordination)

- Reform proposal A: A polyvalent multidisciplinary primary care team is at the center of a system caring for people with chronic care needs
  - This is useful, not only for care but also for global assessment of people's needs and preferences (i.e. mixing nursing and medical assessment) (SGM 1 & 2).
  - It is different from a network of professionals delegated from different organizations (SGM 1 & 2).
  - It may be a way to strengthen the communication between primary care and institutional care (SGM 2).
  - This team can be multi-disciplinary and adapted to the individual needs and preferences of the patient (difficult if the providers' team is a "fixed package").
  - The role of case manager in this team? His/her role is of particular importance during transition periods: early after diagnosis, period around hospital discharge, after an acute episode (linked or not to care, but having a potential impact on the health of the chronic patient). (nurse coordinator, BS 2).
- Reform proposal B: Mid-level scale initiatives to improve seamless care between hospital and home care are needed
  - There is a lack of coordination tools, strategies or structures at a larger scale than the "primary care practice" but at a smaller scale than SISD/GDT (SGM 1 & 2).
  - This level of coordination should focus on coordination between primary care and institutional care (hospital care, but also care in nursing homes and other services).
  - Care trajectories can help in structuring that level of coordination. Existing palliative teams, "Impulseo 2" are also a possible entry point in structuring that level of coordination at a larger scale.
  - We should be careful not to create a new level of coordination but rather build on existing structures (SGM 1 & 2).

- Some initiatives are taken by the “réseaux multidisciplinaires locaux / locale multidisciplinaire netwerken”.

7.3.1.5. Summary: coordination: concrete proposals for the future

Stakeholders at the macro level stress the function of case management, i.e. care coordination at the level of the patient: This function is essential to tackle the issue of care fragmentation for patients with chronic illness(es). The patient as well as his/her informal caregiver have to be at the centre of this case management.

However, the profile of the case manager is unclear (nurse or other health professionals, e.g. social worker):

- Some stakeholders suggest that the coordination should be done by the GP, or by a nurse in tandem with GP. In this case, a social worker should coordinate non-biomedical services.
- For other participants, the case manager should be a health professional, in order to be able to coordinate biomedical as well as non-medical care.

Moreover, participants were unclear about the place of the case manager or the team of case managers in the health care system. This professional (or professionals) might be linked to a group of GPs, or linked to a local system (Centre Public d’Aide Sociale/Openbaar Centrum voor Maatschappelijk Welzijn - CPAS/OCMW). If they are linked to a sickness fund, hospital, etc., there is a risk for further pillarization.

Finally, the management of the needs and preferences of patients with complex chronic conditions is a complex function: it is mandatory for the professional who will take on this function to follow additional specific training in case management.

7.3.2. Theme 2: Redefining the roles of health professionals and training

The following issues were often mentioned for redefining the role of health professionals:

- Position the professional as part of a team,
- Looking at the function of coordination,
- Solutions for the shortage of GPs and nurses.

7.3.2.1. Strengths of the Belgian health care system

- Some professionals (mainly nurses or social workers) take on the role of coordinator and they do this in duo with the GP (BS 2 & 3).
- The proportion of primary care professionals who work in a team tends to increase. This is strength as it facilitates communication between professions and contributes to role distribution (BS 4).
- There are projects or programmes that aim to strengthen the relation between hospitals and primary care (for example a project with liaison nurses who help at discharge, projects for shared patient files to improve information flow) (BS 2).

  Nurse coordinator: “ Nous raccompagnons le patient à domicile le jour de son retour, en l’aidant à faire des courses et à passer à la pharmacie. L’avantage de ce suivi est que nous pouvons mieux évaluer les besoins de la personne que l’assistante sociale de l’hôpital, convaincre le patient, lorsqu’il ne récupère pas assez vite, et activer les aides-familiales de la commune “ (BS 3).

- Specific teams (e.g. in chronic kidney failure) prepare chronic patients and their informal caregivers for returning home or for self-care. This will shortly be made more explicit as a list of these functions will be officialised by the Federal Public Service Health , Food chain safety and Environment (BS 1, 2 & 3).

7.3.2.2. Weaknesses of the Belgian health care system

- The function or the role of possible case manager is unclear as explained above (see 7.3.1.2)

For instance, can we consider social workers as case managers ?

Social worker: "Ne pourrait-on pas faire appel à d'autres types d'acteurs qui pourraient faire les démarches administratives (du MG): des assistants sociaux (AS), des infirmières sociales ? Il y a beaucoup d'AS disponibles, mais on ne les utilise pas suffisamment, il y a une fragmentation des ressources disponibles. L'AS du CPAS, par exemple, dans sa fonction, est une AS généraliste… » (BS 3).

- The GP education is focused on acute and specialized care

GP: "Il y a la problématique de la formation des médecins, qui est essentiellement axée sur l'aigu, le transversal, et la spécialité, ce qui ne va pas inverser la tendance. Dans les pistes du possible, je trouve que la médecine générale doit être beaucoup plus présente dans les facultés… (…)Ce n'est qu'en médecine générale qu'on se rend compte qu'il y a un peu plus que la maladie: il y a l'habitat, les familles, dont on doit tenir compte, mais ce n'est pas dans nos études… "(BS 3).

- Tools do not support the skill-mix

In general, there are difficulties in inter-professional communication because supporting tools (e.g. patient file) are intra and not inter disciplinary (BS 1 & 3).

- The GP working context makes task sharing difficult.

Many GPs are still isolated, lack support and coaching. There is a also a lack of clear task delegation. In order to better complement the GP function, more initiatives should give a stronger or more prominent role to pharmacists and nurses in chronic care (BS 1 & interview1).

- Legislation makes task delegation difficult.

Nurse: "Wettelijk blijft de arts verantwoordelijk, ook al werk je met protocollen en zo. 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! "(BS 4)

- Overburden of possible care managers

Social workers from CPAS/OCMW are possible 'case managers for social coordination issues'. However, in most areas, social workers from CPAS/OCMW are overburdened and as a result, the turnover is incredibly high (BS 2 & 3).

- Need for further training for primary care nurses working in multidisciplinary teams

GP " 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 infirmier va aussi continuer à faire des tâches de soins à proprement parler" (SGM2).

- Interdisciplinary education or broader reflection on training for newly created roles is lacking (BS 2 &3).

7.3.2.3. Comments of the stakeholders in reaction to the statements proposed for a future organization of care

- Reform proposal C: At the primary care level, new functions need to be created and officially recognized (legally and in the organization 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 addition, basic care (e.g. washing) should be delegated to nurse-aids.

Some threats related to this proposal were identified by the stakeholders:

  - Professional organizations tend to protect their current positions, leading to difficulties in creating new functions (BS 2 & 3).
  - There is a need for (new) specific training for primary care nurses working in the primary care team. Training may be different for nurses working in advanced clinical functions (more oriented

towards clinical functions) and case manager (more oriented towards care organization) (SGM 1 & 2).

- The role of (community or clinical) pharmacist is often neglected in primary care. In order to take full responsibility within the primary care team, some requirements are needed, such as an access to the patient file. Additional training is needed to provide adequate patient education.
- Roles of pharmacist and other professions are not included in the current Royal Decree 78 and should also be explored. Legal responsibility of the informal caregiver, when providing technical care for instance, has to be addressed (BS 1 & interview 1).
- Transferring responsibility to less qualified personnel could be a threat for the quality of care when it is not properly supervised (SGM 1 & 2).
- The case manager should be available only for patients with complex needs and not for all patients.
- This function should not only focus on medical needs, but also on social issues (SGM 1 & 2). It could for instance play a key role in anticipation of future needs of the patient and/or preventing acute situations (SGM 1 & 2).
- The case manager could form a "duo" with the GP, with clearly defined roles agreed amongst them. He/she could take responsibility with the GP of the health and social care decisions, services delivery and coordination of those deliveries, including information flow (SGM 1 & 2).
- If this function is organized with a cascade of delegation, there is a risk of loss of quality.

- Reform proposal D: Specialized hospital functions (clinical MD specialists and allied professions) should focus on specific problems in acute contexts. They should also consider patient autonomy before the discharge to ensure the transition towards 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.

Comments from the stakeholders were more illustrations and questions than strengths or weaknesses. One opportunity was also mentioned (i.e. telemonitoring) to follow the patient after discharge.

- The word "coaching" should be replaced by "supporting", more appropriate.
- One question is the real efficacy van de coaching of the first line of care (GP of educator) by hospital care providers (specialists or educators).
- The participants mentioned pilot experiences where an outreach/liaison nurse follows the patient at home, in particular for dialysis. In the same way, protocol 3 projects have many examples of coordination between hospital and home care.
- The preparation before discharge is important, a.o. to check with the first line of care if all conditions allow a patient to go back home (for example stairs).

7.3.2.4. Summary: redefining roles: concrete proposals for the future

Caring for persons living with chronic conditions requires the involvement of skilled professionals of different disciplines. However, some functions might be attributed to different disciplines. A clear definition of each role is needed, especially when the definitions of the roles are changing and when the expectations of professionals and care beneficiaries are unclear.

Additional training should be provided to the case manager about case managementd. Specific training is also needed on inter-professional collaboration and task delegation. This holds for all persons with the common chronic diseases like cardiovascular diseases, chronic obstructive pulmonary disorders and dementia that are most often cared for in primary care.

The admission and discharge of patients from hospital requires careful preparation and it is necessary to provide information across settings. For

[d] rigorous needs and preference assessment of the beneficiary and his caregiver, negotiation of a care plan with both, carrying out the care plan, especially about coordination, evaluation and adjustment, if needed

specialized or high-technological care, hospital teams could guide the primary care level, by providing the specific information and training.

7.3.3. Theme 3: Empowerment and support of the patient and his/her informal caregiver

Autonomy and promotion of self-care for the patient and his/her informal caregiver are important in chronic care. Two key issues are emerging in the stakeholders' groups:

- The way education of chronic patient is structured to improve his self-management (e.g. diabetes, chronic renal failure);
- The care and support activities for the informal caregivers (e.g. project aiming at supporting informal caregivers of Alzheimer patients).

7.3.3.1. Strengths of the Belgian health care system

- In some settings, mostly experimental, specialist staff use telemonitoring to assist the patient with chronic care at home. This may be a help for self-management (BS 1).
- Some examples of third line of care show that specialised nurses can play a strong role in educating the patient for self-care (BS 1 & 3).
- Patient organizations exist for different types of health problems. They bring an added value to the education of specialized nurse (e.g. education by peers). Furthermore, they may act as a support for informal caregivers. Nevertheless, their role could be further reinforced (BS 2).
- Financial support for informal caregivers: a minimal wage is provided in Flanders (mantelzorgpremie) (BS 1 &4).

7.3.3.2. Weaknesses of the Belgian health care system

- Concerning the patient:
  - A serious weakness in patient education is its fragmentation (by disease). However the current Flemish (Treftpunt) and French-speaking (LUSS) "dome" associations that group many disease specific patient associations are an opportunity for generic patient education.
  - There are financial, cultural and inter-professional barriers to increase the patient's autonomy at home (an illustration is the possible lack of trust between GP and home nurses).
  - There is a need for information tools to support the patient in making more informed choices. Among others, the legal framework for patient rights and protection is difficult to understand (BS 2). Moreover, the patient has to be involved when evaluating quality.

  GP: " il faut absolument inclure le patient et tenir compte de son impression sur les services qui sont mis à sa disposition. Dans les projets article 107 en santé mentale, il y a des représentants des associations SIMILES, etc. qui participent aux groupes de travail. Cela nous oblige à prendre du recul par rapport à notre routine et à améliorer les failles du système » (BS 3).

  - Poor consideration of other ways or settings to care for the patient, which might improve patient empowerment

  Coordinator of local multidisciplinary network: "Quand on parle d'espaces les plus adéquats où les soins sont procurés: entre son lieu de vie, l'endroit où il va recevoir des soins et être accompagné, il y a déjà une multitude de possibilités aujourd'hui, mais si on est créatif, on peut encore penser à autre chose. Il y a des patients qui ont besoin de soins chroniques, mais mobiles… » (BS 2).

- Concerning the informal caregiver:
  - There is a lack of support structures for the informal caregivers. Places in day care centres, considered as a way to organise respite care, are lacking. They are almost non-existent for younger patients living with chronic conditions (BS 2 & 4).
  - Incentives are lacking to allow caregivers to suspend or reduce their professional activities (BS 1 &4).
  - Informal caregivers often complain that they are not considered as partners by health care providers and report a loss of control of the situation ("my home is like a railway station hall"; BS 2). They lack support and information about their rights and available services and tools. There is a lack of organised psychological and psychosocial support (all BS).

7.3.3.3. Comments of the stakeholders in reaction to the statements proposed for a future organization of care:

- Reform proposal E: there is a need to clarify the role of patient associations and to offer respite care possibilities for informal caregivers
  - Informal caregivers and patients can be supported by patient associations, sickness funds, and municipalities. Those should target both patients and informal caregivers. These instances could be an adequate place for provision and sharing of information.

Patient association representative: "The role of patient associations is much more than the issue of respite care, it is firstly about helping each other, facilitating the sharing of experiences." (BS 2)

Another patient association representative: "Si on veut que le patient puisse décider pour lui-même, il faut qu'il comprenne les choix. On devrait lui donner l'occasion de rencontrer ses 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 » (BS 2).

7.3.3.4. Summary: empowerment of the patient and informal caregiver: concrete proposals for the future

Improving the support of the informal caregiver is of great importance because he/she plays a crucial role in the health care system. Therefore the current trend to grant a specific social status to the caregiver needs to be further supported by decision-makers. Initiatives to alleviate the burden of care giving (by means of respite care for example) should be promoted.

Patients and Informal caregivers are in need of recognition as true partners in care decisions. It is important to raise the care providers' awareness about this point i.e. the importance of patient participation in care decision. A requirement is the availability of information about treatments, financial, material, social and medical help in the most adequate way.

The role of peers, by means of patient and caregiver associations needs to be recognized and supported.

Strategies to educate the patient for better self-care are at present structured by disease. More reflection is needed to clarify the issue of patient empowerment in chronic care when dealing with multimorbidity and old age.

7.3.4. Theme 4: Payment system influences care

7.3.4.1. Strengths of the Belgian health care system

- Differentiated payment systems

  Other forms of payment than fee for service are being developed at the primary care level. This may be strength for the organization of the care of chronic patients.
- Capitation systems

  On a relatively small scale, a capitation system exists in the "maisons médicales". It has the advantage to allow for more comprehensive care. However, it brings the risk of under-provision of care when the question of quality of care is not adequately addressed (BS 3).
- Payment per episode and/or health problem based payment is developed in care trajectories: care providers find it useful (BS 2& 3).
- Nursing care is provided for complex patients through lump sums ("forfait").

- 20% of gross GP income is made of lump sums (forfaits/forfeit) systems.

7.3.4.2. *Weaknesses of the Belgian health care system*

- The payment system is difficult to understand for care users. Its complexity is particularly high in the case of multiple conditions but also because different types of payment systems exist for the different primary care providers in the same area. For the care providers, this leads to administrative burden (all BS).
- The predominant care payment system is fee for service. This is seen as a push for quantity and may lead to patient selection. Small changes such as financing "global medical file" (DMG-GMD) are not enough to bring about strong changes. Moreover, the (DMG-GDM) is still underused (BS 2& 3).
- The payment system makes task delegation or the involvement of certain types of professionals sometimes difficult. This results in problems for some nurses but also for social workers (BS 3 &4).
- The payment system does not follow the reality of care provision. Some frequent professional acts are still not reimbursed at home (preparation of drugs,…) (BS 2 & 3).
- Coordination is not properly financed. This is especially a problem for self-employed professions (BS 3 & 4).
- New financial modalities that allow for networks organization (payment at network level) are under-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)

- Some payment systems are disease-oriented rather than patient-oriented

  GP: ''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." (BS 3)

  GP: « '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 ?'' (BS 3)

- Criteria for reimbursement are ill-adapted to some situations

  Representative of patient association: '' 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 ''. (BS 2)

- Social worker is not included in the reimbursement system

  GP: '' 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…,'' (BS 3)

- Fee for services system generates professional stress

  GP: "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)

7.3.4.3. Comments of the stakeholders in reaction to the statements proposed for a future (financial) organization of care:

- Reform proposition F: moving from an individual and service-based provider to a team- and patient-based payment system
  - Team-based payment needs a real team spirit (SGM 1 &2).

    "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)

  - Mixed forms of payment are probably the best choice. There is still a need for further research to see what the best compromise could be (SGM 1&2).
  - When choosing other forms of payment, rather than fee for services, the issue of pay for quality may arise. This is a "hot" topic, in particular for professional bodies. The participants mentioned the fear of control (SGM 1&2).

    "Ik vind die link naar kwaliteit heel belangrijk. Maar dan echt kwaliteit gelinkt onder de vorm van indicatoren, 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)

7.3.4.4. Summary: payment systems: concrete proposals for the future

The current fee for service system implies a high administrative burden; it is complex to understand and may lead to stress for the care professionals. Adequacy of mixed forms of payment needs further investigation in different scenarios.

A special attention must be given to the adequate financing of coordination meetings between professionals, especially if those professionals are self-employed and solo working, like many GPs at present.

Finally, it seems important to link the financing to quality issues.

7.3.5. Theme 5: Clinical information systems and e-Data

Huge changes in clinical information systems will have an impact on the organization of care for chronic patients.

7.3.5.1. Strengths of the Belgian health care system

- Progressive generalization of the use of electronic files as a support to more personalized care should be enabled by more secured data processing and transfer (access through secured pathways, systematic encryption of data, etc.) (BS 3 &4). Experiences in that respect are growing, as there is a trend to develop compatible systems.
- Digitalization and shared clinical information becomes possible through E-health, Walloon, Flemish and Brussels networks for information. Specific experiences for frail older persons are under way with the BelRAI (BS 3 &4).

  GP: En Wallonie.." Un professionnel de la santé qui a un lien thérapeutique avec un patient pourra se connecter et voir si le GP y a mis le résumé du dossier du patient… Pensons à un urgentiste qui reçoit un patient victime d'un trauma crânien inconscient… Dans l'autre sens, le GP peut avoir accès à toutes les prestations techniques qui ont été faites à l'hôpital, où que ce soit.» (BS 3).

- Input of electronic data in databases may allow their use for quality assessment by the care providers, for auto-evaluation and benchmarking (BS 3 &4).

  GP: "L'hôpital a mis sur pied un système où je peux avoir l'information sur mes patients, moyennant leur accord. Cela me permet d'avoir une série de rapports que je n'ai jamais reçus d'un patient dont je suis référée comme étant son GP » (BS 3).

- Opportunity to link clinical files with guidelines as a support for clinical decision making (SGM 1 &2).

7.3.5.2. Weaknesses of the Belgian health care system

Weaknesses of the system are mainly related to the many pilot experiments or local successes mentioned in the "strength" paragraph: these experiences are not generalized in the system:

- Many different types of software for e-clinical files: still too many problems of incompatibility between the information systems (BS 3 &4);
- Uniform care language is lacking because of differences in professional background and culture (BS 4);
- Patients need access to claim the provisions and benefits they are entitled to.

  "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)

- At present there is a lack of aggregated data of good quality for management purposes
- Use of algorithms to assess the quality/safety/adequacy of drug prescription

7.3.5.3. Threats in the Belgian health care system

- Fear from patients and professionals (related to privacy, or loss of control): there is resistance in sharing e-clinical files (BS 3).
- Fear for quality control, especially related to the issue of intrusion into the clinical decision-making (BS 3).
- Unsafe data transport and lack of privacy

  Nurse: "Privacy van zo'n dossier is ook een probleem"(BS 4).

  GP: ''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" (BS 3).

7.3.5.4. Comments of the stakeholders in reaction to the statements proposed for a future organization of care.

- Reform proposition G: shared patient file across lines and across disciplines
  - Central files can be in the 'cloud' which makes accessibility among different professional groups easier.
  - The rights of the patient needs to be taken into account (right to access the information and right to privacy).
- Reform proposal H: aggregated patient data at health facility level and local system levels for quality management purpose
  - The digitalization of individual clinical information makes it possible to analyze health (care) data in an aggregated way at different levels of the system. This should help to implement quality assurance systems (SGM 1 &2).
  - This work needs to be associated with the identification of quality indicators focusing on processes rather than outcomes.

7.3.5.5. Summary: clinical information systems: concrete proposals for the future

For continuity and coordination of care purposes, reliable patient files accessible across lines and disciplines are needed. These information systems should include algorithms for care decisions, based on updated evidence, and preferably be accessible for patients.

The building of those systems requires the active involvement of all stakeholders, probably with a multi-professional dimension. This could also reduce somehow the fear for control that was frequently expressed.

These shared files can foster quality issues, at practice, regional or macro level.

7.3.6. Theme 6: Accessibility of care

Access to care is a key issue for people with chronic care needs (i.e. timely, provided by the right professionals, in the right setting):

7.3.6.1. Strengths of the Belgian health care system

- Accessible emergency rooms in hospitals 24 hours a day /7 days a week for chronic patients: facilitated by a delayed payment (BS 2)
- Some local initiatives propose support to patients at risk of exclusion of the health care system AND living with chronic conditions (e.g. drug users, illegal immigrants,…) (BS 3)
- Easy hospitalization is often a solution to a “crisis situation at home”

  Nurse: “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.”(BS 2)

- Emergency line within primary care practice

  GP: “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 in de groepspraktijkaanwezig zijn: op die manier kan er meer ruimte en ondersteuning gegeven worden dan bijvoorbeeld een soloarts die met een volle wachtzaal zit”(BS 1)

7.3.6.2. Weaknesses of the Belgian health care system

- Delays for specialist consultations in hospital

AN increasing number of specialists work in private practice because of better financial conditions (BS 3). As a consequence, diagnoses in hospitals are delayed (BS 2) and also, possible access to care.

- Financial accessibility
  - Most nurse and GP services are partially reimbursed to people with chronic care needs by the NIHDI (INAMI-RIZIV) through the list of billing acts (“nomenclature”). This is not the case however for all interventions (e.g. preparation of drugs, routine screening for vital parameters (heart rate, blood pressure…). In particular this is not the case for supportive care (family aids, home attendants (“garde-malades/nachtoppas”), only accessible for a minority (BS 3).
  - Many old persons with chronic care problems do not have a good "safety net" (i.e. access to care despite of insufficient financial resources). There are a non negligible number of people who do not benefit from OCMW/CPAS allowances but at the same time lack income to pay for the care (BS 3).
- Waiting lists for nursing homes

  Director of nursing home: “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.”(BS 4)”

- Delays for care are especially the case in rural areas

  Hospital medical specialist: “ 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).’’ (Int 1)

- Access to “family aids’’

  Nurse coordinator: ‘’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. ’’ (BS 3)

7.3.6.3. *Comments of the stakeholders in reaction to the statements proposed for a future organization of care:*

- Reform proposal I: the right environment according to the needs of people with chronic health problem.
  - There is a need for more 'respite' care organization, as well as a need for information about the existing formulae, in order to avoid or prevent some hospitalizations.
  - A legal framework and financial incentives have to be tested and implemented to alleviate the burden of the informal caregivers and to allow their formal recognition.
  - Currently, non-medical professions are performing 'illegal' acts. "Nomenclature" and legislation have to be adapted whenever possible, following the requirements of the field (reimbursement by NIHDI (INAMI-RIZIV).
  - The current financing is separated according to two different paradigms: "health" and "well-being". The division between medical care and social care needs to be dealt with at the work floor. The actual state reforms have overlooked that issue. Municipalities could play a role in that aspect (SGM 1).
  - Insufficient day centres in rural areas, as well as information about the existing day centres.

7.3.6.4. *Summary: accessibility of care: concrete proposals for the future*

The support of people with need for chronic care is a challenge for the next decades in Belgium. On the one hand the care in institutions should be dedicated to people with high care/supportive needs. On the other hand, specific support is required for persons with more limited care/social needs, outside institutions. Therefore, it is necessary to increase the offer of care/support in primary care. Also, responsive accommodations as a source of relief help to avoid unnecessary admissions to hospitals and further institutionalisation.

7.3.7. *Strengths and limitations of this SWOT analysis*

A SWOT analysis is a flexible method that allows synthesizing and integrating various types of information. The researchers carefully selected a wide range of stakeholders to collect a wide range of perspectives and interaction. There was a complementary approach between stakeholders close to the people with chronic health problems and those being more involved in making or influencing the health care policy. The objective was to check if ideas coming from the brainstorming sessions could have any impact in the future.

The number of stakeholders remains limited in view of the scope of the discussions. Sometimes information might be inconclusive and subjective to some extent. It has also not been possible to prioritize nor quantify the different elements mentioned by the participants.

7.4. Key points: highlights from the SWOT analysis with stakeholders

The perspectives of stakeholders show interesting highlights.

7.4.1. Lack of efficiency

According to the participants at all levels, the organization of chronic care is sub-optimal in Belgium. In some cases, existing health services are underused. In other cases, there might be an overlap of services, leading to inefficiency. This situation is observed when the pillars of our health care system offer parallel or near identical services to the same target population.

Collaboration to design new and effective approaches can be of value. For instance, cooperation at the level of home services of insurance companies and municipalities can increase scale. Collaboration under the umbrella regional networks can assist in this respect.

7.4.2. Coordination at micro level: a multidisciplinary primary care team is at the centre of a system designed for people with chronic care needs

A coordination of care tailored to the patient is needed to address the medical and the psychosocial issues that relate to the chronic disease(s). For most cases, simple (case) management at the practice level can be sufficient. For more problematic cases or episodes of care, a case manager will be of great value.

Divergence of opinions persisted on the person who can take up this role of coordination. It is clear that the GP plays an important role in that respect for the cases with highest medical burden. However, many participants argued that this profession faces problems to fulfil this role (lack of time, lack of incentives, knowledge of the existing social structures).

Innovative organizational models should be developed: other professionals can take up the coordination role as for example a specialized nurse with training on psychosocial aspects, a social worker. The stakeholders referred to international models with an emphasis on the role of the primary care nurse. There was large agreement that flexible team approaches are best to cope with the increasing needs. The composition of the team and intensity of the intervention will depend upon the type of needs (biomedical and/or social) and their importance.

7.4.3. Coordination at the meso level: mid-level scale initiatives to improve seamless care between hospital and home care

Coordination of care and coherent pathways across different lines of care were seen as facilitators for a more efficient chronic care model. Existing structures can be used, for instance the regional and local networks (for example the manager of a local network can also perform management tasks for a group of solo GPs within a region).

Also medical specialists can transfer knowledge to other professions or coach the local practice level, instead of providing routine care. This approach is part of the agreement of care pathways (zorgpaden/trajets de soins) but seldom implemented in the reality.

7.4.4. Task delegation and new functions in the health care system: the added value of medical assistants and qualified nurses

Participants suggested enhancing task delegation and sharing. New roles can be identified for health care workers: medical assistants can be of value for the care of non-complicated cases whereas specialized nurses can play a role for more complicated cases.

Essentially, task delegation or sharing may increase the efficiency of care. However, a possible pitfall is care fragmentation and attention should be paid to keep the broad picture, particularly when dealing with complex cases and multimorbidity.

Many requirements have been mentioned to implement task sharing and delegation:

- to educate and recruit staff with the right mix of knowledge and skills, broad enough to encompass not only the medical background but also psycho-social issues;
- to formulate new role definitions and bring accordingly legislation and cultural changes. Professional groups (GPs, specialists and nurses) have here an important role to play.

- To develop and use shared tools for communication and data transmission between care providers.

7.4.5. Preventing institutionalization: importance of respite care and coaching the informal caregivers

Respite care, training and coaching of informal caregivers are possible ways to diminish the risk of urgent hospitalization/institutionalisation in case of acute episodes. Illustrations are the projects financed by the NIHDI for alternative care for the older persons ("Protocol 3 projects') (see section 4.5.2.3).

7.4.5.1. Critical period: discharge after hospitalization

Participants reported problems at discharge: the articulation between hospital and primary care calls for improvement. Better communication (e.g. by the use of shared tools) and specialized nurses can play a definite role.

Issues like self management and the needs/competences of the informal caregivers require also specific attention.

7.4.6. Patients and Informal care givers. Roles of their organizations

Organizations of patients and informal caregivers can play their role in three important domains:

- sharing and provision of information;
- empowerment of patients and informal caregivers: a help to take their own responsibilities in the management of their disease,
- representative body for policy makers.

7.4.7. Balancing payment systems

Participants stressed the need to re-evaluate the balance between a fee-for-service and capitation payment for the care of the chronic patient. This financial issue came on the agenda when mentioning the coordination of care, team-based work, task delegation, financing quality of care and support of informal caregivers. These goals are difficult to achieve if the care providers work in a fee-for-service system.

At present, an increasing proportion of the income of GPs is related to capitation based payments (electronic medical record, care trajectories etc). It was stressed that a disease-specific financing may lead to fragmentation of care and lack of efficiency.

7.4.8. Information systems

Carefully designed information systems are a condition for the information flows across and within settings and disciplines, supporting the continuity and coordination of care.

7.4.8.1. Common guidelines

These information systems should include algorithms for care decisions, based on updated evidence, preferably also accessible for patients.

Participants agreed about the necessity to develop these systems further, for example to rely on multidisciplinary guidelines. This means that the guidelines for the follow up and treatment of the most frequent chronic diseases (respiratory, cardiovascular, neurological problems) need to include avenues for task delegation.

7.4.8.2. Common tools across disciplines

There is a need for the development of common communication tools used by different disciplines. At present, medical softwares are developed for specific care providers and this hinders communication between disciplines and even between professionals from the same discipline (e.g. nurses and GPs, different softwares for the GPs with limited compatibility, information from hospitals often not accessible for primary care providers). Interesting initiatives to share information is the development of "réseau santé wallon" [318] and the implementation of BelRAI.

Ethical considerations are important to ensure the patient's right to confidentiality[179, 180]: there is a need for rethinking some privacy issues and patients' (informal caregivers) rights to access the information.

7.4.8.3. Tools for quality initiatives

Finally, shared files that encompass indicators can be used to inform management at different levels. The practice (micro level) can use the information to set up quality improvement initiatives. The use of anonymised data can also be of value at the meso level (region) for epidemiological, health care planning and quality purposes.

The availability of data is a condition for putting quality on the agenda of the stakeholders at all levels.

7.4.9. Accessible care

The Belgian health care system is well known for its accessibility to all lines of care and types of care providers. However, the growing complexity of reimbursement conditions, waiting lists in nursing homes, the multiplicity of information sources and systems, the limitations of accessibility of some services for specific groups of chronic patients are possible threats to accessible care.

The perspectives of stakeholders highlighted major issues in relation to the organization of the Belgian health care system and its capacity to answer to the needs of the patient with chronic disease.

Two major issues were mentioned as weaknesses of the system:

- **Threats for the efficiency of the system: an overlap between health services and structures offered to a target population as well as an underuse by specific categories of patients.**
- **Threats for the accessibility: the growing complexity of reimbursement conditions, waiting lists in nursing homes, the multiplicity of information sources and systems, the limitations of accessibility of some services for specific groups of chronic patients.**

The stakeholders mentioned many avenues to improve the current system:

- **Coordination at the meso level: initiatives to improve seamless care between hospital and home care are conditions for a more efficient chronic care model.**
- **Task delegation and new functions in the health care system: the stakeholders underlined the added value of new functions (medical assistants) and new roles (e.g. qualified nurses). Requirements for this revolution include education and attraction of well trained staff, new role definitions, legislation and cultural (professional) changes.**
- **Major role of patients (and informal caregivers) associations to inform, empower, support and represent the population with chronic disease.**
- **Need to re-evaluate the balance between a fee-for-service and capitation payment for chronic care: coordination, delegation, team work, quality initiatives are difficult to achieve in a fee-for-service system.**

- **Performing information systems: they are a condition for the information flows across and within settings and disciplines, supporting continuity and coordination of care. Three major objectives are the use of common guidelines across disciplines, shared tools for communication between care providers and the set-up of quality initiatives. Ethical considerations are important for rethinking some privacy issues and patients' (informal caregivers) rights to access the information.**

The stakeholders also formulated suggestions to improve the care around the patient

- **Patient centred care: the objectives are to address biomedical as well as psychosocial needs that relate to the chronic disease(s).**
- **Coordination: case management has a definite added value, in particular for the patients with complex biomedical and social problems/episodes. Divergence of opinions persisted on the person who can best take up this role.**
- **Multidisciplinarity: the composition of the team and intensity of the intervention will depend upon the type of needs (biomedical and/or social) and their importance.**
- **Respite care and coaching the informal caregivers to prevent institutionalisation.**
- **Specific support and communication between providers at discharge, a critical period for the patient with chronic disease.**

8. ANALYSIS OF COORDINATION STRUCTURES AND PROGRAMMES IN BELGIUM

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8.1. Objective of this chapter

The stakeholders interviewed in the SWOT analysis (see chapter 7) highlighted the importance, the multiplicity and the complexity of coordination structures and programmes in Belgium. The aim of this chapter is a description and analysis of the coordination structures and programmes to propose perspectives for future organization structures.

Experts with experience in the organization of health care in Belgium compiled a synthesis of the available documents on the topic, completed by international references and interviews with stakeholders from authorities from the French-speaking part of the country (for which less grey literature was initially available).

The authors structured their analysis around the following questions:

- What are the coordination structures in Belgium in the health sector?
- What are their key features?
- What has been their evolution?
- How do the care programmes fit into micro or meso horizontal structures?
- What are the possible perspectives for future coordination structures?

This analysis takes into account the fact that the health care system has to be considered as a complex adaptive system where the agents play an important role through their interactions.

8.2. Background: health care system, a complex adaptive system

International literature describes the evolution of health care to a complex adaptive system. Complex adaptive systems are defined as "a collection of individual agents who have the freedom to act in ways that are not always totally predictable, and whose actions are interconnected such that one agent's action changes the context for other agents".[319] In complex adaptive systems the traditional "reduce and resolve" approaches to clinical care and service (re)organization no longer work[319].

Healthcare is a collection of individual professional agents (doctors, nurses and other professionals) who provide care either in private or in organized services (hospital departments, home care organizations). All these agents have the freedom to act in ways that are not always predictable and their actions are interconnected. One consequence is called "nonlinearity": small actions may have large effects on overall system behaviour, while large actions may result in little overall effect. Because opportunities for change vary between practices, complexity theory predicts that interventions successfully addressing problems or barriers in one setting may be of limited use elsewhere.

The result of considering health care system as a complex adaptive system is that no single centralized control mechanism governs every aspect of system behaviour. Control is said to be distributed among the agents, all of whom being connected through working relationships or other interactions. The intuitive notion of various system "levels," - such as the micro-, meso- and macro-system -, has to do with the number and the strength of interconnections between the elements of the system.

Innovation and progress cannot be imposed, but emerge from the interactions within the complex system when it is properly attracted, supported and stimulated. Agents stick to their freedom but they do also respond to their environment by using internalized sets of rules that drive action.

Successful ways to work with complex adaptive systems are:

- **to focus on multiple interactions and context rather than on single cause-effect mechanisms;**
- **to develop tailored interventions to improve nonlinear processes of care;**
- **to identify essential functional tasks or crucial processes and the monitoring of their implementation;**
- **to foster programmes that were successful in other settings and to understand the conditions under which desirable variation arises;**
- **to create collective ambitions amongst involved agents, to stimulate personal and team commitment through the definition of clear outcomes, leaving some individual freedom and accepting multiform local solutions;**
- **to consider possible conflicting views and interests of care providers from different traditions.**

8.3. Coordination structures and programmes in health care

This section describes coordination structures or programmes that benefit from public financing either regional or at federal level.

8.3.1. Coordination structures

The terms "coordination structure" refers to a person (a coordinator), a formal team, or an organization having the task to coordinate health and/or social care activities.

- In the French-speaking part of Belgium : the analysis focuses on "Associations de Soins Intégrés" (ASI), " Centres de Coordination de Soins et Services à Domicile » (CCSSD), « Services Intégrés de Soins à Domicile » (SISD) ;
- In the Dutch-speaking part of Belgium: the analysis focuses on the « Community Health Centre » movement and the more recent trend to "Interdisciplinary Primary Care Practices, the originally called

"Samenwerkingsinitiatieven voor Thuisverzorging" (SIT), and the "Geintegreerde Diensten Thuiszorg" (GDT). In Flanders SIT and GDT were gradually upgraded and integrated in the new "Samenwerkingsinitiatief Eerstelijnsgezondheidszorg"(SEL).

The main characteristics of these structures are presented in the supplement 4.5).

8.3.2. Coordination programmes

The term 'programme' refers to a coherent set of activities implemented to achieve a specific objective in health care. This analysis focuses on three types of programmes (see supplement 4.5) developed in view of chronic care organization:

1. care trajectories for diabetes and renal failure (see section 4.5.2.1);
2. innovative forms of care delivery financed under "Protocol 3" (see section 4.5.2.3);
3. palliative care platforms as an example of a good working structure for a specific end phase in care delivery.

8.4. Key features of coordination structures and programmes

Healthcare reform with a focus on chronic care is a challenge. The current system, oriented towards acute care has also to consider the importance of chronic care with patient empowerment, team work and coordination as crucial element (cf. chapter 2). To ensure an improved coordination, a reform process needs to:

1. Define the best structures to optimize coordination. International experience[39] shows that care provided by provided by polyvalent multidisciplinary teams have to improve the daily care of the chronically ill. Coordinated networks of providers and supportive regional structures should be structured around teams and ultimately around the patient.
2. Conceive programmes, budgets, tasks and activities so that they would strengthen the above structures.
3. Consider the reality of the system to define workable solutions. Lessons can be learned from abroad but each country should find its own solutions. In particular the Belgian health care system has a tradition of patient's choice of care provider, no gate keeping, limited enrolment in a GP list and fee for service as the most common payment mechanism in primary care. In that context implementing system-wide strategies for the care of patients with multimorbidity is a challenge [45].
4. Consider the Belgian healthcare as a complex adaptive system (see 8.2). "Agents" (actors) play an important role in the success or failure of a reform.

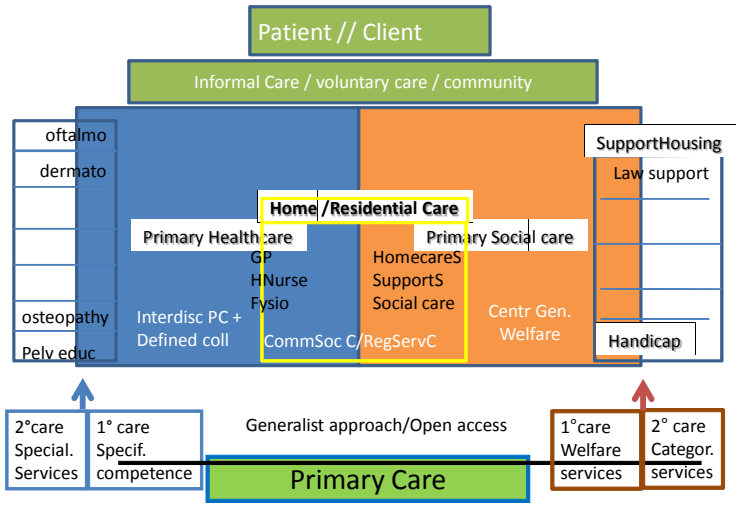
8.4.1. Coordination structures at micro level

8.4.1.1. "Micro-level": multidisciplinary and polyvalent teamwork

- Traditions of primary care giving organization

There are two main primary care giving traditions with limited collaboration (see Figure 13): the "medical tradition of primary healthcare" and the "tradition of primary social care". Home/residential care stands between these traditions. One problem is that within the same region, organization often relies on parallel organizations, called "pillars" (organized for example by Sickness Funds).

Figure 13 – Primary care care giving traditions



o Medical tradition of Primary healthcare

The "medical tradition of primary healthcare" covers different professions that use the medical taxonomy of diseases, therapies, medication, etc. to organize their work, and to collaborate around common tasks. This includes GPs and other physicians, nurses, pharmacists, physiotherapists, psychologists etc. In Belgium the "Maison Medicales/Wijkgezondheidscentra" have a strong tradition of multidisciplinary integration. There is also a tendency of other GP (group) practices to evolve towards "Interdisciplinary Primary Care Practices" with different types of "collaboration and coordination". Episodic referrals to a supportive secondary or tertiary level healthcare are integrated in the daily care routine.

o Tradition of "Primary social care"

This second tradition uses the social care approach, based on patient's help request, problem definition, supportive self-care, financial support, community embedding etc. It includes social workers, family helpers, lawyers and community workers, organized in different services. There is a tradition of social work at municipality level (CPAS/OCMW) and within the sickness funds. In Flanders, 25 "Centra voor Algemeen Welzijn" (centres for general wellbeing) are initiatives of coordination and guidance for patients who needs social help (for example in case of divorce, unemployment, budget management problems).

o "Home and Residential care

This care is at the crossroad between the two traditions mentioned above. Its aim is to strengthen daily care in the home setting or, alternatively, it offers a residential solution and all the intermediate solutions for day care and respite care. This sector is staffed by manpower from the two above traditions.

- Importance of a team around the patient

The "micro level" is the level where coordination takes place around the patient, by the care providers themselves. The traditional acute-care approach emphasizes the unique relationship between patient and doctor. For patients with chronic complex problems the issue of a multidisciplinary team becomes relevant. A literature review found that only one third of the patients thought that their primary care physician had a very good knowledge of their person as a whole, their worries about health and their personal responsibilities care [320]. Moreover, patients expected team care to be visible with clear positions and options, with a contract on shared objectives and responsibilities. In the same way the international literature advocates for multidisciplinary and polyvalent teamwork (see section 2.1).

A theoretically ideal size to strengthen the collaboration within the smallest "natural local community" often refers to a community of 10 to 15.000 inhabitants, where people know and meet each other, and where consequently services and practices can collaborate around the patient.

- Shift from disease-oriented to multidisciplinary care

Authorities have the tendency to organize and finance health care through "vertical models" (disease or problem-oriented). This tendency is problematic in the case of chronic care: people often suffer from multi-morbidity and end up having complex needs (see also1.3.2.2). Most diabetes patients (90%) are treated in primary care: 50% have also hypertension and 33% suffer from chronic heart disease[321]. The care

delivery for the patient with (complex) chronic needs should be therefore 'horizontally' integrated around the patient[39].

This approach by disease is not workable in primary care: primary care providers are requested to integrate all disease oriented innovations into one helicopter view when caring for a patient with multimorbidity. All protocols (for example for diabetes, heart failure, renal failure) should follow the same format, so that they could be easily applied to a patient whose health status requires combining protocols. Goal setting, quality parameters, referral principles, evaluation criteria, exchange of data and parameters, collaboration norms etc. should be as harmonized as possible to make it workable and integrated in the medical record.

It is crucial to have polyvalent multidisciplinary chronic care teams who make the synthesis of the needs and care integration for one patient. The specific involvement of GPs is defined as a difficult though crucial issue, and the level of nurse involvement is a predictor of good practice[39].

8.4.2. Need for a geographically integrated system at meso level

- Integration : Multidisciplinarity at meso level

The multidisciplinary view from the micro level should be also present at the meso level: all programmes should use the same collaboration network from different disciplines. This is in contradiction for example with the current appointment of diabetes educators and cardiac heart failure nurses, rather than educators and case managers for chronic diseases in general.

These programmes should be a coordination point and a supportive organization structure for providers. They should be also large enough to ensure sufficient professionalism and diversity for the different aspects of chronic care. Internationally the level is often defined at an average of 150.000 inhabitants (with local variation).

- Geographical catchment areas

A basic principle for developing coordination at the meso-level is the subdivision of the territory into health care zones ("bassins de soins / zorgzone"). It defines covered populations, the related structures as well as the group of caregivers who work in that area. This official definition does not impose solutions but creates a framework and opportunities for collaboration.

The caregivers themselves can easily make agreements, coordinate their work, elaborate common plans and eventually enhance their work performance through networking. Sharing common buildings, offices or even administrative support teams can contribute to a better collaboration within a catchment area.

All catchment territories of these structures should be fully integrated in other structures without overlap. Smaller territories are acceptable as long as each small structure is an inherent part of one bigger zone. In the same way large territories have to match the territories of the smaller ones. This is the so called "Cube principle". This principle avoids "border problems" i.e. when one caregiver or organization belongs to different care-zones.

8.4.3. Towards a uniform vision at macro level

Belgium is a tangle of federal, regional and community governments, each of them dealing with a part of the regulations, budgets and initiatives for the health and social care systems. There is urgent need for integration of initiatives. Making at least the options explicit gives the opportunity to evaluate their outcomes afterwards.

Coordination structures should be simple and:

- **stimulate multidisciplinary and polyvalent primary care teams at micro-level (around the patient);**
- **use the definition of health care zone and geographically integrated system at the meso level, towards more performing and supportive units within defined territories;**
- **benefit from a clear uniform vision at the macro level: vertical programme planning should move towards a "horizontal" approach for primary care.**

8.5. Evolution of coordination structures in Belgium

Health care policies in Belgium are designed and financed at federal, community and regional levels. This led to the development of similar structures in Flanders, Wallonia and Brussels. These similar structures had different evolutions in the different regions that can be analysed by considering the complex adaptive nature of the health care system. This section reviews the evolution of structures of coordination at micro and meso level.

8.5.1. Micro level: from single-handed practices towards more collaboration

8.5.1.1. Medical care

Single-handed practices have been till recently the most widespread organization model in primary care in Belgium. GPs, nurses, physiotherapists, organized themselves as separate disciplines. This differs from the international situation where nurses usually play an important role in ambulatory healthcare centres (called "medical homes"[322]).

However there is a growing intensity of collaboration, often selective, between disciplines in primary care. Moreover, there is a trend towards what is called "collaboration networks between caregivers, not working in the same practice". GPs preferably work in collaboration with some nurses, with a limited set of physiotherapists, psychologists etc. They establish a more structured collaboration or even reach agreement on their common tasks. There are also more and more multidisciplinary integration efforts in existing group practices towards "interdisciplinary primary care practices" (Interdisciplinaire Eerstelijns Praktijk/ Interdisciplinary Primary Care Practice) [323].

The initiatives of the Maison Médicales / Wijkgezondheidscentra / Geneeskunde voor het volk go in that direction, with the development of coordinated care and teamwork. In Wallonia and Brussels 80 "Maisons Médicales" are officially recognized as "Association de Soins Intégrés". They employ people to spend time on coordination activities. They cover a population of 3000 to 4000 people with an interdisciplinary team of around 12 team members. Given the small size of the team, information can be easily shared between providers of the team.

How to combine a freedom of choice with the chronic care team concept?

In Belgium freedom of choice for all health workers is highly valuated. Every citizen claims the right to choose his own GP, pharmacist, home nurse, physiotherapist etc. Yet, for chronic care programmes, it is not possible to have different teams around each patient. The Stille & Jerant formula shows that a work with good coordination requires open information channels between co-workers: their number is equal to $(n-1)^2/2$, where n is the number of involved professional caregivers[324]. If complex chronic patients have 10 caregivers involved in daily care, the formula indicates that there are $(10-1)^2/2$ or 40 open communication lines around this patient. A team with fixed composition can reduce this communication and coordination challenge, by sharing working rules, open access to patient records, mutual trust within the team. There is already a movement into this direction: an increasing number of practices involve nurses, physiotherapists, dieticians and psychologists as fixed working partners in the practice. Other GPs establish more selective working relations with other care providers in their neighbourhood.

8.5.1.2. Primary social care

In Wallonia, there is a strong diversity of primary social care services with the "Centres de Coordination et de Soins à Domicile" (CCSSD), complemented by an extensive network of CPAS.

In Flanders, there has been a movement towards setting up coordination points for patients, to give them guidance in finding the appropriate social service in relation to their problem. Flemish government asked Centra Algemeen Welzijn (CAW) to develop coordination of all local organizations by 2014.

8.5.1.3. Home and residential care

The coordination structures evolved differently in Flanders, Brussels and Wallonia.

- Evolution in Wallonia and in Brussels (French-speaking)

The first alternatives to hospitalization started in the early 80ths, under the supervision of the GPs, who spontaneously initiated home services for people with complex needs. These initiatives aimed to develop networks for home care encompassing health services (with nurses) and social services (with social aids - « aides familiales »). These initiatives at micro level gave birth to the CCSSD in 1987. These often belong to one of the 4 largest Sickness Funds.

Every patient can get integrated home care: the organization depends on his/her affiliation to a Sickness Fund. This situation allowing local competition between services progressively created a patchwork of organizations in each region. However the 2010-2015 planning for CCSSD "agreement" with Walloon Region now allows between 3 to 5 CCSSD per care area ("zone de soins") corresponding to a geographical area of a SISD (i.e. 1 CCSSD for about 80 000 inhabitants)e.

- Evolution in Flanders

In the same way, "Samenwerkings Intiatief voor Thuisverzorging" (SITs) were launched from 1990 onwards. They also coordinated care with individual care plans as a basic tool. The choice of involved disciplines and territory to be covered was free, with a minimum of at least 25 000 inhabitants. This resulted in SITs ranging from 31 000 to 1 370 000 inhabitants.

The great difference in the Flemish approach was the exclusivity in the territorial basis: there could only be one SIT per defined territory and all involved disciplines should meet in one structure.

Looking back [325], it is important to note that from the beginning the factual organization went into 2 levels of organization: on the one hand a sort of "umbrella structure" level, bringing together the locally involved organizations, and on the other hand the "care-coordination level" of different substructures that organized complex care with the local caregivers. Local people took local options. Hence, these two level's, sometimes called the "umbrella SIT" and the "sub-SIT", were often organized in different ways. For example in the province of Limburg, the 9 big municipalities developed their local sub-SIT, integrating all the municipal support services into one strong local care coordination centre. The umbrella structure at the province level was called LISTEL.

8.5.2. Meso level: from home care coordinating centres (SIT/CCSSD) to Integrated Primary Care Systems (GDT/SISD)

The coordination structures at meso-level also evolved differently in Flanders and in Wallonia.

8.5.2.1. Definition of care zones

In the nineties, the Flemish Healthcare Board (Vlaamse Gezondheidsraad) commissioned a study on health care reorganizations towards functional regions in healthcare [326]. A conclusion was that functional care territories should take into account the existing regions in the society. In 2001 a study defined these natural clusters in Belgium[327] : 5 large city zones, 17 regional city zones and 81 small city zones. Based on this division, a "Care region decree" from the Flemish government defined care regions for Flanders with two integrated levelsf: 14 regional city care zones, each consisting of a number of sub-regions at a smaller city level (small-city care zones).

e Avis visé à l'article 29 du décret du 30 avril 2009 relatif à l'agrément des centres de coordination des soins et de l'aide à domicile en vue de l'octroi de subventions. - Programmation des centres de coordination des soins et de l'aide à domicile en vue de l'octroi des subventions (M.B. du 19/01/2010, p. 2291)

f Decreet van 28 nov 2008 tot wijziging van het decreet van 23 mei 2003 betreffende de indeling in zorgregio's en betreffende de samenwerking en de programmatie van gezondheidsvoorzieningen en welzijnsvoorzieningen,, stuk 1773, gepubliceerd in Belgisch Staatsblad 23.12.2008 p67800.

In a similar way, in 2002, the Walloon government published a similar decreeg, defining care-zones ("zones de soins") and operational subzones ("zone de soins opérationnelles")

8.5.2.2. Integration of home care: SISDs and GDTs

In 2002 the Federal government developed services for integration of home care and coordination between care partners in primary care (GDT-Geintegreerde Dienst Thuiszorg / SISD - Services Intégrés de Soins à Domicile) for primary care integration and team coordination between care partners. They financed e.g. multidisciplinary meetings ("Multi-Disciplinair Overleg"-MDO) whenever requested by the intensity of care.

- Implementation in the French-speaking part of the country

The French speaking part of the country created new structures, the SISD, positioned on a larger scale than the CCSSD. The SISD covered a defined health care zone, with obligatory involvement of all primary care organizations. Thirteen health regions were defined for Wallonia and one for Brussels. The unequal development led to the present situation: only 8 structures in Wallonia, one for the German-speaking area and one for Brussels. Basically, they would cover between 100 000 and 600 000 inhabitants (and the whole population for the Brussels region). Some SISDs succeeded in bringing together a high diversity of organizations (i.e. Liege, Brabant Wallon and Charleroi). They involved all primary care organizations, including GP organizations. They took up the job of evaluation of care needs, definition of care plans and brought the caregivers together.

- Implementation in the Dutch-speaking part of the country

The Flemish community took another option: it integrated the federal GDT structures into the existing SIT tradition, to evolve towards a unique integrated structure. The reform of the SITs aimed to create strong primary care organizations, the SELs (Samenwerkingsinitiatief EersteLijns gezondheidszorg), working at two levels, with territories defined by legislation (eerstelijnsdecreet 2003-2008). The decree defined the principle of the umbrella SEL, covering sub SEL's and integrating all organizational tasks, for the healthcare part as well as for the social part of primary care. In 2009, each of the 14 SELs at regional-city care zone level covered an average of 500 000 inhabitants. They got responsibilities to integrate all healthcare and welfare organizations from primary care. The SEL had the freedom to organize sub-SEL levels according to local needs. The SEL financing is based on individual care plans with the addition of the federal budget for MDO.

8.5.2.3. Lessons learned from the evolutions in the Flemish community, Wallonia and Brussels regions.

The regions evolved quite differently and lessons can be learned from these different options. Flanders focused more on creating strong umbrella, geographically defined (the SEL) when Wallonia and Brussels insisted more on recognizing structures created by the care providers and building the system from the basis (CCSSD, Association de soins intégrés).

As a consequence CCSSD have a strong position in Wallonia and Brussels at the local level. These offer for 25 years a well organized home care structure close to the local population, ensuring freedom of choice in a parallel and patchy way.

The Flemish option offers an example of meso organization at two levels. The umbrella SEL-level is adequate for strategic discussions and decisions taken with all regional primary care organizations. However, one negative consequence is the difficulty to involve the caregivers less organized in representative organizations. Even some GPs organizations do not feel much involved, even though they have a legal representative organization with a chair or co-chair in the local SEL. Many the other professions in primary care do not even have this kind of representation.

[g] 8 juillet 2002 - Arrêté royal fixant les normes relatives à l'agrément spécial des services intégrés de soins à domicile y inclus les zones de soins

8.5.2.4. *Future initiatives to facilitate more structured collaboration*

- Reorganization of coordination structures

In view of 2014, the Flemish government now negotiates with existing coordination structures to (re)organize structures at the small-city care zone level, under the umbrella-SEL coordination. The positive experience with the "Locale Multidisciplinaire Netwerken/Réseaux Multidisciplinaires Locaux (LMN/RLM)" of the chronic care reform has set out the lines. They succeeded in establishing the link between GPs and multidisciplinary care organizations. The authorities negotiate with the 45 existing LMNs to reorganize their areas into 60 small city care zones. At the same time, negotiations are running to upgrade to 60 CAW for social care and 60 centres for childhood prevention ("Kind en Gezin"). All negotiations run under the umbrella of the SEL.

Other existing structures such as the 15 palliative care networks and the 26 LOGOs (LOkaal GezondheidsOverleg) for prevention are also requested to reorganize into 14 structures localized at the regional city care zone level, with a possible later integration within the SEL.

- Development of "Regional Houses for care"

Another interesting evolution is the development of regional houses for care: integration of secretariats, supportive functions and meeting opportunities in one single location appears successful for the support and coordination of care providers. LMNs develop their "regional house for chronic care", often in the same building as the after-hours post. CAWs organize their "regional houses for social care". In the same way preventive child care services (K&G/ONE) move towards "regional houses for the child". This evolution towards structured services settled in specific buildings makes the provided services more visible and accessible for the population. Bringing complementary services in one location helps collaboration and eventually integration.

8.6. Care programmes: fit within "micro" or "meso" horizontal structures

As stated above (see 8.5) many initiatives in the Belgian health care sector were conceived rather "vertically" (focused on diabetes, chronic renal failure, severely mentally ill) or to address intensity-related problems (focus on complex patients or on urgent situations), with little attention for global coherence: different support systems, catchment areas, coordination structures (Figure 14).

Figure 14 – Vertical organization, horizontal integration

Area of care	Program	Coordination	Regio-definition
Prevention	Focus on 6 strategic health achievements	LOGO team	1/300.000
Urgent Care	UC team / UC post	Local GP groups	1/70.000
Residential care	ROB/RVT	Representative CRA	Per institute
Complex Care	SIT/GDT/SEL	CC-coördinator	1/500.000
Chronic Care	Care Trajectories Lokaal Multidisc.Net	Local Multidisc.Network Care trajectpromotor	1/120.000
Mental Healthcare	Art 107 ter /33 reoriented hospital beds	Local Mental Health Teams	Per Psychiatric institution

Chronic Care

According to their nature, the different programmes influence the micro and meso levels of coordination. The next paragraphs illustrate three important programmes for chronic care that were developed in Belgium in the last few years: the local multidisciplinary networks, alternative forms of care ("Protocol 3"), palliative care platforms and teams.

8.6.1. Local multidisciplinary Networks

A pilot project on diabetes care, financed by the NIHDI, was initiated in Leuven and Aalst in the years 2003-2007 [328]. It showed that the GP is a successful care coordinator, if supported by a team (including a diabetologist, an educator and organizational support). Consequently, when the NIHDI initiated the care trajectories in 2009 (see 4.5.2.2), they financed a care team around the patient and also offered the opportunity to create a Local Multidisciplinary Network at the meso-level, supported by a management function (called the "Care Traject Promotor"). This initiative stimulated care coordination at a Local Multidisciplinary Network level.

- In Flanders and Brussels regions the initiative of LMN was fully supported by the local GP organizations. By the official start in September 2009, 90 GP circles organized 45 LMNs. The same number of traject promoters were recruited and got a specific training for their new tasks.
- In Wallonia, care trajectories were less positively perceived, as a top-down approach. This resulted in a very unequal development of the MLN with some areas not yet covered.

In summary, the care trajectories are an important step for the development of integrated care at the micro and meso levels. Two problems were cited by the stakeholders in relation to this initiative (cf. chapter 7 and supplement 4.3): a top-down approach for its implementation and a disease-oriented approach that does not take account the multimorbidity. An evaluation of the care trajectories is ongoing [134].

8.6.2. Alternative forms of care for older persons

The NIHDI is financing 62 innovative projects, called Protocol 3 projects (see general description in 4.5.2.3) [135]. The focus is on innovative interventions to keep frail older persons longer in their own home or residency settings.

More specifically, innovation in case management is the main focus of 19 projects. "Case management" encompasses needs assessment, care plan, and evaluation. The projects use the BelRAI instrument[136]: this international multidisciplinary scoring instrument aims at objectively identifying the frailty of people, and deducting from the scores the care needs of the patient and areas of vulnerability.

An ongoing evaluation currently assesses the lessons to be learnt from the protocol 3 initiative.

8.6.3. Palliative care platforms and teams

The organization of palliative care initiated by the federal authorities illustrates the combination of coordination at meso and micro levels. There are 25 platforms in Belgium: 15 in Flanders, 8 in Wallonia, 1 in the German community and 1 in Brussels. Each platform covers a population between 200 000 and 1 000 000 inhabitants. The role of the platform and of the support team is to support primary (health) care providers. Palliative care teams are connected with CCSSD and/or SISD but are administratively independent from them. The Flemish government asked them to consider the regional-city care zone as their catchment area, to foster integration within primary care structures like SEL.

Palliative care platforms and teams are a positive example of vertical project, in this case acceptable because this type of care only occurs once in a life. It combines and harmonizes parallel initiatives in hospital, hospice and home care, including also non professional caregivers. The horizontal integration in primary care is quite unique: the catchment areas are clearly defined for the 25 palliative care platforms. The local palliative teams employ specialized people, supported by the knowledge and experience of hospital-based palliative teams. They also integrate "reference nurses and GPs" from primary care structures, that are trained and positioned to make the link with the usual primary care professionals of the patient.

8.7. From lessons learned to future perspectives

The Belgian health care system is an illustration of complex adaptive system. Public governance is structured at various levels (federal, regional and community). Sickness Funds as insurers and the medical profession further play an important role. The system relies on independent but very interdependent (private) agents and structures. Favourable evolution depends on the creation of win/win situations.

Based on the analysis above, a simplified backbone structure for the organization of primary care could be as follows:

Table 8 – Simplified backbone structure for organization primary care

A simplified backbone structure for organized primary care
1 Macro-organization, e.g. 1 Federal + 3 regional structures + 3 communities for visionary care development
------- 28 Umbrella structures at Meso level (14 SEL + 14 SISD incl. 2 Brussels+ 1 German Community) 1/400 000 inhabitants, following regional city care-zones , covering all primary care organizations
---------- 100 operational Meso level structures, 3 to 4 per Umbrella: (60 Flemish, 40 Walloon), 1/120 000 inhabitants at small-city care zone level at present with different support clusters (LMN/RLM – K&G/ONE – CAW/CPAS) per zone + working together in “regional houses”, recognizable for caregivers/patients
---------- 1000 local district clusters at Micro level, 10 per operational Meso level, that emanate from multidisciplinary collaboration between practices, integrating also the patchwork of CCSSD in the Walloon Region.

In summary, the new challenge for reorganization of chronic care gave an impetus to multidisciplinary work, with care trajectories in 2009 and Local Multidisciplinary Networks.

At the micro level, GPs also developed different types of informal or formal collaborations with other disciplines. At one extreme the GP works within an informal network of health professionals (home nurses, physiotherapists) . At the other extreme group practices (IELP/ASI) are the most structured model, where GPs, nurse practitioners, clerical staff, dieticians and possibly also the health psychologist work together. The concept of chronic care team finds its application in each of these practice formats.

For persons with disabilities, a well structured collaboration is required between home care and home help services. Social services may be grouped in “social houses”(CAW), offering a unique entry point to guide patients to the appropriate service. Another option may be to reinforce the link with home care services, as in Québec (see 2.3.2.1) making easier coordination between these services.

Some Local Multidisciplinary Network structures recently developed “Regional houses for care”, to foster coordination between care providers. Different services are offered (dieticians, psychologists) in close collaboration with the local teams of health professionals. The chronic care dimension is often integrated in service structures: some have preventive care units, others have after-hours services.

The general strategy of all these initiatives is supported by the Integrated Primary Care Services umbrella’s (SEL), a larger steering body for all primary care initiatives in the region (cf. 8.5.2). This committee encompasses delegations from all primary care disciplines who work in the region (GPs, nurses, pharmacists, physiotherapists, coordination centres). They have three main missions: to foster the collaboration between care providers from the same region, to stimulate multidisciplinary collaboration and to facilitate the collaboration with care institutions. In a central decision-making structure the stakeholders decide upon different care programmes that will be translated later on to local agreements. Is this the way forward?

Some interesting suggestions to simplify and strengthen coordination strategies are:

- **Use emerging dynamics rather than imposing new structures;**
- **Define clear-cut geographical areas with non-overlapping boundaries within which caregivers are supposed to organize themselves. There is international experience to help solving the size issue;**
- **Support strong umbrella organizations with a clear catchment area and a representation of all involved disciplines and structures;**
- **Accept for the time being the three different traditions in care giving: the medical, the social and the home care tradition. Help them to organize themselves in close relationship and in visible support for their micro level practitioners;**
- **Stimulate the evolution towards multidisciplinary teams for daily care-at the micro level;**
- **Develop programmes that take into account the horizontal integration in daily care and the strengthening of the existing collaboration and coordination structures.**

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