KCE REPORT 299S

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

AN EVALUATION PROTOCOL FOR NIHDI CONVENTIONS

SUPPLEMENT

KCE REPORT 299S
HEALTH SERVICES RESEARCH

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

AN EVALUATION PROTOCOL FOR NIHDI CONVENTIONS

SUPPLEMENT

PHILIPPE VANDENBROECK, WENDY CHRISTIAENS, MARIE DAUVRIN, RACHEL WICKERT, KIM BECHER, ERIK HENDRICKX, JO GOOSSENS, LIESBETH JENNÉ, MARIJKE EYSSEN

COLOPHON

Title:	An evaluation protocol for NIHDI conventions – Supplement
Authors:	Philippe Vandenbroeck (shiftN), Wendy Christiaens (KCE), Marie Dauvrin (KCE), Rachel Wickert (MetM), Kim Becher (shiftN), Erik Hendrickx (KCE), Jo Goossens (shiftN), Liesbeth Jenné (shiftN), Marijke Eyssen (KCE)
Project coordinator:	Marijke Eyssen (KCE)
Reviewers:	Anja Desomer (KCE), Arnaud Fouchard (Haute Autorité de Santé, France), François Schellevis (NIVEL), Koen Van den Heede (KCE)
External experts:	Valère Akafomo(ULg), Valérie Bartsch (ULg), Petra Berth (UZ Gent), Micheline Bon (ULg), Liesbeth Borgermans (Vrije Universiteit Brussel), Bertien Buyse (KULeuven), Jean-Pierre Bronckaers (Liberale Mutualiteit, College van artsen directeurs), Martin Caillet (CHU St-Pierre), Michel Cailliau (Clairs Vallons), Carine De Buck (Clairs Vallons), Ann De Guchtenaere (Zeepreventorium), Bart De Bock (Az St-Lucas & Volkskliniek Gent), Eric Derom (UZ Gent), Philippe Duval (Cliniques de l'Europe), Arnaud Fouchard (Haute Autorité de Santé, France), Aiden Fowler (NHS Quality Improvement and Patient Safety, 1000 Lives Improvement Service, Public Health Wales), Alain Gadisseur (UZ Antwerpen), Marjorie Gangolf (CHU Liège), Michelle Hall (HUDERF), Denis Herbaux (PAQS - Plateforme pour l'Amélioration continue de la Qualité des soins et de la Sécurité des patients), Khalid Ismaili (HUDERF), Michel Mahaux (Santhea), Els Meerbergen (Vlaams Patiëntenplatform), Marc Moens (Imelda), Frank Nobels (OLV Aalst), Koen Peers (UZ Leuven), Philippe Persoons (KULeuven), Christian Pirard (ULg), Rudi Reyntjens (Zeepreventorium), Camelia Rossi (CHU Ambroise Paré), Chantal Seret (Cliniques de l'Europe), Bart Thomas (UZ Gent), Marie Thys (CHU Liège), Jan Maarten van de Berg (IGZ, The Netherlands), Dominique Vandevelde (Ugent), Viviane Van Elshocht (CM, College van artsen directeurs), Omer Vanhaute (UZ Gent), Chris Van Hul (MLOZ, College van artsen directeurs), Ilse Weeghmans (Vlaams Patiëntenplatform), John Willems (Socmut, College van artsen directeurs, Eric Wilmet (Mutsoc, College van artsen directeurs), Bert Winnen (Kabinet Minister van Sociale Zaken en Volksgezondheid), Antonine Wyffels (Voorzitter College artsen directeurs), Marc Xhrouet (Santhea)
External validators:	Report validated by Pascal Mertens (CHRSM) and Jan Maarten Van den Berg (IGZ). A third validator, Georges Vereecke had major remarks which were not supported by the other two validators.
Acknowledgements:	Olivier Schmitz (UCL), Tinne Vandensande (KBS – FRB)
Reported interests:	'All experts and stakeholders consulted within this report were selected because of their involvement in the topic of Evaluation Conventions Rehabilitation. Therefore, by definition, each of them might have a certain degree of conflict of interest to the main topic of this report' Membership of a stakeholder group on which the results of this report could have an impact: Michel Cailliau (Member of the staff direction of a conventional centre – Clairs Vallons CMP asbl), Rudi Reyntjens (Board of directors independent sickness funds)

	Consultancy or employment for a company, an association or an organisation that may gain or lose financially due to the results of this report: Carine De Buck (Medical direction of a private convention), Marijke Eyssen (Centrum voor ambulante revalidatie) Presidency or accountable function within an institution, association, department or other entity on which the results of this report could have an impact: Michel Cailliau (Adjunct medical direction of CMP Clairs Vallons (convention INAMI – RIZIV)), Carine De Buck (See point 7), Omer Vanhaute (Convention coordinator UZ Gent) Other possible interests that could lead to a potential or actual conflict of interest: Tinne Vandensande (The KBS-FRB has already collaborated with shiftN in the past. shiftN has used the soft systems methodology for a study about patient participation)
Layout:	Ine Verhulst

Disclaimer:

- **The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.**
- **Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.**
- **Finally, this report has been approved by common assent by the Executive Board.**
- **Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.**

Publication date:	13 February 2018
Domain:	Health Services Research (HSR)
MeSH:	Multidisciplinary health care; Interdisciplinary health care team; Organizational innovation; Rehabilitation; Chronic diseases; Outpatient care; Long term care; Quality of health care; Organizational efficiency
NLM Classification:	WA 525
Language:	English
Format:	Adobe® PDF™ (A4)
Legal depot:	D/2018/10.273/22
ISSN:	2466-6459

How to refer to this document?

Vandenbroeck P, Christiaens W, Marie Dauvrin M, Wickert R, Becher K, Erik Hendrickx E, Goossens J, Jenné L, Eyssen M. An evaluation protocol for NIHDI conventions– Supplement. Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE). 2018. KCE Reports 299S. D/2018/10.273/22.

This document is available on the website of the Belgian Health Care Knowledge Centre.

APPENDIX REPORT

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ACP	Anticipatory Care Plans
ALD	Affections de longue durée (FR) / *Long term affections*
ANSM	Agence Nationale de Sécurité du Médicament et des produits de santé (FR)/ *National Agency for Drugs and Health Products safety*
ARS	Agence Régionale de Santé (FR) / *Regional Health Agency*
ASALEE	Actions de SAnté Libérales En Equipe (FR) / *Liberal Health Practices in Team*
ATIH	Agence technique de l'information sur l'hospitalisation (FR) / *Technical Agency of information on hospitalisations*
BNDMR	Base Nationale de Données Maladies Rares (FR) / *National database on rare diseases*
CAS	Clinical Audit System
CCC	Comprehensive Care Centres
CCMR	Centre de Compétences pour les Maladies Rares (FR) / *Competences center for Rare Diseases*
CME	Commission Médicale d'Etablissements (FR) / *Medical Commission of Institutions*
CMU	Couverture Maladie Universelle (FR) / *Universal Healthcare coverage*
CMU-C	Couverture Maladie Universelle-Complémentaire (FR) / *Complementary Universal Healthcare coverage*
CNAMTS	Caisse Nationale d'Assurance Maladie des Travailleurs Salariés (FR) / *National Sickness Funds for Salaried Workers*
CRAG	Charging for Residential Accommodation Guidance
CRMR	Centre de Référence pour les Maladies Rares (FR) / *Reference Center for Rare Diseases*
CRTH	Centre de Référence du Traitement de l'Hémophilie (FR) / *Reference Treatment Center for Hemophilia*

CRMH	Centre de Référence pour l'Hémophilie et les maladies hémorragiques (FR) / *Reference Center for Haemophilia and Haemorragic diseases*
CRMW	Centre de Référence pour la Maladie de Willebrand (FR) / *Reference Center for Willebrand Diseases*
CRPP	Centre de Référence des Pathologies Plaquettaires (FR) / *Reference Center for Clotting Diseases*
CTH	Centre de Traitement de l'Hémophilie (FR) / *Treatment Center for Haemophilia*
DAPHNEE	Doctor and Advanced Public Health Nurse Experiment Evaluation (FR)
DGOS	Direction Générale de l'Organisation des Soins (FR) / *General Direction of Healthcare Organisation*
DGS	Direction Générale de la Santé (FR) / *General Direction of Health*
FGM	Female Genital Mutilations
FSMR	Filières de Soins Maladies Rares (FR) / *Rare Diseases health care network*
GP	Generalist practitioner
HAS	Haute Autorité de Santé (FR)
HC	Haemophilia Centre
HEAT	Health Improvement, Efficiency, Access and Treatment
HIT	Health system In Transition
HPHS	Health Promoting Hospital Service
IAS	Infection Associée aux Soins (FR) / *Healthcare related infections*
IRDES	Institut de recherche et de documentation en économie de la santé (FR)
IQSS	Indicateur de qualité et de sécurité de soins (FR) / *Quality and safety indicator*
ISD	Information Service Division
KIS	Key Information Summary
LDP	Local Delivery Plan
MCN	Managed Clinical Network

MERRI	Missions d'enseignement, de recherche, de référence et d'innovation (FR) / *Mission of education, research, reference and innovation*
MIGAC	Missions d'intérêt général et d'aide à la contractualisation (FR) / *Mission of general interest and support for contract formalization*
MIPROF	Mission Interministérielle pour la PROtection des Femmes et la lutte contre les êtres humains (FR) / *Interministry mission for the protection of women and the fight against human trafficking*
NACS	National Advisory Committee for Stroke
NGO	Non-Governmental Organisations
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PMSI	Programme de médicalisation des systèmes d'information (FR) / *Program of medicalisation of information systems*
PNDS	Plan National de Diagnostics et de Soins (FR) / *National plan of diagnosis and care*
PNMR	Programme National Maladies Rares (FR) / *National program rares diseases*
PRAPS	Programme Régional d'Accès à la Prévention et aux Soins (FR) / *Regional program of access to prevention and health care*
PRS	Programmes Régionaux de Santé / *Regional health programs*
QIS	Quality Improvement Standards
RCP	Réunion de Concertation Pluridisciplinaire (FR) / *Pluridisciplinary Concertation Meeting*
SDG	Scottish Diabetes Group
SGHSCD	Scottish Government Health and Social Care Directorate
SHI	Statutory Health Insurance
SIBDN	Scottish Inherited Bleeding Disorders Network
SIGN	Scottish Intercollegiate Guidelines Network

SNIIRAM	Système national d'information inter-régimes de l'Assurance maladie (FR) / *National system of information of Sickness Funds*
SROMS	Schéma Régional d'Organisation Médico-Sociale (FR) / *Regional Scheme of Medicosocial organisation*
SROS	Schéma Régional de l'Organisation des Soins (FR) / *Regional Scheme of Healthcare organisation*
SSIT	Scottish Stroke Improvement Team
SSR	Soins de Suite et de Réadaptation (FR) / *Rehabilitation care*
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
UKHCDO	United Kingdom Haemophilia Centre Doctor's Organization

APPENDIX 1. LIST OF REHABILITATION CONVENTIONS

	Rehabilitation conventions
1	Aids-reference centres
2	Centres for medical and psychosocial care for victims of genital mutilation
3	Memory clinics
4	Long term oxygen therapy at home
5	Respiratory rehabilitation
6	Centres for support in case of unwanted pregnancy
7	Follow up of sudden and unexplained death of a child younger than 18 months.
8	Cardiorespiratory monitoring van new-borns
9	Follow-up-centres for children born prematurely
10	Treatment of obstructive sleep apnoea syndrome
11	Respiratory support at home
12	Respiratory support at home in case of obesity hypoventilation syndrome
13	Diabetic self-regulation
14	Insulin pump
15	Centres for paediatric diabetes
16	Diabetic foot clinics
17	Continuous glucose monitoring
18	Reference centres metabolic diseases
19	Reference centres for cystic fibrosis
20	Reference centres neuromuscular diseases
21	Reference centres for refractory epilepsy
22	Diagnostic centres for patients with chronic fatigue syndrome
23	CP-Reference centres
24	Spina-bifida reference centres
25	Reference centres child nephrology

26	National centre for haemophilia
27	Reference centre for haemophilia
28	General centres for locomotor and neurological rehabilitation (9.50-centres)
29	Hospitals with a locomotor and neurological rehabilitation program (9.50 or 7.71) via R30-R60
30	Cardiac rehabilitation: not financed by convention but by nomenclature
31	Implantable cardiac defibrillators
32	Rehabilitation centres for specialised locomotor and neurological rehabilitation (7.71 centres UZ Gent, UZ Pellenberg, Centre neurologique William Lennox, Cliniques Universitaires Saint. Luc and Hôpital Erasme)
33	Paediatric rehabilitation centres (Clairs Vallons in Ottignies, Zeepreventorium in De Haan)
34	Centres for children with neurological and psychiatric pathology (Centre neurologique William Lennox, La Porte Ouverte Blicquy)

APPENDIX 2. DESCRIPTION OF THE QUALITY ASSESSMENT IN BELGIUM, FRANCE, SCOTLAND AND THE NETHERLANDS

Appendix 2.1. Belgium

Appendix 2.1.1. Institutions monitoring the quality of health care

As a result of the 6th State Reform, quality evaluation of care institutions became the responsibility of the regions and the communities [gemeenschappen/ communautés]. This implies that from 2015 onwards Flanders and the Brussels-Walloon Federation are responsible for the quality assurance in health care institutions. Evaluations of individual care providers and elaboration of norms for agreement of the hospitals however remain a Federal competence[1].

Federal level

At the federal level, the cell Quality of the FPS Public Health aims at stimulating the development of a patient-centred, integrated and evidence-base health policy, through innovative and sustainable programs and in concertation with their partners. The year 2007 saw the launch of the first national patient safety plan. To this aim, a specific team and a strategic workgroup were created. They produced a strategic note, aiming at raising the awareness of health care providers regarding the quality and the safety of patients in their institution[2]. This is supported by a structural funding since then: hospitals are stimulated to develop and improve quality and safety of patient care through multiannual programs “Coordination quality and safety of patients”. The second plurennial program covers the period 2013-2017 and is articulated around four major themes: the systems of safety managements, leadership, communication and patient empowerment. Four specific themes are also included: high risk medications, *safe surgery*, identity vigilance (or contention in psychiatric care), and transmural care [3, 4].

Quality and safety of the pharmaceutical care, intercultural mediation and recommendations for best practices are the three other components of quality of care managed at the federal level by the FPS Public Health.

The second key actor at the federal level is the NIHDI which supports various aspects of quality of care: training and licensing of health care professionals, guidelines and recommendations of best practices, evaluation of the quality of care, etc. The service of medical evaluation and control is responsible for the control of the health care activities covered by the compulsory health insurance (information, evaluation and sanctions in case of non-respect), advises for modifications of the nomenclature and indicators of follow-up regarding implementation of guidelines. In the service Health Care, the Directorate Research, Development and Quality Promotion also plays a role of monitoring of the quality of care inside the health insurance [5, 6].

Walloon region

Quality of care is a competence managed by the Agence pour une Vie de Qualité (AVIQ), a public administration of the Walloon region.

- Policies for quality of care: In 2012, Fadila Laanan, French Minister of Culture, Audio-visual, Health and Equal Opportunities commissioned the santhea hospital federation and the research center “Economie de la santé, gestion des institutions de soins et sciences infirmières – CREGISI” of the Free University of Brussels in order to develop a textbook supporting hospitals willing to engage in the accreditation process[7]. This research was, at first, aiming at targeting university hospitals but had a larger scope as it may interest all hospitals. In 2013, Eliane Tillieux, Walloon minister of Health, Social Action and Equal Opportunities, presented the Walloon plan for quality of hospital care. This plan suggested 6 main axes: evaluating the current norms, production of indicators, supporting accreditation process, ensuring the coherence between inspection/norms/indicators/accreditation, developing a benchmarking between health care institutions and reflecting about the public diffusion of results. In 2013, Regarding the agreement of hospitals, only the federal norms are applicable to the Walloon hospitals, under the authority of the General Operational Directorate of the local authorities, social action and health (DG05). The DG05 is member of the Walloon Movement for Quality. However, after

the 2014 elections, there was no follow-up of this proposal as the Ministry changed. To this day, there is no strategic plan for the Wallonia, similar to the one of the Flemish region.

- Platform for Continuous Improvement of Health Care and Safety of Patients: Since 2013, a concertation platform exists for Brussels and the Wallonia: the PAQS (Platform for Continuous Improvement of Health Care and Safety of Patients). The PAQS was created at the initiative of the hospital federations and gathers representatives of the sickness funds, hospital federations of Brussels and Wallonia and 4 French universities. Its statutes include the possibility for a formal representation of the public authorities. Public authorities of Brussels and Wallonia mandated, alongside with subventions, the PAQS to develop a network including all actors concerned with the quality of care, to provide a comprehensive offer of services to match the needs of the field and to promote the coherence of initiatives developed by actors already involved in quality and safety of care. Currently, the PAQS is selecting and testing a common set of indicators for hospitals in Brussels and Wallonia. Final outcomes are expected by end of 2017.
- Hospitals accreditation: similarly to Flanders, hospitals may voluntary engage in an accreditation process by an external agency.

Flanders

Since 2012 the Flemish government collaborates with organisations representing general hospitals, professional organisations, patient organisations, sickness funds and universities. This collaboration gave way to a three tiers approach:

- The Care Inspection Agency (Zorginspectie): is part of the department Wellbeing, Public Health and the Family (Departement Welzijn, Volksgezondheid en Gezin) of the Flemish government. The Care Inspection continuously monitors and improves quality of care in Flemish general hospitals in two ways[a]:
  - Compliance monitoring: this type applies to all Flemish hospitals and consists of unannounced inspection to make sure care meets predefined criteria, agreed upon by the sector.
  - System surveillance: the system behind the care provision is evaluated in those hospitals who are not accredited.
- The Flemish Indicator Project for Patients and Professionals (Vlaams Indicatorenproject voor Patiënten en Professionals, VIP²): The project came about as a collaboration between the Agency Care and Health of the Flemish Government (het Agentschap Zorg en Gezondheid), the Flemish Union of Chief Physicians (de Vlaamse Vereniging van Hoofdgeneesheren) and the Flemish network of care institutions 'Zorgnet-Icuro'[b]. VIP² measures the quality of care in most Flemish general hospitals on a voluntary basis. The hospitals determine themselves which indicators they register. If the hospital agrees, results are publicly accessible online[c]. Results can be used to guide initiates of quality improvement, benchmarking and informing patients.
- Hospital accreditation: an external audit organisation evaluates whether hospitals offer high quality and safe care. Hospitals are accredited for a limited number of years. Hospitals decide themselves whether they want to be accredited.

---

[a] Source: https://www.departementwvg.be/zorginspectie/algemene-ziekenhuizen

[b] Zorgnet-Icuro is a network grouping and representing care institutions in Flanders, more specifically, general hospitals, residential and ambulatory initiatives in mental health care, and organisations in elderly care.

[c] See the website http://www.zorgkwaliteit.be

Brussels

In Brussels, quality of care depends on the linguistic regimen of the health care institution. Consequently, quality of care is either managed by the Common Communitarian Commission (COCOM), either by IRIScare, the OIP for health, social care and family affairs. Agreement norms of the general hospitals are those of the federal authority.

- COCOM: Bi-communitarian hospitals are under the authority of the COCOM, which managed the agreement procedure. Regarding accreditation, the 2013 Declaration of Governmental Policy of the COCOM explicitly stated that hospitals in Brussels should be accredited and that the COCOM has to be associated to the reflexion process with the PAQS. However, the accreditation should be on a voluntary basis and, in 2014, no general bi-communitarian hospital was involved in such process [8]. In Brussels, there is an ongoing discussion between the public authorities and the PAQS regarding the formal attribution of a mandate to launch a quality strategy for the Brussels region.
- IRIScare: IRIScare is still under construction but should be equivalent in its competencies to the Walloon AVIQ.

Appendix 2.1.2. Development and selection of the indicators

In Flanders, indicators in the VIP² program are determined and refined by development groups. Groups are organised around six domains: care for mother and child, orthopaedics, cardiology, oncology, patient experiences and hospital indicators, and stroke. The development groups consist mainly of clinicians, quality coordinators and data specialists. One of the main challenges is to align these indicators with existing indicators collected for the accreditation process.

In Wallonia and Brussels, there is no additional quality indicators.

Several projects aiming at improving quality of care are currently ongoing. The Integreo Program, led by the FAITH consortium, aims at evaluating the Triple Aim Policy for the patients suffering from a chronic disease[9, 10]. In its research protocol, the FAITH consortium describes the selection, the development and the implementation of these quality indicators. They rely, among others, on the PROMS and PREMS indicators[d].

Appendix 2.1.3. Type of indicators and data collection

At national level, all hospitals should participate to the compulsory registrations requested by the FPS Public Health: RHM (Minimal Hospital Summary), FINHOSTA (Financial Hospital Statistics), indicators of the Federal Council for the Quality of Nursing Care (CFQAI) and indicators of hospital hygiene (Scientific Institute of Public Health).

In Flanders, besides the compulsory registration, data collection also includes clinical indicators, process indicators and outcomes indicators in the hospitals as described in the project VIP² (see above).

In Wallonia and in Brussels, there is no yet additional data collection for specific indicators.

[d] See, for example, the page 131 of the protocol presenting process indicators that may serve for a process evaluation.

Appendix 2.1.4. Quality control of data collection

In Flanders, to ensure the quality of the data collection, a Thrusted Third Party has been launched: this TTP checks the reliability and the validity of the provided data and ensures that those accessing the data respect the confidentiality and the privacy of information.

As the test of the indicators is still ongoing, there is not yet a specific mechanism for quality control of data collection in Wallonia and Brussels.

Appendix 2.1.5. Availability of the indicators

In Flanders, a maximum of transparency is pursued: indicators and inspection reports are publicly available online. Publication of the results is let at the discretion of the hospitals but they are advised to publish it. Indicators are available on the website of the Health & Care Agency[e].

Inspection reports related to agreement are not available to the public in Brussels and Wallonia. The question of availability was highlighted by the Tillieux report but no final decision has been taken yet.

Appendix 2.1.6. Patient participation

Patients are not directly involved in quality assessments, nor the development of indicators, but they are represented by patient organisations at least for quality assessments in Flemish general hospitals.

Although patient empowerment is one of the objectives of the Federation Wallonia-Brussels, there is no clear evidence that patients are associated to the quality assessment. The current project led by the PAQS did not involve patients although the PAQS actively collaborates with the league of the users of health services (LUSS).

[e] See the quality indicators here (in Flemish): http://www.zorg-en-gezondheid.be/kwaliteitsindicatorenziekenhuizen

Appendix 2.2. France

Appendix 2.2.1. Institutions monitoring the quality of health care

Since 2008, the HAS coordinates the national data collection on quality and safety indicators (IQSS) and, since 2016, and on nosocomial infections (IAS) in all healthcare facilities. IQSS are measuring tools that are applied to a health status, a care practice or an event, allowing a valid measuring of health care quality and its variations in space and time. The IQSS policy is a shared strategy between the HAS and the Ministry of Health. It aims at improving the practice and the quality of care at the level of health services; at planning health care policies at regional and national level; and at informing patients about the quality of care in health services through a website, including the results of the IQSS and the quality certification of the hospitals. Results also have to be displayed in hospitals. Each IQSS has a national objective of performance that is a minimal level of quality that all health care services should have. Moreover, the IQSS are included in the quality-based pay-for-performance system. Denial of collection also leads to the exclusion of the payment for quality.

Data collection of indicators is compulsory: it is part of a legal obligation and is required for accreditation of the hospitals.

Appendix 2.2.2. Selection and development of the indicators

Since 2004, quality management is under the authority of the HAS: the HAS develops the indicators, mostly based on the requests from the Ministry of Health and the priorities in health policy. Every year, the IQSS indicators are chosen by a steering committee, animated by the HAS and the DGOS. This steering committee includes the federations of health services, the delegates of managers and presidents of CME, the general directors of the ARS, the CNAMTS and representatives of the patients. Every year, a national decree fixes the list of compulsory IQSS and the conditions under which they should be made available to the public[11]. A legal framework also

delimitates some of the indicators such as the quality of the letter of discharge.

Indicators are supported by the recommendations of the HAS, international recommendations or by the law. Indicators need to be based on the literature, clinically relevant, feasible, relevant for the improvement of quality, metrological, and adjustable[12]. Most of the current process IQSS indicators are inherited from a previous project-COMPAQ[f]- in which researchers identified indicators that were feasible and realist to collect. Since 2013, the HAS develops the national IQSS.

Indicators are assessed and evaluated annually. Type 3 and type 4 indicators experience a rapid development.

Appendix 2.2.3. Type of indicators and data collection

The HAS actually produces and collects 4 types of IQSS based on different data collection methods. There are currently 79 indicators in France. Data collection of indicators is planned every 2 year to lighten the burden of data collection for institutions and to leave room for changes before next evaluation. The data collection mainly consists in a retrospective audit, based on a random selection of patient health records in the health services. Data are registered through an online secured platform managed by the ATIH. If necessary, specific questionnaire for the health institution or for the patient are launched. National database are the third source of information (e.g. PMSI or SNIIR-AM).

Type 1: Structural indicators

Structural indicators concern the quality of management of the human, material or financial resources aimed at supporting the health care processes. They are used to assess healthcare related infections management.

Type 2 Process indicators: IPAQSS

Process indicators concern the quality of the implementation of a health care activity related to the process of caring for the patients. They are based on the patient health record (PMSI). They are organized in two categories: transversal and specialty themes. Transversal themes concern the whole health care system (whatever the underlying condition is) while specialty themes focus on specific health conditions such stroke, haemodialysis, myocardial infarction, screening and prevention of post-partum bleeding, or obesity management in pre-surgery. IPAQSS are based on a sample of patients health records review. Eligible patients health records are counted by the HAS based on the PMSI to decide if the collection is mandatory or not (when there are few eligible patient records the collection can be done but it is not mandatory for the institution). For the data collection, the healthcare institutions perform a random selection of 60 to 80 health records of patients concerned by the health care activity under scrutiny. Health professionals (preferably (but not often) medical doctors) complete an online grid, based on guidelines.

Type 3: Outcomes indicators

Outcomes indicators aim at directly measuring the risks or benefits for the patient in terms of efficiency, satisfaction or safety at the end of a health care processes. They are based on the PMSI / on coded data. The HAS develops an algorithm to screen events codes in the PMSI. The HAS realizes the data analysis. These data are sent for benchmark and feedback to the institutions. Outliers are expected to check for their coding and, if confirmed,

[f] For more information, see the website of the COMPAQ project: http://*www.compaqhpst.fr/*

to analyse their practices through a retrospective review of the patient health records.

Example of indicators are the rate of deep vein thromboses and pulmonary embolisms after total hip prosthesis / total knee prosthesis, readmissions in the 3 days following a day surgery, number of converted day surgery.

Type 4: patient satisfaction

These indicators are collected through online questionnaire completed by the patient after discharge. The first one has been issued in December 2016. It assesses the patient satisfaction in medicine/surgery/obstetrics for all patients that stayed more than 2 days in the hospital. Indicators concern the global health care and service provision (catering, reception, discharge, etc.) and measure then the global satisfaction. Indicator related to day-surgery, with a dedicated questionnaire, is currently under development.

Appendix 2.2.4. Quality control of data collection

The quality of indicators 1 & 2 is controlled by the ARS, mostly of the free choice of the ARS. Around ten per cent of hospitals are visited for cross-check. In case of divergences, opinion of the ARS weight more than assessment by the institutions. In case of false/misleading declaration, the penalty is the exclusion of the HCO from the P4P program during the time the indicator is included in the model (basically 2 years) and the advertising on the public reporting site (see further) that this HCO has been controlled and the collection was found not valid.

Appendix 2.2.5. Availability of the indicators

Indicators 1-2-4 are made available to the public. Hospitals have to display their results through posters or their website. The website Scope Santé gathers the information based on these three indicators and on the French HCO accreditation. Patients are associated to the development of the website, may compare institutions and access additional information. However, as the indicators displayed are the same than for the pay-for-performance scheme, it appears that they are not enough meaningful for patients. A major difficulty is that a same indicator should respond to the needs of patients/ professionals/public authorities. For those interested, tools for data collection remain available, even when indicators are no longer collected.

Appendix 2.2.6. Patient participation

Patients are involved in both the stakeholder group and in the expert workgroup[g] that discuss the instrument developed.

Appendix 2.2.7. Incentives for indicators collection

Indicators types 1, 2 and 4 are included in the financial incentives of the P4P as a bonus (not included in the basic dotation). P4P were developed in acute services in 2016, and will be implemented in the SSR in 2017.

Some national indicators are also considered for the eligibility to the CAQES which is a contract between the ARS, the medical insurance and the HCO. If an HCO has a quality measured below a (very) low threshold, it is eligible to the contract. If an institution does not succeed in reaching the minimum expected, it faces financial sanctions as, 1% of financial products (perceived by the ARS or the national health insurance).

[g] To prevent conflicts of interests, experts are not representatives of scientific societies or hospital federation or linked to pharmaceutical industry for instance.

Appendix 2.3. Scotland

Appendix 2.3.1. Institutions monitoring the quality of health care

Health Improvement Scotland is the main national body in charge of the assessment of quality and safety and report on performance. It supports the clinical governance at national and local levels. It ensures 7 key missions:

- Supporting people to have a meaningful say in how services are designed, delivered and experienced.
- Providing independent quality assurance that gives people confidence in the quality of services and helps providers to improve.
- Supporting providers to redesign services so that people in Scotland are able to live longer, healthier lives at home or a homely setting.
- Supporting services to reduce harm, waste and unnecessary variation in practice and outcomes.
- Providing evidence and knowledge that enables people to get the best out of the services that they use and helps services to improve.
- Supporting the use of data and information, alongside bespoke support, to help services to improve.
- Supporting leaders to create the conditions where quality will flourish[h]

HIS is also *an authority on the development of evidence-based advice, guidance and standards* [i]. HIS provides public assurance about the quality and safety of healthcare through the scrutiny of NHS hospitals and services, and independent healthcare services.

Other key organizations concerned with quality of care are Audit Scotland, The Social Care and Social Work Improvement Scotland, the Mental Welfare Commission for Scotland, the NHS Education for Scotland and 9 professional regulators [13, 14].

Appendix 2.3.2. Ongoing reform of the quality of care

Scotland has a longstanding reputation of pioneer in the field of quality of care and this current reform reinforces this culture of excellence. Quality objectives are part of a larger strategy – the National Performance Framework that aims at focusing "government and public services on creating a more successful country, with opportunities for all of Scotland to flourish, through increasing sustainable economic growth" [15]. The National Performance Framework is guided by 10 principles: Openness and transparency, Accountability and responsibility, Objectivity, Independent assessment, Dynamic site: real data, real time, Accessibility 24/7, Simplicity and clarity, Credibility to Parliament and the wider public, Shared responsibility for outcomes-based performance, Sharpening focus - driving improvement. Overall performance is evaluated by an independent group, the Scotland Performs Technical Assessment Group.

The ongoing reform to reviewing the quality of care is supported by the 2020 vision for health and social care and the Quality Strategy Scotland [16]. In 2015, a Design Panel was commissioned to set out the principles for the new approach to quality of care. This new approach has two major perspectives:

- Patients and service users can be clear as to what they can expect from service providers and that providers know what is expected from them
- The future approach involves a more consistent and flexible approach to reviewing the quality of care through a combination of comprehensive reviews of healthcare providers, service-specific reviews, where required, and local and national thematic reviews across similar services in Scotland [14]

All NHS Boards have to develop their Local Delivery Plans in order to implement the priorities of the Scottish Government for the NHS boards that were issued in the Health and Social Care Delivery Plan of December 2016 [17, 18]. This should enhance the Triple Aim policies: better care, better health, better value. The LDP should present the process and steps of the regional

[h] Information retrieved from: http://www.healthcareimprovementscotland.org/about_us.aspx

[i] Information retrieved from: http://www.healthcareimprovementscotland.org/evidence.aspx

planning and delivery of the NHS Boards. In spring 2017, the Scottish government will publish the national review of target and indicators for health and social care.

Appendix 2.3.3. Development and selection of the indicators

In the new approach of quality of care, outcomes have been based on a selection of relevant sources such as the *Patient Rights (Scotland) Act 2011, the National Health and Wellbeing Outcomes Framework, The Scottish Health Council Stronger Voice work and Participation Standard, the Care Inspectorate SHANARRI wellbeing indicators, and NHS England Patient Reported Outcomes Measures* [14]. User's involvement being a major concern of the Scottish Government and of the NHS Scotland, patients and service users are regularly involved in the development of the quality approach.

Appendix 2.3.4. Type of indicators and data collection

Currently, HIS perform three distinct types of inspection: announced inspection, unannounced inspection and (un)announced follow-up inspection. They inspect both NHS services and independent healthcare services (e.g. in the rehabilitation sector). Specific attention is paid to care for older people in acute hospitals[j].

The suggested reform to scrutiny proposes four different reviews with different levels of implementation as illustrated by the Table 1.

[j] See here for examples of inspection reports: http://www.healthcareimprovementscotland.org/system_pages/published_resources_search.aspx?q=&f=5:308

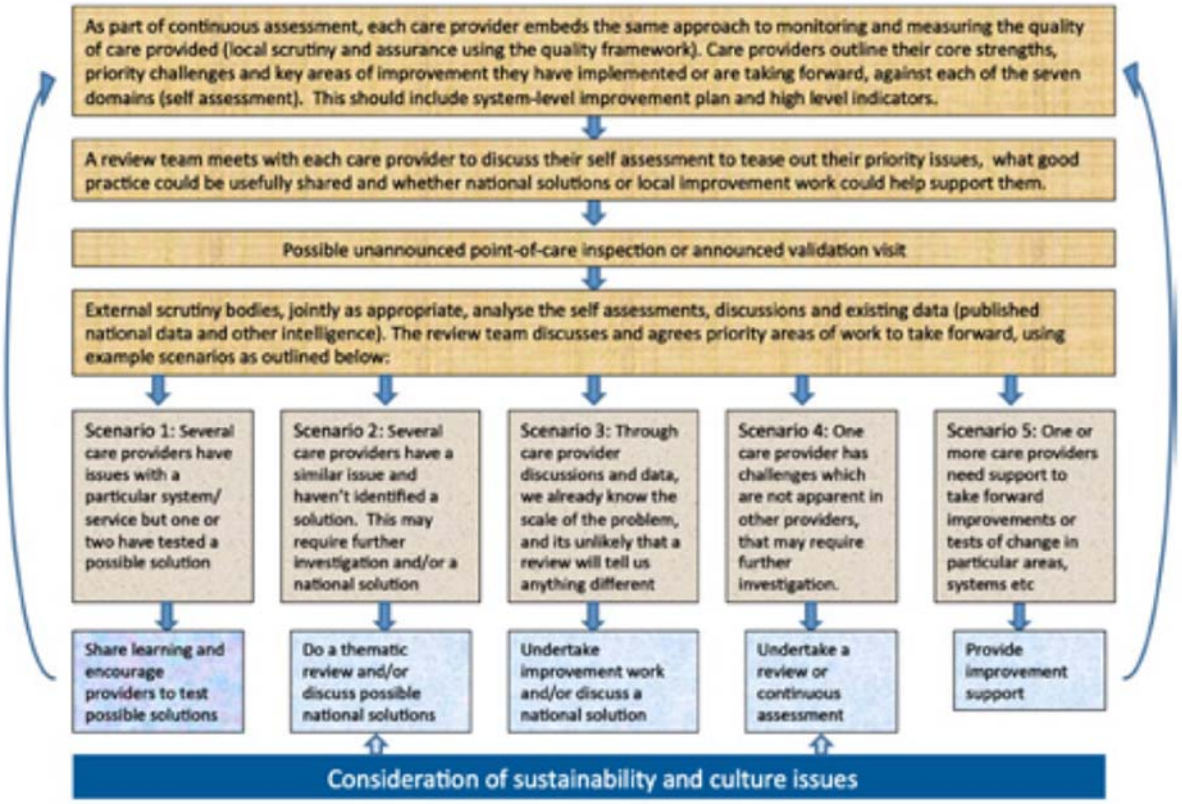
Table 1 – Proposed approach to scrutiny of Health Improvement Scotland

Dimension	Level	Description	Essential elements	Frequency
Thematic Quality of Care	Macro	These would be thematic reviews of services across the range of providers delivering those services, or across providers in a locality such as reviews of pre-hospital care, vascular surgery, trauma, child and adolescent mental health services, clinical governance. The thematic reviews would be supported by the new quality framework, and relevant indicators and standards.	Undertaken by multidisciplinary teams of experts, including public partners. Structured around the quality framework with appropriate other evidence/standards/ indicators. Focused, in the first instance, on major national service issues which may include a regional dimension. Includes a service sustainability component.	Up to two major themed reviews each year
Organisational Quality of Care Reviews	Macro Meso	These would be reviews to assess the quality and sustainability of care at an organizational provider level as part of an ongoing or triggered approach. These reviews will also be underpinned by the new quality framework	Organisational wide reviews which may encompass NHS board or elements thereof or elements of health and social care partnership services. Undertaken by multidisciplinary teams of experts, including public partners. Structured around the quality framework, with appropriate reference to evidence/indicators/ standards. Draws on appropriate intelligence, interviews and surveys. Includes appropriate point-of-care inspections.	Variable and ongoing
Service Level Reviews	Meso	These would be reviews of specific services, encompassing a range of dimensions set out in the quality framework, including sustainability.	Undertaken by multidisciplinary teams of experts, including public partners. Structured around the quality framework with appropriate other evidence/standards/indicators. Examining a particular service within an NHS board or provided by a health and social	Variable and ongoing
Point of care Reviews or Inspections	Micro	These would be reviews and inspections based on intelligence received. They would be assessed against relevant standards and the new quality framework. They would cover a range of topics including, but not limited to, the care of older people across all healthcare settings, healthcare associated infection (HAI), and inpatient mental healthcare.	Undertaken by inspectors and public partners with appropriate clinical expertise as appropriate. Structured around the quality framework with appropriate other evidence/standards/ indicators. May be standalone such as for the safety and cleanliness of hospitals (Healthcare Environment Inspectorate) or increasingly as part of broader reviews as set out above.	regular

Source: Adapted from Health Improvement Scotland, 2015, p23-24.

Figure 1 presents the application of the new approach to reviewing quality.

Figure 1 – Application of the new approach to reviewing quality based of the guidance of Health Improvement Scotland



Source: Health Improvement Scotland, 2015

Appendix 2.3.5. Quality control of data collection

As displayed in the figure below, the new approach allows a control of the data collection by independent bodies such as the Health Improvement Scotland and Care Inspector.

Appendix 2.3.6. Availability of the indicators

Transparency is one of the leading principles of the quality framework. All results related to quality of care are available to the public. Transparency also applies to the selection of tools, methodology or other support.

Appendix 2.3.7. Patient participation

The Design Panel launched a consultation document in summer 2015 with guidance questions regarding the proposed framework to reviewing quality. The Design Panel invited service providers, patients and service users to react over this document. Regional discussion groups were held to collect additional perspectives. These groups were open to everybody.

Appendix 2.3.8. Incentives for indicators collection

The NHS Scotland is characterized by a high degree of accountability. Quality reviewing is part of the duty of service providers. Health Improvement Scotland and the other official bodies have the possibility of closing services whenever appropriate.

Appendix 2.4. The Netherlands

Appendix 2.4.1. Institutions monitoring the quality of health care

Instruments for quality assurance in healthcare are provided by the Quality of Health Facilities Act (Kwaliteitswet ZorgInstellingen KZi), the Individual Health Care Professions Act (Wet Beroepen in de Individuele Gezondheidszorg , BIG: licensing of individual health care professionals) and the Medical Treatment Agreement Act (Wet Geneeskundige Behandelovereenkomst, WGBO) [19]. For care that is regulated by the Health Insurance Act (mainly curative care), managed competition applies. Health insurers and providers negotiate on price and quality of care. The Dutch Health Care Authority oversees whether the competition is fair and establishes the care products for which prices can be negotiated. For care for which negotiation is not feasible, such as emergency care (not plannable) or organ transplantation (too few providers), the Dutch Health Care Authority establishes maximum prices [19].

The Dutch Health Care Inspectorate

The Dutch Health Care Inspectorate (Inspectie voor de Gezondheidszorg) is responsible for monitoring quality and safety. In addition, the Dutch Health Care Institute (Nederlands zorginstituut) promotes quality of health care and audits the basic care package. Both institutions oblige health care institutions to register a set of quality indicators. In the Netherlands quality registration is part of the DBC, hence remunerated by the insurer. The Dutch Health Care Inspectorate (Inspectie voor de gezondheidszorg (IGZ)) plays an important role in maintaining quality of care. The Inspectorate enforces statutory regulations on public health; investigates complaints and irregularities in healthcare; and can take relevant measures. The Inspectorate uses quality indicators to monitor the quality of care; if necessary site visits or investigations can be made [19]. The Dutch Health Care Inspectorate monitors the quality and safety of health care in two ways: risk assessment and calamity surveillance. The former refers to the proactive identification of risks, while the latter is a more reactive approach to reported incidents.

Especially the former could serve as an example of good practice or at least a source of inspiration to our project.

To learn about potential risks the Dutch Health Care Inspectorate collects and analyses information about provided health care. The information is shaped by means of a set of indicators covering all medical disciplines working in hospital settings. Ambulatory care is not included.

Indicators are measurable care properties providing information on the quality of care, for example the occurrence of pressure ulcers. Thirty four scientific organisations are involved to develop indicators for their specialism. The indicators should reflect the state of the art within their field. A limited set of indicators enables the Inspectorate to estimate whether health care institutions are competent to follow developments in medical

specialisms. The health care institutions know in advance which information they should register and deliver yearly at the Inspectorate. The Inspectorate analyses the data, correlates the data with other sources, validates the data by means of unannounced visits to health care institutions, compares health care institutions, and makes the information publicly available. Health care institutions with outlying scores are solicited to explain their outlying position. The focus is on what health care institutions learn about their own functioning, rather than on the fact that there are outlying. The Inspectorate especially wants to survey the adaptability and learning capacity of health care institutions. Once high quality thresholders are reached on a specific indicator and the Inspectorate is confident that the high quality measures will persist, the indicator is replaced by new one, again nominated by scientific organisations.

The Dutch Health Care Institute

A similar quality assessment is set up by the Dutch Health Care Institute (Zorginstituut Nederland). They developed a set of indicators per pathology. The indicators are nominated by patient organisations, insurers and health care providers. The data is also made publicly available.

BIG registration

Professional self-regulation is an important instrument in policies on quality assurance, for instance on the development of professional guidelines [20]. In addition, the BIG registration is obligatory for individual healthcare providers and, since 2012, five-yearly re-registration is obligatory. In 2015 more than 354 000 professionals were included in the register, more than half of them nurses. The BIG Act aims to safeguard the quality of the practice of professions and to protect patients from incompetent practitioners. BIG stipulates that professionals should provide “responsible care”, and identifies “reserved operations” which can only be performed by a recognized professional. Based on the BIG Act, healthcare providers can be subject to measures from disciplinary committees or the Health Care Inspectorate, such as fines, reprimands, suspension and, ultimately, removal from the register [19].

Appendix 2.4.2. Selection and development of the indicators

Mechanisms to ensure quality of care provided by individual professionals include reregistration/recertification of specialists based on compulsory continuous medical education; regular on-site peer assessments by professional bodies; and profession-owned clinical guidelines, indicators, and peer review. The main methods used to ensure quality in institutions include accreditation and certification; compulsory and voluntary performance assessment based on indicators; and national quality improvement programs based on the breakthrough method (known as Breakthrough Series, proposed by Berwick D. to implement evidence-based knowledge).

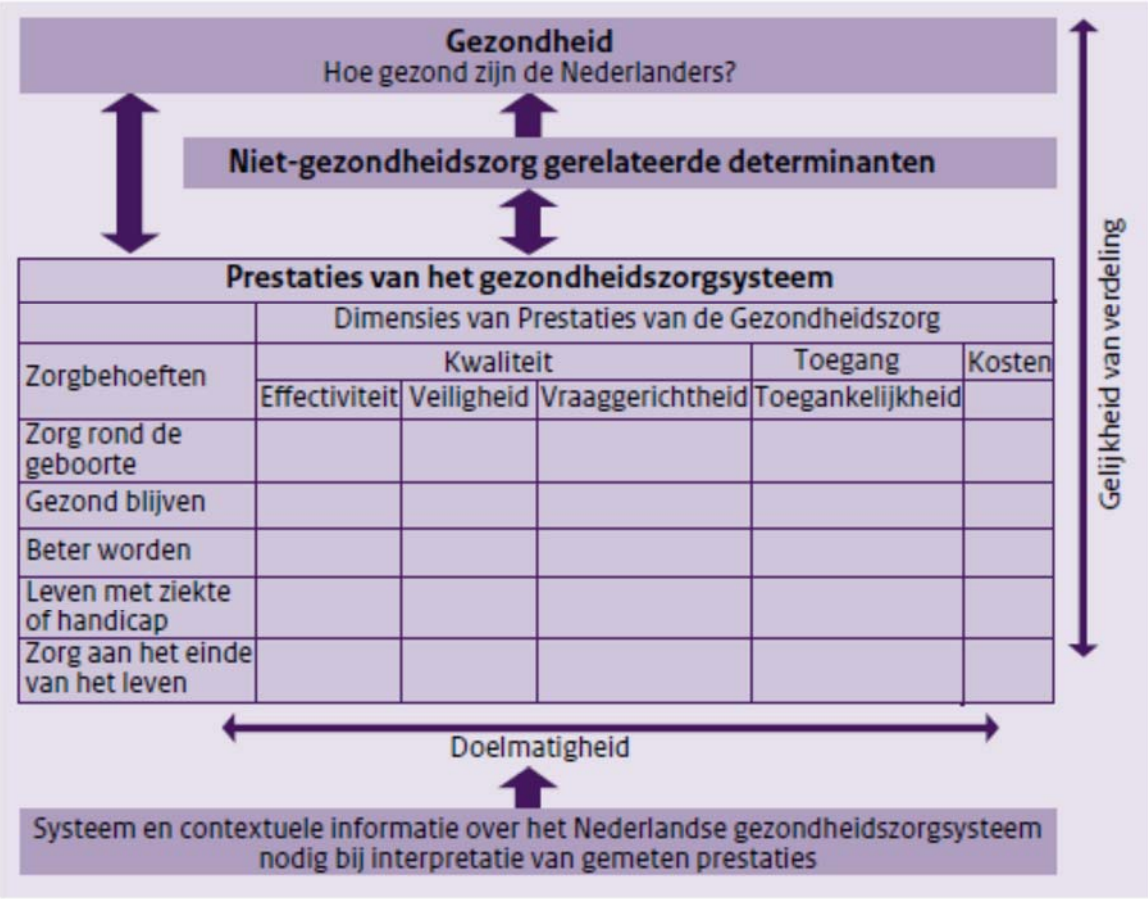
Patient experiences are also systematically assessed and, since 2007, a national centre has been working with validated measurement instruments in an approach comparable to that of the Consumer Assessment of Healthcare Providers and Systems in the United States.

Appendix 2.4.3. Type of indicators and data collection

Numerous indicators have been developed for quality monitoring. Figure 2, retrieved from the Dutch performance review, present the conceptual framework used for such monitoring. Indicators have been developed for the dimensions displayed in the framework. In 2014, the performance assessment had a special focus on the transparency of quality.

For the data collection, see above.

Figure 2 – Conceptual framework for the performance, including quality, of the Dutch healthcare system



Source: RIVM, 2014

Appendix 2.4.4. Quality control of data collection

See above

Appendix 2.4.5. Availability of the indicators

The national centre on patient experiences generates publicly available information for consumer choice on waiting lists, patient satisfaction, and a few quality indicators. The Dutch Patient organization launched a website for public reporting of quality of care and provider performance [21].

Appendix 2.4.6. Patient participation

Since 2005, patient participation and patient choice are key components of the Dutch healthcare system. A governmental website offers all information to support informed choice.

Health care organisations have the obligation of having a representative patient council that is likely to advice the organisation regarding patient needs and rights. Patients are also represented in the purchasing decisions by health insurers [19].

However, patients seem not involved in the quality assessment of the health care system.

Appendix 2.4.7. Incentives for indicators collection

See above

APPENDIX 3. THE ORGANISATION OF CARE AND FINANCING OF FOUR EXAMPLES OF HEALTH CONDITIONS AND DISEASES

1. INTRODUCTION

According to the WHO, "*75% of the total number of years lived with disability in the world are linked to health conditions for which rehabilitation is beneficial",* supporting the need for efficient and quality rehabilitation care [22]. Since 2005, the need for rehabilitation care has increase by 23% and the curve is still rising due to the epidemiologic transition and the aging of population. Alongside the obvious needs in rehabilitation after a stroke, a traumatic event or a neurologic disease, additional pathologies have seen their morbidity profiles changing and also contribute to the needs in rehabilitation care such as the HIV/AIDS or other communicable diseases. However, despite the increasing needs in rehabilitation care, even in high income countries, there is an underuse of rehabilitation care. To this aim, the WHO recommends the development of a comprehensive strategy to "*strengthen rehabilitation and address global unmet needs"* [22]. This supplement presents the full comparison of the organisation of rehabilitation care three high-income countries, namely France, Scotland and the Netherlands

2. FRANCE

2.1. Description of the French health care system

2.1.1. Governance and organisation of the health care system

The French health care system is the combination of a Bismarckian approach at the structural level, mixed with a Beveridge approach at the financial level. The HCS pursues universality and solidarity. Although the patient has the freedom to choose a GP and there is no compulsory gatekeeping system, the public health authorities are pushing towards a "médecine de parcours", to increase the efficiency of the overall system, to reduce the fragmentation and to provide health care in the closest setting of the patient. The "médecine de parcours" also called "parcours de soins coordonné" implies that the patient chooses a treating GP that will coordinate his/her medical care, centralises the medical record, refers the patient to other (specialist) health professionals, establishes the care protocol in case of chronic diseases (in collaboration with other professionals) and delivers a personalised prevention based on patient characteristics [23].

Three main actors share governance responsibilities: the State (Ministry of Health), the Statutory Health Insurance (SHI) and the local communities (regions). Although from Bismarckian inspiration, the French SHI has no management responsibilities as the state took over the financial and operational management of the SHI[24]. The SHI includes three main schemes: the general SHI scheme organised by the CNAMTS, the agricultural SHI fund[k] and SHI scheme for self-employed[l]. Additional schemes exist but represent a minor part of the whole SHI [24]. Funding of the Statutory Health Insurance is constituted by payroll contributions and earmarked taxes[m] on all sources of income, the latter becoming the most important contribution to the SHI [24]. As a result, the French SHI ensures a nearly universal coverage: in 2013, almost 99.9% of the population was

[k] Mutualité Sociale Agricole

[l] Régime social des Indépendants

[m] An earmarked tax is a tax whose revenues (by law) are reserved solely for a specific group or usage.

covered by the SHI through the universal health insurance coverage CMU, including an additional coverage for those with a low income, the CMU-C.

Since 2010, the health care competencies are partly deconcentrated to the regional authorities through the Agences Régionales de Santé (ARS). The ARS are public and autonomous institutions under the authority of the ministries of public health, social security, elders and handicapped persons. The ARS have been created by the 2009 Law on Hospital, Health, Patients and Territory[n]. The 17 ARS ensure the coordination of prevention, health care and patient support to prepare the development of the "parcours de soins". The ARS have to implement the national policies but have the necessary autonomy to adapt the national health plans and policies to the regional specificities in terms of demography, epidemiology and geography. They pursue two main objectives: the management of public health (including health promotion) and the regulation of the health care delivery. This is achieved through the regional health care programmes (PRS), declined in prevention programmes (PRAPS), health organisation programmes of inpatient and outpatient care (SROS), and health and social programmes for elders, disabled and indigent persons (SROMS). Regional programmes are elaborated by the ARS in collaboration with the regional health actors. Each ARS has a local implementation, at the departmental level, to ensure the territorial proximity. The 2015 Territorial Reform[o] and the 2016 Law on the modernisation of the HCS[p] reinforces the role of the ARS. At the local level, the ARS coordinate the organization of the health care professionals, the hospitals and all institutions related to health and social care.

Three categories compose the health and social sector:

- Outpatient care (called "*structures de ville*"), including both self-employed and salaried healthcare professionals
- Hospital care: private clinics, public hospitals and private health centers with a collective interest (e.g. reference center for cancer)
- Health and social institutions: residential services for elders, disabled and indigent persons

2.1.2. Chronic diseases

In 2007, the Ministry of Health issued a national plan on improving the quality of life of patients with a chronic condition. Emerging from a collaboration between health care professionals, patient associations and institutions (e.g. insurance), this national plan for the period 2007-2011 was articulated around 4 objectives:

- Supporting each patient to improve his/her self-management
- Enlarging the scope of medical practice towards prevention
- Improving the daily activities of the patients
- Improving the understanding of the impact of chronic diseases on quality of life.

An interim report in 2009 presented the first evaluation of the 4 domains, where the degree of achievement of the 15 initial measures was used as a progress indicator.

In 2013, the High Council for Public Health published the final evaluation of the plan. The first positive point was a strong, participative and dynamic governance, highlighting the integration of health, medical and social aspects of chronic diseases as a strength. However, as no logical model

[n] Loi 2009-378 du 21 juillet 2009 portant réforme de l'hôpital et relative aux patients, à la santé et aux territoires

[o] Loi du 7 août 2015 portant sur la Nouvelle Organisation Territoriale de la République (NOTRe)

[p] Loi du 26 janvier 2016 de modernisation de notre système de santé

was used to build the action plan and to link actions to the improvement of quality of life, it prevented an in-depth and thoughtful assessment of its achievement. Efforts have been made regarding the improvement of patient education, patient participation remains therefore poorly developed. To support the implementation of patient education and prevention, the national action plan recommended the creation of new profiles of health care professionals, specialized in prevention but this is scarcely implemented. The High Council also highlighted the threats posed by the reform of the HCS that was launched after the implementation of the plan. Further actions should support the coordination between the different actors. To the best of our knowledge there is no specific ongoing plan regarding chronic diseases.

The long-term diseases (ALD) is one of the two approaches in chronic disease management in the SHI. The SHI has established a list of 30 (chronic) affections: any patient suffering from one (or more) diseases from this list will have all the expenses related to the treatment fully covered by the SHI. Patients may also have an exemption of co-payment. From January 1, 2017, the third payer is compulsory for all patients with ALD.

Three categories of ALD exist: ALD 30 (ALD on list), ALD 31 (ALD out list) and ALD 32 (polypathologies). The ALD 30 includes 30 health conditions leading to an exemption of co-payment, established by decree and updated on January 2011 [25]. The 2011 list includes the following ALD:

- Disabling stroke
- Medullary insufficiency and other chronic cytopenias
- Chronic arteriopathies with ischemic manifestations
- Complicated Bilharziasis
- Severe heart failure, severe rhythm disorders, severe valvular heart disease, severe congenital cardiopathy
- Active chronic diseases of the liver and cirrhosis
- Primary severe immunodeficiency requiring long-term treatment, infection with human immunodeficiency virus (HIV)
- Type 1 and type 2 diabetes mellitus
- Severe forms of neurological and muscular affections (including myopathy), severe epilepsy
- Severe chronic constitutional or acquired haemoglobinopathy or hemolysis
- Haemophilia and severe constitutional haemostatic diseases
- Coronary disease
- Severe chronic respiratory insufficiency
- Alzheimer's disease and other dementias
- Parkinson's disease
- Hereditary metabolic diseases requiring long-term specialised treatment
- Mucoviscidoses
- Severe chronic nephropathy and primitive nephrotic syndrome
- Paraplegia
- Polyarteritis nodosa, acute disseminated erythematous systemic lupus, generalised progressive scleroderma
- Severe evolutive rheumatoid polyarthritis
- Long-term psychiatric affections
- Ulcerative colitis and evolutive Crohn's disease
- Multiple sclerosis
- Evolutive structural scoliosis (the angle of which is equal or over 25 degrees) until rachidian maturation
- Severe ankylosing spondylarthrosis
- Organ transplant sequelae
- Active tuberculosis, leprosy

- Malignant tumour, malignant affection of the lymphatic or hematopoietic tissue

The ALD list is regularly updated, e.g. high blood pressure was suppressed of the ALD list in 2011[26]. The ALD 31 concerns patients suffering from a severe form of a disease or a scalable or disabling form of a severe disease, not mentioned on the ALD 30 list. The planned treatment should last more than 6 months and/or include an expensive treatment [27]. The ALD 32 concerns patients suffering from several chronic diseases, leading to a disabling state and requiring continuous health care for more than 6 months [27].

The article L.324-1 of the Social Security Code defines ALD that are not subjected to the exoneration of the user fees. It concerns affections engendering a (temporary) work interruption or continuous care for at least 6 months but without exemption of the user fees. If granted, the patient benefits from compensations for transportation costs related to the ALD and transportation/hotel costs related to thermal cures.

If a patient suffers from an ALD 30/31/32, the GP is in charge of establishing a care protocol in collaboration with the medical specialist(s). The care protocol should be based on the guidelines edited by the Haute Autorité de Santé (HAS). Based on the care protocol, the SHI will cover all the fees related to the ALD. The medical specialist may introduce the care protocol but it has to be confirmed by the GP within the following 6 months [28].

2.1.3. Rehabilitation and intermediate care

After the acute phase, patients either return home, either go to a rehabilitation centre (Soins de Suite et de Réadaptation SSR). Direct transfer from hospital to home is recommended to patients that did not experience postoperative complications or patients with extensive social support that is patients with a strong informal support network. The SSR's main objective is to prevent or reduce the functional, physical, cognitive or social consequences of the patient's disability and to promote their rehabilitation and the reintegration within society. An inpatient SSR may be a specialised unit or a general rehabilitation unit. Continuity of rehabilitation will be ensured by an outpatient physiotherapist and coordinated by the GP.

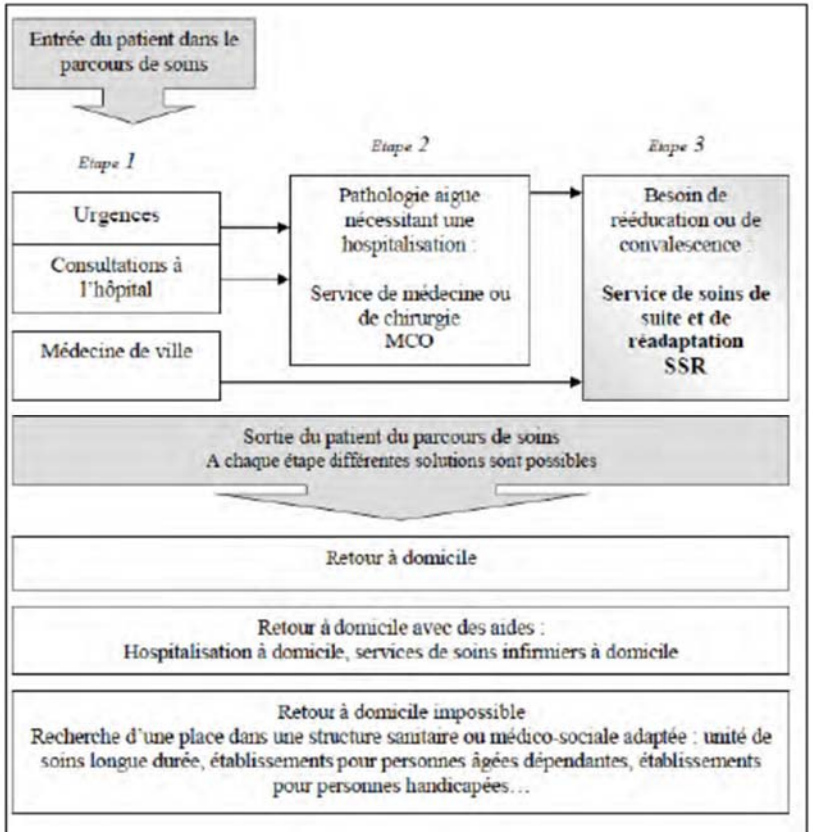
In 2016, France had 1 700 structures of SSR, among which one hundred were specifically for children and youths. On average, an SSR has 69 beds.

In 2008, the SSR underwent a major organizational and financial reform. The SSR should offer polyvalent services. Activities should be organized around 9 specialized activities: locomotor, nervous, cardiovascular, respiratory, digestive, metabolic and endocrine, oncology and haematology, severely burned patients, addictions and poly pathologies. At the local level, the ARS plan and optimise the organisation of SSR but also support the SSR in developing specific national plans (e.g. stroke national plan) and care pathways for chronic patients. Recently, efforts have been done to improve the coordination between the medical social care, the health care and the development of alternative rehabilitation facilities (e.g. day hospitalization, HAD and mobile rehabilitation teams). However, despite the expansion of the capacity of SSR services, some regions are still lacking access to such services.

The SSR sector is currently underfunded [29]. The expected reform should result in a better integration of the lump sum system in the funding scheme. The lump sum system will include 4 components, the major component being the activity of the SSR. The 3 additional components include the specialized technical equipment, costly treatments and the MIGAC/MERRI. Moreover, the SSR will be included in the national program of financial incentives to quality improvement. This pay for performance system is currently deployed in hospitals and clinics and will be extended to SSR in 2018. The HAS has already developed quality indicators and indicators for specific conditions for SSR (e.g. health care of stroke patients).

Standards amenities are covered by the SHI while additional services – e.g. private room- are covered by the VHI of the patients (if they have one).

Figure 3 – Place of the SSR in care pathways of the patients



Source : Rapport de la cour des comptes, 2012, p 344

2.1.4. Quality and safety monitoring in the health care system

Since 2008, the HAS coordinates the national data collection on quality and safety indicators (IQSS) and on nosocomial infections (IAS). IQQS are measuring tools that be applied to a health status, a care practice or an event, allowing a valid measuring of health care quality and its variations in space and time. The IQSS aim at improving the practice and the quality of care at the level of health services; at planning health care policies at regional and national level[q]; and at informing patients about the quality of care in health services through a website, including the results of the IQSS and the quality certification of the hospitals[r]. Each IQSS has a national objective of performance that is a minimal level of quality that all health care services should have. Moreover, the IQSS are included in the quality-based pay-for-performance system.

Three distinct types of indicators exist: structural indicators (quality of management of the human, material or financial resources aimed at supporting the health care processes); process indicators (quality of the implementation of a health care activity related to the process of caring for the patients); and outcomes indicators (direct measure of the risks or benefits for the patient in terms of efficiency, satisfaction or safety at the end of a health care processes). Indicators need to be based on the literature, clinically relevant, feasible, relevant for the improvement of quality, metrological, and adjustable [12]. There are currently 79 indicators, organised in two sets: transversal themes and IQSS and specialty themes and IQSS. Transversal themes and IQSS concern the whole health care system while specialty themes focus on specific health conditions such stroke, haemodialysis, myocardial infarction, screening and prevention of post-partum bleeding, or obesity management in pre-surgery.

Every year, the IQSS indicators are chosen by a steering committee, animated by the HAS and the DGOS. This steering committee includes the federations of health services, the delegates of managers and presidents of CME, the general directors of the ARS, the CNAMTS and representatives of the patients. Every year, a national decree fixes the list of compulsory IQSS

[q] They are included in the CPOM: long-term contracts of means and objectives.

[r] See the website of Scope Santé : http://www.scopesante.fr/#/

and the conditions under which they should be made available to the public [11, 30].

The data collection mainly consists in a retrospective audit, based on a random selection of patient health records in the health services. Data are registered through an online secured platform managed by the ATIH. If necessary, specific questionnaire for the health institution or for the patient are launched. National database are the third source of information (e.g. PMSI or SNIIRAM).

In 2016, the IQSS for the patient health record in rehabilitation services have been collected for the fifth time. Among the 7 IQSS, 4 are made available to the public. The 7 IQSS are: management of the health record for the patient, delay for the sending of the discharge letter, screening for nutrition problems (including severity levels 1-2-3), traceability of pain assessment and traceability of the risk assessment of bedsores. The first IQSS "Patient health record" includes: contact data of a medical practitioner chosen by the patient, medical information related to admission, medical exam at admission, assessment of autonomy, psychological evaluation, therapeutic project, participation of the patient to the therapeutic project or consent to the therapeutic project, at least one interdisciplinary concertation, drugs prescriptions during stay, discharge treatment, discharge letter, and organisation of the health record. A completion guide supports the quality of the data collection by the clinicians.

2.2. Diabetes

2.2.1. Supporting policies and governance

Diabetes was previously included in the plan 2007-2011 on chronic diseases and quality of life but there is currently no more specific plan on chronic diseases and/or diabetes. Prevention of diabetes is part of a larger national health plan: "*programme national nutrition santé*" but, to our knowledge, no specific national health policy focuses on diabetes [31].

2.2.2. Organization and funding of health care

Diabetes mellitus type 1 and diabetes mellitus type 2 are both included in the ADL list: all diabetic patients have all the expenses related to the treatment of the diabetes fully covered by the SHI. A diabetic patient is defined as one having a least twice a fasting glucose level equals or over 7mmol/L in venous plasma [32]. To benefit from the ALD exemption, the patient should be registered with a GP, in charge of establishing a care protocol, in collaboration with the medical specialist(s). If the patient does not have a regular GP, the medical specialist may introduce the care protocol but it has to be confirmed by the GP within the 6 months, forcing thus the patient to register with a GP[s]. The exoneration is granted for a 5-years period, renewable. SHI coverage is deemed to offer an adequate coverage of the financial consequences of diabetes [33].

[s] Registration is not compulsory but leads to a reimbursement rate of 70% for the beneficiaries of the general SHI and 100% for those benefiting from an exemption of the user fee. If not, the patient gets only 40% of reimbursement.

2.2.3. Care pathways

The Haute Autorité de Santé (HAS) regularly publish and update guidelines regarding diagnosis, treatment and follow-up of diabetic patients. These guidelines should be used by the GP or the specialist to elaborate the personalized and individualized care protocol [34]. The HAS also establishes the list of acts and treatments covered by the SHI, including severity thresholds for additional treatments and specialist acts [32].

In 2014, the HAS elaborated specific guidelines for a typical care pathway of T2DM patients, focusing on general practice and on inter professional collaboration [35]. It gives the principles and conditions of care coordination and cooperation between the different health care providers. At each step of the care pathway, the guidelines clarify the roles and responsibilities of health care professionals, give indications regarding the clinical investigations or drug prescription, identify existing assessment tools that should be used (e.g. identification of frailty risk for elders) and the treatment options that should be offered. Specific attention is devoted to vulnerable groups such as persons living in precarious socioeconomic conditions, high cardiovascular risk and gestational diabetes [36]. The local organization of the care pathways should be managed by the ARS and the providers.

This organization by programs therefore impedes the focus on the specific needs of patients and prevents them from participating in care plans. Patient education in primary care setting remains insufficient because of the lack of an adequate funding system for the health care professionals [37]. This report concludes by the need of developing and funding therapeutic education delivered by pedagogic and inter professional teams outside hospital settings [37].

2.2.4. Health networks[t]

Health networks have been developed to cope with the lack of continuity and coordination between the different actors. The 2002 Patient's Rights and Quality Care Acts formalised the organisation of the health networks. These networks, which are not specific to diabetes, have for common objectives the improvement of the coordination of severe/chronic conditions and/or the improvement of the management of vulnerable groups. The HAS established agreement and evaluation criteria of the health networks. A major asset of these networks has been the inclusion of dieticians and nurses.

There is a diversity of networks, data from 2006 estimating around 450 networks for France. In 2006, 69 networks were specifically focusing on diabetic patients. All these diabetes networks are coordinated by the National Association of Coordination of Diabetes Networks. Each network proposes a range of services and activities to the patients, health professionals and relatives. For example, the Diabetes Network RevesDiab proposes the following activities:

- Coordination of the care pathway of the patient: assessment and identification of patient needs, elaboration of personalised health plans, coordination and follow-up of the PPS with the patients and the relevant actors, offering a personalised follow-up in collaboration with the different partners (hospitals, GP, primary care professionals), facilitation of the access to support care (cardiology, patient education, nutrition) and prevention of the diabetes related complications
- Support of the GP in partnership with key actors to develop a PPS and coordinate the care: collaboration to cope with complex situations, elaboration of protocol, interdisciplinary concertation, exchanges of practices and training

[t] At the time of the research, the official website was not accessible and the contact person did not respond to email contacts: http://www.ancred.fr/

2.2.5. Therapeutic education[u]

Patients often access the network through their GP, or may access it directly. Activities and services offered by the network are free. Health care professionals have to comply with guidelines and protocols to take care of the patients.

2.2.6. SOPHIA program for improving patient support

Alongside with the ALD system, the SOPHIA project offers additional support for diabetic patients. SOPHIA is funded by the CNAMTS. Sophia is a differentiated support program for patients suffering from long-term affections. It was first developed in 2007 for diabetic patients (T1DM and T2DM) and is now also accessible to asthmatic patients. To be included in the program, the patient should be beneficiary of an ALD exemption, be aged of 18 and over and use insulin or other antidiabetic drugs for at least one year [38].

The program proposes a wide range of advices and patient-tailored information, specific to the patient situation, to complement the recommendations of the doctor. The objective of the program are the improvement of the overall care for diabetic patients, the improvement of the health status and quality of life and an improved management of health care costs [39].

2.2.7. ASALEE protocol in first line of care

The ASALEE protocol aims at supporting a team for the care management of chronic conditions, including for type 2 diabetes. It supports the development of a partnership between general practitioners and nurses for the follow-up of patients in first line of care, as established by the Article 51 on the cooperation protocols [40]. ASALEE is funded by the College of the Financers at the level of the ministry of health.

Before entering the program, health care professionals should join the non-profit association ASALEE that will organise the training and the cooperation. The nurse takes over the therapeutic education of the patient and a defined list of medical acts is devoted to the nurse. The patient is included in the protocol after initial screening by the GP. The nurse organises a first screening consultation, writes a synthesis to be included in a shared medical file and in the centralised ASALEE database. The nurse then organises the follow-up of the patient, including clinical examinations (redaction and prescription of HbA1c, micro-albuminuria, HDL cholesterol, blood creatinine, eye exam, prescription and realisation of ECG, prescription and realisation of foot exams). Patient should be informed of the derogation of acts and should give his/her informed consent [40,41].

In 2008, a first evaluation showed that the T2DM patients had an improved glycaemic balance, a better follow-up regarding quality guidelines, without additional costs for the SHI. In 2010, an economic study concluded that the ASALEE protocol leads to a 10% relative economy of health care consumption when compared to the rest of the population. There was an increase in prescription of clinical exams but less acute hospitalisations. From the patient perspective, the nursing consultation is a free space for listening and support; their exams are regularly scheduled and the treatment is adjusted by the GP. Overall patients in the ASALEE program are satisfied with the care delivered [42].

[u] See the website of the RevesDiab for detailed information http://www.revesdiab.fr/qui-sommes-nous/missions

Since 2014, the IRDES also assess the collaboration between generalist practitioner and advanced public health nurses involved in the ASALEE program through the DAPHNEE evaluation [43]. The DAPHNEE protocol is based on a qualitative evaluation through semi-directive interviews and on-site visits by researchers and a quantitative evaluation, based on pairs of doctors and nurses and patients. The qualitative phase aims at exploring the transformation of the medical and nursing practices, the interactions between doctors and nurses, the surrounding relational dynamics, the experience and the meanings of these for the actors [41]. The quantitative phase aims at identifying the impact of the ASALEE program on the availability of the generalist practitioner and on the quality of health care and services [41]. These evaluations are ongoing and are expected by 2017.

2.2.8. Patient participation

The French Federation of Diabetes is represented at the HAS, the CNAMTS, the ANSM and the DGS. The Federation pursues 4 missions: advocacy and counselling at individual and group levels, support of diabetic persons, information and prevention of diabetes and associated complications, support of research and innovation [44].

Since 2009, the French Federation of Diabetics proposes a program of peer support: “Patient Expert”. Volunteer trained diabetic patients organise and anime group sessions for diabetic patients. Individual peer support could also be provided by the patient expert.

Since 2015, volunteer patients could join the Diabetes LAB, an innovative program aiming a supporting a patient-centred vision of innovation, products and services and technological progresses. Patients are associated to the elaboration, development and evaluation of services and devices targeting diabetic patients in order to contribute directly to their quality of life [45].

2.2.9. Evaluation

In 2006, the SHI and the medical unions agreed on an annual follow-up of diabetic patients. GP should collect 4 quality indicators in order to follow the patient clinical pathways [46].

2.3. Stroke

2.3.1. Supporting policies and governance

In 2010, the Ministry of Health and Sports, the Ministry of Work, Solidarity and Public Function and the Ministry of High Education and Researcher launched a national plan “Accidents vasculaires cérébraux 2010-2014”[47]. It includes a strategic plan with generic and specific objectives; an operational actions program at national or regional levels; and a toolbox for actors. The national plan includes not only the rehabilitation but also the early detection, the acute treatment and the training of the population and professionals.

2.3.2. Organisation and funding of health care

Stroke is also included in the ALD list for exemption of the user fee in case of persisting neurological troubles after 24h requiring a complex medical treatment, maintenance care and active rehabilitation. The renewal will be conditioned by the evolution of the stroke, if a permanent disability persists or if less important consequences persist, but still needing rehabilitation [28]. The HAS guideline of 2016 identifies the list of health care professionals involved in the health care pathways of stroke patients and the list of acts and services provided to the patients in acute and chronic phases [48].

So far, as post-stroke rehabilitation programs are organized by local SSR and ARS, there is no unique program similar to the convention system in Belgium. The HAS establishes guidelines for the management of stroke during the early and acute phases but does not provide recommendations regarding the rehabilitation.

2.3.3. Patient participation

Patients are likely to be involved in the choice of IQSS indicators. Patients have also access to information about quality and safety of stroke care through the Scope Santé website.

2.3.4. Evaluation

Since 2013, specific IQSS on stroke has been included in the national quality plan. During the 2015 campaign, 10 process indicators have been retrospectively collected by clinicians in hospitals caring for stroke patients. These indicators however concern the initial treatment of stroke: delay between arrival and first medical imagery exam, datum and hours of the first symptoms, neurovascular expertise, evaluation by a rehabilitation professional, evaluation by a rehabilitation on first day of hospitalisation, screening of deglutition troubles, transfer to a specialised SSR, appropriate anticlotting treatment at discharge, planning of a follow-up consultation and patient health record. Interdisciplinary care is recommended but is not part of a quality indicator. A new campaign is planned from March to June 2017 on the 2016 data.

2.4. Haemophilia

2.4.1. Supporting policies and governance

The decree of October 9, 1989 specifically organized health for patients suffering from haemophilia and other haemostasis-related diseases. It created treatment centres (CTH) and regional treatment centres (CRTH). This was then evaluated and updated in1997 and 2001 [49, 50].

In 2005 the Ministry of Health and Solidarity produced the first national plan for rare diseases (PNMR) aiming at ensuring the equity in access to diagnostic, therapies and treatments. It included 10 strategic axes, including improving the knowledge on epidemiology, specify and treatments of rare diseases, supporting access to diagnostics and treatments, and training health care professionals [51]. This plan did not specifically refer to haemophilia as haemophilia was already targeted by a specific organization before the PNMR1.

A second national plan was launched in 2011 [52]. Initially planned for 2011-2014, it was extended to 2016 and final evaluation is now available [53]. The second PNMR included three axes: improving the quality of the patient management, developing research on rare diseases, and expanding European and international cooperation. The PNMR2 was endorsed by the Ministry of Economy, the Ministry of Research, the Ministry of Solidarities and Social Cohesion, and the Ministry of Labour, Employment and Health. The existing CRTH and CTH were then included in the PNMR and modified accordingly.

2.4.2. Organisation and funding of health care

Haemophilia and severe affections of the haemostasis are included in the ALD system (long term affections), entitling the patients to a full coverage of health care fees related to haemophilia and exempting them from co-payments [46].

2.4.2.1. Rare Diseases Healthcare Networks (FSMR)

Networks for rare diseases aim at facilitating the orientation of the patients, the data collection, the diffusion of best practices, the coordination of research / training / education. Each FSMR is organized around a (group of) rare diseases at the national level [49].

A FSMR is constituted of CRMR, CCMR, specialized laboratories in diagnostics and research, social and medico social institutions, universities, associations and all those that may bring additional expertise to the rare disease. A FSMR should at least include 3 CRMR to reach a minimal number of patients, actors and data to conduct national actions. A FSMR is designed for a 5 years period, under the coordination of an animator chosen among its members. The action plan should include objectives and actions for the 5 years. An annual activity report is sent to the General Direction of Health Care Delivery (DGOS) of the Ministry of Health. First evaluation of the FSMR is expected for 2017.

The FSMR MHémo (rare constitutional haemorrhagic disorders), regrouping 3 CRMR[v], includes the reference centres for haemophilia and other haemorrhagic diseases (CRMH), the reference centres for the Willebrand diseases (CRMW) and the reference centres for constitutional platelets diseases (CRPP).

2.4.2.2. Reference centres for rare diseases (CRMR)

A reference centre for a (group of) rare disease gathers multidisciplinary hospital competencies organized around a highly specialized medical team with an acknowledged expertise in health care, research and training. It includes practices and expertise of social and paramedical professionals[w].

A CRMR is an expert and reference centre with a regional, inter regional, national or international attractiveness, depending on the scarcity of the disease, aiming at supporting equity in terms of accessing the diagnosis, the treatment and the comprehensive care of patients [51, 52].

A CRMR could be constituted of one or several sites. In case of a multicentre CRMR, all sites should be involved in the 5 missions. The action plan defines the implication of the sites[x].

There are 5 missions specifically devoted to the CRMR:

- Coordination
  - Identification, coordination and animation of the care network inside and outside the catchment area (depending of his area of action); animation and coordination of the structures included in the catchment area (CCMR, hospital networks, health and social care professionals, medical and educational professionals)
  - Integration of patient associations in the activities and definition of the objectives of the CRMR
  - Definition of information and communication strategies
  - Definition of objectives, action plan and organization of activities[y]
- Expertise
  - Organization of synthesis meetings or multidisciplinary concertation (RCP)
  - Elaboration and diffusion of recommendations and national protocols of diagnosis and care (PNDS)
  - Collection of epidemiologic data with a priority for the BNDMR
  - Development of quality control procedures in collaboration with the hospital of the CRMR
- Remedy
  - Attraction of patients at regional / inter regional / national level (outside the catchment area of the hospital)
  - Ensuring a multidisciplinary / multi professional management of the patient regarding diagnostic, treatment, and follow-up
  - Delivering directly health care to the patient or organizing it inside the FSMR
  - Research: promotion, participation or animation of research activities (clinical, translational or organizational, assessed through publications

---

v See the list of the health care services included in the FSMR MHémo here: http://www.cometh.net/content/fili%C3%A8re-mhemo-1#.WJiWPfJCiM1

w Paramedical professionals include : care assistant, ambulance staff, dental care assistant, hearing aid specialist, child care auxiliary, dietician, occupational therapist, nurse, nursery, medical imagery assistant, physiotherapist, optician, speech therapist, orthoptist, osteopath chiropractor, podiatrist pedicure, foot-orthotic, dental prosthesis, psychometrician, medical secretary, laboratory technician, medical visitor

x A call for agreement is currently ongoing with the accreditation criteria for the centres.

y All these missions should be coordinated within the FSMR – in collaboration with the other partners

- Training and education: promotion, participation or animation of university / post-university/extra-university activities for rare disease(s)

2.4.2.3. Competence centres for rare diseases (CCMR)

CCMR aim at ensuring the care and the follow-up of the patients as close as possible to their home. They collaborate to the diagnostic, ensure the treatment when available, and organize the overall health care of the patients in collaboration with their supervising CRMR and other local actors. The CCMR follow the recommendations of the CRMR and refer to them when needed. The CCMR contribute to the BNDMR and may participate to the other missions of the CRMR.

Each CCMR has a coordinator, is connected to one or several CCMR and is organized around a hospital multidisciplinary and multi professional team, in charge of the continuity of patient care.

2.4.3. Patient-level care

Diagnosis and treatment should be delivered according to the recommendations of the HAS through the PNDS [54, 55]. The PNDS should be updated every three years where the list of acts and other treatments are listed and updated by the HAS every year[z].

2.4.4. Patient participation

Patients and their relatives are represented by the French Association of Haemophilic patients at local, regional and national levels. The French Association of Haemophilic Patients has also several workgroups managed by patients, with support of salaried workers. The association aims at improving patient therapeutic education, participating at local and regional levels in relevant institutions, supporting research and collaborating at international level[aa].

2.4.5. Evaluation

In 2016, the High Council for Public Health evaluated the 2011-2016 national plan for rare diseases [53].

The authors recommended a clarification of the missions of the different structures caring for haemophilic patients, a clearer agreement system – including funding rules, to reduce heterogeneity. Progress has been made regarding access to diagnostics and treatments, information and training of both patients and professionals. There is therefore still a lack of national protocol for the diagnostic and care for rare diseases. The fragmentation between health and social was also identified as a weakness of the national plan.

The evaluation also highlighted the need for a performant health information system regarding haemophilia but also additional factors such as social health inequalities.

The lack of governance impeded the implementation of some actions although the plan was elaborated with key players through a participative approach. The authors recommended a separation between the operational governance and the strategic governance.

2.5. Female Genital Mutilations

2.5.1. Supporting policies and governance

The French Law punishes the FMG committed in France or outside France, as well as the acts of violence leading to permanent mutilations. Exemptions of the medical secrecy are allowed in case of (suspicion of) female genital mutilations [56].

[z] However it seems that the last update was in 2010 for the list of acts and in 2007 for the PNDS. This was confirmed by email exchange with the HAS.

[aa] See the website of the association at: http://www.afh.asso.fr/

2.5.2. Organisation and funding of health care

Regarding the provision of health care, girls and women are entitled to reconstructive surgical interventions according the national health insurance scheme, without any specific care programs. If a women needs psychiatric care, it will be provided though the national health system but without consideration of her status of victim. Specialized multidisciplinary health care teams offer several services free of charge for the persons thanks to charity funds or public funding. For example, in Paris, la Maison des Femmes offers the service of a psychologist, a sexologist, several midwifes and surgeons (with a specific training in reconstructive surgery)[bb].

2.5.3. Patient participation

There is no information of participation of the patient to the public services on FGM although they may be associated to the actions of NGO and other support associations.

2.5.4. Evaluation

As there is no public program for delivering specific health care for FGM victims, there is consequently no official evaluation program. Again NGO and other actors may have local assessment systems.

2.6. Summary table

Table 2 – Organisation and financing of care for diabetes, stroke, haemophilia and female genital mutilation in France

	Health Conditions And Diseases			
	Diabetes	*Stroke*	*Haemophilia*	*Female genital mutilation*
Elements of the health care system				
• **Supporting policy**	None	National plan	National plan	None
• **Organisation**	Care pathways Health networks Support program Interdisciplinary team in first line of care	No specific program	Rare diseases Healthcare Network Reference centres for rare diseases Competences centres for rare diseases	No specific public program
• **Funding**	Capitation based on the severity of the disease	Capitation based on the severity of the disease	Capitation based on the severity of the disease	Included in the regular funding system
• **Patient participation**	Representatives in several public institutions Diabetes Lab	Representatives in several public institutions	Representatives at local, regional and national levels	None
• **Evaluation**	At GP level	Specific quality indicators	Evaluation of the national plan	None

[bb] Email conversation with Isabelle Gilette-Faye, sociologist, general director of the GAMS Federation, Paris

3. SCOTLAND

3.1. Description of the Scottish health care system

3.1.1. Organisation and governance of the health care system

The Scottish health care system is characterized by a high degree of accountability to the Scottish Parliament and by its financial accessibility, comprehensive free healthcare being available to people living in Scotland.

The National Health Service (NHS) Scotland is mainly managed by the Scottish Government. Scotland has full autonomy regarding health policies, although the funding arises from the UK Treasury. The Scottish Government elaborates the national framework, including the key targets to be achieved by local NHS boards. These key targets are included in the National Performance Framework of the Scottish Government, meaning that health policies are integrated in a larger society project [57].

The NHS boards are responsible for strategy development, resources allocation, implementation of health plans and performance management. Each board elaborates a 3-years local delivery plan, integrating both health targets and objectives and the National Performance targets.

The majority of NHS Scotland provision is paid for through general taxation. Private care is paid for, usually, through a private health care insurance scheme or individuals but the independent health care sector – including private and non-profit services- is rather small. Since 1999, there is no more purchaser-provider separation, meaning that most of the primary care professionals have contracts with the NHS boards; these contracts fixing the terms of reimbursement. The NHS boards employ hospital staff and community staff through salaried contracts. At the primary care level, the NHS boards also organise the contracts of independent health care professionals through the community health partnerships (CHP) such as the GP or the dentists[57]. Members of the NHS Boards are appointed by ministers through a transparent and open process of selection.

These last years, major reforms of the NHS Scotland supported the need for increased integration and collaboration, with a clear focus on local communities and the individualisation of the patient needs, the re-design of all public services around the needs of communities and people, and the implementation of a quality strategy. This is, for example, highlighted in the 2020 vision of health and social care. The 2020 vision of health and social care is built on a three domains – also called the Triple Aim: quality of care, health of the population, and value and financial sustainability[16]. Specifically, care for chronic and multiple diseases should focalise on effectiveness and should be achieved through the identification of *key pressure points* in the patient's pathways, agreement on actions on these *pressure points* and identification of at-risk profiles of patients through detailed analyses of existing data. The focus is also on person-centred care with the information and support for "*enable people at home and during time of transition*", as expected deliverable for 2013/2014.

As part of these major (organisational) changes, health and social care are now integrated within the communities, improving the partnerships between local authorities and NHS. Primary care is then at the heart of the HCS, where the GP are included in multidisciplinary teams [57]. Moreover, in order to be as close as possible to the needs of the population, each NHS board is expected to develop its own health and social care plan. For example, the NHS Lothian[cc] held consultations with patients and staff to set out the priorities and actions to be implemented for the period 2014-2024. NHS Lothian aims at providing rehabilitation care at home rather than in hospitals,

[cc] "*NHS Lothian provides a comprehensive range of primary, community-based and acute hospital services for the populations of Edinburgh, Midlothian, East Lothian and West Lothian. NHS Lothian provides services for the second largest residential population in Scotland - circa 850,000 people. It employs approximately 24,000 staff*". Retrieved from the NHS Lothian website

when there is no acute clinical need. To ensure the transparency of the process, all documents are made available to the public[dd].

3.1.2. Intermediate care sector

Since 2005, Scotland has developed several policies to improve access and quality of care for people with long term conditions. Intermediate care is mainly a home-based service. Depending on the severity or the complexity of the patient needs, other services such as community hospital or care at home could be preferred [58].

In 2006, the Scottish Executive integrated community hospitals as part of the primary care system to improve access and availability to an extended range of services and to promote intersectoral and multidisciplinary work [59].

In 2007, the Scottish government did a first attempt at harmonising the intermediate care sector by publishing the report "Co-ordinated, integrated and fit for purpose: the delivery framework for adult rehabilitation in Scotland". The objective is to implement "integrated models of delivering seamless rehabilitation services". This report is inscribed in the agenda of health and social care in Scotland, supporting the need for a reform in health and the social care sector [58, 60]. Eight common principles guide the actions towards rehabilitation care:

- Community capacity building
- Whole-system approaches
- Prevention and early intervention
- User involvement
- Carers as partners
- Self-management of care
- Systematic approach to long-term conditions management
- Competent workforce

As stated by Steel and Cylus (2012), intermediate care "*encompasses a range of functions that focus on prevention, rehabilitation, enablement and recovery so as to prevent unnecessary hospital admission, delayed discharge from hospital and premature admission to long-term care*". Intermediate care involves actors from health and social care, housing, third and independent sectors as well as the communities (including relatives and informal carers). Intermediate care aims at integrating, linking and providing a transition between locations, sectors and states (i.e. illness and recovery, management of acquired or chronic disability) [61].

Intermediate care should include the following elements:

- Clear and agreed scope on prevention/rehabilitation/reablement/recovery: this could be achieved through Anticipatory Care Plans (ACP). In addition, health care professionals may use the Key Information Summary (KIS).
- Time limited, in collaboration with existing facilities, free of charge
- Accessible, flexible and responsive (single point of access, 24/7) – supporting the need for effective collaborations between emergency services, hospitals, GP and home care services
- Comprehensive assessment and individualised care plan
- Coordination, multidisciplinary care and intersectorial care to respond to the complex needs of the patients: coordination may occur at system level (strategic) and at individual level (operational)
- Quality monitoring at three levels: individual, local intermediate care service and system [61]

[dd] See the presentation of the 2014-2024 of the NHS Lothian on their website: http://www.nhslothian.scot.nhs.uk/OurOrganisation/OurHealthOurCareOurFuture/Pages/default.aspx

In 2012, the Scottish Government published an update of its strategy regarding community hospitals as well as the report "Maximising recovery and promoting independence" as part of the 2011-2021 strategy aiming at reshaping the health and social care for elders [61-64].

As rehabilitation encompasses a wide range of actors (NHS, social services, independent services and voluntary organisations), there is so far no comprehensive view of services, care provision and professionals involved [65].

In 2012, the effectiveness of intermediate care was assessed through two outcomes included in the HEAT evaluation system: prevention of unnecessary acute hospital admissions and support of timely hospital discharges. The HEAT has been now replaced by the LDP standards. The Scottish Government and the local boards establish and agree upon Local Delivery Plan (LDP) standards [13].

3.1.3. Patient participation

Since 2008, the Better Together program assesses the patient experience within the NHS Scotland through a systematic questionnaire [66].

Since 2010, the NHS24 aims at providing a single unique online resource about national health information and support services to the population. This platform has been developed in partnership with voluntary sector. It includes: quality local and national information of the NHS and other sectors, national health information helpline and information about local health information centres in the communities [57]. Information is available in several languages[ee]. It is connected to the NHS Inform that provides specific information about health, diseases and treatments, to cite a few.

One of the core points of the NHS Scotland reform establishes that Scottish citizens and NHS staff both own the NHS Scotland, as stated in the concept of mutuality. Guidance helps staff to better integrate citizens within the NHS system. The local CHP are required to have a Public Partnership Forum where staff and the local community could have a formal meeting place.

Besides, patient experience is also considered as a key point of the system. The Better Together Scotland's patient experience of 2008 aims at integrating patient experiences as part of the NHS activities [57].

Availability of the information also concern the quality and the performance of the services delivered by the NHS boards and the NHS Scotland. The meetings of the local NHS boards are open to the public, all reports presented during boards meetings and annual activities reports are made available to the public.

3.1.4. Quality objectives

Scotland is considered as a pioneer in the field of quality of care. It includes the development of clinical audit, guidelines, outcomes indicators, standards and their use; this is used for the assessment of the clinical performance. These indicators are not specific to the NHS Scotland. The added-value of the NHS Scotland is the inclusion of "*clinical leadership and ownership while working in partnership with government and NHS management*". Health Improvement Scotland is the national body in charge of the assessment of quality and safety and report on performance.

Quality objectives are part of a larger strategy – the National Performance Framework that aims at focusing "*government and public services on creating a more successful country, with opportunities for all of Scotland to flourish, through increasing sustainable economic growth*" [15, 67]. The National Performance Framework is guided by 10 principles: Openness and transparency, Accountability and responsibility, Objectivity, Independent assessment, Dynamic site: real data, real time, Accessibility 24/7, Simplicity and clarity, Credibility to Parliament and the wider public, Shared responsibility for outcomes-based performance (with our partners), Sharpening focus - driving improvement. Overall performance is evaluated by an independent group, the Scotland Performs Technical Assessment Group.

[ee] Access the website of NHS24 here : http://www.nhs24.com/

All NHS Boards have to develop their Local Delivery Plans in order to implement the priorities of the Scottish Government for the NHS boards that were issued in the Health and Social Care Delivery Plan of December 2016[17]. This should enhance the Triple Aim policies: better care, better health, better value. The LDP should present the process and steps of the regional planning and delivery of the NHS Boards. An updated review of target and indicators for health and social care is expected in 2017. The former HEAT targets were reviewed annually, with an annual update of targets to be achieved. HEAT targets are integrated into the daily routine once they are achieved (HEAT standards).

3.2. Diabetes

3.2.1. Supporting policies and governance

These last years, the Scottish Government has done significant investments in the management of long-term conditions. It firstly aimed at identifying those with the highest risk of hospital admissions and appropriate preventive measures. It also focused on the reinforcement of the self-management capacities of the patients [58]. The Better Health, Better Care of 2007 evidenced the need for an action plan for long-term conditions, leading to the 2009 national action plan. This action plan suggested a re-design of the NHS Scotland based on the Chronic Care Model [68] and the specificities of Scotland. It emphasized the quality improvement and the mutual care approach.

In 2008, the NHS Scotland launched the *Long Term Conditions Collaborative*, in charge of supporting NHS boards to improve access and quality of care for patients with long-term conditions [62, 69-71]. This was followed by the *Route Map to the 2020 Vision for Health and Social Care* (2013) [16].

In 2014, the Scottish Government issued the Diabetes Improvement plan as part of the 2010 Quality Strategy focusing on *safe, effective and person-centred care*. This Diabetes Improvement includes 8 priorities for the patients across Scotland in order to improve their experiences and outcomes in the NHS [72]. It also reinforces the previous generic recommendations of the Long Term Conditions Collaborative such as *Improving Care Pathways, Improving Complex Care,* and *Improving Self-Management Support* and *Making the Connections – Food For Thought: Anticipatory Care, Self-Management and Community-Led health improvement approaches for people with long term conditions*.

3.2.2. Organisation and funding of health care

Patients needing insulin or medicines to manage their diabetes are entitled to free prescriptions in Scotland, comprehensive health care being free of charge at the entry point.

3.2.2.1. The Scottish Diabetes Group

The Scottish Diabetes Group (SDG) is a national Steering Group which coordinates the implementation of the health policies related to diabetes. Several thematic subgroups complete the action of the SDG [73].

3.2.2.2. Managed Clinical Networks[ff]

Managed clinical networks (MCN) are "*linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland*" (Retrieved from Diabetes in Scotland, 2017). Regarding diabetes, these MCN aim at gathering health professionals, patients and care providers in order to work "*across traditional boundaries in planning and delivering diabetes care"* (Retrieved from Diabetes in Scotland, 2017).

[ff] Detailed presentation of a Diabetes MCN: http://www.nhsgrampian.org/nhsgrampian/diabetesnew.jsp?pContentID=3324&p_applic=CCC&p_service=Content.show&w

The Health Department Letter in 2007 HDL (2007)21 established the principles of MCN, whereas the NHS boards were in charge of their implementation [74]. Quality of the MCN is supervised by the NHS Quality Improvement Scotland [75].

3.2.2.3. Primary care level and specialised care

Primary care plays a gatekeeping role in accessing specialised care. Most of the health care related to diabetes are performed by the community health partnerships, including GP, nurses and other social and health professionals. Specialised exams are performed in hospitals after referral by the primary care. According to Steel and Cylus (2012), "*around 90% of patient contact is with primary care and most of patient journeys begin and end in primary care".*

Healthcare professionals may access guidelines through the platform of Health Improvement Scotland [13]. Diabetes UK, a registered charity, also provides guidelines and recommendations for health care professionals [76]. NHS Boards in Scotland are required to follow the guidelines of the Health Improvement Scotland or, when relevant, the NICE recommendations.

3.2.3. Patient-level care

Patients may access a unique interactive website "My diabetes, my way", hosted by the NHS Scotland. The website includes leaflets, videos, educational tools and games containing information about diabetes. Patients can also access their own up-to-date diabetes clinic results to help them manage their condition more effectively[gg].

Patient education is one of the major priorities of NHS Scotland. Numerous resources support the health care professionals and the patients. NHS Scotland has a unique website gathering information and resources specifically dedicated to diabetes education. The website is managed by the Scottish Diabetes Education Advisory Group[hh].

As the prevalence of T2DM is higher among Black and Ethnic Minorities, specific attention is dedicated within NHS Scotland to deliver culturally appropriate health care (e.g. provision of interpreters, culturally sensitive patient education or using community health workers). The Structured Diabetes Education site is one of the resources for health care professionals[ii]

3.2.4. Patient participation

For this section, please refer to the general section on patient participation in Scotland. User involvement and patient experience are two key aspects of the NHS Scotland; diabetic patients may then be then consulted or involved in case of service development or change [57].

3.2.5. Evaluation

There is no specific evaluation for diabetes care. However, three instruments monitor the improvement in access and quality of care: the National Performance Framework, the Local Delivery Plan (LDP) standards (formerly HEAT targets) and the Community Care Outcomes Framework [57] [77].

[gg] See the website of My Diabetes, My Way of the NHS Scotland: http://www.mydiabetesmyway.scot.nhs.uk/

[hh] See the website of Diabetes Education Scotland: http://www.diabeteseducationscotland.org.uk/

[ii] See the website of Diabetes in Scotland: http://www.diabetesinscotland.org.uk/MEG/home.php

3.3. Stroke

3.3.1. Supporting policies and governance

Alongside with cancer and mental health, stroke has been targeted for years by the Scottish Government. In 2009, the Scottish Government issued the *Better heart disease and stroke action plan* [78]. In this action plan, 62 actions specifically targeted stroke, from acute phase to palliative care. Seven actions supported the long term support and the rehabilitation and recovery from stroke. Areas of improvements in rehabilitation includes the referrals to allied health care professionals, the improvement of access to exercise and fitness training, the provision of occupation therapy, the implementation of best practices, the provision of speech and language therapy and the delivery of information to patients and their carers [78]. Additional non-specific actions to stroke and heart diseases include the training of health care professionals, the regular audits, the support for self-management, to cite a few.

In 2014, the Scottish Government updated this action plan with the objective of reaffirming the priority dimension of stroke management [79]. It also reinforces the quality improvement and patient safety dimensions of parallel policies.

3.3.2. Organisation and funding of health care

3.3.2.1. National Advisory Committee for Stroke (NACS)

Since 2002, the National advisory Committee on Stroke aims at providing and supervising the issues related to stroke within the Coronary Heart disease and Stroke Strategy of the Scottish Government [80]. The committee is responsible for the advising of authorities regarding all aspects of stroke, for ensuring the development of stroke services according to guidelines and quality standards, for allocating and monitoring additional funding and for supervision the work of the thematic subgroups.

NACS also benefits from the inputs of the Scottish Stroke Improvement Team (SSIT), including the Scottish Stroke Improvement Program, the Scottish Government Health and Social Care Directorate and the clinical coordinator of the Scottish Stroke Care Audit. The SSIT itself benefits from inputs of the third sector, the Scottish Stroke Research Network, the Scottish Stroke Nurse Forum, the Scottish Stroke Allied Health Professionals Forum, the Scottish Stroke Care Audit and the Stroke MCN [79].

3.3.2.2. Stroke managed clinical networks

"The Coronary Heart Disease and Stroke Task Force report points to the significant amount of previous work undertaken in the area of stroke, including that of SIGN and CRAG. The Task Force recommends that, as for CHD, Managed Clinical Networks be established, proactively supported by NHS Boards. Such Managed Clinical Networks should include a ***dedicated stroke unit serving a specific geographical area and pay particular attention to the issue of integrated discharge planning and co-ordinated stroke rehabilitation****. The report also recommends that NHS Boards review current provision of "one stop clinics" for assessment of transient ischaemic attacks (TIAs), but acknowledges that currently this will not be feasible in all parts of Scotland.*[jj]*"*

Since 1999, several managed clinical networks have been developed across Scotland, in order to connect health care professionals and organisations to support the delivery of health care. It promotes an integrated approach, with a particular focus on some chronic conditions such as stroke. The strengths of managed clinical networks are "*the promotion of consistency and quality of service throughout the care pathway and the bringing of service user and provider views to the service planning process...developing services which are truly person-centred, delivered locally wherever possible but specialised where need be*"[kk].

Managed clinical networks are led by a clinical and a network manager in order to support a strong clinical leadership. They play a key role in quality improvement, exchanges of practices, measurement and monitoring of activities, health promotion and prevention as well as in the reduction of

jj Retrieved from [81]

kk Retrieved from [82], page 7

health inequalities, the latter being done in collaboration with the Health Promoting Hospital Service (HPHS). Each local NHS Board develops and supports its own MCN.[ll]

3.3.2.3. Intermediate care[mm]

After the acute episode, stroke is mainly managed in the intermediate care sector, depending on the severity and the evolution of the disease. Key players are the NHS and local authorities alongside the third sector and the independent sector. In 2012, Scotland had 58 community hospitals, offering a diverse panel of services. Besides, their locations are not based on the existing needs in the area [57]. Health and social care in the NHS Scotland is free of charge but as intermediate care is also delivered by independent contractors, patients may have to pay for it – with supposedly variations in fees depending on the services offered.

3.3.2.4. Resources for health care professionals

The Scottish Intercollegiate Guidelines Network (SIGN) publishes and updates guidelines for health care professionals regarding stroke management. The SIGN 118 is specifically dedicated to the rehabilitation of stroke [83, 84]. It highlights the key roles, the tasks and the health care professionals of the interdisciplinary team. However, an important recommendation states that "*The routine implementation of integrated care pathways for acute stroke management or stroke rehabilitation is not recommended where a well organised multidisciplinary model of care exists."*

Guidelines also inform about the current training programs that the multidisciplinary team should attend as part of the continuing education.

3.3.3. Patient level of care

The Scottish Parliament Cross Party Group on Heart Disease and Stroke have elaborated the Stroke Charter. It was developed to ensure that the patients receive the support and care they deserve in terms of recovery, rehabilitation and the self-management. It includes health care but also social support, services for carers, equipment, transport, support for those willing to get back to work, voluntary activities, social services, housing, financial benefits and information and communication [85]. A dedicated website presents the Charter. This may also serve as a template to facilitate the communication and the elaboration of the care protocol between the patients and the professionals.

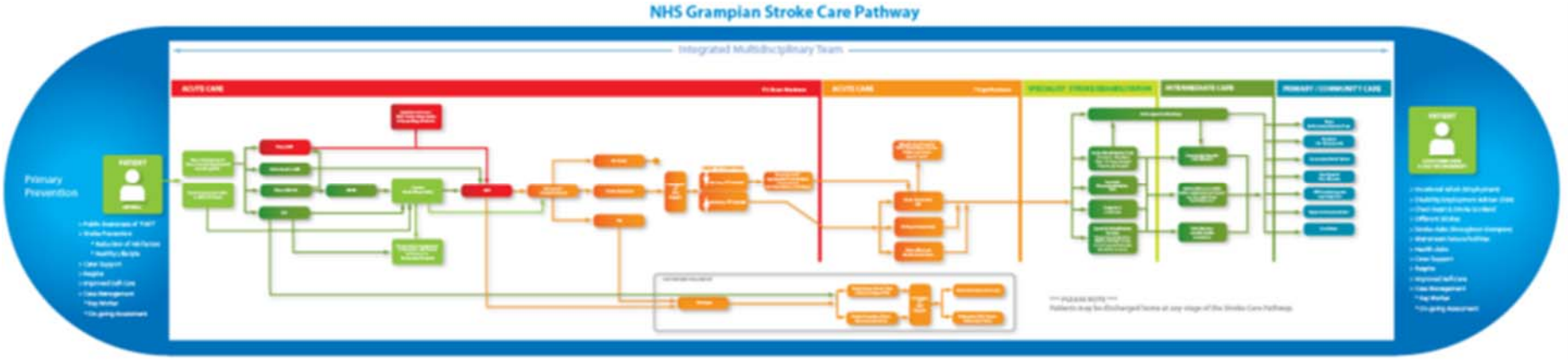
The NHS Grampian also proposes an overview of the patient pathway[nn] (see below).

[ll] For example, see the website of the NHS Grampian on stroke http://www.nhsgstrokemcn.scot.nhs.uk/

[mm] See the general presentation of intermediate care in the introduction of this appendix

[nn] Retrieved from [86]

Figure 4 – Overview of the patient pathway



Source: NHS Grampian, 2010

The story of Eddie presents a patient case into the intermediate care sector [61].

Figure 5 –The story of Eddie

Eddie - is recovering from a stroke, whose housing no longer suits his needs.

Eddie is 70 yrs old, living alone with no immediate family, but with a network of close friends living nearby. He suffered a stroke 2 weeks ago and is recovering in hospital.

Eddie is showing good signs of recovery, but has a right sided weakness, is unable to walk, can sit unaided and is continent. His has speech difficulties but this is improving.

He is expected to continue to improve and is keen to return home as soon as possible.

Eddie's home is currently unsuitable for his needs, requiring major adaptations. Despite this he is keen to leave hospital and continue his recovery and rehabilitation in the community.

Personal Outcomes expressed by Eddie

- ✓ To get out of hospital as soon as possible return to his own home
- ✓ To receive regular therapy to continue recovery and be fully independent again including communication
- ✓ To be in control of his future
- ✓ For personal outcomes known and respected.

How could Intermediate Care respond?

Assessment & Discharge Planning

- A full outcomes based assessment is carried out to establish what options are viable, whilst Eddie is recovering in hospital. A Full Multi-Disciplinary Team, including key worker or case manager, experienced in Stroke rehabilitation are involved from the early stages to ensure best recovery.

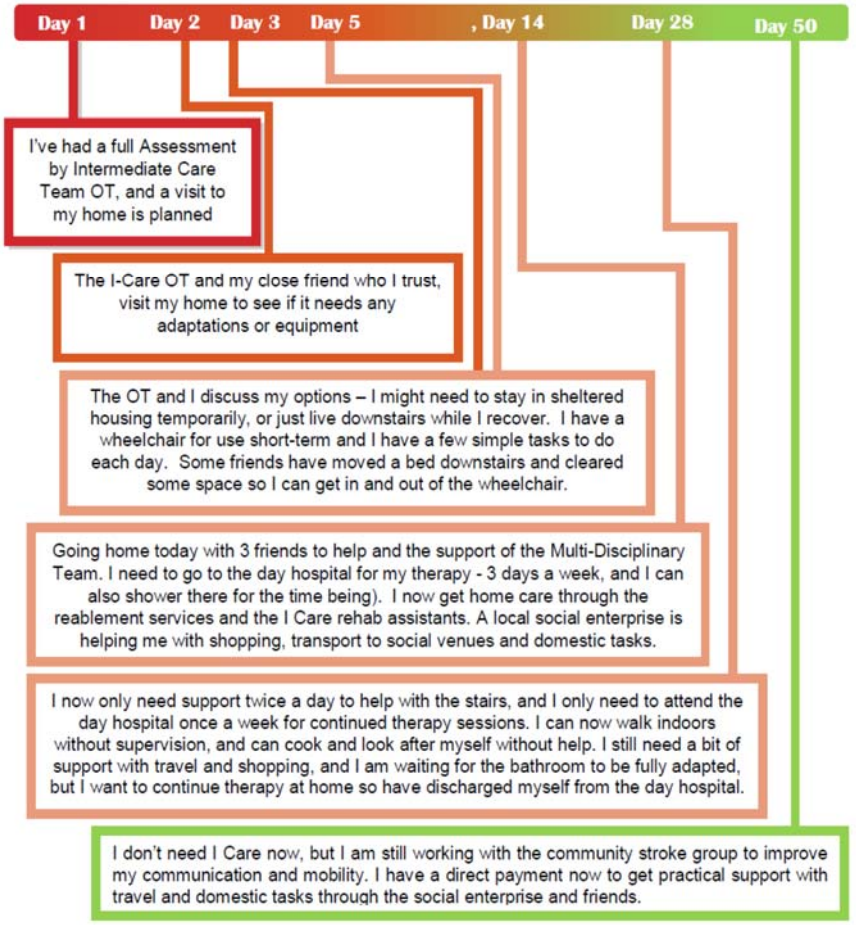
Housing

- Rapid assessment by community team carried out to establish whether own home can be used in recovery phase. Alternatives, such as Intermediate Care housing within a sheltered housing unit, or care home should be available if own home is unsuitable.
- Housing and Occupational Therapy teams are fully involved from the outset to ensure any equipment or adaptations required are actioned immediately.

Voluntary Sector contribution

- Links are made with a local voluntary organisation that can provide support and companionship for Eddie when he returns home. Specialising in stroke they are able to help Eddie understand the condition and continue to recover at his own pace at home.

Time line – How was it for Eddie?



Source: Scottish Government, 2012.

3.3.4. Patient participation

Three main patient associations are identified as key actors to be involved in service delivery, planning and health policies (British Heart Foundation Scotland, Chest, Heart and Stroke Scotland and the Stroke Association in Scotland). These associations, alongside with other key associations, are represented in the different National Advisory Committees. However, although the SIGN guidelines support the need for an early involvement of the patient, they do observe that evidence about the process of involving the patient is less clear [83].

3.3.5. Evaluation

The 2009 *Better heart disease and stroke action* included the development of a minimum dataset to assess the performance of pre-hospital and hospital stroke care against NHS QIS Stroke Standards, under the responsibility of the Information Service Department [78].

Since 2002, a specific audit, the *Scottish Stroke Care Audit*, is published annually by the NHS Scotland and the ISD Scotland. This audit support local NHS boards in improving their stroke care, according to the National Standards. In April 2011 a new Stroke Admission HEAT Target was launched: "*To improve stroke care, 90% of all patients admitted with a diagnosis of stroke will be admitted to a Stroke Unit on the day of admission or the day following presentation by March 2013*." (Retrieved from [87]). However, it focuses on acute management of the stroke and not on rehabilitation care. The Stroke Audit is public on the Internet[oo].

3.4. Haemophilia

3.4.1. Supporting policies and governance

Health care for Haemophilia is considered as specialist services and is then managed by the National Services Division, a sub-branch of the NHS National Services Scotland of the NHS Scotland. The NSD commissions and manages at the Scottish level the specialist services and screening programmes. The NSD is funded with a top-sliced ring-fenced funding of the Scottish Government Health and Social Care Directorates (SGHSCD).

There is 6 Haemophilia Centres for the whole Scotland. However, to ensure the fairness between the 14 Scottish regional health boards, there is a regional agreement for risk sharing for recombinant factors products [88]. The main area where all the UK jurisdictions work formally together concerns the UK tender for clotting factor products as the correlation between volume and price means "*that it is mutually beneficial to purchase clotting factor products together. Although technically Scotland has the power to make its own purchasing arrangements, in practice the decision is always to purchase with the rest of the UK"*.

Contrary to England[pp], the Scottish approach for haemophilia has been to develop a network of health care professionals and patients which seeks to raise standards in haemophilia care. In England, the NHS England identifies the services that will be purchased. For Dan Farthing-Sykes, CEO, Haemophilia Scotland, the main weakness of the English system is the *tendency to describe the service already being provided rather than be aspirational for improvements in care*.

Healthcare for haemophilia in Scotland includes Haemophilia A, Haemophilia B, Acquired Haemophilia, von Willebrand Disease and other inherited bleeding disorders such as the deficiencies of other clotting factors

oo Website of the Stroke Audit http://www.strokeaudit.scot.nhs.uk/index.html

pp As stated by Dan Farthing-Sykes, "NHS England runs an internal market with a split between commissioners and providers. This relationship doesn't operate in Scotland. Instead we have local health boards who are responsible for planning and providing care in their areas."

(e.g. factor V, factor X, factor XI and fibrinogen) and abnormalities of platelet function.

3.4.2. Organisation and funding of health care

Health care delivered inside the NHS is free for haemophilia patients.

3.4.2.1. Scottish Inherited Bleeding Disorders Network

The Scottish Inherited Bleeding Disorders Network (SIBDN) aims at "*facilitating clinical and other improvements for individuals with inherited bleeding disorders. A key aim of the Network is to enable timely and effective care for individuals with inherited bleeding disorders across Scotland*" (Retrieved from [89]. The SIBDN is responsible for the issuing of care protocols and other policies. Although the standards have been adapted for the Scottish local context, they are heavily influenced by the directives of the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO).

The steering committee of the SIBDN has to be representative *of patients and the different professional disciplines involved in the provision of services for patients with inherited bleeding disorders and their geographical boundaries*. It regularly issues work plan in order to define the strategic vision of Haemophilia care in Scotland.

The SIBDN includes three work streams "*to direct and oversee specific projects listed in the work-plan. Each work stream is comprised of NHS staff, third sector organisations and patient and career representatives with experience and an interest in the projects overseen by each work stream".* It includes stakeholder engagement and communication; best practices, policies and protocols; and quality improvement, audit and data.

3.4.2.2. Comprehensive care centres

There are 2 Comprehensive Care Centres (CCC) in Scotland (Edinburgh and Glasgow). The CCC provide both routine care as HC but also specialised care. Specialised care activities include:

- "*genetic counselling and diagnosis/testing*
- *a 24-hour advisory and response service for haemophilia centres, GPs, dental surgeons, hospital doctors, patients and families*
- *counselling and support services (non-genetic), social work support and welfare advice*
- *specialist care such as: children's care, obstetrics/gynaecology, physiotherapy, dentistry,*
- *rheumatological and orthopaedic follow-up and intervention*
- *specialist support for people with inhibitors*
- *participation in clinical research and trials*
- *education programmes for healthcare professionals, patients and families including home treatment training programmes, and home and school visits where appropriate*
- *Co-ordination of home delivery services*" (Retrieved from [90]).

3.4.2.3. Haemophilia centres

When diagnosed, the patient should register to the local Haemophilia Centres (HC)[qq]. HC are small centres, serving a limited number of patients and non-specialised care for haemophilic patients. A centre often includes a multidisciplinary team: doctors, nurses, physios and counsellors, plus administrative staff like data managers and secretaries/receptionists. There

[qq] List of the haemophilia centres http://www.ukhcdo.org/haemophiliacentresa-c/

are around 64 haemophilia centres in United Kingdom but only 3 in Scotland (Aberdeen, Dundee and Inverness).

HC centres provides the following services to the patients:

- “diagnosis of inherited coagulation disorders
- treatment monitoring
- 24-hour emergency access and treatment for people with bleeding disorders
- clinical advice for patients and families
- support for home therapy programmes
- Participation in quality control and audit schemes” (Retrieved from [90]

The UKHCDO provides useful resources for medical practitioners involved in the HC and CCC of the UK, such as the guidelines for the diagnosis and the treatment of rare coagulation disorders [91]. Haemnet brings together haemophilia nurses, physiotherapists and allied health care professionals [92].

3.4.3. Patient participation

NSD coordinates regular meetings between the Scottish Haemophilia Centres and Haemophilia Scotland, a representative association of the patients. These meetings aim at supporting the quality and the improvements of services for haemophilic patients and their relatives, for example the Scottish set of Protocols and Guidelines for Haemophilia. The current activities of this group focuses on the assessment of health outcomes achieved by Scottish Haemophilia Services for people with bleeding disorders. This is supported by a Clinical Audit System (CAS). Haemophilia Scotland is working on the formalisation of the meetings by creating a National Managed Clinical Network for Inherited Bleeding Disorders.

3.4.4. Evaluation of the system

The SIBDN and Haemophilia Scotland are currently conducting a national survey of people with bleeding disorders and family members or carers to find out about needs and challenges facing people affected by bleeding disorders. The survey includes the following topics: health and wellbeing, lifestyle, employability, treatments and issues affecting specific groups with bleeding disorders; children, women and older people. Results are expected to be presented at the Scottish Parliament in spring 2017.

3.5. Female genital mutilation

3.5.1. Supporting policies and governance

Since 1985, FGM has been illegal. In 2005, the Scottish Government issued the Prohibition of Female Genital Mutilation (Scotland) Act 2005 [93]. Contrary to England, Wales and Northern Ireland, there is no mandatary reporting in Scotland. The duty of reporting is explained in the Serious Crime Act of 2015 [94]. The National Child Protection guidance indicates the responsibilities of the different actors involved in such topic in case of minor children [95].

A national Action Plan to Prevent and Eradicate FGM (2016-2020) has been published in 2016 to support the inclusion of FGM sensitive care into the NHS Scotland [18]. This action plan has to be considered within the larger framework of the “Equally safe – Scotland’s Strategy to Prevent and Eradicate Violence against Women and Girls”[96].

Health care is provided within the NHS Scotland. There is no specific status attached to the women or girls. Main efforts have been put in raising the awareness and the expertise of health and social care professionals.

3.5.2. Organisation and funding of health care

Health care delivered inside the NHS is free for FGM patients.

The 2014 report “Tackling Female Genital Mutilation in Scotland. A Scottish model of intervention” identifies areas of actions and suggests interventions that should be supported to improve health care for victims of FGM [97]. It includes recommendations around 5 key domains of actions: participation of communities; strategy, policies and research; prevention; legal protection and interventions. Regarding interventions, the major recommendation concerns the development of specialist and multidisciplinary “hub and spoke” services, with a network of practitioners across Scotland. It recommends the opening of a GP/hospital consulting hours in the cities likely to be concerned by the issue (e.g. NHS Greater Glasgow and Clyde). It also stresses the need for culturally competent health care and training of health care professionals. The 2016 action plan clarifies the actions and activities to be implemented, the objectives, the action owner and the timescale. The provision of care focuses on “*access to relevant, effective and integrated services”,* including mental health care [18].

3.5.3. Patient participation

All recommendations highlight the need for a reinforced collaboration with the communities, as the final objective is the eradication of FGM [18, 96, 97].

3.5.4. Evaluation of the system

All statutory agencies have to include specific data for FGM in their daily routine [18]. The action plan is however too recent to have more detailed evaluation.

3.6. Summary table

Table 3 – Organisation and financing of care for diabetes, stroke, haemophilia and female genital mutilation in Scotland

	Health Conditions And Diseases			
	Diabetes	*Stroke*	*Haemophilia*	*Female genital mutilation*
Elements of the health care system				
• **Supporting policy**	National plan	National plan	No specific plan	National plan (not only health aspects)
• **Organisation**	National steering group Managed clinical network Integrated primary health care team	National Advisory Committee for Stroke (NACS) Stroke managed clinical networks Intermediate care services (rehab)	Scottish Inherited Bleeding Disorders Network (SIBDN) Comprehensive care centres Haemophilia centres	Unique model of interventions to be integrated in existing services
• **Funding**	Free at the entry point	Free at the entry point Intermediate care: depends on the service	Free at the entry point	Free at the entry point
• **Patient participation**	Representatives of patients in various committees and advisory boards in the NHS Scotland	Representatives of patients in various committees and advisory boards in the NHS Scotland	Representatives of patients in various committees and advisory boards in the NHS Scotland, specific working group for haemophilia	Representatives of patients in various committees and advisory boards in the NHS Scotland
• **Evaluation**	Included in the mainstream quality assessment	Stroke charter Stroke Audit (public)	Ongoing evaluation by the SIBDN and Haemophilia Scotland	Obligation of collecting data on FGM in daily routine

4. THE NETHERLANDS

4.1. Description of the Dutch health care system

Recent reforms aimed specifically at a more demand-driven and patient-centred system powered by market incentives and reduced government interference [19]. As a consequence, the operational role of the government in the delivery of services is very limited, as this is largely delegated to private initiative and non-governmental organizations: responsibilities have been transferred to insurers, providers and patients for both acute and long-term care and the responsibility for home care services has been delegated to the municipalities [19 98].

4.1.1. Dutch health care policy and financing

The Dutch health care insurance system is governed by four basic health care-related acts: the Health Insurance Act ("Zorgverzekeringswet" of June 2005, in force from January 2006 onwards), the Long-Term Care Act ("Wet langdurige zorg" of december 2014), the Social Support Act ("Wet maatschappelijke ondersteuning 2015" of July 2014, replacing the Wet maatschappelijke ondersteuning of June 2006) and the Youth Act ("Jeugdwet" of March 2014). The last three entered into force in January 2015 [99]. In addition, the Healthcare Insurance Allowance Act (Wet op de zorgtoeslag) introduced with the 2006 reform foresees a tax subsidy to compensate lower-income groups for an excessive premium burden for basic health care insurance [19].

The financing of the Dutch curative health care system is based on Social Health Insurance and managed competition [19]. There are two main financing schemes: one for curative and one for long-term care [19]. The government finances social health insurance for the basic benefit package and the compulsory social health insurance scheme for long-term care. Prevention and social support are not part of social health insurance but financed through general taxation. Under the Health Insurance Act (Zorgverzekeringswet), statutory coverage is provided by private insurers and regulated under public law. Health care insurers are given the task of increasing health care system efficiency through prudent purchasing of health services on behalf of their enrolees [21]. Enrolees have the right to change insurer each year [21].

4.1.2. Curative care

Since 2006, all residents (and non-residents who pay Dutch income tax) aged 18 and above are mandated to purchase statutory health care insurance from private insurers [19]. Health care insurers have to accept anyone who applies for an insurance policy for the basic benefit package [19]. In addition to statutory coverage, most of the population (85%) purchases a mixture of complementary and supplementary voluntary insurance [21].

Insurers can compete on the price of policies and the quality of care offered, as long as they observe the legal obligations to accept applicants without risk selection, to abstain from premium differentiation and to offer adequate care [19]. In their policies, health care insurers may impose restrictions on the patients' free choice of provider (usually in return for a lower premium) and regulate who provides the care and where it is to be provided [19].

Providers can compete for patients by offering good quality of care and for insurers by offering attractive (e.g. integrated) care arrangements [19].

4.1.2.1. Covered services

Health care insurers are legally required to provide a standard benefits package covering: medical care, including care provided by general practitioners, hospitals, medical specialists, and midwives; dental care through age 18; medical aids and devices; prescribed drugs; maternity care; ambulance and patient transport services; limited allied health care (physical/remedial therapy, speech therapy, occupational therapy, and dietary advice); home nursing care; district nursing; basic ambulatory mental health care for mild to moderate mental disorders (including some sessions with a primary care psychologist); and specialized outpatient and inpatient mental health care for complicated and severe mental disorders [19, 21, 99]. If the latter takes more than three years, the Long-Term Care Act takes over [21]. Some treatments are only partially covered or excluded: physical therapy (except treatments for some people with specific chronic conditions); dental care above age 18; optometry; sleep medication and antacids for most patients; walkers and other simple mobility aids; and a limited number of

health improvement programs (e.g., smoking cessation and three hours per year of weight management advice [21].

4.1.2.2. Financing

The statutory health care insurance system under the Health Insurance Act is financed through a nationally defined, income-related contribution that is pooled in the Health Insurance Fund, a government grant to pay for children's coverage up to the age of 18 and through premiums set by each insurer (average annual premium for adults in 2015 was EUR 1,158) [19 21]. Children under the age of 18 are insured free of charge but have to be included in one of the parents' plans [19]. Employers must reimburse employees for this contribution, and employees pay tax on the reimbursement. For the self-employed, the income-related contribution is 5.4 percent. Contributions are collected centrally and distributed among insurers in accordance with a risk adjusted capitation formula that considers age, gender, labour force status, region, and health risk (based on past drug and hospital utilization) of enrolees [21]. This risk adjustment should make it equally attractive to sell a health plan to a sick person as to a healthy person and take away incentives to select on the basis of risks [19]. Insurers or payers are supposed to engage in strategic purchasing with regard to the prices, quality and volume of care that they will offer, and contracted healthcare providers are supposed to provide their enrolees selectively with the best value [19, 21]. For a part of the care however, maximum prices have been established by the Dutch Healthcare Authority [19].

4.1.3. Long-term care

Long-term disability protection is organized separately from health insurance. People residing legally in the Netherlands and non-residents who pay Dutch (payroll) (income) tax are compulsorily insured for long-term care[21].

The Exceptional Medical Expenses Act has been replaced by the Long-Term Care Act (Wet Langdurige Zorg) in January 2015 [19, 21 99-101]. As a result, long-term care underwent a fundamental reform. All extramural care and nursing has been transferred to the Health Insurance Act and municipalities became responsible for all social support, sheltered living and assistance under the adjusted Social Support Act. As a result, the former Exceptional Medical Expenses Act transformed to a far smaller provision for people requiring intramural long term care [19, 21].

4.1.3.1. Covered services

The Long-Term Care Act (Wet Langdurige Zorg) offers services for those whose physical, medical or mental chronic conditions require continuous care (24 hour supervision) and have considerable financial consequences [19, 21, 102].

Applicants are subjected to a nationally organized needs assessment procedure according to uniform and strict standards. Types of care and financing of the corresponding costs are authorized on an individual basis (allocation of "care profiles" or "care intensity packages"). Residential care will only remain available to clients for whom non-residential care is no realistic option and is based upon the assumption that persons with mild problems may better be cared for in their home-setting resulting in a more client-centred long-term care. Under the new law, clients may also apply for a personal budget. The care provided in institutions cannot be combined with a personal budget [19]. A new option is to organize full care at home (via the complete care package at home: Volledig Pakket Thuis).[19, 100]. Care at home can be provided in kind or purchased via a personal budget [19].

4.1.3.2. Financing

A large part of long-term care is financed through the Long-Term Care Act (Wet Langdurige Zorg), a statutory social insurance scheme. It is a largely income-dependent contribution-based scheme [21].It operates nationally and is marginally complemented with mainly income-related co-payments with private delivery of care mainly by not-for-profit provider organizations [19, 21, 100]. The remainder is financed through the Social Support Act, financed from general taxation [21].

4.1.3.3. Social support

According to the Social Support Act (Wet Maatschappelijke Ondersteuning, Wmo), which was extended in 2015, municipalities must support people, with professional care or otherwise, to live in their home situation for as long as possible. Support may include: counselling and day care; respite care for informal carers; sheltered housing for mentally disabled people; and relief in case of domestic violence. As municipalities are the direct purchasers, no third party payers are involved. Municipalities are free to organize the availability of these services [19].

Municipalities receive extra funding for these tasks (from general taxation), but these funds are not earmarked. This gives the municipalities the freedom to organize care to their own discretion. The idea behind the reform is that municipalities are closer to the citizens and better positioned to organize tailor-made care solutions for their population. Furthermore, long-term care seekers should first explore a solution within their personal social network. Only if that is not feasible or insufficient can professional care step in. However, the social network cannot be forced to provide care. As of 2015, it remains unclear how this will be effected in practice [19].

Except for home nursing all other types of long-term care have been the responsibility of municipalities since January 2015 [19].

Home help and social support are paid by municipalities under the Social Support Act (Wmo, 2015)[103]. Youth mental health care and disease prevention are also paid by municipalities under the new Youth Act. Municipalities negotiate with providers of home and youth care about price and volume of care. They receive a non-earmarked government contribution from the municipality fund for both types of care. This fund is a tax-based fund that is the main source of financing for municipalities. Home nursing care and personal care have shifted to the Health Insurance Act. One of the aims of the long-term care reform was to contain costs by organizing care closer to the citizens and thus enabling tailor-made solutions that are more efficient. To what extent the aims of cost containment and efficiency will be achieved is not yet clear (2015) [19].

4.1.4. Dutch health care organization

4.1.4.1. Primary care

All citizens are registered with a GP of their choice, usually in their own neighbourhood. Patients can switch GP without formal restriction. GPs are paid by a combination of fee-for-service, capitation and pay-for-performance [19]. GP remuneration includes three segments. Segment 1 funds the core of primary care, and consists of a capitation fee per registered patient, a consultation fee for GPs, including phone consultations, and provision for ambulatory mental health care at the GP practice. The Dutch Health Care Authority (Nederlandse Zorgautoriteit) determines national provider fees for this segment. Segment 2 consists of funding for programmatic multidisciplinary care for diabetes, cardiovascular risk management, asthma and chronic obstructive pulmonary disease. GPs have to negotiate prices and volumes with health care insurers for this segment. Segment 3 provides GPs and insurers the opportunity to negotiate additional contracts – including prices and volumes - for pay-for performance and innovation [21]. To incentivize care coordination, there are bundled payments for some chronic diseases (diabetes, cardiovascular risk management, and COPD).

Primary care comprises a broad range of personal curative and preventive services. General practice forms the heart of the system in which general practitioners (GPs) hold a gatekeeping position to hospital and specialist care and independent community-based midwives are responsible for prenatal care and uncomplicated deliveries in low-risk women [19, 104]. Basic mental health care services are provided in primary care by GPs and mental health practice nurses and, after referral, by psychologists and psychotherapists. More severe mental health problems can be treated in secondary care services, on referral by a GP [19].

All Dutch residents are registered in one general practice [20]. Last decade, collaboration among practices has increased, moving to larger teams and organizational networks, including other disciplines, such as physical therapists, psychologists, and community nurses [104].

4.1.4.2. Secondary care

Hospital and specialist care (except emergency care) are accessible only upon GP referral; only 4 percent of (appointments) (consultations) with a GP result in a referral to secondary care [21].

4.1.4.3. Outpatient specialist care

Almost all specialists are hospital-based and are either in group practice (40-45%, paid under fee-for-service) or on salary (most but not all in university clinics). Since 2015 specialist fees (as part of Diagnosis Treatment Combinations) are freely negotiable as a part of hospital payment. During the last decade, the proportion of medical specialists working on salary has increased considerably. There is a nascent trend of working outside hospitals—for example, in growing numbers of ambulatory surgery centres—but this shift is marginal, and most ambulatory surgery centres remain tied to hospitals. Ambulatory surgery centre specialists are paid fee-for-service and the fee schedule is negotiated with health care insurers. Patients are free to choose their provider (following referral), but insurers may apply (?) restrictions (cost-sharing) on choice within their policies [102]. In 2016, a third insurance policy type (merely a variant of the restitution policy) has been introduced to control health care costs via providing more opportunity for selective contracting. In this so called 'budget policy', choice of specialist is restricted to contracted specialists - reimbursement for not-contracted care will be 0% [21].

4.1.4.4. Hospitals

Practically all hospital institutions are private and non-profit. There exist also independent private and non-profit treatment centres whose services are limited to same-day admissions for non-acute, elective care (e.g., eye clinics, orthopaedic surgery centres) covered by statutory insurance. Hospitals budgets are determined through negotiations between insurers and hospitals over price and volume [19]. The great majority of payment takes place through the case-based Diagnosis Treatment Combinations system (a Diagnosis-Related Group-like system) and rates of approximately 70 percent of hospital services are freely negotiable: each hospital negotiates with each insurer to set the rates. The remaining 30 percent are set nationally. In 2012, the Diagnosis Treatment Combinations system was fundamentally reformed and the number of Diagnosis Treatment Combinations was reduced from 30,000 to 4,400. Diagnosis Treatment Combinations cover both outpatient and inpatient as well as specialist costs[21].

4.1.4.5. Long term care

Long term care (LTC) in the Netherlands includes a broad range of health and social-care services for various categories of clients including persons with cognitive, physical or sensory handicaps, persons with long-term mental health problems and older persons with somatic and/or psychogeriatric problems [104] [100]. Long-term care can be institutional, in nursing homes, or community- based as home nursing care [19].

Long-term care, previously financed by the Exceptional Medical Expenses Act, but since 2015 by the Long Term Care Act and Social Support Act, accounts for 44 percent of government's total health care budget. The Long Term Care Act covers most expenditures, such as the costs of personal and nursing care, counselling, medical treatment and accommodation. Cost-sharing for long-term care depends on the number of people within the household, annual income, indication, and assets (and length of stay). In 2011, co-payments covered 7.2% of total spending. Health care insurers are formally responsible for implementing the Long Term Care Act, but delegated this task to regional care offices (Zorgkantoren). The Centre for Needs Assessment (Centrum Indicatiestelling Zorg) is commissioned by government to carry out eligibility assessments, which is dependent on a patient's situation, needs and the ability of informal caregivers to help. Patients, their relatives, or their healthcare providers can file a request with the Centre for Needs Assessment, which then sends its decision to a care office (Zorgkantoor). Municipalities are responsible for services including household services, medical aids, home adjustments, services for informal carers, preventive mental health care, transport facilities and assistance via the Social Support Act (Wet Maatschappelijke Ondersteuning). Municipalities are funded through the Municipality Fund, provided by national government, and local taxes. They have a great deal of freedom in organizing services - including needs assessments. As a result, there are variations and to some extent inequalities in access to care [21].

4.1.4.6. Integrated care (Ketenzorg)

Although not originally developed for this purpose, care standards (clinical practice guidelines) are used as a purchasing instrument within the Dutch bundled payment approach as the care can be organized in so called chains (chain Diagnoses Treatment Combination (DTC), comparable to 'Diagnoses Related Groups' (DRC's); in Dutch "keten-zorg", "keten-diagnose-behandelingscombinatie" or "keten-dbc") and purchased through a bundled-payment contract. Main objectives of this approach are to improve the effectiveness and quality of care and to ensure affordable costs. Bundled Payment, also known as "case rates"," is a single payment for all services related to the treatment/management of a specific condition, possibly spanning multiple providers in multiple settings. Providers would assume financial risk for the cost of services for a particular condition as well as costs associated with preventable complications. It is assumed that this improves multidisciplinary collaboration and affordability of health care for patients with chronic diseases. [105-109]. A bundled-payment approach to integrated chronic care is used nationwide for diabetes, Chronic Obstructive Pulmonary Disease, and cardiovascular risk management.

In the Netherlands, insurers pay a single fee to a principal contracting entity—the "care group"—to cover a full range of chronic disease services for a fixed period. The care group is a legal entity formed by multiple healthcare providers, often exclusively general practitioners, which assumes clinical and financial responsibility for all assigned patients in the care program and either delivers services itself or subcontracts with other providers. The price for the bundle of services is freely negotiable by insurers and care providers. This allows flexibility in developing the different models. Health insurers purchase the services and care as described in the care standard from a general contractor called the care group, which ends up in a so called bundled payment contract. The care standard serves therefore also in the cost negotiations, making these more structured since care has to be delivered and purchased in accordance with the care standard. At the same time the insurer is stimulated to negotiate the lowest price possible, with the expected result that the care group will rearrange and divide the different tasks as efficiently as possible. Bundled payment contracts should furthermore allow to overcome major stumbling blocks to collaborative multidisciplinary efforts, caused by often fragmented funding structures of the respective components of care for chronic conditions and the lack of funds for components that do not directly involve treatment or care but which are essential for delivering cohesive care (coordination of health care services, information technologies, collecting and reporting of reflective feedback data, etc.) [105, 107-110].

Care groups are relatively new actors in the Dutch health care system and are being established to improve the quality of chronic care. The term care group refers to the principal contracting organisation of an integrated bundled payment contract, not to the team of health care providers that are the members of the juridical entity who work together to deliver the actual care. The idea is that acting as one contractor will stimulate the care group to collaborate more efficiently and form an integrated group containing all the professional disciplines involved in the contracted care. Based on the bundled payment contract, the care group assumes financial and clinical accountability for organising the care and ensuring its delivery to all assigned patients and in turn subcontracts individual care providers (like general practitioners, dieticians, ophthalmologists, laboratory services etc.) or delivers parts of the services itself for the various components of care [107, 109].

4.1.4.7. Governance

At the national level, the Health Council advises government on evidence-based medicine, healthcare, public health, and environmental protection; the newly established Dutch Health Care Institute (formerly known as the Health Care Insurance Board) advises government on care, professions and training, and the insurance system (content of the basic benefit package, risk-adjustment).The Medicines Evaluation Board oversees efficacy, safety, and quality of medicines. Health technology assessments (HTAs, including cost-effectiveness analysis) are carried out or commissioned by the Health Council and the Dutch Health Care Institute, but decisions about the benefit package rest with the Minister. The Dutch Health Care Authority has primary responsibility for ensuring that the health insurance market, the health care purchasing market, and the health care delivery market function appropriately (e.g., they set prices for 30 percent of Diagnosis Treatment Combinations), while the Dutch Competition Authority (Autoriteit Consument en Markt) enforces anti-trust laws among both insurers and providers.

Diagnosis Treatment Combination Maintenance (DBC-Onderhoud) is an independent organization responsible for the design, construction, and maintenance of the Diagnosis Treatment Combinations system.

With the 2006 health care reform, a regulated market system was created which is not compatible with extensive central planning [98]. As a consequence the government has changed its role from direct steering of the Dutch health care (and wellbeing) system to safeguarding the process by controlling quality, accessibility and affordability of health care and monitoring for undesired market effects [98].

Only a few instruments have been left to the central government to directly interfere in the health care system, such as for example setting the budget for health care expenditures, setting tariffs and performance directions for health care services if not negotiable (based on advice by the Dutch Health Care Authority (Nederlandse Zorgautoriteit, NZa)), extending the share of freely negotiable services, setting public health targets, deciding capacity in long-term care institutions (budget allocation based on advice by the Dutch Health Care Institute (previously the Health Care Insurance Board (College voor zorgverzekeringen, CVZ; named Ziekenfondsraad before 1999)) creating the preconditions for quality, accessibility, safety and affordability of the care for people with chronic conditions [98].

The central government sets and revises the contents and the size of the basic insurance package [19] [99]. It is advised on these issues by the independent authority responsible for the basic health insurance package, the Dutch Health Care Institute (Zorginstituut Nederland) [99]. The government also pays the so-called “healthcare allowance” (zorgtoeslag) and sets the rules for risk adjustment among health insurers and levies social health insurance contributions via employers and income taxes to fund complementary health-related social security schemes covering sickness and disability benefits (also institutional long term care) but its operational role is very limited: delivery of services is largely delegated to private initiative, non-governmental organizations and local authorities [19].

Negotiation on price and quality is regulated by the supervisory bodies and is being introduced gradually [19].

The Health Care Inspectorate (IGZ) supervises the quality and accessibility of healthcare: it investigates accidents and complaints about healthcare and takes appropriate measures [19].

The Dutch Health Care Authority (Nederlandse Zorgautoriteit NZa) is in charge of monitoring the proper functioning of the healthcare markets and the provision of proper care. It imposes tariff and performance regulations, defines the – negotiable – units of care that providers can declare and can set rules for care providers and health insurers to increase their transparency [19].

The Dutch Health Care Institute (Zorginstituut Nederland, ZiNL, before known as CVZ (College voor Zorgverzekeringen)) advises the Minister on the quality, accessibility and affordability of the healthcare system and the basic health benefit package [19].

The Dutch Organization for Health Research and Development (ZonMw) holds an overarching role in funding health (care) research and promotes the application of knowledge for the benefit of health and health care [19].

4.2. Diabetes in the Netherlands

4.2.1. Supporting policies and governance

In the Netherlands, the policy for diabetes is based on four elements: 1) the Netherlands Diabetes Federation (NDF) care standard as basis for the quality of care, 2) the integration of prevention in care, 3) stimulating self-management by patients and 4) stimulating the formation of multidisciplinary teams [107].

Therefore the Ministry of Health, Welfare and Sport started in 2008 to promote an integrated, programmatic approach of diabetes (launched through the Nationaal Actieprogramma Diabetes funded by the Ministry, 2009-2013, € 10 million). Its objectives included implementing the NDF care standard for diabetes to slow down the increase in the number of people with diabetes, to reduce complications in diabetes patients and to focus on five subthemes for which instrumental objectives were formulated: ‘Prevention’, ‘Position of the patient and client’, ‘Quality, organization and knowledge’, ‘Rules and funding’ and ‘E-communication and ICT facilities’.

These subthemes are in line with the concepts of the Expanded Chronic Care Model which also advocates integrated care, disease management and the use of evidence-based care guidelines [107, 108].

4.2.2. Organization and funding of health care

4.2.2.1. Work division between primary and secondary care

Care for diabetes type 2 patients in the Netherlands is mainly provided in primary care and delivered by care groups. Over the years, these care groups have delegated gradually the care for diabetes patients, educating patients and encouraging overall adherence to treatment to other professional disciplines, both within the primary care sector and between the secondary and primary care sectors (vertical substitution): most of standard check-ups are performed by specialized practice nurses or diabetes nurses under the supervision of a general practitioner, many eye examinations previously carried out by ophthalmologists had now been reallocated to optometrists, retinal graders, specialised nurses or general practitioners and insulin-dependent patients without complications are increasingly managed within GP practices rather than by secondary care providers [107, 111].

The care for patients with diabetes type 1 and more complex type 2 patients, for example with insufficient improvement, acute dysregulation or multiple complications, is mainly provided in secondary care by internal medicine physicians and diabetes nurses, who are surrounded by a multidisciplinary team of professionals ('complex care') [107, 110]. Together with the patient, multidisciplinary treatment teams in hospitals or diabetes centres set up an individual care plan comprising for example a treatment description, agreements with care providers on treatment and education, and an emergency plan.

4.2.2.2. Diabetes care standard

As for other pathologies, a care standard is available for diabetes. The care standard describes standards for good practice in diabetes care (e.g. how often a diabetic patient should be seen by the treatment team, when a referral to a specialist is necessary, the sharing of patient information). The care standard has been developed and is continuously updates by the Dutch Diabetes Federation (Nederlandse Diabetes Federatie (NDF)).The Dutch Diabetes Federation is an umbrella organisation uniting patients, health care professionals and researchers. The Federation is committed to improving quality of care and life for diabetes and acts as a representative and spokesman vis-à-vis authorities, media and other actors in health care.

A care standard differs from clinical guidelines, in that it is a general overarching framework outlining the content, organization and quality of services, treatment and multidisciplinary approach to be delivered to people with a specific condition: it provides health care practitioners, patients and funding bodies with a specification of the components of care (including paramedical treatment and prevention), general treatment goals and tools to evaluate the quality of care. Clinical guidelines on the other hand describe the content of medical care to be provided. In the Netherlands, the NDF care standard for type 2 diabetes mellitus is promoted as the norm for the content, organization and quality of generic multidisciplinary diabetes care [107-109].

The care standard is constantly being updated and extended, and is based on evidence-based guidelines. A patient version of the care standard (the Zorgwijzer) has been produced as well to explain what can be expected from health care providers [108].

The care standard for type 2 diabetes does not apply to type 1 diabetes in adults and children. To fill this gap, a two-part addendum for type 1 diabetes is available, in which the care for adults and for children and adolescents with diabetes type 1 is described. Indicated prevention was also added to the care standard by means of an addendum in 2012 [107].

Although not originally developed for this purpose, the care standard is in addition used as a purchasing instrument within the Dutch bundled payment approach as the care can be organized in so called chains (chain Diagnoses Treatment Combination (DTC), comparable to 'Diagnoses Related Groups'

(DRC's); in Dutch "keten-zorg", "keten-diagnose-behandelingscombinatie" or "keten-dbc") and purchased through a bundled-payment contract. Main objectives of this approach are to improve the effectiveness and quality of care and to ensure affordable costs. Bundled Payment, also known as "case rates"," is a single payment for all services related to a specific treatment or condition, possibly spanning multiple providers in multiple settings. Providers would assume financial risk for the cost of services for a particular treatment or condition as well as costs associated with preventable complications. It is assumed that this improves multidisciplinary collaboration and affordability of healthcare for patients with chronic diseases [105-109].

The Netherlands can be regarded as unique in the use of the care standard for diabetes. The first Dutch care standard for diabetes was published in April 2003. This coincided with the development of the 'bundled payment' approach for integrated chronic care (2003). Both were included as elements within the integrated, programmatic approach of chronic diseases and the bundled payment approach has laid the foundation for delivering and funding diabetes care in accordance with the care standard [107].

4.2.2.3. Care groups

In the Netherlands, the price for the bundle of services is freely negotiable by insurers and care providers. This allows flexibility in developing the different models. Health insurers purchase the services and care as described in the care standard from a general contractor called the care group, which ends up in a so called bundled payment contract. The care standard serves therefore also in the cost negotiations, making these more structured since care has to be delivered and purchased in accordance with the care standard. At the same time the insurer is stimulated to negotiate the lowest price possible, with the expected result that the care group will rearrange and divide the different tasks as efficiently as possible. Bundled payment contracts should furthermore allow to overcome major stumbling blocks to collaborative multidisciplinary efforts, caused by often fragmented funding structures of the respective components of diabetes care and the lack of funds for components that do not directly involve treatment or care but which are essential for delivering cohesive care (coordination of health care services, information technologies, collecting and reporting of reflective feedback data, etc.) [105, 107-110].

Care groups are relatively new actors in the Dutch health care system and are being established to improve the quality of chronic care. The term care group refers to the principal contracting organisation of an integrated bundled payment contract, not to the team of health care providers that are the members of the juridical entity who work together to deliver the actual care. The idea is that acting as one contractor will stimulate the care group to collaborate more efficiently and form an integrated group containing all the professional disciplines involved in diabetes care. Based on the bundled payment contract, the care group assumes financial and clinical accountability for organising the care and ensuring its delivery to all assigned patients and in turn subcontracts individual care providers (like general practitioners, dieticians, internal medicine physicians, etc.) or delivers parts of the services itself for the various components of diabetes care [107, 109, 110].

4.2.3. Evaluation

Two evaluation studies have been performed. Three years after the introduction of the care standard and the Dutch bundled payment arrangements for the management of diabetes mellitus, provision of care was largely in line with the NDF Health care standard. The effects of bundled payments on the quality of diabetes care could not yet be clearly interpreted, partly due to a lack of transparency and partly due to the use of insufficiently informative indicators which are not standardised nationwide (in- and exclusion criteria, case-mix, registration and extraction problems, etc.). Another concern is that much of the information is produced by providers themselves, raising questions about impartiality. Mild to moderate improvements were observed on both process and outcome indicators, but which could to a certain extent be explained as well by better record-keeping discipline. In addition, it is unclear whether these changes are clinically relevant or whether they may have an impact on 'hard' medical outcome measures like cardiovascular illness and mortality. It was not yet possible to identify long-term effects, such as the prevention or delay of disease complications because this would require analysis of multiple years which is not really feasible with the patient record systems now in use and because

of the lack of accurate data on patient turnover, 'patient attrition' from disease management programmes and transfers to or from secondary care. Widespread reallocation and delegation of tasks (vertical substitution) was observed which calls for more quality assurance measures to counter the potential risks. Comorbidity and polypharmacy, which are common in diabetes patients, were found not to be high on the agenda of the multidisciplinary management protocols used by the care providers with e.g. a limited involvement of pharmacists as a consequence. Coordination among care providers improved, as did protocol adherence, attendance at multidisciplinary consultations, and further training of providers to facilitate protocol-driven work processes and use of the electronic health records. Patient participation was still inadequately developed. Care providers did not yet provide systematic and integrated support for self-management (e.g. group education sessions, electronic patient portals that enabled patients to log into their patient files from home, etc.) nor did they have any concrete strategies in this regard. Moreover, patients were not always informed about their participation in a care program which made them clients of a care group in addition to their GP-patient relationship. Patients expressed positive judgments about the cooperation and coordination between their various health care providers. ICT systems did not yet satisfy the growing needs for interchange of data among all involved care parties and did not yet meet all parties' data needs due to a lack of uniformity how to register health care quality information, because integrated health care information systems (IISs) could still not be accessed by all associated health care providers and because the integration between the IISs and the GP information systems (GISs) was anywhere near satisfactory. Also health insurance companies were not always satisfied about the quality of the accountability information they received [105, 110-112].

Health care standards and the development of performance and quality indicators should be further strengthened through inclusion of indicated prevention interventions, a clear definition of the services to be included in the bundled pricing arrangements (with possibility of task delegation, substitution and reallocation), specification of which data are to be recorded and how they are to be operationally defined, and specification of the tasks and activities that do not qualify as direct care provision but are essential to the integrated delivery of diabetes care (information and communication technology, coordination activities, record-keeping and data and accountability reporting) as it was found that it is difficult securing funds in the bundled payment contracts for ancillary activities such as these, which are not mentioned in the health care standard. Bundled payment arrangements need also to be harmonised with existing pricing mechanisms to avoid double insurance claims and 'bypass constructions' (claiming fees for diabetes services in circumvention of the bundled payment agreements). The feasibility of integrating medication into the bundled pricing arrangements deserves study as does also the inclusion of the development, implementation and strengthening of effective methods of patient participation. Elaborating new health care standards or updating existing ones should be based solely on the necessary care services as the role of care standards in the care purchasing process raises the risk that other considerations may influence the formulation process. Finally, bundled pricing arrangements focus only on one particular disease making that the issue of management for multi-morbid patients and provision of care via multiple bundled payment systems (overlap between programs) needs a solution (through approaches such as population management, the INCA-model with stepped care modules, etc.) [110, 112-115].

4.3. Stroke/CVA/cardiovascular diseases and risk management

4.3.1. Organization and funding of health care

In the Netherlands, individuals who need integrated care, such as stroke patients, receive integrated care in collaborative networks of health and social care providers [116]. A stroke service is a network of providers working together during the acute, the rehabilitation and the chronic phase of care for stroke patients [117]. A large number of disciplines and organisations such as hospitals, nursing homes, rehabilitation centres, general practitioners and home care providers, are involved in the provision of stroke care. Stroke services aim to deliver coherent and patient centred integrated care [118]. This requires a regional setting with all relevant health and social care stakeholders and the local community, working together to provide multidisciplinary, coordinated care and support [119]. Currently, there are approximately 75 stroke services in the Netherlands [118].

In the Netherlands integrated stroke care started its development in the nineties with the organisation of specific stroke units in hospitals and nursing homes. Next steps were further development into integrated stroke networks or services. This development was stimulated by the Dutch Heart Association and a number of national initiatives [117]. A number of innovations such as the development of care pathways, indicator frameworks and care standards followed. This resulted in more coherent care for stroke patients, increased satisfaction among patients and caregivers, and also leading to more cost-effective care [105].

In 2006 the Stroke Knowledge Network of the Netherlands ("Kennisnetwerk CVA Nederland") was founded by professionals and coordinators in stroke care. The network searched for a conceptual framework that could help them to assess and improve the organisation of integrated stroke care. The network adapted the Development Model for Integrated Care as their framework for this purpose [120].

In addition to the organisation of stroke care, the Netherlands also pay attention to cardiovascular risk management (CVRM). This includes diagnostic, treatment and follow-up of risk factors regarding cardiovascular disease, inclusive life style guidance for patients with an increased risk. Care programs target patients with increased risk of cardiovascular disease in order to prevent the occurrence or progression of the disease [121].

4.3.1.1. Bundled payment

In addition to diabetes, cardiovascular risk management is a chronic disease for which a bundled payment approach (so called chain care or ketenzorg in Dutch) is nationwide implemented in the Netherlands. In this approach insurers pay a single fee to a principal contracting entity—the "care group"—to cover a full range of chronic disease services for a fixed period. The care group is a legal entity formed by multiple healthcare providers, often exclusively general practitioners, which assumes clinical and financial responsibility for all assigned patients in the care program and either delivers services itself or subcontracts with other providers [105-109]. Care standards are used as a purchasing instrument within the Dutch bundled payment approach offering care in so called chains (chain Diagnoses Treatment Combination (DTC); in Dutch "keten-zorg", "keten-diagnose-behandelingscombinatie" or "keten-dbc").

The "chain" (keten-DBC) cardiovascular risk management describes the organisation of cardiovascular risk management and the care for cardiovascular disease in primary care. The goal is to provide optimal cardiovascular risk management to patients with an increased risk for cardiovascular disease and patients who already suffered from cardiovascular disease and prevent new manifestations and complications of cardiovascular disease [121].

4.3.1.2. CVRM care standard

A care standard differs from clinical guidelines, in that it is a general overarching framework outlining the content, organization and quality of services, treatment and multidisciplinary approach to be delivered to people with a specific condition: it provides health care practitioners, patients and funding bodies with a specification of the components of care (including paramedical treatment and prevention), general treatment goals and tools to evaluate the quality of care. Clinical guidelines on the other hand describe the content of medical care to be provided. In the Netherlands, the NDF care standard for type 2 diabetes mellitus is promoted as the norm for the content, organization and quality of generic multidisciplinary diabetes care [107-109].

The care standard is constantly being updated and extended, and is based on evidence-based guidelines. A patient version of the care standard (the Zorgwijzer) has been produced as well to explain what can be expected from health care providers [108].

The care standard can be used to develop and organize a local or regional CVRM care program. Although not originally developed for this purpose, the care standard is used as a purchasing instrument within the Dutch bundled payment approach as the care can be organized in so called chains (chain Diagnoses Treatment Combination (DTC), comparable to 'Diagnoses Related Groups' (DRC's); in Dutch "keten-zorg", "keten-diagnose-behandelingscombinatie" or "keten-dbc") and purchased through a bundled-payment contract [122].

4.3.1.3. Care groups

Health insurers purchase the services and care as described in the care standard from a general contractor called the care group, which ends up in a so called bundled payment contract. The care standard serves therefore also in the cost negotiations, making these more structured since care has to be delivered and purchased in accordance with the care standard. At the same time the insurer is stimulated to negotiate the lowest price possible, with the expected result that the care group will rearrange and divide the different tasks as efficiently as possible. Bundled payment contracts should furthermore allow to overcome major stumbling blocks to collaborative multidisciplinary efforts, caused by often fragmented funding structures of the respective components of diabetes care and the lack of funds for components that do not directly involve treatment or care but which are essential for delivering cohesive care (coordination of health care services, information technologies, collecting and reporting of reflective feedback data, etc.) [105, 107-110].

Care groups are relatively new actors in the Dutch health care system and are being established to improve the quality of chronic care. The term care group refers to the principal contracting organisation of an integrated bundled payment contract, not to the team of health care providers that are the members of the juridical entity who work together to deliver the actual care. The idea is that acting as one contractor will stimulate the care group to collaborate more efficiently and form an integrated group containing all the professional disciplines involved in CVRM. Based on the bundled payment contract, the care group assumes financial and clinical accountability for organising the care and ensuring its delivery to all assigned patients and in turn subcontracts individual care providers (like general practitioners, dieticians, internal medicine physicians, etc.) or delivers parts of the services itself for the various components of diabetes care [107, 109, 110].

In the Netherlands GPs are assigned a central role in the detection and adequate treatment of cardiovascular risk factors and diseases [123]. Cardiovascular diseases are preventable if risk factors are timely identified and treated. To encourage prevention, national multidisciplinary guidelines have been developed in 2006, and updated in 2011 and 2012 [123].

4.3.1.4. Individual care plan

Patients participate in the development and adherence to their individual care plan. Also an integrated approach is pursued. Care providers are stimulated to cooperate in order to come to optimal outcomes [121].

For each team of care providers a coordinator is appointed. This central care provider makes sure that agreements are coherent, aligned with patients' needs and followed [121].

4.3.1.5. The CVRM care process

The CVRM care process consists of the following stages: identification, diagnostics, the development of an individual care plan, treatment of cardiovascular risk factors, rehabilitation [124]. A patient can start cardiovascular risk management at each stage. Consequently this may take place in primary care, secondary care, during a hospital stay or stay in a rehabilitation centre. Which type of care provider is involved depends on the patient's risk profile, (co)morbidity and preferences. Potentially involved care providers are: general practitioners, pharmacists, (specialised) nurses, dieticians, physiotherapists, internists, cardiologists, neurologists, vascular surgeons, and psychologists. Patients can participate in several health promotion programs such as to quit smoking, self-help groups, and rehabilitation.

4.3.2. Patient participation

The CVRM care standard emphasises active patient involvement in risk management. Adequate risk management builds on a strong partnership between the patient and the care providers. Patients must be involved in all decisions and must understand what increased risk means, what the treatment consists of, what the influence is of life style etc. Self-management is stimulated to increase patient involvement. To support shared decision-making, a CVRM decision aid is available[rr] [124].

4.3.3. Evaluation

4.3.3.1. Individual feedback

Quality of CVRM is assured by means of individual feedback from care providers to patients. Through the comparison of experiences with predefined targets, effectivity of the risk management is evaluated. Targets are described in an individual care plan. Experiences of both the patient and the care providers are registered. Care providers receive structural feedback both on the level of individual patients as on the team level. Teams are anonymously compared to other teams [124].

4.3.3.2. Quality indicators

The care standard includes two types of quality indicators: one related to the content of care, the other related to the way care is organised [124].

4.4. Haemophilia

4.4.1. Supporting policies and governance

Although a formal haemophilia registry is still lacking in the Netherlands, the estimated number of patients with haemophilia is 1,600 to 1,800, including around 800 with severe haemophilia [125].

Accusations of negligence over the handling of the risk of infection (HIV, infectious hepatitis) in 1995, obliged the Minister of Health, Welfare and Sport to pay more attention to the regulation of care for haemophilia patients [126].

In 1999, The Ministry of Health, Welfare and Sport in collaboration with the physicians from the Dutch Haemophilia Centres Organisation (Nederlandse Vereniging van Hemofiliebehandelaars, NVHB) and the Dutch Haemophilia Patient Society (NVHP), wrote a haemophilia management policy stating that care for patients with haemophilia should be centralised in haemophilia treatment centres to ensure quality of care by concentrating expertise. No distinction was made between national and regional centres, nor between treatment centres and comprehensive care centres at that time. In 2000 this finally resulted in including haemophilia care under article 8 of the Special Medical Treatments Act, the assignment of a separate national budget for the purchasing of clotting factors by 16 dedicated centres only and the exclusion of haemophilia medication from standard hospital budgets. To ensure treatment in hospitals nearby for all patients, these centres were geographically distributed over the country. Most of these centres treated adults only [125, 126].

In 2002 and 2003 the 1999-haemophilia management policy was evaluated and only 6/16 centres were found to comply with the standards of care [125].

[rr] See the website Kies Beter: www.kiesbeter.nl

4.4.2. Organization and funding of health care

In the Netherlands, health insurance is mandatory and up to 2012 all costs for clotting factor concentrates were covered without restriction. Since 2012, hospital budgets, including budget for clotting factor concentrates, are fixed at the level of 2010, with a maximum annual growth of 2.5%. As consumption shows a yearly increase of around 5 %, among others due to increasing survival rates and life expectancy of patients and elderly patients needing more care, these budgets prove to be insufficient. In 2012 financing of care for haemophilia was transferred to private health insurance. In consequence the separate national budget for the purchasing of clotting factors ceased to exist and health insurers became theoretically entitled to negotiate indiscriminately with any provider to purchase haemophilia care. Furthermore, in 2012 compensation of health insures for incurred costs higher than estimated by the risk adjusted capitation was abolished and in 2014 risk adjusted capitation through the Health Insurance Fund became limited to 6%. Both developments increase the possibility of assigning higher weight to cost considerations and risks by health insurers and hospitals and might impact quality and accessibility of care for haemophilia patients. Therefore the Minister of Health, Welfare and Sport decided in March 2016 to keep haemophilia care in the Special Medical Treatments Act and it is expected that future reimbursement of haemophilia care by private insurers will be conditional on certification of the HTCs. Costs for clotting factor concentrates and haemophilia medication are furthermore considered as add-on drugs, meaning they are invoiced to the health insurers separately by the hospitals and are not included in the cost of a Diagnoses Treatment Combination (DTC) chain. NZa is the organization in charge of managing and updating the official lists with add-on drugs (orphan drugs, clotting factors, etc.) [125-128].

4.4.3. Evaluation

4.4.3.1. Quality assurance

In 2009 the NVHB took the initiative to start work on a new quality system for haemophilia care in the Netherlands. With financial support of the Ministry of Health a formal development process was undertaken from 2009 to 2011. First, a multidisciplinary project group consisting of physicians and nurses involved in haemophilia care and patient representatives undertook a study of available literature on quality standards in collaboration with the institute for harmonisation of quality standards in clinical care (Stichting HKZ). Secondly, concept standards were defined, which were validated in two treatment centres to test their use in clinical practice. Next, the concept standards were evaluated by members of the NVHB, patients, health insurance representatives and regulators. The final version of the standards of care was then approved by Central body of Experts on quality standards in clinical care (CCvD-Z/W) and submitted to the regulatory body at the Dutch Ministry of Health which endorsed it in March 2013 [125].

Certain of these 2013-quality standards are considered mandatory for certification as a haemophilia treatment centre. These include: a minimal number of patients treated yearly; a minimal yearly number of follow up contacts per patient; a patient mix of adults and children (to guarantee better transition of care for children to adult care, optimal genetic counselling for haemophilia carriers and integrated care for affected women and/or new-borns during pregnancy and at delivery); minimal staffing and training requirements (internist- and paediatrician-haematologists, specialised haemophilia nurses, physical therapists, orthopaedic surgeons, rehabilitation doctors, clinical genetic specialists and social workers or psychologists); provision of curative and preventive care in case of bleedings; offering coordination of care before and after surgical procedures or other interventions; provision of instruction and teaching programmes for both children and adult patients; access in case of need to haematologists (hepatitis B, C and V-infections through blood products), specialists in infectious diseases (HIV -infections through blood products), gynaecologists, dedicated dentists or surgeons for dental care; minimal frequencies of multidisciplinary team meetings; having dedicated laboratory facilities at their disposal, offering a minimal set of tests on a 24 hours basis;

and having adequate supplies of coagulation factor concentrates for all bleeding disorders available at all times. For every patient an individual treatment plan is made and available in the electronic patient files. In this treatment plan, the diagnosis, treatment in case of acute bleeding or surgery, and co-morbidity are specified. Routine molecular diagnostic analysis of mutations on the other hand are performed and centralised in four treatment centres [125].

Starting from 2014, candidate centres have to apply for formal certification as a Haemophilia Treatment Centre (HTC), which may be granted after a 1–2 day visit by a team of expert auditors. The certificate will be evaluated yearly and audits will be performed every three years [125].

4.5. Female Genital Mutilation

4.5.1. Supporting policies and governance

In the Netherlands (as in Belgium) all types of FGM are considered as serious maltreatment and therefore forbidden by law. All types of FGM are considered as irreversible injuries with considerable risk for enduring physical and psychological complaints [129, 130].

Health care professionals having the Dutch nationality or officially living in the Netherlands, who carry out FGM or provide some kind of support to FGM can be prosecuted, even if the FGM was carried out abroad.

The Dutch Health Inspectorate made an overview of all legislation relevant to FGM [131]. Every case of FGM must be reported to the Health Inspectorate. Every care provider suspecting the intent to mutilate a girl, must inform parents about the Dutch norms and the fact that the practice is prohibited by the Dutch law. Every suspicion of a planned or already executed mutilation should be reported to the hotline child abuse (Advies- en Meldpunt Kindermishandeling, AMK).

4.5.2. Notification code domestic violence (Meldcode intrafamiliaal geweld)

In the Netherlands care providers and institutions have the obligation to have a notification procedure for (the suspicion) of domestic violence, including FGM.

4.5.3. Prevention FGM

Between 2006 and 2009 a pilot prevention project has been carried out regarding the prevention, the early detection and registration of FGM. The pilot used an integrated “chain” (keten) approach, meaning that several disciplines were involved: youth health care, midwives, gynaecologists, GPs and hotlines child abuse.

The health care department of 6 pilot cities, supported by the Centre of Expertise on Health Disparities (Pharos) and the Federation for Dutch Somali Associations (FSAN) were responsible for the project. Key persons from communities at risk were trained to provide information sessions and home visits to make FGM negotiable. Key persons could refer victimized women to a specialised FGM consultation. During this consultation anamnesis is done by a specialised nurse or physician. In addition physical and psychological complaints are linked with mutilation, treatment options are discussed and if the client agrees she is referred to the right health care professional. The number of consultations necessary depends on the needs of the client. The client can bring a family member or friend to the consultation. Interpreters are available. The nurse or physician doing FGM consultations follows referred clients by means of phone calls. From 2010 onwards the pilot has been rolled out in the whole country.

4.5.4. Example protocol medical care after FGM

An example protocol for medical care after FGM has been developed encompassing prevention, guidance and treatment to victimised women[ss].

[ss] The protocol could be found here: http://www.pharos.nl/documents/doc/modelprotocolversie2.pdf

4.6. Summary table

Table 4 – Organisation and financing of care for diabetes, stroke, haemophilia and female genital mutilation in The Netherlands

	Health Conditions And Diseases			
	Diabetes	*Stroke*	*Haemophilia*	*Female genital mutilation*
Elements of the health care system				
• **Supporting policy**	No specific plan for diabetes	No specific plan for stroke, included in the integrated care policy	Vision plan for haemophilia (1999) [132]	No specific plan
• **Organisation**	Multidisciplinary treatment teams in hospitals or diabetes centres.	Integrated care in collaborative networks of health and social care providers [116] "*In 2006 the Stroke Knowledge Network of the Netherlands ("Kennisnetwerk CVA Nederland") was founded by professionals and coordinators in stroke care*".	Collaboration between the GP and specialized treatment centres (16 in the whole country)	Availability of care guidelines for health care professionals caring for FGM victims [133]
• **Funding**	Included in the regular funding system	Included in the regular funding system	Included in the regular funding system	Included in the regular funding system
• **Patient participation**	Care standards are developed and updated by the Dutch Diabetes Federation (Nederlandse Diabetes Federatie (NDF)), an umbrella organisation uniting patients, health care professionals and researchers	Dutch Heart Association	Nederlandse Vereniging van Hemofiliepatiënten : patient are associated in the development of guidelines for health care professionals and validated the quality standards for the haemophilia treatments centres[125]	None
• **Evaluation**	Included in the mainstream quality assessment	Assessment of the integrated stroke care service based on the Development Model for Integrated Care [116]	Evaluation of the haemophilia treatments centres based on national quality standards [125]	None

5. CROSS COMPARISON

5.1. General comments

Overall, **diabetes** and **haemophilia** appear to be the most structured and organized health care programs. Lots of efforts have been put on patient education and patient self-management for both conditions. The structuration of health care for haemophilia is mostly influenced by the European regulations but also by the high costs of the treatments. Regarding diabetes, the structuration is motivated by the high prevalence of the disease (at least for T2DM), the risk of complications and the burden of costs on the health care system (and the whole society). Besides, both conditions offer lots of opportunities for patient empowerment. Patients associations are associated with the health care authorities in decision-making processes but also in program development and evaluation (this latter is particularly true for Scotland where there is a massive reform of public institutions with an affirmed objective of transparency).

Stroke appears as the most blurred health care program. In both countries, rehabilitation care could be delivered either at home, either in specialised centres. Focus has been put on prevention, early response and treatment rather than on rehabilitation – although in Scotland, there are managed clinical networks for stroke and, in the Netherlands, specific care standards have been developed. Patient associations are also active partners in decision-making in Scotland and user-friendly material is available for patients in the Netherlands.

When looking at care for victims of **female genital mutilations**, in both countries, priorities have been the awareness and the training of health care professionals regarding this specific issue. Legal aspects and protection of children were both highlighted. There is no official care program in France, despite the existence of reference centres and non-profit associations. In Scotland, the health authorities have published a Scottish model of interventions while the Netherlands could benefit from the care model and recommendations developed by Pharos. This difference could be partially explained by the different perspectives on culture and ethnicity between France on the one hand and Scotland and the Netherlands on the other hand.

5.1.1. Provision of a setting for the organization and provision of multidisciplinary rehabilitation and care

For all conditions but FGM in France, the organisation of the HCS supports the provision of multidisciplinary rehabilitation and care. For example, the ASALEE project supports the inclusion of nurses within the care programs for diabetic patients. As health and social care are integrated in Scotland, community health partnership (CHP) cover not only for health issues but also for social support, social benefits and other activities that may support the rehabilitation process of the patients. In the Netherlands, integrated care is provided thorough networks of providers, supporting the collaboration between hospitals and primary care services.

5.1.2. Provision of space for innovative, future-oriented practices

In France, the ASALEE project supports the delegation of medical acts to nurses for the follow-up of diabetic patients. This helps to reduce the workload of GP by reorienting the delivery of health care to other qualified health care professionals. Similarly, the SOPHIA project enhances patient education through telehealth.

In Scotland, health care is always provided by an integrated health and social care team, able to cope with the complexity of both the chronic diseases and the social issues of the patients.

5.1.3. Simulation of specialization, concentration of expertise and networking

While Scotland is promoting integrated health and social care, France and the Netherlands are pushing towards a care pathway system – with all systems focusing on patient-centred care.

The three countries support the networking for diabetes and haemophilia – with various degrees of development. In diabetes care, these networks support the provision of additional free services for the patients and supports the coordination of care, especially in France and Scotland. Scotland has also managed clinical networks for stroke, with activities ranging from early detection to rehabilitation and palliative care while the Netherlands support integrated collaborative networks for stroke care.

5.1.4. Enhancing ease of financing

The ALD system in France enhances the ease of financing for chronic patients. Moreover, the health insurance also funds initiatives to improve patient education and empowerment (the SOPHIA project).

As the health and social care systems in Scotland are free of charge at the entry point, the need for easing the financings appears less important than in France or in the Netherlands. However, despite the comprehensive coverage of the NHS Scotland, some expensive treatments are not covered and need to be approved on an individual basis by the local NHS Boards. There is no specific funding mechanism for the 4 investigated conditions in the Netherlands.

5.1.5. Provision of low-threshold and affordable care to patients

As the Scottish HCS is free at the entry point, affordability of care is not a concern for Scottish patients. The ALD system is a major strength of the French HCS in order to provide affordable care to chronic patients. In the Netherlands, the 4 conditions are included in the mainstream funding system.

In the three countries, patients have to comply with a gatekeeping system. All Dutch residents have to be registered with a GP of their choice. In Scotland, the gatekeeping system is compulsory and based on catchment area while, in France, it is recommended but not compulsory for the overall population. However, patients with a long term affection should be registered with a GP to benefit from the co-payment exemption.

5.1.6. Factors supporting the development of ad hoc rehabilitation programs

5.1.6.1. Accountability of health care professionals

The high degree of accountability in Scotland, and to a lesser extent, in France and the Netherlands, has put the burden of the proof on the institutions and on the health care professionals rather than on the patients. The Scottish NHS boards have to develop their own local delivery and quality plan to cope as much as possible with the needs of the population they served. These plans should take into account the national policies. By integrating the health sector inside the National Performance Framework, Scotland emphasizes the need for "*a better care, better health, better value*" at all levels. To monitor the progress, Scotland issues specific indicators, integrated into routine care once reached. This calls for an adequate health information system where data are registered and up-to-date.

Similarly, in France, national plans have been regularly evaluated. In haemophilia references centres, the evaluation system includes an auto evaluation by the centre combined with on-site visits by the HAS when needed. The Dutch Health Care Inspectorate (IGZ) monitors the quality and accessibility of healthcare while the Dutch Health Care Authority monitors the proper functioning of the healthcare markets and the provision of proper care.

In the three investigated countries, one institution is accountable for the evaluation and the monitoring of the health care and health outcomes of the HCS. Evaluation is often related to the funding of the services. The Netherlands, Scotland and France have invested in performant health information system to monitor the health status of the population but also to identify progress in quality. Some data are routinely registered, e.g. the FGM in Scotland.

5.1.6.2. *Use of guidelines and standardised care protocols*

In France, the use of the PNDS supports the implementation of guidelines at practitioner level while guidelines are spread by the SIGN in Scotland. As the reimbursement of ALD is conditioned by the care protocol, this is likely to raise the use of such PNDS by health care professionals. It seems however that these guidelines mainly concern GP and medical doctors rather than other health care professionals. In the Netherlands, together with the clinical guidelines, the care standards ensure the quality of the health care delivery and are regularly updated and extended. Patient-friendly version have been developed to facilitate the communication and to explain what the patient should expect from health care providers.

5.2. Summary table

Table 5 – Key dimensions of the generic quality evaluation in France, Scotland, The Netherlands and Belgium

Countries included in the international comparison				
	France	**Scotland**	**The Netherlands**	**Belgium**
Dimensions of quality evaluation				
Responsibility	**Haute Autorité de Santé (HAS)**: coordination of the national data collection on quality and safety indicators (IQSS) and on nosocomial infections (IAS) in all healthcare facilities.	**Health Improvement Scotland (HIS):** assessment of quality and safety and report on performance.	• **Health Care Inspectorate (IGZ):** quality and accessibility of healthcare • **Dutch Health Care Authority:** monitoring the proper functioning of the healthcare markets and the provision of proper care	• **FPS Public Health:** national quality & safety plan • **NIHDI** • **Zorginspectie, Flanders** • **AVIQ, Wallonia** • **IRIScare or COCOM, Brussels**
Available quality assessments	• IQSS: measuring tools that are applied to a health status, a care practice or an event, allowing a valid measuring of health care quality and its variations in space and time, applicable at the level of health services (including patient experiences).	Quality assessment at macro / meso / micro levels aiming at improving the overall quality of the system (including patient experiences)	Patient experience, quality and performance indicators in general and specialised care	Quality assessment at macro / meso / micro levels aiming at improving the overall quality of the system (including patient experiences) but availability depends on the region of Belgium

	• Also used for planning health care policies at regional and national level; and to inform patients about the quality of care in health services			
Role of health care providers in data collection	• Data collection of indicators is compulsory: it is part of a legal obligation and is required for accreditation of the hospitals. • Health care providers collaborate with the HAS by providing the data.	• Depending on the indicators, data registration is collected by health care providers as part of the routine or by external evaluators. • Participation to quality assessment is compulsory.	Most quality assurance is carried out by providers, sometimes in close cooperation with patient and consumer organizations and insurers. The Inspectorate is more closely monitoring care for vulnerable people like the elderly, for example by carrying out more workplace visits.	Depending on the indicators, data registration is collected by health care providers as part of the routine or by external evaluators. Data collection is compulsory.
Development and selection of indicators	The HAS develops the indicators, mostly based on the requests from the Ministry of Health and the priorities in health policy, after discussions with an intersectoral steering committee	• Health Improvement Scotland selects and develops the indicators based on available evidences and legal texts • User's involvement being a major concern of the Scottish Government and of the NHS Scotland, patients and service users are regularly involved in the development of the quality approach.	• Each health profession usually has its own organization, association, college or society to advocate for professional interests as well as to contribute to scientific development and quality, including guidelines that may serve as template for the assessment of quality of care. • The Health Care Inspectorate (IGZ), the Dutch Health Care Authority (NZa) and the Health Care Insurance Board (CVZ) develop indicators.	• Indicators in the Flermish VIP² program are determined and refined by development groups, gathering mainly of clinicians, quality coordinators and data specialists. • Integreo Program : PROMS and PREMS indicators [9, 10] . • Wallonia & Brussels: the development of indicators is currently managed by the PAQS. The final set will be communicated to the public authorities beginning
Recurrence of data collection	Every two years	Dependent on the type of indicators: yearly assessment, ongoing and variable assessment, regular assessment	Annual production of quality report, supported by a systematic data collection on the effectiveness, patient centeredness and efficiency of the provided care	Dependent on the type of indicators: yearly assessment, ongoing and variable assessment, regular assessment
Types of indicators and data collection	• Structural indicators • Process indicators, via patient health records + additional data from clinicians	• Structural, process, outcomes and patient indicators via systematic registration and ad-hoc data collection	• 62 performance indicators to allow patients to choose their preferred supplier developed by the Dutch	• RHM • FINHOSTA

	• Outcomes indicators, via patient health records • Patient satisfaction, self-reported by patients	• Three distinct types of inspection: announced inspection, unannounced inspection and (un)announced follow-up inspection (for both NHS services and independent healthcare services (e.g. in the rehabilitation sector))	Health Care Inspectorate, completed by care providers. • Set of performance indicators for each health insurer, completed by care providers • Publicly reporting of approximately 115 performance indicators, covering 42 diseases, completed by the hospitals for the For the Dutch Health Care Transparency Program	• Quality of nursing care • Indicators of hospital hygiene • VIP² in Flanders: clinical, process and outcomes indicators • Under development in Wallonia & Brussels
Assessment of the quality of collected data	The quality of some indicators is controlled by the regional health agencies, on the basis on a list provided by the HAS.	Independent bodies such as the Health Improvement Scotland and Care Inspector assess the quality of the data.	The Inspectorate analyses the data, correlates the data with other sources, validates the data by means of unannounced visits to health care institutions, compares health care institutions, and makes the information publicly available.	In the Flemish VIP², a Thrusted Third Party checks the reliability and the validity of the provided data and ensures that those accessing the data respect the confidentiality and the privacy of information. Ad-hoc controls are performed
Availability of the indicators for the public	• Regulation of the publication of the indicators by a national decree. • Availability of a selection of indicators to the public. • Obligation of displaying the results for hospitals. • Official website Scope Santé gathering quality assessment	Compulsory, all results related to quality of care are available to the public.	• Publicly available information for consumer choice on waiting lists, patient satisfaction, and a few quality indicators, through a website of the Dutch Patient organization • Availability of data collected by the Dutch Health Care Institute and the Dutch Health Care Inspectorate	• Flanders: indicators and inspection reports are publicly available on the website of the Health & Care Agency . • Inspection reports related to agreement are not available to the public in Brussels and Wallonia.
Participation of the patients	Representatives in the steering committee developing the quality indicators.	Compulsory, representatives at various levels, collaboration with patient associations	• Obligation of having a representative patient council in health care organisations. • Representatives of patients in the purchasing decisions by health insurers	• Indirect involvement through the patient organisations at least for quality assessments in Flemish general hospitals. • In the Federation Wallonia-Brussels no clear evidence that patients are associated to the quality assessment

				• No formal involvement in the quality assessment of the health care system	although collaborations exist.
Incentives for indicators collection	• Inclusion of indicators in the quality-based pay-for-performance system (sanction of no data collection) • Legal obligation for data collection of indicators, related to the accreditation of the hospitals.	Legal obligation for all service providers	Inclusion of the indicators in the funding of the health services.		Indicators measuring the activity of the health services serve as a basis for funding

APPENDIX 4. LIST OF PARTICIPANTS TO STAKEHOLDER WORKSHOP

Participants	Institution
Buyse B.	KULeuven
Caillet M.	CHU St-Pierre
Cailliau M.	Clairs Vallons
De Buck C.	Clairs Vallons
De Guchtenaere A.	Zeepreventorium
Derom E.	UZ Gent
Duval P.	Cliniques de l'Europe
Gangolf M.	CHU de Liège
Nobels F.	OLVz Aalst
Pirard C.	ULg
Reyntjens R.	Zeepreventorium
Rossi C.	HAP
Thys M.	CHU de Liège
Vandevelde D.	UGent
Vanhaute O.	UZ Gent
Xhrouet M.	Santhea

APPENDIX 5. SUMMARY PRESENTATION USED AT THE STAKEHOLDER WORKSHOP

Towards an instrument to evaluate NIHDI 'rehabilitation conventions'

Project KCE-HSR-2015-018

Contractor: shiftN

KCE

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

The assignment

Assignment

- NIHDI has created an instrument – 'rehabilitation conventions' – to facilitate the provision of multidisciplinary care and rehabilitation. The instrument is coupled to a distinctive financing mechanism ('flat fee'). Conventions have existed for a long time, in various forms of organisation and care provision, for a wide range of target groups.
- The leading question is: **to what extent conventions guarantee a high quality, cost-efficient and needs-driven provision of care?**
- To answer that question an evaluation instrument is needed. The aim of this assignment is to develop such an instrument.

Research questions (from KCE TOR)

- RQ2: How can the conventions create the conditions that facilitate the cost-effective delivery of care aligned with care needs?
- RQ 2 b Are conventions the appropriate way to organise multidisciplinary care for the envisaged target groups (mostly patients with chronic/rare diseases)? What is the added value of conventions compared to the fee-for-service model? Are patients better served compared to other organisational models of care (e.g. fee-for-service)?
- RQ 2c: How to make sure that care is delivered in accordance to the terms of the conventions?
- RQ 2d: How to make sure that the conventions mirror the care needs of the patients (rather than or in addition to being provider/supply-driven)?

Approach

- Step 1: **data** collection (interviews).
- Step 2: development of a **prototype** instrument.
- Step 3: **validation** of prototype instrument (stakeholder workshop)
- Step 4: **testing** of prototype instrument.
- Step 5: **finetuning** to work instrument.
- Step 6: **report**.

Agenda

- 17:00 Welcome, intro, personal introductions
- 17:15 Insights presentation (45')
- 18:00 Survey (30')
- 18:30 Break
- 18:45 Discussion (75')
- 20:00 End

This workshop

- Formally: a 'stakeholder workshop' to validate a prototype evaluation instrument.
- Format:
  - Share of insights from our research and contours of a prototype evaluation instrument.
  - Inventorise your perception of this prototype instrument (survey).
  - Break.
  - Assess collective perception.
  - Discuss improvements and operationalisation.

Conventions

Basics

- Agreement between NIHDI and one or more care providing institutions.
- Pathology-oriented.
- Flat-fee based financing.
- Total health care budget of 500 million euro.

Governance: College of Physician-Directors

- Composition: representatives of the co-administrators of the health insurance. It is the only committee that is not joint (care providers are not represented). All members are MD.
- Positioning: 'at the hinge between NIHDI and mutuality'.
- Mandate: to establish, modify, regulate and terminate rehabilitation conventions.
- Operation: very labour-intensive consensus model. EBM as guiding framework. Interactions with existing conventions via an 'Agreement Council'. College meets +/- 6 hours/week.
- Support: a technical unit within the NIHDI (< 10 FTE).

Dynamics

- Long history.
- Significant heterogeneity of care practices financed.
- Dynamic portfolio. Transfer to the Communities (6th State Reform). Pipeline of new conventions.
- The establishment of conventions happens in ad hoc way, supply driven and as a result of lobbying. No systematic programming.
- Gradual blurring with projects financed under Art. 56.

Purpose

- Care angle
  - To create settings for the organisation of multidisciplinary care and rehabilitation.
  - To stimulate specialisation and concentration of expertise.
- Institutional-managerial angle
  - To flexibly allocate financial resources.
  - To allocate resoures within a tailor-made and (in principle) manageable framework.
  - To compartmentalise potentially escalating financing needs in health care.
  - To integrate non-licensed care providers.
- Systems-innovation angle
  - To provide opportunities for innovative care practices that cannot be easily accomodated by the Nomenclature.

Typology of conventions

- Segmentation by focus (and contact patterns with patients):
  - Rehabilitation.
  - Multidisciplinary care (case management).
  - Multidisciplinary diagnosis and support.
  - Multidisciplinary counsel.
  - Outliers: vb. abortion clinics.
- Segmentation by presence of a materials component in the financing package.

Concerns of the College

- Lack of a standardised evaluation protocol. Few 'outcome'-based quality indicators (particularly so for rehabilitation-oriented care programs).
- Difficult to exploit opportunities for cost savings and rationalisation (both in the primary care process and supporting processes).
- Degree to which the care offer is tailored to the needs of patients.
- Degree to which conventions genuinely lead to concentration of expertise.
- Transparency of the cost structure for providers, particularly as regards purchasing of materials and patient transport.
- Real-estate assets financed by public money.
- Degree to which the College/NIHDI can mobilise adequate governance capacity to optimally support conventions.

Flat fee financing

- Flat fee can be linked to different time intervals: from 1 day to a year, or can be linked to patient contact moments.
- Inevitable tension between standardisation of care protocols and the variability of patient needs.
- Advantage: control over budget (on the side of the financing authority); flexibility in care practice and allocation of available resources per patient (on the side of the care provider).
- Managerial flexibility must be supported by a minimum level of trust between financing authority and care provider.

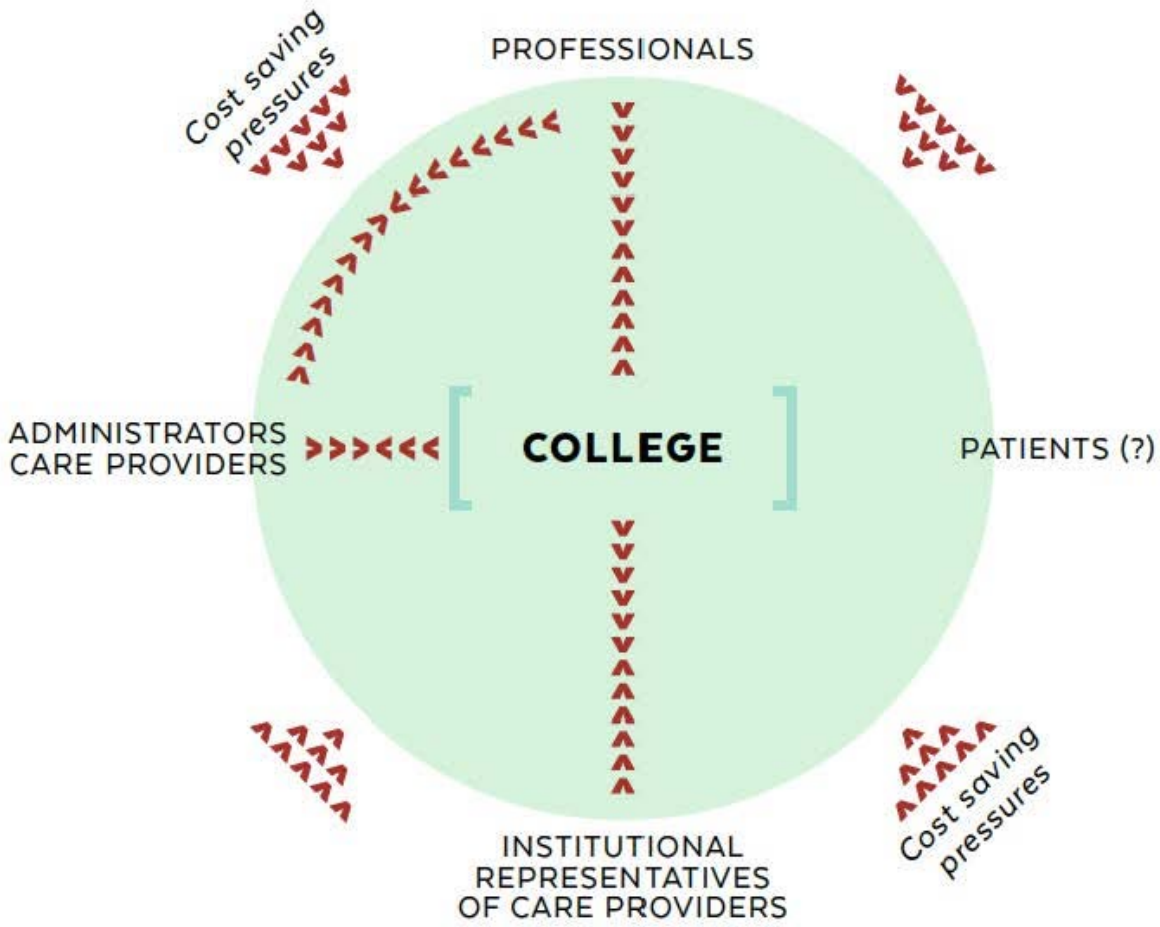
Concerns of the College

- "Is care provided within a convention distinct enough from nomenclature-financed care? Is the reliance on conventions always justified?"
- "Are conventions always needed, given that today there are alternative instruments to finance integrated care?"
- "Are providers not doing their own thing after they have put their signature to a convention?"

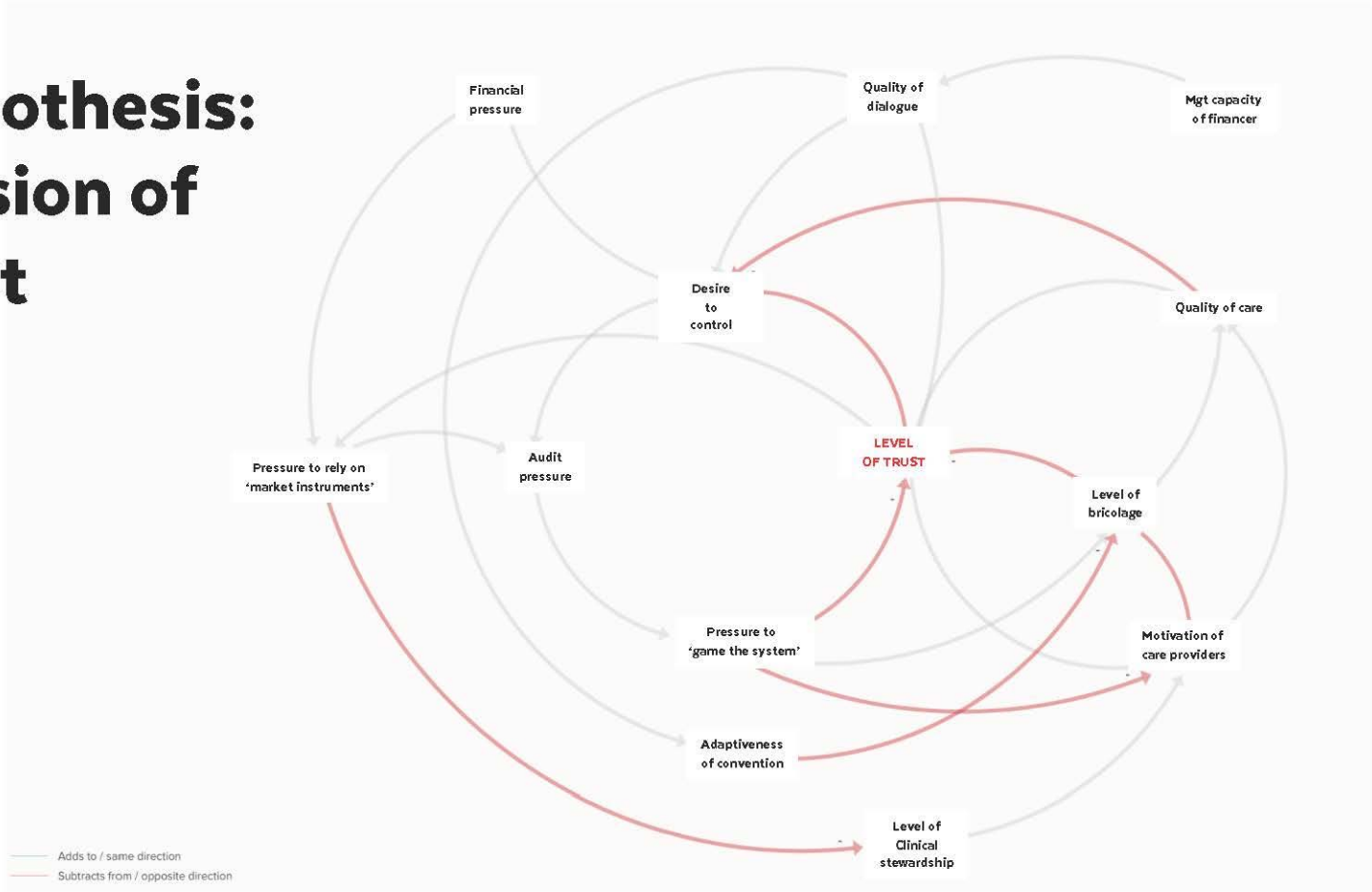
Evaluation today

- Every convention stipulates a particular mode of data registration. Given the diversity in care practices, there is no standardised protocol. Also registration is not financially compensated.
- Registered data are not being centrally integrated and managed.
- Conventions follow a 'logic of resources', not a 'logic of results'. Outcomes are often not defined and measured. Also patient satisfaction is in many cases not monitored.
- Audits or control visits by the NIHDI are very infrequent. The College does not impose sanctions. However, conventions have been terminated.

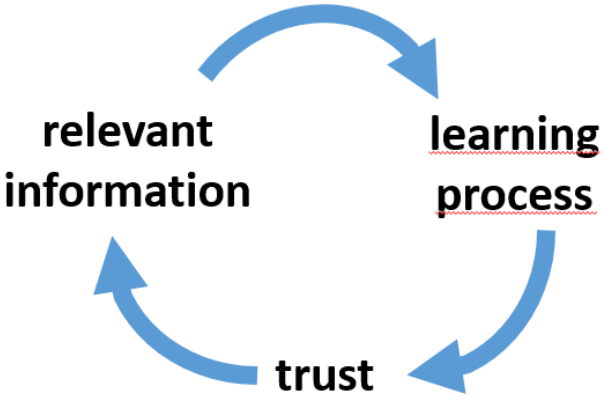
Hypothesis: Pressure to save costs creates tensions.



Hypothesis: Erosion of trust



Back to the research question



Reframing

- Original question: an instrument 'to evaluate conventions'.
- Reframed question:
  - An instrument **to mobilise relevant information streams** between key actors.
  - An instrument **to support a learning process**. Five levels:
    - Between care provider and patient.
    - Within multidisciplinary teams that operate within a convention.
    - Within the ecosystem of providers that operate within a given convention.
    - Between providers and the financing authority.
    - Between institutional actors within the financing authority.
  - An instrument **to rebuild trust between the key actors** in the convention system.

Operationalisation of our approach

Research methodology

1. Articulate a system definition connected to an overarching **'purpose'** of the 'convention system'.
2. Develop one or more '**activity models**' to realise that purpose.
3. Identify relevant '**measures of performance**' to monitor.

'Evaluation instrument' =
activity model(s) + measures of performance

System definition

"A system | governed by renewable contracts | mandated by the College of Physician-Directors of the NIHDI | to develop, manage, and operationalise tailor-made, multidisciplinary care and rehabilitation programs | operated by skilled clinical professionals and technical experts | for the benefit of specific patient groups | functioning within governing financial and political constraints and complying with the highest applicable standards of professionalism and scientific evidence."

Measures of performance

Unbundling the overarching purpose in three 'transformations' and associated MOPs

- **Patient-level Transformation, leading to …**

  … patients with complex health needs and suffering with a chronic condition who function better at home, in school, in the community and throughout life.

  The operation of the system is judged based on criteria of effectiveness, i.e.

- improved clinical outcomes,
- improved functional outcomes (improved functioning in home, school, work)

Unbundling the overarching purpose in three 'transformations' and associated MOPs

- **Service-level Transformation, leading to ...**

  ... rehabilitation and multidisciplinary care services and supports that are coordinated and efficient.

  The operation of the system is judged based on criteria of efficiency

- i.e. degree to which the system operates within human, financial and infrastructural resource constraints.

Unbundling the overarching purpose in three 'transformations' and associated MOPs.

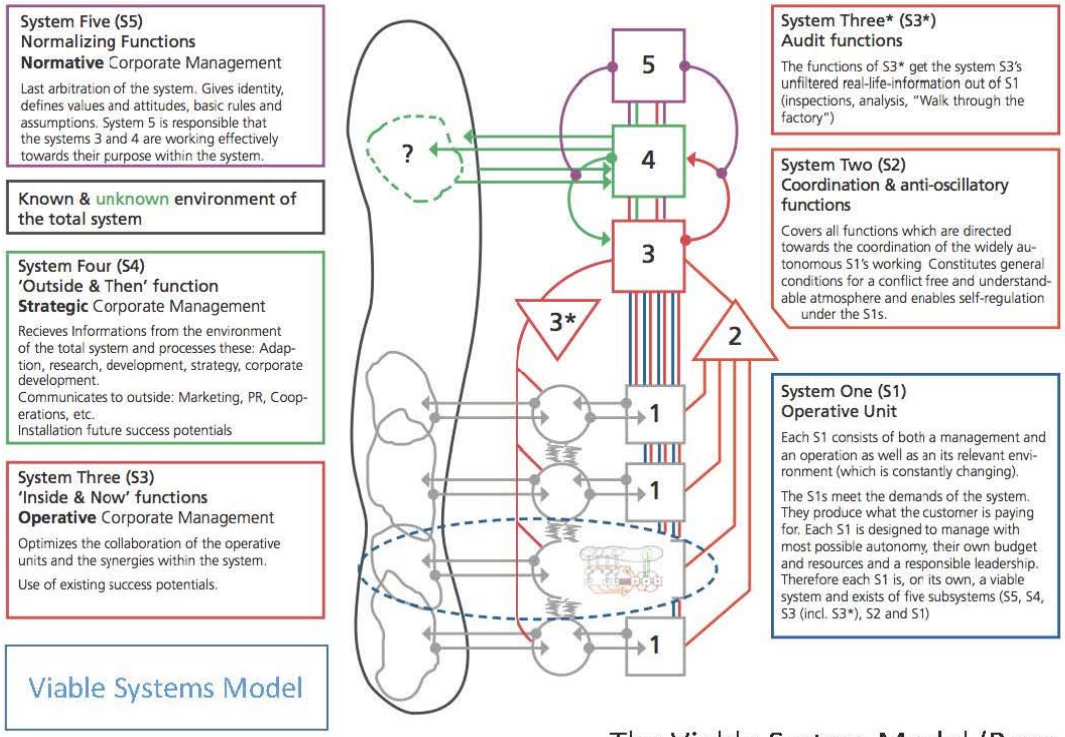
- **System-level Transformation, leading to ...**

  ... conventions that are evidence-informed, needs-oriented, resilient, capable to deal with the evolving requirements and needs of contemporary society and developments in the wider health care system.

  The operation of the system is judged based on criteria of ethicality, professionalism and adaptiveness, i.e.

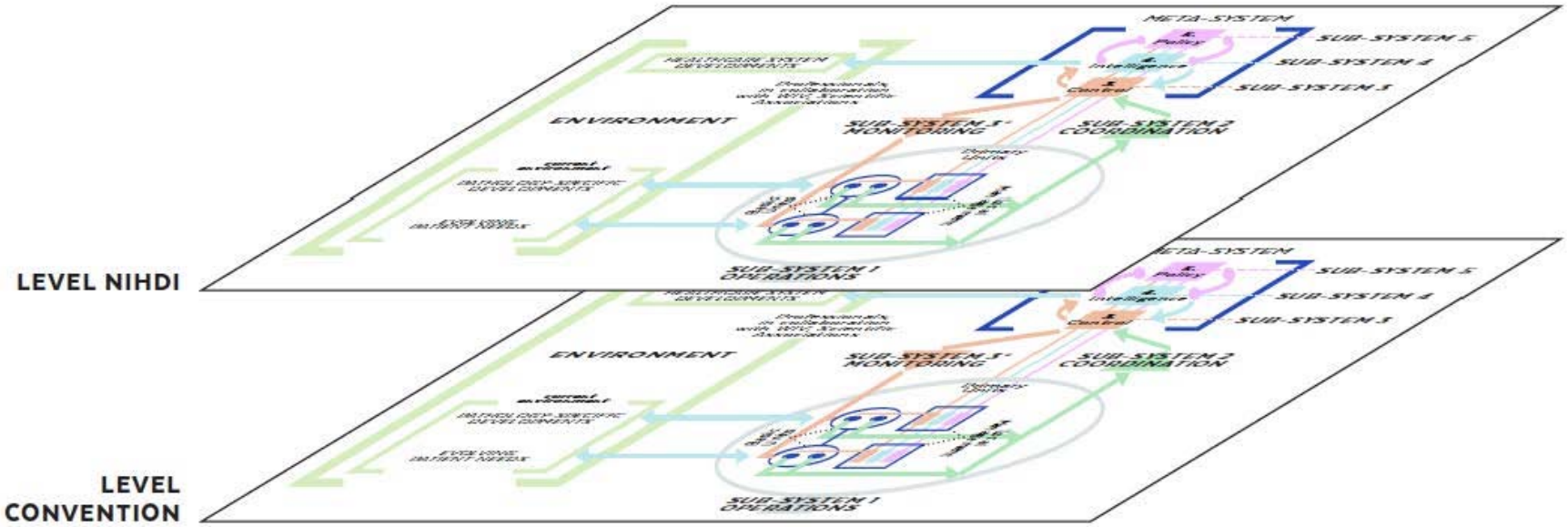
- fidelity with value base (needs oriented, patient-guided),
- degree to which the system is able to learn and evolve with changing demands,
- degree to which it incorporates best available evidence.

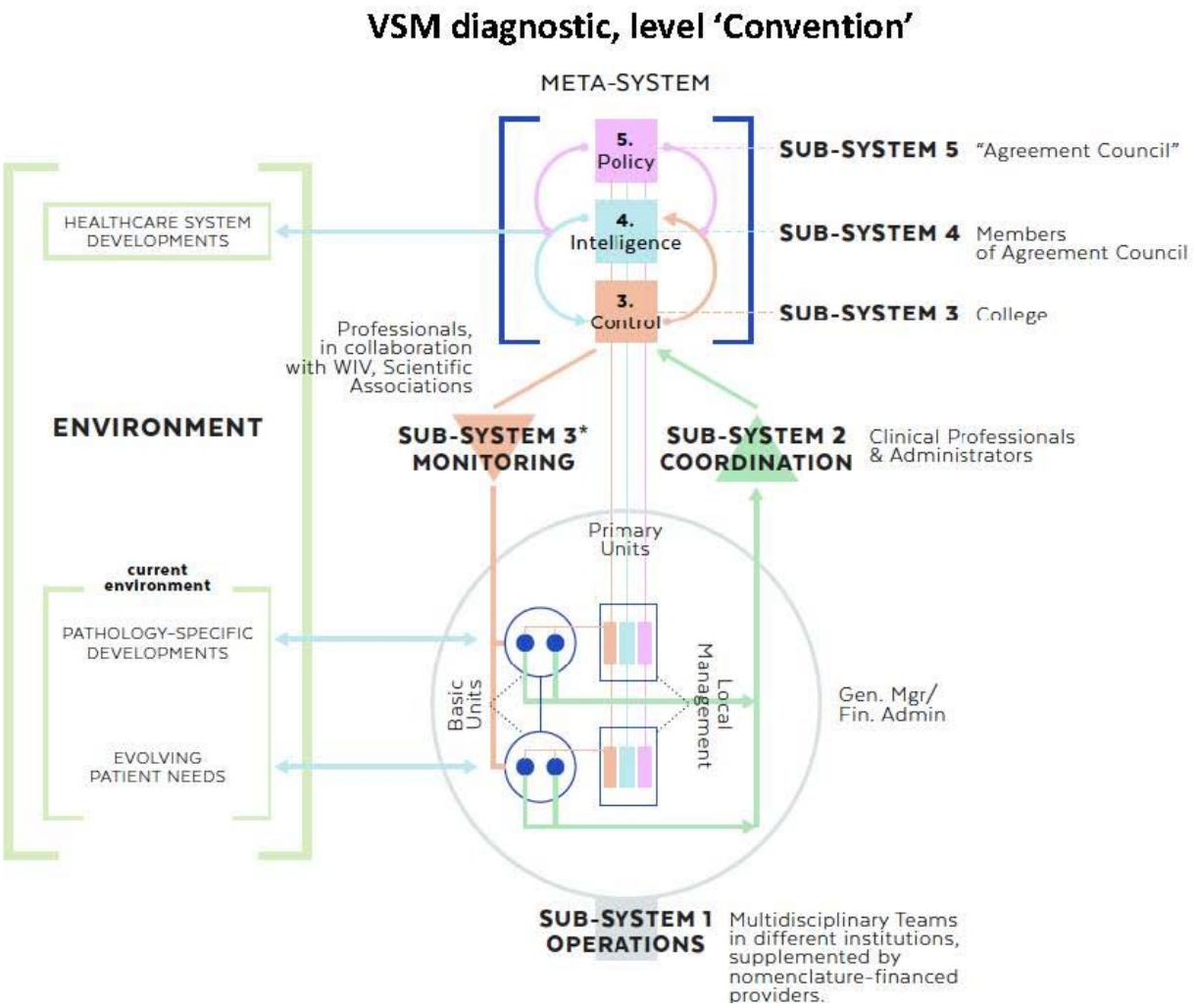
Viable Systems Model as a framework for building activity models

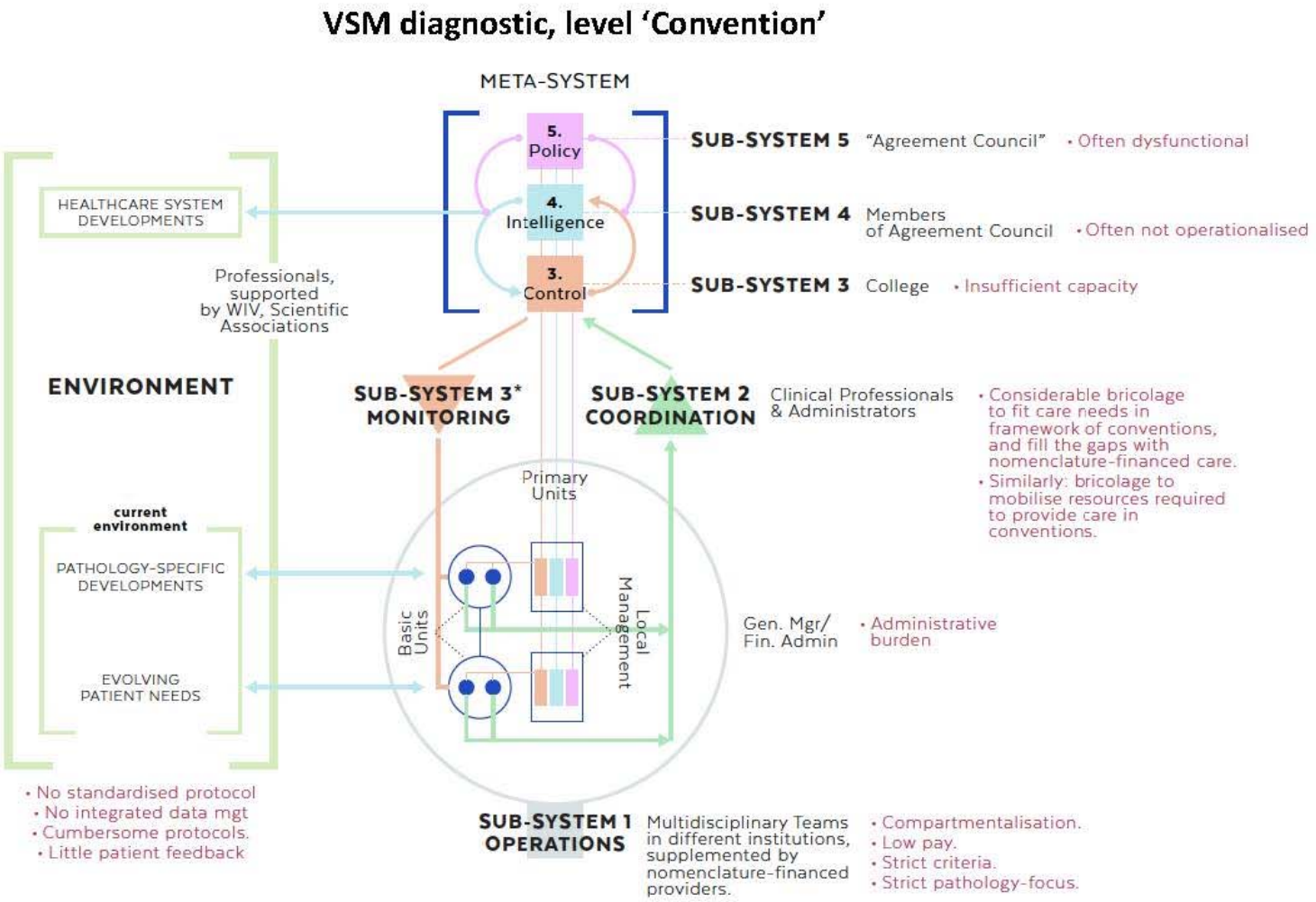


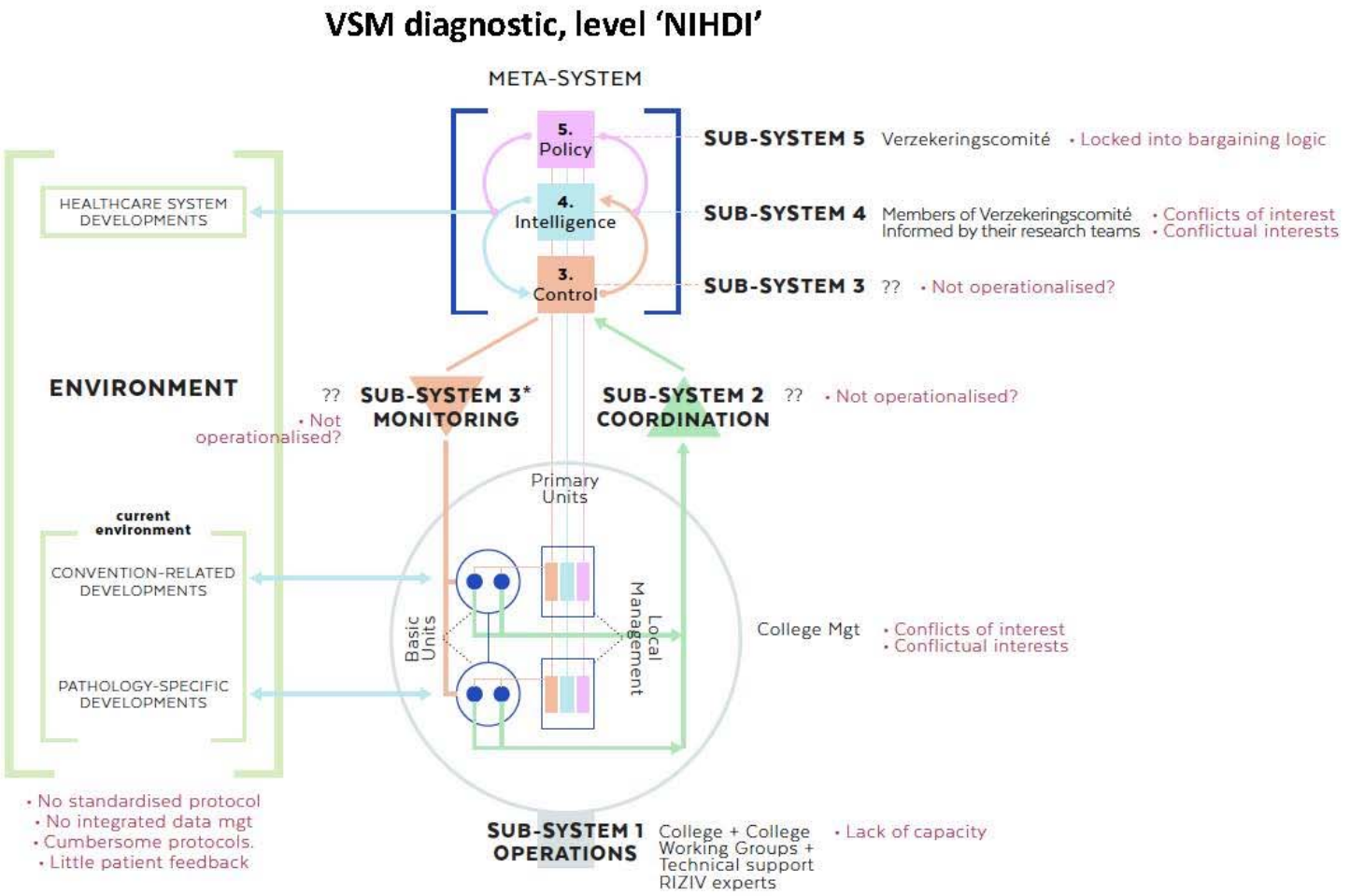
The Viable System Model (Beer, 1985) is an archetypal 'activity model' of a system that is able to maintain its own 'viability' in a dynamic environment.

Analysis at two levels

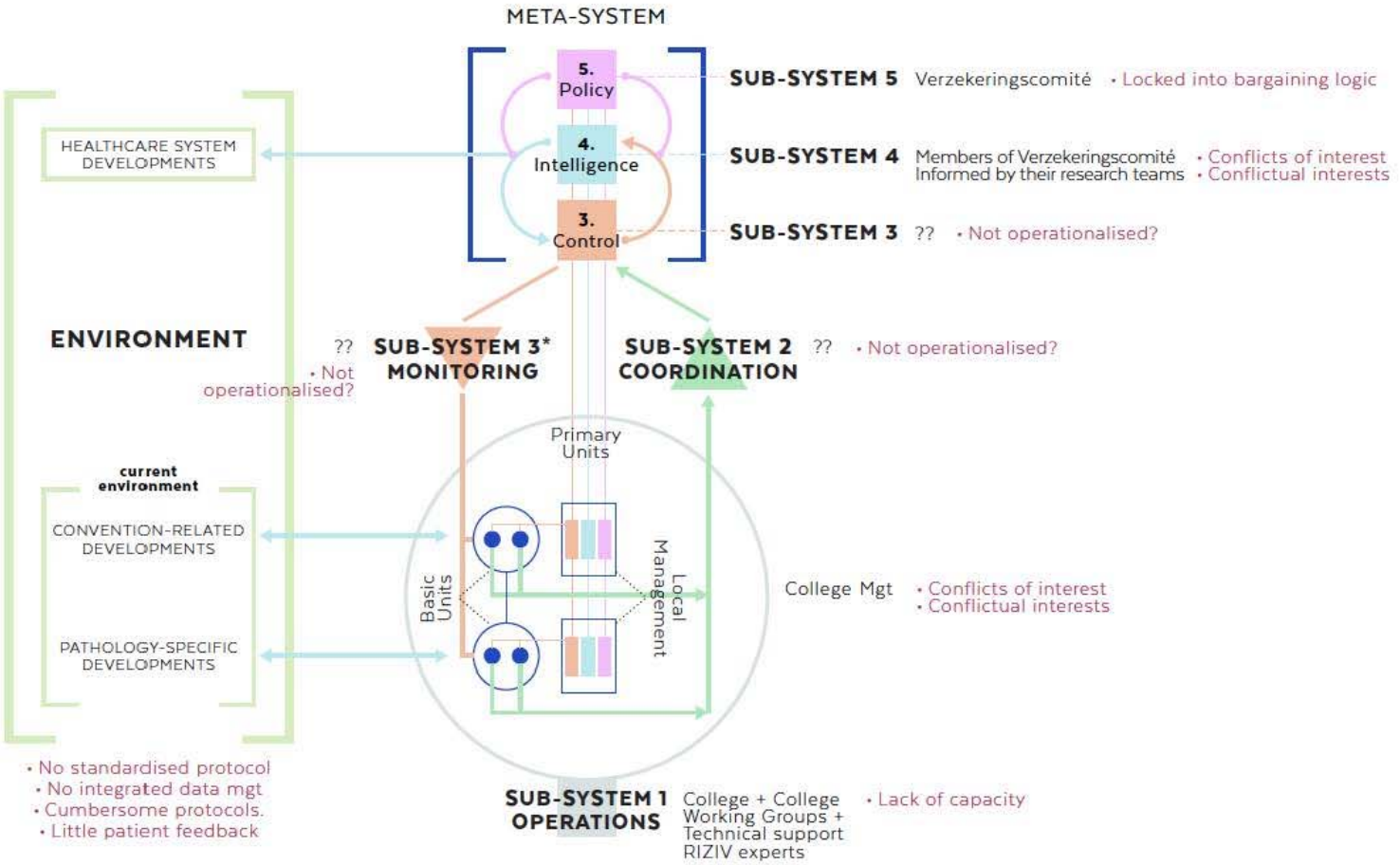



VSM diagnostic, level 'Convention'
META-SYSTEM
5. Policy
4. Inteligence
3. Control
SUB-SYSTEM 5 "Agreement Council"
SUB-SYSTEM 4 Members of Agreement Council
SUB-SYSTEM 3 College
HEALTHCARE SYSTEM DEVELOPMENTS
Professionals, in collaboration with WIV, Scientific Associations
ENVIRONMENT
SUB-SYSTEM 3* MONITORING
SUB-SYSTEM 2 COORDINATION
Clinical Professionals & Administrators
Primary Units
current environment
PATHOLOGY-SPECIFIC DEVELOPMENTS
EVOLVING PATIENT NEEDS
Basic Units
Local Management
Gen. Mgr/ Fin. Admin
SUB-SYSTEM 1 OPERATIONS
Multidisciplinary Teams in different institutions, supplemented by nomenclature-financed providers.


VSM diagnostic, level 'Convention'
META-SYSTEM
5. Policy
4. Intelligence
3. Control
SUB-SYSTEM 5 "Agreement Council" • Often dysfunctional
SUB-SYSTEM 4 Members of Agreement Council • Often not operationalised
SUB-SYSTEM 3 College • Insufficient capacity
HEALTHCARE SYSTEM DEVELOPMENTS
Professionals, supported by WIV, Scientific Associations
ENVIRONMENT
SUB-SYSTEM 3* MONITORING
SUB-SYSTEM 2 COORDINATION
Clinical Professionals & Administrators
• Considerable bricolage to fit care needs in framework of conventions, and fill the gaps with nomenclature-financed care.
• Similarly: bricolage to mobilise resources required to provide care in conventions.
Primary Units
current environment
PATHOLOGY-SPECIFIC DEVELOPMENTS
EVOLVING PATIENT NEEDS
Basic Units
Local Management
Gen. Mgr/ Fin. Admin
• Administrative burden
• No standardised protocol
• No integrated data mgt
• Cumbersome protocols.
• Little patient feedback
SUB-SYSTEM 1 OPERATIONS
Multidisciplinary Teams in different institutions, supplemented by nomenclature-financed providers.
• Compartmentalisation.
• Low pay.
• Strict criteria.
• Strict pathology-focus.


VSM diagnostic, level 'NIHDI'
META-SYSTEM
5. Policy
4. Intelligence
3. Control
SUB-SYSTEM 5 Verzekeringscomité • Locked into bargaining logic
SUB-SYSTEM 4 Members of Verzekeringscomité Informed by their research teams • Conflicts of interest • Conflictual interests
SUB-SYSTEM 3 ?? • Not operationalised?
HEALTHCARE SYSTEM DEVELOPMENTS
ENVIRONMENT
?? • Not operationalised?
SUB-SYSTEM 3* MONITORING
SUB-SYSTEM 2 COORDINATION ?? • Not operationalised?
Primary Units
current environment
CONVENTION-RELATED DEVELOPMENTS
PATHOLOGY-SPECIFIC DEVELOPMENTS
Basic Units
Local Management
College Mgt • Conflicts of interest • Conflictual interests
• No standardised protocol
• No integrated data mgt
• Cumbersome protocols.
• Little patient feedback
SUB-SYSTEM 1 OPERATIONS
College + College Working Groups + Technical support RIZIV experts
• Lack of capacity

VSM diagnostic, level 'NIHDI'



Proposal

Suggested interventions

- Reinforce the technical unit to support the College.
- Activate 'agreement councils' for the whole convention landscape.
- Operationalise a standardised, but generic 'meta-evaluation protocol'.
- Develop integrated data management and quality control for each convention.
- Dynamise the policy system at NIHDI level. Realign around a shared vision on the conventions instrument.
- Identify 'measures of performance' for College/NIHDI.
- Develop transparent 'termination scenarios' for conventions.

A two-tiered approach

- We propose to operationalise a generic 'evaluation protocol'.
- But this evaluation protocol is part of a broader set of interventions to revitalise the convention system by mobilising relevant streams of information, support a learning process and build trust amongst key actors.
- These proposals do not yet take into account pragmatic considerations about implementation.

Meta-evaluation protocol (I)

1. Is the convention still necessary? Does it correspond to a genuine public health need? Are there alternative care/financing models?
2. Does the convention lead to a geographic coverage of services that corresponds to demand?
3. Does the provider work cost efficiently within the framework of the convention?
4. Is the provider offering best-in-class care within the convention?
5. Does the convention lead to a de facto concentration of expertise?
6. Does the convention create for the exercise of professional judgment? (> clinical, functional outcomes; cost efficiency)

Each of these aspects links to the set of performance measures proposed earlier: effectiveness (clinical, functional outcomes), efficiency, ethicality, professionalism and adaptiveness.

Meta-evaluation protocol (II)

7. Does the convention stimulate a culture of clinical stewardship in care providing organisations?
8. Does the convention stimulate innovation?
9. Is the convention not used in an unorthodox way?
10. What is the experienced tension between the care model and financial conditions associated to the convention and the patient needs ?
11. What is the tension between the current practice and the boundary conditions associated to the original convention?
12. To what extent does a convention integrate input of patients or their representatives?

Each of these aspects links to the set of performance measures proposed earlier: effectiveness (clinical, functional outcomes), efficiency, ethicality, professionalism and adaptiveness.

Survey

APPENDIX 6. COMMENTS TO A PRELIMINARY VERSION OF THE META-EVALUATION INSTRUMENT BY A REPRESENTATIVE OF A SUBSET OF MULTIDISCIPLINARY CARE CONVENTIONS

Appendix 6.1. Fine-tuning in collaboration with a representative of the subset of 'multidisciplinary care' conventions

The comments by Dr. Frank Nobels are recaptured here on a question by question basis. A ranking of the questions in terms of perceived need for specificity and elaboration was not part of this interaction.

Question 1: Is the convention still necessary? Does it correspond to a genuine public health need? Are there alternative care/financing models?

- Comment: clear and legitimate question, but relevant over a longer time frame. No need to to make this case on a yearly basis.

Question 2: Does the convention lead to a geographic coverage of services that corresponds to demand?

- Comment: clear and legitimate question, no further comment.

Question 3: Does the provider work cost efficiently within the framework of the convention?

- Comment: question needs to be rephrased and unpacked in multiple questions.
  - Are resources adequately used to meet the objectives agreed in the convention?
  - Is the staffing allowed by the convention adequate to meet the care package demanded?
  - Are health outcomes commensurate to the resources allocated?
  - Note: cost efficiency of a care protocol embedded in a convention is/ought to be determined a priori, based on a health economic analysis and most probably with an international perspective. RIZIV ought to lead this effort and share results with care providers.

Question 4: Is the provider offering best-in-class care within the convention?

- Comment: question needs to be rephrased. 'Best in class' suggests a benchmark but it is unclear what that should be.
  - Are care providers able to meet the clinical goals stated in the convention?
  - Are care providers able to perform complex case management for the target group associated to the convention?
  - Are care providers committed to increasing the quality of care financed by the convention within their institution?
  - Is there a demonstrable effort to operationalise a convention-wide quality management system?

Question 5: Does the convention lead to a de facto concentration of expertise?

- Comment: concentration of expertise relates to the establishment of a critical scale. But it also has a bearing on the range of disciplines that are joined in the provision of care.
  - Does the convention lead to a de facto pooling of expertise at the level of the target group-related health care system as a whole?
  - Does the convention lead to an adequate pooling of multidisciplinary expertise within a participating care institution?

Question 6: Does the convention create space for the exercise of professional judgment?

- Comment: the term 'professional judgment' needs to be clarified.

- Does the convention allow to engage in effective case management?
- Does the convention allow the flexible pooling of multidisciplinary expertise in line with case requirements?

Question 7: Does the convention stimulate a culture of clinical stewardship in care providing organisations?

- Comment: relevant but complex question. Strict requirements qua staff help care providers the make their case vis-à-vis administrators. However, the financing requirements cannot be too strict to accomodate institution-specific conditions qua seniority and wage scales of staff.
  - Is the convention signed by both medical professionals and administrators?
  - Does the convention help to accomodate the tension between quality and cost of care provided?

Question 8: Does the convention stimulate innovation?

- Comment: need to make a distinction between two key dimensions: a) where innovation takes place (technological vs organisational model) and b) whether the innovation caters for needs directly connected to the target group or generates benefits for parties outside of the convention.
  - Does the convention stimulate innovation (technological, organisational) for patients who receive care inside and outside the convention?

Question 9: Is the convention not used in an unorthodox way?

- Comment: eleminate the word 'not' to avoid an unwarranted hint of suspicion. Also, being unorthodox can be very positive when this creates added value for patients, hospital or the broader health care system.
  - Is the convention used in an unorthodox way?
  - Does the convention generate positive spinoffs of any kind (i.e. not limited to benefits within the scope of the convention only)?

Question 10: What is the experienced tension between the care model and financial conditions associated to the convention and the patient needs?

- Comment: no comment.

Question 11: What is the tension between the current practice and the boundary conditions associated to the original convention?

- Comment: relevant question but difficult to objectify. There is a certain amount of drift that can be accomodated (by care providers and financing authorities). Unclear when a critical threshold is being reached.

Question 12: To what extent does a convention integrate input from patients or their representatives?

- Comment: relevant question, but critical how patient input is operationalised. Preference to include representatives of the Diabetes Association (and not of the VPP/LUSS) in the Agreement Council. Asking for direct patient feedback is another option (happens today, but not in a very structured way).

No further comments were made as regards the grouping of questions in the final version of the meta-evaluation protocol.

5.2.1.1. *Fine-tuning in collaboration with a representative of the subset of 'multidisciplinary diagnosis and support conventions*

Comments by Dr. Bertien Buyse (UZ Leuven) were captured on question by question basis.

Question 1: Is the convention still necessary? Does it correspond to a genuine public health need? Are there alternative care/financing models?

- Comment: relevant question but should be formulated also on grounds of principle. Is a convention an adequate instrument to guide providers towards high quality care and to incentivise patients towards higher levels of therapy compliance?

Question 2: Does the convention lead to a geographic coverage of services that corresponds to demand?

- Comment: relevant question.

Question 3: Does the provider work cost efficiently within the framework of the convention?

- Comment: this question should be expanded: does the convention promote therapy compliance? Does it help to avoid alternative health care costs?

Question 4: Is the provider offering best-in-class care within the convention?

- Comment: assessing quality of care is difficult in care settings where trustworthy (i.e. clinically correct, simple to communicate and to process administratively) outcome parameters are not available. Developing these requires upfront investment of resources.

Question 5: Does the convention lead to a de facto concentration of expertise?

- Comment: relevant question but it should also probe for the (absolute) level of multidisciplinary clinical expertise in a given institution. How can this be assessed? Also, a smaller number of care providers does not automatically guarantee better quality care. Finally, concentration of expertise needs to be coupled to a segmentation of the patient population in 'standard' vs 'complex' cases. The latter warrant the mobilisation of the highest level of expertise.

Question 6: Does the convention create space for the exercise of professional judgment?

- Comment: crucial question. A subsidiary question might probe for the degree to which this professional judgement is exercised in a multidisciplinary team setting. This requires coordination resources that are often not available in a convention.

Question 7: Does the convention stimulate a culture of clinical stewardship in care providing organisations?

- Comment: not discussed.

Question 8: Does the convention stimulate innovation?

- Comment: relevant question but could be expanded by probing to the extent a convention is able to keep pace with recent technological developments. This could also link to Q3. However, technical infrastructure can only be leveraged for diagnostic streamlining when there is a strong basis of clinical expertise.

Question 9: Is the convention not used in an unorthodox way?

- Comment: this is an ambiguous question and can be interpreted in a number of ways. Unorthodoxy can sometimes be very beneficial from a patient point of view whilst sticking to the letter of the convention isn't.

Question 10: What is the experienced tension between the care model and financial conditions associated to the convention and the patient needs?

- Comment: this is pertinent but very tricky question in the context of our clinical practice. Ideally the NIHDI takes the long view. They need to understand that improving clinical outcomes requires the patient development of clinical expertise, supported by appropriate, state-of-the-art technological supports. But the clinical expertise is leading. Eventually this will lead to cost savings. The current model does not support such an evolutionary perspective.

Question 11: What is the tension between the current practice and the boundary conditions associated to the original convention?

- Comment: this is a very pertinent question. The existing convention is geared towards the reimbursement of medical devices, not primarily towards funding the multidisciplinary 'search process' that is typical for our clinical practice. How can this be reflected in the protocol?

Question 12: To what extent does a convention integrate input from patients or their representatives?

- Comment: relevant question. But the relationship has to be reciprocal in the sense that patients also engage to guarantee a maximum level of therapy compliance.

A thematic clustering was not extensively discussed during this session but Dr. Buyse indicated that Q4, Q5 and Q6 seemed to belong together as they addressed various aspects of quality of care.

5.2.1.2. Fine-tuning in collaboration with a representative of the subset of 'multidisciplinary counsel' conventions

First the 12 questions of the draft protocol were ordered in decreasing order of need for specificity and/or rewording. The ranking proposed by Dr. Caillet (Female Genital Mutilation (FGM) convention, St Pierre Hospital, Brussels) was as follows:

1. Question 3 (cost efficiency)
2. Question 7 (clinical stewardship)
3. Question 4 (best-in-class care)
4. Question 6 (professional judgment)
5. Question 10 (tension with patient needs)
6. Question 11 (tension with original convention)
7. Question 1 (public health need)
8. Question 5 (concentration of expertise)
9. Question 8 (innovation)
10. Question 9 (unorthodox use)
11. Question 12 (input from patients)
12. Question 2 (geographic coverage)

Question 3, 7 and 4 were considered by Dr. Caillet to be the most sensitive. Also Q1 was potentially a sensitive question.

The questions are now discussed and deepened in the order ranked.

Question 3: Does the provider work cost efficiently within the framework of the convention?

- Comment: relevant question. Q10 and Q11 could be seen as sub-questions to support the answer to Q3. It is also closely linked to Q7 that probes about the relationship between clinician and administration. A strong partnership enables the multidisciplinary team to amplify the impact of the convention by providing the necessary extra support needed to adapt to evolving circumstances.

Question 7: Does the convention stimulate a culture of clinical stewardship in care providing organisations?

- Comment: the notion of 'clinical stewardship' needs to be explained. But it is relevant to probe for the quality of the relationship between the medical and administrative departments in institutions working in a convention.

Question 4: Is the provider offering best-in-class care within the convention?

- Comment: the concept of 'best-in-class' needs to be elucidated. It can be referred to in a strict sense, i.e. according to specific standards set in the convention, or in a larger sense in reference to the evolving set of international standards applied to the specialist care provided. The latter is better suited to centers providing multidisciplinary counsel for which there is no scientific basis to objectively measure its impact.

Question 6: Does the convention create space for the exercise of professional judgment?

- Comment: this question ought to be rephrased in such a way that it requests examples rather than a yes/no answer. There are two levels of professional judgment involved: the judgment that is brought to bear on ensuring good clinical practice. And there is the professional judgment that plays out in adequately managing all the professionals involved in case management.

Question 10: What is the experienced tension between the care model and financial conditions associated to the convention and the patient needs?

- Comment: this appears to be a sub-question of Question 3 (cost-efficiency).

Question 11: What is the tension between the current practice and the boundary conditions associated to the original convention?

- Comment: this appears to be a sub-question of Question 3 (cost-efficiency) and linked to question 4 (standards).

Question 1: Is the convention still necessary? Does it correspond to a genuine public health need? Are there alternative care/financing models?

- Comment: relevant question but potentially delicate for centers that serve relatively small patient groups. It should be clarified how 'genuine public health needs' are identified.

Question 5: Does the convention lead to a de facto concentration of expertise?

- Comment: important question as it connects directly to the raison d'être as stated in the convention. The question should be reworded to explicity encompass the paramedical expertise which is very important in a center such as CeMAVIE where the surgery and gyneacology consultations (medical acts) crucially need the psycho-social support to achieve and sustain their impact.

Question 8: Does the convention stimulate innovation?

- Comment: the question should be reworded to make explicit that this concerns the whole lifetime of a convention. It should unearth whether the relationship between parties to the convention has over time enabled a culture of trust that encourages innovation at the clinical and case management level (see link to Question 6).

Question 9: Is the convention not used in an unorthodox way?

- Comment: this question might be perceived to probe for fraudulent actions, hence it is unlikely to be self-reported. Ideally the question should point to both positive and negative ways of working within the framework of a convention. It could also seek to reveal instances where inherent limitations of conventions (budget, authorisation required) spur innovation in an unexpected way and hence have unintended but rather positive consequences in terms of quality of care provided.

Question 12: To what extent does a convention integrate input from patients or their representatives?

- Comment: important question in a very practical sense. But should be reworded to express that the patient could suggest adaptation to the care provided. In the case of FGM professionals are particularly attentive to the behaviour of patients. By listening and adapting to the cultural context, ability and gender of their patients they made choices that reconfigured the services provided.

Question 2: Does the convention lead to a geographic coverage of services that corresponds to demand?

- Comment: good question, but could be delicate for FGM as there are only two centers in Belgium (one in Brussels and one in Gent).

The elaboration of the individual questions was followed by a concluding session of clustering the questions in thematic groups. The following clusters were identified by Dr. Caillet:

- Cluster 1 – strategic and contractual aspects
  - Q1, Q2, Q3, Q7, Q10, Q11, Q4a. This cluster of questions probes to what extent a) the convention as a whole fulfills its strategic

mission of addressing a public health need in a geographically balanced way, and b) how the participating institutions fulfill its contractual obligations.

- Cluster 2 – capacity for innovation: Q8, Q9 and Q12. The inclusion of Q12 in this group is justified by the requirement that patients must have a place in the overall dynamic at every stage of the convention process (setting up, implementation, and evolution over time).
- Cluster 3 – level of expertise: Q6 and Q5.
- Question 4b (best in class as per evolving international standards) was kept apart as an intermediary question with links to clusters 2 and 4 but not really belonging to either.

5.2.1.3. Fine-tuning in collaboration with a representative of the subset of 'rehabilitation' conventions

The fine-tuning session with Philippe Duval and Chantal Seret (Cliniques de l'Europe, Brussels) led to a lively discussion about each of the individual questions.

Question 1: Is the convention still necessary? Does it correspond to a genuine public health need? Are there alternative care/financing models?

- Comment: this is a relevant question, since it refers to health needs and patient access. The sub-question about alternative care and financing models is also relevant, since the current model is very stringent and doesn't always allow for sufficient professional judgement or flexibility to do what's best for the patient. Also, conventions are often not adapted to modern technology or the types of patients hospitals receive.

Question 2: Does the convention lead to a geographic coverage of services that corresponds to demand?

- Comment: a relevant question. An additional problem regarding geographic coverage and rehabilitation is that some hospitals who perform a particular type of surgery don't have a convention to do the associated rehabilitation. Geographic coverage could be tailored the same way as care networks functioning within a "bassin de soins".

Question 3: Does the provider work cost-efficiently within the framework of the convention?

- Comment: the notion of "provider" should be clarified. Does it mean an individual, a multidisciplinary team, an institution? Another relevant question is whether the convention itself is cost-efficient? In many cases, the fee provided by the convention doesn't cover all expenses, so care providers are obliged to work undeclared hours if they have the best interest of the patient in mind.

Question 4: Is the provider offering best-in-class within the convention?

- Comment: again, the question should be asked whether the convention allows for best-in-class care? And who is the provider? Maybe one should just look at the medical act itself: is best-in class care being offered? Q3 and Q4 are also about trust; trust in the knowledge and experience of doctors and other clinicians to make the best and most cost-efficient decisions.

Question 5: Does the convention lead to a de facto concentration of expertise?

- Comment: relevant question. Creating a concentration of expertise should be the aim of every convention. It should be the ultimate reason why a convention is granted to some centers and not to others. Also, if a convention leads to more expertise, it will automatically respond to a public health need and become necessary (Q1). But the current convention model doesn't always allow for more expertise, see the administrative burden to get an innovative health product or new laboratory technology registered.

Question 6: Does the convention create conditions for the exercise of professional judgment?

- Comment: a very relevant question. This also relates to what was mentioned under Q3 and Q4. The answer to the current convention is clearly 'no'.

Question 7: Does the convention stimulate a culture of clinical stewardship in care providing organizations?

- Comment: equally, a good question. Partnership is very important, not just within an institution, but on a network level too. This is sometimes the only way to ensure patients get the care they deserve.

Question 8: Does the convention stimulate innovation?

- Comment: a very relevant question. The answer to the current situation is 'no'. We need more innovation and more liberty. This also relates to Q6 regarding professional judgment. The current network is too stringent and too narrow.

Question 9: Is the convention used in an unorthodox way?

- Comment: this question sounds pejorative. Innovation could perhaps be regarded as 'unorthodox' too. So, maybe the question is relevant in the sense that it points to adaptations that have proven to be sensible, or interpretations that might be interesting to hear about. This will require more dialogue and, again, the exercise of professional judgement.

Question 10: What is the experienced tension between the care model and financial conditions associated to the original convention and the patient needs?

- Comment: relevant question. It relates to the administrative burden. There is a general problem of a society that progresses and finds ways to prolong life, but doesn't know how to finance the well-being of its elder citizens. The needs are endless, the budget isn't.

Question 11: What is the tension between the current practice and the boundary conditions associated to the original convention?

- Comment: relevant question.

Question 12: To what extent does a convention integrate input of patients or their representatives?

- Comment: this is a relevant question, as the patient should have a better understanding of the access to care. Also, in the context of multidisciplinary care, the input of the patient is important. And there's a general movement in society towards participation. But some patient associations take a 'syndicalist' position and don't always know what's best for the patient. What's much needed, is time to explain things well to the patient, but there is little finance for that.

REFERENCES

1. Ramaekers D. Kwaliteit in de Gezondheidszorg: Toekomstige organisatie en structuren in Vlaanderen. Rapport aan de Minister. Brussels: 2014. Available from: https://www.zorg-en-gezondheid.be/sites/default/files/atoms/files/Rapport%20-%20Organisatie%20en%20structuren%20Kwaliteitsbeleid%20in%20Vlaanderen%202014.pdf
2. Groupe de travail Sécurité des Patients de la Commission Nationale d'accompagnement pour la Performance hospitalière. La sécurité du patient : éviter l'évitable. Note stratégique sur la sécurité des patients. . Bruxelles: Service public fédéral Santé publique, Sécurité de la Chaîne alimentaire et Environnement. ; 2007. Available from: https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/note_securite_des_patients_fr_0_15772533_fr_1.pdf
3. Service Public Fédéral Santé Publique. Note d'accompagnement. Plan Pluriannuel 2013-2017. . Bruxelles: Service public fédéral Santé publique, Sécurité de la Chaîne alimentaire et Environnement. ; 2013. Available from: https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/contrat_qs_-_note_daccompagnement_def.pdf
4. Federale Overheidsdienst Volksgezondheid. Begeleidende Nota. Meerjarenplan 2013-2017. . Brussels: Federale overheidsdienst Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu; 2013. Available from: https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/qs_contract_-_begeleidende_nota-def.pdf
5. Institut National d'Assurance Maladie Invalidité. Qualité des soins [Web page].Bruxelles;2017 [cited 10/07/2017]. Available from: http://www.riziv.fgov.be/fr/themes/qualite-soins/Pages/default.aspx#.WWM_9VElGpo
6. Rijksinstituut voor Ziekte-en Invaliditeitsverzerkering. Kwaliteitszorg [Web page].Brussels;2017 [cited 10/07/2017]. Available from: http://www.riziv.fgov.be/nl/themas/zorgkwaliteit/Paginas/default.aspx#.WWNASFElGpo

7. Bury J, Delmotte N, Fima O, Gainvorste D, Goossens A, JHerbaux D, et al. L'accréditation des hôpitaux : l'indispensable phase de réveil. Bruxelles: Fédération Wallonie-Bruxelles; 2013.

8. Jacquerye A, Lecocq D, Tercelin de Joigny I, Gainvorste D, Belghezli N, Zandecki N, et al. Préparer les hôpitaux à l'accréditation : la période d'éveil: Rapport sur les 7 Journées de formation-action (JOPERA 5S+) adressées aux directions des hôpitaux de Wallonie-Bruxelles en 2014. Bruxelles: Université Libre de Bruxelles; 2015. Available from: http://hdl.handle.net/2013/ULB-DIPOT:oai:dipot.ulb.ac.be:2013/186377

9. FAITH. Protocol voor de Wetenschappelijke ondersteuning en evaluatie van de pilootprojecten voor geïntegreerde zorg voor chronisch zieken in België (Het Integreo Programma). Brussels: Université catholique de Louvain, Vrije Universiteit Brussels, Université de Liège, Universiteit Antwerpen, Katholiek Universiteit Leuven; 2017.

10. FAITH. Évaluation scientifique et appui aux projets pilote de soins intégrés (PSI) pour les personnes atteintes de maladies chroniques en Belgique (Programme Integreo). Protocole. Bruxelles: Université catholique de Louvain, Vrije Universiteit Brussels, Université de Liège, Universiteit Antwerpen, Katholiek Universiteit Leuven; 2017.

11. Haute Autorité de Santé. Indicateurs de qualité et de sécurité des soins obligatoires et soumis à diffusion publique [Web page].2016 [updated 09/01/2016]. Available from: http://www.has-sante.fr/portail/jcms/c_2037368/fr/indicateurs-de-qualite-et-de-securite-des-soins-obligatoires-et-soumis-a-diffusion-publique

12. Haute Autorité de Santé. Validation des indicateurs de qualité et sécurité des soins [Web page].2017. Available from: http://www.has-sante.fr/portail/jcms/r_1456647/fr/validation-des-indicateurs-de-qualite-et-securite-des-soins

13. NHS Scotland. Healthcare Improvement Scotland [Web page].2015. Available from: http://www.healthcareimprovementscotland.org/

14. Health Improvement Scotland. Building a comprehensive approach to reviewing the quality of care: Supporting the delivery of sustainable high quality services. A consultation paper. Edinburgh: NHS Scotland; 2015. Available from: http://www.healthcareimprovementscotland.org/our_work/governance_and_assurance/quality_of_care_reviews/qoc_reviews_consultation.aspx

15. Scottish Government. The National Performance Framework (NPF). Edinburgh: Scottish Government; 2016. Available from: http://www.gov.scot/Resource/0049/00497339.pdf

16. NHS Scotland. A Route Map to the 2020 Vision for Health and Social Care. 2013 Available from: http://www.gov.scot/Topics/Health/Policy/Quality-Strategy/routemap2020vision

17. Scottish Government. Health and Social Care Delivery Plan. Edinburgh: Scottish Government,; 2016.

18. Scottish Government. Scotland's national action plan to prevent and eradicate female genital mutilation (FGM) 2016-2020. Edinburgh: Scottish Government,; 2016.

19. Kroneman M, Boerma W, van den Berg M, Groenewegen P, de Jong J, van Ginneken E. The Netherlands: health system review. Health Systems in Transition. 2016;18(2):1-239.

20. Boot JMD, Knapen MJHM. De Nederlandse gezondheidszorg. Houten: Bohn Stafleu Van Loghum; 2005.

21. Wammes J, Jeurissen P, Westert G. The Dutch Health System, 2014. Radboud: Radboud University; 2014. Available from: http://www.nvag.nl/afbeeldingen/Netherlands%20Health%20Care%20System%202014%20(PDF).pdf

22. World Health Organisation. The need to scale up rehabilitation. Geneva: WHO; 2017. Rehabilitation 2030, a call for action WHO/NMH/NVI/17.1 Available from: http://www.who.int/disabilities/care/NeedToScaleUpRehab.pdf?ua=1

23. AMELI. Le parcours de soins coordonnés [Web page].2017 [updated 2017]. Available from: http://www.ameli.fr/assures/soins-et-remboursements/comment-etre-rembourse/le-parcours-de-soins-coordonnes/objectif-des-soins-coordonnes.php

24. Chevreul K, Berg Brigham K, Durand-Zaleski I, Hernandez-Quevedo C. France: Health System Review. Health Syst Transit. 2015;17(3):1-218, xvii.

25. Décret n° 2011-77 du 19 janvier 2011 portant actualisation de la liste et des critères médicaux utilisés pour la définition des affections ouvrant droit à la suppression de la participation de l'assuré, Journal officiel de la république française 2011. Available from: https://www.legifrance.gouv.fr/jo_pdf.do?id=JORFTEXT000023456250

26. Décret 2011-726 du 24 juin 2011 supprimant l'hypertension artérielle sévère de la liste des affections ouvrant droit à la suppression de la participation de l'assuré mentionnée au 3 de l'article L. 322-3 du code de la sécurité sociale, Journal officiel de la république française 2011. Available from: https://www.legifrance.gouv.fr/jo_pdf.do?id=JORFTEXT000024249276

27. Décret n° 2008-1440 du 22 décembre 2008 relatif aux conditions de suppression de la participation de l'assuré aux frais de soins, Journal officiel de la république française 2008. Available from: https://www.legifrance.gouv.fr/jo_pdf.do?id=JORFTEXT000020010002

28. Assurance Maladie Invalidité. Critères médicaux. Admission et Prolongation d'une Affection de Longue Durée Exonérante du Ticket Modérateur. Assurance Maladie Invalidité; 2016.

29. Cour des Comptes. Les activités de soins de suite et de réadaptation. In: Cour des Comptes, editor. Sécurité Sociale. Paris, France: Cour des Comptes; 2012. p. 341-69.

30. Arrêté du 3 mai 2016 fixant la liste des indicateurs obligatoires pour l'amélioration de la qualité et de la sécurité des soins et les conditions de mise à disposition du public de certains résultats par l'établissement de santé Journal Officiel de la République Française 2016. Available from: https://www.legifrance.gouv.fr/jo_pdf.do?id=JORFTEXT000032539995

31. Haut Conseil de la Santé Publique. Diagnostic et prise en charge précoces des maladies chroniques. Paris: La Documentation Française; 2017.

32. Haute Autorité de Santé. Actes et Prestations - Affection de Longue Durée. Diabète de type 1 et diabète de type 2. Saint-Denis La Plaine, France: Haute Autorité de Santé; 2014. Les Parcours de Soins / Service des maladies chroniques et des dispositifs d'accompagnement des malades Available from: http://www.has-sante.fr/portail/upload/docs/application/pdf/lap_diab_actualis__3_juillet_07_2007_07_13__11_43_37_65.pdf

33. Chevreul K, Berg Brigham K, Bouché C. The burden and treatment of diabetes in France. Globalization and Health. 2014;10(1):6.

34. Haute Autorité de Santé. Actualisation du référentiel de pratiques de l'examen périodique de santé. Prévention et dépistage du diabète de type 2 et des maladies liées au diabète. Haute Autorité de Santé, editor. Saint-Denis La Plaine, France: Haute Autorité de Santé, ; 2014.

35. Haute Autorité de Santé. Guide Parcours de Soins. Diabète de type 2 de l'adulte. Saint-Denis La Plaine, France: Haute Autorité de Santé,; 2014.

36. Ministère des Affaires Sociales et de la Santé. Diabète [Web page].2016 [updated 16/11/2016; cited 12/12/2016]. Available from: http://social-sante.gouv.fr/soins-et-maladies/maladies/article/diabete

37. Morel A, Lecoq G, Jourdan-Menninger D. Evaluation de la prise en charge du diabète. Paris, France: Inspection générale des affaires sociales; 2012. 1 (RM2013-033P) Available from: http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/124000256.pdf

38. SOPHIA. Sophia, le service d'accompagnement de l'assurance maladie [Web page].2016. Available from: https://www.ameli-sophia.fr/diabete/mieux-connaitre-diabete/diagnostic-et-surveillance-du-diabete/surveillance-du-diabete/surveillance-du-diabete-les-fondamentaux.html#c548

39. Couralet P-E. Evaluation médico-économique du programme SOPHIA. Paris, France: Caisse Nationale d'Assurance Maladie des Travailleurs Salariés, ; 2015. Available from: http://www.ameli.fr/fileadmin/user_upload/documents/Rapport_d_evaluation_sophia_2010-2013.pdf

40. Simondon A. L'infirmière « déléguée à la santé publique Asalée » : analyse de la figure infirmière construite au sein d'une organisation innovante en soins primaires. Revue d'Épidémiologie et de Santé Publique. 2015;63(2):147-8.

41. Institut de recherche et de documentation en économie de la santé (IRDES). Evaluation Asalée : Daphnee Doctor and Advanced Public Health Nurse Experiment Evaluation. Evaluation de l'expérimentation de coopération entre généralistes et infirmières Asalée; Protocole d'évaluation. Paris: IRDES; 2015. Available from: http://www.irdes.fr/recherche/projets/daphnee-doctor-and-advanced-public-health-nurse-experiment-evaluation/evaluation-asalee-daphnee-protocole-d-evaluation.pdf

42. Haute Autorité de Santé. Les protocoles de coopération art 51. Bilan du dispositif. Évaluation 2014. Saint-Denis La Plaine, France: Haute Autorité de Santé,; 2015.

43. Décret 2014-1181 du 13 octobre 2014 autorisant la création d'un traitement automatisé relatif à l'évaluation du module 3 des expérimentations de nouveaux modes de rémunération prévues par l'article 44 de la loi 2007-1786 du 19 décembre 2007 de financement de la sécurité sociale pour 2008, relatif à la coopération entre professionnels de santé Journal officiel de la république française 2014. Available from: http://www.irdes.fr/recherche/projets/daphnee-doctor-and-advanced-public-health-nurse-experiment-evaluation/decret-n-2014-1181-du-13-octobre-2014.pdf

44. Fédération Françaises des Diabétiques. Fédération Française des Diabétiques [Web page].2017 [cited 2017/05/05]. Available from: https://www.federationdesdiabetiques.org/

45. Fédération Françaises des Diabétiques. Diabète Lab [Web page].2017 [cited 2017/05/05]. Available from: https://www.federationdesdiabetiques.org/information/diabete-lab

46. Nolte E, Knai C, McKee M. Managing Chronic Conditions: Experience in Eight Countries. Copenhaguen: WHO Regional Office Europe; 2008.

47. Ministère de la Santé et des Sports, Ministère du Travail dlSedlFP, Ministère de l'Enseignement Supérieur et de la Recherche. Plan d'actions national « accidents vasculaires cérébraux 2010-2014 » Paris: République Française; 2010. Available from: http://www.cnsa.fr/documentation/plan_actions_avc_-_17avr2010.pdf

48. Haute Autorité de Santé. Actes et prestations - Affection de longue durée. Accident vasculaire cérébral invalidant. Saint-Denis La Plaine: Haute Autorité de Santé, ; 2016. Les Parcours de Soins

49. Circulaire DGS/DH/DSS n° 97-142 du 24 février 1997 relative à l'organisation des soins aux hémophiles et aux patients atteints d'autres troubles héréditaires de la coagulation, Journal Officiel de la République Française 1997.

50. Circulaire DGS/DHOS n° 2001-413 du 22 août 2001 relative au suivi national des personnes atteintes de maladies hémorragiques dues à des déficits héréditaires en protéines coagulantes et à l'organisation des centres de traitement de l'hémophilie, Le Journal Officiel de la République Française 2001.

51. Ministère de la Santé et de la Solidarité. Plan National Maladies Rares 1 (PNMR1) 2005-2008. Paris: République Française; 2005.

52. Ministère de l'Economie des Finances et de l'Industrie, Ministère de l'Enseignement Supérieur et de la Recherche, Ministère des Solidarités et de la Cohésion Sociale, Ministère du Travail de l'Emploi et de la Santé. Plan national maladies rares 2011-2014.

Qualité de la prise en charge, Recherche, Europe : une ambition renouvelée. Paris: République Française. ; 2011.

53. Haut Conseil de la Santé Publique. Evaluation du plan national maladies rares 2 2011-2016. Paris, France: Haut Conseil de la Santé Publique, ; 2016. Evaluation Available from: http://social-sante.gouv.fr/IMG/pdf/hcsp_pnmr2_evaluation.pdf

54. Haute Autorité de Santé. Hémophilies et affections constitutionnelles de l'hémostate graves. Protocole national de diagnostic et de soins pour une maladie rare. Saint-Denis La Plaine, France: Haute Autorité de Santé, ; 2007. Guide- Affection de Longue Durée Available from: http://www.has-sante.fr/portail/upload/docs/application/pdf/07-030_hemophilies-guide_edite_sans_lap.pdf

55. Haute Autorité de Santé. Hémophilies et affections constitutionnelles de l'hémostase graves (en dehors des thrombopathies constitutionnelles). Saint-Denis La Plaine, France: Haute Autorité de Santé; 2010. LISTE DES ACTES ET PRESTATIONS AFFECTION DE LONGUE DUREE

56. Direction générale de la santé (DGS), Mission interministérielle pour la protection des femmes contre les violences et la lutte contre la traite des êtres humains (MIPROF), Delespine M, Foldès P, Piet E. Le/la praticien-ne face aux mutilations sexuelles féminines. Paris, France: Ministère des affaires sociales, de la santé et des droits des femmes, ; 2016.

57. Steel D, Cylus J. United Kingdom (Scotland): Health system review. Health Syst Transit. 2012;14(9):xv-xxii, 1-150.

58. Scottish Executive. Delivering for Health. Edinburgh: Scottish Executive; 2005.

59. Scottish Executive. Developing community hospitals. A strategy for Scotland. Edinburgh: NHS Scotland, ; 2006. Available from: http://www.gov.scot/Resource/Doc/161360/0043790.pdf

60. Scottish Executive. Changing Lives: Report of the 21st Century Social Work Review. Edinburgh: Scottish Executive, ; 2006.

61. Scottish Government. Maximising Recovery, Promoting Independence: An Intermediate Care Framework for Scotland. Edinburgh: The Scottish Government, ; 2012.

62. Scottish Government. Long Term Conditions Collaborative. Making the Connections – Food For Thought: Anticipatory Care, Self Management and Community-Led health improvement approaches for people with long term conditions. Edinburg, Scotland; 2010.

63. Scottish Government. Reshaping care for older people. A programme for change 2011 – 2021. Edinburgh: NHS Scotland, ; 2010. Available from: http://www.gov.scot/Resource/0039/00398295.pdf

64. Scottish Government. Community hospitals strategy refresh. Edinburgh: 2013. Available from: http://www.gov.scot/Resource/0039/00391837.pdf

65. Scottish Executive. Co-ordinated, integrated and fit for purpose. A Delivery Framework for Adult Rehabilitation in Scotland. Edinburgh: NHS Scotland; 2007. B49488 02/07 Available from: http://www.gov.scot/resource/doc/166617/0045435.pdf

66. Reeves R. Health and Community Care: Patient Experience. Better Together: Scotland's Patient Experience Programme. Building on the Experiences of NHS Boards. Edinburgh: Scottish Governement; 2008. Scottish Governement Social Research Available from: http://patientperspective.org/wp-content/uploads/2014/10/Scottish-Government-Building-on-the-Experiences-of-NHS-Boards.pdf

67. Scottish Government. The National Performance Framework. Edinburgh: Scottish Governement; 2016. Available from: http://www.gov.scot/Resource/0049/00497339.pdf

68. Singh D, Ham C. Improving care for people with long-term conditions: a review of UK and international frameworks. Birmingham University of Birmingham Health Services Management Centre, NHS Institute for Innovation and Improvement; 2006.

69. Scottish Government. Long Term Conditions Collaborative: Improving Care Pathways. Edinburg, Scotland; 2009.

70. Scottish Government. Long Term Conditions Collaborative. Improving Complex Care. Edinburg, Scotland: Scottish Government, ; 2009.

71. Scottish Government. Long Term Conditions Collaborative. Improving Self Management Support. Edinburg, Scotland; 2009.

72. Scottish Government. Diabetes Improvement Plan. Edinburgh Scottish Government, ; 2014. Available from: http://www.diabetesinscotland.org.uk/Publications/Diabetes_Improvement_Plan_2014.PDF

73. Scottish Diabetes Group. Diabetes in Scotland [Web page].2017 [cited 2017/05/05]. Available from: http://www.diabetesinscotland.org.uk/Groups.aspx

74. Scottish Executive. Strengthening the role of managed clinical networks 2007 Available from: http://www.scot.nhs.uk/sehd/mels/HDL2007_21.pdf

75. Diabetes In Scotland. Managed Clinical Networks [Web page].n/a. Available from: http://www.diabetesinscotland.org.uk/mcn.aspx

76. Diabetes UK. Competencies [Web page].2017. Available from: https://www.diabetes.org.uk/Professionals/Training--competencies/Competencies/

77. NHS Scotland. NHSScotland 2015-16 Local Delivery Plan Guidance. Edinburgh: NHS Scotland, ; 2015. Available from: http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/NHSScotland/LDPGuid1516

78. Scottish Government. Better heart disease and stroke action plan Edinburgh: Scottish Government; 2009.

79. Scottish Government. Stroke Improvement Plan. Edinburgh: Scottish Government,; 2014.

80. NHS Scotland. Welcome to the Stroke Website [Web page].Edinburgh: NHS Scotland,;n/a. Available from: http://www.sehd.scot.nhs.uk/stroke/index.htm

81. NHS Scotland. Chapter 2: Focusing on priority health topics [Web page].2001 [updated 2005]. Available from: http://www.gov.scot/Publications/2002/07/15153/9249

82. NHS Grampian. NHS Grampian Framework For Managed Clinical/Care Networks Aberdeen: NHS Grampian, ; 2009. Available from: http://www.nhsgrampian.co.uk/nhsgrampian/files/NHS_Grampian_Framework_For_MCNs-Finalised_July_2009.pdf

83. Scottish Intercollegiate Guidelines Network. Management of patients with stroke: Rehabilitation, prevention and management of complications, and discharge planning. A national clinical guideline. Edinburgh; 2010.

84. Scottish Intercollegiate Guidelines Network. Guidelines by topic [Web page].2017. Available from: http://www.sign.ac.uk/guidelines/published/index.html#CHD

85. NHS Scotland. Charter for people living with stroke in Scotland. n/a.

86. NHS Grampian. NHS Grampian Stroke Care Pathway [Web page].Edinburgh;2010. Available from: http://www.nhsgstrokemcn.scot.nhs.uk/wp-content/uploads/2010/09/stroke-flow-d09-september-2010.pdf

87. Scottish Stroke Care Audit. Quality [Web page]. NHS Scotland 2015. Available from: http://www.strokeaudit.scot.nhs.uk/Quality.html

88. NHS Scotland. Policies and Protocols for the Management of Recombinant and Coagulation Products in Scotland Edinburgh: NHS Scotland; 2012. Available from: http://www.nsd.scot.nhs.uk/Documents/HaemophiliaProtocolv2.0.pdf

89. NHS Scotland. Scottish Inherited Bleeding Disorders Network [Web page].n/a. Available from: http://www.mcns.scot.nhs.uk/sibdn/

90. The Haemophilia Society. What to expect from your treatment centre [Web page].2017. Available from: http://haemophilia.org.uk/bleeding-disorders/treatment-centres/expectations-treatment-centre/

91. Mumford AD, Ackroyd S, Alikhan R, Bowles L, Chowdary P, Grainger J, et al. Guideline for the diagnosis and management of the rare coagulation disorders: a United Kingdom Haemophilia Centre Doctors' Organization guideline on behalf of the British Committee for Standards in Haematology. Br J Haematol. 2014;167(3):304-26.

92. HAEMNET. HAEMNET [Web page].2017. Available from: https://www.haemnet.com/external/homepage

93. Prohibition of Female Genital Mutilation (Scotland) Act 2005 The Stationery Office Limited 2005.

94. Serious Crime Act, The Stationery Office 2015. Available from: http://www.legislation.gov.uk/ukpga/2015/9/pdfs/ukpga_20150009_en.pdf

95. National Guidance for Child Protection in Scotland, 2014. Available from: http://www.gov.scot/Publications/2014/05/3052

96. Scottish Government. Equally Safe Scotland's strategy for preventing and eradicating violence against women and girls. Edinburgh: Scottish Government; 2016.

97. Baillot H, Murray N, Connelly E, Howard N. Tackling Female Genital Mutilation in Scotland. A Scottish model of intervention. Glasgow: Scottish Refugee Council, ; 2014.

98. World Health Organisation. The Netherlands. European Region. Copenhaguen: WHO; 2017. Available from: http://www.who.int/health-laws/countries/nld-en.pdf?ua=1

99. Ministry of Public Health Welfare and Sport. Healthcare in the Netherlands. The Hague: Ministry of Public Health, Welfare and Sport; 2016. Available from: https://investinholland.com/nfia_media/2015/05/healthcare-in-the-netherlands.pdf

100. Maarse JA, Jeurissen PP. The policy and politics of the 2015 long-term care reform in the Netherlands. Health Policy. 2016;120(3):241-5.

101. Patiëntenfederatie Nederland. Veranderingen in de langdurige zorg [Web page].Utrecht: Patiëntenfederatie Nederland, ;2015 [cited 2016/12/15]. Available from: https://www.patientenfederatie.nl/themas/veranderingen-in-de-langdurige-zorg/

102. Schafer W, Kroneman M, Boerma W, van den Berg M, Westert G, Deville W, et al. The Netherlands: health system review. Health Syst Transit. 2010;12(1):v-xxvii, 1-228.

103. Wet maatschappelijke ondersteuning 2015, 2015. Available from: http://wetten.overheid.nl/BWBR0035362/2016-08-01

104. Nederlands Huisartsen Genootschap. Dutch healthcare system [Web page].2017 [cited 2017/05/05]. Available from: https://www.nhg.org/dutch-healthcare-system

105. Bonney A, Iverson D, Dijkmans-Hadley B. A review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare. . Wollongong, Australia: University of Wollongong; 2015. Available from: https://www.peoplecare.com.au/Portals/1/Documents/uow%20commissioned%20report.pdf

106. Bertko J, Effros R. Analysis of Bundled Payment. RAND Corporation; 2010. Technical Report TR-562/20-HLTH, Available from: http://www.rand.org/pubs/technical_reports/TR562z20/analysis-of-bundled-payment.html

107. Raaijmakers LG. Diabetes Care And The Introduction Of A New Standard In The Netherlands. A closer look from the perspectives

of health care professionals and patients Maastricht: Universiteit Maastricht,; 2014. Available from: https://cris.maastrichtuniversity.nl/portal/files/667917/guid-a2e7169e-6a52-4493-93eb-1289cde5b09c-ASSET1.0

108. Raaijmakers LG, Hamers FJ, Martens MK, Bagchus C, de Vries NK, Kremers SP. Perceived facilitators and barriers in diabetes care: a qualitative study among health care professionals in the Netherlands. BMC Fam Pract. 2013;14:114.

109. ZonMw. Programme Diabetes [Web page].2017 [cited 2016/12/01]. Available from: https://www.zonmw.nl/en/research-and-results/quality-in-health-care/programmas/programme-detail/diabetes/

110. Struijs J, van Til J, Baan C. Experimenting with a bundled payment system for diabetes care in the Netherlands. The first tangible effects Bilthoven: National Institute for Public Health and the Environment (RIVM); 2010.

111. Struijs J, de Jong-van Til J, Lemmens L, Drewes H, de Bruin S, Baan C. Three years of bundled payment for diabetes care in the Netherlands. Impact on health care delivery process and the quality of care. Bilthoven: National Institute for Public Health and the Environment (RIVM); 2012.

112. Rutten-van Mölken M. Bundled payment for integrated chronic care: the Dutch experience. In. Rotterdam: Institute for Medical Technology Assessment; 2014. p. 15.

113. Drewes H, Heijink R, Struijs J, Baan C. Landelijke monitor populatiemanagement. Deel 1: beschrijving proeftuinen Bilthoven: Rijksinstituut voor Volksgezondheid en Milieu (RIVM); 2014. RIVM Rapport 133001001/201 Available from: http://www.rivm.nl/dsresource?objectid=dbd5b2c2-2abe-49a7-97bb-891c7af54b41&type=org&disposition=inline

114. Rijken M, de Bruin S, Snoeijs S, van Bijnen E, Daphne L, Jansen D, et al. Caring for people with multiple chronic conditions in the Netherlands: policy and practices. The Netherlands: NIVEL; n/a. Available from: http://www.icare4eu.org/pdf/Country_Factsheet_The_Netherlands_ICARE4EU.pdf

115. Snoeijs S, Struckmann V, van Ginneken E. INCA model, the Netherlands. Innovating care for people with multiple chronic conditions in Europe (ICARE4EU). . The Netherlands: NIVEL; n/a. Available from: http://www.icare4eu.org/pdf/INCA_Case_report.pdf

116. Vat LE, Middelkoop I, Buijck BI, Minkman MM. The Development of Integrated Stroke Care in the Netherlands a Benchmark Study. Int J Integr Care. 2016;16(4):12.

117. Minkman MMN, Schouten LMT, Huijsman R, van Splunteren PT. Integrated care for patients with a stroke in the Netherlands: results and experiences from a national Breakthrough Collaborative Improvement project. International Journal of Integrated Care. 2005;5:e14.

118. Kennisnetwerk CVA Nederland [Stroke Knowledge Network Netherlands]. Zorgstandaard CVA/TIA. Maastricht: Kennisnetwerk CVA Nederland; 2012. Available from: http://www.hersenletsel.nl/images/downloadables/zorgstandaard-cva-tia.pdf

119. Heijnen R, Limburg M, Evers S, Beusmans G, van der Weijden T, Schols J. Towards a better integrated stroke care: the development of integrated stroke care in the southern part of the Netherlands during the last 15 years (Special 10th Anniversary Edition paper). International Journal of Integrated Care. 2012;12:e123.

120. Star M, Lammers E, te Vaarwerk M. Zorgstandaarden in Nederland: 'de balans opgemaakt'. Utrecht: Coördinatieplatform Zorgstandaarden; 2012.

121. Tjon-A-Tsien M, Aren J, Lobo C. Draaiboek keten-dbc Cardiovasculair risicomanagement (CVRM). The Netherlands: HartVaatHAG; 2012.

122. Nederlandse Zorgautoriteit. DBC-systematiek [Web page].Utrecht: NZA;2017 [cited 2017/03/01]. Available from:

https://www.nza.nl/zorgonderwerpen/zorgonderwerpen/ziekenhuiszorg/veelgesteldevragen/dbc-systematiek/

123. Chronos Zorggroep. Zorgprogramma Keten DBC CVRM Hertogenbosch: Chronos Zorggroep; 2014. Available from: http://zorggroepchronos.nl/images/uploads/pdf/Zorgprogramma_Chronos_DBC_CVRM_augustus_2014.pdf

124. Platform Vitale Vaten. Zorgstandaard CVRM 2013. Gouda: Platform Vitale Vaten; 2013. Available from: http://rohmh.nl/wp-content/uploads/2014/09/Zorgstandaard_CVRM_2013_Patientenversie_012.pdf

125. Leebeek FW, Fischer K. Quality of haemophilia care in The Netherlands: new standards for optimal care. Blood Transfus. 2014;12 Suppl 3:s501-4.

126. Gezondheidsraad. Hemofilie, HIV en de Wbmv. Den Haag: Gezondheidsraad; 2015.

127. Nederlandse Zorgautoriteit. Add-ongeneesmiddelen en ozp-stollingsfactoren [Web page].Utrecht: NZA;2017 [cited 2017/03/10]. Available from: https://www.nza.nl/zorgonderwerpen/zorgonderwerpen/ziekenhuiszorg/Add-on-geneesmiddelen-en-stollingsfactoren/;jsessionid=156EBD8BA83DD47B7038F590EDE0D504.nza-live

128. 33 693 Evaluatie Wet op bijzondere medische verrichtingen (Wbmv). Brief van de Minister van Volksgezondheid, Welzijn en Sport aan de Voorzitter van de Tweede Kamer der Staten-Generaal., Minister Van Volksgezondheid, Welzijn En Sport 2016. Available from: https://zoek.officielebekendmakingen.nl/dossier/33693/kst-33693-7?resultIndex=1&sorttype=1&sortorder=4

129. Naleie Z, Vloeberghs E, Hummeling T. Evaluatierapport Project 'Toeleiding naar zorg voor besneden vrouwen. 2012-2015. The Netherlands: Federatie Somalische Associaties Nederland, PHAROS, GGD GHOR Nederland; 2015. Available from: http://www.pharos.nl/documents/doc/rapport_monitoring-zorg-besneden-vrouwen-2015.pdf

130. Exterkate M. Female Genital Mutilation in the Netherlands. Prevalence, incidence and determinants. Utrecht: PHAROS; 2013. Available from: http://www.pharos.nl/documents/doc/webshop/vrouwelijkegenitaleverminkinginnederland-finalreportfgminnl1.pdf

131. Inspectie voor de Gezondheidszorg. Vrouwelijke genitale verminking. Staatstoezicht Op De Volksgezondheid; 2010. Bulletin Available from: https://www.ggdghorkennisnet.nl/?file=2452&m=1311080371&action=file.download

132. Borst-Eilers E. Beleidsvisie hemofilie. Staatscourant. 1999;161.

133. Pharos. Female genital mutilation [Web page].2017 [cited 10/07/2017]. Available from: http://www.pharos.nl/information-in-english/female-genital-mutilation