

University of Liège Faculty of Social Sciences Doctoral School of Social and Political Sciences

### When Integrating Care is not Just a Question of Care: The Case of the Implementation of the Plan "Integrated Care for Better Health" for Chronic Patients in the Belgian Health Sector

Mélanie DE WINTER

Dissertation carried out under the supervision of Frédéric SCHOENAERS (University of Liège) and Daniel FAULX (University of Liège) and presented in order to obtain the degree of PhD in Political and Social Sciences

#### MEMBERS OF THE JURY:

Frédéric SCHOENAERS	Full Professor, Faculty of Social Sciences, University of Liège	
Daniel FAULX	Full Professor, Faculty of Psychology, Speech Therapy and	
	Education, University of Liège	
Patrick CASTEL	Director of Research FNSP, Sciences Po, Centre for the	
	Sociology of Organisations	
Fabienne FECHER	Full Professor, Faculty of Social Sciences, University of Liège	
Jean MACQ	Professor, Public Health Faculty, Catholic University of Louvain	
Sophie THUNUS	Professor, Public Health Faculty, Catholic University of Louvain	

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What is good in the long run is not always good in the short run. What is good at a particular historical moment is not always good at another time. What is good for one part of an organization is not always good for another part. What is good for an organization is not always good for a larger social system of which it is a part.

— James G. March, 1991, p. 73.

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#### Résumé Général

Cette recherche doctorale, qualitative et inductive, contribue au champ de recherche relatif aux politiques publiques en analysant différents aspects du processus d'implémentation d'une politique publique spécifique dans le secteur belge de la santé : le plan "Des soins intégrés pour une meilleure santé", lancé le 19 octobre 2015 et destiné à intégrer les soins pour les patients chroniques en Belgique. Basée sur une approche ethnographique, cette recherche s'appuie sur plusieurs méthodes de collecte de données : des entretiens (N=24), des focus groupes (N=7), de l'observation directe (N=97 — correspondant à 213 heures d'observation), de l'analyse documentaire (documents opérationnels) et une revue de littérature multi-focalisée.

Ce manuscrit est composé de sept chapitres différents. Le premier chapitre est consacré aux aspects méthodologiques tandis que les quatre chapitres suivants correspondent chacun à un article spécifique (publié ou en processus de reviewing et donc non encore publié) résumé dans un abstract au début de chacun desdits chapitres. Chaque article traite d'une question de recherche précise, cela afin d'étudier différentes dimensions relatives à l'implémentation du plan susmentionné.

Le premier article (Chapitre 2) aborde la question de savoir comment la configuration fédérale belge, configuration spécifique, a pu avoir une influence sur la mise en œuvre de cette politique publique dans le secteur des soins de santé en Belgique, et plus précisément sur le décalage que l'on peut constater en comparant les résultats attendus et les résultats effectifs dans le cadre de l'implémentation du plan. C'est ce que l'on appelle en anglais un « *implementation gap* ».

Le deuxième article (Chapitre 3) se concentre sur le phénomène des projets pilotes, considérés comme un objet de recherche à part entière, en essayant de comprendre comment l'utilisation de projets pilotes multidisciplinaires comme instruments d'implémentation a pu contribuer à remodeler les modes de gouvernance publique dans le secteur de la santé belge, cela dans un contexte de transition et de décentralisation.

Le troisième article (Chapitre 4) aborde la question de savoir comment l'utilisation de projets pilotes comme instruments d'implémentation peut structurer horizontalement la collaboration entre les parties impliquées dans un projet pilote. Il semblerait que l'utilisation de l'instrument du projet pilote ait créé les conditions permettant l'émergence progressive de formes spécifiques d'organisations, à savoir des réseaux de soins collaboratifs, et plus particulièrement de ce que l'on pourrait appeler des réseaux intégrés de santé communautaire.

Enfin, le quatrième article (Chapitre 5) combine les résultats de trois études différentes dans une analyse secondaire inductive et présente une approche transversale du concept d'empowerment, l'une des composantes des soins intégrés, considéré comme un terme générique (*umbrella term*) dans la littérature scientifique. Les chercheurs analysent comment la polysémie de ce concept pourrait avoir une influence sur son opérationnalisation collective, quand différents acteurs du secteur des soins de santé doivent travailler ensemble.

Après avoir développé une série d'éléments empiriques supplémentaires dans le Chapitre 6, la discussion se concentre sur certain.e.s présupposés, lacunes, ambiguïtés, paradoxes et absurdités identifiés grâce au travail ethnographique effectué dans le cadre de cette recherche doctorale et qui pourraient avoir contribué à l'émergence du décalage (*implementation gap*) mentionné ci-dessus durant la phase d'implémentation.

A cette fin, le matériau empirique recueilli dans le cadre de cette recherche ethnographique est d'abord analysé en mobilisant notamment un cadre analytique produit par Vreugdenhil et al. (2010) relatif au phénomène « projet pilote ». Ensuite, les notions de co-création et de « *process inclusivity* » sont examinées dans le contexte de l'implémentation des plans d'action loco-régionaux des projets pilotes. Ensuite, avant de conclure ce chapitre, sont détaillées les perspectives de recherche identifiées grâce à cette recherche doctorale. Enfin, une conclusion générale clôture le manuscrit.

**Mots clés :** Soins intégrés, maladie chronique, politique publique, implémentation, projet pilote, réseaux, organisation, collaboration.

#### **General Abstract**

This qualitative and inductive doctoral research makes a contribution to public policy sciences by analysing different aspects of the process pertaining to the implementation of a specific public policy in the Belgian health sector: the "Integrated Care for Better Health" plan (IC4BH), launched on 19 October 2015 with the intention of integrating care with regard to chronic patients in Belgium. Based on an ethnographic approach, this research draws on several data collection methods: interviews (N=24), focus groups (N=7), direct observation (N=97 — corresponding to 213 hours of observation), documentary analysis (operational documents) and a multifocused literature review.

This manuscript is comprised of seven different chapters. The first chapter is dedicated to methodological aspects, while the next four chapters each correspond to a specific paper (published or as yet unpublished) summarized in an abstract at the beginning of each of those chapters. Each paper deals with a precise research question in order to study different dimensions pertaining to the implementation of the IC4BH plan.

The first paper (Chapter 2) addresses the question of how the particular Belgian federal configuration may have had an influence on the implementation of this public policy in the health care sector in Belgium, and, more specifically, on the implementation gap that is apparent when comparing expected and real outcomes in terms of the IC4BH plan implementation.

The second paper (Chapter 3) focuses on the pilot project phenomenon, regarded as an object for research, trying to understand how the use of multidisciplinary pilot projects as implementation instruments contributed to reshaping the modes of public governance in the Belgian health sector, in a context of transition and ongoing devolution.

The third paper (Chapter 4) tackles the issue of knowing how the use of pilot projects as implementation instruments structured horizontal collaboration between the parties involved in a pilot project. It would seem that the use of the pilot project instrument created the conditions allowing the progressive emergence of specific forms of organisation, taking the form of collaborative care networks, and more specifically, of what could be called community-based integrated care networks.

Eventually, the fourth paper (Chapter 5) combines the results of three different studies in an inductive secondary analysis, and presents a cross-level approach of the concept of

empowerment, one of the integrated care components, which is viewed as an umbrella term in the scientific literature. The paper analyses how the polysemy of this concept might have an influence on its collective operationalisation, when different health care stakeholders have to work together.

After having developed additional empirical elements in Chapter 6, the discussion focuses on certain presuppositions, shortcomings, ambiguities, paradoxes and absurdities, all of which were identified during the ethnographic fieldwork carried out as part of this doctoral research and that might have contributed to the emergence of the previously noted implementation gap. The empirical material collected as part of this ethnographic research is first analysed by mobilising, *inter alia*, the analytical framework produced by Vreugdenhil et al. (2010) pertaining to the project phenomenon. Second, the notions of co-creation and process inclusivity are discussed in the context of the implementation of the pilot projects' loco-regional action plans. Later, the research perspectives identified thanks to this doctoral research are presented before concluding the discussion. Last, but not least, a general conclusion is presented.

**Key words:** Integrated care, chronic disease, public policy, implementation, pilot project, networks, organisation, collaboration.

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#### Abbreviations

AFSDI	Auxiliary Fund for Sickness and Disability
	Insurance
APA	Adapted Physical Activity
ASBL	Association Sans But Lucratif
CCM	Chronic Care Model
CDO	Chronic Diseases Observatory
CRIS	Centre de Recherche et d'interventions
	sociologiques
ELADEB	Echelles Lausannoises d'Auto-évaluation
	des Difficultés et des Besoins
EP	Execution Phase
FFP	Filtering Facepiece
FPS	Federal Public Service
FTE	Full-Time Equivalent
GP	General Practitioner
IAC	Inter-Administrative Cell
IC4BH	Integrated care for better health
ICWG	Inter-Cabinet Working Group
IMA	Inter-mutualist agency
IMC	Inter-Ministerial Conference
MHC	Medical Health Centre
NIHDI	National Institute for Health and Disability
	Insurance
PBI	Plan de besoins individualisé
VAT	Value Added Tax

## Introduction

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A verb like implement must have an object like "policy". — Jeffrey L. Pressman & Aaron Wildavsky, Implementation, 1984, p. xxi.

#### 1. The Launch of a New Public Policy

#### 1.1. The Joint Plan "Integrated Care for Better Health"

On 19 October 2015, the Belgian health ministers launched a new public policy: a joint plan entitled "Integrated Care for Better Health" (IC4BH) for patients with chronic diseases. The purpose was to move from a fragmented institutional system to an integrated care system for those patients. This marked an important milestone in the long reflection regarding the way of dealing with the challenges posed by the prevalence of chronic diseases in Belgium. This epidemiologic burden, which created a need to transform systems historically-focused on acute care (Wagner et al., 2001), is not specific to Belgium (Paulus et al., 2012); it is a feature which concerns countries throughout the world, and one which has led the search for innovative solutions.

In this context, several models have been developed, one being the well-known Chronic Care Model (CCM) (Wagner et al., 2001), which widely inspired the Belgian authorities. This model emphasises the development of integrated care as an essential to tackle the challenges posed by chronic diseases (Paulus et al., 2012). Nevertheless, given the huge number of definitions that can be found in the scientific literature, the notions of care integration and integrated care are difficult to define. Some even use the idea of "conceptual soup" (Amelung et al., 2017, p. 21) regarding those notions.

In any event, it is clear that the former refers to a process whereas the latter refers to an outcome. Indeed,

integration (from the Latin integer, meaning whole or entire) generally means combining parts so that they work together or form a whole. Care, which can have many meanings, does in this context refer to providing attentive assistance or treatment to people in need. Hence, integrated care results when the former (integration) is required to optimise the latter (care) and so is particularly important where fragmentations [and silo-based working] in care delivery have led to a negative impact on care experiences and outcomes (Amelung et al., 2017, p. 11),

which is precisely the case in Belgium. In parallel, in a recent overview of integrated care (WHO, 2016), one can find three different main definitions coming from the literature:

• A process-based definition: "Integration is a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings. Where the result of such multi-pronged efforts to promote integration leads to benefits for people, the outcome can be called *integrated care*" (WHO, 2016, pp. 3–4);

- A user-led definition: "My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes" (WHO, 2016, p. 4);
- A health system-based definition: "Integrated health services' delivery is defined as an approach to strengthen people centred health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through intersectoral and multisectoral actions" (WHO Regional Office for Europe, 2016, p. 10).

Logically, in opposition to silo-based working, a key characteristic of integrated care resides in inter-professional collaboration. It is a prerequisite to effective co-ordinated care around people's needs (Amelung et al., 2017). Achieving this type of collaboration in Belgium is quite a challenge given the high level of segmentation of the Belgian health care system. Hence, it requires an important culture change.

So, when launching the IC4BH plan, the Belgian authorities stressed the urgency of developing the health care system:

FROM	INTO
A fragmented system	More care continuity and integration
Reactive care (Ex post)	Planned and proactive care (Ex ante)
A diseased-centred approach	A patient-centred approach
A medical model	A multidisciplinary model
A supply-oriented model	A demand-oriented model
An passive patient	An active patient

#### Table 1 – An Ongoing Paradigm Shift

#### Reference: De Ridder & Goemans (2016)

To achieve this transition, the Belgian authorities decided to follow the principles of the Triple Aim model, which consist of a combination of three interdependent objectives : "improving the individual experience of care, improving the health of populations, and reducing the per capita costs of care for populations" (Berwick et al., 2008, p. 760). That being said,

the [official] plan mission is to support an improvement of the population life quality, and in particular, in favour of people suffering from one or several chronic disease(s) so that they can live at best in their own environment (family, school, workplace) as well as in the community, and can manage their own care process in an active manner (Belgian Ministry of Social Affairs and Public Health, 2015, p. 6).

The target population of this plan included

"all those in the population who have to face health problems requiring long term care due to a non-communicable disease (diabetes, cancer, asthma, etc.), a persistent communicable disease (HIV-aids), a mental illness (psychosis, etc.), anatomic and functional damage (blindness, multiple sclerosis, etc.), a rare disease, sequelae of an accidental event (amputation, paralysis, etc.), a state of complex multimorbidity or of great dependence, or a state of terminal illness. Given that integrated care requires a mindset change at the level of the overall population, healthy people are also targeted in order to reduce the development and aggravation of chronic diseases (preventive healthcare)" (Belgian Ministry of Social Affairs and Public Health, 2015, p. 7).

In conjunction with this, the authorities referred to the Kaiser Permanente risk stratification pyramid as a central tool:

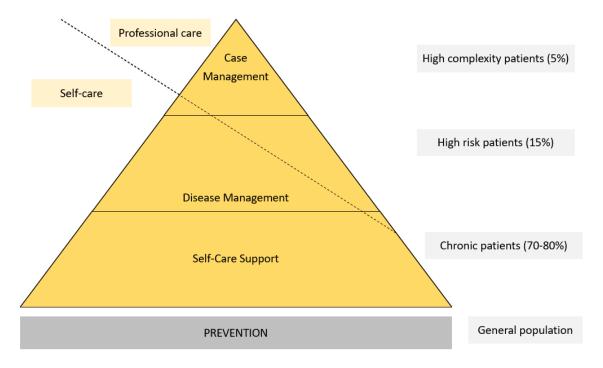


Figure 1 - Kaiser Permanente Risk Stratification Pyramid

#### Reference: Belgian Ministry of Social Affairs and Public Health (2015)

Depending on the stratum in which the patient lies, the solution to fulfil his/her need(s) will be different, the purpose being that people remain at the lowest level possible.

Nevertheless, the question of how to concretely and practically apply integrated care remains difficult to answer due to the polymorphous nature of this concept (Goodwin, 2013a), but also because the emerging discipline of implementation science regarding care integration contains several gaps (Goodwin, 2013b). Indeed, "despite the plethora of pilot projects around the world, there is a knowledge deficit on what works in what context to guide the design and evaluation of integrated care projects" (Amelung et al., 2017, p. vi). As a result, there is no "one best way" or unique approach to achieving care integration. It strongly depends on the context in which actions will be initiated (Minkman, 2020).

In the view of this vagueness regarding the concrete integrated care implementation modalities, the Belgian authorities gave a specific structure to the IC4BH plan and opted for original implementation modalities. The plan was divided into four action lines as follows (Belgian Ministry of Social Affairs and Public Health, 2015):

1. Integrated care pilot projects with the purpose of testing new care modalities on the ground

- 2. Methodological, scientific and technic support
- 3. The plan governance intended to support and steer the implementation of integrated care
- 4. Specific initiatives from the different ministers whose competences are involved in the development of integrated care

#### **1.2.** Presentation of the Four Action Lines<sup>1</sup> of the Plan

#### First Action Line: Integrated Care Pilot Projects with the Purpose of Testing New Care Modalities on the Ground

With regard to the first action line, the authorities opted for an iterative and incremental implementation. The purpose was to identify bottom-up solutions to experiment integrated care in its diverse dimensions (Belgian Ministry of Social Affairs and Public Health, 2015) while paying attention to equity and care accessibility (Cellule Inter-Administrative, 2016). This gave the opportunity for hands-on professionals to suggest, design and implement specific actions as part of pilot projects intended to initiate a global cultural change in the field regarding practices:

- at the micro level regarding the care delivered to patients;
- at the meso level regarding the collaboration modalities between professionals as well as the structure, organisation and management of their network as part of their pilot project (Cellule Inter-Administrative, 2016).

In other words, the authorities determined the general purpose (implementing integrated care), but did not express concrete ways in which to achieve it. They let hands-on professionals imagine new ways of working based on their day-to-day practice and personal professional experience, itself anchored in the Belgian local context. Each pilot project had the opportunity to define its own target group among the different categories of chronic patients. They did not have to include all the categories of the initial planned target population listed above<sup>2</sup>, even if the ambition was to fully cover all these categories by the end of the expansion phase (Cellule Inter-Administrative, 2016).

<sup>&</sup>lt;sup>1</sup> Belgian Ministry of Social Affairs and Public Health (2015)

<sup>&</sup>lt;sup>2</sup> See p. 4

In the IC4BH plan, it states that the implementation process would be divided into four phases: the preparation phase, the conceptualisation phase, the execution phase and the expansion phase. These phases are described synthetically in Table 2.

Preparation Phase		
Expected timing	Beginning: February 2016, when the authorities launched a call for	
	expressions of interest following the publication of a guidance leaflet	
intended to help pilot project consortia understand what was expected		
	them at each phase of the implementation process.	
	<u>End</u> : May 2016	
Real timing	February 2016 – May 2016 as planned.	
Purpose and	Constitution of pilot projects consortia and submission of expressions of	
tasks	interest.	
Conceptualisation Phase		
Expected timing	Beginning: July 2016 (after the first selection procedure)	
	End: January 2017	
Real timing	Beginning: July 2016 (September 2016 for four consortia after an	
	unplanned second selection)	
	End: September 2017	
Purpose and	Elaboration of an action plan (called the loco-regional action plan) on the	
tasks	part of each selected pilot project consortium, with the aim of designing	
	and implementing integrated care for their target group of patients with	
	chronic diseases in a specific geographic zone covering a population of at	
	least 75,000 inhabitants, and ideally of 100,000 to 150,000 inhabitants.	
Execution Phase		
Expected timing	Beginning: March 2017	
	End: March 2021	
Real timing	Beginning: January 2018	
	End: Probably January 2022	
Purpose and	Implementation of the action plans designed during the conceptualisation	
tasks	phase by pilot project members, the inclusion of beneficiaries* and the	
identification of best practices.		
Expansion Phase		
Expected timing	4 to 5 years after the beginning of the execution phase	
Real timing	(To be determined)	
Purpose and	Generalisation of best practices identified during the execution phase and	
tasks	the evolution of pilot projects to cover the entire Belgian population.	

#### **Table 2- An Implementation in Four Phases**

\*During the execution phase, projects would have to "include" beneficiaries via an inclusion application. This process of inclusion was designed with the purpose of identifying those people

among the total project population who would benefit from the project actions, in order to have a recorded follow up of their care trajectory and analyse the actions' potential effects. This seemed important in order to be able to identify which actions could be kept or adapted and even implemented in other zones.

Before being included, a beneficiary would mandatorily have to give his/her informed consent regarding two elements:

- his/her participation in the project
- his/her participation in a study intended to evaluate the project in which he/she has been included, involving the use of her/his personal data in accordance with the GDPR regulation.

The included patients would be required to take the "BelRAI screener", a new need assessment tool in the form of a short questionnaire. The BelRAI screener would be a first step, the administration of which was estimated to be 10-15 minutes. This test is used to determine if a person could benefit from a full BelRAI evaluation, comprised of several questionnaires intended to produce a global need-assessment of a person (relating to physical, cognitive, psychological and social needs)<sup>3</sup>. During the conceptualisation phase, the authorities specifically requested that the projects carefully describe, in their loco-regional action plan, how they intended to implement the BelRAI tool. Given the novelty of this tool, the training of the professionals involved would be required.

#### Second Action Line: Methodological, Scientific and Technical Support

This support was intended to help identify, develop and implement best practices. It was divided into nine work packages, four pertaining to pilot projects, and the other five pertaining to the IC4BH plan. A group called the "support platform" was constituted, and assigned the role of coordinating the work packages. It consisted of a variety of experts from both the private and the public sectors. The work packages are listed in Table 3 below.

<sup>&</sup>lt;sup>3</sup> <u>https://www.belrai.org/fr</u> (accessed 21 February 2020)

#### Table 3 – Work Packages

Work packages pertaining to pilot projects	Work packages pertaining to the plan
WP1: Coaching during the conceptualisation phase	WP5: Design of the communication plan and follow up
Specific support was provided by external coaches to help pilot project consortia design and write their action plans.	This WP concerned the communication aspects of the plan (logo, slogan, website) and the promotion of the initiatives taken as part of the plan, and as part of the pilot projects.
WP2: Needs stratification and	WP6: Evidence-Based Practice (EVP)
<b>environment cartography</b> The purpose was to help pilot project determine priority actions to be achieved by:	EVP was supposed to support the identification of best practices and the development of new tools.
<ul> <li>identifying the demographic, medical and socio-economic characteristics of their target population as well as gathering information regarding its care consumption;</li> <li>identifying the existing (and the missing) service offer in the project geographical zone (environment cartography).</li> </ul>	
<b>WP3: Training for local coordinators</b> The purpose was to train local coordinators to	WP7: Quality culture and change management
allow them to cope with the changes transforming the Belgian healthcare landscape.	The aim was to help stakeholders manage change, and develop a quality culture by providing them with specific tools.
WP4: Scientific support and evaluation	WP8: Development of e-health tools
An inter-university scientific team was mandated to help pilot project consortia develop their own auto-evaluation tools based on specific indicators.	This WP involved creating synergies with the e-health plan which was implemented in parallel.
In parallel, the scientific team was assigned	WP9: Performance measure and global evaluation
the mission of carrying out an external evaluation of each project.	Specific indicators had to be created to evaluate to what extent the initiatives taken

as part of the IC4BH plan would meet the
Triple Aim philosophy.

Reference: Belgian Ministry of Social Affairs and Public Health (2015)

Third Action Line: The Plan Governance Intended to Support and Steer the Implementation of Integrated Care

All the entities represented in Figure 2 were expected to be involved in the governance of the plan:

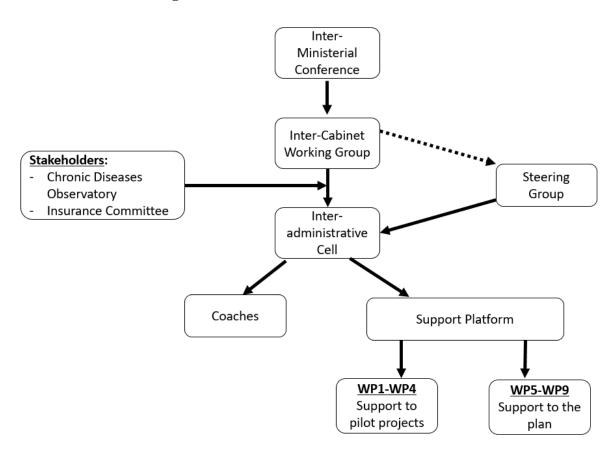


Figure 2 - The Plan Governance Structure

Reference: Belgian Ministry of Social Affairs and Public Health (2015, p. 20)

The plan governance was managed by the Inter-Ministerial Conference (IMC) and the Inter-Cabinet Working Group (ICWG) dedicated to chronic diseases. The IMC brought together the different Belgian health ministers and was the decision-making body regarding:

- the IC4BH plan
- the plan vision and the plan strategy

- the guidance leaflet for pilot projects
- the communication strategy
- the Support Platform inception
- the follow-up plan
- the plan evaluation

The ICWG dedicated to chronic diseases brought together the representatives of ministerial cabinets and administrations pertaining to the different levels of power. It was in charge of:

- coordinating the plan;
- checking the coherence between the plan measures and those initiated by the federate entities;
- preparing political decisions and their submission to the IMC;
- preparing the plan's intermediary evaluation, and its presentation to the IMC.

The Inter-Administrative Cell (IAC) was created by the Public Health Federal Public Service (FPS) and the National Institute for Health and Disability Insurance (NIHDI). It was constituted of public officials coming from these two institutions. The initial intention was to include public officials of the federate entities, a proposal which subsequently did not happen. The IAC was in charge of:

- managing the operational implementation of the plan and its follow-up;
- preparing the ICWG decisions;
- managing pilot projects;
- the follow-up of the Support Platform and of scientific teams;
- the coaching support.

The IAC was supervised by a Steering Group emanating from the ICWG.

The Chronic Diseases Observatory (CDO) is a NIHDI entity which brings together a diversity of stakeholders including patient's organisations. It had the role of identifying the needs of patients with chronic diseases. The Insurance Committee of the NIHDI is composed of insurance institutions 'representatives, care providers' representatives and social partners' representatives. As part of the implementation of the IC4BH plan, it was mandated to conclude covenants with third parties (scientific teams, pilot projects consortia, etc.).

Fourth Action Line: Specific Initiatives from the Different Ministers whose Competences are Involved in the Development of Integrated Care

In the plan, it is stated that the development of integrated care initiated at the federal level had to be coordinated with the ongoing and future actions initiated at the federate entities level (e.g., prevention actions, implementation of the "BelRAI" tool, development of e-heath tools, case management aspects, etc.). Furthermore, this innovation was expected to go beyond the field of health. It would also involve the intervention of other fields (e.g., employment, finances, education, justice, housing, etc.).

#### 2. Topic of this Doctoral Research

This doctoral research analyses the implementation process of the IC4BH plan, a specific public policy, i.e., "an action programme proper to one or several public or governmental authorities" (Hassenteufel, 2011, p. 7). As part of a non-evaluative approach, it focuses on political and organisational governance aspects in order to understand the social mechanisms at play. Before diving into the core topic, it seems important to dwell a little on the relevance of focusing on those aspects as part of a doctoral research pertaining to healthcare. Indeed, some may be puzzled by the fact that this research does not include a component analysing the therapeutic relationships as they occur in the field between patients and caregivers in the context of the IC4BH plan.

First of all, for a number of reasons that will be explained in subsequent chapters and for practical reasons, this would not have been possible given that this research began three years before the actual launch of actions in the field involving patients. Secondly, the scientific team in charge of the evaluation of each project was mandated to follow the actions' implementation and analyse the related therapeutic aspects pertaining to integrated care, i.e., what will be referred to with regard to the third point, the tip of the iceberg.

Indeed, therapeutic aspects and relationships are the most obvious and visible parts of a healthcare system, which can metaphorically be compared to an iceberg. Everyone can observe and experience them as patients. However, there are many other nontherapeutic aspects (e.g., governance, institutional, organisational, financial, political, managerial aspects, etc.), corresponding to the submerged part of the iceberg (or the "behind-the-scenes" work to draw a parallel with the world of theatre), that will influence directly or indirectly, the therapeutic work of professionals and underpin patients' experience in the field. Just as a side note, it was the

submerged part of the iceberg that was responsible for the sinking of the Titanic, which shows that this part should definitely not be neglected, and deserves as much attention as the tip.

A Belgian example from the covid-19 crisis corroborates this vision: the now famous problem posed by the destruction of a strategic stockpile of several million FFP2 protective masks which had reached their expiry date but had not been renewed, apparently to save money<sup>4</sup>. Technically, ordering protective masks is not a therapeutic act, but it had serious therapeutic consequences in the field through a domino effect. Without that kind of mask, professionals were not perfectly protected against the virus, and it made it more complicated for them to care for patients who were hospitalized due to the covid-19 infection. A simple logistical and accounting act of non-renewal of stock, which could have gone completely unnoticed without the covid-19 crisis, had considerable consequences at the therapeutic level. It shows that care delivery is not just a therapeutic issue, that and health is not just a question of care.

So, getting back to the matter at hand, this doctoral research is *inter alia* comprised of four complementary papers, each corresponding to a specific chapter of this manuscript. Each paper addresses a specific research question and, as a result, analyses different dimensions pertaining to the implementation of the above-mentioned plan, as summarised in Table 4.

	Paper No. 1: Integrating Care in a Disintegrated Country: the Case of Integrated Care Pilot	
Projects in the Belgian Federal State (Unpublished)		
Research question	How can the federal configuration influence the implementation	
	of a public policy in the health care sector of a multi-layer federal	
	state?	
Key elements	Multi-level governance, inter-institutional coordination and	
	collaboration in a multi-layer context.	
Paper No. 2: De Winter, M. « Reshaping health care governance using pilot projects as		
public policy implementation instruments », International Review of Public Policy [Online],		
2:3   2020, Online since 15 December 2020, DOI: https://doi.org/10.4000/irpp.1422.		
Research question	How does the use of multi-disciplinary pilot projects as	
	implementation instruments reshape modes of public	
	governance in the Belgian health sector in a context of transition and ongoing devolution?	

Table 4 – Four Comp	lementary Papers
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<sup>&</sup>lt;sup>4</sup> More information via this link: https://www.rtbf.be/info/belgique/detail\_la-belgique-a-detruit-son-stock-de-masques-ffp2-en-fevrier-2019-sans-le-remplacer?id=10465547

Key elements	Vertical collaboration, crossed-regulation
Paper No. 3: De Winter, M. Towards Integrated Care for Chronic Patients in Belgium: The	
Pilot Project, an Ins	strument Supporting the Emergence of Collaborative
Networks. Societies 2019, 9, 28.	
Research question	How does the use of pilot projects as implementation instruments structure the collaboration between parties involved in a pilot project?
Key elements	Horizontal inter-organisational and inter-professional collaboration, network constitution.
Paper No. 4: Tilkin, C.; De Winter, M.; Ketterer, F.; Etienne, AM.; Vanmeerbeek, M.;	
Schoenaers, F. Considering Patients' Empowerment in Chronic Care Management: A Cross-	
Level Approach. Eur. J. Investig. Health Psychol. Educ. 2020, 10, 134-142.	
Research question	What are the consequences of such an elusive concept [the concept of empowerment] when different health care stakeholders have to work together?
Key elements	Practical implementation and interpretation of integrated care components, e.g., the umbrella concept of empowerment in this specific paper

Chapter 1 which precedes these four articles (Chapters 2 to 5) is dedicated to the presentation of the methods used to conduct this research. Chapter 6 is dedicated to the presentation of additional empirical elements necessary for a good understanding of the general discussion constituting Chapter 7. Finally, this manuscript closes with a general conclusion. However, before that, in order to understand the context as well as the whys and wherefores of the IC4BH plan implementation, it seems necessary to describe the current functioning of the Belgian health care system.

#### 3. The Belgian Healthcare System

In the literature, three types of health care systems can be distinguished (Palier, 2017):

- 1. National health care systems (Beveridge Model): financed through tax payment, these systems are regulated by the government (Schokkaert & Van de Voorde, 2011).
- Social health insurance systems (Bismarck Model): financed through social security contributions and/or insurance premiums in which insurers/sickness funds play the role of intermediaries between patients and health practitioners (Schokkaert & Van de Voorde, 2011).

3. Liberal health care systems: following free market principles, individuals rely on private health insurance (Palier, 2017).

Belgium mainly displays the characteristics of the Bismarckian model with its compulsory health insurance system, being part of the global Belgian social protection system, and is primarily financed through social security payroll deductions. In addition, beneficiaries can combine this compulsory health insurance with supplementary health insurance, which is provided by sickness funds upon payment of insurance premiums. It is interesting to note that, following the evolution of the social security system, the Belgian health care system has incorporated some characteristics of the Beveridge model over time (Service Public Federal (SPF) Securité Sociale, 2016). As Schokkaert & Van de Voorde (2011, p. 7) commented: "the Belgian system turns out to be a somewhat strange hybrid". As an example, the compulsory health insurance for medical care, one of the social security components, has become universal (Beveridge) and encompasses all citizens, regardless of their professional and social status (employees, public officials, self-employed workers, the unemployed, the retired, students, people entitled to social integration income/social benefits, orphans, the disabled) (Service Public Federal (SPF) Securité Sociale, 2016).

To rephrase, the current Belgian health care system combines a compulsory health insurance, with a non-mandatory supplementary health insurance, both based on the principle of solidarity (Saltman et al., 2004). The compulsory health insurance, which is part of the global Belgian social protection system, is not only applied to workers (salaried workers, self-employed people, civil servants). Indeed, access to health insurance does not depend on professional and/or social status. Rather, the entire Belgian population is entitled to medical care, either as a beneficiary or as a dependent (spouses, children, grandchildren). The supplementary health insurance is provided by sickness funds (health mutuals) upon payment of insurance premiums, and provides access to additional benefits, reimbursements and services.

Sickness funds play the role of intermediaries between the NIHDI, the patients, and their health practitioners, regarding the reimbursement of medical expenditures. In order to enable their rights to compulsory health insurance benefits, beneficiaries have to affiliate with a sickness fund of their choice. They can choose:

 either one of the different mutual insurance funds belonging to the not-for-profit private sector, which also provide their affiliate members with supplementary health insurance as long as they are up-to-date with the payment of their insurance premiums,  or the regional service of the "Auxiliary Fund for Sickness and Disability Insurance" (AFSDI), a public entity which does not provide supplementary health insurance<sup>5</sup> (no insurance premiums) and only reimburses medical expenditures covered by compulsory health insurance.

In Belgium, the majority of physicians are self-employed and remunerated on a fee-for-service basis (Organisation for Economic Co-operation and Development & European Observatory on Health Systems and Policies, 2017), therefore they are paid for each service performed, such as medical consultations, tests, etc.<sup>6</sup> Patients pay their medical costs upfront and in exchange receive a certificate, in effect a receipt, from their practitioner, proving that payment has been made. Upon presentation of this document, patients can be partly refunded by their sickness funds (mutual insurance fund or AFSDI). The amount of reimbursement covered by compulsory insurance is set by the NIHDI and listed in an official "nomenclature" as with all the other reimbursement rates related to every refundable medical act. The part that is not reimbursed, the proportion assumed by the patient, is called the user fee or patient fee (Service Public Federal (SPF) Securité Sociale, 2016).

In some specific cases (low income, disability, etc.), a third-party payer system is applied.<sup>7</sup> Then, patients only pay their user fees to their practitioners: "the reimbursement rates are applied directly" (Federal Public Service (FPS) Social Security, 2012, p. 44). Practitioners receive the rest of their fees, the amount covered by compulsory insurance, from their patients' sickness funds. This situation differs from the previous one as these particular patients pay nothing upfront. In Belgium, 1.9 million people, who are entitled to a higher reimbursement rate due to their financial situation, benefit from this system (De Block, 2017). Furthermore, this system is almost always applied by pharmacists as well as hospitals in the event of a hospital stay.<sup>8</sup>

In addition, Belgium applies the principle of freedom of choice (Organisation for Economic Co-operation and Development & European Observatory on Health Systems and Policies, 2017), which is a common feature of social health insurance systems (Saltman et al., 2004). Importantly, it sometimes leads to an over-consumption of health care, and, consequently, an

<sup>&</sup>lt;sup>5</sup> <u>https://www.caami-hziv.fgov.be/fr/concernant-la-caami</u> (accessed 20 January 2020)

<sup>&</sup>lt;sup>6</sup> <u>https://www.healthcare.gov/glossary/fee-for-service/</u> (accessed 20 January 2020)

<sup>&</sup>lt;sup>7</sup> <u>http://www.riziv.fgov.be/fr/themes/cout-remboursement/facilite-financiere/Pages/tiers-payant.aspx#.Waq8YchJY2w</u> (accessed 20 January 2020)

<sup>&</sup>lt;sup>8</sup> <u>http://www.riziv.fgov.be/fr/themes/cout-remboursement/facilite-financiere/Pages/tiers-payant.aspx#.Waq8YchJY2w</u> (accessed 20 January 2020)

increase in healthcare expenditure (Palier, 2017). Specifically, the principle of freedom of choice means that "patients can select their provider" (Saltman et al., 2004, p. 249). Consequently, they are free to choose their sickness fund, their doctor(s) (GPs and specialists) and to go to the hospital of their choice. In other words, GPs do not play the role of gatekeepers as they do in national health care systems (e.g., as in UK, Sweden). In such systems, patients have to go to their GP first, before being allowed to consult a specialist (Palier, 2017; Saltman et al., 2004).

Alternatively, patients are also free to enrol at a Medical Health Centre (MHC, *maisons médicales* in French). MHCs operate an alternative health care model gathering together firstline care workers (general practitioners, nurses, physiotherapists, psychologists, social workers, etc.) in multidisciplinary teams. They work in concert in order to care for their patients, and in order to enhance or maintain their social welfare. It should be added that most of Belgian MHCs have recourse to an alternative funding model relying on capitation payments for first-line medical acts (general medicine, physiotherapy, nursing care),<sup>9</sup> in contrast to the prevailing fee-for-service model.<sup>10</sup> In 2015, the number of MHCs amounted to 151,<sup>11</sup> compared to 67 in 2005. Furthermore, 3% (336,247 patients) of the Belgian population was affiliated with an MHC in 2015.<sup>12</sup>

Finally, it seems important to emphasise that Belgium is a federal state. From an institutional point of view, competencies related to health care are divided between the federal level and the level of the regions, which is not without consequences, as it will be explained in Chapter 2.

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<sup>&</sup>lt;sup>9</sup> <u>http://www.riziv.fgov.be/fr/themes/cout-remboursement/par-mutualite/maison-medicale/Pages/default.aspx#.WapxpMhJY2w (accessed 20 January 2020)</u>

<sup>&</sup>lt;sup>10</sup> <u>http://www.maisonmedicale.org/En-quelques-mots.html</u> (accessed 20 January 2020)

<sup>&</sup>lt;sup>11</sup> <u>http://www.lejournaldumedecin.com/actualite/plus-de-150-maisons-medicales-en-belgique/article-normal-</u> 22247.html (accessed 20 January 2020)

<sup>&</sup>lt;sup>12</sup> <u>http://www.dhnet.be/actu/belgique/la-belgique-compte-plus-de-150-maisons-medicales-579f96fc35705dcbd70cf3a2</u> (accessed 20 January 2020)

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# Chapter 1: Materials and Methods

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Sometimes we simply have to keep our eyes open and look carefully at individual cases not in the hope of proving anything, but rather in the hope of learning something!

— Hans J. Eysenck, 2015, p. 9

#### 1. An Ethnographic Approach

This qualitative and inductive doctoral research, based on an ethnographic approach, also known as field research, started in December 2016, five months after the beginning of the conceptualisation phase. This research was conducted completely independently and, as a reminder, was not intended to produce an evaluation of the policy under consideration. Indeed, it was not part of the scientific support and evaluation planned by the authorities<sup>13</sup> as part of the WP4 of the second action line of the plan<sup>14</sup>. Field work ended in April 2020 during the execution phase.

"A qualitative research approach does only make sense if it shows and analyses the intentions, the discourse and the actions and interactions of the actors, from their point of view and from the researcher's point of view" (Dumez, 2016, p. 13). For that purpose, the triangulation approach (Dumez, 2016; Jick, 1979) seemed the most suitable. Incidentally, according to Angrosino (2007, p. 36), "good ethnography is usually the result of triangulation", relying "on a composite of observational, interview, and archival sources" (Angrosino, 2007, p. 51). Triangulation particularly helps ensure the soundness of the analysis (Dumez, 2016; Soukup et al., 2017). Therefore, the researcher combined three types of information sources: written documents, actions and interactions and, eventually, discourses, i.e., what interviewees agree to explain about their own and specific experience. In the next section, a more thorough description of the methods used to collect the data is presented.

#### 2. Data Collections Methods

#### 2.1. Written Documents

#### 2.1.1. Literature Review

A literature review consists of a "coverage or review of a body of literature and integration and synthesis of what has already been done in the literature" (Rocco & Hatcher, 2011, p. 146). As part of this doctoral research, a multi-focused literature review (Turner, 2018) was conducted regarding several topics related to this research, *inter alia* health care management, integrated care, chronic diseases, policymaking, public policy implementation, public policy instruments,

<sup>&</sup>lt;sup>13</sup> See p. 9.

<sup>&</sup>lt;sup>14</sup> Some results of this scientific support and evaluation are developed in the following paper:

Goderis G, et al. Evaluating Large-Scale Integrated Care Projects: The Development of a Protocol for a Mixed Methods Realist Evaluation Study in Belgium. International Journal of Integrated Care, 2020; 20(3): 12, 1–15. DOI: https://doi.org/10.5334/ijic.5435

pilot projects, etc. The topics specifically addressed in terms of each paper, are detailed in each of the next four chapters.

#### 2.1.2. Documentary Analysis

"Archival research is the analysis of materials that have been stored for research, service, and other purposes both official and unofficial" (Angrosino, 2007, p. 49). In the framework of this research, several political, legal and operational documents, e.g., minutes of meetings and pilot projects' expressions of interest and "loco-regional action plans", were read and analysed in depth. This also includes the joint plan itself and the documents available on the website http://www.integreo.be/fr/documentation. This website is a communication tool created by the public authorities involved, where documents related to the joint plan implementation were published, including political and legal documents, fact sheets, templates and application guidelines, and PowerPoint presentations. The analysis of these documents provided an overview of the issues authorities sought to communicate and the information they wished to be explicitly known.

Besides these formal archival sources, more informal written sources were also used, e.g., collective email conversations between the members of a same body or working group.<sup>15</sup>

#### 2.2. Actions and Interactions

#### 2.2.1. Direct Observation

"Observation is the act of perceiving the activities and interrelationships of people in the field setting through the five senses of the researcher" (Angrosino, 2007, p. 37). Interestingly, "attendance to project meetings, discussions and workshops [is] very valuable to gain inside understanding of pilot projects' dynamics" (Vreugdenhil & Ker Rault, 2010, p. 122). Therefore, the researcher attended 97 meetings corresponding to a total of 213 hours of attendance. Let us add parenthetically that she was also able to take advantage of moments of informal exchange with meeting participants as a means of gathering information, e.g., small talk before and after meetings and during breaks.

172 hours were spent observing meetings of two pilot projects - Projects A and B - located in the French-speaking Walloon Region of Belgium (66.5 hours for the first project, and 105.5 hours for the second one). Interestingly, they covered adjacent geographical zones, a large rural one for Project A including 44 municipalities, and a small urban one for Project B including 8

<sup>&</sup>lt;sup>15</sup> See p. 94 and 125

municipalities, each zone having a different level of population density. They also opted for different target groups. Project A decided to basically target almost all chronic diseases, whereas project B decided, at least initially, to target people having:

- Diabetes or COPD or cardiovascular conditions
- a mental health condition

Consequently, each project designed specific actions corresponding to the needs of its target group.

In parallel, the researcher also attended plenary sessions and intervisions organised by the public authorities (41 hours) to observe what was happening through interactions as part of a co-creation process, and to observe innovation in action.

	Project A	
Phase	Number of Attended	Total in Hours
	Meetings	
Conceptualisation phase	11	25.5
Execution phase	21	41
	Project B	
Phase	Number of Attended	Total in Hours
	Meetings	
Conceptualisation phase	22	45.5
Execution phase	31	60
Ple	enary Sessions and Intervisions	5
Phase	Number of Attended	Total in Hours
	Meetings	
Conceptualisation phase	6	19.5
Execution phase	6	21.5

#### Table 5 - Observation Overview Table

#### 2.3. Discourses

2.3.1. Interviews

"Interviewing is a process of directing a conversation so as to collect information" (Angrosino, 2007, p. 42). Twenty-four people were interviewed as part of this doctoral research. These 24

semi-structured interviews lasted between 33 and 98 minutes. They were all fully transcribed and analysed through open coding, a method of analysis from grounded theory methodology (Bryant & Charmaz, 2011). A specific interview guide<sup>16</sup> was written for each interviewee. Almost all the interviews were conducted during the conceptualisation phase, with the exception of three, which were conducted at the beginning of the execution phase. These can be identified thanks to the acronym "(EP)" in the overview tables below.

Interviewing these people helped identify formal and informal actors' roles, the way they personally experienced the process (Quivy & Campenhoudt, 2009), their knowledge (what they knew, but also what they did not know), their feelings, etc. The interviewees belonged to the following different categories of actors:

- policy-advisers and public officials (FPS Public Health, NIHDI, IAC) involved in devising and implementing the new policy, as well as an umbrella organisation representative;
- pilot project coordinators and coaches;
- pilot project stakeholders.

Table 6.a - Policy-advisers and Public Officials			
	Category of Actor	Duration	Date of Interview
1.	A high-ranking official (Federal level)	66'	6 January 2017
2.	A public official (Federal level)	95'	16 January 2017
3.	A high-ranking official (Federal level)	63'	1 March 2017
4.	A public official (Federal level)	63'	1 March 2017
5.	A public official (Federal level)	59'	27 March 2017
6.	A policy-adviser (Regional level)	54'	5 April 2017
7.	A public official (Regional level)	63'	6 April 2017
8.	A representative of a general practitioners'	85'	6 June 2017
	association		
9.	A policy-adviser (Federal level)	63'	23 June 2017

#### **Tables 6 - Interviews Overview Tables**

Table 6.b - Pilot Project Coordinators and Coaches			
	Category of Actor	Duration	Date of Interview
1.	Project B coordinator	72'	9 January 2017
2.	Two Project A coordinators (joint interview)	63'	11 January 2017
3.			

<sup>&</sup>lt;sup>16</sup> See appendixes 1, 2, 3 and 4 to have concrete examples of interview guides.

4.	A coordinator of a project non selected after the preparation phase	87'	26 January 2017
5.	The Project A coach	56'	30 March 2017
6.	A coordinator whose project stopped during	87'	19 April 2017
	the conceptualisation phase		
7.	Coaches' coordinators who was also coach	45'	15 May 2017
	of some projects		
8.	Project C coordinator (see below regarding	75'	1 February 2018
	project C)		(EP)

Table 6.c - Stakeholders of Project A			
	Category of Actor         Duration         Date of Interview		
1.	A general practitioner	44'	13 March 2017
2.	A representative of patients' associations	48'	9 June 2017

	Table 6.d - Stakeholders of Project B		
	Category of Actor	Duration	Date of Interview
1.	A general practitioner	47'	15 December 2016
2.	A social worker (also member of Project A)	33'	18 January 2017
3.	A health mutual director	54'	3 April 2017
4.	A home-care nurse involved in other projects	76'	28 February 2018
	for the elderly		(EP)
5.	A psychologist	98'	2 March 2018
			(EP)

# 1.3.2. Focus groups

Eventually, this research also relied on data collected via seven focus groups (7 FG – 16.5 hours in total) on the topic of governance. In the application file designed during the conceptualisation phase, pilot projects had to describe their future legal structure and governance modalities. In this regard, three pre-projects wished to gather the views of their stakeholders. To that end, they called on an external, independent and neutral actor: the Centre of Research and Sociological Intervention of the University of Liège (CRIS) that organised focus groups. The researcher who happened to be a CRIS member, was part of the team that organised the focus groups. It is in this context that she had access to the focus groups' data.

Concretely, the centre organised two sessions:

- A session for a project located in the Brussels-Capital Region of Belgium, i.e., project C, on 7 March 2017, during which the participants were divided into 3 focus groups made up of 10 to 15 people and lasting 3 hours each;
- A joint session for the two above-mentioned projects, Projects A and B, on 5 May 2017, during which the participants were divided into 4 focus groups made up of 10 to 15 people and lasting 2.5 hours each: these two projects, geographically adjacent, had common stakeholders and considered the possibility of pooling resources, which explains why it was decided to organise a joint session.

The CRIS researchers wrote a fictitious case to help guide discussions during the sessions, and to help members express their opinions about what they wanted for their projects in terms of governance. In a second phase, the discussions were recorded and analysed by the researchers. This was done in order to produce a report summarizing what had been expressed by the partners during the focus groups.

### 3. Limitations

One of the important limitations of this research, inherent to the ethnographic approach, is its non-replicability:

Qualitative ethnographic researchers are not usually concerned with reliability, since they recognize the fact that much of what they do is, in the last analysis, not truly replicable. There is, in other words, no expectation that one researcher observing a community at one time will exactly duplicate the findings of a different researcher observing that same community at a different time. By contrast, a biologist observing cellular processes under a microscope should come up with standard results no matter who he or she is, when the observation was made and so forth (Angrosino, 2007, pp. 58–59).

So, the ambition of this research was to understand the social mechanisms (Dumez, 2016) at play, not to produce predictive scientific laws. Incidentally, "there does not and probably cannot exist predictive theory in social science. Social science has not succeeded in producing general, context-independent theory and, thus, has in the final instance nothing else to offer than concrete, context-dependent knowledge" (Flyvbjerg, 2006, p. 223). However, this does not mean that this type of knowledge is irrelevant.

Another limitation resides in the fact that "the cases you choose affect the answers you get" (Geddes, 2003, p. 89). If the focus had been on other pilot projects, the results would probably not have been the same, given that each project:

- did not involve the same partners;
- opted for a specific organisational structure, more or less formal (e.g., *de facto* association vs. official legal structure);
- had its own governance dynamic (more or less peaceful/conflictual, more or less reactive);
- related to a specific geographical zone (rural/urban) encompassing a specific number of inhabitants (population density);
- chose a specific target group (e.g., all people whatever the chronic disease they had vs. a part of the population having specific chronic diseases), which means that the targeted chronic diseases differed from project to project;
- had its own risk stratification requiring specific actions.

Eventually, an important limitation to take into account is that Projects A and B were both located in the Walloon Region, the French-speaking part of Belgium. Some results might have been different if the same focus had been on Brussels or on Flemish pilot projects, given that they depended from other regions. Unfortunately, given that the researcher does not speak Dutch, it was not possible for her to focus on Flemish pilot projects due to the language barrier.

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# **Chapter 2**

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Integrating Care in a Disintegrated Country: the Case of Integrated Care Pilot Projects in the Belgian Federal State

# Status

Draft in second submission after major revision in the journal: Regional and Federal Studies (Taylor and Francis)

# Abstract

Chronic diseases have become the leading cause of mortality worldwide. In Belgium, these are responsible for about 87% of total deaths. In 2015, the Belgian authorities decided to take action; they launched a new public policy to integrate care for patients with chronic diseases in Belgium: the plan "Integrated Care for Better Health". The national political and institutional context in which this plan takes place is not insignificant. Interestingly, Belgium is a federal state, which has impacted the plan's implementation to date. Accordingly, this paper elaborates on the following research question: how can the federal configuration influence the implementation of a public policy in the health care sector of a multi-layer federal state? This ethnographic research highlights the blockages that may occur in a multi-layer federal country like Belgium, showing that federalism can become dysfunctional if the allocation of competences has not been made in a coherent manner, especially in a context of innovation.

Keywords: Implementation, public policy, federalism, integrated care

#### 1. Introduction

Countries all over the world have been facing a sharp rise in chronic diseases in recent years (Riley et al., 2017). Their prevalence is expected to continue to increase if no action is taken, with all the consequences that this will bring for the sustainability of health care systems. Indeed, chronic diseases have become the leading cause of mortality worldwide. They negatively affect the health and life quality of populations (Paulus et al., 2012) and put health care systems under budgetary pressures (Schokkaert & Van de Voorde, 2011). Belgium is no exception (Riley et al., 2017); the percentage of the population suffering from chronic diseases amounts to 27.2% (Paulus et al., 2012) and chronic diseases are responsible for about 87% of total deaths (WHO, 2014).

As it is, the Belgian authorities consider that the current Belgian health care system is not adequate when it comes to meeting chronic patients' needs (Belgian Ministry of Social Affairs and Public Health, 2015) given that they are very specific (Baszanger, 1986) and that those patients have to manage their particular condition in the long term. What is more, they often have several (two or more) chronic affections, a phenomenon called multi-morbidity (Ording & Sørensen, 2013). Dealing with multi-morbidity implies the intervention and collaboration of multiple care professionals and organisations (from first and second lines of care) in chronic patients' care trajectories, and also of non-medical stakeholders (Amelung et al., 2017).

The problem is that the single disease approach has predominated in the Belgian health care system since its inception. This has led to a high degree of specialisation, but also a lack of effective coordination, cooperation and collaboration between practitioners (Belgian Ministry of Social Affairs and Public Health, 2015). These are, nevertheless, indispensable when dealing with the challenge posed by chronic diseases (Amelung et al., 2017) and characterise, among other features, what is called "integrated care", which is identified in the scientific literature as a good solution for enhancing the care delivered to chronic patients (Contandriopoulos et al., 2001; Minkman, 2017). Integrating care is not an insignificant undertaking. It requires a global "system transformation" (Amelung et al., 2017, p. 7), or, in other words, a paradigm shift (Belgian Ministry of Social Affairs and Public Health, 2015; Hall, 1993).

In view of all these elements, the Belgian Public Health ministers decided to take action in order to simultaneously reduce Belgian health care expenditure, and to tackle the issue of chronic diseases. In October 2015, they launched a new joint public health plan in support of chronic

patients entitled "Integrated Care for Better Health" (IC4BH), with the purpose of moving from a fragmented institutional system to an integrated care system for patients with chronic diseases.

Interestingly, integrated care can be achieved in several ways, depending on the context in which it takes place (Borgermans et al., 2017). Accordingly, this raised the question of how such a system could be successfully implemented in Belgium. The authorities chose to put this joint plan into practice through an iterative and incremental implementation process and opted for a project-based approach. They thought that this would be less daunting for hands-on professionals and more easily reversible than a change in legislation (Musselin, 2005). Instead of designing concrete actions themselves, they asked interested workers in the field to gather by territory, and to build their own experimental integrated care pilot projects. The aim was to identify and test bottom-up solutions on a relatively small scale at the local level.

On another note, the national political and institutional context in which this plan takes place is not unimportant. Indeed, Belgium is a multi-layer federal state, a state of affairs which has had (sometimes unexpected) consequences on the sequence of events to date, as will be shown in this paper. This observation led to the raising of the following research question: how can the federal configuration influence the implementation of a public policy in the health care sector of a multi-layer federal state? To answer this question, the focus was put on the attempt to implement integrated care in the specific Belgian federal context, focusing on the particular empirical case of Belgian integrated care pilot projects for chronic patients intended to reform the national health care system in Belgium.

As part of this research, implementation is viewed as an action process, which is an integral part of the policy process in the same way as are decision-making processes (Hupe & Hill, 2016). Interestingly, as Lascoumes and Le Galès (2012, p. 27) state, "analysing the implementation [consists of] explicating how a public program is appropriated, and not only the way it has been designed". Browne and Wildavsky (Pressman & Wildavsky, 1984, p. 217) also argue that "it is only in implementation analysis that kaleidoscopic understanding of the relationship between policy intent and policy outcome can be achieved". Eventually, "the analysis of public policies [...] enables a concrete understanding of a State in action" (Hassenteufel, 2011, pp. 5–6).

#### 2. Materials and Methods

This paper is based on an ethnographic approach, also known as field research, which is a holistic discovery-based and hypothesis-free research method originating from the social sciences (Robinson, 2013; Soukup et al., 2017).

This inductive (Musselin, 2005) research began in December 2016. The data were collected during the conceptualisation phase, as well as at the beginning of the execution phase (see below). As part of a triangulation approach (Jick, 1979), three complementary types of information sources listed below were mobilised with the purpose of establishing the validity and reliability of the analysis (Robinson, 2013):

- Written documents through a literature search of the scientific literature and a documentary analysis of political, legal, and operational documents;
- Actions and interactions through direct observation (attendance at 85 meetings—191 hours in total, of which 148 hours were spent attending and observing meetings (preparatory meetings during the conceptualisation phase, follow-up meetings during the execution phase, etc.) of two pilot projects (55 hours for the first project and 93 hours for the second one). The researcher also attended meetings and events organised by the public authorities (43 hours) to observe what was happening in terms of interactions, and to observe innovation in action;
- Discourses: the researcher conducted 24 semi-structured interviews, lasting between 33 and 98 minutes, with different categories of people policy-advisers and public officials involved in devising and implementing the new policy, pilot project coordinators, and pilot project stakeholders. These interviews were fully transcribed and analysed manually through open coding.

To analyse those data, elements of the sociology of public action and the sociology of organisations were mobilised. Furthermore, this paper is intended to contribute to several fields of research: public policy implementation research, federal studies and research on integrated care.

# 3. Results

# 3.1. What is Federalism?

According to Watts (Watts, 2008, p.8 as cited in Caluwaerts & Reuchamps, 2015), federalism

refers to the advocacy of multi-tiered government combining elements of shared rule and regional self-rule. It is based on the presumed value and validity of combining unity and diversity, i.e. of accommodating, preserving and promoting distinct identities within a larger political union. The essence of federalism as a normative principle is the perpetuation of both union and non-centralization at the same time. (p. 280)

As a result, "the federal form of organisation of a State is characterised by a layered multiplicity of autonomous decision-making levels within it" (Tulkens, 2007, p. 65). In other words, each federate entity has an important degree of autonomy with regards to its competencies (Blaise, 2015).

What is more, "in classical federal theory, autonomous political communities freely join together to form a new, complex polity from which all will benefit and by which all will be bound. The constitution is federalism's social contract" (Cameron, 2009, p. 311). Interestingly, the case of Belgium is not as classical as this description, as explained below.

#### 3.2. Belgium: A Federal State

Belgium is a parliamentary monarchy, which became independent in 1830 and was then a unitary state.<sup>17</sup> Over the years it has become a layered federal state, the polity of which has changed a great deal since the first State Reform, which occurred in 1970. This marked the beginning of the process of federalisation and devolution, which is still ongoing in Belgium in 2021. At that time, it resulted in the creation of two types of autonomous federate entities in addition to the federal government: three linguistic Communities and three economic Regions (Blaise, 2015), which are represented in Figures 3 and 4 below.

As already mentioned, in general, the creation of a federal state consists of the gathering of independent entities, which decide to share certain competencies at a federal level and stay autonomous regarding others. The dynamics in Belgium have been quite the opposite. It is a wish for more autonomy and a process of devolution which led to the creation of the Belgian federal state. Since 1970, the central state has delegated more and more competencies to the federate entities, a process called "defederalization" or "regionalization" or also "regional decentralization" (Schokkaert & Van de Voorde, 2011, p. 6). The Belgian federal state also differs from other federal states because of its limited number of federate entities (6 in total

<sup>&</sup>lt;sup>17</sup> https://www.belgium.be/en/about\_belgium/government/federale\_staat (accessed 15 July 2019)

against, for example, 16 *Länder* in Germany, 50 states in the US and 26 states in Brazil) and the coexistence of two types of federate entities (Communities and Regions) (Blaise, 2015).

The three economic regions are as follows:

- The Flemish Region
- The Walloon Region
- The Brussels-Capital Region

# The Flemish Region

Belgium has three official languages: Dutch, French and German. The three communities correspond to the three following linguistic groups as follows:

- The Flemish Community
- The French Community, also called the Wallonia-Brussels Federation
- The German-speaking Community

# **Figure 4 – The Three Belgian Linguistic Communities** <sup>19</sup>



# **Figure 3 – The Three Belgian Economic Regions** <sup>18</sup>

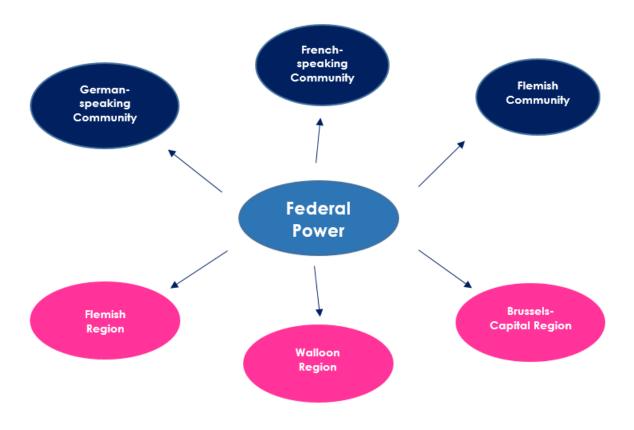
<sup>&</sup>lt;sup>18</sup> <u>https://www.belgium.be/en/about\_belgium/government/federale\_staat/map</u> (accessed 4 September 2017)

<sup>&</sup>lt;sup>19</sup> https://www.belgium.be/en/about\_belgium/government/federale\_staat/map (accessed 4 September 2017)

It may be noted that:

- The Flemish Region territory corresponds to the Flemish Community territory, excluding the Brussels-Capital Region.
- The Walloon Region territory encompasses the French and the German-speaking communities, but does not include the Brussels-Capital Region.
- The Brussels-Capital Region is a bilingual region; its territory is simultaneously part of the Flemish and French Communities.

In Belgium, the allocation of powers between the central and sub-state levels is based on the principle of the exclusivity of the distribution of competencies; the federal level, as well as Communities and Regions have each their own competencies. This configuration is expected to avoid conflict in terms of authority between the different levels, and to guarantee the federal entities' autonomy (Popelier et al., 2011). Each entity also has its own government, its own parliament, and its own administration. Each manages its own budget and can launch its own policies in their territory in accordance with its competencies. For every level, elections are organised every five years so that Belgian citizens can elect their representatives. As each level has its own parliament and its own government, they do not each have the same majority coalition. "The stereotypical view is one of Wallonia being to the left and in favour of more government - with Flanders being more liberal and less reluctant to accept market forces" (Schokkaert & Van de Voorde, 2011, p. 15). As a result, each federate entity has its own political rhythm and orientations (Blaise, 2015) which can lead to the emergence of disparities between territories. They often make different choices and allocate resources differently. To sum up, Figure 5 below demonstrates the different entities in charge of running Belgium, which have different competencies but are legally on an equal footing regarding their power to make decisions within their own territory.



# Figure 5 – Belgium, Three Communities and Three Regions

Reference : Blaise (2015, p. 65)

# 3.3. The Sixth State Reform

The institutional agreement that officially crystallises the wish to launch the Sixth State Reform dates from December 2011. The legal conception of this reform, entitled "A more efficient federal State and more autonomous entities"<sup>20</sup> has been divided into several phases. The second stage was completed in 2014 and concerned the transfer and redistribution of some competencies and financial means between the federal state, the Communities and the Regions. In that context, health competencies were mainly allocated to the federal and regional levels, whereas they had previously mainly been split between the federal state and the Communities.

Therefore, the Walloon Region is now inter alia in charge of:

- prevention and health promotion,
- organising front-line care and services,

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https://www.belgium.be/fr/la\_belgique/connaitre\_le\_pays/histoire/la\_belgique\_a\_partir\_de\_1830/constitution\_de <u>l etat\_federal/sixieme\_reforme\_etat</u> (accessed 31 July 2019)

- developing new instruments to support front-line care providers, apart from what is related to health insurance matters,
- financing general practitioners' associations and defining the rules related to their governance,
- managing the multi-disciplinary local networks, the integrated home care services, the palliative care associations, the multi-disciplinary palliative teams and the "Impulseo fund" for general medicine created to provide general practitioners with financial help regarding their settlements.

The federal state is still responsible for:

- compulsory health insurance,
- defining care professions as well as determining the required associated skills and qualifications,
- setting medical fee standards for doctors, nurses, midwifes, physiotherapists, dieticians, dentists, etc.,
- the definition and allocation of authorised medical acts between these different professions,
- managing medical on-call services.

Since 2014, the federal entities have been in a transitory phase during which they have assumed their new competencies and progressively begun to put them into practice. This is the context in which the IC4BH plan took shape.

#### 3.4. How to Define the Concept of Integrated Care?

The concept of "integrated care" can be seen as an umbrella term (Amelung et al., 2017), given the huge number of definitions pertaining to this concept, as Armitage et al. (2009) demonstrate in their literature review. Actually, integrated care is often considered to be the opposite of fragmented or episodic care (WHO, 2016) and, as a result, encompasses the ideas of "managed care, coordinated care, collaborative care, disease management, case management, transmural care, continuity of care, seamless care, service-user-centred care and many others" (Amelung et al., 2017, p. 7).

In the IC4BH plan, the authorities refer to the World Health Organization's (WHO) definitions of:

- Care integration, defined as "the organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money" (WHO, 2008a, p. 1).
- Integrated care delivery, described as, "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system" (WHO, 2008b, p. 1).

Accordingly, one can conclude that collaboration, cooperation and coordination are key elements when it comes to integrating care (Amelung et al., 2017). In Belgium, the challenge is to encourage hands-on professionals who usually do not work together, and sometimes even ignore everything about their mutual existence and roles, interact with each other.

# 3.5. The Case of the Belgian Joint Plan Integrated Care for Better Health: Background

In 2008, the federal plan "Priority to chronic patients" was launched. In October 2010, in the context of the Belgian Presidency of the Council of the European Union, the conference "Innovative Approaches for Chronic Illnesses in Public Health and Healthcare Systems" was organised on the initiative of the Federal Public Service (FPS) of Public Health. This marked the beginning of a reflection about a more global approach to chronic diseases in Belgium. In July 2011, the KCE<sup>21</sup>, the Belgian Health Care Knowledge Centre, was asked to produce a position paper on that topic (Belgian Ministry of Social Affairs and Public Health, 2015). This report, summarising the challenges in this field through 20 recommendations, was published in December 2012. It stressed that, according to the international literature, patient-centered integrated care systems are particularly effective at tackling the chronic diseases challenge (Paulus et al., 2012). This is also why the WHO and other international organisations foster such health care systems.

In parallel, the Sixth State Reform was initiated, redesigning the institutional landscape by redistributing health competencies mainly between the federal and regional levels. Through the IC4BH plan, originally initiated at the federal level, the federal authorities notably intended to

<sup>&</sup>lt;sup>21</sup> The KCE is "a parastatal body funded by the federal government" (<u>https://kce.fgov.be/en/funding</u>, accessed 24 July 2020). It "is an independent research centre that provides scientific advice on topics related to health care". (<u>https://kce.fgov.be/en/missions-and-values</u>, accessed 24 July 2020).

develop/transform some elements that were transferred under the competence of Regions. Accordingly, inter-institutional collaboration then became necessary. As a result, on 10 December 2012, during an inter-ministerial conference, the Belgian Health Ministers decided to create an inter-cabinet working group on chronic diseases. This wrote a guidance note entitled "An integrated vision of care for patients with chronic conditions in Belgium". From that moment on, the authorities began the conception of the future plan intended to implement integrated care for chronic patients, which would need to be a joint plan, after the Sixth State Reform.

On 30 March 2015, the Belgian Health Ministers signed a joint declaration outlining the plan's mission and vision. It also established the first collaboration modalities between the federal state, the Communities and the Regions regarding integrated care for patients with chronic disease(s). Eventually, on 19 October 2015 the joint plan for chronic patients entitled "Integrated Care for Better Health", initiated at the federal level, was approved by the Belgian Health Ministers.

#### 3.6. Integrated Care Pilot Projects

The plan's implementation began in January 2016, when the authorities published a guidance leaflet for future pilot projects. In this document, they described their aim as well as the eighteen integrated care components identified following the KCE position paper publication and which had to be developed to achieve integrated care. These are summarised in Table 7.

1.	Empowerment
2.	Support for caregivers
3.	Case-management
4.	Maintenance at work as well as educational, professional and social reintegration
5.	Prevention
6.	Dialogue and coordination
7.	Care continuity (extramuros, intramuros and "transmuros")
8.	Accenting the experience of patients and families' organisations and of mutual health insurers
9.	Integrated electronic health records
10.	Multi-disciplinary guidelines
11.	Development of a quality culture
12.	Adaptation of financing systems
13.	Risk stratification and resources mapping

Table 7 – Eighteen	n Components of	f Integrated Care
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14.	Change management	
15.	Training for professionals regarding empowerment and multi-disciplinary	
	collaboration	
16.	Continuing training regarding integrated care	
17.	Evaluation of the system performance	
18.	Attractiveness of professions	

Reference: Belgian Ministry of Social Affairs and Public Health (2015, p. 10)

In the guidance leaflet, one can also find the specific modalities and guidelines pertaining to the future experimental pilot projects, which would be launched to gradually implement integrated care with the help of local partners, in an iterative and incremental manner.

The authorities envisaged an implementation process divided into four phases (Belgian Ministry of Social Affairs and Public Health, 2015):

- The preparation phase, the first phase of the selection procedure. In February 2016, the authorities called for expressions of interest. This event marked the beginning of this four-month phase, during which the stakeholders interested in creating an integrated care pilot project were asked to gather in multi-disciplinary local consortia and write a joint expression of interest, which they had to submit by 31<sup>st</sup> May 2016.
- The conceptualisation phase, the second phase of the selection procedure. This phase began in July 2016 and ended in September 2017, instead of January 2017 as expected, according to what was written in the guidance leaflet. During this period, the members of the twenty selected consortia designed their projects together. They had to write a detailed application file including a "loco-regional action plan" in which they described their common vision, their strategic and operational objectives, as well as the actions they would implement to achieve these objectives in the event that they were selected for the execution stage.
- The execution phase. This began in January 2018 and is supposed to last four years, during which twelve out of the fourteen selected pilot projects (two pilot projects withdrew) are expected to implement their "loco-regional action plan".
- The expansion phase. This phase is supposed to occur after the four-year execution phase. The successful pilot projects will have to evolve to cover the entire Belgian population.

What is more, the IC4BH plan is based on the Triple Aim principles. These involve reallocating available financial means more effectively, while at least preserving or even enhancing equity and quality of care. In other words, the Belgian authorities intend to reduce national health care expenditure in order to maintain a sound financial position, without affecting equity or quality of care. For this purpose, the pilot projects consortia have the mission of reducing health care expenditure in their pilot zone. The actions launched during the execution phase are expected to affect the Belgian health care budget by generating savings at the national level. In return, the authorities planned that, at the end of each year, each pilot project would be provided with a budgetary envelope called the "budgetary guarantee", corresponding to the savings they would have generated in their pilot zone, and intended to be used to implement new actions, generate new savings, and so forth. It is interesting to note that, in October 2018, the pilot projects' members received information which indicated that the mathematical formula supposed to be used to calculate the "budgetary guarantee" was not reliable and, as a result, would have to be adapted. Pending the adaptation of this formula, the federal authorities announced that each project would receive a one-time lump sum of €208,333.

As mentioned in the introduction, the federal context in which these phases had to take place has impacted the sequence of events. It has created gaps between what the authorities had planned and what really happened during and between the different phases, as illustrated in the empirical example below.

#### 3.7. Empirical Example: The Application Period Opening

As already explained, the conceptualisation phase lasted longer than expected. According to details in the guidance leaflet, the pilot project consortia had to submit their application files by the end of January 2017 and the execution phase was supposed to begin in March 2017. In practice, the deadline was postponed several times between January 2017 and September 2017. On the first occasion, the pilot project coordinators and members asked for this postponement. They negotiated a deadline extension because they needed more time to build their projects and complete the application form.

Subsequently, the deadline was again postponed several times to later dates, but for other reasons. Under the existing legislation, the authorities had to publish a Royal Decree (RD) in order to open the one-month application period following the conceptualisation phase. This was a mandatory legal prerequisite. In this document, they had to describe, in legal terms, the conditions under which pilot projects would be selected for the execution phase. Before

publication, the RD project had to be approved by several institutions, notably the Inspectorate of Finance<sup>22</sup> and the Council of State.<sup>23</sup> It appeared that the Inspectorate of Finance took more time than expected to analyse and approve the document, and that the Council of State asked the authorities to make modifications to the RD text, which again they did not expect.

Actually, the Inspectorate of Finance was concerned that the anticipated savings at the federal level, as a result of pilot project actions, would not be actual savings, but would rather consist of a displacement of costs towards the Regions and, consequently, would involve an unwanted increase in their expenditure. This fear was shared by regional public officials, as illustrated in this interview extract:

"The purpose of these projects is to save money at the level of hospitals, it is crystalclear! The purpose is to reduce the number of days of hospitalisation, which will have consequences in terms of home-care ... And further, on whom does it depends? It depends from the regions! [while hospitals depend financially from the federal level] So, more funding will be necessary for the regions [but will probably not be provided]. [...] There will be outgrowths on the first care line and on the help and home care services, for which we are competent" (Interview with a regional public official, 2017).

As for the Council of State, it declared the collaborative RD proposal illegal given that it mixed elements falling under the jurisdiction of the federal government and others pertaining to regional competencies (e.g. health promotion, health prevention and well-being matters), as illustrated in this interview excerpt:

"It is not very gracious that we lag behind on this process. [...] It took a little more time than expected. In our country, we have something that is called the 'Council of State' and if this institution does not give a positive opinion, we simply can't [...] publish the Royal Decree. It is the situation we are in right now because we wanted the projects to include health promotion and welfare actions [as stated in the draft RD], two fields of

<sup>&</sup>lt;sup>22</sup> The Inspectorate of Finance is an interfederal public institution which is in charge of controlling the legality, the regularity and budgetary feasibility of public spending initiated by all the different governments in Belgium (Federal State, Regions, Communities) (<u>https://www.inspfin.be/en</u>, accessed 17 February 2021).

<sup>&</sup>lt;sup>23</sup> The Council of State is "an advisory and jurisdictional institution at the junction of the legislative, executive and judicial powers". This institution "owes its existence [...] to the wish of the legislator to offer recourse to all natural and legal persons being wronged by irregular administrative acts". It has "the power to suspend and annul administrative acts that are contrary to the legal rules in force. The Council of State is also the Administrative Supreme Court. As a cassation court it reviews the external and internal legality of the decisions of lower administrative jurisdictions. The Council of State rules by means of judgments on the applications" (http://www.raadvst-consetat.be/?page=about\_competent&lang=en, accessed 17 February 2021).

competence that fall within the jurisdiction of federate entities (Regions) [following the 6<sup>th</sup> State Reform]. We said 'we are going to include federate entities in the process, so that they can make suggestions'." (Interview with a ministerial advisor, 2017).

The Council of State expressly asked to eliminate the elements that were not under the federal government's jurisdiction, although they were indispensable to the development of integrated care (e.g. health prevention and promotion, a regional competence, is listed as one of the eighteen components of integrated care in Table 7 above). Accordingly, those items relating to regional competencies were removed from the RD text, which was resubmitted and then approved. Eventually, the Royal Decree was published by mid-August 2017. The application files had, thus, to be submitted by mid-September 2017, eight months after the initial deadline.

The RD proposal rejection and the related delays had not been anticipated by the public officials in charge of the plan, who blamed the reshaped institutional landscape stemming from the Sixth State Reform. The latter impacted the whole process, making the implementation of an integrated care system more complicated:

"The big problem is that, in Belgium, regarding everything pertaining to curative aspects and medical care, it is the federal which is competent, but everything that pertains to well-being and prevention, it is the federate entities. [...] This Sixth State Reform led us to a situation in the context of which working together around the patient has become almost impossible [...]. It has brought more disintegration whereas we want to integrate things together" (Interview with a ministerial advisor, 2017).

Nevertheless, according to the public officials and pilot project stakeholders who were interviewed in the course of this research, a non-fragmented and patient-centred governance is required to evolve towards more care integration:

"When we say 'integrated', in the plan, we wrote it, it is integrated from the micro to the meso and up to the macro political level. It really has to be integrated between all the levels, and also with other public policies" (Interview with a federal public official, 2017).

Nevertheless, this global integration has apparently not yet been achieved and is difficult to apply due to the Sixth State Reform:

*"It is not easy to create something integrated while being in a federal legal base"* (Interview with a federal public official, 2017).

"Following this Sixth State Reform, we are in a hyper-paradoxical and 'pardoxing<sup>24</sup>' situation [...], which entails that this health care reform will [probably] not come into being precisely because of the current division of competencies" (Interview with a regional public official, 2017).

"This regionalisation is not completed, it has gone too far, or not enough ... I don't know, but it jeopardises a lot of things." (Interview with a general practitioner, representative of a GPs' association, 2017).

"De Gaulle said about France that it was an ungovernable country because there are more than 50 types of cheese. But in Belgium, there are not 50 types of cheese, but at least 50 levels of power, it is far worse." (Interview with a pilot project member, 2018)

Pilot project stakeholders explain that this situation creates confusion and misunderstandings when it comes to putting things into practice. The distribution of health competencies at the macro level does not coincide with the differentiation between stakeholders' roles on the ground. As a result, the same professional can rely on both the federal and regional levels regarding his/her work and can receive orders from both levels, without these levels necessarily conferring with each other. Consequently, hands-on professionals can feel powerless with regard to the often uncoordinated – sometimes even contradictory – instructions they receive from the different levels of power.

If the pilot project consortia want to launch innovative actions simultaneously involving federal and regional competences, they do not always know who their interlocutor should be. They often lose a great deal of time trying to identify who they have to contact to discuss the matter. Then, if the suggested actions seem relevant to the chosen interlocutor, it takes further time for the different levels of power to consult and coordinate with each other, sometimes even leading to lasting blockages. The federal and regional levels do not have the same work culture or the same funding rules. They are governed by different political coalitions and do not have the same political agenda or priorities. For instance, if, for the federal level, integrating care is viewed as a top priority, it is not necessarily the case for the Regions, which are still appropriating the competences they inherited after the Sixth State Reform and launching their own public policies regarding other matters. As a result, coordinating their respective work is quite difficult.

<sup>&</sup>lt;sup>24</sup> This neologism means that this situation begets new paradoxes according to the interviewed public official.

More than that, as what happened with the RD, during the execution phase, pilot project consortia learned that they were simply not legally allowed to finance some of the actions of their loco-regional action plan (for example, certain types of health prevention actions) with the budgetary guarantee paid by the federal level, because those actions fall under the exclusive competence of the Regions. These actions are, nevertheless, completely relevant in a context of care integration (see Table 7), but pilot project consortia will probably not be able to implement them due to a lack of eligible financial resources. The situation seems quite absurd for hands-on professionals who consider that, from a long-term perspective, prevention could be very fruitful and should be a priority. The reasoning behind this is that it will always be better to prevent people from becoming sick rather than taking care of them once they have a chronic condition.

As a result, several hands-on professionals also expressed the fact that, in this context, they were unable to have full confidence in the authorities, who were losing their credibility:

"We are asked to integrate [things], to think about the powder that explodes twice while we have already invented the wheel. The only problem is that they do not talk to each other and they do not finance things so that they interleave [in an integrated manner]" (Interview with a pilot project member, 2018).

This excerpt also suggests that the authorities are not able to set an example. They ask pilot project stakeholders to do something they are not able to do themselves, given that it is apparently difficult for them to overcome the structural fragmentation arising from the Sixth State Reform.

#### 4. Discussion

After analysing the actual course of events as part of the implementation of the IC4BH plan, one can notice a gap between policy goals initially set by policy-makers and real outcomes on the ground (Hill & Hupe, 2003), e.g., the delays with respect to what was originally planned, or the fact that the pilot project consortia would not be able to implement some actions which did not fall under the federal level jurisdiction, even if the latter seemed relevant with regard to integrating care. In the policy implementation literature, this distortion phenomenon is referred to as an implementation gap (Hupe & Hill, 2016), an implementation deficit (Pressman & Wildavsky, 1984) and even sometimes an implementation failure (Hupe & Hill, 2016).

An implementation gap is often attributed to unclear or irrelevant goals, implementers' disobedience (Hill & Hupe, 2003) and/or also to what Hupe (2011) calls the multi-layer problem, i.e., the numerous layers of government involved. Indeed, "if there are multiple layers, then some transformation is inevitable in the transmission of a policy objective from top to bottom, whatever the degree of consensus" (Hill & Hupe, 2003, p. 472). Thus, the greater the number of the layers, the greater the implementation gap is likely to be (Pressman & Wildavsky, 1984).

In a centralised state, the implementation of the IC4BH public policy would have required the involvement of a variety of stakeholders from all levels of the health care system. In the case of a multi-layer federal context (Hill & Hupe, 2003), as in Belgium, an even greater number of layers and stakeholders were expected to play a role in the process. Consequently, it would be risky to deny the impact of the number of layers involved in terms of this implementation gap, the latter being viewed as a multi-factorial phenomenon. That being said, regarding the multi-layer problem, one can nevertheless notice, thanks to this ethnographic research, that aspects other than the number of layers have had an influence on the IC4BH policy implementation gap, e.g., the specific Belgian institutional configuration and the way health competencies were distributed between the different autonomous entities.

Implementing integrated care, which is by nature inter-sectoral, entailed working on different aspects ranging from prevention to the management of complex cases (see Table 7 regarding the components of integrated care). So, well-being policies (including health prevention, health promotion and home care services), and health care policies are intertwined in terms of care integration. They both contribute to enhancing people's quality of life and health (Schokkaert & Van de Voorde, 2011). However, in Belgium they fall under the competences of different jurisdictions and are designed separately, although their implementation often involves the same workers in the field.

Accordingly, integrating care appears to be neither just a health insurance matter, nor just a care question; it goes far beyond medical aspects. Moreover, this is not only a matter of local handson professionals who would get along with each other and succeed in working together. It is definitely not as simple as making hands-on professionals collaborate on the ground (microlevel). This is obviously necessary to develop integrated care, but not sufficient. This therapeutic collaboration at the micro-level is only the tip of the iceberg. Integrating care also raises important organisational issues, requiring inter-organisational, interprofessional and also inter-institutional collaboration between the structures and the people involved (Axelsson & Axelsson, 2006; D'Amour et al., 2008), especially in the Belgian federal context characterised by entangled levels of authority (Lascoumes & Le Galès, 2012). This means 'that apparently simple sequences of events, depend on complex chains of reciprocal interaction' (Pressman & Wildavsky, 1984, p. xxv) and further that 'the success of the policy implementation depends on an uncertain "complex web of exchanges" (Pressman & Wildavsky, 1984, p. 193).

The wish to integrate care created horizontal interdependences between the stakeholders at every level of the health care system: between the pilot project stakeholders (meso level) who depended on each other to initiate the implementation of the actions they designed together and between the professionals (micro level) expected to work together to provide integrated care to their patients on the ground, but also between the federal and regional levels (macro level) depending on each other to achieve their respective agendas, due to the specific Belgian health competencies' distribution.

These horizontal interdependences are coupled with vertical interdependences between the macro, meso and micro levels. Indeed, the authorities inevitably depended on the meso and micro levels stakeholders for the IC4BH plan implementation, while the stakeholders depended on the authorities to initiate innovative actions on the ground, e.g., requiring changes in legal texts or authorised exceptions to current legal provisions. From these interdependences stemmed the need to interact in order to create dynamics of cooperation, collaboration and coordination (Friedberg, 1997) at and between all the levels (macro, meso and micro) of the health care system, i.e., both horizontal and vertical multi-level collaboration, cooperation and coordination. The latter were nevertheless difficult to achieve in practice due to the institutional autonomy of the different governing entities each having different priorities and goals. This impacted the work of professionals in the field.

Indeed, all these professionals had their own institutional constraints, since they did not have the same role in the care production chain and did not fall under the same level of authority jurisdiction, which made collective action complicated by a mirror effect. Indeed, they had different interlocutors, who asked them to change many things simultaneously. They received different and, according to them, uncoordinated requests from the federal and the regional levels, which was destabilising and time-consuming. This put them under pressure and led to inconsistencies or sometimes even absurdities (Morel, 2018) in the actions' implementation process.

As part of the IC4BH policy implementation, the current federal configuration even created competition between policies on the ground. Hands-on professionals had to choose what was their priority. Besides, those policies were sometimes even directly incompatible (Pressman & Wildavsky, 1984), making things even more complicated. Thereby, the way the multi-layer federal context in which the actions had to happen was designed created blockages, hindering the implementation process as originally intended and creating distortions between the authorities' decisions and the concrete implementation of these decisions (Hassenteufel, 2011).

Metaphorically, one could say that Belgium looks like a hydra, in reference to the Lernean Hydra in Greek mythology. This beast, which Hercules had to fight, had several heads on one body. If the heads want to go in different directions, this will probably lead to a standstill at the body level and endanger the equilibrium of the entire body, heads included. Importantly, the comparison stops at the question of the disequilibrium and/or standstill resulting from the existence of several heads. The purpose is obviously not to say that Belgium is or should be as monstrous as the Hydra.

Integrating care is intrinsically not easy, but the Belgian federal context resulting from a still ongoing process of federalisation made it even more difficult given the complexity in the functioning of the Belgian apparatus. This federalisation process, synonymous with regionalization and devolution, has progressively disintegrated the former centralised state, leading to more differentiation and greater fragmentation in terms of competency distribution.

In sociological terms, Lawrence & Lorsch (1967) define differentiation as

the state of segmentation of [an] organizational system into subsystems, each of which tends to develop particular attributes in relation to the requirements posed by its relevant external environment. Integration is defined as the process of achieving unity of effort among the various subsystems in the accomplishment of the organization's task. (pp. 3–4)

Hence, fragmentation arises in a context of differentiation when there is a lack of collaboration and communication between those subsystems, which seemed to be the case between the federal level and the federate entities in the context of the IC4BH plan implementation. Designed with the purpose of avoiding conflicts in terms of authority, this uncoordinated multilevel governance (Torenvlied & Akkerman, 2004) has created a lack of global coherence in the decision made by the different levels, as well as an incoherent implementation process leading to the development of an implementation gap. Based on this observation, one can even claim that there is a lack of coherence in the healthcare competencies' distribution itself between the federal level and the federate entities, which impacted the implementation of the IC4BH plan and probably that of other policies. Incidentally, the legal constraints regarding the use of the budgetary guarantee illustrates how "the fragmentation of competencies generates a dispersion of already very limited means and prevent sometimes from having a global view of the healthcare system" (De Troyer & Krzeslo, 2004, p. 114), which seems nevertheless essential when implementing integrated care.

The research confirms the idea of Tulkens (2007) who states that, in a federal state, the entities' autonomy is coupled with an inevitable coexistence between those entities, which creates a need to organise the coexistence and cooperation between the entities - to integrate their decisions and actions, one might even say. Accordingly, the challenge is to find a way to design coherent public policies and to implement them in a coherent manner in the Belgian multi-level policy-making system, as there is a lack of what Torenvlied and Akkerman (2004, p. 32) call "cross-level policy coherence".

So, to answer the research question of this paper, one could say that, in the case of the IC4BH plan implementation, the cross-level incoherence of the Belgian federal institutional configuration pertaining to healthcare influenced the IC4BH policy implementation by acting as a multiplying factor in the constitution of the implementation gap. This can be noticed when comparing the expected outcomes and the real unfolding of events as part of the IC4BH policy implementation.

Just before the Sixth State Reform, Schokkaert and Van de Voorde (2011) declared that

coordination problems arise when prevention and long term non-medical care are decentralized, while curative medicine remains at the federal level. And the situation gets even more complicated if the federal level keeps implementing prevention measures. [...] Belgium urgently needs to develop a coherent long-run vision on the decision structures within its health care system. Regional decentralization is one of the crucial issues in that debate. (p. 13).

Several years and a State Reform later, it would seem that the empirical analysis of the implementation of the IC4BH plan tend to confirm this assertion. It denotes the need to work

in an integrated manner at every level of the health care system and, accordingly, to deal with conflicts and discrepancies that may occur between the levels, both vertically and horizontally.

# 5. Conclusion

This paper presents a comprehensive analysis of federalism in action by focusing on the implementation of a specific innovative public policy in a federal context. It highlights the absurdities and blockages that may occur in a multi-layer federal country like Belgium. It shows that federalism can become dysfunctional if the allocation of competencies is not made in a coherent manner.

Indeed, as part of the IC4BH plan implementation, the governing entities' autonomy, coupled with institutional fragmentation, has led to a lack of coherence between the decisions made at the different levels, involving in turn a lack of coherence between the actions undertaken in the field. This multi-level incoherence has acted as a multiplying factor in the constitution of the implementation gap with regard to undertaking the task of integrating care.

So, the wish to integrate care has raised the issue of the multi-level integration, i.e., integration at and between all the levels of the Belgian health care system, each of which are strategically interdependent. The Sixth State Reform exacerbated the need to oil Belgium's complex machinery, so that the different levels and sectors can interact and work in a coherent manner as from the planning stage at the decision-making level, and not only in the field at the therapeutic level. Hence, this research stresses the importance of working in a comprehensive integrated manner at every level of the health care system.

To conclude, it is important to underline that the conclusions of this research only apply to the specific empirical case analysed in this paper. As this stage, it would be relevant to conduct similar research in other sectors and countries to make comparisons in order to be able to produce more generalizable conclusions, given that each federal state has its own competencies distribution.

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# **Chapter 3**

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Reshaping Health Care Governance Using Pilot Projects as Public Policy Implementation Instruments: The Case of Integrated Care Pilot Projects for Chronic Patients in Belgium



Please note that Chapter 3 corresponds to the last preprint version of the paper. The postprint version can be found in Appendix 5 of this manuscript.

# Abstract

Pilot projects are often used to test innovations; however, pilot projects, as an action mode, are rarely addressed as an object for research. This paper, in which pilot projects are viewed as public policy instruments producing specific effects, addresses the research question: how does the use of multidisciplinary pilot projects as implementation instruments reshape modes of public governance in the Belgian health sector in a context of transition and ongoing devolution? An ethnographic study was conducted, focusing on the specific case of the Belgian joint plan, "Integrated Care for Better Health", which targets chronic patients and was intended to initiate a major transition from a fragmented to an integrated care system for chronic patients.

The analysis concerns the specific implementation modalities designed by the authorities, which consisted of the launch of pilot projects involving professionals in the field coming from different sectors in an iterative and incremental co-creation process. This choice caused new vertical interdependences to emerge between the levels of the health care system, transforming the roles of both the authorities and the hands-on professionals involved; it also denoted a transition towards a more negotiated governance, in the course of which several types of knowledge and evidence have been mobilised.

Keywords: Pilot projects; policy instruments; integrated care; knowledge; public policy implementation

#### 1. Introduction

The Belgian authorities<sup>25</sup> have often used pilot projects in the health sector to test new solutions and new ways of working. For more than ten years, there has been a proliferation of calls for pilot projects in the Belgian health sector: "therapeutic projects" and "psy 107" projects in the mental health sector; "multidisciplinary local networks" for Type 2 diabetics and patients with renal insufficiency; mobile health projects and "integrated care" pilot projects for chronic patients (this list is far from exhaustive). The latter were launched as a means of implementing the joint plan, "Integrated Care for Better Health" (IC4BH), which was approved in October 2015.

Chronic diseases are now the leading cause of mortality across the globe and constitute one of the major public health challenges of the 21st Century (Riley et al., 2017; WHO, 2014a). In Belgium, 27.2% of the population suffers from chronic disease(s) (Paulus et al., 2012). These are responsible for about 87% of total deaths (WHO, 2014b). Nevertheless, the current Belgian health care system, characterised by a high degree of specialisation and a lack of cooperation between practitioners, is more suited to the management of acute diseases and does not meet the chronic patients' needs (Belgian Ministry of Social Affairs and Public Health, 2015). Accordingly, the Belgian Public Health Ministers called for a substantial change to the system: a paradigm shift (Hall, 1993). They expressed their intention to bring about a major transition from a fragmented care system to an integrated care system for chronic patients (Belgian Ministry of Social Affairs and Public Health, 2015).

The authorities could have negotiated the content of this policy at the macro level, as they usually do, and then pass a mandatory law, with which workers in the field would have had to comply in the second phase with no possibility of renegotiation. Nevertheless, whilst the authorities knew that they wanted to move towards an integrated care system, which requires increased collaboration between the different health care professionals, they were not sure how this should be implemented in the Belgian-specific context due to the contextual nature of integrated care (Amelung et al., 2017; Minkman, 2020).

Therefore, they opted for an experimental iterative and incremental implementation: they launched a call for multidisciplinary four-year pilot projects involving a diversity of hands-on

<sup>&</sup>lt;sup>25</sup> The term "authorities" refers to the health ministers, policy makers and advisers from the federal and regional levels who are involved in decision-making regarding health care in Belgium.

professionals in a participative and phased co-creation process to generate "bottom-up" solutions. These different stakeholders, from the macro, meso and micro levels of the care production chain, include policy-makers, civil servants, patients' representatives, first-line and second-line care stakeholders (hospitals, medical health centres, general practitioners, nurses, etc.) together with non-medical workers (e.g., social and cultural). Making all those stakeholders collaborate is quite a challenge: this entails transcending traditional professional boundaries (vertical and horizontal).

Pilot projects are often used in a variety of sectors, but viewing the pilot project as a tool is rarely addressed as an object for research. In general, research focuses on the experiment conducted as part of the pilot project, not on the pilot project as a phenomenon, which should, nevertheless, also be worthy of scientific attention (Vreugdenhil et al., 2010). Indeed, one can find a large number of articles relating the results of a specific pilot project in a particular sector, whereas literature analysing the pilot project as an action mode is much rarer (Pinson, 2005).

In this paper, pilot projects are analysed in an original manner, i.e., as public policy instruments (Lascoumes & Le Galès, 2005) specifically selected by the authorities to implement their plan. The purpose is to contribute to the scant literature focusing on the pilot project phenomenon, as well as to the public action instruments studies by providing an in-depth analysis of the use of this specific instrument in the health care sector by policy-makers, which does not seem to have been done before. Before presenting the research question addressed in this paper, and in order to understand its relevance, it seems appropriate to present the theoretical framework of Lascoumes and Le Galès (2005) regarding public policy instruments, which belongs to the sociology of public action.

Lascoumes and Le Galès (2005) analyse public action and state governance modes by focusing on public policy instrumentation, which constitutes "a means of orienting relations between political society (via the administrative executive) and civil society (via its administered subjects)" (Lascoumes & Le Galès, 2007, p. 1). They define public policy instrumentation as:

the set of problems posed by the choice and use of instruments (techniques, methods of operation, devices) that allow government policy to be made material and operational. Another way of formulating the issue is to say that it involves not only understanding the reasons that drive towards retaining one instrument rather than another, but also envisaging the effects produced by these choices. (2007, p. 4)

As much as the objectives of a public policy, instrumentation is also a political choice (Howlett, 1991). Indeed, the choice of modes of action, and therefore of instruments, which can be the

subject of political conflict, will partly structure the process and its results and have an impact on power relationships (Lascoumes & Le Galès, 2005). Interestingly:

a public policy instrument constitutes a device that is both technical and social, that organizes specific social relations between the state and those it is addressed to, according to the representations and meanings it carries. It is a particular type of institution, a technical device with the generic purpose of carrying a concrete concept of the politics/society relationship and sustained by a concept of regulation. (Lascoumes & Le Galès, 2007, p. 4).

This means that the choice of one instrument rather than another is not trivial and is not only a technical choice, as suggested in the functionalist approach. Instead, instruments structure public action and produce specific, sometimes unexpected, effects, independent of the primary purposes assigned to them (Lascoumes & Le Galès, 2005). Indeed, as Lascoumes & Le Galès (2007) put it, "public policy instruments are not tools with perfect axiological neutrality, equally available: on the contrary, they are bearers of values, fuelled by one interpretation of the social and by precise notions of the mode of regulation envisaged" (p. 4).

In view of all this, this paper is based on the following research question: how does the use of multidisciplinary pilot projects as implementation instruments reshape modes of public governance in the Belgian health sector in a context of transition and ongoing devolution?

### 2. The Pilot Project: Contributions of the Scientific Literature

The pilot project is a specific work method fulfilling a function of experimentation, and has been mobilised in a plethora of sectors. This tool offers the possibility to test the innovation under consideration in real-world settings, on small and controlled scales, which limits the impact of potential failure or the emergence of negative side effects (Vreugdenhil & Ker Rault, 2010). This also means that the actions undertaken as part of the experiment are expected to be more reversible (Musselin, 2005; Zurlo & Nunes, 2016) and, for this reason, are supposed to be less frightening for the stakeholders involved.

As a result, such an approach is often used by policy makers in innovative contexts (Vreugdenhil et al., 2010), to learn from the experimentation process (Engström & Lidelöw, 2015), to create new knowledge and to produce evidence for policy-making (Sanderson, 2002; Vreugdenhil & Ker Rault, 2010). This in turn will orient future political action and policy development. In this way, the pilot project constitutes a tool for, "improving the effectiveness

of policy responses" (Sanderson, 2002, p. 4). In other words, the purpose is to work collaboratively (Zurlo & Nunes, 2016) in order to identify what works in what context (Sanderson, 2002; Vreugdenhil & Ker Rault, 2010).

Nevertheless, Sanderson (2002) argues that politicians/policy makers often divert pilot projects from their primary function of experimenting and learning. Instead, they only use them as the means of exemplification, demonstration and legitimation when the produced evidence corroborates their political priorities. Actually, according to Cook (1997, p. 40, as quoted in Sanderson, 2002, p. 5), "the politician's prime goal is to be re-elected rather than to respect technical evidence", which constitutes political short-termism. On the other hand, experimentation conducted as part of a pilot project is often long-term endeavour, which requires, in contrast, enough time to produce effects from which lessons can be learnt (Sanderson, 2002).

As collective experiments (Zurlo & Nunes, 2016), pilot projects also gather a diversity of stakeholders, who will have to interact and work together to create new solutions to solve a problem by exchanging their respective knowledge and stances (Segrestin, 2004): as the old proverb says, *two heads are better than one*. In this way, due to their inherent interactionist nature (Pinson, 2005), "pilot projects are [also] means to establish communication between actors that usually do not cooperate" (Vreugdenhil & Ker Rault, 2010, p. 122). This is one of the reasons why, beside experimentation, pilot projects can also be mobilised for policy implementation (Vreugdenhil et al., 2010) when, for example, the policy programme cannot be implemented in a conventional manner. In this case, the use of the pilot project tool provides a means for a staged implementation process (Vreugdenhil & Ker Rault, 2010), leveraging the collaborative dynamic between the involved stakeholders in order to, "pragmatically put fully developed policy into practice" (Vreugdenhil et al., 2010, p. 13).

#### 3. Methods

This inductive ethnographic study began in December 2016. Ethnography, also referred to as field research, is a holistic discovery-based and hypothesis-free research method coming from the social sciences (Robinson, 2013), and, more specifically, from anthropology and sociology (Soukup et al., 2017). In this approach, people and groups are studied in their real-world settings, in other words, "mundane settings in which people lead their lives naturally and that are not designed for the purposes of research" (Maner, 2016, p. 101), e.g., schools, homes, the workplace, hospitals, meetings, and court rooms. (Maner, 2016; Soukup et al., 2017).

Accordingly, ethnographic studies distinguish themselves from experimental ones, which are conducted in simulated or controlled environments (Angrosino, 2007; Soukup et al., 2017).

Field research is characterised by a combination of several complementary research methods (observation, interviews, secondary data analysis) allowing a deep and detailed understanding of a setting, a context and/or a phenomenon (Quivy & Campenhoudt, 2009), which is why it seemed relevant to study the integrated care pilot projects' dynamics which depend on interactions between stakeholders. This type of research is inherently flexible and non-linear given that no definitive research protocol is determined once and for all at the beginning of the research, but rather is expected to evolve during the research (Quivy & Campenhoudt, 2009). This approach also has downsides: conducting field work requires a great deal of time and the findings can often not be generalised (Soukup et al., 2017). However, as Flyvbjerg (2006) puts it, the fact that, "knowledge cannot be formally generalized does not mean that it cannot enter into the collective process of knowledge accumulation in a given field or in a society" (p. 227).

According to Soukup et al. (2017), "there is a general lack of field research within the healthcare setting, although it is particularly useful for understanding complex systems" (p. 58). This can be explained by the historical predominance of quantitative research in the health sector (Soukup et al., 2017). As a result, the ethnographic approach seemed innovative and relevant for studying the implementation of integrated care for chronic patients in Belgium. As part of her specific ethnography, taking the form of a qualitative and inductive (Musselin, 2005) research, the researcher immersed herself mainly in two pilot projects. The data were collected during the fourteen-month conceptualisation phase (see below), i.e., the application writing period, as well as during the first nine months of the execution phase, during which the pilot project consortia began to implement the loco-regional action plan they conceived during the conceptualisation phase.

According to Dumez (2016), "a qualitative research approach does only make sense if it shows and analyses the intentions, the discourse and the actions and interactions of the actors, from their point of view and from the researcher's point of view" (p. 13). So, to ensure the soundness of the analysis (Dumez, 2016), and achieve a good level of saturation (Bryant & Charmaz, 2011), three types of information sources were triangulated: written documents, actions and interactions, and discourses, the last of which refers to what people have to say about their experience. Indeed, triangulation of information (Dumez, 2016; Jick, 1979) helps establish validity and reliability regarding the studied phenomenon (Robinson, 2013). Table 8 presents a more thorough description of the methods combined to collect the data:

#### **Type of information source : Written documents** Data collection **Additional information** methods Literature A thorough literature study was conducted with regard to the following topics: integrated care, chronic diseases, pilot projects and public policy study instruments. (scientific literature) Several political, legal and operational documents were consulted, notably Documentary the joint plan itself and the documents available on the website analysis (political, legal http://www.integreo.be/fr/documentation. This website is а communication tool created by the public authorities on which documents and operational relating to the IC4BH implementation plan were published, including political and legal documents, fact sheets, templates and application documents) guidelines, and PowerPoint presentations. Analysis of these documents provided an overview of the issues that authorities sought to communicate, and the information they wished to be explicitly known. The researcher also read and analysed the documents produced by the pilot projects she focused on throughout her fieldwork. **Type of information source : Actions and interactions** Data collection **Additional information** method The researcher attended several types of meetings as an external observer Direct observation and took field notes for every one of those. In total, she attended 67 meetings, which correspond to 148 hours of observation. She spent 105 hours observing the meetings of two pilot projects (e.g., preparatory meetings during the conceptualisation phase, follow-up meetings during the execution phase): 35 hours for the first project and 70 hours for the second. The researcher also attended specific meetings, entitled plenary sessions and "intervisions", organised by the public authorities (43 hours). Regarding the analysis of the collected information, the notes taken were

# **Table 8 – Research Methods**

Regarding the analysis of the collected information, the notes taken were read several times to ensure a precise and global understanding of the course of events and also in order to put into perspective the qualitative data collected with those gathered during the interviews.

Type of information source : Discourses	
Data collection method	Additional information
Semi- structured interviews	<ul> <li>Twenty-four semi-structured interviews were conducted by the researcher with different categories of actors identified thanks to the snowball effect.</li> <li>These were people with whom the researcher had no prior relationship: <ul> <li>policy-advisers and public officials involved in devising and implementing the new policy (n=9)</li> <li>pilot project coordinators (n=8)</li> <li>different pilot project stakeholders, e.g., general practitioners, nurses, social workers, etc. (n=7)</li> </ul> </li> <li>The purpose of meeting these people was to identify, through their discourse, their formal and informal roles, the way they personally experienced the process, their knowledge (what they knew, but also what they did not know) and their feelings about it. A new interview guide was written for each of them. These interviews lasted between 33 and 98 minutes; they were all fully recorded and transcribed. The transcriptions were read several times and then analysed manually through open coding, again by the researcher working alone. Open coding is a method of analysis from grounded theory methodology that allows the emergence of <i>ad hoc</i> core categories identified in the empirical material through repeated successive readings (Bryant &amp; Charmaz, 2011).</li> </ul>

# 4. Findings

# 4.1. Towards Integrated Care: Opting for Pilot Projects

At the international level, integrated care is considered to be a relevant solution for dealing with care fragmentation (Contandriopoulos et al., 2001; Minkman, 2017) and to tackle the challenge of long term care patients (Borgermans & Devroey, 2017). Nevertheless, it can take a variety of forms depending on the context in which it is implemented (Borgermans et al., 2017). There is no consensus on one single and universal definition of this concept due to its polymorphous nature (Amelung et al., 2017; WHO, 2016). In the IC4BH plan, integrated care delivery is defined as, "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system" (WHO, 2008b, p. 1). Furthermore, the World Health Organization (WHO) defines care integration as, "the organization and management of health services so that

people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money" (WHO, 2008a, p. 1).

National institutional arrangements and culture have a significant influence on how innovative solutions are translated locally (Marmor et al., 2005). The health care systems each have their own history, which has led them to reach their, "own individual equilibrium" (Schokkaert & Van de Voorde, 2011, p. 7). They result from specific building processes deeply linked to their history, traditions and national contexts (Minkman, 2017). Transferring isolated policy measures from one country to another, without considering the context in which they will be implemented, can be fruitless or even risky (Schokkaert & Van de Voorde, 2011). This explains why the Belgian authorities mobilised field workers, connoisseurs of the Belgian-specific context, as part of an iterative and incremental implementation through pilot projects, the idea of co-creation being the guiding thread of the process.

Indeed, other implementation methods could have been used. As an example, the authorities could have passed a law after having negotiated the reform, as usual, in the decision-making organs of the NIHDI, two of the most important being:

- the "General Council of the Health Insurance", which gathers together employer's representatives, workers' representatives, government's representatives and insurers' representatives (healthcare mutuals);
- the "Health Insurance Comity", which gathers together insurers' representatives and healthcare providers' representatives (INAMI, 2019).

However, the authorities opted for another way of proceeding, as already explained. So, why mobilise workers in the field specifically through pilot projects? Here are some of the reasons mentioned during the interviews explaining this choice:

"We discovered the international reference framework [of integrated care], which was not very well known in our country, to help us put in place a real plan of approach by choosing to embark on a bottom-up approach. And we had good reasons, because we knew very well that trying to fundamentally change the way care is organized, if we want to do it in a [traditional] concerted way, we will never reach a national consensus, it's impossible. We are not going to get all the medical unions and all the hospital networks and everyone to agree ... Oh yes, yes, we are going to change. That's not how it works. So, the only way, the idea, and I still believe in it, is that we can change things through a bottom-up approach. If we do it in a sufficiently substantial and global manner [...], it is much better supported by [specific] needs or by a way of demonstrating that we have succeeded in shifting the paradigm. This is change management, but by looking for the avant-garde in it". (Interview with a high-ranking official, 2017).

"Pilot projects are [...] less frightening than a change of law, regulation or financing mode" (Interview with a high-ranking official, 2017).

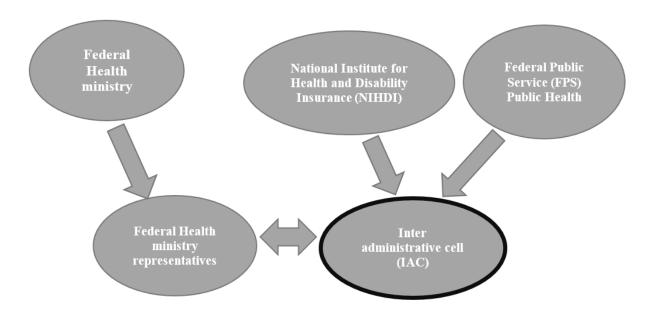
"The important thing is really to set up a methodology so that all things are taken into account, and that it is also sufficiently participatory because the element of co-creation is really essential for me in this project, and I often stress this. Sometimes, more than the result to be achieved, it's the whole method to get there that is very important, the involvement of all the actors" (Interview with a coach, 2017).

In these extracts, the interviewees expressed the advantages they see in the use of pilot projects as implementation instruments. The first interviewee explained that the traditional way of making decisions, at the level of the NIHDI bodies, would simply have hindered the possibility of finding an agreement on how to implement integrated care, due to the diverging interests of the sectors represented. Such an agreement would, nevertheless, have been a prerequisite for any legal text intended to bring about structural changes in the way of working in the care sector. Therefore, the use of pilot projects was a way around this problem. The purpose was to show that some projects would have succeeded in implementing integrated care in their geographic area, hoping that they would serve as successful examples and produce a snowball effect in the areas in which no integrated care projects had been implemented. The second interviewee stressed that the actions undertaken on a small scale, at the pilot project level, should be less frightening for hands-on professionals because they are more reversible than those that would have been directly implemented on a large scale to comply with the law. Finally, the third interviewee underlined the importance of working in co-creation with handson professionals. They should be able to produce innovative propositions anchored in their dayto-day reality, including elements that the authorities would not have considered.

#### 4.2. Integrated Care Pilot Projects

At the federal level, the inter-administrative cell (IAC) was created pursuant to the Protocol of Understanding of the inter-ministerial Conference of the 24th February, 2014, regarding the

health policy for chronic patients. The IAC was assigned the role of managing and coordinating the operational implementation of the plan, and to help, guide and collaborate with the pilot projects as part of the iterative and incremental co-creation dynamic. This department gathers together public officials of the NIHDI and of the Federal Public Service (FPS) Public Health. They also work in close collaboration with representatives of the federal health minister's office (Belgian Ministry of Social Affairs and Public Health, 2015).



#### Figure 6 – The Inter-Administrative Cell

In January 2016, the Belgian health authorities published a guidance leaflet for future pilot projects in which they described the specific modalities of the implementation process. The guidance leaflet specifically stated that it was meant to be evolutionary: this means that they were meant to be modified, if necessary, or even that new guidelines could be articulated in the future, depending on the turn of events. This relates to the willingness for iterative and incremental co-creation expressed by the authorities in the plan.

The implementation process has been divided into four main phases (Belgian Ministry of Social Affairs and Public Health, 2015):

1. The preparation phase (the first phase of the selection procedure): the four-month preparation phase began in February 2016, when the authorities launched a call for expressions of interest. Hands-on professionals, interested in creating a pilot project, had to gather in multidisciplinary local consortia. They had to submit a joint expression

of interest by 31<sup>st</sup> May, 2016, defining, approximately, their target groups, as well as the geographic area covered by their projects.

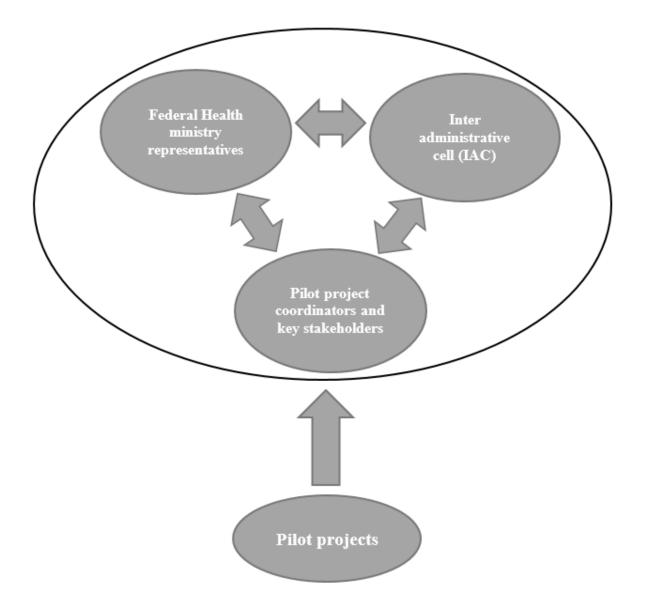
- 2. The conceptualisation phase (the second phase of the selection procedure): between July 2016 and September 2017, the 20 selected pilot project consortia had to write a more detailed application file containing a 'loco-regional action plan'. This plan needed to describe their common vision, and their strategic and operational objectives, as well as the actions they would implement to achieve their objectives if they were selected for the four-year execution stage. As from this phase, each consortium had to appoint a local coordinator whose remit was to lead the process of creating the loco-regional action plan. The local coordinator was the main point of contact between the project and the authorities. During this phase, a lump sum funding of €40,000, payable in two instalments, was provided to pay the coordinator's salary.
- 3. The execution phase: in January 2018, the twelve selected pilot projects entered the four-year execution phase and began to implement their loco-regional action plan.
- 4. The expansion phase: after the execution phase, the successful pilot projects will have to evolve to cover the entire Belgian population.

So, one can see that the two first phases were dedicated to designing the experiments that would be carried out in the field during the third phase. The third phase was actually both an implementation and an experimentation phase. The expansion phase will be an implementation phase intended to implement actions identified as best practices at a wider scale.

#### 4.3. A Continuous Co-construction Process

Achieving co-creation requires regular contact between the parties involved. During the preparation and the conceptualisation phases, several meetings ("kick off meetings", information and plenary sessions, and "intervisions") gathering together the IAC members, some representatives of the federal health minister's office, the coordinators and some pilot project members, were organised in this respect. The first three types of meetings were more formal and less regular than the intervisions, which were organised on a monthly basis.

Intervisions were key moments of discussions between the authorities, the coordinators, and the pilot projects' key stakeholders who accompanied them. The authorities give presentations on specific topics, provide additional instructions, new guidelines and answer coordinators' questions. The coordinators also have the opportunity to relay the difficulties, fears, disagreements and requests of their respective pilot project consortium and to ask for clarification regarding some elements or procedures. They also communicate with their peers and talk about their respective practices.





Intervisions are not often peaceful due to the frequent divergence of opinions regarding several matters between the authorities and the pilot project members, whose opinions are relayed by the coordinators. For instance, one disagreement pertained to financial aspects and, more precisely, to the notion of bundled payment.

Actually, in July 2011, the Belgian Health Care Knowledge Centre (KCE), a research centre that provides scientific advice on topics related to health care, was asked to produce a position paper related to future health care for chronic diseases. This scientific report, published in December 2012, summarised the challenges in this field through eighteen integrated care

components (see Table 9). These are based on a consultation with experts and a thorough international literature study regarding integrated care (Belgian Ministry of Social Affairs and Public Health, 2015). The IC4BH plan is an attempt to put into practice these recommendations.

18 components of integrated care	
1.	Empowerment
2.	Support for caregivers
3.	Case-management
4.	Maintenance at work as well as educational, professional and social reintegration
5.	Prevention
6.	Dialogue and coordination
7.	Care continuity (extramural, intramural and transmural)
8.	Accenting the experience of patients and families' organisations and of mutual
	health insurances
9.	Integrated electronic health records
10.	Multidisciplinary guidelines
11.	Development of a quality culture
12.	Adaptation of financing systems
13.	Risk stratification and resources mapping
14.	Change management
15.	Training for professionals regarding empowerment and multidisciplinary collaboration
16.	Continuing training regarding integrated care
17.	Evaluation of the system performance
18.	Attractiveness of professions

**Table 9 – Integrated Care Components** 

Reference: Belgian Ministry of Social Affairs and Public Health, 2015, p. 10

One of the KCE recommendations, which has become the 12th of the 18 components of integrated care in the IC4BH plan, refers to the adaptation of financing systems. As a reminder, the majority of physicians in Belgium are self-employed and remunerated on a fee-for-service basis. However, the federal authorities expressed their intention to move from a fee-for-service system to a bundled payment model, at least for certain types of medical services, justifying their choice by reference to international scientific literature regarding this topic.

In this literature, one can read that fee-for-service rewards volume instead of quality of care (Borgermans & Devroey, 2017; Hirsch et al., 2015) and, in this way, can hinder the implementation of integrated care based on a global patient-centred approach. According to the

scientific literature, a bundled payment system would seem more appropriate (Quinn et al., 2017). Bundled payment actually refers to, "a fixed payment that includes the prices of a group of services that would typically treat an episode of care in a defined period of time" (Quinn et al., 2017, p. 114). Using bundled payment could help neutralise expenses, enhance value of care and, consequently, improve the system's sustainability at the macro-level.

As a result, during the conceptualisation phase, the authorities encouraged the pre-project consortia to include actions in their loco-regional action plans that would help develop and test bundled payment at the local project scale. However, the professionals in the field quickly opposed this request for several reasons. This came as a surprise for the authorities, given all the advantages of this payment model as identified in the literature.

In an atmosphere of mistrust and suspicion, professionals argued that the concrete implementation modalities of such a transition were not sufficiently clear. They did not have sufficient guarantees of support from the authorities to achieve this economic transition. Here is an interview excerpt illustrating this idea: *"It is like buying a car. But, when you drive it, you realise that they are still building the car while you are driving it and you cannot get out of it anymore"* (Interview with a coordinator, 2017).

Furthermore, this would require a huge cultural change at every level of the Belgian care production chain. The professionals stressed that the authorities wanted to impose things and put the cart before the horse regarding this matter, arguing that Belgium is not yet ready for bundled payments: "*I cannot prevent myself from thinking that it is pretending to be bottom-up and is really top-down. They are going to compel us to work in a certain way*" (Interview with a pilot project member, 2016).

While this choice is understandable at the macro level given that it could help reduce health expenditure, at the micro level, the professionals were worried, particularly the doctors, because their remuneration mode and their income would probably be impacted. As such, what would be a saving for the government would be a loss of income for medical professionals. Indeed, bundled payment transfers the risk from payers to providers, sometimes even resulting in financial losses for the latter (Quinn et al., 2017). Some GPs even threatened to leave their respective projects, which would have prevented the other stakeholders from submitting the application at the end of the conceptualisation phase: GPs were, indeed, mandatory project members.

At the request of those in the field (so not only GPs), several additional meetings were set up to discuss the matter, which, among other factors, contributed to the lengthening of the conceptualisation phase, which was supposed to finish at the end of January 2017, but which actually ended mid-September 2017. Both parties tried to convince the other of the validity of their vision based on different types of arguments, i.e., scientific- (authorities) or experience-based (field workers). In the end, despite the authorities' insistence, no project complied with the request of designing actions to test actual bundled payment during the execution phase. Actually, *"[the authorities] adapt, they are open to discussion with the projects but in this case, they [simply] had no choice. [They] felt that if GPs blocked the integrated care pilot projects, there would not be any integrated care pilot project anymore. [Dealing with] chronic diseases without GPs is not feasible"* (Interview with a pilot project coordinator, 2018).

This empirical example illustrates the strong interdependence between the different levels of the health care system. Here are some other interview excerpts confirming this assertion:

"Obviously, the powerful argument of pilot project professionals is to say: anyway, without us, what do you want to do? If no one wants to participate in your pilot projects, what are you [the authorities] going to do?" (Interview with a pilot project member, 2018).

"Could they compel us [to do what they want us to do]? No [...], but what is the alternative? If we [hands-on professionals] do not comply voluntarily, we may be compelled, that is the threat. [The authorities could say]: 'If you do not want it, then, we will see if we cannot pass a Royal Decree'" (Interview with a pilot project member, 2018).

"Change is frightening. [...] We [the authorities] know that there is a lot to do in the field. It is the reason why it seems essential to take action at several levels and with hands-on professionals, because we cannot impose change alone. We can write a Royal Decree but ..." (Interview with a high-ranking official, 2017).

*"If we want to change things, dialogue [is a compulsory step] "* (Interview with a pilot project member, 2018), people from all the levels have to gather and negotiate.

#### 5. Discussion

#### 5.1. A Journey Through the Unexpected

The meetings of the IAC members, the representatives of the federal health minister's office, the coordinators and key pilot project members, i.e., GPs, nurses, social workers, etc., progressively contributed to the creation of a new dynamic of vertical interactions and vertical communication between stakeholders at the macro and the meso levels and, in this way, to alleviate the fragmentation between these levels. Gathering these different types of people on a regular basis is quite unusual in Belgium. Indeed, as already mentioned, health matters are normally discussed in the decision-making organs of the NIHDI, in which all the sectors involved in the pilot projects are not represented.

These specific meetings, which have been particularly crucial throughout the process, had a goal of sustaining the iterative and incremental co-creation process by providing the coordinators with support for the needs they had expressed. While these meetings were initially meant to be mostly informative, the participants appropriated the encounters, viewing them as a venue for expression, as opportunities to negotiate their participation in the projects or even call into question the content of the authorities' guidelines, which surprised the authorities.

The IC4BH plan is the result of a long reflection process in which, "knowledge [played] a fundamental justification function" (Radaelli, 1995, p. 174): the guidelines were built on the basis of scientific expertise on integrated care. Indeed, several Belgian public officials and policymakers took a closer look at successful cases of integrated care abroad; they attended scientific conferences abroad on the topic and relied on the KCE position paper.

"The relationship between expertise and politics has traditionally been described in terms of science speaking truth to power" (Pellizzoni, 2011, p. 765). Nevertheless, the recommendations and the guidelines designed by the authorities did not always seem relevant to the pilot projects' stakeholders, as shown in the empirical example above pertaining to bundle payment. Their divergence of opinions led to a cultural clash (Moran & Rau, 2016) and strong negotiations to deal with the controversy (Callon, 1984). Hands-on professionals openly questioned and negotiated the authorities' guidelines built on scientific expertise, the legitimacy of which they put into question by justifying their opinion on the strength of their place-based knowledge of the health care system at the local level (Moran & Rau, 2016) related to their practice and their experience (Wagenaar & Cook, 2011).

This example illustrates that, "instruments at work are not neutral devices: they produce specific effects, independently of the objective pursued (the aims ascribed to them), which structure public policy according to their own logic" (Lascoumes & Le Galès, 2007, p. 3). Indeed, the use of pilot projects allowed their members to question and renegotiate the framework set by the authorities, which the latter did not expect. Pilot project stakeholders took advantage of these moments of interaction to define, clarify or redefine their respective roles and responsibilities. They sometimes even refused to achieve what was expected of them, arguing that the authorities were imposing autocratic top-down measures (O'Riordan et al., 2015) based on de-contextualised scientific knowledge (Moran & Rau, 2016), which was irrelevant in the Belgian specific context. Not all of this would have been possible if the authorities had passed a law to implement the IC4BH plan. In such a situation, hands-on professionals would have been considered passive implementers, and would have had to comply with the law, under pain of sanctions.

In the case of integrated care pilot projects, implementers (pilot project stakeholders) were involved in a decision-making process at the local level: they were responsible for building and implementing their own loco-regional action plans. They were supposed to be active and to be involved voluntarily in the co-creation process initiated by the authorities. They were, but not always in the manner expected by the latter, as illustrated by the example of their reaction to the idea of bundled payments. This situation gave power to pilot project stakeholders who had the opportunity to influence the course of events and, consequently, brought a good deal of unpredictability to the process.

Indeed, the result of local people's reflections were found to be different from the authorities' expectations and wishes. Local stakeholders were able to question everything, and even leave the process at any time without sanction if they chose to do so, a situation which the authorities feared given that they were depending on them to implement integrated care in Belgium. On the other hand, the local professionals feared that the authorities might pass a law to impose their framework without taking their opinion into account if they left the process, which explains why, even if some stakeholders threatened to give up and leave the process, few actually carried out this threat.

Through their regular interactions, IAC members, health ministry representatives, as well as pilot project coordinators and key stakeholders (see Figure 7 above) transformed the IC4BH plan implementation modalities. In this way, they transformed the public policy itself, creating a tripartite, "crossed-regulation" (Crozier & Thoenig, 1975). This means that each of the three

parties involved regulated the others and were regulated by them in return: they were actually interdependent (Crozier & Thoenig, 1975, p. 12), each holding power.

Eventually, a serendipitous observation lies in the fact this process was neither completely bottom-up, as the authorities argued, nor entirely top-down, as several pilot project stakeholders put it. The authorities set the initial framework for action and determined the general aim, i.e., the metaproject (Lascoumes & Le Galès, 2005) (implementing integrated care), which was non-negotiable. They articulated guidelines and took the initiative to launch the call for pilot projects to materialise this metaproject. This gave pilot project members the impression that the process, which was supposed to be bottom-up, was actually disguised top-down, and that this was no real co-creation.

Nevertheless, as explained in the example above, pilot project stakeholders have actually had the opportunity to make proposals, negotiate certain aspects and influence the unfolding implementation process. Accordingly, if this was not co-creation, as pilot project stakeholders put it, it was at least a process punctuated by constant interactions, discussions and negotiations, probably inherent in iterative and incremental innovation. Therefore, in general, the achieved result was never completely what the authorities or the pilot project stakeholders anticipated, but rather was the outcome of successive mutual adjustments between them (Lascoumes & Le Galès, 2005).

#### **5.2. Becoming Representatives**

According to Lascoumes and Le Galès (2007), "Every instrument constitutes a condensed form of knowledge about social control and ways of exercising it" (p. 3). Using pilot projects to implement the plan has involved reshaping, "the relationship between the governing [the usual decision-makers] and the governed [the usual implementers]" (Lascoumes & Le Galès, 2007, p. 7) and has had consequences in terms of citizenship. It has begun to blur the lines between these two statuses, creating a new intermediary local level at which people gather to design joint projects and make important decisions.

Indeed, pilot project stakeholders (corresponding to the governed in Lascoumes and Le Galès's framework) have been increadingly involved in the decision-making process. They have acquired a certain capacity for influencing things and questioning the authorities' framework by acting as representatives of their profession and of their project, a role to which they were not accustomed. Progressively, they have learned to assume this new role by taking part in pilot

projects, exchanging ideas, and defending their interests and opinions. On the other hand, those at the macro level were put in a position in which they had to listen to the field workers' demands and consider them in order to orient their future decisions and provide them with support.

As a result, one can argue that the use of pilot projects supported the development of a, "negotiated governance" (Lascoumes & Le Galès, 2005, p. 23). It denoted a transition from a social guardian state, which commands and controls, towards a mobilizing state (Lascoumes & Le Galès, 2007), which sets the general framework for action, provides general direction, mobilises local people by delegating certain tasks to them, and lets them take concrete action to achieve the general aim, in this case achieving integrated care in Belgium.

#### 5.3. An Uncomfortable and Risky Endeavour

In an iterative regime of innovation involving constant confrontation of opinions, the project approach generates discomfort, immersing stakeholders at every level in a climate of (sometimes huge) uncertainty. Setbacks and changes of direction are frequent, which provokes anxiety and fatigue. As Segrestin (2004, p. 244) puts it, "they have embarked on projects as one would have on a risky expedition", betting on the future without completely knowing what would be asked of them and to what this would actually lead, e.g., regarding bundled payment.

Except for the coordinators, no additional human resources were financed: pilot project members took part voluntarily in pilot project meetings on a regular basis as representatives. This additional task required massive time investment, making their workload heavier and heavier and reducing the amount of time left to achieve their other tasks, for which some receive subsidies from the Belgian federate entities. Progressively, they have had to deal with several workloads (and sometime incompatible guidelines) attributed by different levels of power (federal level, federate entities).

As a result, field workers were put under pressure to take innovative initiatives, but had to deal simultaneously with many constraints (institutional, financial, organisational, legal, etc.) reducing their flexibility. Incidentally, some interviewees stressed the psychological costs related to the process due to the heavy workload and the constant uncertainty inherent in the project's approach.

#### 6. Conclusion

This paper addressed the following research question: how does the use of multidisciplinary pilot projects as implementation instruments reshape modes of public governance in the Belgian health sector in a context of transition and ongoing devolution? One could have imagined, for example, that this new way of working would have resulted in a simple transfer of tasks to the members of the pilot projects, the main task delegated being the design of innovative concrete actions to implement integrated care in Belgium. Instead, this research suggests that the use of pilot projects contributed to reshaping modes of public governance by transforming the roles of both the authorities and the actors involved in the pilot projects, i.e., creating new roles they had to learn.

The authorities were supposed to shoulder a role of support, which, in this case, led to the creation of a new department, the IAC, dedicated to this support mission. On the other hand, pilot projects stakeholders still shouldered the role of implementers as they would have done traditionally. However, in this scenario, they were implementing actions that they themselves had designed, not actions designed by the authorities in collaboration with scientific experts. As such, to a certain extent, they were both implementers and decisions-makers given that they had to make decisions about what should be done in the field. Therefore, the use of pilot projects, with the initial purpose of experimentation and implementers.

Importantly, this role transformation required new modalities of collaboration between the authorities and the pilot project consortia. It gave birth to new practices: regular meetings between people who usually did not meet. Indeed, the iterative and incremental transition towards integrated care required that the authorities and local professionals collaborate closely. To that end, they met on a regular basis, notably during monthly intervisions. This led to building bridges between the different levels of the care production chain, notably between ministry representatives, public officials (IAC members) and pilot project stakeholders. This resulted in the emergence of vertical collaboration, and one can even say the emergence of the early stages of a vertical integration (Axelsson & Axelsson, 2006). In this context, the local professionals progressively learned to assume the new role of representatives of their project and profession, which is symptomatic of a more negotiated governance (Lascoumes & Le Galès, 2005).

Nevertheless, given that these different stakeholders each had their own logic of action (expertise-based vs. practice-based), some unexpected controversies emerged during the process, e.g., regarding financial aspects. Through this example, one became aware that pilot project members succeeded in influencing the process, calling into question the framework set by the authorities, an aspect which the latter did not expect. Accordingly, they all entered a non-linear process of constant interactions, discussions, negotiations and successive mutual adjustments as part of a tripartite crossed-regulation (Crozier & Thoenig, 1975).

The lesson to be drawn here is that interacting is a first step, but not a sufficient one to achieve real co-creation, which should result in vertical integration. Real co-creation entails that all stakeholders, regardless of their position in the care production chain (policy-makers included), interact regularly and also make the effort to stand in the shoes of the others to understand their respective day-to-day realities by *really* listening to what they have to say, which does not seem to be a natural practice at present.

Eventually, the research underlines that the project approach also has its downsides: the additional workload, the inherent constant confrontation of opinions and changes of direction creating an uncomfortable climate of uncertainty, raising questions in terms of well-being at work.

In conclusion, because of the general uncertainty about how best to integrate care, other countries may be tempted to launch pilot projects to this effect. The practical findings presented in this paper could be useful for policy makers who may wish to use pilot projects to test and implement policy. Some of the findings may also be useful for the use of pilot projects in other sectors.

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# **Chapter 4**

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Towards Integrated Care for Chronic Patients in Belgium: The Pilot Project, an Instrument Supporting the Emergence of Collaborative Networks





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# Towards Integrated Care for Chronic Patients in Belgium: The Pilot Project, an Instrument Supporting the Emergence of Collaborative Networks

#### Mélanie De Winter

Centre of Sociological Research and Interventions, Faculty of Social Sciences, University of Liège, 4000 Liège, Belgium; mdewinter@uliege.be

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# Abstract

In 2015, the Belgian Health Ministers launched a plan intended to evolve towards an integrated care system for chronic patients. This plan is implemented through pilot projects involving local actors. Therefore, the researcher raised the following research question: how does the use of pilot projects as implementation instruments structure the collaboration between parties involved in a pilot project? The term "pilot project" refers to a collaborative work method coupled with an experimentation purpose. This is further developed in the paper via a literature study. This qualitative research draws on interviews, focus groups, direct observation, and a documentary analysis. During the two first phases of the process, field workers had to create multidisciplinary local consortia and write an application file describing the project they would implement during the third phase, which raised challenging collaboration issues. Many people learned to work together over time, progressively overcoming the traditional fragmentation of care. They met regularly, understood their respective roles, and dealt with controversies through negotiation to reach an agreement on a common project. In conclusion, the researcher shows that, thanks to its characteristics, the pilot project instrument supports the development of collaborative care networks; in this example of community-based integrated care networks.

Keywords: Integrated care; pilot project; health networks; community health; chronic diseases

#### **1. Introduction**

#### 1.1. Background

For the last ten years, numerous pilot projects have been launched in the Belgian health sector, including "therapeutic projects" and "psy 107" projects in the mental health sector, multidisciplinary local networks for diabetics (type 2) and for patients with renal insufficiency, "protocol 3" projects for frail old people, and also, more recently, integrated care pilot projects for chronic patients. The latter were initiated as part of the "Integrated Care for Better Health" plan targeting chronic patients, which was approved on October 19, 2015. This plan was launched in reaction to the current fragmentation of care, which impedes the delivery of quality care to chronic patients, puts the health care system under budgetary pressure, and as a result, reduces the health care system's efficiency (Amelung et al., 2017; Belgian Ministry of Social Affairs and Public Health, 2015).

The prevalence of chronic diseases is one of the major public health challenges worldwide (Riley et al., 2017). In Belgium, 27.2% of the population are suffering from chronic disease(s) (Paulus et al., 2012). These are also the leading cause of mortality, being responsible for about 86% of deaths (World Health Organization, 2018). As in other European countries, from a financial perspective, their ever increasing prevalence (Ording & Sørensen, 2013; Paulus et al., 2012) has resulted in a constant and important increase in Belgian health care expenditure (Schokkaert & Van de Voorde, 2011) over the last 15 years (OECD.stat, 2017), and the latter are expected to continue to rise if no action is taken.

Chronic patients often combine several diseases, which can make things even more complicated. In Belgium, more than one in three people over 65 suffer from at least two chronic diseases (Van der Heyden & Charafeddine, 2014). This coexistence of several chronic affections (two or more) is referred to as "multi-morbidity" (Ording & Sørensen, 2013). Managing multi-morbidity over the long term requires the intervention of multiple care professionals and organisations (from first and second lines of care) and also of non-medical stakeholders (Amelung et al., 2017). It is now also a major challenge given that the "single disease approach", leading to a high level of specialisation, has dominated medicine for centuries (Ording & Sørensen, 2013). Chronic patients have indeed very specific and complex needs in terms of care (Baszanger, 1986; Czernichow, 2015), which require strong and effective coordination, cooperation and collaboration between practitioners (Amelung et al., 2017).

The Belgian health care system is, nonetheless, characterised by a high degree of fragmentation and does not meet the needs of chronic patients. Admittedly, this fragmentation can be explained by the predominance of the single disease approach, but it is also a legacy of the historical 'pillarisation', which has characterised Belgium since its creation (Thunus, 2015). Actually, this country can be seen as a consociational democracy emanating from a society characterised by a sharp segmentation related to denominational communities, namely Catholics and non-Catholics (Mangez, 2010), the latter encompassing liberals and socialists (Thunus, 2015). Historically, each of the three communities created "a wide range of organisations dealing with almost every aspect of daily life, i.e., a pillar" (Mangez, 2010, p. 60). Among these organisations, one can find schools and universities, political parties, trade unions, youth organisations, and in the health sector, health care services, health insurance, and hospitals. The three pillars have each had their own path and have evolved independently in a context of parallel "segmental autonomy" (Mangez, 2010, p. 61). They have avoided building bridges between each other, which explains the resulting societal fragmentation. "As consociations are composed of societies-in-a-society and systems-in-a-system, creating an integrated system is a major challenge" (Mangez, 2010, p. 64). In Belgium, the ideological boundaries and tensions existing between the three pillars have underlined the functioning of the Belgian institutional edifice for decades (De Troyer & Krzeslo, 2004). Even if their influence is less important than before, they still have an influence on the way care is organised in Belgium and at the different levels of the Belgian health care system.

According to international scientific literature (Amelung et al., 2017; Paulus et al., 2012), an integrated care system would seem more appropriate to deal with the challenges posed by the current chronic disease epidemic (Riley et al., 2017; WHO, 2014). Care integration can be defined as "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system" (WHO, 2008, p. 1). Accordingly, through their plan, the Belgian health ministers—Belgium is a federal state, which explains why there are several health ministers—advocated a transition towards such a collaborative system, drawing on the Triple Aim model principles, which have guided health system reforms in many countries (Amelung et al., 2017). The Triple Aim model combines these interdependent goals: "improving the individual experience of care, improving the health of populations, and reducing the per capita costs of care for populations" (Berwick et al., 2008, p. 160). In other words, the purpose is to

simultaneously improve quality, equity, and efficiency by moving from a competitive to a collaborative health care system (Buttard et al., 2012).

Nevertheless, if there was an agreement on the general aim, i.e., achieving integrated care, the question of how it could concretely be done in the Belgian-specific context was more uncertain. This explains why the Belgian authorities decided to use pilot projects as implementation instruments. It was a way to involve field actors in an iterative and incremental co-creation process, giving them the opportunity to build their own project at a local level and to make propositions on the strength of their field experience, which should be more adapted to patients' needs. Indeed, hands-on professionals have an experience-based knowledge of the Belgian health care system, anchored in their day-to-day practice, which the authorities do not have.

These new integrated care pilot projects are particular in the sense that they simultaneously target several diseases, encompass larger target groups than the previous pilot projects in health care (thousands of people per project), do not overlap geographically, and cover larger geographic areas. Above all, they involve many more different actors from the different pillars, from the different care lines, and from the different levels of the care production chain (macro, meso-, and micro levels) in a phased co-creation process, i.e., policy-makers, civil servants, patients' representatives, first-line and second-line care actors (hospitals, medical health centres, general practitioners, nurses, etc.), together with non-medical actors (e.g., social and cultural actors). These actors, who would probably not have met otherwise (or, if so, not under the same terms), have different and often diverging interests, which raises major inter-pillar, inter-sectorial, inter-organisational, and inter-professional collaboration issues.

This expected major transformation of the Belgian health care system denotes the authorities "wish to achieve a paradigm shift" (Belgian Ministry of Social Affairs and Public Health, 2015; Hall, 1993), as they state it in the plan 'Integrated Care for Better Health'. A paradigm shift can be defined as a change "in the framework of ideas and standards" (Hall, 1993, p. 279) shared and used by policymakers to define policy goals, instruments, and the problems to be addressed, as well as regulatory mechanisms (Hall, 1993). In this paper, the researcher focuses on the change of instruments, i.e., the use of pilot projects, instead of passing a law as the authorities did before. In an original manner, she focuses on the instrument "pilot project" as an action mode (Lascoumes & Le Galès, 2005). She addresses it as an object for research and raises the following research question: how does the use of pilot projects as implementation instruments structure the collaboration between parties involved in a pilot project? To answer this question, she has focused on two pilot projects launched as part of the Belgian plan "Integrated Care for

Better Health". In this paper, the researcher intends to understand how the pilot project approach structures the interactions and the relationships between the numerous pilot project stakeholders who have to learn how to work together, cooperate, and collaborate to achieve integrated care in Belgium. In other words, the analysis deals not only with the need to re-invent health care, but also with the evolution in the means selected to re-invent health care systems.

Her contribution also resides in the fact that she analysed her data by combining elements from three theoretical frameworks:

- The framework of project management stated by Segrestin pertaining to the sociology of organisations;
- The framework of public policy instruments of Lascoumes and Le Galès belonging to the sociology of public action—this framework has already been used to analyse the specific case of an urban project, but not yet to analyse pilot projects in the health sector;
- The framework of sociology of translation by mobilising the work of several authors— Callon, Latour, Akrich, Monaghan, and Freeman.

The next section consists of a literature review regarding the "pilot project" as an object for research.

#### 1.2. Pilot Project: Two Words for one Single Public Policy Instrument

The project-based approach is a work method used in many different sectors. Vreugdenhil and Ker Rault (2010, p. 122) see pilot projects as a "means to establish communication between actors that usually do not cooperate". In this way, due to their dynamic nature, they help trigger collaboration (Zurlo & Nunes, 2016).

The project approach "applies to complex and tailor-made actions" (Segrestin, 2004, p. 233) and is supposed to help go beyond traditional solutions when innovation is needed to meet singular and specific needs (Dumoulin et al., 2015; Segrestin, 2004). Based on the idea of "creative cooperation" (Segrestin, 2004, p. 232), "the project logic is the one which consists of mandating a team, the project team, to complete successfully the conception of the adequate solution to a mission" (Segrestin, 2004, p. 234). Breaking down the traditional hierarchies, this team often gathers professionals of various origins who have to cooperate in an uncertain context of continual negotiation and imperative exchange of ideas, which can be the source of important new uncertainties (Lascoumes & Le Galès, 2005). Indeed,

exchanging points of view not only entails admitting once and for all that no one owns the good solution, but also that a collective task cannot come down to the addition of individual or local contributions—it is the exchange by itself which is the source of knowledge, contributing to making creation unpredictable. (Segrestin, 2004, pp. 244–245)

The pilot project constitutes, therefore, a social mobilisation instrument characterised by an interactionist and processual rationale, taking what already exists as a starting point for reflection and action (Lascoumes & Le Galès, 2005).

Another characteristic trait of the project approach is that the aims it sets out to achieve are strictly defined, while the participants are free to achieve them in the way they choose, often with limited resources. As a result, a project group always has to handle the challenge of combining and finding a balance between exploration of new possibilities and exploitation of old certainties (March, 1991). This means that "whatever its mission, it will have to create, invent, and also deal with constraints of efficiency" (Segrestin, 2004, p. 232), sometimes forcing them to avoid risks linked to the exploration of new possibilities and leading them to resort to more familiar and predictable solutions.

In addition, behind the word 'pilot' hides the idea of experimentation, of being (one of) the first trying to achieve a particular task. In a variety of sectors, pilot projects, viewed as collective experiments (Zurlo & Nunes, 2016), are often used in innovative contexts to develop and test new solutions, methods, concepts or practices (Engström & Lidelöw, 2015; Vreugdenhil et al., 2012). They constitute "common means by which innovations (...) are applied and adapted (or even translated, one might say (Callon, 1984; Freeman, 2009)), to real-world situations" (Engström & Lidelöw, 2015, p. 289). As such, the innovative actions undertaken at the pilot project level are reversible. Indeed, pilot projects "configure a space to introduce and test innovations with smaller risks, either on smaller geographical scales or in short times" (Zurlo & Nunes, 2016, p. 29). In this way, they "perform as platforms for learning" (Engström & Lidelöw, 2015, p. 289), which leads to knowledge development (Vreugdenhil & Ker Rault, 2010; Zurlo & Nunes, 2016). Consequently, they are also used by policy-makers to produce evidence for policy-making (Vreugdenhil & Ker Rault, 2010).

Eventually, this instrument is often used collectively to initiate and pilot innovation by putting into perspective, on the one hand, the existing local resources on a specific territory, and on the other hand, the public action objective(s). It is expected to induce a better understanding of

local issues and a better appropriation of the policy objectives by the mobilised actors (Lascoumes & Le Galès, 2005).

In conclusion, the pilot project is an instrument that has the potential to gather people with very different backgrounds and make them collaborate, even if it is unusual for them. Beyond the fact that it can trigger collaboration, the pilot project also brings about new challenges and structures collaboration in a certain way. This is precisely what the researcher analyses in the case of integrated care pilot projects in light of the literature regarding pilot projects.

#### 2. Materials and Methods

This sociological qualitative and inductive (Musselin, 2005) research began in December 2016 during the conceptualisation phase (see below) and it draws on several data collection methods. The data were collected during the 14-month conceptualisation phase, i.e., the application writing period, as well as at the beginning of the execution phase, which started in January 2018 (see below). Inspired by the triangulation approach (Jick, 1979), the three types of information sources listed below were combined:

1. Written documents through a literature study (scientific literature) and a documentary analysis (political, legal, and operational documents);

2. Actions and interactions through direct observation (attendance at 67 meetings—148 h in total): 105 h were spent attending and observing meetings (preparatory meetings during the conceptualisation phase, follow up meetings during the execution phase, etc.) of two pilot projects (35 h for the first project and 70 h for the second one). The researcher also attended plenary sessions and intervisions organised by the public authorities (43 h) to observe what was happening through interactions and to observe innovation in action;

3. Discourses: the researcher conducted 24 semi-structured interviews, lasting between 33 and 98 min, with different categories of actors—policy-advisers and public officials involved in devising and implementing the new policy, pilot project coordinators, and pilot project stakeholders. Furthermore, this research relies on data collected via seven focus groups (n = 7–16,5 h) on the topic of governance, the purpose of which was to determine the governance modalities of three projects (the two mentioned above and a third additional project).

# 3. Results

# 3.1. Launching Integrated Care Pilot Projects: A Phased Process

In January 2016, the publication of the guidance leaflet for future integrated care pilot projects by the Belgian authorities marked the beginning of the implementation of the plan, "Integrated care for better health". This leaflet contained the specific modalities and guidelines pertaining to the process.

As already explained above, it has been divided into four main phases (Belgian Ministry of Social Affairs and Public Health, 2015):

- The preparation phase and the conceptualisation phase, which are the two phases of the selection procedure, during which field actors designed their projects together;
- The execution phase, which began in January 2018, which should last for four years, and during which the twelve out of the fourteen selected pilot projects (two pilot projects gave up) are expected to implement their "loco-regional action plan" (see below);
- The expansion phase, which will occur after the four-year execution phase, during which the successful pilot projects will have to evolve to cover the entire Belgian population.

In this paper, the researcher focuses mainly on the two first phases, the preparation and the conceptualisation phase:

1. The preparation phase (first phase of the selection procedure): in February 2016, the authorities launched a call for expressions of interest, which marked the beginning of the four-month preparation phase. Field actors who were interested in creating a pilot project had to constitute multidisciplinary local consortia. By doing so, the political will was to gather a variety of people working with chronic patients so that each consortium properly reflected the care offer of the geographical zone covered by its project. Stakeholders had to submit a joint expression of interest approximately defining their target groups, as well as the geographic area covered by their projects, by May 31, 2016. This expression of interest had to be signed by all of the partners who had joined the pilot project consortium.

2. The conceptualisation phase (second phase of the selection procedure): between July 2016 and September 2017, each of the twenty selected pilot project consortia had to

write a more detailed application file containing a loco-regional action plan. In this plan, pilot project stakeholders had to describe their common vision, their strategic and operational objectives, as well as the actions they would implement to achieve their objectives if they were selected for the four-year execution stage. These had to be based on an analysis of local needs, of available and missing resources in the pilot zone, as well as a risk stratification pertaining to their respective populations.

The application file also had to include:

- a financial plan;
- a communication plan;
- a time line taking the form of a Gantt Chart;
- the description of their future governance structure and legal personality;
- a description of how responsibilities would be distributed among partners during the execution phase (Belgian Ministry of Social Affairs and Public Health, 2015).

From this phase, each consortium had to appoint a local coordinator, working at least part-time for the project and whose role is described below. In order to achieve these tasks, the coordinators and their consortia members were assisted by external coaches hired by the authorities. The coaches had, inter alia, the mission to provide the coordinators with methodological assistance regarding the analysis of the existing situation in their pilot zones and the conception of the loco-regional action plan (Belgian Ministry of Social Affairs and Public Health, 2015). Therefore, at the beginning of the conceptualisation phase, the coaches suggested a non-mandatory governance structure for the pilot projects specific to this phase, which is represented in the organisation chart below (Figure 8):

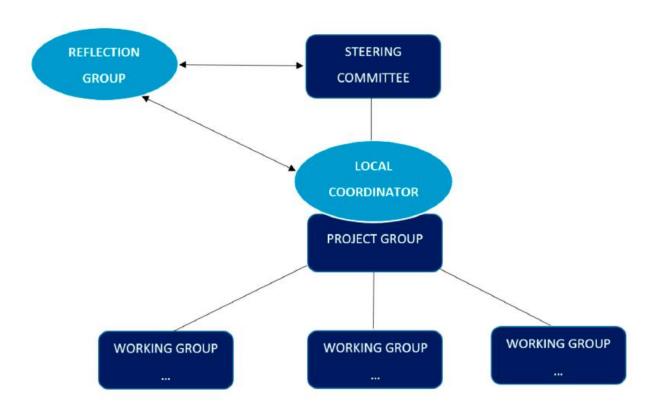


Figure 8 – Pilot Projects' Governance Structure

Each type of group gathered specific partners and had its own meeting frequency. The reflection group referred to the entire consortium and gathered all the pilot project partners. This group had to meet at least once during the conceptualisation phase on the initiative of the local coordinator. It had a reflective role on the basis of the proposals received from the project group. The latter was a smaller group, gathering between four and seven key partners, who were expected to meet at least eight times during this phase (around once a month). Its role was to make proposals and to detect problems, among other tasks. The steering committee was larger than the project group and gathered the most concerned people of the consortium. They were supposed to meet four times. Their role was to validate the proposals and documents. Working groups were small groups that gathered experts in their respective fields. Set up to meet specific needs, these ad hoc groups had to develop some ideas further by mobilising their expertise. Finally, the local coordinator was the contact person between all of these stakeholders. They were also the single point of contact for the coach and the authorities, and in charge of organising the meetings for each group (invitation, chairmanship, writing meeting minutes, follow-up, etc.) and of writing the application file. Eventually, the local coordinator was responsible for practical aspects, such as managing the budget, distributing attendance fees, among other tasks.

The structure set out in Figure 8 and the meeting frequencies related to each group were no mere coincidence, as illustrated in this interview extract: *"We created a kind of reverse planning model that we gave to the coordinators saying 'according to us, from this day, here are the steps to perform and the chronology that we have imagined'. So we suggested an entire governance structure including a reflection group and a project group"* (Interview with a coach, 2017). The rationale behind this was that according to the coaches, a certain number of meetings were required for each group to be able to submit the application file on time. Interestingly, it appeared that this was not enough, and that pilot project members set up additional meetings.

#### **3.2. Financial Aspects**

During the conceptualisation phase, a lump sum funding of 40,000 euros, payable in two instalments, was provided to pay the part-time coordinator's salary. This was the only funding that the consortia received during this phase. Since the beginning of the execution phase, each consortium has had to appoint a full-time coordinator to lead the execution process (not mandatorily the same person who coordinated the project during the conceptualisation phase).

Another question of importance is how these pilot projects are expected to be financed during the execution phase. It was planned that each year, pilot project consortia would be paid a lump sum of exactly 150,000 euros. It is explicitly written in the guidance leaflet that this amount of money is intended to finance the coordinator's salary, as well as the management costs (administrative expenses, attendance fees, etc.), and to hire additional staff, if needed. In other words, this budget is not supposed to finance the pilot projects' actions in the domain of health care provision for the patient.

Through the joint plan, the authorities are following the Triple Aim principles, which specifically entail reallocating the available financial means more effectively, while preserving or even enhancing equity and quality of care. To that end, pilot projects, due to their actions, would have to reduce health care expenditure in their pilot zone, which would affect the Belgian health care budget by generating savings at the national level. In return, in addition to the lump sum funding of 150,000 euros, each pilot project will receive, at the end of each year, a budgetary envelope corresponding to the savings they will have helped to generate in their pilot zone. This sum, called the "budgetary guarantee", would be redistributed to them each year so that they could implement new actions, generate new savings, and so forth. As a result, given

the scarcity of financial resources, the stakeholders took part in meetings voluntarily, without being paid.

#### 3.3. Building Integrated Care Pilot Projects

When co-designing integrated care pilot projects at the local level, coordination, cooperation and multidisciplinary collaboration are some of the key components of integrated care (Contandriopoulos et al., 2001; WHO, 2016). Triggering a collaborative culture between the different actors of the care production chain has been precisely one of the major innovations at stake in the plan, given the level of fragmentation in the Belgian health care system. As a result, in a context in which health care professionals do not collaborate spontaneously, the first step was to make them meet, communicate, and be aware of the existence of each other, as well as of their respective roles in the care production chain. This process was initiated during the preparation and conceptualisation phases.

The authorities' guidelines were listed in the guidance leaflet published in January 2016, in which they set up the framework for action in a top-down manner. In this document, the authorities describe the integrated care framework and determine the general and inescapable objective they want to attain—achieving integrated care in Belgium with limited resources, given the current context of budgetary pressures. On the basis of these guidelines, pilot project stakeholders were invited to think outside of the box and collectively imagine new ways of working, while mobilising what already exists in terms of resources. As proof of this, here is what a public official said to pilot project members during an intervision: "We do not ask you to do better with less, but to do better with what already exists" (Field notes of observation, 2017). In this context, pilot project members were given the freedom to make bottom-up innovative and creative proposals anchored in the reality of their day-to-day experience of care (as professionals, patients, etc.), as illustrated by this interview extract: "In my opinion, and we often repeat it: we do not have all the answers. [...] Consequently, it is important for us to have a co-creation process as we often repeat it, that field actors involve themselves, create and make propositions" (Interview with a high-ranking official, 2017).

During the preparation phase, the interested people had to gather in multidisciplinary local consortia, or in other words, to constitute their project teams and design together the first elements of a common project. They were put in a situation in which they had to identify the other relevant actors present in their territory, and with whom they would collaborate to imagine

new ways of organising and delivering care for chronic patients at the local level on a delimited territory.

According to one pilot project stakeholder, "*It is the first time that we have had so many different actors around the table*" (A pilot project stakeholder, Field notes of observation, 2018). Indeed, pilot project consortia are very heterogeneous. Interestingly, their composition blurs the explicit or implicit routine hierarchical reports, which sometimes initiates a redistribution of the roles between the participants. They actually gather, on a voluntarily basis, a variety of stakeholders who do not usually collaborate directly, but who each have a role to play in the care trajectories of the types of chronic patients included in the target population. One can mention general practitioners, nurses, pharmacists, physiotherapists, occupational therapists, specialist doctors, hospitals (directors and managers of specific departments who function within the pilot project target population), social workers, home help- and care partners, home care coordination centres, patients' associations, as well as associations of their relatives, health care insurance companies, called health care mutuals in Belgium, social aid and social welfare actors, such as public centres for social help, day care centres, and rest homes, along with other non-medical partners, such as the cultural, employment, agricultural, and environmental sector representatives.

Another very unusual thing is that institutions historically related to the three different pillars are simultaneously represented in several consortia, as stated in this interview extract:

"The divisions are different [in the integrated care projects]. In x [name of the project], you can find public and private providers, you have everything. Why would it be this federation instead of this one that would [take the lead]? The conflict resides [in] this pillar logic, i.e., this logic of ideological and confessional division, which has structured the Belgian society since the outset. We would try to evolve towards something more rational in the 21st century, which is not only based on political convictions or beliefs. [...] We would try to evolve towards something more rational" (Interview with a pilot project member, 2018).

Actually, one might have imagined that having intra-pillar pilot projects, i.e., different pilot projects, each gathering professionals from one specific pillar, would have possibly facilitated the implementation process, leading to the development of intra-pillar collaborations and intra-pillar care integration. It would also have contributed to reproducing the societal segmentation characterizing the Belgian consociational democracy (Mangez, 2010), but it would probably

have led to new redundancies in terms of offers of care. Instead, following the authorities' instructions, consortia are expected to develop territorialised actions and involve the most relevant partners possible, whatever the pillar they are related to. By operating in this way, one of the purposes is notably to reduce, or even eliminate, useless duplications in the care system, which lead to a lack of efficiency.

During the conceptualisation phase, getting to know each other was admittedly a timeconsuming, but also an essential, step for all the aforementioned local people who participated voluntarily to build a multidisciplinary pilot project. "*If the project is not selected, we will at least have got to know each other. It is not wasted—things have already changed [in terms of collaboration and integration]*" (A pilot project stakeholder, Field notes of observation, 2018). This aspect is clearly stated as a positive consequence of being involved in the project given that, so far, a lot of stakeholders used to work in silos.

Drawing on the governance structure mentioned above, the people involved in the selected preprojects met regularly to brainstorm, discuss, and articulate objectives in order to write collaboratively their loco-regional action plan, as well as the other elements of their application file. They had to reach an agreement on their common vision and goals, and their strategic and operational objectives, as well as the future actions they would implement. This was a challenging task given the diversity of the assembled stakeholders' profiles. Numerous points of view were indeed represented, which made things even more complex, e.g., a hospital director will not have the same vison of care as a general practitioner or a home care worker. Each partner had their own practice-based knowledge, their own personal interests, and their own opinions to express, which sometimes created important controversies (Callon, 1984) and led to hard and long negotiations. These controversies concerned various matters, e.g., the name chosen for the project, the way financing resources would be allocated, the governance modalities and the project's potential legal structure, patients' data protection, the concrete actions that should be launched to achieve integrated care, the selection of priority targets and actions, etc. (this list is far from exhaustive). Pilot project members even felt the need to organise additional meetings with respect to what was planned in the beginning of the process to deal with all the matters aforementioned. As a result, the conceptualisation phase lasted fourteen months instead of seven.

## **3.4. Empirical Example: Choosing a Governance Structure and Legal Personality** for the Future Execution Phase

As a reminder, during the conceptualisation phase, pilot project consortia had to decide which governance structure they would adopt. Each pilot project had also to identify a structure with a legal personality to receive their funding—an existing one (e.g., a partner organisation), or a new one to be created specifically for the project. After having decided this point, the partners had to either decide which organisation would be mandated to receive the funding (in the first case) or to choose the legal personality they would adopt during the execution phase (in the second case). Several scenarios could be considered. Regarding the governance structure, they could create (or not) a new independent structure and choose between several configurations, e.g., a de facto association, a non-profit making organisation, called an ASBL in Belgium (*Association Sans But Lucratif* in French, which means not-for profit association in English), which is an often-used specific kind of legal personality, or even innovate and imagine new configurations. In this regard, three coordinators wished to consult their stakeholders and organise focus groups to discuss that matter. Concretely, two sessions of focus groups were organised:

- A session for a first project, during which the participants were divided into three focus groups gathering ten to fifteen people and lasting three hours each;
- A joint session for two projects, during which the participants were divided into four focus groups gathering ten to fifteen people and lasting two and a half hours each: these two projects had common stakeholders and considered the possibility of pooling resources, which explains why it was decided to organise a joint session.

In each focus group, every participant had the opportunity to express their opinion regarding the matter at stake. Again, in each focus group, a specific and similar controversy emerged— some participants wanted to create a new "ASBL" for the project and others did not, preferring to keep the governance structure used during the conceptualisation phase. The participants talked about the pros and cons pertaining to each scenario. "*We should not put the structure before the horse*", said a participant (Focus group extract, 2017). This illustrates the vision of some partners, according to whom building an ASBL without knowing if the project could be fruitful would be too premature and cumbersome. Indeed, creating an ASBL involves a lot of time-consuming administrative procedures. Others claimed there was a need to create a new and autonomous structure, such as an ASBL, considering that this would be a guarantee of transparency and neutrality regarding the management of the project. Also, many participants

stressed that they did not have the proper legal expertise to select the adequate legal structure. "*There are probably other solutions that we do not know*" (Focus group extract, 2017). Accordingly, it was difficult for them to explore new possibilities and select innovative solutions, which brought them back to exploiting old certainties. In almost each focus group, the majority opted for creating an ASBL, the legal structure they knew best. Surprisingly, the first project members, after having discussed and negotiated the matter again during additional meetings, opted for a *de facto* association. They designated an organisation member of the project to be the legal mandated person to receive and manage the funding. As for the two other projects, they also set up additional meetings for further discussions and negotiations to agree finally on creating two independent ASBLs.

#### 4. Discussion

#### 4.1. The Case of Integrated Care Pilot Projects: Emerging Collaborative Networks

During the numerous meetings the researcher attended, the diversity of the participants' profiles often resulted in a melting pot of opinions (Segrestin, 2004). In an uncertain and sometimes uncomfortable (Segrestin, 2004) climate of perpetual negotiation, the partners dealt with controversies (Callon, 1984) by exchanging ideas. Progressively, the stakeholders overcame their personal interests through successive mutual adjustments (Lascoumes & Le Galès, 2005; Segrestin, 2004) and inter-professional mutual learning (Amelung et al., 2017; March, 1991). They interacted face-to-face with each other on a regular basis (Segrestin, 2004) and took the time to grasp their respective roles, "to tame each other" (A pilot project stakeholder, Field notes of observation, 2018). They identified the assets already present in their consortia and in their geographical area. Step by step, the stakeholders collectively built their project, articulated the reason for its existence, as well as their common philosophy, and defined or adjusted their own individual role in this complex system (Schweyer et al., 2002). By doing so, the stakeholders stabilised a common identity (Lascoumes & Le Galès, 2005) and a "common language", which crystallised the compromise achieved through successive iterations (Akrich et al., 2002). In this way, they made their relationship intelligible, and they united "universes (that) were separate and had no means of communication with one another" (Callon, 1984, p. 223). It is in this sense that the pilot project is a social mobilisation instrument—using it as an implementation instrument leads to "the implication of the actors of the concerned territory and the valorisation of the resources harboured on this territory" (Pinson, 2005, p. 201).

This way of working led progressively to the emergence of the early stages of a new culture of horizontal collaboration between pilot project members. Indeed, during the preparation and the conceptualisation phases, numerous different people, who might not have otherwise met, came to work together and learned from each other (March, 1991). They made different worlds communicate (Segrestin, 2004) and began to alleviate the traditional fragmentation between first- and second-lines of care. The project approach ignores frontiers (Segrestin, 2004) between professions, hierarchic levels, or sometimes even between structures. By also including non-medical stakeholders, the pilot project consortia even extended to the community, the involvement of which is crucial for the development of integrated care according to the scientific literature (Amelung et al., 2017). In this way, they began the development of what could become (and what the researcher would call) collaborative community health networks or collaborative community health microcosms in the future. As proof of this, the elements shown in Figure 9 below characterise both integrated care pilot projects and community health care (Prévot, 2016).



**Figure 9 – Community Health Characteristics** 

Accordingly, as an answer to her guiding question, the researcher argues that the pilot project appears to be an instrument of the interactionist and processual rationales that support the development of a specific form of organisation, i.e., collaborative networks (Powell, 1990; Schweyer et al., 2002), in this specific case of community-based integrated care networks (Plochg & Klazinga, 2002). As a result, "the project has not only the purpose of designing and implementing [political] objectives (...), it has also the vocation of asserting action identities, stabilising groups of actors united by the sharing of the same objectives" (Pinson, 2005, p. 201).

In this way, it creates conditions over the interactions that are conducive to the emergence of a system, i.e., an autonomous collective actor fitted with a collective and cohesive action capacity (Lascoumes & Le Galès, 2005). In the three projects which the researcher has focused on, these collective actors, i.e., the nascent networks, take the form of a *de facto* association in one case and of two independent "ASBLs" in the other case. Each of these three entities has a real autonomous existence, a name, and specific governance modalities decided by the project members themselves.

#### 4.2. Collaboration as a Means, Collaboration as an End to Integrating Care

In this endeavour of implementing integrated care in Belgium, collaboration appears to be both a means and an end—a means to exchange ideas, learn from each other, and imagine collectively how to implement integrated care in Belgium, and an end as a major component of integrated care. More specifically, the researcher argues that the transition into practice during the execution phase does not involve the same collaboration modalities as during the preparation and the conceptualisation phases. Indeed, as Segrestin puts it, "a project is divided into distinct phases, and each phase requires different forms of action, cooperation, and technical formalisation" (Segrestin, 2004, p. 242).

During these two first phases, the researcher argues that the partners entered a process of creative "cogitating collaboration", resulting in the production of discourses that pertained to "what should be done" on the ground during the next phase. It took the form of face-to-face deliberative interactions during meetings; stakeholders brainstormed on the basis of their respective knowledge of the field, explored hypotheses, and finally made decisions after having reached consensus regarding their common purposes (Schweyer et al., 2002; Segrestin, 2004). They formalised the results of their discussions in their loco-regional action plan, which can be viewed as an artefact of their collegial appropriation of the integrated care policy initiated by the authorities. Cogitating collaboration (see empirical example at point 3.4), inherent in the project approach, was necessary to the network emergence. It was the way through which the partners built their common project, crystallising the network's reason for existence, and planned the innovative actions they intended to achieve in real-world situations during the execution phase.

The collaboration, viewed as an end in itself, refers to the "operational collaboration" on the ground to deliver quality care, which is one of the core elements of integrated care, and as a result, one of the aims pursued. It requires moving from discourse to practice, from the

collective designing process to the collective experiment on the ground, and from the "what are we going to do?" to the "let's try it". Even if the cogitating collaboration seems to be a prerequisite to develop operational collaboration on the ground, the latter is not necessarily its corollary. As a result, translating the "loco-regional action plan" into practice constitutes a central issue at this stage of the process and should not be taken for granted. Nevertheless, a lesson that can be learned from this case study is that "the process and the elaboration method are as important as the plan (...) to which they lead" (Pinson, 2005, p. 205). In other words, the *modus operandi* is as important as the desired outcome (Lascoumes & Le Galès, 2005).

#### 5. Conclusions

In this paper, the researcher has focused on the use of pilot projects and analysed how they specifically structure collaborative work in the Belgian health sector. Thanks to this case study, she has shown that "the project serves both to constitute sustainable systems of actors, as well as to build and implement decisions" (Lascoumes & Le Galès, 2005, p. 217). The researcher has stressed that pilot projects are instruments that create the conditions enabling the emergence of care networks, and more specifically, of what she calls community-based integrated care networks. In this way, she links a specific type of instrument, i.e., the pilot project, to a specific form of organisation, i.e., the network. One should be careful, though, not to consider this link as a systematic cause and effect relationship. Using pilot projects will probably not always lead to the emergence of networks; this depends on the context in which they are used and on the way they are used.

This study has also shown that becoming a group, a cohesive community, or a network that is aware of its existence, is a task in itself, a time-consuming one not to be neglected, and a first step before collaborating on the ground. Indeed, enhancing quality of care is more than collaboratively achieving a task in the field. It requires, first of all, taming each other in order to develop inter-professional mutual learning, so as to define and agree on what has to be done together, and on the role of each other in this endeavour (Schweyer et al., 2002). The preparation and conceptualisation phases were dedicated to this process of defining the pilot projects' essence and designing what should be done in the field, which took more time than expected.

The partners of the selected pilot project were able to work together in their respective consortium to build a project and plan actions to meet the objectives they jointly defined during the preparation and the conceptualisation phases. At this stage, two important questions can be raised. First, will they be able to move into practice and concretely implement their loco-

regional action plans during the execution phase? In other words, will they be able to entrench their nascent integrated care networks and collaborate on the ground in a therapeutic context to experiment collectively with the innovative actions they imagined together? This translation into practice will surely raise unexpected questions of practical feasibility, which the partners did not anticipate before, and which will probably require adjustments (Segrestin, 2004) or possibly new explorations (Freeman, 2009). Second, will the pilot project members be able to elicit the interest and the involvement of the field actors who did not participate in the preparation and conceptualisation phases? Behind this question hides the issue of enrolling hands-on professionals who work in the pilot zone and whose role is relevant to, or even sometimes crucial for, the implementation and the survival of the project during its operationalisation.

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## **Chapter 5**

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Considering Patients' Empowerment in Chronic Care Management: A Cross-Level Approach





## Article Considering Patients' Empowerment in Chronic Care Management: A Cross-Level Approach

Caroline Tilkin <sup>1,\*</sup>, Mélanie De Winter <sup>2</sup>, Frédéric Ketterer <sup>3</sup>, Anne-Marie Etienne <sup>1</sup>, Marc Vanmeerbeek <sup>3</sup> and Frédéric Schoenaers <sup>2</sup>

- <sup>1</sup> Health and Society Interfaculty Unit, University of Liège, 4000 Liège, Belgium; am.etienne@uliege.be
- <sup>2</sup> Social Sciences Research Institute, University of Liège, 4000 Liège, Belgium; mdewinter@uliege.be (M.D.W.); f.schoenaers@uliege.be (F.S.)
- <sup>3</sup> Primary Care & Health Research Unit, University of Liège, 4000 Liège, Belgium; frederic.ketterer@yahoo.fr (F.K.); marc.vanmeerbeek@uliege.be (M.V.)
- \* Correspondence: ctilkin@uliege.be

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### Abstract

This paper consists of an analysis of the concept of empowerment—which is often defined as a key issue in health care—at the macro, meso, and micro levels by focusing on health care reform in Belgium. Three research teams collected data and combined them in an inductive secondary analysis. Our preliminary results demonstrate that patient empowerment does not always encompass the same scientific reality. At the macro level, this concept is linked to the authorities' wish to support at-home care for chronic patients. At the meso level, the role of caregivers in maintaining patients' autonomy, but also the social conditions of their lives, is a salient component of empowerment. At the micro level, individual and personal features such as identity can influence patient empowerment and behavior in the health care system. This cross-level research suggests that patient empowerment is not sufficiently clearly defined at each level of the care production chain, which could impede the reform of health care. This paper underlines the polysemy of a concept viewed as a milestone in European health care policy and the necessity of a clear, collective definition to operationalize and implement it.

Keywords: Empowerment; patient; integrated care; cross-level analysis

#### **1. Introduction**

The ongoing increase in chronic illness poses new challenges for European countries. In Belgium, more than one in four people aged 15 and over have at least one chronic condition (European Union Policy Forum, 2012). According to the literature, this situation has led to an increase in health care expenditures (Ording & Sørensen, 2013; Paulus et al., 2012; Schokkaert & Van de Voorde, 2011). In this context, the Belgian Government has decided to initiate a health care reform through the launch of a joint plan called "Integrated Care for Better Health" (IC4BH) (Belgian Ministry of Social Affairs and Public Health, 2015). The authorities have chosen to implement this joint plan through an iterative, incremental process, by launching multidisciplinary local pilot projects involving a variety of local partners (hospitals, medical health centers, general practitioners, ambulatory home care nursing clinics, representatives of patients and informal caregivers, etc.).

One of the main goals of this plan is to shift from a fragmented system to an integrated and more competitive one. The World Health Organization (WHO) refers to care integration as "the organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results, and provide value for money" (WHO, 2008, p. 1). Dealing with the problem of chronic diseases necessitates this kind of paradigm change. With this aim in mind, the plan (IC4BH) was structured into 20 central components, including patient empowerment (Belgian Ministry of Social Affairs and Public Health, 2015).

According to Aujoulat et al. (2007), the concept of empowerment is rooted in an ideology that emerged in social work during the 1960s. At that time, the focus was on individuals' and communities' rights and competences more than their needs and shortfalls. At the end of the 1970s, the term empowerment was widely used in domains as varied as social services, public health, community development, etc. (Calvès, 2009). In the specific domain of health, the WHO's Ottawa Charter for Health Promotion in 1986 made empowerment a cornerstone of health promotion; it promoted a positive definition of health that is not limited to the prevention of health issues, but rather stresses social circumstances and their improvement (Aujoulat et al., 2007). In this context, health promotion was seen as "the process of enabling people to increase control over, and to improve, their health" (WHO. Regional Office for Europe, 1986, p. 1). Nowadays, empowerment is often considered to be an "umbrella term", meaning that many interpretations of this concept exist. It can be defined simultaneously as a process, an education strategy, or even an outcome (Aujoulat et al., 2007). Other terms are sometimes used in place of *empowerment* such as *patient participation* or *patient-centered care*, which can lead to a lack of clarity for researchers, patients, health care providers, and policy makers (Funnell, 2016). However, the crux of this concept is the idea of helping patients to become more responsible for their own health, by giving individuals and community groups more power over the definition and nature of changes affecting them (Rappaport, 1987). Indeed, according to many experts, "chronic diseases are managed most effectively when patients take an active role in this themselves" (Amelung et al., 2017, p. 386). Empowerment can be considered a health-enhancing process, which led us to raise some questions about the different meanings concealed behind the term *empowerment* in the context of the Belgian care management chain (Amelung et al., 2017; Aujoulat et al., 2007).

The goal of this study was to investigate with an inductive perspective how the concept of empowerment is viewed at each level of the Belgian health care production chain by the different stakeholders involved or concerned by the reform (political, institutional, caregivers, patients). This multifaceted concept can have a lot of different meanings, as shown above. In addition, in the Belgian reform, patient empowerment is defined as an ongoing process in the course of care of the patient and his or her caregiver (Belgian Ministry of Social Affairs and Public Health, 2015). What are the consequences of such an elusive concept when different health care stakeholders have to work together? Our purpose here was to try to highlight this issue in the context of integrated care. Indeed, the scientific literature stresses the need for a greater understanding of the concept of empowerment to guide clinical care, research, and health systems to create powerful interventions and policies (Anderson & Funnell, 2010). Consequently, we decided to undertake an inductive analysis of empowerment, starting from empirical conceptions expressed by the stakeholders involved in the chronic care reform, at the different levels of the health care production chain.

#### 2. Materials and Methods

To answer this research question, three research teams, coming from three different schools (social sciences, medicine, and psychology), decided to combine the results of their respective studies to produce a new inductive analysis. Therefore, this article presents a secondary analysis of data that aims to explain how the concept of empowerment is expressed at different levels.

Each research team worked on a specific level of the care production chain, identified as the macro, meso, and micro levels. The macro level considers political and organizational aspects. The meso and micro levels take therapeutic aspects into account, from the perspective of health practitioners, informal caregivers, and sick people (meso level) to that of patients (micro level). In the context of health care, we have to consider that these three levels are embedded (Granovetter, 1985). Consequently, they are interdependent in our analysis. A more exhaustive presentation of the aim of each study was presented in 2018 at the International Conference on Integrated Care and is summarized in Table 10 (Tilkin et al., 2018).

School and Level	Research Question/Aim of the Study	Perspective on Empowerment	Data Collection
Social Sciences	Focus on political and organizational governance through the prism of managerial innovation to grasp the whys and wherefores of the ongoing paradigm shift intended to implement integrated care in Belgium.	1. Definition in the plan	Thematic literature review Operational document analysis Qualitative interviews with policy advisors and
Macro Level	Analysis of the reform design process and the national and international context in which it took place; the rationale for reform; and the specific way the reform was implemented through bottom-up pilot projects.	2. Vision circulated by the authorities	circulated by public officials involved in devising and implementing the new policy, pilot project coordinators, and pilot project stakeholders
Medicine Meso Level	To better grasp the different implications of situations related to chronic illness as experienced by patients and their family caregivers; in particular, acceptance of the social status of chronically ill people, which conditions the place and role of family caregivers, and the manner in which informal and professional caregivers work together.	Perspective of multimorbid patients in relation to professionals and informal caregivers	Qualitative interviews with "triads" (one patient, one of his/her health professionals, and one of his/her informal caregivers) 23 interviews were conducted and analyzed
Psychology Micro Level	To better understand how having a chronic illness changes chronic patients' self-representation and to study the risks and protective factors that impact self-representation in patients with different chronic conditions such as cancer, multiple sclerosis, chronic obstructive pulmonary disease, and diabetes.	Perspective of patients stemming from their personal experiences related to their health	Mixed-method study design with qualitative exploratory interviews and scoping research (questionnaires).

#### 3. Results

This study was an initial step in integrating a cross-level perspective on empowerment. Our results highlight the inherent complexity of the concept through the point of view of the various stakeholders involved, the levels of analysis (macro, meso, and micro), and the conditions on the ground.

#### 3.1. Macro Level

The results of our qualitative analyses show that empowerment is a major component of the Belgian joint plan and entails a major shift in terms of professional practice. Historically, the

Belgian health care system developed in response to the challenges posed by acute diseases. Progressively, the system became increasingly specialized and fragmented. As a result, the predominance of chronic diseases led to the emergence of a paradoxical situation: in its current state, the Belgian health care system does not meet chronic patients' needs. The high degree of specialization and the lack of cooperation between practitioners that characterize the current system impede the delivery of care adapted to chronic patients' specific characteristics (Belgian Ministry of Social Affairs and Public Health, 2015). By definition, those patients are not expected to be cured; instead, they must deal with their condition in the long run (see Amelung et al., 2017). In their case, the issue is not to cure them quickly, but rather to help them live with their chronic disease(s) at home over the long term, which raises questions of social integration.

In the IC4BH plan, patient empowerment is mainly defined as providing support and information for chronic patients, who are expected to play a more active role in their own care, and is also viewed as necessary to reduce hospital stays and costs. This principle is supposed to help create a new type of therapeutic relationship that is more patient-centered. In this therapeutic configuration, patients'empowerment appears to be important, which explains why it was identified as major component of IC4BH. Chronic patients do need to be able to deal with their conditions and care for themselves on a daily basis, even if they are not in hospital or if no health care professional is there to assist them.

"And what happens if the patient can't be empowered?" (Home care worker, Field observation notes, 2017). On the basis of their professional experience, many pilot project stakeholders argued that certain patients do not have the ability or the wish to be empowered, and that trying to empower some types of patients can be counterproductive. This shows that, although empowerment is defined as a key issue in the plan, it is often addressed differently by the different pilot project stakeholders, which can lead to misunderstandings. For instance, empowerment does not imply the same concrete professional practice on the ground for a general practitioner (GP) as it does for a health insurance provider. Accordingly, the solutions proposed by each party to foster empowerment generally differ, and will not automatically lead to shorter hospital stays and lower costs. They might even have an opposite effect and increase health care expenditures.

Behind the concept of empowerment lies the idea of making patients autonomous, of giving them an active role in their own care process so that they can achieve their goals and live as normally as possible, as illustrated in these interview extracts: "It [the patient's care trajectory] is not predetermined, because patients who have the same medical status can have different ambitions: staying independent and being able to keep traveling or to look after their kids or ... The starting point is what the patient wants ... and is able to do, obviously. [...] The part about empowerment can also motivate them to seek treatment or look for what could motivate them to seek treatment". (High-ranking public official, 2017)

"Forcing the patient to do something which does not correspond to what he/she wants would risk not being effective and, as a result, [would lead to] compliance problems regarding the treatment and unnecessary waste". (High-ranking public official, 2017)

For health care professionals, the challenge here is to move from a diseased-centered approach to a patient-centered approach, and consider patients as people whose identity cannot be reduced to their health condition. These elements denote an individual-centered vision of the concept of empowerment, given that they pertain to what patients want as individuals.

#### 3.2. Meso Level

The triad analysis that was performed among health professionals, sick persons, and family caregivers revealed the limits of the approach taken by the plan for integrated chronic care. First, the sick persons coped in various ways with their health problems and multiple chronic conditions. Some of them had accepted their status as chronically ill people, and had adapted their behaviour and lifestyle according to the medical recommendations, while others had not. Since some found it difficult to consider themselves as chronically ill, they were not very invested in the normative expectations concerning them. Their varying acceptance of their status as chronically ill people was linked to the impacts of their diseases on their daily lives: in general, the smaller the practical impact, the less concerned the sick person was (Ketterer & Vanmeerbeek, 2017). This first observation demonstrates a potential limitation of empowerment: patients who do not recognize their chronically ill status appear to be less likely to modify their behavior and life habits in accordance with medical guidelines or family recommendations. This idea is illustrated in the following two quotations:

"Even after suffering from his embolism and myocardial infarction, there was no awareness of its severity or ... Eating was his only ... his only pleasure. Therefore, psychologically speaking ... even involving psychologists ... other providers ... Well, he's not a manageable person". (GP about his 60-year-old patient) "I'll take my coffee, a cup of coffee; I won't drink it without sugar. If I have to add sweetener, I find it doesn't taste the same. Well, in the evening, I'll take the sweetener if my children are there. That's really a small detail, isn't it?" (70-year-old woman with diabetes and hypertension)

The differences in the subjective appropriation of chronically ill status can also be seen in the way these people coped with the health system. Some patients adapted their behavior and the information they delivered to the health professionals depending on their own interest in and acceptance of their status. This was generally ignored by the health professionals, as well as by some family caregivers, especially if the latter were not living in the same household as the sick persons. This raises the question of which strategy should be prioritized in empowerment: not being reduced to the status of a chronically ill person, as some patients wanted, and thus engaging in behaviors with other objectives than health management, or empowerment in accordance with medical requirements, which may be inconsistent with the sick person's own objectives.

The following two examples show the possible gap between medical requirements and how patients view their health:

"I agree to make all the efforts required, but ... but not to sit all day long while waiting for the day to end. To be allowed to do something, to have little pleasures and eat this or do that and ... Except for walking, she (the diabetologist) doesn't allow me to do anything, you see ... [...] It's too much, you know. No, I can't!" (70-year-old woman with diabetes and hypertension)

"At this time, we had Glucophage [metformin]. Because I was a sales representative, I was annoyed. It gave me gas, and as I was frequently ... I stopped taking this drug. So, each time there was a blood test, they said: "But did you take it ...?" "Yes, yes, no problem!" So they increased the amount to take. And I didn't take it." (60-year-old man with diabetes)

In addition to patients' willingness or unwillingness to comply with their chronically ill status, some external factors may impede the empowerment promoted in the plan for chronic care. The social environment and issues related to people's life experiences need to be considered. The lives of some of the sick persons interviewed had been marked by serious psychosocial events: financial difficulties, social isolation, or a history of psychiatric disorders. These factors were

well known to the GPs, who mentioned them as additional obstacles for chronic condition management.

The sick people's presumed intellectual or understanding level was also mentioned as a possible barrier, which could lead GPs to reduce their patients' accountability, for example for self-measurement device use (blood pressure, blood glucose, etc.).

"Obviously, there are some people I will never give this kind of tool to! Because ... well, because they don't have the brains to cope with it. Clearly. It is ... it requires a little judgment to understand and think about". (50-year-old GP)

These health professionals' strategies based on the patients' social environment reflected the (supposed) reduced relevance of empowerment for some patients.

Finally, empowerment also came up against the working habits and regulatory framework characterizing medical practice. All of the family caregivers interviewed reported inadequate consideration by some health professionals. They particularly singled out hospital specialists, who provided scant information or paid little attention to the impact of diseases on sick people's daily lives—an aspect that was mainly managed by the family caregivers. The lack of consideration was all the more problematic, given that family caregivers were frequently essential for the sick persons' home care. The patient-centered approach promoted by health professionals, which they considered as the most relevant, could reduce empowerment to its individual dimension, neglecting the role of family caregivers. Other situations demonstrated that family caregivers exerted social control on sick persons' behavior, as an extension of the health professionals' role. The caregivers acted as regulators, ensuring that patients complied with the medical requirements for their disease. Again, empowerment was inappropriate) and adapting their behavior, as required by health professionals and echoed by the family caregivers who supported patients in their daily life activities.

#### 3.3. Micro Level

An exploratory qualitative workshop was conducted with five chronic patients who were cancer survivors: four women and one man with different types of cancer (mean age = 44.2 years). The participants were recruited through a former patients' association. The content of the workshop was analyzed thematically with the Montreal model in mind (Pomey et al., 2015). It highlighted the fact that various different self-representations can emerge from former patients

after an illness. Since identity after illness can be related to empowerment and patient participation, we were interested to see how chronic patients identified characteristics related to their specific identity after illness, defined those characteristics, and articulated them in the context of their health. The procedure for this workshop with chronic patients and the results are presented below.

The first step was to consider the terms that chronic patients used to define their illness experiences and their current self-perceptions. These terms and the related detailed features were determined in association with patients' personal knowledge of their illness (mostly cancer) and the health care system. Workshop participants compiled these features into major categories: global themes emerged and were formed thanks to this first step. As a first result, these categories were broadly related to a new time frame (e.g., illness as an endless process), a new sense of belonging and community (e.g., cancer as a specific experience), and new individual, social, and medical representations (e.g., weakness, stigma, data). Some of the themes were more important for some patients and less for others, but all patients were able to agree on a final selection of themes and features.

"We have to be flexible. While we have already gone through the disease, we have already experienced the disease in our body, then we have to get used to this new "me", to this new body, to all these limits, but at the same time, we have to adapt to people's new behaviors, to how people perceive us, to those changing attitudes, and all those changes around us ... [...] And I would say that adapting to oneself is not the most complicated thing; it's mostly adapting to others". (48-year-old woman, breast cancer survivor)

As a second result, we found that self-representations were not always relevant to understanding empowerment for these patients. Indeed, patient empowerment was never a central category when chronic patients had to define themselves after illness. Thus, each main theme was related to terms or ideas that referred to patient empowerment, engagement, or participation. Patient empowerment was not the door to a new definition of the self; instead, it appeared in subtler ways in terms of patient advocacy, resiliency, changes, and turning points.

A third finding was that patient empowerment emerged differently depending on the life domain (personal, social, or medical). One patient emphasized that the medical discourse did not always allow him to play an active role in his follow-up. However, he could embody this feeling of being actively engaged with his health in his personal and social life, as was shown in some of the self-perceptions he described. To illustrate this observation, we present some extracts from our interviews:

"I had the feeling of being considered as a medical statistic".

"I don't want to be seen as a victim by other people, or someone who always complains about his situation. I can take care of myself". (59-year-old man, head and neck cancer survivor)

This extract also reveals the patient's expectations about how he wants to be seen by significant others and by medical staff. More specifically, medical representations were associated with the style of communication used by physicians, a lack of information, and how patients or survivors are considered. Social perceptions were defined in a similar way to medical perceptions and tended to imply risk, weakness, complaints, loneliness, and inconvenience. All these representations contrasted with the way patients defined themselves: *"meaningful"*, *"resilient"*, *"coping"*, *"desire to live"*. These observations demonstrated that the way that identity is impacted after illness is very subjective, and varies depending on the domain. Patient empowerment or participation can be a way to explain these changes, but sometimes guilt and vulnerability prevail in how former patients see themselves.

Finally, all these elements helped us to formulate new questions about self-representations after illness and how the experience of illness can empower a patient's identity. However, this study also emphasizes the central ambivalence of the process, which is an ambivalence that was shored up by social and health care perceptions. According to chronic patients, the experience of illness can develop resiliency and empowerment. It can also lead to a "new kind of living", but it is still seen as a weakness by other people and especially by health practitioners, which does not necessarily lead to patient empowerment.

#### 4. Discussion

The aim of this article was to compare—by following an inductive approach—different levels of analysis (macro, meso, and micro levels) and different points of view on patient empowerment in the context of the Belgian health care system. We wanted to understand how the same concept was applied at each level, compare our results with this perspective in mind, and finally see what would emerge from this comparison. We have summarized all our results in Table 11 in order to provide a quick overview of the work, which will be discussed below.

	Meaning	Expectations	Reality
Macro Level	Definition of the joint plan	Shorter hospital stays Cost reductions	Misunderstandings between stakeholders
Meso Level	Patient-centered care	Support autonomy Maintain social situation	Collective meaning vs. individual meaning
Micro Level	Patient participation: being active and sharing decision making	Foster patients' involvement Hear patients' voices and rights	Disruptions in terms of representations and roles

#### Table 11 – Overview of Results

Regarding meanings, we have already indicated that multiple definitions of empowerment exist, and that the concept is generally used as an "umbrella term" in the scientific literature and in operational documents, as it is also the case in the joint plan defining the Belgian health care reform. Our results reflect the complexity of the concept and show that patient empowerment encompasses a wide range of meanings. A recent literature review has clearly summarized this complexity:

Patient empowerment is a very complex and paradoxical concept: it is situated at several levels (macro, meso, micro), can be approached on several perspectives (the patient, the health care provider, or the health care system) that lead to different interpretations (a theory, a process, an intervention, an outcome, a feeling, or a paradigm) and surfaces in several areas (e.g., (mental) health and welfare) and disciplines (psychology, sociology, nursing, social work). Different definitions, each with a different emphasis, are consequently in use. (Castro et al., 2016, p. 1925)

More specifically, at the macro level, the meaning of patient empowerment was determined by the IC4BH plan. This definition tends to focus on different aspects of patient empowerment, which is understood as an individual issue. Therefore, this plan also offers meanings at the micro level, but fails to provide a meso point of view.

A trend to reduce empowerment to the single dimension of individual capacity is reported in the literature regarding changes in the concept as used in public policies. According to Calvès (2009), although, in its initial acceptance, empowerment was a complex, multidimensional concept that placed the emphasis on the individual and collective dimensions of power, the use of the term in the discourse on development was accompanied by an individualization of the notion of power, which was regarded as individual and economic choices (Calvès, 2009). According to the most judgmental view, "liberator empowerment" has become "liberal empowerment", which is more focused on maximizing individual interests (Bacqué & Biewener, 2015; Sardenberg, 2009).

As for expectations related to patient empowerment, we also found contradictory points of view between each level. At the macro level, the economic argument was central in the debate between stakeholders. As a major component of the joint plan, the implementation of empowerment should lead to reduced health care costs and hospital stays. At the meso level, analyzing interactions in triads of physicians, caregivers, and patients reveals that empowerment did not correspond to the authorities' expectations or to the expectations of patients and their caregivers, who view empowerment according to their own interests and strategies. As an individual issue, patient empowerment does not take all parties into account. At the micro level, expectations concerning patient empowerment should lead to patients' participation and engagement. However, role reorganization did not always allow this change in patient involvement.

Finally, regarding real conditions on the ground, there is a gap between the normative definition of empowerment and the way that this concept is understood by actors in the field. They can either use political, professional, or experiential definition depending on the area of expertise to which they belong. The assumption that a scientific definition could be implemented in a similar way in various health fields could not be demonstrated by our analysis on the ground.

#### **5.** Conclusions

The contrast between meanings, and then expectations, and the implementation of patient empowerment in the field is striking. The polysemy of this concept has made the implementation of patient empowerment more complex. However, the observations collected with our multiple methodologies did not reveal any contradictions with the term "patient empowerment" defined in IC4BH.

This initial definition of empowerment is connected with the idea that each patient can take responsibility for his/her life and health. However, more specifically, our results showed that empowered patients can decide what they want for their life, which also means that they can decide whether to be treated or not, whether to be hospitalized or not, and whether to be active or not (Aujoulat, 2007). Consequently, being empowered does not necessarily imply making a decision about health that is related to the guidelines imposed by a plan or by health practitioners. This vision is also coherent with the observation that some patients cannot appropriate an identity that will lead to empowerment or resiliency in the context of their illness.

Applying a global concept of patient empowerment does not make sense when working at different levels. Moreover, the advantage of the concept of empowerment is that it can have

different uses depending on the type of stakeholder. Clear definitions of these terms are essential in order to make them effective and relevant; without them, there's a risk that empowerment will remain a vague and empty objective that cannot be implemented in the field (Bebbington et al., 2007; Oxaal & Baden, 1997).

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# **Chapter 6**

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Additional Empirical Elements: The Execution Phase As stated in the introduction, this empirical chapter is not a paper. It is dedicated to the presentation of additional empirical elements that could not have been developed in any of the four former papers due to the respective words limits set by the different journals. These additional empirical elements are nevertheless necessary to understand the analytical reasoning presented in Chapter 7, i.e., the discussion.

In January 2018, the selected pilot projects entered the execution phase, during which they were expected to implement the actions of their respective loco-regional action plans, i.e., 65 actions for Project A and 56 actions for Project B. Importantly, each action will not be presented in detail in this manuscript in order to respect as much as possible the anonymity of the projects studied. However, it seems important to specify that these actions did not all concern the therapeutic level, as illustrated below<sup>26</sup>. For example, several actions concerned communication and governance aspects (e.g., ASBL creation).

That being said, one can notice that events did not happen exactly as planned. This chapter is dedicated to the description of the course of events as they occurred between January 2018 and April 2020, i.e., the first half of the execution phase.

#### 1. Governance Aspects

Pilot projects were expected to implement their actions and begin the inclusions of patients as quickly as possible. The authorities even asked them to focus on the launch of "quick win actions", i.e., actions that could be quickly implemented and that had the potential of rapidly producing what they called "efficiency gains". Nevertheless, for projects A and B, as with the majority of other projects, the priority was to work on their governance to clarify the work organisation between their numerous partners. To give an order of magnitude, both projects A and B consortia were each composed of 60 partners at the beginning of the execution phase, some partners being involved in both projects. As a result, they started the process for creating their ASBL<sup>27</sup>, which would prove to be a long-term endeavour. Indeed, this process required the setting-up of working groups to brainstorm and make decisions, as well as a great deal of

<sup>&</sup>lt;sup>26</sup> See also p. 143

<sup>&</sup>lt;sup>27</sup> An ASBL (Association sans but lucratif in French), i.e., "a non-profit association, is a group of natural or legal persons who pursue a disinterested goal. The ASBL consists of at least two persons. The members of an association may not receive any financial benefit from the association". (<u>https://justice.belgium.be/fr/themes\_et\_dossiers/societes\_associations\_et\_fondations/associations/asbl#:~:text=Une%20association%20sans%20but%20lucratif,qui%20poursuivent%20un%20but%20d%C3%A9sint%C3%A9 ress%C3%A9s, accessed 24 November 2020)</u>

administrative work. As an indicator, the Project A ASBL was formally set up in June 2018 and the Project B ASBL was formally set up in April 2018.

The concrete structure chosen by both projects A and B for their respective ASBL was inspired by the informal governance structure adopted during the conceptualisation phase, and described in Chapter 4<sup>28</sup>. Both ASBLs were comprised of different bodies, each of which had a specific meeting frequency, as show in Table 12.

Bodies	Meeting frequency		
	Project A	Project B	
The General Assembly	At least once a year		
The Executive Board	Four times a year	Once a month	
Body corresponding to			
the former "project	Once a month		
group"			
Working groups each	For each working group, the frequency of meetings was variable,		
corresponding to a	depending on the progress of the action and of its degree of		
specific action and in	priority.		
charge of implementing			
this action.			

 Table 12 – Meeting Frequencies of the ASBLs' Bodies

Importantly, once the ASBLs had been created, the work was not finished as managing an ASBL requires constant work (decision-making, modification of the way of functioning, etc.). As a reminder, attending the meetings of the above-mentioned various bodies and working for their respective pilot project was not part of the partners' main professional activity, meaning that they were not able to work full-time for their project. People who viewed themselves as able to involve a lot devoted 2 to 8 hours per month to their pilot project, and more often 2 than 8. The others were sometimes just able to attend the General Assembly.

## 2. Budgetary Aspects

In parallel, it was also crucial to receive the promised lump sum fund of €150,000 intended to finance the "integration management" and which pilot project consortia were supposed to receive each year. In the Royal Decree of 31 July 2017 laying down the conditions by which the Insurance Committee of the NIHDI may conclude covenants for the funding of pilot integrated care projects, the integration management was defined as "the operational steering

<sup>&</sup>lt;sup>28</sup> See p. 94

within a pilot project aimed at integrating care at the levels of individual care services, professional offer, organization within the network and support systems" (p.80399). Concretely, as written in the guidance leaflet, this lump sum was intended to finance the full-time coordinator's salary and the operating costs (which is why it was so crucial to receive it quickly), but not the different actions designed by the consortia and listed in their loco-regional action plans. The latter were supposed to be financed via the budgetary guarantee.

The budgetary guarantee corresponded to the efficiency gains, which pilot project consortia were expected to realise thanks to their actions. As a reminder, pilot projects were asked to design and implement actions that would help reduce health care expenditure as part of the Triple aim philosophy. The savings they would have helped generate would be referred to as efficiency gains, and would be redistributed to them at the end of each year, in a form of a budgetary envelope called the budgetary guarantee. It was not foreseen that pilot projects would have any budgetary guarantee at their disposal during the first year of their execution phase. On the other hand, they had the constraint of launching their actions as soon as possible to generate savings.

During the conceptualisation phase, pilot projects regularly asked for an initial public investment in order to finance their actions as from the beginning of the start-up year, a request which was never accepted by the authorities. Instead, the latter encouraged the pilot projects to mobilise existing resources and to look for alternative sources of funding, *inter alia*, in the not-for-profit sector, which pilot project stakeholders did not expect. Few projects mobilised that kind of prefunding. Instead, several projects (including projects A and B) decided to begin by implementing actions that would not require additional resources and to wait for the payment of the first efficiency gains pertaining to the year 2017.

#### 3. Covenant and Annexes

At the beginning of January 2018, the pilot projects selected for the execution phase had to sign a covenant with the Insurance Committee of the NIHDI, which was the legal prerequisite to obtain their start-up budget, the first integration management funding of  $\in 150,000$  ( $\in 150,520$ after indexation). The deadline for the signature of the covenant, the content of which was the same for every project, was set at  $31^{st}$  January 2018. In addition, pilot projects stakeholders were very surprised to learn that the integration management budget would be paid in three instalments, an element that had never been mentioned in these terms before. After the signing of the covenant, the first instalment of the integration management funding amounting to €52,520 was supposed to be paid out around 15<sup>th</sup> February 2018. The consortia were also asked to fill in seven annexes to the covenant in which they each had to develop the specific elements pertaining to their project. These documents should be submitted for approval to the Permanent Working Group of the Insurance Committee of the NIHDI. The latter was in charge of monitoring the conventions established between the pilot projects and the Insurance Committee. The different annexes 'topics are shown in Table 13:

#### Table 13 – Topics of the Seven Annexes to the Covenant

	First annex: project administrative data		
Content	The following different elements had to be included in this annex: name of the		
	project, contact details, name of the contracting party, name of the project		
	coordinator, identification of the geographical zone covered by the project and		
	description of the consortium composition.		
	Second annex: project loco-regional action plan (Gantt Chart)		
Content	This part had to contain the Gantt Chart that the project wrote in its loco-		
	regional action plan during the conceptualisation phase.		
Third anr	nex: the recommendations made to the project after the evaluation of the		
	application file		
Content	The project had to provide the list of recommendations received from the jury		
	that evaluated their application files.		
Fourth a	nnex: concrete description of the administrative and operational target		
gı	groups as well as of the ways and means of beneficiaries' inclusion		
Content	In their loco-regional action plan, pilot projects had to define two types of		
	target groups: the administrative target group and the operational target group.		
	The administrative target group had to be comprised of "all beneficiaries		
	having their domicile in the project area pilot and which meet the measurable		
	characteristics defined by the project. [] Unless a pilot project [chose] to		
	include the entire population in the target group, it [had to] be (groups of)		
	beneficiaries with different chronic conditions, with no age limit, with		
	possible comorbidity or polypathology or period of care" <sup>29</sup> . This group would		
	be the base for financial monitoring at the level of the federal authority, <i>inter</i>		
	alia for calculating efficiency gains.		
	The <b>operational target group</b> corresponds to the group of beneficiaries for		
	which all the actors within a project have concluded agreements and are		
	committed to the integrated management of this target group in order to		
	achieve the objectives set out in the IC4BH plan. "The operational target group		

<sup>&</sup>lt;sup>29</sup> Royal decree of 31 July 2017 laying down the conditions to which the Insurance Committee

of the National Institute for Health and Disability Insurance may conclude covenants for the funding of pilot integrated care projects, p. 80398.

	must respectively represent, during the first, second, third and fourth 12-month	
	period, 1%, 3%, 6% and 10% of the total population in the [pilot project]	
	geographic area <sup>30</sup> .	
	geographic area .	
	Eventually, the category of included beneficiaries refers to beneficiaries	
	within the operational target group who have been individually informed	
	regarding the methods of care in the context of integrated care and with which	
	concrete agreements, resulting from the development of the components of	
	integrated care, are concluded. Beneficiaries can have their domicile outside	
	the project area. In this fourth annex, pilot project consortia had to describe	
	how they intended to proceed to include beneficiaries.	
Fi	Fifth annex: Concrete description of the integration management	
Content	In this part, pilot project consortia had to describe the composition of their	
	integration management team, what would be its role as well as how they	
	would concretely implement integration management and make it work.	
	Sixth annex: List of alternative provisions and services	
Content	Pilot projects had to describe the new alternative care services they intended	
	to create, and explain if these would involve additional costs for patients	
	and/or additional costs that might be borne by the project itself. It was	
	explicitly forbidden to finance those alternative care services from the	
	integration management budget.	
Se	Seventh annex: Concrete description of the use of efficiency gains	
Content	Pilot project consortia were asked to describe concretely how and for which	
	actions of their loco-regional action plan they would wish to use their future	
	efficiency gains, without even knowing if they would have efficiency gains	
	or, if so, to how much they would amount.	

The approval of these annexes by the Insurance Committee of the NIHDI was a precondition to the payment of the future efficiency gains, the payment of the first efficiency gains pertaining to the year 2017 being planned for October 2018. As a result, the authorities encouraged the projects to deliver the annexes as soon as possible and set the deadline at 31<sup>st</sup> March 2018. This meant that pilot project consortia were asked to sign the covenant without knowing the exact future content of the annexes. This point became a major cause of concern and caused considerable debates within pilot projects consortia. It even led a pilot project stakeholder to say: *"in other words, they [the authorities] ask us to sign a blank check"* (Field notes of observation, January 2018). The lack of trust was so prevalent that none of the pilot project

<sup>&</sup>lt;sup>30</sup> Royal decree of 31 July 2017 laying down the conditions to which the Insurance Committee

of the National Institute for Health and Disability Insurance may conclude covenants for the funding of pilot integrated care projects, p. 80398.

consortia agreed to sign the covenant by 31<sup>st</sup> January 2018. The payment of the first instalment of the integration management budget was therefore also postponed.

Instead, the French-speaking pilot projects listed their fears, questions and requests, and sent a joint note to the authorities, who also were questioned and challenged by Flemish umbrella agencies in the care sector. A concertation meeting between the authorities (the Federal Health Ministry, the NIHDI and the Public Health PFS) and umbrella agencies was organised for 8<sup>th</sup> February 2018 to exchange their respective points of views and clarify things. Following this meeting, the pilot projects received a circular letter from the authorities in which it was *inter alia* mentioned that:

- pilot projects would henceforth have representatives sitting on the Permanent Working Group of the Insurance Committee to maintain a regular dialogue (two pilot project coordinators, one for the Flemish projects and one for the Frenchspeaking projects;
- the deadline to sign the covenant was postponed to the 31<sup>st</sup> March 2018 and the deadline to deliver the annexes was postponed to 30<sup>th</sup> June 2018 at the latest.

Similarly to other projects, pilot projects A and B eventually signed the covenant and began to work on the annexes with the support of the IAC, but they encountered difficulties in this process, for example regarding the seventh annex, as illustrated in this excerpt:

"Given that it is difficult to know exactly what we will receive as efficiency gains (and if we will have any), the inter-administrative cell proposes to operate with a percentage of distribution. [...] Above all, it is a question of thinking about for which actions we want to use the efficiency gains" (A pilot project coordinator, Field notes of observation, 2018).

It was indeed difficult to provide a financial projection without knowing the amount of money that would be available, but projects A and B eventually complied, and indicated percentages in their seventh annexe. Annexes were approved during the summer of 2018. Not surprisingly, pilot projects were avidly waiting to know to how much their efficiency gains would amount in order to have a precise idea of what they could undertake on the ground. They were supposed to receive an answer to this question by the autumn of 2018.

In parallel, projects A and B had mainly worked on governance aspects and organised working groups with the intention of initiating reflexions in order to imagine concrete ways of implementing their actions on the ground. They also had been working on the development of a joint action that they were allowed to finance with the integration management budget. Indeed,

given that project A and B were geographically adjacent and had some partners in common, they decided to work in synergy and conceived joint actions. During the conceptualisation phase, both projects A and B had imagined an action consisting of setting up a telephone line accessible to professionals and chronic patients located in their territory. This would have the purpose of orienting them with regard to the social and care local fabric, so that they could obtain relevant information related to the pathology or to other problems encountered. Given that the projects had limited resources, they eventually decided to launch a joint telephone line during the execution phase and pool financial resources from their respective integration management budgets to hire a respondent.

### 4. Key Moment: Problem with the Calculation Model

In October 2018, contrary to what had been foreseen, the pilot projects did not receive their eagerly-awaited efficiency gains. Actually, on 18<sup>th</sup> October 2018, a new twist occurred, which both frightened and angered the pilot project stakeholders. Coordinators received an email from IAC stipulating that the results of the calculation intended to determine the efficiency gains pertaining to the year 2017 was available. It was also vaguely mentioned that "the calculation results required a more detailed analysis of the calculation model", with no further information apart from the fact that the authorities decided to organise a concertation meeting with pilot projects representatives on 20<sup>th</sup> November 2018 to talk about the situation.

Between 18<sup>th</sup> October 2018 and 20<sup>th</sup> November 2018, coordinators tried to obtain more information about the problem, without success. After a month of stressful waiting, uncertainty and mistrust, the big day arrived. During the concertation meeting on 20<sup>th</sup> November 2018, the authorities explained that the efficiency gains calculation model, which had been presented to pilot projects since the beginning of the conceptualisation phase and on the basis of which they had designed their loco-regional action plan, was not reliable and, as a result, had to be adapted. They also added that they expected to be able to propose a new calculation model by June 2019, after having received the result of a study carried out by the Inter-mutualist agency<sup>31</sup> (IMA) regarding the efficiency gains and the budgetary guarantee. Meanwhile, given the impossibility

<sup>&</sup>lt;sup>31</sup> The IMA manages a wide range of health care data collected by the seven health mutuals. On the basis of this information, this agency supports the health mutuals and health care policy with data, analyses and studies. In the context of the IC4BH policy, it is responsible for calculating efficiency gains and monitoring the progress of pilot projects using different indicators to analyse, in the case of each project, the socio-economic characteristics of the target group and the overall population, the proportion of patients with chronic conditions as well as health care and drug use. (retrieved from: <u>https://www.ima-aim.be/Des-soins-integres-pour-une-meilleure-sante</u>, accessed 13 May 2020)

of reliably calculating efficiency gains pertaining to the year 2017, the authorities proposed an alternative solution.

They decided to release a budget of &2.5 million to be shared between the projects so that each project would receive, after the approval of a new version their respective seventh annex by the Insurance Committee, a one-shot lump sum of &208.333 to be regarded as the efficiency gains of 2017. In order to be legally allowed to make this unplanned payment, the authorities would have to adapt the Royal Decree of 31<sup>st</sup> July 2017 laying down the conditions with regard to which the Insurance Committee of the NIHDI may conclude covenants for the funding of integrated care pilot projects.

This unexpected turn of events also led the authorities to orally provide new guidelines regarding the seventh annex, *inter alia* that it should comprise a more detailed description of the way efficiency gains would be used, this time with exact amounts, not percentages. A new rule added as from the concertation meeting was that the lump sum of €208.333 could be used for two domains:

- A maximum of 20% of this sum could be used at the level of the project to finance such aspects as running costs, governance costs, stakeholders training and project promotion. A part of those elements could also be financed with the integration management budget.
- A minimum of 80% of this sum should be used at population level, i.e., to finance actions for the benefit of patients or of the population as a whole (e.g., patient education, case-management and telemonitoring).

To help pilot projects write their seventh annex, the IAC was assigned the mission of producing a framework document listing the different guidelines pilot projects had to follow. The next steps presented by the authorities during the concertation meeting were as follows:

- November 2018: proposition of framework document by the IAC
- December 2018: discussion about the framework document with pilot projects
- January 2019: discussion and approval of the framework document by the Insurance Committee of the NIHDI
- January-February 2019: period during which pilot projects were supposed to write their seventh annexes

 February-March 2019: evaluation of the seventh annexes by the Permanent Working Group of the Insurance Committee and approval by the Insurance Committee of the NIHDI

On 10<sup>th</sup> December 2018 (so later than expected), pilot projects received an email from the IAC with a provisional framework document pertaining to the seventh annex, and also another one pertaining to the sixth annex. Pilot projects were invited to send back their comments by 8<sup>th</sup> January 2019 at the latest. On 9<sup>th</sup> January 2019, a meeting was organised between the IAC and the pilot projects to talk about their remarks and answer their questions.

# 5. Key Moment: the Intervision of 23<sup>rd</sup> January 2019

On 23<sup>rd</sup> January 2019, an intervision was organised, at which coordinators received new information regarding the sixth and seventh annexes and the way efficiency gains could or could not be used. Importantly, since 20<sup>th</sup> November 2018, the pilot projects had already thought about the way they would use their lump sum. Several of them, including projects A and B, wanted to set aside a part of their efficiency gains in reserve, to allow them to spread the use of their 2017 efficiency gains out over the next three years. The rationale here was that they wanted to be able to finance actions for more than one year, in case they would not receive other efficiency gains in the years to come.

However, during the intervision of the  $23^{rd}$  January 2019, coordinators received the information that this would not be possible. Each year, pilot projects would be allowed to set aside only 20% of their efficiency gains (with a maximum cumulative amount of  $\in$ 500,000), with the restrictive condition that this money could be exclusively used to finance patient-oriented actions. For instance, they would not be allowed to use this sum to finance social liabilities. In other words, it meant that they would have to spend the remaining 80% during the year following the payment of the efficiency gains, and give back any money that was not be spent. Each year, after publication of the amount of the efficiency gains achieved, pilot projects would have to write a new seventh annex in accordance with the framework document, detailing concrete expenditure items and amounts.

As a reminder, in the sixth annex, the pilot projects had to list their innovative actions for which a financial compensation would be paid to the professionals, and/or for which a personal financial contribution would be asked of the beneficiary. Pilot projects were forbidden to put in this annex:

- actions falling under the jurisdiction of the federate entities, given that no federal budget could be used to finance such actions;
- actions which were contrary to current legislation;
- actions for which the absence of added value had already been proven.

Importantly, recording a BelRAI screener for a patient could not be considered an innovative action that could be financially compensated and as result could not be included in the sixth annex. In addition, pilot projects were asked to demonstrate that the innovative actions would not incur additional costs for the beneficiaries compared to conventional care delivered to patients with a similar profile. Finally, pilot projects had to prove that the allowances that would be paid to the professionals would not involve a double funding for the latter.

Furthermore, the creation of innovative actions, which did not exist at that time in the NHIDI nomenclature required the creation of "pseudo-codes". A pseudo-code was a code corresponding to an action which could be used to record electronically the participation of a patient to an action, and in this way create a systematic monitoring of the number and profile of the patients (or informal carers) and the care/support providers involved in the action. The other purpose was to analyse the relationship between participation in an action and the results achieved. As a result, by the 31<sup>st</sup> January 2019, pilot projects had to provide the IAC with a list of their actions for which they thought a pseudo-code would be necessary, which projects A and B did.

During the intervision of 23<sup>rd</sup> January 2019, the authorities also underlined that very few inclusions had been carried out by the projects during the first year of the execution phase. Concretely, during the conceptualisation phase, pilot projects were asked to define the geographical zone they planned to cover, the population of which had to amount to at least 75,000 inhabitants, and ideally to between 100,000 and 150,000 inhabitants. The authorities gave this specific guideline so that the actions initiated would have a significant effect in the field, that could be identified and measured in order to be able to produce relevant statistics.

In fact, among the pilot projects that entered the execution phase, the project that covered the least number of inhabitants had a population of about 97,000 people, while the one that covered the most inhabitants had a population of about 360,000 people. The average population per project was 195,000 inhabitants. As a reminder, pilot projects were expected to include beneficiaries as from the beginning of the execution phase, to constitute their operational target

group<sup>32</sup>, which was expected to grow each year so that it would "represent, during the first, second, third and fourth 12-month period, 1%, 3%, 6% and 10% respectively of the total population in the [pilot project] geographic area"<sup>33</sup>. In practice, this meant that each pilot project had a different objective to achieve in terms of inclusions. So, for example, after the first, second, third and fourth year, the project with the smallest population was expected to include about 970; 2910; 5820 and 9700 beneficiaries respectively, whereas the one with the biggest population was expected to include around 3,600; 108,000; 216,000 and 360,000 beneficiaries respectively.

Nevertheless, during the intervision of 23<sup>rd</sup> January 2019, it was highlighted that only 166 inclusions were registered in total for the twelve projects, including 106 made by Project A. So, it was far fewer than the thousands of inclusions expected at this time by the authorities, who urged the projects to include beneficiaries as quickly as possible. The pilot projects representatives explained that this lack of inclusions was due to some problems with the inclusion procedure, which was too laborious for workers in the field.

This inclusion procedure was comprised of several steps:

- (1) The professional had to identify who among his/her patients could be included, on the basis of the inclusion criteria corresponding to the project target group.
- (2) The professional had to inform each patient individually about the project, give him/her the 5-page informed consent document written by the scientific team and ask for his/her informed consent regarding to elements:
  - his/her participation in the project
  - the sharing of his/her data with the scientific team in charge of project evaluation as of the execution phase in accordance with the GDPR regulation

The written consent of the patient was not mandatory but recommended. Specifically, two options were possible:

Either, at the time of the consultation, write in the electronic medical record that the patient agreed to be included (e.g., "Mr/Mrs X agreed on [date] to the scientific follow-up of the project and to be contacted again by the researchers").

<sup>&</sup>lt;sup>32</sup> See p. 128 for the definition of the operational target group

<sup>&</sup>lt;sup>33</sup> Royal decree of 31<sup>st</sup> July 2017 laying down the conditions by which the Insurance Committee of the National Institute for Health and Disability Insurance may conclude covenants for the funding of pilot integrated care projects, p. 80398.

- Or, ideally at the time of the consultation, have the patient read and sign the 5-page informed consent document written and provided by the scientific team and retain the document in hard copy or electronic format. Importantly, the projects only received the informed consent document on 30<sup>th</sup> October 2018, after its approval by the Ethics Committee of the university coordinating the scientific team and 10 months after the beginning of the execution phase.
- (3) Only then, was the professional allowed to include the patient via the specific inclusion application. Importantly, this involved only those professionals were able to connect directly: doctors, dentists, pharmacists, nurses, assistant nurses, physiotherapists, midwifes and paramedical workers. The others (e.g., social assistants) had to request an initial registration to be able to access the inclusion application and include beneficiaries. Nevertheless, important technical problems were encountered with regard to the inclusion application, which made the inclusions difficult or even impossible for certain categories of professionals.
- (4) Eventually, as explained in the introduction, beneficiaries, as part of the inclusion process, had to take the BelRAI screener test, which was expected to take 10 to 15 minutes according to the authorities and more according to the professionals. However, providers could not be compensated through efficiency gains for having used that tool, so they simply refused to do it. In any case, they had not been trained at that point and, as a result, were not able to use the BelRAI screener test. Consequently, no one used this tool.

Furthermore, during the Intervision of the 23<sup>rd</sup> January 2019, the above-mentioned agenda was modified slightly. The following is a list of the next steps presented during the intervision:

- February 2019: discussion and approval of the framework documents by the Insurance Committee of the NIHDI
- February-March 2019: pilot projects propose a first version of their sixth and seventh annexes
- March 2019: evaluation of the seventh annexes by the Permanent Working Group of the Insurance Committee and approval by the Insurance Committee of the NIHDI
- After approval of the seventh annex: payment of a lump sum of €208,333 to each project

- June 2019: proposal of new calculation models
- Autumn 2019: calculation of the efficiency gains pertaining to the year 2018 based on the new calculation model

### 6. Writing the Annexes and the Annual Report for the year 2018

On 4<sup>th</sup> March 2019, the pilot projects coordinators received an email informing them that the Insurance Committee of the NIHDI had approved the framework documents pertaining to the sixth and seventh annexes. Pilot projects were asked to hand in their annexes by 31<sup>st</sup> March 2019 at the latest, the date on which they also had to hand in their annual reports for the year 2018. The pilot projects argued that this represented too much work, and negotiated an extension of the deadline for the annexes, which they obtained. The new deadline to hand in the annexes was set at the 15<sup>th</sup> May 2019, while the date of 31<sup>st</sup> March 2019 was maintained for the annual report. Table 14 summarises the salient elements of Projects A and B annual reports, translating the points of view of the projects stakeholders.

# Table 14 – Salient Elements of Projects A and B Annual Reports Pertaining to the Year2018

		Governance aspects	
Both projects	s A and B	devoted a great deal of time during 2018 to working on their	
governance a	spects and c	creating their respective ASBLs. As a result, a large part of their	
respective and	nual reports	was logically dedicated to describing in details:	
	1. the	creation process with regard to their ASBL,	
	2. the list of partners and their role(s),		
	3. the different entities making up the ASBL and their roles,		
	4. the way these entities were supposed to interact and communicate with		
	eac	h other,	
	5. the	decision making modalities.	
		Evaluation of actions implementation	
Both projects	underlined t	he fact that they were only at the beginning of the implementation	
process of the	eir actions.	Therefore, the latter were difficult to evaluate at this stage. They	
were neverth	were nevertheless able to list what they viewed as their strengths and underlined the		
difficulties of	difficulties of taking action as part of this implementation process.		
Project A S	Strengths	(1) Many disparate initiatives and projects existed before the	
		project, in a fragmented way: Project A brought them	
		together and promoted them. So in the end, the actors who	
		had developed these projects beforehand were logically	
		motivated; they had not to change in depth the way they	

	Difficulties	<ul> <li>carried out their initiative(s). The real advantage, the novelty, was the emerging dialogue between stakeholders.</li> <li>(2) The integration management was ensured by a small group of key people, each of whom had their own circle of colleagues and acquaintances with whom they talked about the project.</li> <li>The important difficulty was to go beyond the actions of the leaders of the former project group to involve workers in the field, who were not necessarily aware of the project's existence in the early stages. The information did not always reach the workers of the institutions represented in the project, e.g., of large structures like hospitals.</li> </ul>
		According to Project A stakeholders, if one wants to initiate change without changing the law, leaders are needed. Metaphorically, one needs convincing "locomotives", i.e., leaders who are able to get others to follow, who can promote actions and convince providers in the field to get involved and to change their practice. The drawback regarding the fact of depending on "locomotive people" is that there is a certain dependence on their availability: they are not always replaceable, which can be problematic, e.g., in the event of illness, and this creates the need to think about alternative modalities.
Project B	Strengths	Compared to the conceptualisation phase, it was often the same people who were in the same working groups. There was therefore a continuity between the design and the implementation of the project, which was viewed as a positive element by the project stakeholders.
	Difficulties	<ul> <li>(1) It was difficult to operationalise the loco-regional action plan. Moving from the application file, which was very voluminous and difficult to operationalize, to its implementation appeared to be very complex. It required reworking certain points extensively to move from intentions to concrete changes in practice on the ground. This therefore required time.</li> <li>(2) It was also difficult to move from principles to practice and put concrete actions in place because people who had designed the actions during the conceptualisation phase were not necessarily those who had to assimilate the project and implement the actions in the field. Everybody agreed that the actions seemed relevant, but it was more complicated to concretely integrate those into daily practice, e.g., due to a lack of time or because they did not really understand what was expected of them.</li> </ul>

·	
	<ul> <li>(3) It was difficult for the project stakeholders to have a comprehensive vision of the project, even for those who were heavily involved. The project scope of action was too wide given the diversity of actions. Stakeholders did not have enough time to track and assimilate the huge amount of information transmitted pertaining to the project.</li> <li>(4) Ever-changing rules and guidelines tarnished the projects' credibility. It was difficult to understand things that were played out at the federal level (insurance committee, cabinet, etc.), but which had direct impacts on projects. Field workers were tired of constant change. For the project, it was particularly problematic because it had to pass on ever-changing and inconsistent messages to field workers.</li> <li>(5) There really was a negative perception of the field vis-à-vis the federal government because, given their negative experience in other pilot projects, workers in the field no longer believed in effective reforms, and no longer believed in promises that were made but often not kept. Consequently, some providers who had experience of participating in several previous pilot projects, were less willing to get involved, <i>inter alia</i> due to previous negative experiences, which damaged the trust they had in the Belgian authorities.</li> </ul>
	Consequently, some providers who had experience of participating in several previous pilot projects, were less
	experiences, which damaged the trust they had in the Belgian authorities.
	(6) It was difficult to have a clear idea of the resources available to the project due to the uncertainties surrounding the sixth and seventh annexes. As long as the annexes were not approved, providers did not want to
	invest time and effort. Stakeholders asked for clarity regarding the inclusion application, the efficiency gains
	calculation model and the annexes approval process. (7) Providers feared administrative overload.
	Patients' inclusion

## Patients' inclusion

Both projects encountered difficulties regarding patient inclusion. During the year 2018, Projects A and B registered 106 and 11 beneficiary inclusions respectively (with no BelRAI), whereas they were expected to each have included 1% of their population after the first year of the execution phase, i.e., around 2,500 patients for each project. Both projects emphasised that:

(1) The BelRAI was not available at the time of writing, nor had the training courses been organised yet due to several postponements. These delays with regard to training did not allow the partners to fill in the BelRai screener for their patients as part of the inclusion process. In addition, given that no federal

r		
	-	as planned to be given for the BelRAI screener, it was difficult to the partners to use this tool.
	(2) The project calculated This event	cts had no information regarding the way efficiency gains would be due to the problems identified with regard to the calculation model. t degraded the credibility of the authorities, and created a feeling of on the part of stakeholders.
		des were not available at the time of writing the annual report,
		essential for the implementation and the follow-up of certain actions.
	-	ains why practitioners refused to start actions purveyors of
	-	(e.g., STOPP/START action, which is described below), as long as
		les were not available, given that it would not be possible to identify
	-	of these quick-win actions that were supposed to generate speedy
	efficiency	
	-	Is intended to facilitate work did not operate properly, e.g., the
		application, which was not in operation due to persistent glitches.
		t, there was a lack of means for tracking the patients included, and
	to assess t	he impact of the projects.
	(5) It was diff	icult to communicate efficiently the details of the informed consent
	process to	those who had to administer it.
Project A		(1) General practitioners were viewed as the main entry point
		for the inclusion of patients in the project (via the inclusion
		application). More generally, in the long run, the wish was
		that all consortium members would be able to include any
		person corresponding to the project target group, which was not the case at this stage.
		(2) Information regarding the informed consent and the
		operation of the study did not percolate clearly to all the
		professionals in charge of patients' inclusion; some did not
		fully grasp the details of the informed consent process,
		which was intended to support the collection of private
		health data for evaluation and research purposes.
Project B		(1) Regarding the informed consent, it was unclear whether or
		not the patient had to sign a document or if oral consent
		was sufficient. In any case, the approved consent form was
		only received in October 2018 (10 months after the
		beginning of the execution phase), after being validated by
		the ethics committee of the universities involved.
		Beginning the patients' inclusion and then having to hand them the concernt form at a later data did not ecorry to be
		them the consent form at a later date did not seem to be practicable.
		(2) The fact that inclusion could not be realised through the
		software used by practitioners in their daily practice was
		problematic; it was only possible to include patients via a
		problematic, it was only possible to include patients via a

	specific inclusion application (with no integration between
	the softwares systems).
Additional re	emarks made by the projects in their respective report
Project A	<ul> <li>(1) The report stressed how crucial the role of the authorities was: it was difficult to develop the project and implement actions if the framework provided by the federal level was not consistent. There was a lack of responsiveness and coherence on the part of the political-administrative authorities. It seemed difficult for both the authorities and the actors in the field to understand their respective positions and difficulties.</li> <li>(2) Nevertheless, Project A stakeholders underlined that the work done would not be lost even if the project stopped: they would continue to work together, at their level. The project constituted a new space in which they had the opportunity to talk to one another, which had not existed previously. According to them, this was already a significant evolution, which could increase the effectiveness of actions, but there was still a big change in thinking to be made in order to move from a system where one works alone, to a system in which professionals work together.</li> <li>(3) In addition, many actors in the field were not familiar with the concept of "integrated care". There was sometimes reluctance and/or fear among partners regarding care integration. As a result, the project organised meetings to</li> </ul>
Project B	<ul> <li>provide information to convince those who were reluctant of the added-value of working together. All of this was a time-consuming work.</li> <li>(1) The creation of the ASBL, as well as the finalisation of the</li> </ul>
	<ul> <li>mode of governance took more than half of the time of the year. Nevertheless, this was necessary to build trust and confidence within the consortium, and to be able to collaborate effectively thereafter.</li> <li>(2) The actions were still unclear for the actors in the field. It took a lot of time to inform them and to convince them of the value of implementing the project actions.</li> <li>(3) The actions implementation still required a lot of discussions with the actors in the field so that they could concretely articulate the actions with their missions.</li> <li>(4) Bringing together stakeholders from different sectors and backgrounds took time: it entailed learning to get to know and trust each other, and to work together.</li> </ul>

In conclusion, moving from a multidimensional, ambitious and
voluminous loco-regional action plan to operational and concrete
actions appeared to be an important, time-consuming and complex
task. The work of conceptualising the application file had made
things very complex. During the execution phase, a first step had
been to discuss the actions again during meetings to think about
how to implement them in practice and to sometimes simplify
them. The project also decided to test the actions on a very small
scale before going further.

### 7. Pending the Annexes Evaluation and Approval

After having handed in the annexes and pending the annexes evaluation and approval, a concertation meeting gathering the authorities' and pilot projects' representatives was held on  $28^{\text{th}}$  May 2019 at the NIHDI to take stock. The conclusions of the annual reports, the use of the €208,333 for actions, the accompaniment provided by the scientific team and the pseudocodes were on the agenda.

After having received the annual reports in March, the authorities realised that, since the beginning of the execution phase, there had been only 204 inclusions in total, for all the twelve projects combined. From their perspective, it was far too little given that after the first year of implementation, the government expected that each project would have included 1% of its population, i.e., 23,000 people in total. For the permanent working group and for the policy makers, this observation was seen as a sign that, after one year of implementation of their plan, the projects had not yet taken the step towards actions that should have had a direct impact on the included beneficiaries.

As a result, in a tense atmosphere, pilot projects were put under pressure: they were expressly urged to include 1% of their administrative population (i.e., around 2,300 patients for Project A and around 2,500 patients for Project B) by 31<sup>st</sup> December 2019, under penalty of stopping the projects. As a response to this demand, the projects' representatives argued that this objective was unrealistic. Furthermore, they emphasized the problem of only focusing on the number of inclusions as a means of assessing project performance. This would also involve a need to focus on qualitative aspects to provide a more accurate assessment of the work achieved during 2018.

Interestingly, at the beginning of July 2019, the pilot projects received a new draft document from the IAC presenting a new model of evaluation. This was entitled the "performance model"

and was intended to take into account dimensions other than the number of inclusions, in order to assess projects performance. This performance model listed several criteria highlighting the government expectations vis-à-vis the projects. Some of the listed criteria, viewed as essential by the authorities, would have to be met by 1<sup>st</sup> October 2019.

The criteria were divided into five categories, each corresponding to a specific level of action:

- 1. The project level, also referred to as "project management", corresponding to expectations in terms of management and project functioning, e.g., governance and communication aspects, convention signature and annexes approval, existence of a GANTT chart and collaboration with the scientific team.
- 2. The meso level in the form of "integration management", relating to actions in the field of cooperation/collaboration, pooling and integration, between actors and partners within the project.
- 3. The population level including actions aimed at reaching the entire target group/population of the projects, e.g., through awareness-raising actions.
- 4. The micro level referring to actions the tangible impact for beneficiaries of which could be directly linked to these actions, e.g., via the inclusion application.
- 5. The macro level referring to the achievement of the Triple Aim.

For each level, the authorities set aims to be achieved, and criteria determining the (non-) achievement of these objectives. Table 15 is what was received by the pilot projects from the IAC summarizing the objectives and criteria that were to be met, by level. The criteria in bold were supposed to be met by 1<sup>st</sup> October 2019.

Project Management Level		
Objectives	Criteria	
1. All preparations in the	1) Criterion: Validated, clear and pragmatic internal rules	
field of governance	and regulations (agreements at governance level). $\rightarrow$ Roles	
and communication	and responsibilities are 100% clear for all partners involved.	
have been finalised so	2) Criterion: A signed covenant with approved annexes	
that a project can be	(1 to 7). $\rightarrow$ Agreements with the government are 100%	
fully operational as	clear to all partners involved.	
from 1 October 2019.	3) Criterion: A validated, clear and pragmatic	
	communication plan $\rightarrow$ the communication strategy, in	
	order to be operational, is 100% clear to all partners	
	involved.	

 Table 15 – Performance Model (Draft)

		4) Criterion: An updated, clear and achievable Gantt chart (SMART) $\rightarrow$ the actions to be implemented and the corresponding timetable are perfectly clear for all partners involved.	
2.	The pilot project	5) Criterion: The inclusion procedure is described in an	
	includes patients	operational guidebook $\rightarrow$ the inclusion procedure is 100%	
	selected according to	clear for all actors involved.	
	the inclusion		
	procedure described		
	in the fourth annex of		
	the convention.		
3.	The integration	6) Criterion: Integration management will be	
	management is	coordinated by a full-time coordinator by 1 <sup>st</sup> October	
	coordinated by a full-	2019.	
	time coordinator.		
	Integrat	ion Management Level (Meso Level)	
1.	Mandatory	7) Criterion: to be defined for each project separately, []	
	stakeholders remain	e.g., depending on the number of inhabitants in the pilot	
	involved.	zone.	
2.	Social and health data	8) Criterion: Social and health data were provided with the	
	will be recorded and	patient's consent.	
	communicated for		
	each beneficiary.		
3.	The project strives to	9) Criterion: Number of training courses organised for	
	create support for	health and social care professionals.	
	integrated care and to	10) Criterion: Number of actors involved in training and	
	bring about change	awareness-raising activities.	
	towards integrated	(11) Criterion: Number of different disciplines reached	
	care in the project	through training and awareness-raising activities.	
	zone.		
		Population Level	
1.	The operational target	12) Criterion: A target is proposed for the number of	
	group reaches a	citizens to be reached per project (to be assessed per	
	sufficient number of	project).	
	citizens.	13) Criterion: A plan is available to enlarge the operational	
		target group for the coming years.	
2.	The pilot project	14) Criterion: Number of actions in preparation/planned for	
	implements the action	the population level.	
	plan as described in	15) Criterion: Number of actions and planned actions for	
	the project's Gantt	operational population level.	
	chart.		
		Micro-level	

1. A	A sufficient number	16) Criterion: Number of patients included/targeted: to
0	of patients are	be set according to the action plan.
iı	ncluded [] via the	17) Criterion: A plan is available to increase the number of
iı	nclusion application.	beneficiaries included in the coming years.
2. T	The pilot project	18) Criterion: Number of actions at the micro level prepared
iı	mplements the action	initiated, implemented, completed / number of actions
р	olan as described in	planned at the population level.
tl	he project's Gantt	
c	hart.	
		Macro-level
1. T	The pilot project	19) Criterion: The (actual) expenditure for the
re	espects the budgetary	administrative target group of the project does not
n	nargins imposed.	exceed the expected expenditure for the project in that
		year (to be further specified according to the new
		efficiency gains' calculation model).
2. T	The pilot project	20) Criterion: Included patients' satisfaction is greater than
n	neets the requirement	or equal to the baseline measure (to be made operational as
re	egarding patients'	soon as measurable).
S	atisfaction	
iı	mprovement	

## 8. Postponement of the Annexes' Evaluation and Approval

On 16<sup>th</sup> July 2019, coordinators received an email regarding the approval procedure for the sixth and seventh annexes, in which they learned that the annexes had not been submitted for approval to the Insurance Committee on  $15^{th}$  July 2019 as announced to the projects after several postponements of the deadline. Actually, the Committee on Budgetary Control of the NIHDI pointed out that some projects did not comply with the guidelines listed in the document framework pertaining to the seventh annex, and, more precisely, the guideline according to which pilot projects had to allocate the compulsory minimum of 80% of their efficiency gains at the population level with a maximum of €41,666.6 (20% of their efficiency gains) in reserve.

This concerned a number of projects that had not reached the minimum threshold of 80 %, with a maximum of  $\notin$ 41,666 in reserve, at the time of submission of their proposal, or projects which no longer met this threshold because some of the actions listed in their annexes had not been approved by the Permanent Working Group of the NHIDI. As a result, the Committee on Budgetary Control of the NIHDI was unable to give an opinion, which is why the annexes were not submitted to the Insurance Committee, the last step in the evaluation and approval procedure prior to payment of the lump sum of  $\notin$ 208,333. A new evaluation by the Committee on

Budgetary Control of the NIHDI was planned on 9<sup>th</sup> September 2019. In the meantime, the concerned pilot projects had to adapt their annexes.

In addition, a number of umbrella agencies urgently requested clarifications with regard to the annexes, on the IMA's study regarding the budget guarantee calculation model, and on the proposal regarding the use of efficiency gains for the years 2018 and 2019. In this respect, a Permanent Working Group meeting had been planned at the end of August 2019. In preparation for the meeting, pilot projects, on the initiative of the Flemish projects, sent a joint note to the IAC in order to share some of their concerns pertaining to:

- the payment of efficiency gains: they asked for assurance that no new threshold preventing the payment of the one-off lump sum would be fixed. They also asked that the permanent working group, at their meeting on 23<sup>rd</sup> August 2019 formulates a substantiated and decisive favourable opinion regarding the specifications and conditions for the disbursement of the 2017 efficiency gains, and to submit this to the next Committee on Budgetary Control and to the Insurance Committee for formal approval.
- the lack of clarity regarding the new calculation model of the efficiency gains, with the new restriction that the latter would now be capped at €2.5 million in total (also the efficiency gains pertaining to the year 2018): they underlined the uncertainties surrounding this model leading to the creation of a counterproductive atmosphere of distrust. They also asked for a transparent and open discussion of the results of the study conducted by the IMA.
- the performance model: they called the relevance of this model into question, underlining that it was somewhat premature to determine if a project worked or not. They argued that it would only be possible to verify whether or not a project worked, and to measure its impact, after four years of development. They also pointed out the danger of applying a generic performance model to all the projects, given that each had a different and specific starting situation (different populations, different targeted diseases, different geographical zones, etc.). Eventually, they acknowledged that projects had to initiate change, but stressed that predicting the speed of that change was impossible, given that it depended on the characteristics of the local context and on the stakeholders' ability to accept these changes and to adapt.
- the lack of efficient digital communication tools.

- the inclusion application, which was not working properly and involved a lot of administrative work.

Annexes pertaining to the efficiency gains of 2017 were eventually approved mid-September 2019 and the efficiency gains were paid mid-November 2019, more than one year after the initial planned date. This allowed the projects to really begin and to speed up the implementation of concrete actions. Interestingly, the deadline of 1<sup>st</sup> October 2019 with regard to meeting the criteria proposed by the performance model was postponed, given that the latter was approved later than expected (see below).

# 9. Approval of the Performance Model

In October 2019, although they had not received the 2017 efficiency gains, pilot projects already had to think about the efficiency gains pertaining to the year 2018. Pilot projects representatives were invited to attend an important meeting on  $23^{rd}$  October 2019 at which the authorities presented:

- the IMA propositions regarding the new efficiency gains' calculation model: actually, different models and *scenarii* to calculate efficiency gains were presented in the IMA report. Consequently, a model still had to be chosen from these propositions. The report also stressed the lack of comparability between projects due to the diversity of the target groups among the different projects, and the diversity of expenditure groups, all of which had to be taken into account.
- the last version of the performance model approved by the Insurance Committee in September 2019 was comprised of several criteria, the achievement of which would determine the payment of efficiency gains for 2018. Importantly, the Insurance Committee had the option to decide, if necessary, to stop a project if it emerged from intermediary or annual reports that one or more of these criteria was not met.

As a reminder, the efficiency gains for 2018 would be capped at €2.5 million in total, and were planned to be paid in May 2020. An important new element here was that the (non-)achievement of the criteria listed in the performance model would determine the (non-)payment of 50% of the efficiency gains pertaining to the year 2018. The other 50% would be determined via the new calculation model proposed by the IMA.

The criteria listed in the last version of the performance model were divided into two categories:

- generic criteria, identical for all projects
- criteria specific to each project

In these two categories, some criteria had to be met by 1<sup>st</sup> November 2019 and other by 31<sup>st</sup> December 2019. Table 16 offers an overview of these criteria.

Criteria to meet by 1 <sup>st</sup> November 2019		
Generic criteria	- The agreements made with the administration are 100% clear to	
	all the partners involved.	
	- The actions to be implemented and the corresponding timetable	
	are 100% clear to all the partners concerned.	
	- A full-time coordinator is in post for each pilot project.	
	- The project involves all mandatory partners.	
	- A plan is available for the expansion of the operational target	
	group for the coming years.	
	- A plan is available for increasing the number of beneficiaries	
	included for the coming years.	
	- Expenditure for the administrative target group cannot increase	
	faster than the expected cost increase <sup>34</sup> .	
Specific criteria	- Each project had a specific objective to meet in terms of the	
	number of citizens "to reach" in its operational target group. The	
	group of reached citizens, a new category created as part of the	
	performance model, referred to the citizens directly informed	
	about the project through participation in the project action(s). A	
	formal inclusion (in the inclusion application) was not necessary,	
	but the project had to be able to indicate (per action) how many	
	people were involved, how they were directly informed and via	
	which actions. It was also possible to measure this indirectly, e.g.,	
	via the number of press articles published, the number of visits to	
	the project website, the number of likes and followers of the	
	project's Facebook page, etc. As written in the performance	
	model, when managing the health of a population, the use of new	
	communication tools seemed crucial in the opinion of the	
	authorities. Specifically, the performance model provided that	
	pilot projects reach a number of citizens corresponding to 2.5% of	
	their total population on 1 <sup>st</sup> November 2019. For Project A, it	
	corresponded to almost 6,000 citizens, and for Project B, it	
	corresponded to around 6,500 citizens.	

<sup>&</sup>lt;sup>34</sup> The assessment of this criterion could only be achieved after the budget guarantee calculations had been carried out at IMA level.

	- As a reminder, according to the initial guidelines, during the first and second year of the execution phase, the operational target group had to represent respectively 1% and then 3% of the total population in the [pilot project] geographic area <sup>35</sup> . This group referred to the people belonging to the operational target group who were registered in the inclusion application. So, each project had also a specific objective to meet regarding the number of beneficiaries to include in the project. Pilot projects were expected to include 1% of their total population by 1 <sup>st</sup> November 2019, which corresponded to 23,303 people in total for all projects, and 3% of their total population for 31 <sup>st</sup> December 2020, i.e., 69,909 people again in total for all projects. On 10 <sup>th</sup> October 2019, only 1,312 inclusions were registered in total for all pilot projects, with an average of 109 inclusions per project. Projects A and B had included 128 beneficiaries and 28 beneficiaries respectively. One can see that this was still very far from the authorities' expectations.
	Criteria to meet by 31 <sup>st</sup> December 2019
Generic criteria	<ul> <li>Agreements regarding governance aspects (distribution of roles and responsibilities) are 100% clear to all the partners involved.</li> <li>The communication strategy is 100% clear to all the partners involved.</li> <li>The inclusion procedure is 100% clear to all the actors involved.</li> <li>Social and health data have been communicated with the consent of the patient.</li> <li>The project strives to support change management at the meso level.</li> <li>The project gives a description of the state of play of the actions at the population level.</li> <li>The project gives a description of the state of play of actions at the micro level.</li> <li>Included patients' satisfaction is greater than or equal to the zero reference measurement that would be determined by the scientific team. (It was impossible to measure this criteria before 31 December 2019).</li> </ul>
Specific criteria	<ul> <li>The performance model provided that pilot projects reach a number of citizens corresponding to 3% of their total population for 31 December 2019.</li> <li>The performance model provided an objective to be set regarding the involvement of mandatory stakeholders. This objective concerned partners who were identified as being responsible for, or as an implementing partner for, one or several concrete actions.</li> </ul>

Nevertheless, the calculation model was yet to be determined. As
a result, no concrete objective was provided.

Importantly, fifty percent of the maximum available budget of  $\in 2.5$  million, i.e.,  $\in 1.25$  million, was planned to be allocated to pilot projects based on the degree to which they met the abovementioned performance criteria. The authorities created a distribution key based on a points system. Each criterion corresponded to a certain number of points. The total of points obtained by each project would determine the amount of money to be allocated to each. Pilot projects had to hand in their completed performance model by 8<sup>th</sup> November 2019, a deadline that was eventually postponed to the end of November 2019.

# **10.** Actions Implementation

The pilot projects eventually received the budget replacing the 2017 efficiency gains in November 2019. So, as of December 2019, projects A and B were able to work on the concrete implementation of their actions, most of which required financial resources. Those actions are briefly described in Table 17 on the basis of the descriptions provided by Project A and Project B members.

Joint a	actions
The telephone line: (this action was described	above, p. 130).
The website (and other communication aspect	ts): As part of their communication strategy, it
was decided to create a common website for b	both projects, inter alia to reduce the costs for
each project due to their respective limited	budgets, and also because projects A and B
launched certain joint actions.	
Similar	actions
STOPP/START action (Drug revision): This	action was intended to limit drug interactions
in the case of people with one or more ch	ronic conditions. The project also aimed to
strengthen collaboration between general practitioners and pharmacists, which involved	
adapting IT tools to allow better communication between these two categories of	
professionals.	
Prescription sport/Adapted physical activity: T	The objective of this action was to offer adapted
physical activity (APA) sessions to people suffering from chronic conditions. The APA	
sessions had to be given by a physiotherapist associated with a physical educator trained to	
the specificities of the APA.	
Actions specific to Project A	Actions specific to Project B
Screening and Treatment of Obstructive	Case management: this action targeted
<u>Sleep Apnea</u> : Obstructive sleep apnea	complex chronic patients. Case managers had
syndrome is estimated to affect between 5%	the role of analysing and managing the

Table 17 - Projects A and B Ongoing Actions

and 30% of the population. The health repercussions of this syndrome are numerous: fatigue, increased cardio-vascular risk, work accident, driving accident, etc. The aim of this action was to screen patients as early as possible during a consultation with their general practitioner in order to make up for a lack of space in the somnology departments by relieving congestion. Indeed, the waiting time in these services is usually very long (6 months to 2 years), which is a hindrance to improving the patient's quality of life. This action offered screening and a treatment solution of the same quality in the shortest possible time.	psycho-medico-social problems encountered by patients and their relatives, this in collaboration with the professionals who were already in contact with the patients.
Development of a mobile application for multiple sclerosis patients: The goal was to fill identified gaps in the current care pathway for multiple sclerosis patients. More concretely, it involved the development of an e-health application enabling the user to benefit from information, a communication platform with professionals and daily multidisciplinary clinical monitoring, adapted to his or her needs.	"Prioritizing patient needs" action: The aim of this action was to assess individualised needs in collaboration with the patient in order to promote quality and continuity of care via an integrated care and support pathway. The needs assessment would be carried out using two tools: the PBI ( <i>Plan de besoins</i> <i>individualisé</i> , which means "individualized needs plan") and ELADEB ( <i>Echelles</i> <i>Lausannoises d'Auto-évaluation des</i> <i>Difficultés et des Besoins</i> , which means "Lausannoises Scales of Self-evaluation of Difficulties and Needs"). These tools were used to identify the patient's needs, prioritize them and, if necessary, establish an "Individualized Service Plan" involving the distribution of tasks between caregivers and the patient during a consultation meeting.
Screening and follow-up of chronic back pain <u>patients</u> : Chronic back pain is a common condition that diminishes the quality of life of patients. This problem is very costly to society, both in terms of the medical care required and work incapacity. Consequently, the purpose was to screen the risk of transition to chronicity in patients consulting for an inaugural back pain and to adapt	<u>Therapeutic patient education</u> : With this action, the purpose was to develop collective sessions of Therapeutic Patient Education in order to support patients in the management of their chronic disease. The novelty lay in the fact that these sessions have, to date, been given on an individual basis.

interdisciplinary support according to the	;
risk.	
Screening and follow-up of frail patients:	
Frailty is a clinical syndrome characterized	l
by a decrease in physiological reserve	;
capacity that alters the mechanisms of	1
adaptation to stress. Its clinical expression is	,
modulated by comorbidities and	
psychological, social, economic and	
behavioural factors. Frailty syndrome is a	
marker of risk of mortality and adverse	
events, including disabilities, falls,	
hospitalization, and institutionalization.	
Detecting frailty and acting on the factors that	
lead to frailty prevents dependency, and can	
delay it for many years. So, the general	
objective of the project was to offer patients	
aged 65 and over, screening for frailty and	1
then appropriate support.	

# 11. Annual Report Pertaining to the Year 2019

Importantly, in mid-March 2020, the coronavirus pandemic reached Belgium, forcing the projects to suspend most of the activities, due to the national containment measures. Beyond this, several partners (nurses, doctors, hospital directors, etc.), involved in the various governing bodies (including the working groups in charge of implementing the actions) were called upon to manage the crisis in the field, each at their own level. The progress of many aspects of the pilot projects were therefore put on hold. Furthermore, the deadline for handing in the annual reports pertaining to the year 2019, initially set at 31<sup>st</sup> March 2020, was extended to 30<sup>th</sup> April 2020. The stakeholders of both Projects A and B stressed several similar success factors and difficulties in their 2019 annual reports, which are summarised in Table 18.

# Table 18 – Salient Elements of Projects A and B Annual Reports Pertaining to the Year2019

	The governance structure
Project A	Project A stakeholders viewed the governance model, described on pp. 125-
	126 in this chapter, as a success factor because it allowed a regular follow-up
	of the actions, and encouraged fluid communication between the partners
	attending the meetings.

Project B	The organisation characterised by the coexistence of several working groups,
	and even sub-working groups for some actions, was not always easy to understand for the partners. It created the need to clarify the roles of each body of the governance structure, and develop internal communication procedures in order to ensure efficient communication between those different bodies.
	Furthermore, some working groups were also organised in collaboration with Project A, in order to focus on common actions, e.g., the telephone line or communication aspects. Nevertheless, the projects' action plans had been drafted in different ways, and the joint working groups therefore did not necessarily refer to the same strategic axis in each project. This made things complicated to understand for participants who were part of both Project B and Project A.
	The report stressed that the role of a working group in charge of an action evolved as the action was progressively implemented: the composition of the working group may change, the frequency of meetings may be reduced and the tasks of the working group may, for example, evolve from design to (auto-)evaluation. So, it required reflection to make it as simple as possible for the participants, and to ensure that their role and mission were clear and regularly updated, depending on the different phases of the action. Importantly, since 1 <sup>st</sup> June 2019, coordination of the Project B had rested on the shoulders of three people, i.e., the initial coordinator and two other people working part-time, thus breaking the rule according to which the project coordination should be carried out by a single person hired on a full-time basis. In the annual report, this choice was nevertheless justified by the following points, described as positive ones:     The workload could be distributed more efficiently. The coordination of this type of ambitious project, which did not quickly produce tangible results and which sometimes required delicate negotiations, was very demanding. Having a coordination team meant having more resources to carry out the project. Even if the partners were involved and willing, the workload remained enormous and required more than one FTE at the coordination level, especially when it came to increasing the number of professionals involved and therefore the number of inclusions. For example, an important strategy for the sustainable adhesion to the project were the meetings with the partners vere involved them into their practice. Having a coordination team was therefore a big advantage
	when meeting the numerous partners in the territory. This helped reach

more professionals within the structures than if a single coordinator had taken on this task.
- There were more and diverse skills available within the team.
- It helped ensure the sustainability of the project by perpetuating the
project with the support of several heads, as it seemed very risky to rely
on one single person for everything.
 project with the support of several heads, as it seemed very risky to rely

### Implementation of the loco-regional action plan

Both projects A and B stressed that some actions had fallen behind schedule for several reasons:

- The budget replacing the 2017 efficiency gains was paid far later than expected, i.e., in November 2019 instead of in October 2018 as initially planned. This delay as well as the uncertainties and ever-changing rules regarding the way this budget could be used considerably hampered the implementation of actions, for the majority of which such financial resources were necessary. Furthermore, it was difficult to mobilise stakeholders for new actions when there were significant uncertainties about funding and operational rules: some actors in the field were progressively losing confidence. Accordingly, both projects A and B indicated that they were able the implement some actions only as from December 2019 instead of from January 2018, the date on which the execution phase officially started. This meant that it would take some time before actions eventually showed measurable impacts.
- Due to the authorities' pressure to expand inclusion, the consortia favoured the development of actions that would help include patients, resulting in delays or even adjournments with regard to the development of other actions.
- It took a great deal of time to inform potential partners and, make them perceive the added value of the actions designed by the projects. This constant "behindthe-scenes work" of informing, networking and motivating partners to develop actions in their organisation required a significant investment of time and energy, features which were not reflected in the performance model, even if all this networking was expected to facilitate inclusions in the future.
- Furthermore, each care and support professional had his/her own vision of his/her profession, and of the roles attributed to him/herself as a member of this profession. This sometimes led to mechanisms for defending his/her professional identity, which created a need for dialogue and communication to preserve the quality of relationships between partners. This communication exercise was essential to maintain healthy relationships, but was also very complex and time-consuming.
- Bringing together stakeholders from different sectors and backgrounds also took time because they had to get to know each other, trust each other and learn how to work together.
- The implementation of the actions also still required a lot of discussions with the actors in the field to see how these actions could be integrated into their daily work and match with their missions.

wi lo de an	ventually, both projects stressed the short duration of integrated care projects ith respect to the huge amount of time taken by the task of implementing their co-regional action plan. The deadlines were very short for projects that had been esigned in a very ambitious way, e.g., the required inclusion rate was very high, and it seemed very difficult if not impossible to include so many patients in such short period of time.
Project A	As a reminder, Project A's overall strategy consisted of launching actions in
	the form of micro-projects, each targeting a very small population within a specific restricted territory to serve as a test. Indeed, between 50 and 100 patients were included per action purveyor of inclusions. Furthermore, the report stressed that the micro-projects should not be regarded as isolated actions with no links to each other, but as a set of coordinated actions ultimately aiming at the integration of care for the chronically ill in general.
	These actions, launched at very small scale and each managed by a specific interdisciplinary working group dedicated to this action, would progressively be adapted until they appear to be viable and transposable. These "turnkey" projects would then be proposed to other geographical areas in Project A's territory.
	According to Project A members, this strategy seemed judicious in view of the reticence of professionals in the field. Offering them actions that worked elsewhere seemed to be the best way to convince and motivate them to commit themselves as facilitators of actions in favour of integrated care. Indeed, during 2018, the presentation of the project to potential new partners was rather difficult given that the project and the actions were not very concrete, and therefore were somewhat unclear to those professionals. Having developed more concrete and precise actions was a first step to progressively solving this problem, given that it facilitated contacts with professionals when presenting the project.
	In addition, as already explained in the 2018 Annual Report, Project A had key resource people and organisations who played the role of facilitator, e.g., the coordination and some "leader" partners also called "locomotives" in the previous Annual Report. The latter were able to explain the project to other professionals in their structure/sector and possibly motivate new partners to join the project, which seemed very important for the development of concrete actions in the field.
Project B	Project B Stakeholders did not use the world "micro-projects" when referring to their actions, but followed the same operating principle, and decided to begin by implementing their actions on a very small scale during "test phases".
	The Project B report also stressed how important the role of the stakeholders was. They were active in working groups or on the Executive Board, and activated other key people in their network or structure to promote the project.

The questions asked by the authorities in the report template focused on the number of ongoing actions and the number of actors who carried out such actions, but the Project B report stressed that much time throughout 2019 had still been dedicated to the preparation of the actions, and was the way to move from the action described in the loco-regional action plan, to practice.

During the conceptualization phase, projects were encouraged to be ambitious. This resulted in an action plan containing a large number of actions. However, the quantity of actions in relation to human and financial resources made it difficult to keep all working groups active.

Inclusions

Both projects were still encountering difficulties in terms of meeting the ambitious objectives with regard to inclusions set by the authorities. Since the beginning of the execution phase, on 30<sup>th</sup> April 2020, Project A had included 253 beneficiaries while Project B had included 76 beneficiaries.

Actually, both projects' partners were reluctant to include beneficiaries; they argued that the inclusion process was very time-consuming and created a lot of additional work in addition to their usual workload. Both projects also stressed that the inclusion procedure needed to be simplified as much as possible to get the project partners on board, otherwise it would not be possible. Furthermore, partners again reported technical difficulties with the inclusion application during 2019, e.g., difficulties to connect and problems to activate the consent form.

In addition, for some reasons, pseudocodes were still not available despite the many requests from all the projects. Furthermore, projects were informed that only a healthcare provider having a therapeutic relationship with the patient would be able to encode the pseudocode in the inclusion application. This was problematic because patients had been included, for practical reasons, by the project coordinators so far as well as by the respondent to the telephone line. In order to encode the pseudocode, the health care providers who carried out the actions would have to redo the inclusion themselves and therefore replicate the work that had already been done, which was viewed as a waste of time. This procedure would cause additional administrative work for professionals who already felt overburdened at this level and would accordingly be happy to delegate the inclusion of their patients to the above-mentioned project collaborators.

Project A	It was recalled that general practitioners were viewed as the main entry point
	for the inclusion of patients in the project (via the inclusion application).
	Furthermore, the wish was that all consortium members would be able to
	include any person corresponding to the project target group, which was still
	not the case at this stage.
Project B	As in the 2018 report, it was stressed that inclusion could still not be realised
	through the software used by practitioners in their daily practice; it was still

only possible to include patients via the specific inclusion application
(indicating a lack of integration between softwares).

### **External Communication**

Faced with the difficulty of inclusion, both projects decided to put into place an inclusion strategy specifically aimed at making themselves known to as many people as possible in their territory who might be interested in their integrated care approach, i.e., both professionals who could include beneficiaries and patients who could be included as beneficiaries. In other words, as part of their change management strategy, both projects decided to make communication a top priority in order to enhance project visibility, and generate interest and motivate people who did not know about the project.

They also stressed that communication is a job in itself, which led them to call on an external service provider, a communications agency, to set up an efficient global communication strategy.

In parallel, they asked for support from the authorities regarding communication aspects to promote integrated care on a large scale, initiate a change of culture from the top among the actors in the field, and mobilise field actors for inclusion. The relevance of the concept of "integrated care and assistance" did not seem to be perceived at the time by a majority of field actors. The projects' members argued that they were doing their part to act on this situation at the local level, but that they had neither the human nor the financial means to act as a catalyst for change on a global (macro) scale. Therefore, it was stressed that a more intensive involvement on the part of the public authorities in spreading the theme of "integrated care and support", could seriously boost the effectiveness of the projects.

### Efficiency gains

A first difficulty mentioned in both projects' reports concerned the obligation to spend the efficiency gains in one year which, according to the project partners, was much too short a time to be able to implement the actions they had designed, and which were approved by the authorities. Indeed, before proceeding further, the implementation of the actions implied modalities' clarifications concerning action implementation with the partners, and communicating information about the actions to professionals as well as to the target audience, which, again, was a time consuming endeavour. So, having to spend almost the entire budget in one year seemed particularly counterproductive according to the projects' stakeholders.

Furthermore, at the beginning of 2020, the coronavirus epidemic forced the project consortia to temporarily suspend or delay the launch of a plethora of actions. It would thus have been impossible to spend the  $\in$ 208,333 received in November 2019 within the year and respect the initial time limit. In this sense, in their report, both projects A and B asked for a postponement of the use of this budget, knowing that a refusal would lead to a large loss of resources for the projects. This would, in turn, certainly accentuate the difficulties of inclusion in the future. Indeed, financial resources (and consequently, efficiency gains) were necessary to implement actions, themselves being the means by which inclusions could be generated, knowing that the achievement of the inclusions objective was an important indicator in the performance model used the determine the amount of the next efficiency gains. So, if the number of inclusions was low, the efficiency gains were also expected to be low, and so forth.

Importantly, this reasoning was nonetheless nuanced through the example of the casemanagement action, which should theoretically have an impact on people in complex situations, who have significant health care costs, but who represent only a small part of the population. So, it concerned only a small number of inclusions. Furthermore, this action required a larger budget than other actions, despite its significant potential in terms of efficiency gains.

They also asked for more information regarding the calculation model with regard to the efficiency gains, given that several *scenarii* were presented to them at the end of 2019, but no choice was made at that time. They *inter alia* wanted to know whether or not the projects will have a say in the proposals selected for the calculation of the efficiency gains and the drafting of the new Royal Decree, which had still not been rewritten.

All the budgetary uncertainties put the consortia in a situation in which it was only possible to schedule work in the very short term, and therefore to sometimes try to implement actions in far too short a timeframe, in this way increasing the risk of action failure, *inter alia* due to a lack of time to launch, create support for the action, mobilise partners and patients, etc.

So, projects' stakeholders asked for more certainties about the means that would be at their disposal to develop actions, arguing that it would motivate stakeholders to include beneficiaries. Some even suggested that it would be simpler to have a fixed budget base for the following years to finance micro/meso/macro actions, which could be complemented with efficiency gains.

# 12. Impact on the Work of the Scientific Team

As explained throughout this chapter, events did not unfold as planned and the work of pilot projects was considerably impacted by unexpected twists and turns, as was the work of the scientific team. As a reminder, an inter-university scientific team was mandated until mid-2020 to focus on evaluation aspects. Importantly, the mandate of the scientific team was not extended even though the execution phase started later than planned. As part of their missions, this scientific team had *inter alia* to collect both quantitative and qualitative data to analyse pilot projects actions and then identify "best practices" that could be replicated on a large scale during the expansion phase.

Nevertheless, pilot projects were only able to begin the real implementation of the majority of their actions around December 2019. Consequently, it was difficult, or even impossible, for the scientific team to evaluate actions that had not yet begun. Furthermore, the scientific team depended on the success of the inclusion procedure, the availability of pseudo-codes, and the work of field professionals to collect the above-mentioned data. Indeed, the scientific team was

only able have access to the data of included beneficiaries who had given their informed consent, which corresponded to only a few people given the low inclusion rate.

For information, the scientific team was also tasked with providing support for the development of a quality culture within the integrated care pilot projects. This involved:

- providing assistance in writing annual reports;
- developing a dashboard of indicators;
- analysing reported significant events;
- setting up learning communities and meeting with each pilot projects' members at least once a year;
- providing individualized support for each pilot project according to their specific requests;
- helping organising intervisions in collaboration with the IAC;
- helping pilot projects develop the PDSA (Plan, Do, Study, Act) self-assessment approach regarding the different actions they initiated.

# **Chapter 7: Discussion**

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Literal implementation is literally impossible

— Jeffrey L. Pressman & Aaron Wildavsky, 1984, p. 179.

### 1. Analysing Public Policies: Background

The first reflections in the field of public policy analysis are not new: they started in the USA during the first half of the twentieth century and became, thereafter, during the 1950s, a field of study referred to as the "policy sciences" (Duran, 2010; Hassenteufel, 2011). The purpose of this new field of study, focusing on public decisions, was to help rationalise public action by enhancing public policy efficiency. Interestingly, at that time, policy sciences were built on two premises:

- Decisions can be rational;
- Implementation flows naturally: a rational decision is necessarily a good one, and therefore will be easily implemented, without any difficulties (Hassenteufel, 2011; Pressman & Wildavsky, 1984).

This vision, in which implementation is viewed as a technical and an a-political administrative matter, was taken for granted (Hupe & Hill, 2016). It was thereafter put into question with the advent of the field of sociology of organisations, the originators of which began to criticise the very idea of rational choice, replacing it with the notion of bounded rationality (Friedberg, 1997; Simon, 1990). They also highlighted the difficulties met by the administration when it came to putting into practice the decisions made by policy-makers (Duran, 2010; Kay & Boxall, 2015; Lascoumes & Le Galès, 2012). Actually, "many policies based on apparently sound ideas have encountered difficulties in practical application" (Pressman & Wildavsky, 1984, p. xv). Progressively, the focal point moved to the implementation and evaluation processes, as well as to the interactions between the diversity of actors involved, acknowledging the fact that they each have their own action logic (Hassenteufel, 2011; Howlett, 1991).

In the 1970s, Pressman and Wildavsky (1984) were regarded as pioneers in the field of public policy implementation analysis. In their book *Implementation*, published for the first time in 1973, they provided an in-depth analysis of the implementation of a specific pilot project, the Oakland project, which took shape in the federal American context during the 1960s. Interestingly, their analysis highlighted the existing distortions between the decisions made and their concrete implementation, and between expected outcomes and what really happens during the implementation of a public policy.

This project was intended to deal with the problem of minorities' unemployment by financing public works and business loans in the city of Oakland, California, hoping that such actions would allow the creation of new jobs for minorities. However,

although, EDA officials [the officials in charge of managing the project] had thought that designing the innovative policy, committing funds, and obtaining initial local agreement were the most crucial parts of the program, the implementation of the program proved surprisingly difficult. [...] The technical details of implementation, which had not initially been a source of concern, combined to delay the program and frustrate its sponsors 'hopes. (Pressman & Wildavsky, 1984, p. 35).

Actually, this observation also seems to apply to the IC4BH implementation process, which was actually two-fold. Indeed, one can observe the following levels of implementation:

- the level of the IC4BH plan implementation through the launch of pilot projects (cf. first action line<sup>36</sup>);
- the level of "loco-regional actions plans" implementation by pilot projects consortia within their geographical zone.

Hence, the implementation and the achievement of the IC4BH plan directly depended on the implementation of the projects' loco-regional actions plans.

However, it is clear that there were several gaps between what was written in the IC4BH plan and the guidance leaflet - two documents resulting from a long policy-making process - and what really happened during the implementation of this public policy. The same could be said with regard to projects' loco-regional action plans, when comparing what the projects wrote during the conceptualisation phase in their respective loco-regional action plans, and what really happened during the two first years of the execution phase. Indeed, events did not always unfold as planned as has been shown in Chapter 6 (numerous delays, change in the calculation model, necessary adjustment of actions when moving to practice, etc.), which seemed to be viewed by the authorities as an indicator of failure.

Importantly, this observation of discrepancies between what was planned at the abovementioned levels and what actually happened during implementation, is the starting point for this discussion. The objectives are to understand the reasons that led to such discrepancies and to analyse these reasons in the light of different theoretical frameworks:

- Theoretical frameworks pertaining to the pilot project phenomenon (Vreugdenhil et al., 2010; Sanderson, 2002; Lee, 1999);
- Public policy analysis (Implementation studies; policy design studies; frameworks pertaining to relationships between science, knowledge, evidence and policies)

<sup>&</sup>lt;sup>36</sup> See p. 6

(Hupe & Hill, 2016; Howlett, 2012; Lascoumes & Le Galès, 2012; Hassenteufel, 2011; Powell, 2011; Howlett, 1991; Pressman & Wildavsky, 1984);

- Sociology of organisations (Morel, 2018; Friedberg, 1997; March, 1991; Crozier & Thoenig, 1975; Powell, 1990);
- Sociology of translation (Needham, 2011; Freeman, 2009; Callon, 1984).

With this aim in mind, the analysis presented in this discussion and inspired by the work of Morel (2018) on absurd decisions, focuses on certain presuppositions, shortcomings, ambiguities, paradoxes and absurdities which were identified during the ethnographic fieldwork carried out as part of this doctoral research, and which might have contributed to the emergence of the above-mentioned discrepancies.

In the next section, the empirical material collected as part of this ethnographic research is analysed by mobilising an analytical framework produced by Vreugdenhil et al. (2010) pertaining to the project phenomenon. This framework is combined with the above-mentioned theoretical frameworks. The third section pertains to the notions of co-creation and process inclusivity in the context of the implementation of the pilot projects' loco-regional action plans. Then, the research perspectives identified thanks to this doctoral research are presented in the fourth section before concluding this chapter.

## 2. The Pilot Project Phenomenon: Six Descriptors for Analysing Pilot Projects

When designing a new policy, policy makers can either exploit existing knowledge and what is identified as working, or they can choose to explore new innovative possibilities (Compton et al., 2019). "Exploration includes things captured by terms such as search, variation, risk taking, experimentation, play, flexibility, discovery, innovation. Exploitation includes such things as refinement, choice, production, efficiency, selection, implementation, execution" (March, 1991, p. 71). Regarding integrated care, the Belgian authorities explicitly chose the exploration path by opting for the use of pilot projects, at least on the surface. So, it seems important in this discussion to focus again on what bound the authorities and the field workers within the framework of the IC4BH policy: the pilot projects, viewed as policy instruments and objects for research, in which they all had a role to play.

The purpose in this section is to further analyse the use of this specific instrument as part of the IC4BH plan implementation, by mobilising the research of Vreugdenhil et al. (2010). These authors studied innovative pilot projects in water management in the Netherlands about ten

years ago, and produced an interesting analytical framework about the pilot project phenomenon and the way it is related to policy development. This is why this analytical framework is used to structure this section. They identified six descriptors that apply to pilot projects: "(1) relationship to policy and local context, (2) scale, (3) innovation, (4) knowledge orientation, (5) special status, and (6) actor network" (Vreugdenhil et al., 2010, p. 7). So, let us analyse the integrated care pilot projects in the light of these descriptors, defined in more details below, by identifying the concrete realities to which they can be linked in the context of the IC4BH plan implementation.

#### **2.1. Relationship to Policy and Local Context**

Pilot projects are not independent entities. They cannot be isolated from their biophysical, societal, political and institutional context, a phenomenon referred to as contextual dependence (Lee, 1999; Vreugdenhil et al., 2010). This is why, as Browne and Wildavsky put it: "we should expect new programs to experience difficulties. Given that the span of influences on implementation can never be entirely preconceived, the actual implementation process will always be less structured than the expected process" (Browne and Wildavsky in Pressman & Wildavsky, 1984, p. 220).

For example, the unfolding of the integrated care projects was influenced by the specific federal context in which they were launched, as explained in Chapter 2, but also by important events and parameters over which no one could have had control, such as the societal crisis caused by the coronavirus pandemic, which reached Belgium in March 2020. One can easily understand that, in such a situation, integrated care pilot projects were probably no longer viewed as a top priority by the federal government, the different ministers in charge of health competencies and obviously by the medical stakeholders, who instead focused on the provision of urgent care.

But even before that, other important contextual parameters influenced the turn of events, e.g., the implementation process of the Belgian Sixth State Reform<sup>37</sup> and the change of Health Minister at the federal level in 2014, both of which occurred during the design of the IC4BH plan. Indeed, the federal plan "Priority to chronic patients"<sup>38</sup>, which marked the beginning of a national reflection about a more global approach to chronic diseases, was launched in 2008 under Laurette Onkelinx, the Walloon and French speaking politician belonging to the PS (a left-wing party) who was then Federal Public Health Minister. In 2014, Maggie De Block, a

<sup>&</sup>lt;sup>37</sup> See p. 37

<sup>&</sup>lt;sup>38</sup> See Chapter 2, p. 39

Flemish and Dutch speaking politician belonging to the Open VLD (a right-wing party), took over from Laurette Onkelinx. About one year later, in 2015, she signed and launched the IC4BH plan, designed mainly during the term of office of her predecessor. However, Maggie De Block and her collaborators took the opportunity to inject a dynamic that was more in line with their political ideas during the implementation of the IC4BH plan, through the launch of pilot projects, e.g., encouraging pilot project consortia to look for alternative sources of funding<sup>39</sup>.

So, if the projects had been launched five years before, or five years later, the context would have been totally different. Indeed, history never repeats itself, at least never identically. In fact, when one says that history repeats itself, one is referring to the repetition of social mechanisms (Dumez, 2016), not the repetition of the same situation over and over again, which is impossible and would defy physical laws, *inter alia* those of time irreversibility and causality (Elias, 1996; Klein, 2016). Incidentally, this is why, in the social sciences, which deal with topics which are historical by nature (Coenen-Huther, 2007), it is impossible to identify general predictive laws or produce predictive theories (Dumez, 2016; Flyvbjerg, 2006). Historical and contextual circumstances are unique, and so are the people involved. Therefore, one will never know how the events would have unfolded if the IC4BH plan had been implemented in another context.

Furthermore, pilot projects can be more or less connected to ongoing policies and other projects. On the one hand, they can be peripheral to public policies or constitute a major source of inspiration for those; they can even be part of a policy programme (Vreugdenhil et al., 2010) as in the case of the IC4BH plan. Actually, integrated care pilot projects were at the core of this policy. One could even say that *they were the policy* given that they constituted the first and main line of action that the authorities had to launch to gradually implement their plan.

Two other important elements to take into account are the intrinsic local contextual dependency of the pilot projects as well as their incidence of occurrence (i.e., is the pilot project a one-shot occurence or are there several similar experiments?) (Vreugdenhil et al., 2010). As a reminder, the Belgian authorities received more than seventy applications following the preparation phase, with twenty pilot projects being selected for the conceptualisation phase. Then, 19 projects submitted their application at the end of the conceptualisation phase, while one dropped out. In December 2017, fourteen pilot projects were selected, but only twelve actually entered the execution phase in January 2018 because, again, two projects dropped out. So, at first

<sup>&</sup>lt;sup>39</sup> See p. 127

glance, regarding the incidence of occurrence, one would have twelve similar experiments conducted in parallel.

However, if those twelves pilot projects were all intended to test actions to develop integrated care for chronic patients, a closer look reveals that they were also very different. For example, each pilot project had its own specific target population (some had a bigger target population than others) and, as a result, their respective inclusion aims were different. In addition, they did not target the same specific diseases (diabetes, BPCO, cardio-vascular diseases, mental health diseases, renal failure, etc.) and, thus, developed very different courses of action. During the conceptualisation phase, each consortium also opted for a specific governance structure (ASBL, *de facto* association, inter-communal structure, etc.) and developed its own loco-regional action plan based on its population needs, after having realised a risk stratification allowing them to identify what was specifically missing on their geographical zone.

In other words, in each pilot project consortium, the individual stakeholders' experienced-based local knowledge was mobilised as part of "a process of creative cogitating collaboration" (De Winter, 2019, p. 11) to create local collective knowledge. This context-dependant knowledge (Flyvbjerg, 2006; Vreugdenhil et al., 2010) would serve as a basis for the development of tailor-made loco-regional action plans, based on the specific characteristics and needs of the target population and of the pilot zone. Importantly, according to some health economists involved in the design of the new calculation model, this low level of standardisation created a lack of comparability between the projects. One could even ask if it is relevant to consider them as occurrences of the same type of experiment, as the authorities seemed to do.

Due to the above-mentioned intrinsic local contextual dependency of the pilot projects, another characteristic that can be questioned is the reproducibility of the experiments conducted as part of a pilot project. The reproducibility of an experiment is a major concern in the exact sciences (Plesser, 2018), given that it allows researchers to repeat the experiment several times. Logically, "repeated experiments with similar findings will generate strong cumulative evidence, which can confirm or refute an initial finding" (Goodman et al., 2016, p. 4). As a result, experiment reproducibility is viewed as a guarantee of reliability regarding the research and the results. Importantly, experiments are repeated in laboratories, isolated from the real world, in order to contain the possible negative effects of the experiment, such as, for example, disseminating a vaccine too early, without being certain that its side effects are not harmful to the health of the people to whom it would be administered.

This is obviously not possible in the case of a pilot project conducted in real settings. Beyond that, in addition to the pilot aspect, integrated care itself is recognised as strongly dependant on the context in which it is provided. So, in the case of integrated care pilot projects, « the contextual dependency [of integrated care also contributes to] make every project unique to some extent" (Vreugdenhil et al., 2010, p. 10). This is therefore a further argument highlighting the reduced comparability between the twelve integrated care pilot projects which entered the execution phase.

### 2.2. Scale

The notion of scale refers to the level of scope of a pilot project in terms of time and space. In other words, the question behind this notion when analysing a pilot project is: is the innovation tested on a small scale, a big scale or a full scale and over what period of time? The value of conducting a pilot project on a small-scale lies in the fact that it avoids having potentially-damaging large scale irreversible effects, avoids investing too many resources in a project that might prove unsuccessful, and therefore avoids large-scale failure or damage if the project does not work (Vreugdenhil & Ker Rault, 2010).

The notion of scale is indeed directly related to that of reversibility, which refers to "the ability to return to the reference situation following the implementation of the project" (Vreugdenhil et al., 2010, p. 9). Reversibility depends *inter alia* on the scale on which the actions were implemented (Vreugdenhil et al., 2010). Importantly, according to Vreugdenhil et al., (2010, p. 9), "reversibility of pilot projects is [...] limited to biophysical aspects and formal institutions, but is not achievable for softer aspects such as relations among involved actors and acquired experience".

With the integrated care pilot projects, the final aim pursued by the authorities was to achieve integrated care for chronic patients on a national scale, which is why an expansion phase had been planned after the four-year execution phase. The latter was intended to test the innovative actions imagined by pilot projects consortia during the conceptualisation phase. The actions identified as best practices at the end of the execution phase were to be adopted on a wider scale during the expansion phase.

Importantly, in contrast to laboratory experiments, integrated care pilot projects were carried out in real world settings, in other words, not isolated from the real world. It simply would not have been possible in a laboratory given their social nature, and entailed adopting a *learning while doing* approach (Kay & Boxall, 2015; Lee, 1999). As explained above, each project

constituted a life-sized laboratory for a social experiment anchored in a specific historical context in which contextual factors could not be controlled (Lee, 1999; Vreugdenhil et al., 2010). The consequence here is that the actions initiated at the level of pilot projects had real impacts (Vreugdenhil & Ker Rault, 2010), good or bad, which might not be reversible, especially regarding human aspects (interpersonal relationships, trust/distrust between stakeholders, conflicts, controversies, failed/successful collaboration, etc.). The question of scale is therefore crucial for the analysis.

As a reminder, pilot projects had to cover a geographical zone with a population which had to be between 75,000 and 150,000 inhabitants. The reason behind this guideline was that the authorities wanted the actions initiated by the pilot projects to have a statistically significant effect that could be identified and measured using different indicators. In fact, during the execution phase, the respective real pilot projects' populations ranged from about 97,000 to about 360,000 people, and each project had to begin the inclusion process from the beginning of the execution phase, with the objective of including 1% and 3% of their respective total populations after the first and second year.

Importantly, to the displeasure of the authorities, no pilot project succeeded in achieving the objective of 1% of inclusions after the two first years of the execution phase, for the reasons explained in Chapter 6. So, while filling in the annexes, and waiting for the problems with the inclusion application to be resolved, for receiving the pseudocodes and for the first efficiency gains to be paid out, projects A and B worked on the development and implementation of what members of Project A called "micro-projects". They began to implement their actions on a very small scale, with very few patients. The purpose was to test the actions they had imagined in order to see if these actions were relevant on a very small scale. If it appeared to be the case, they would then try to grow progressively.

The important thing to note here is that, out of caution, they spontaneously opted for beginning by working on a very small scale, during a sort of exploratory phase, *inter alia* in order to preserve the reversibility of their actions, and make any subsequent potential necessary adjustments easier to achieve, before pursuing the objective of having a significant effect. One can assume that the reversibility of the actions tested would have been lower if the projects had achieved their respective inclusion objectives, had carried out actions with all beneficiaries included and had had a significant effect. This potential lack of reversibility with regard to a large scale action could have been a problem in event of significant, but negative, effects relating to the implemented actions.

#### 2.3. Innovation

Testing of an innovation or stimulating innovation in general are the reasons often given for conducting pilot projects in the first place. However, innovation is a relative notion, depending on what is known to actors in particular areas at a certain period of time [and in a specific context]. (Vreugdenhil et al., 2010, p. 9).

To define this notion, one could say that

innovation involves the development and implementation of new ideas that disrupt the common wisdom and habitual practices that hitherto dominated the solution context. [...] It involves a step change that problematizes and transforms the way that things are usually imagined and done. (Torfing, 2019, p. 1).

Accordingly, innovative contexts are also often characterized by a high level of unpredictability requiring a high level of adaptability (Caldwell & O'Reilly, 2003; Segrestin, 2004). Importantly, "innovation demands creative, nonroutine responses, [which] makes it difficult to design a priori programmed actions that will lead to innovative outcomes" (Caldwell & O'Reilly, 2003, p. 500). Paradoxically, in the light of the empirical elements developed in Chapter 6, one can note that the macro-level bureaucratic mode of operation acted as a brake on innovation in the field. Indeed, the strong rigidity of pre-established rules at the macro level, and the proliferation of monitoring and reporting procedures, led to an administrative overload at the meso and micro levels. This hampered the creativity and flexibility necessary for the emergence of a favourable context for networking, in which hands-on professionals were expected to imagine and implement innovative practices.

Furthermore, in the context of the implementation of the IC4BH plan, one can identify several levels and types of innovation. The obvious level of innovation refers to the innovative actions designed and tested by pilot project stakeholders in the field, in the form of micro-projects, each of which was potentially an innovation *per se*. But the specific way of delegating the design of concrete actions to workers in the field through the launch of pilot projects, i.e., what the authorities referred to as co-creation, was also an innovation at another level in the Belgian context. It was an innovation in terms of the way of innovating, which simultaneously transformed the roles of the authorities and the actors involved in the pilot projects, as shown is Chapter 3.

The authorities put themselves in a position in which they had to assume a supporting role, a new role they nevertheless had to learn, even if final decisions officially rested with them. For example, the actions that the projects wanted to launch, and the way in which they wished to use the budget they were provided with, were still subject to the authorities' approval. Furthermore, the authorities had the power of stopping the projects. On the other hand, pilot project stakeholders had to make decisions about what should be done in the field in order to integrate care, which put them, to a certain extent, in the position of decision-makers in addition to their initial role of implementers, again as explained in Chapter 3.

An innovation can be either radical or incremental (Vreugdenhil et al., 2010). Integrated care pilot projects can be characterised as incremental. Paradoxically, it seems that the authorities expected radical effects on the health of beneficiaries, on their care consumption, and on health care expenses, given the high and very ambitious objectives set in terms of inclusion, as well as the pressure put on consortia to launch quick-win actions that would rapidly produce efficiency gains.

Not only did the projects fail to achieve their inclusion objectives for the reasons detailed in the previous chapter, but it would also appear that the amount of time given to them to launch their actions and have an impact on health care expenditure in such a way as to produce efficiency gains was largely underestimated. Importantly,

the time needed for the effects of new policies to be manifested and [the time needed] to become capable of measuring and isolating [those] from other factors, particularly where policies are seeking to tackle deep-seated economic and social problems [is a great source of uncertainty]. It may take some considerable time for pilot projects to become fully established so as to represent the conditions under which a policy would work when fully implemented. If the policy aims to change attitudes and behaviour or achieve institutional reform, effects may be difficult to achieve during the course of a pilot project. (Sanderson, 2002, p. 11).

Nevertheless, policy makers are eager for concrete and measurable effects from the policies they have launched, as their political mandate is limited in time. However, this logic, imbued with political interests, is nevertheless rarely compatible with the research and experimentation logic, given that such logic requires time to test, understand what is happening during the experiment, possibly make mistakes, analyse and understand the latter, and adjust the course of the experiment accordingly, because "surprise is endemic to experimental learning" (Lee, 1999,

p. 16). So, the research logic involves in-depth evaluation over a long period of time to identify what works and what does not work in the context of the pilot project under consideration (Sanderson, 2002).

A lesson that can be drawn here is that, in a context of innovation, "the idea of a social experiment has considerable appeal, but no worthwhile experiment can be carried out in an environment where all decisions and procedures are determined by a rule of 'minimum delay' " (Pressman & Wildavsky, 1984, p. 126) and, one could add, immediate efficiency, which nevertheless is often an important political concern (Sanderson, 2002). Of course, "the potential promise of new possibilities and practices is enticing but inherently laden with uncertainty and thus risk. Strong reliance on exploration can mean that undeveloped ideas turn into costly investments which may not yield the expected public value" (Compton et al., 2019, p. 125). Policy-makers should be aware of that when they choose to opt for pilot projects, and bear that in mind throughout the experimentation process.

### 2.4. Knowledge Orientation

"Knowledge orientation refers to the way in which a project is designed for knowledge creation and learning" (Vreugdenhil et al., 2010, p. 9). So, knowing that the term 'experiment' can be defined as "a scientific test that is done in order to study what happens and to gain new knowledge"<sup>40</sup>, the pilot project instrument is a specific work method which allows experimentations in real settings, to test and learn something about how the innovation under consideration interacts with the context (Flyvbjerg, 2006; Vreugdenhil et al., 2010). This also means that "the boundaries between phenomenon and context are not clearly evident" (Yin, 2009, p. 18). It is therefore, difficult, sometimes almost impossible, to infer unequivocal causal relationships as part of this kind of experiment. Indeed, as Sanderson (2002) put it:

a [...] set of difficulties arises in seeking to isolate effects of pilot programmes from exogenous change and from the effects of other initiatives that may also be having an impact on the same problems as those addressed by the pilot. (p. 11)

Among other things, the Belgian authorities explained that they had chosen to use pilot projects and mobilise hands-on professionals' experience and expertise due to the contextual nature of integrated care (Amelung et al., 2017; Minkman, 2020) and the lack of knowledge regarding the way integrated care could/should be implemented in the Belgian context. So, one could say

<sup>&</sup>lt;sup>40</sup> <u>https://www.oxfordlearnersdictionaries.com/definition/english/experiment 1?q=experiment</u> (accessed 30 June 2020)

that each integrated care pilot projects constituted a specific social experiment, conducted in real settings, intended to design and test new ways of working in the Belgian care sector in order to identify what works in what context in order to integrate care for a specific target group, i.e., chronic patients.

In this context, a public health inter-university scientific team was mandated to follow and evaluate the actions developed by the different pilot projects consortia during the execution phase. One of their tasks was to work in collaboration with the consortia to identify their best practices, and think about how these practices could be reproduced and diffused in other contexts so that they become common practices through a process of routinisation (Williams, 2011).

In terms of knowledge management, this means, by the way, that when designing the IC4BH plan, the authorities presupposed that there would necessarily be best practices to identify, that these would be measurable through the use of quantitative indicators, would necessarily have a quantifiable impact, *inter alia* helping produce efficiency gains, and would be reproducible and transferable to other contexts. "[This reasoning] is rooted in an approach to policy that assumes it is stable, observable and amenable to predictive analysis and generalizable patterns of cause and effect" (Needham, 2011, p. 32). It denotes an evidence-based rationalist and positivist vision (Dumez, 2016) based on an evidence-into-practice mechanistic approach and characterised by "a mania for quantification" (Porter, 1995, p. 20) producing a 'framing by numbers discourse' leading to information reductionism (Russell & Greenhalgh, 2011).

This vision is reassuring because it gives an illusory impression of objectivity and control over the situation (Morel, 2018; Sanderson, 2002) but seems biased, inappropriate and utopian in a context of social experimentation (Powell, 2011; Williams, 2011), *inter alia* because it does not allow us to grasp knowledge of a soft or tacit nature, particularly crucial in pilot projects, but the transferability of which is also particularly low given it is specific to the individuals involved (Vreugdenhil et al., 2010). Another problem refers to the fact that, by its very nature, a social experiment does not allow us to identify general causal and predictive laws that would apply to every context and would allow us to "always say unequivocally what works" (Powell, 2011, p. 25), but are social mechanisms anchored in concrete realities, as already explained above. Eventually, the quantification approach does not allow either to have a comprehensive approach in view of the social experiment's complexity (Porter, 1995; Russell & Greenhalgh, 2011). This is why an interpretivist approach would appear to be more appropriate (Dumez, 2016; Needham, 2011). So, the reason that led to call into question the reproducibility of integrated care pilot projects, i.e., their contextual dependency, also allows us to call into question the transferability of the potential best practices to be identified from one context to another. As a reminder, each project had a specific target population and each covered a specific geographical zone with very different socio-demographic and socio-economic realities. Consequently, a successful action developed in a specific context may be irrelevant in another and, if they appear relevant in this other context, their implementation in the latter may probably involve a translation process (Callon, 1984; Freeman, 2009; Needham, 2011), i.e., a transformation of these actions so that they make sense and fit with the local context and culture.

Accordingly, one can only call for caution with regard to this type of reasoning in terms of simple transfer of best practices from one place to another without taking the change of context into account. To paraphrase Williams (2011, p. 99), no, it is not possible to state that "All we have to do is roll out best practice everywhere else", due to the contingency principle (Friedberg, 1997; Powell, 2011; Sanderson, 2002). "Change, transformation and improvement cannot be delivered through the adoption of a recipe or formula that has been successfully implemented elsewhere" (Williams, 2011, p. 114).

Another important element to emphasise refers to the fact that during the conceptualisation phase, the scientific team collaborated with pilot projects to refine their evaluation models and to identify the indicators that could allow them to evaluate the future actions to be implemented during the execution phase. However, the scientific team was not in charge of analysing what would happen during the preparation and the conceptualisation phases in terms of social dynamics, which nevertheless appeared to be crucial, although difficult to quantify statistically.

Apparently, during the design of the IC4BH plan, what would happen during the preparation and the conceptualisation phases were not viewed as elements which should be analysed as part of the evaluation of the plan's implementation. According to the authorities, and maybe also according to some members of the scientific team, this would not have been relevant given that *the pilot projects would not have begun yet*. Therefore, there would be nothing to analyse and evaluate. Indeed, pilot project stakeholders were not officially implementing actions on the ground, but important things, worthy of scientific attention, were happening, e.g., the social collaborative dynamics that emerged in the different consortia when designing the loco-regional action plans and which were analysed in Chapter 4. Consequently, this ethnographic doctoral research highlights that the real beginning of the pilot projects might not have been the official one, namely, the beginning of the execution phase. On the contrary, one can put forward the view that the pilot projects began on the first day of the preparation phase, when stakeholders began to gather to constitute consortia in the field.

Hence, if one does not know what one is going to find, perhaps one should be aware that one may not know how to evaluate what one is going to find. Normal quantitative methods might appear to be insufficient or even irrelevant, and should possibly be used in combination with other new or less usual methodological approaches, such as field research. Innovation sometimes also requires innovation in (self-) assessment methods and thinking outside the box regarding evaluation.

Finally, a last important element to emphasise regarding the knowledge orientation descriptor refers to the fact that, in political contexts, pilot projects are not only used from a learning perspective. According to Vreugdenhil and Ker Rault (2010, p. 118), "policy-makers seem to 'abuse' pilot projects as alibi to show supremacy of their personal ideas, rather than using them to learn from", which denotes a strategic use of knowledge (Howlett, 2012; Vreugdenhil et al., 2010). As already mentioned in Chapter 3, Cook (1997, p. 40 as quoted in Sanderson, 2002, p. 5) even goes as far as to say that "the politician's prime goal is to be re-elected rather than to respect technical evidence", which means that their reputation is an important concern and depends on the accomplishments they have made during their tenure.

Consequently, one might wonder if the purpose of the integrated care pilot projects was to learn and produce new knowledge to inform policy making and make informed decisions, or to produce evidence intended to corroborate the initial vision of the policy-makers in charge and support political directions already taken. One will never know for sure. The interesting thing here is to note that pilot projects can be diverted from their primary exploratory function of engaging in collective social experiments to create knowledge that might help (re)orient action (Sanderson, 2002), and this can lead to some problems.

In the context of the IC4BH policy, pilot projects were both and simultaneously used as instruments of experimentation and implementation, i.e., they were simultaneously used for exploration and exploitation (March, 1991). This can be problematic given that "the trade-off between exploration and exploitation [...] involves conflicts between short-run and long-run concerns" (March, 1991, p. 74). Indeed, "the essence of exploitation is the refinement and extension of existing competences, technologies, and paradigms. Its returns are positive, proximate, and predictable. The essence of exploration is experimentation with new alternatives. Its returns are uncertain, distant, and often negative. Thus, the distance in time and

space between the locus of learning and the locus for the realization of returns is generally greater in the case of exploration than in the case of exploitation, as is the uncertainty" (March, 1991, p. 85).

This put stakeholders in a paradoxical situation. They were simultaneously expected to test innovative way of working with chronic patients, which should logically take time, and to have a visible positive impact on the Belgian healthcare system by implementing quickly, and on a pretty large scale, those innovative ways of working that should have been tested before, but were not, without knowing for sure that they would work. In other words, they were asked to exploit in a very short period of time what they had not been able to previously explore, which would nevertheless have been a prerequisite for being aware of the effects of the things to be exploited. This could be characterized as a double bind situation, i.e., "a situation in which no matter what a person does, he "can't win" " (Bateson et al., 1956, p. 251), which could impede the healthy development of the IC4BH policy.

Importantly, in Chapter 3, one might recall that pilot projects were described both as means of experimentation and implementation, when writing (p. 61) that

the use of the pilot project tool provide a means for a staged implementation process (Vreugdenhil & Ker Rault, 2010) leveraging the collaborative dynamic between involved stakeholders in order to "pragmatically **put fully developed policy** into practice" (Vreugdenhil et al., 2010, p. 13).

The important thing to understand and stress here is that Vreugdenhil et al. (2010) talked about a fully developed policy, which is not the case of the IC4BH plan given that when the authorities launched it, they were not even aware of the concrete innovative actions that would be designed, launched and tested as part of this public policy, delegating the design of those actions to the pilot projects stakeholders. It is the simultaneous injunction to quickly and simultaneously experiment and implement actions that produce visible results in the short term as part of a nonfully developed policy that was problematic here.

In other words, a simple lesson that can be drawn here is the following: before opting for the pilot project approach, it seems important to ask oneself whether one is pursuing an exploration or exploitation objective (March, 1991) and only then choose the appropriated method, no matter if it is top down or bottom up, as long as it is in line with the objective being pursued. The pilot project approach seems quite suited to exploration, but may not be a panacea in a process of exploitation with the constraint of obtaining tangible results quickly. More than that,

due to their explorative nature, pilot projects allow solutions to emerge which can then be exploited in a systematic way, for example as part of what Vreugdenhil et al. (2010) call "routine projects", i.e., conventional projects, the purpose of which is not to test new ways of working.

## 2.5. Special Status

"The special status is reflected in attitudes towards the project, its flexibility and the level of resource allocation" (Vreugdenhil et al., 2010, p. 10). In this section, integrated care pilot projects are analysed in the light of the following three dimensions.

a. Attitudes towards the project

Attitudes towards the project illustrates this special status, e.g., the allowance for failure. Indeed, "pilot projects are associated with innovation and one can identify a learning attitude and a tolerance toward what under non-pilot conditions would be considered failure" (Vreugdenhil et al., 2010, p. 10). Nevertheless, nothing is certain regarding the integrated care pilot projects. As Pressman & Wildavsky put it: "Should lack of knowledge be admitted and the program emerge as a so-called experiment, we like to think that the activities involved must be so arranged that the people who run them can learn from their errors" (1984, p. 126), which presupposes that they are also allowed to make errors in the first place.

Paradoxically, this did not seem to be the case for integrated care pilot projects in view of the pressure for attaining the inclusion objectives to which they were subjected, with apparently no acceptance of failure. Indeed, the rules relating to the inclusion procedure had to be applied to the letter, which created a situation characterised by what Morel (2018, p. 18) calls the "hell of rules, [which refers to the facts that the rules are] excessive in number, frequently inappropriate, overly complex, absurd, and associated with an often counterproductive punitive pressure".

As a reminder, there was the threat that pilot projects would be stopped if they did not succeed in achieving the number of inclusions expected of them, this being viewed by the government as a sign that the pilot projects were not implementing their actions as they should<sup>41</sup>, and, as a result, as a sign of failure (Dickinson, 2011). This presupposed that the level of development of the actions would necessarily be reflected in the number of inclusions, a presupposition established even before the actions were formulated by the pilot projects. Parenthetically, one

<sup>&</sup>lt;sup>41</sup> See p. 142

can argue that establishing evaluation protocols and indictors before knowing what actions are to be evaluated seems rather risky.

Actually, at the beginning, the success (or failure) of pilot projects was supposed to be mainly measured using two important numeric parameters: the number of inclusions and the efficiency gains they would have realised, with the presupposition that the latter would be proportionate to the former. As explained in Chapter 6, not only did pilot projects not succeed in achieving their respective objective regarding the number of inclusions they had to realise, but there was also a problem with the efficiency gains' calculation model, which means that, at first sight, after two years of operation, there were no reliable numeric parameters available to evaluate the projects' work. Nevertheless, "absence of evidence is not evidence of absence" (Altman & Bland, 1995, p. 485). Indeed, lack of evidence does not mean that no information was available, or that nothing had happened (Altman & Bland, 1995; Quertemont, 2011). Actually, "non-significant results are just as often the consequence of an insufficient statistical power" (Quertemont, 2011, p. 109).

Incidentally, the projects' stakeholders put the relevance of only considering these two indicators in isolation into question. Indeed, the administrative act of registering patients in an application did not mean that the latter would concretely benefit from actions, and that pilot projects would have an impact on their medical condition, their healthcare costs as well as the quality of services which were delivered. Theoretically, taking the issue to the extreme, one could even say that if the entire population of a project was administratively included in the application, it would be possible that no impact would be noted if nothing was concretely undertaken with them on the ground to enhance their situation (which was admittedly unlikely in the context of integrated care pilot projects). On the other hand, an impact could logically be noted if non-included patients benefited from project actions, provided that the latter have positive effects. Consequently, pilot projects' stakeholders stressed the need to also take qualitative indicators into consideration to faithfully reflect all the work done at the level of projects, which is why the performance model was developed, taking new criteria into account in terms of project evaluation. In view of this two paradoxes can be identified.

The first one refers to the frantic injunctions to achieve the objective pertaining to the number of inclusions, which were based on the fake assumption that efficiency gains would be proportional to the number of inclusions. Indeed, the example of the case management action seems to prove otherwise<sup>42</sup>. This led to a counterproductive mad race for inclusions at the projects level, some projects even deciding to set aside certain actions to give priority to actions that would increase their inclusion rate. Nevertheless, it would seem that the primary function of inclusion was to be able to identify patients who had formally agreed to participate in a project and to monitor the evolution of their situation over time, on the assumption that it would be influenced by the participation of these patients in the actions launched by the project. Patients' inclusion was supposed to be a means to evaluate the impact of the actions taken.

Perversely, due to the high pressure to increase the number of inclusions, the inclusion of patients became an end in itself. Actions became a means to include patients, and thereby attain the objective set by the authorities in order to be able to receive efficiency gains, the number of inclusions being an important criterion in the performance model. Importantly, the time spent to think about how to maximise the number of inclusions, and write an inclusion guidebook to make the inclusion procedure clearer for the partners, was not spent on implementing concrete actions in the field, which might have had a real impact, e.g., in terms of the amount of efficiency gains.

The second paradox pertains to the stopping of pilot projects before the end of the execution phase. Stopping them so early, before the end of the four-year execution phase, would prevent them fulfilling one of the inherent missions of a pilot project, i.e., learning from experimentation and creating knowledge, both in terms of success and failure (Pressman & Wildavsky, 1984), in order to enlighten future political decisions (Weiss, 1977). As Lee (1999, p. 3) puts it: "Note that the goal is to learn something: experiments can surprise the experimenter, and one mark of a good scientist is that she recognizes surprise and pursues its implications".

Actually, deception, mistakes and failure are real options when it comes to pilot projects, which entails adopting a reflexive posture in order to learn from them. Importantly, one could argue that saying that something does not work is creating knowledge as much as saying that something does work. Indeed, for example, in medical research, finding that a treatment does not work to cure a disease is certainly not as appealing as finding a cure, but it is helpful as a means of learning and making progress. So, why would this not be applicable to social experiments, such as integrated care pilot projects? This is of course a rhetorical question and as Kay & Boxall (2015, p. 34) put it: "policy failures might count as feedback and input into future [maybe successful] policy development".

<sup>&</sup>lt;sup>42</sup> See p. 158

More than that, one could even ask if it is relevant to talk about success and failure as part of a process of experimentation, even if it is as part of a policy. Incidentally, as Majone & Wildavsky (1984) put it:

Outside the static world of programmed decisions, "good" and "bad", ["success" and "failure"], take on multiple meanings. In an evolutionary context "good" means "faithful", but interestingly enough, it might also mean "faithless". A faithful translation of an ill-formed policy idea or theory would bring into being all the inconsistencies, inadequacies, and/or unfortunate consequences inherent in the pristine conception. A faithless interpretation would straighten out logical defects and/or alter elements so that the consequences were more desirable than those in the original plan. But immediately an objection springs to mind: this is not the original policy idea at all, but a new one transformed into something quite different [and maybe more relevant]. Quite right! If the implementation were faithful, then an imperfect idea would have been nursed along only to produce unsatisfactory effects. (p. 178)

So, would not it be more relevant to speak in terms of expected to unexpected outcomes instead of success and failure? Indeed, unexpected outcomes are not necessarily synonymous with failure. The possibility that unexpected outcomes, by luck, might even appear to be better than the expected ones truly exists. In hard sciences, this actually is an old phenomenon referred to as serendipity (Dumez, 2016), which, for example, allowed Alexander Fleming to discover penicillin, a discovery for which he received the Nobel Prize (Goggin & Goggin, 2018; Sand, 2020). So, it seems important not to conclude too quickly that the experiment carried out is just a failure even if the experiment deviated from what was originally planned. Anyway, as Compton et al. (2019, p. 121) put it : "to claim that a public policy, program or project 'X' is a success [or a failure] is effectively an act of interpretation"

## b. Pilot project flexibility

Special status is also reflected in pilot project's flexibility, i.e., "the freedom not to have to follow standard procedures" (Vreugdenhil et al., 2010, p. 10), at least during the design phase. An example of such flexibility was the possibility for integrated care pilot projects to create new types of care delivery that did not exist in the current NIHDI nomenclature, but which nevertheless created the need for pseudocodes. However, the latter were not available until at least April 2020, which was a problem in terms of launching and evaluating the actions requiring them.

## c. The level of resources allocation

The last dimension of the pilot project special status refers to the level of resources allocation, i.e., the fact that the pilot projects generally benefit from additional resources in comparison with routine circumstances. These additional resources can be financial but also material or human (Vreugdenhil et al., 2010). For example, in the context of the IC4BH plan, the federal authorities provided the budget for financing the coordinator's salary, a person who had to work exclusively on project development. During the execution phase, they also released a budget of  $\epsilon$ 2.5 million to provide each project with a one-shot lump sum of  $\epsilon$ 208,333 following the problem identified with the calculation model, to replace the long-awaited 2017 efficiency gains. In terms of resources, one should also mention that, in the case of projects A and B, some partner institutions made premises available free of charge to host project meetings during the conceptualisation phase and at the beginning of the execution phase, until the projects found their own premises.

In addition, and importantly, most of the people attending meetings did so voluntarily and without any payment, thereby reducing the amount of time left to carry out their other tasks. In other words, they gave working time for free to support their project. Vreugdenhil et al. (2010, p. 11) explain that "enhanced allocation of resources occurs because actors wish to be at the forefront of innovation, make societal contributions or try to influence the course of the pilot and related policies". One might add that, as explained in Chapter 3, pilot project stakeholders also feared to being compelled to work in certain ways if they were not involved in the setting up of integrated care pilot projects, given that they would probably have latitude for influencing the course of events.

#### 2.6. Actor Network

This last descriptor refers to the actors involved in the pilot project as well as the project governance style. Indeed, pilot projects generally involve a greater and wider range of different actors than those involved in laboratory experiments or in projects that are not pilots, leading to a multi-actor alliance (Vreugdenhil et al., 2010). With regard to the integrated care pilot projects, one can see that the building of this multi-actor alliance began with the preparation phase, when interested field workers were asked to gather and constitute local multidisciplinary consortia, which shows again that something in terms of social dynamics, although unquantifiable but worthy of scientific attention, happened before the execution phase.

As a reminder, during the conceptualisation phase, in order to organise their collaboration and to be able to hand in their applications on time, pilot projects candidates were advised to follow the non-mandatory open governance structure presented in Chapter 4<sup>43</sup>. During this phase, pilot project stakeholders had to make decisions about their future governance, including the way they would work together and make decisions during the next phase. Specifically, they had to choose a governance structure for adoption during the execution phase, and identify or create a structure with a legal personality to receive the management integration budget and the efficiency gains.

As also explained in Chapter 4, Projects A and B decided to create two independent ASBLs, whereas Project C opted for a *de facto* association<sup>44</sup>. What is important to stress here is the emergence of three new collective actors, each crystallising a multi-actor alliance within a specific territory (Vreugdenhil et al., 2010) and taking the form of a network (Axelsson & Axelsson, 2006; Powell, 1990). These specific networks had many characteristics in common with what is called an "integrator" (Berwick et al., 2008, p. 763) in the scientific literature on integrated care, even if it seems that the pilot projects' networks were never explicitly designated as such, neither in written documents, nor orally during interactions observed as part of this research. As part of this discussion, it now seems important to develop this argument in more detail.

As a reminder, as part of the IC4BH plan implementation, the Belgian authorities pursued the achievement of the Triple Aim. Interestingly, Berwick et al.

suggest that three inescapable design constraints underlie effective accomplishment of the Triple Aim: (1) recognition of a population as the unit of concern, (2) externally supplied policy constraints (such as a total budget limit or the requirement that all subgroups be treated equitably), and (3) existence of an "integrator" able to focus and coordinate services to help the population on all three dimensions at once. (2008, p. 762)

Furthermore, Berwick et al. define the integrator as

an entity that accepts responsibility for all three components of the Triple Aim for a specified population. [...] It will be able to recognize and respond to patients' individual

<sup>&</sup>lt;sup>43</sup> See p. 94

<sup>&</sup>lt;sup>44</sup> See p. 100

care needs and preferences, to the health needs and opportunities of the population (whether or not people seek care), and to the total costs of care. (2008, p. 763).

This entity can take a variety of concrete forms. For example, it can be an insurer, a hospital, a primary care group in partnership with payers, etc. The integrator is assigned the role of linking organisations that have a role to play in the health of the population for which they are responsible, including health care, public health and social organisations, and coordinating their work in order to create a continuum of care so that they can jointly deliver integrated care to the population. For this reason, the integrator has to be a single organisation (Berwick et al., 2008).

Interestingly, these characteristics also picture the ASBLs and the *de facto* association emanating from integrated care pilot projects, as not being direct care providers. Their role consists of helping organise care in a coherent way for the population living in their respective geographical zone using the resources at their disposal, in the manner of a conductor who would allow the musicians to collectively perform a work, without himself playing an instrument. In this way, each project consortia ensures coherence between the actions launched on the territory of the project, whether they are new or already existed. In the case of actions that already existed, the pilot project consortium viewed as an integrator, plays the role of a catalyst for the diffusion and implementation of those actions within the project territory.

The networking process, and the resulting emergence of an integrator-like actor, is probably a consequence of the use of the pilot project instrument, but one will never know if it was a stated purpose of the authorities when they chose to use this instrument. In any case, whether or not it was an a priori objective, it seems important to highlight that a side effect of the use of the pilot project instrument was the emergence of collective actors on the Belgian territory that seem to have the characteristics of the integrator as defined by Berwick et al. (2008).

A lesson to draw from this observation is that when developing integrated care, analysing the process of the constitution of the "integrator" actor seems relevant, given its strategic importance in the achievement of the Triple Aim, which is precisely why one can say, *a posteriori*, that the preparation and conceptualisation phases were worthy of scientific attention. After all, as Axelsson & Axelsson (2006, p. 79) put it: "integration in public health is primarily a question of co-operation and collaboration between different organisations".

## 3. Implementing the Loco-Regional Actions Plans: Process Inclusivity

In an explorative context, workers in the field were delegated the task of both designing and testing new actions which, if successful and identified as best practices, could lead to the development of integrated care for chronic patients on a national scale. In the literature on policy making and policy design, this approach relates to the notions of "collaborative innovation" (Torfing, 2019, p. 4) and "process inclusivity" (Compton et al., 2019, p. 124), both of which refer to the degree to which diverse interests are represented in the decision-making process, *inter alia* those of the directly affected stakeholders.

Including the latter in decision-making is considered desirable for several reasons. Given their experience and proximity to the field, they are more aware of the local context, which would allow them to produce tailored solutions and, as a result, solutions that should be more adequate. Furthermore, bottom-up collaboration between those stakeholders is also viewed as an advantage in terms of enhancing the legitimacy of the policy and helping build trust. Eventually, given that they will have a role to play in the implementation of the decisions made (Compton et al., 2019; Lee, 1999), it is also expected to enhance the acceptance of these decisions (Vreugdenhil et al., 2010).

In the context of the IC4BH plan, the use of pilot projects was a way to achieve inclusivity by including workers in the field in the process, by encouraging them to work in "co-creation"<sup>45</sup> in order for the project to benefit from their respective experience (Gouillart & Hallett, 2015). Nevertheless, if this inclusive co-creation approach leading to multi-actor collaboration (Torfing, 2019) may be seen as a key facilitating factor (Compton et al., 2019), especially in a context of innovation (Torfing, 2019), an important lesson do draw from this research is that it alone does not guarantee the achievement of the desired outcome, or that events unfold as planned. This doctoral research actually shows that it also brought with it new issues that needed to be addressed, as explained in the previous chapters of this thesis. In the specific case of the IC4BH plan, one could also note that process inclusivity did not solve the difficulties linked to the question of moving to practice that professionals would probably also have faced if the actions had been designed by the authorities instead of by their peers: it would seem that it simply shifted the problem.

<sup>&</sup>lt;sup>45</sup> See interview excerpts pp. 65-66 and p. 96

Indeed, it seems that the authorities thought that the implementation of the loco-regional action plans would flow naturally without a hitch. Instead, both pilot Projects A and B stressed that they experienced unanticipated difficulties when it came to moving from discourse to practice, and to implement their loco-regional action plans in the field. This was, in addition to the difficulties related to budgetary aspects, to cumbersome administrative procedures, to faulty IT tools and to the inclusion procedure. They stressed the importance of what was called the "behind-the-scenes work"<sup>46</sup>, referring to the time spent to make the project known, involve new partners in going beyond the group of project originators, and think about how actions could be operationalised concretely.

Importantly, an intermediate phase of cogitating collaboration (De Winter, 2019), between the conceptualisation and the execution of actions, appeared to be necessary to focus on the latter aspect. So, to complete the argument developed in Chapter 4<sup>47</sup>, this additional intermediate phase was necessary after having answered the question "What are we going to do?" during the conceptualisation phase. There was a need to answer a second question before moving to the "let's try it", i.e., "Concretely, how do we do that on the ground, and with whom?", and, more specifically "How do we do that with people who were not involved in the decision-making process pertaining to the loco-regional action plan during the conceptualisation phase?" Indeed, in order to move to practice during the execution phase, most of the actions designed during the conceptualisation phase required the engagement, intervention and collaboration of people who had not participated in the design of these actions.

So, regarding the loco-regional actions plans, the group of potential implementers was far larger than the group of pilot project stakeholders who took on the role of decision-makers during the conceptualisation phase. This means that a handover process was necessary so that the implementers could appropriate, both individually and collectively, the loco-regional action plan and the actions they were expected to help implement, which again required time. It involved this new group being informed of the actions involved, understanding the logic behind those, and recognising them as being relevant. Then, the interested professionals had to understand the role they were supposed to play in the implementation of these actions and with whom they should collaborate, estimate the additional workload that this would potentially place on them, possibly formulate an opinion on the actions in question (for example, they did

<sup>&</sup>lt;sup>46</sup> See p. 154

<sup>&</sup>lt;sup>47</sup> See pp. 102-103

not seem to be operational as they stood), sometimes even propose certain adaptations to make actions correspond to their concrete reality on the ground, in such a way as to eventually allow them to be able to translate actions into practice. Only then, could a test phase in the field be envisaged.

Again, this learning and appropriating stage, requiring both individual and organisational learning (March, 1991) and receptiveness (Williams, 2011) when implementing loco-regional action plans, was not anticipated neither by the authorities, and nor perhaps by the pilot projects stakeholders. These stakeholders depended on each other to achieve the missions assigned to them, but the role they each would accept to play was nevertheless uncertain. They could accept or refuse, totally or partially, to do what was expected of them and, even if they accepted, they were not sure whether or not they could succeed in their endeavour. The central issue here resides in the fact that their behaviour regarding the policy was not predictable, which made the implementation very uncertain.

So, if process inclusivity is obviously important and is recognised in the scientific literature as a success factor (Compton et al., 2019; Torfing, 2019), it is also important not to view it as a magical wand that alone would erase all the uncertainties and guarantee the implementation of a policy. To use mathematical language, one could say that it may potentially be viewed as a necessary condition, but certainly not as a sufficient one.

## 4. Research Perspectives

## 4.1. Next Steps of this Ethnographic Research

In view of what has been achieved so far in terms of research regarding the IC4BH plan, several research perspectives can be identified. The first one, and perhaps the most obvious, consists of continuing the ethnography study during the rest of the execution phase, as well as during the expansion phase. It would seem relevant to focus on the following three elements:

- The way pilot projects consortia will continue to implement their actions and move to practice.
- The way users experience the actions intended for them, especially the new ways of delivering care at the micro-therapeutic level.
- The way the expansion phase will operate. This would entail focusing on the way the practices identified as best practices will be translated from a context to another.

Furthermore, it would seem interesting to put the results of this doctoral research into perspective with the work carried out by the scientific research team in charge of evaluating the projects. Eventually, there would probably also have been something to learn from the projects that dropped out during, or just after, the preparation phase, during the conceptualisation phase, and just after the conceptualisation phase, before the execution phase begins.

#### **4.2.** A Comparative Approach Regarding the Pilot Project Phenomenon

From a comparative perspective, this research could be put into perspective with similar research focusing on other pilot projects in the Belgian health sector, or even pilot projects conducted in other countries. Furthermore, a comparison could also be made with pilot projects conducted in other sectors both in Belgium and abroad, e.g., education, employment, social action, etc., to identify what is specific for each sector regarding the use of pilot project and what are the common characteristics of the pilot project instrument, whatever the sector in which it is used.

## 4.3. The Belgian Lasagne of Pilot Projects and its Consequences

Another new research issue emanating from this doctoral research relates to the proliferation of pilot projects in different healthcare sub-sectors in Belgium, and its consequences for stakeholders who are involved in several of them. As already explained in both Chapters 3 and 4, integrated care pilot projects are part of a long series of pilot projects launched over time in the Belgian health care sector. Importantly, these different pilot projects do not cover the same geographical zones, and can overlap, but often not completely. This means that a pilot project of a certain type may straddle the areas of several pilot projects of another type. Furthermore, one can also find several pilot projects of a certain types on the territory of one pilot project of another type. This gives birth to important issues of coordination, concertation and collaboration between the different types of pilot projects and networks.

Indeed, over time, different pilot project consortia/networks have realised in retrospect that they had more or less the same idea(s) and put a lot of energy into developing very similar actions in parallel, e.g., developing a directory of existing services in their territory or developing a communication strategy from A to Z, when they could have saved time by benefiting from the experience of other pilot projects, whether or not they belonged to the same category. Another problems resides in the fact that some partners were involved in several pilot projects and had accordingly to attend numerous meetings for each type of project, which appeared to be very time-consuming and created important additional workload for them.

So, if the initial purpose with regard to the different types of pilot project was, more or less explicitly, to integrate care, one can observe that an unanticipated effect resides in the emergence of counterproductive new fragmentations at other levels due to the current (and possibly incoherent) "lasagne" of networks emanating from different pilot projects. As a result, there is need for further research regarding this issue by focusing, in a more transversal manner, on the different types of pilot project and the extent to which they on the way they interact or not, as the case may be.

## 4.4. The Concept of Integrated Care and its Semantic Ambiguity

According to Woolf (2008, p. 211), "translational research means different things to different people, but it seems important to almost everyone". The same could be said of integrated care. Indeed, this research indicates that an important semantic ambiguity relates to the concept of "integrated care" itself. Indeed, similarly to the concept of empowerment, analysed in Chapter 5, the concept of integrated care is also an umbrella term. Amelung et al. (2017, p. 21) even talk of "conceptual soup", as explained in the introduction. Some problem can arise from this polysemy when attempting to develop and implement integrated care.

A same word does not necessarily refer to the same reality for everyone. This will depend on the position occupied by a person. For example, if two people facing each other say "let's go left", they will not go in the same direction even if they have used the same words. Similarly, several people can collectively decide to move towards integrated care and go in different directions when translating the concept into practice. It is problematic because this would mean that there had been no prior agreement and common understanding on the very nature of the problem, which could lead to a 'dialogue of the deaf' (Torfing, 2019).

Metaphorically, the idea of moving towards integrated care seems to be as vague as the sentences "I feel like traveling. Would you come with me?". Concretely, if you say that to someone, your interlocutor know that you want to leave and go from one place to another with him or her. Nevertheless, he/she would not know where exactly you want to go, nor how you want to get there, i.e., by what mode of transportation, and would have no idea of some very concrete and practical aspects, e.g., how much the trip would you cost. Maybe each of you will have different destinations, modes of transportation and budgets in mind.

It seems that the Belgian authorities and pilot project stakeholders engaged in a trip towards integrated care without agreeing on a very concrete definition of the concept, and on the concrete modalities and aspects hidden behind this concept. Actually, it is logical, because if everyone seems to agree on the fact that integrated care is a solution to care fragmentation, all the actors do not concretely experience care fragmentation in the same way. As a result, they will almost inevitably imagine different solutions to overcoming the specific type of fragmentation they have experienced, knowing that they perhaps do not even use the word 'fragmentation'. Instead, they will probably talk about the difficulties they experience in their work.

This does not mean that the concept of integrated care should be scrapped, but rather that this ambiguity must be taken into account when initiating care integration. One may assume that defining integrated care involves initially defining care fragmentation. This would involve grasping how the different categories of actors in the healthcare system (that is those from macro, meso and micro levels) experience care fragmentation by asking what difficulties they experience, and to what concrete realities the notion of care fragmentation means to them, e.g., inadequate care delivery, bad results in terms of public health, difficulties in terms of collaborating with other actors, patients' dissatisfaction, loss of time, loss or waste of money, etc.

On this basis, in a second step, they may be asked what solutions would be appropriate to overcome this specific type of fragmentation. Their answers could be similar, different, complementary or even incompatible, but one would then have a very clear and concrete idea of what (care) fragmentation is, and what integrated care is/should be, according to the various actors, which could be a useful starting point. Nevertheless, this doctoral research is not an appropriate vehicle for exploring this hypothesis scientifically. Rather, this would require further research, at least with regard to the concept of fragmentation.

## 5. Conclusion

As a reminder, the starting point of this discussion referred to the observation that events did not unfold as planned during the implementation process of the IC4BH plan: there existed an implementation gap between the expected outcomes and those concretely achieved in the field. So, the purpose was to highlight and analyse certain presuppositions, shortcomings, ambiguities, paradoxes and absurdities pertaining to the IC4BH plan implementation, as noted throughout the ethnographic work on which this doctoral research is based.

In the second section of this discussion, integrated care pilot projects were analysed in the light of six descriptors identified by Vreugdenhil et al. (2010). Firstly, the focus was on the global and local contextual dependency of pilot projects, which cannot be isolated from their biophysical, local, societal, political and institutional contexts, e.g., the federal institutional configuration that hindered the implementation of integrated care. The contextual dependency of integrated care pilot projects induced a low level of reproducibility of the social experiments conducted in real settings. Furthermore, concerning the incidence of occurrence, if, at first glance, one might think that the twelve pilot projects that entered the execution phase constituted comparable experiments, this is not entirely true on closer inspection. Indeed, each pilot project had its own specific target population, arrived at different inclusions aims, targeted different diseases, and designed different actions. So, from this low level of standardisation there stemmed a lack of comparability between the projects.

Secondly, regarding the scale descriptor, contrary to what really happened in the field, the authorities expected pilot projects to rapidly initiate actions on a relatively large scale in order to quickly identify best practices which could be expanded at a national level after the four-year execution phase. However, the pilot projects under consideration in this research chose to begin by testing their actions in real settings on a very small scale in order to preserve the reversibility of their actions, and to avoid having potentially damaging irreversible effects on a large scale. Consequently, it would seem that this sort of small scale exploratory phase, although relevant, was missing in the initial plan.

Thirdly, innovation is at the core of pilot projects. As part of the IC4BH implementation plan, the obvious level of innovation refers to the innovative actions designed by pilot project members to integrate care for chronic patients. Nevertheless, other levels of innovation can be identified, *inter alia* the specific way of delegating the design of concrete actions to workers in the field through the launch of pilot projects, involving a redefinition of the roles of the parties involved. One can argue that this constitutes an innovative way of innovating.

Fourthly, an inherent purpose of using pilot projects consists of learning from the experiment carried out to create new knowledge. The authorities launched pilot projects with the purpose of identifying best practices, measurable through the use of quantitative approaches, which could be transferred to other contexts during the expansion phase. This research put into question the transferability of those best practices, as well as the evidence-based rationalist and positivist vision reflected in this exclusively quantitative approach, leaving aside knowledge of a soft or tacit nature, e.g., the social collaborative dynamics emerging during the two first phases of the plan implementation. On another note, it is difficult to infer unequivocal causal relationships as part of the social experiments conducted in real settings with regard to integrated care pilot projects, due to the diversity of contextual factors that can influence the

actions conducted. Eventually, this ethnographic research helped identify a paradox in the way the pilot projects were used, i.e., both as instruments of experimentation and implementation, putting pilot projects stakeholders in a double bind situation, i.e., a situation in which they were asked to simultaneously fulfill incompatible goals. Actually, the authorities were eager to measure the effects of the pilot projects' actions, but their short-notice expectations were incompatible with the experimentation logic. Experimentation is indeed a long-term endeavour, hence the importance of choosing methods appropriate for the objectives being pursued.

Fifthly, pilot projects are generally given special status, involving specific attitudes toward the projects, a certain degree of flexibility, and a specific level of resources allocation. In principle, this special status is *inter alia* reflected in the tolerance for what would be viewed as a failure in other circumstances, a tolerance from which the integrated care pilot projects could apparently not benefit. Indeed, the projects were put under a lot of pressure, *inter alia* regarding the achievement of their respective inclusions aims. The findings of this ethnographic research nevertheless show that the number of inclusions, taken alone, were not sufficient to evaluate the pilot projects' achievements. In the view of this, it may be useful to reconsider the notions of success, mistakes and failure and talk instead of expected and unexpected results in a context of experimentation, allowing the experimenters to adopt an open posture towards the discovery of new elements.

The "actor network" is the last descriptor identified by Vreugdenhil et al. (2010) and refers to the diversity of actors involved in a pilot project constituting a multi-actor alliance. This descriptor is particularly relevant in the case of integrated care pilot projects because it highlights the importance of the social dynamics at work in a pilot project, that seem nevertheless to have been given little consideration in the context of the IC4BH plan implementation. Actually, the pilot project consortia, which progressively formed during the preparation and conceptualisation phases and took the form of nascent networks, might be viewed as the so-called *integrators* in the scientific literature pertaining to integrated care. This observation seems important given that the existence of an integrator, which links organisations that have to play a role in care integration, is viewed as crucial for the achievement of the Triple Aim.

The third section discusses the conceptual notion of process inclusivity viewed as a success factor in public policy literature, and materialized in the case of the IC4BH plan through the involvement of hands-on professionals in pilot projects. This research suggests that, while process inclusivity might be a key facilitating factor, it does not in itself guarantee that the

implementation process will run smoothly. Uncertainties pertaining to the fact of moving to practice, which requires individual and organisational learning remain, whatever the number of actors involved, the number of layers with regard to which implementation is conducted, and by whom it is conducted.

The last part of this discussion is dedicated to the presentation of several research perspectives: continuing this ethnographic research including a focus on users' experience, adopting a comparative approach regarding the pilot project phenomenon and/or focusing on the Belgian 'lasagne' of pilot projects and its consequences. However, the most promising one emphasises that, after all, perhaps the first thing one should focus on, when working on integrated care, may not be integrated care *per se*, or care integration, but care fragmentation.

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## **General Conclusion**

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It is only when the research is completed that one can tell where it should have started — Hervé Dumez, 2016, p. 34 Through this doctoral research, the purpose was to make a contribution to public policy science by analysing different aspects of the implementation process of a specific public policy intended to integrate care for chronic patients in Belgium: the "Integrated care for Better Health" plan, launched on 19 October 2015. With this aim in mind, this manuscript was structured to include seven chapters. The first chapter was dedicated to methodological aspects. The next four chapters, each corresponding to a specific paper, each addressed a specific research question to study different dimensions pertaining to the IC4BH plan implementation.

The first paper (Chapter 2) addressed the question of how the specific Belgian federal configuration may have had an influence on the implementation of this public policy in the health care sector in Belgium. It showed that, in addition to the number of layers composing the Belgian federal state, other factors may have contributed to producing the implementation gap that is apparent when comparing expected and real outcomes with regard to the implementation of the IC4BH plan. Indeed, the autonomy of the governing entities, coupled with a lack of coordination as well as an incoherent distribution of competences, resulted in a lack of coherence between the decisions made and the instructions given at the different levels, involving a lack of coherence between the actions undertaken in the field due to the mirror effect.

The second paper (Chapter 3) focused on the pilot project phenomenon, regarded as an object for research, trying to understand how the use of multidisciplinary pilot projects as implementation instruments reshaped modes of public governance in the Belgian health sector in a context of transition and ongoing devolution. Instead of leading to a simple transfer of tasks to the pilot projects consortia, it modified the roles of both the authorities and the hands-on professionals involved in the pilot projects. The former were progressively taking on a new role of support, whereas the latter were taking on a new role of representation and, to some extent, of decision-makers in addition to the role of implementers. This shift in roles required the development of vertical collaboration as part of a co-creation dynamic and gave birth to new practices, e.g., intervisions during which the authorities (policy-makers and IAC members) could interact with pilot projects representatives. Nevertheless, these interactions were not always peaceful, the people involved in those interactions each having their own logic of action (expertise-based vs. practice-based) and each having their own views as to what needed to be done. Hence, one can note the emergence of a more negotiated governance characterised by a tripartite crossed-regulation (Crozier & Thoenig, 1975). The third paper (Chapter 4) tackled the issue of knowing how the use of pilot projects as implementation instruments would structure the collaboration between parties involved in a pilot project. Actually, thanks to its interactionist and processual rationales, it would seem that the use of the pilot project instrument created the conditions allowing the progressive emergence of specific forms of organisations, i.e., collaborative care networks and, more specifically, of what could be called community-based integrated care networks. Importantly, a network is not decreed. Rather, it is built and lives through the interactions between its members. So, an interesting lesson that might be drawn from this paper is that the constitution of a cohesive network, aware of its existence, is a long term endeavour. This requires that the partners involved tame each other and define together, as part of a cogitating collaboration process, their common identity, the reason for the existence of their project, as well as the common goal(s) they would want to achieve together. This constitutes a first necessary step before moving to operational collaboration in the field.

Combining the results of three different studies in an inductive secondary analysis, the fourth paper (Chapter 5) presented a cross-level approach of the concept of empowerment, one of the integrated care components, which is viewed as an umbrella term in the scientific literature. It indeed encompasses different concrete realities, and means different things to different people. So, more specifically, the analysis related to the consequences that might stem from the polysemy of this concept when different health care stakeholders have to work together, and showed that the lack of agreement on a common meaning can make this concept difficult to appropriate and operationalise at the different levels of a health care system.

Then, Chapter 6 was dedicated to the development of additional empirical elements which were not presented in the four papers, although important to support the arguments developed in the discussion (Chapter 7). The latter *inter alia* echoed the old but not outdated work of Pressman & Wildavsky (1984) and of Morel (2018): it highlighted certain presuppositions, shortcomings, ambiguities, paradoxes and absurdities that might help understand why one can note an implementation gap when comparing the expected and real outcomes achieved as part of the IC4BH plan implementation.

Interestingly, the different chapters of this manuscript have one thing in common: they all focus on the softer aspects of a human, social or contextual nature, which were passed over in silence as if they were unworthy of political and scientific attention as part of the predominantly quantitative approach adopted by the authorities. Just as a side note, quantification is obviously not a problem *per se*. It is quite useful when it comes to analysing and understanding the reality under consideration. Quantification becomes a problem when the numbers produced and mobilised are disconnected from the reality they refer to, and when they are too much trusted, i.e., when quantification is elevated to the status of dogma. After all, to escape this quantitative fantasy, it is important to remember that numbers are only signifiers that refer to signifieds. In other words, numbers constitute a language which makes it possible to seize reality, but they are not the reality they help understand. Taken alone, they may give a reductive vision of the studied phenomenon.

Actually, although evolving in a context of innovation inherently characterised by unpredictability, the authorities seemed paradoxically to search for predictability in the view of the numeric indicators they had chosen to evaluate projects achievements. Furthermore, they seemed to be in no doubt that reproducible and transferable best practices could be identified. However, this approach led them to miss a major point. As explained several times, building collaborative capacity is a prerequisite when integrating care (Amelung et al., 2017): collaboration, intrinsically human, is the cornerstone of integrated care. So, if the abovementioned contingent human, social and contextual aspects addressed in this manuscript were inherently unpredictable, they nevertheless (for some, unexpectedly) played a decisive role in the course of events and, as a result, would have been important factors to take into account when analysing the implementation of the IC4BH plan.

As a reminder, when analysing the diversity of actions designed by the different pilot projects, one can conclude that they were often not comparable and, as a result, did not constitute occurrences of the same experiment. However, by focusing on contingent softer aspects (organisational structure, levels of interdependences, multiple interpretations of mobilised ideas/concepts, emotional aspects, e.g., group cohesion and climate, good or bad relationships, level of conviviality in the exchanges, ...), this research has revealed that the social dynamics at work (e.g., in terms of governance, leading to the constitution of integrators taking the organisational form of networks on determined geographical zones) may be precisely what the pilot projects have in common, and may be the component in terms of which they are comparable.

This observation, although unexpected, can be of interest for anyone who wishes to embark on a care integration process. Let us add that "the exploration of more open styles of governance could [even] be a goal in itself" (Vreugdenhil et al., 2010, p. 11). Consequently, just because human factors are unpredictable does not mean that they should be set aside. On the contrary, "taking into account the black box of field human factors is an unavoidable requirement in the quest for high reliability" (Morel, 2018, p. 238). More than that, human collaboration is not a medical disease or phenomenon and, as a result, should not be treated as such when it comes to evaluation and analysis. It requires specific analytical approaches and tools that can be both quantitative and qualitative in nature.

So, to conclude, let us recall an important observation, which ties together and summarises all the disparate parts of this research: integrating care is not just a question of care. So, when integrating care, the issue is not so much to think about new treatments, but rather to think about new ways of administering existing treatments, and how to initiate actions to prevent people from getting sick. The innovation at stake seems therefore more of an organisational and social nature than therapeutic.

# Appendices

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# Appendix 1: Example of Interview Guide with a High-ranking Official (Federal Level)

Thématiques	« Indicateurs »
Identification	Quelle est sa formation initiale ?
	Quel est son parcours ?
	Sa position actuelle ? Son travail quotidien ?
	Quel rôle est-ce que cette personne a joué/joue dans la réforme ?
	Quel rôle jouera-t-elle à l'avenir dans cette réforme ?
La réforme : les acteurs	Qui sont, à son avis, les acteurs à l'origine de la réforme ? (impulsion)
	Qui sont les acteurs qui ont contribué à définir cette réforme ? (conception)
	Qui sont les acteurs responsables de la prise de décision dans le cadre du lancement et du suivi de la réforme ? (décision)
La réforme : processus de lancement	Quelles ont été les grandes étapes dans la conception et le lancement de la réforme ?
	Quelles sont, à son avis, les moments-clés au cours de son implémentation ?
	Comment a été diffusée l'information de la nouvelle de la création du plan et comment a été accueillie la nouvelle ?
	Quels obstacles/difficultés ?
	Quels soutiens ?
La réforme : les « bonnes raisons »,	Qu'est-ce qui, à un moment donné, a provoqué le besoin d'un changement dans la gestion des soins de santé dédiés aux patients chroniques ? (éléments déclencheurs)
sa rationalité	Volonté politique/idéologique ?
	• Nécessité économique ? Contexte sociodémographique ?
	Connaissances scientifique ?
	• Evolution « historique » ? Quelles sont les initiatives annonciatrices d'un tel changement au niveau belge ?
	• Contexte international ? Quels sont les exemples étrangers qui ont pu servir de sources d'inspiration, qu'est-ce qui est transposable ou non en Belgique ?

La réforme : le programme (modèle de soins- aspects substantiels)	<ul> <li>Pourquoi être si général par rapport à la définition des maladies chroniques ? Pourquoi dans le guide on parle des maladies chroniques en général et que les projets en cible des spécifiques ? Comment est-ce qu'on va élargir par la suite ? (parce que les spécificités des maladies ne vont pas changer).</li> <li>On parle d'<u>extension progressive</u> au niveau des groupes cibles : comment va-t-elle s'opérer ?</li> </ul>
La réforme : le processus (plan d'implémentation – aspects instrumentaux et procéduraux)	Les projets-pilotes sont-ils, à son avis, la meilleure façon de débuter une telle réforme ? Est-ce que cette solution comporte cependant des risques, lesquels ? Quelles sont, au contraire, les opportunités présentées par les projets pilotes ?
	<ul> <li>Quels sont les éléments-clés, les enjeux centraux des projets-pilotes ? (la coordination, standardisation, procéduralisation, évaluation continue, formation ?)</li> <li>Comment sélectionner les projets ? 16 projets à la base, on est passé à 20, pourquoi ?</li> <li>Comment évaluer les projets ?</li> </ul>
L'implémentation de la réforme : premiers constats	Problème avec les médecins généralistes : quels types de problèmes et pourquoi d'après lui/elle ? Autres difficultés ? Des « réussites » ? Des « surprises » ?
Question spécifique	Phase conceptualisation : fin le 31/1 ou pour mars ? combien de projets seront choisis pour la phase d'exécution ?
Thématiques de recherche à cibler	La formation professionnelle ? Le métier de coordinateur ? Autres ???
Autres acteurs à rencontrer ?	Qui serait-il pertinent de rencontrer dans le cadre de cette recherche ?

## **Appendix 2: Example of Interview Guide with a Public official (Regional level)**

## 1. Présentation/Identification de l'interviewé.e

Quelles sont les études et le parcours professionnel de l'interviewé.e ?

Quelle est <u>sa fonction</u>/Quelles sont <u>ses fonctions actuelles</u> et comment est-il/elle arrivé à cette/ces fonction(s) ?

Quel est le rôle de l'Aviq et des régions dans le plan conjoint sur les soins intégrés en faveur des patients chroniques ?

Depuis quand l'Aviq/le cabinet régional est-il impliqué dans le projet soins intégrés pour patients chroniques ?

Depuis quand est-ce que l'interviewé.e travaille sur ce projet ? En quoi est-ce que cela

consiste ? Est-ce une occupation à temps plein ou la personne a-t-elle d'autres choses à gérer en parallèle ?

Comment est-ce que la nouvelle du plan a été accueillie au niveau régional ? : Favorable ? Défavorable ?

Est-ce que d'autres personnes travaillent sur ce sujet ? Qui fait quoi ?

## 2. Implémentation du plan : Les projets pilotes

Quel est le lien entre le plan et la 6<sup>e</sup> Réforme de l'Etat ? Quelles compétences ont été transférées ?

Est-ce que le niveau fédéral et le niveau régional travaillent ensemble ? Comment ?

Quelle est la fréquence des groupes de travail Inter-cabinets ? Qui est présent et de quoi y parlet-on ?

Quelles sont les obstacles rencontrés jusqu'à présents ? Ou au contraire quels soutiens peut-on identifier dans le cadre de l'implémentation du plan ?

Quels financements sont prévus dans le cadre de l'implémentation du plan et du lancement des projets pilotes ?

Quel est son avis sur la réforme : que garder et que changer/améliorer ?

Qui serait-il pertinent de rencontrer dans le cadre de cette recherche par ordre de priorité ?

## **Appendix 3: Example of Interview Guide with a Coordinator**

### 1. Présentation/Identification de l'interviewé.e

Quelles sont les études et le parcours professionnel de la personne ?

Comment est-elle/il devenu.e coordinatrice/coordinateur du projet ? Est-ce qu'on lui a demandé ? Si oui, qui lui a demandé ?

Comment est-ce qu'on lui a présenté la réforme ? Comment a été diffusée l'information de l'existence du plan ? Comment la nouvelle a-t-elle été accueillie/Comment est-ce qu'elle/il a accueilli la nouvelle ?

A-t-il/elle reçu une formation pour occuper la fonction de coordinateur ? (en plus du coaching) ?

A-t-il/elle d'autres activités en parallèle ? Si oui, lesquelles ?

### 2. Historique et nature du projet

Demander à l'interviewé.e de ré-expliquer le projet avec ses mots : quelle est la pertinence de ce projet ?

Est-ce qu'il a été créé de toutes pièces ou a démarré à partir de quelque chose d'existant, le financement du SPF étant une aide supplémentaire pour asseoir la démarche ?

Pour quelle raison cibler tel public de patients chroniques plutôt qu'un autre ?

Dans le guide, pour quelles raisons parle-t-on des maladies chroniques en général et que certains projets ciblent des maladies spécifiques ? Comment est-ce qu'on va élargir par la suite ?

Quel est le rôle de la cellule inter-administrative ? Qui est sa personne de contact ?

Quel est le rôle du coach ?

Quelles sont ses tâches concrètes du coordinateur/de la coordinatrice (décrire une journée type) ?

Quelles sont les obstacles et rencontrés jusqu'à présents ? Quels sont les facteurs facilitateurs qu'on peut identifier ?

Quel est son avis sur la réforme : que garder, que changer ?

Quel est le prochain événement/la prochaine réunion importante dans le cadre du projet ?

Qui serait-il pertinent de rencontrer dans le cadre de cette recherche par ordre de priorité ?

## Appendix 4: Example of Interview Guide with a Pilot Project Stakeholder

## 1. Présentation/Identification de l'interviewé.e

Quelles sont les études et le parcours professionnel de la personne ?

Quelle(s) est/sont sa/ses fonction(s) actuelle(s)/tâches actuelles ? A-t-elle/il d'autres activités en parallèle ? Si oui, lesquelles ?

Quelle est son implication et son rôle dans le projet pilote dont il/elle est partenaire ?

Comment a-t-il été mis au courant de l'appel à projets pilotes ? Comment a été diffusée/mis au courant l'info de l'existence de la réforme ?

Comment est-ce qu'il a accueilli la nouvelle (enthousiaste ou sentiment d'être obligé) ?

## 2. Le projet pilote

Demander à l'interviewé.e de ré-expliquer le projet avec ses mots : quelle est la pertinence de ce projet d'après lui/elle?

Est-ce que le projet a été créé de toutes pièces ou a démarré à partir de quelque chose d'existant,

le financement du SPF étant une aide supplémentaire pour asseoir la démarche ?

Comment est-ce que les partenaires du projet ont été contactées et sélectionnées ?

Qui décide de quoi dans le projet ?

Quelles sont les obstacles et rencontrés jusqu'à présents ? Quels sont les facteurs facilitateurs qu'on peut identifier ?

Quel est son avis sur la réforme et les projets pilotes : que garder, que changer ?

Qui serait-il pertinent de rencontrer dans le cadre de cette recherche par ordre de priorité ?

# Appendix 5: Post-Print Version of the Paper Accepted for Publication in the International Review of Public Policy

Reshaping Health Care Governance Using Pilot Projects as Public Policy Implementation Instruments: the Case of Integrated Care Pilot Projects for Chronic Patients in Belgium

### 1. Introduction

Pilot projects are often used in a variety of sectors in innovative contexts. In the scientific literature, one can find numerous articles relating the results of a specific pilot project in a particular sector, whereas the literature analysing the pilot project tool as an object for research is much rarer (Pinson, 2005). In other words, research focuses generally on the experiment conducted as part of the pilot project under study, and *not* on the pilot project tool as a phenomenon *per se*, which should, nevertheless, also be worthy of scientific attention (Vreugdenhil et al., 2010).

The pilot project is a specific work method, fulfilling a function of experimentation, which is mobilised in a plethora of sectors and allows *a learning while doing* approach (Kay & Boxall, 2015; Lee, 1999). This tool offers the possibility to test the innovation at stake in real-world settings at small and controlled scales, which limits the impact of potential failure or negative side effects (Vreugdenhil & Ker Rault, 2010). Furthermore, the actions undertaken as part of the experiment are expected to be more reversible (Musselin, 2005; Zurlo & Nunes, 2016) and, for this reason, are supposed to be less frightening for the stakeholders involved.

Therefore, pilot projects are often used by policy makers in innovative contexts (Vreugdenhil et al., 2010), to learn from the experimentation carried out (Engström & Lidelöw, 2015) and to create new knowledge and produce evidence for policy-making (Sanderson, 2002; Vreugdenhil & Ker Rault, 2010). They are thus expected to help orient future political action and policy development. In this way, the pilot project constitutes a tool for, "improving the effectiveness of policy responses" (Sanderson, 2002, p. 4). The purpose is to work collaboratively (Zurlo & Nunes, 2016) in order to identify what works in what context (Sanderson, 2002; Vreugdenhil & Ker Rault, 2010).

Nevertheless, Sanderson (2002) argues that politicians/policy makers often divert pilot projects from their primary function of experimenting and learning. Instead, they only use them as a means of exemplification, demonstration and legitimation when the produced evidence corroborates their political priorities. Actually, according to Cook (1997, p. 40, cited in Sanderson, 2002, p. 5), "the politician's prime goal is to be re-elected rather than to respect technical evidence", which constitutes political short-termism. On the contrary, experimentations conducted as part of pilot projects are often long-term endeavours, which require, in contrast, sufficient time to produce effects from which lessons can be learnt (Sanderson, 2002).

As collective experiments (Zurlo & Nunes, 2016), pilot projects also gather a diversity of stakeholders who have to interact and work together to create new solutions to solve a problem by exchanging their respective knowledge and stances (Segrestin, 2004): as the old proverb says: *two heads are better than one*. In this way, due to their inherent interactionist nature (Pinson, 2005), "pilot projects are [also] means to establish communication between actors that usually do not cooperate" (Vreugdenhil & Ker Rault, 2010, p. 122). This explains why, besides experimentation, pilot projects can also be mobilised for policy implementation (Vreugdenhil et al., 2010) when, for example, the policy programme cannot be implemented in a conventional manner. In this case, the use of the pilot project tool provides a means for a staged implementation process (Vreugdenhil & Ker Rault, 2010), leveraging the collaborative dynamic between involved stakeholders in order to, "pragmatically put fully developed policy into practice" (Vreugdenhil et al., 2010, p. 13).

In this paper, which in a certain sense echoes the old, but not outdated, research of Pinson (2005) on urban projects, pilot projects are not analysed only as simple tools or work methods but as specific public policy instruments (Lascoumes & Le Galès, 2005). Accordingly, before presenting the research question addressed in this paper, it seems appropriate to dwell a little on the very notion of public policy instruments in order to understand the reasoning behind the formulation of this research question as well as its relevance. It would nevertheless seem illusory and unnecessary to develop all the plethora of different approaches and taxonomies that were developed regarding policy instruments in the scientific literature. Therefore, in the next section, I will select the elements which seem relevant for analysing the central object of this article: the pilot project phenomenon.

# 2. Policy Instruments: Contributions of Scientific Literature and Research Question

Policy instruments are one of the three main components of a public policy, the two others being the policy foundations, referring to the aims pursued via the policy, and the public targeted (Hassenteufel, 2011). Policy instruments constitute the means by which ideas stabilised during the policy formulation process are supposed to be implemented (Ali, 2013). They can be viewed as "a set of techniques by which governmental authorities wield their power in attempting to ensure support and effect (or prevent) social change" (Vedung, 1998, p. 21, cited in Borrás & Edquist, 2019, p. 215). So, "policy instruments are techniques of governance that, one way or another, involve the utilization of state authority or its conscious limitation" (Howlett, 2005, p. 31).

The scientific literature pertaining to policy instruments revolves around three main topics:

- the numerous categorisations and typologies of policy instruments produced over time in this field of research, e.g., the well-known NATO<sup>48</sup>-scheme developed by Christopher Hood (Hood et al., 2007) or the "carrots, sticks and sermons-approach" developed by Vedung (Vabo & Røiseland, 2012);
- the way instruments are chosen by governments through the identification of instrument choice patterns; and, more recently
- the way instruments are combined in specific mixes (Capano et al., 2020; Howlett et al., 2018). (This third topic will not be addressed in this paper).

If listing all the existing categorisations and typologies of policy instruments would not be of much use in the case at hand, the interesting distinction between substantive and procedural instruments should be mentioned. Substantive instruments are "policy techniques or mechanisms designed to directly or indirectly affect the production, consumption and distribution of different kinds of goods and services in society" (Howlett et al., 2018, p. 7), whereas procedural instruments, "on the other hand, affect production, consumption and distribution processes only indirectly, if at all, and instead are concerned with altering aspects of a governments own workings" (Howlett et al., 2018, p. 9). Due to the above-mentioned elements that characterise the pilot project, the latter can be viewed as a procedural instrument which help define the content of substantive policies.

<sup>&</sup>lt;sup>48</sup> Nodality, Authority, Treasure, and Organization

Regarding the choice of public policy instruments, the theoretical framework of Lascoumes and Le Galès (2005), which belongs to the sociology of public action, is particularly relevant to the case at hand. These two scholars analysed public action and state governance modes by focusing on public policy instrumentation, which constitutes "a means of orienting relations between political society (via the administrative executive) and civil society (via its administered subjects)" (Lascoumes & Le Gales, 2007, p. 1). They define public policy instrumentation as:

the set of problems posed by the choice and use of instruments (techniques, methods of operation, devices) that allow government policy to be made material and operational. Another way of formulating the issue is to say that it involves not only understanding the reasons that drive towards retaining one instrument rather than another, but also envisaging the effects produced by these choices. (2007, p. 4)

As much as the objectives of a public policy, instrumentation is also a political choice (Howlett, 1991; Howlett et al., 2018) because the choice of modes of action, and therefore of instruments, which can be the subject of political conflicts, will partly structure the process and its results and have an impact on power relations (Lascoumes & Le Galès, 2005). Interestingly:

a public policy instrument constitutes a device that is both technical and social, that organizes specific social relations between the state and those it is addressed to, according to the representations and meanings it carries. It is a particular type of institution, a technical device with the generic purpose of carrying a concrete concept of the politics/society relationship and sustained by a concept of regulation. (Lascoumes & Le Gales, 2007, p. 4)

This means that the choice of one instrument over another is not trivial and is not only a technical choice, as suggested in the functionalist approach. Instead, instruments structure public action and produce specific, sometimes unexpected, effects, independent of the primary purposes assigned to them (Borrás & Edquist, 2019; Lascoumes & Le Galès, 2005). Indeed, as Lascoumes & Le Galès (2007, p. 4) put it, "public policy instruments are not tools with perfect axiological neutrality, equally available: on the contrary, they are bearers of values, fuelled by one interpretation of the social and by precise notions of the mode of regulation envisaged".

In view of all this, this paper intends to contribute to the scant literature focusing on the pilot project phenomenon as well as, to some extent, on the public action instruments studies by providing an in-depth analysis of the consequences of the use of this specific instrument by policy-makers in terms of public governance. The focus here is on the specific case of the implementation of a public policy in the Belgian health sector via the launch of pilot projects simultaneously used as experimentation and implementation instruments: the "Integrated Care for Better Health" (IC4BH) joint plan targeting chronic patients. Therefore, this paper is based on the following research question: how does the use of multidisciplinary pilot projects as experimentation and implementation instruments reshape modes of public governance in the Belgian health sector in a context of transition and ongoing devolution?

The choice of analysing this specific case comes from the fact that it can be noticed that for the past fifteen years there has been an increasingly systematic recourse to the use of pilot projects by the Belgian authorities to implement new public policies, especially in the health care sector. One can mention, *inter alia*: "therapeutic projects" and "psy 107" projects in the mental health sector; "multidisciplinary local networks" for diabetics (Type 2) and patients with renal insufficiency; mobile health projects and "integrated care" pilot projects for chronic patients launched as a means to implement the joint plan entitled "Integrated Care for Better Health" (IC4BH), which was approved in October 2015.

The interest of focusing on this case is twofold:

- lessons can be learnt regarding this way of operating at the national Belgian level, which is of interest for the Belgian authorities; and
- it may be of interest at an international level for countries that are tempted to resort to pilot projects as part of the implementation of their public policies.

### 3. Background

### 3.1. The Belgian Healthcare System

The current Bismarckian Belgian health care system combines a compulsory health insurance, which is part of the global Belgian social protection system, with a non-mandatory supplementary health insurance, both of which are based on the principle of solidarity (Saltman et al., 2004). The entire Belgian population is entitled to medical care, either as a beneficiary or as a dependent (spouses, children, grandchildren). The supplementary health insurance is provided by sickness funds upon payment of insurance premiums and gives access to additional benefits, reimbursements and services.

Sickness funds play the role of intermediaries between the National Institute for Health and Disability Insurance (NIHDI), i.e., the parastatal institution in charge of managing the national

health care budget, the patients and their health practitioners regarding the reimbursement of medical expenditures. In order to ensure their rights to compulsory health insurance benefits, beneficiaries have to affiliate with a sickness fund of their choice.

In Belgium, the majority of physicians are self-employed and remunerated on a fee-for-service basis (OECD & European Observatory on Health Systems and Policies, 2017): they are paid for each service performed. Patients pay their medical costs upfront and, in exchange, receive a certificate that proves the payment has been made. Upon presentation of this document, patients can be partly refunded by their sickness funds. The amount of reimbursement covered by compulsory insurance is set by the NIHDI and listed in an official "nomenclature" as is the case with all reimbursement rates related to every refundable medical act. The part that is not reimbursed, the proportion assumed by patients, is called the user fee or patient fee (Service Public Federal Securité Sociale, 2016).

In certain specific cases (low income, disability, etc.), a third-party payer system is applied.<sup>49</sup> Then, patients only pay their user fees to their practitioners and, "the reimbursement rates are applied directly" (Federal Public Service Social Security, 2012, p. 44). Practitioners receive the rest of their fees, the amount covered by compulsory insurance, from their patients' sickness funds. The difference here is that patients pay nothing upfront.

Belgium applies the principle of freedom of choice (OECD & European Observatory on Health Systems and Policies, 2017), which is a common feature of social health insurance systems (Saltman et al., 2004). Sometimes, this leads to an over-consumption of health care and, consequently, an increase in healthcare expenditure (Palier, 2017). Specifically, the principle of freedom of choice means that, "patients can select their provider" (Saltman et al., 2004, p. 249). They are free to choose their sickness fund, their doctor(s) (GPs and specialists) and to go to the hospital of their choice. In other words, GPs do not play the role of gatekeepers as they do in national health care systems (such as in the UK and Sweden). In the latter, patients first visit their GP, before being allowed to consult a specialist (Palier, 2017; Saltman et al., 2004).

Alternatively, patients are also free to enrol at a Medical Health Centre (MHC, *maison médicale* in French) of their choice. MHCs operate an alternative health care model, bringing together first-line care workers (general practitioners, nurses, physiotherapists, psychologists, social

<sup>&</sup>lt;sup>49</sup> <u>http://www.riziv.fgov.be/fr/themes/cout-remboursement/facilite-financiere/Pages/tiers-payant.aspx#.Waq8YchJY2w</u> (accessed 20 January 2020)

workers, etc.) into multidisciplinary teams. They work in concert in order to care for their patients and enhance or maintain their social welfare. Importantly, most Belgian MHCs have recourse to an alternative funding model that relies on capitation payments for first-line medical acts (general medicine, physiotherapy, nursing care),<sup>50</sup> in contrast to the prevailing fee-for-service model.<sup>51</sup> The most recent figures available show that in 2015, the number of MHCs amounted to 151,<sup>52</sup> compared to 67 in 2005. Furthermore, 3% (336,247 patients) of the Belgian population was affiliated with an MHC in 2015.<sup>53</sup>

### 3.2. A joint plan

Belgium is a federal state made up of a federal government and federate entities with their own competencies, i.e., three economic regions (the Flemish, Walloon and Brussels-capital regions) and three linguistic communities (the Flemish Community, the French Community, also called the Wallonia-Brussels Federation, and the German-speaking Community), which use the three official languages: Dutch, French and German. This structure is the result of an ongoing process of federalisation and devolution that began in 1970. Following the Sixth State Reform, the second step of which occurred in 2014, public health competencies were redistributed and mainly split between the federal and regional levels, which explains why there are several health ministers in Belgium (see Appendix 1 summarising the distribution of health competencies in Belgium). The IC4BH plan was originally initiated at the federal level, but the federal authorities intended to develop some elements that are now under the competence of the regions, which explains why the IC4BH plan is a joint plan.

## 4. Methods

This inductive ethnographic study began in December 2016. Ethnography, also referred to as field research, is a holistic discovery-based and hypothesis-free research method emanating from the social sciences (Robinson, 2013), more specifically, from anthropology and sociology (Soukup et al., 2017). In this approach, people and groups are studied in their real-world settings, in other words, "mundane settings in which people lead their lives naturally and that are not designed for the purposes of research" (Maner, 2016, p. 101), such as schools, homes,

22247.html (accessed 20 January 2020)

<sup>&</sup>lt;sup>50</sup> <u>http://www.riziv.fgov.be/fr/themes/cout-remboursement/par-mutualite/maison-medicale/Pages/default.aspx#.WapxpMhJY2w</u> (accessed 20 January 2020)

<sup>&</sup>lt;sup>51</sup> http://www.maisonmedicale.org/En-quelques-mots.html (accessed 20 January 2020)

 $<sup>^{52} \ \</sup>underline{http://www.lejournaldumedecin.com/actualite/plus-de-150-maisons-medicales-en-belgique/article-normal-interval} \ \underline{http://www.lejournaldumedecin.com/actualite/plus-de-150-maisons-medicales-en-belgique/article-normal-interval} \ \underline{http://www.lejournaldumedecin.com/actualite/plus-de-150-maisons-medicales-en-be$ 

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<sup>579</sup>f96fc35705dcbd70cf3a2 (accessed 20 January 2020)

the workplace, hospitals, meetings, court rooms, etc. (Maner, 2016; Soukup et al., 2017). Accordingly, ethnographic studies distinguish themselves from experimental ones, which are conducted in simulated or controlled environments (Angrosino, 2007; Soukup et al., 2017).

Field research is characterised by the combination of several complementary research methods (observation, interviews, secondary data analysis), allowing a deep and detailed understanding of a setting, a context and/or a phenomenon (Quivy & Campenhoudt, 2009), which is why it seemed relevant to study the integrated care pilot projects' dynamics depending on interactions between stakeholders. This type of research is inherently flexible and non-linear given that no definitive research protocol is determined at the beginning of the research, but rather is expected to evolve *during* the research (Quivy & Campenhoudt, 2009). This approach has its limitations: conducting field work is time consuming and the findings are often not generalisable (Soukup et al., 2017). However, as Flyvbjerg (2006) puts it, the fact that, "knowledge cannot be formally generalized does not mean that it cannot enter into the collective process of knowledge accumulation in a given field or in a society" (Flyvbjerg, 2006, p. 227).

As part of her specific ethnographic research, which took the form of a qualitative and inductive (Musselin, 2005) research, the researcher immersed herself mainly in two pilot projects. The data were collected during the conceptualisation phase, i.e., the application writing period, as well as during the first nine months of the execution phase, during which the pilot project consortia began to implement the loco-regional action plan they conceived during the conceptualisation phase.

According to Dumez (2016), "a qualitative research approach only makes sense if it shows and analyses the intentions, the discourse and the actions and interactions of the actors, both from their point of view and from the researcher's point of view" (Dumez, 2016, p. 13). To ensure the soundness of the analysis (Dumez, 2016), and achieve a sound level of saturation (Bryant & Charmaz, 2011), three types of information sources were triangulated:

- written documents, through a literature review and the reading of operational documents;
- actions and interactions: the direct observation method was used in which the researcher attended 67 meetings, corresponding to 148 hours of observation; and
- discourses, referring to what people had to say about their experience, during semi-structured interviews (N=24).

Indeed, triangulation of information (Dumez, 2016; Jick, 1979) helps establish validity and reliability regarding the studied phenomenon (Robinson, 2013). Appendix 2 presents a thorough description of the methods combined to collect the data.

#### 5. Findings

#### 5.1. Towards integrated care: opting for pilot projects

At the international level, integrated care is considered to be a relevant solution to deal with care fragmentation (Minkman, 2017) and tackle the challenge of long-term care patients (Borgermans & Devroey, 2017). Nevertheless, it can take a variety of forms depending on the context in which it is implemented (Borgermans et al., 2017). There is no consensus on one single and universal definition of this concept due to its polymorphous nature (Amelung et al., 2017). In the IC4BH plan, integrated care delivery is defined as, "the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system" (WHO, 2008b, p. 1). Further, the World Health Organization (WHO) defines care integration as, "the organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money" (WHO, 2008a, p. 1).

National institutional arrangements and culture have a significant influence on how innovative solutions are translated at the local level (Marmor et al., 2005). Health care systems result from specific building processes deeply linked to their history, traditions and national contexts (Minkman, 2017), which give them their "own individual equilibrium" (Schokkaert & Van de Voorde, 2011, p. 7). Transferring isolated policy measures from one country to another, without considering the context in which they will be implemented, can be fruitless or even risky (Schokkaert & Van de Voorde, 2011). Therefore, the Belgian authorities mobilised field workers, connoisseurs of the Belgian-specific context, as part of an iterative and incremental implementation through pilot projects, the idea of co-creation being the guiding thread of the process.

Indeed, other implementation methods could have been used. As an example, the authorities could have passed a law after having negotiated the reform, as usual, in the decision-making organs of the NIHDI, two of the most important ones being:

- the "General Council of the Health Insurance", which gathers employers' representatives, workers' representatives, government's representatives and insurers' representatives (healthcare mutuals);
- the "Health Insurance Comity", which gathers insurers' representatives and healthcare providers' representatives (INAMI, 2019).

However, the authorities opted for another way of proceeding, as already explained. Why, then, were workers mobilised in the field specifically through pilot projects? Here are some of the reasons explaining this choice that were mentioned during the interviews:

We discovered the international reference framework [of integrated care], which was not very well known in our country, to help us put in place a real action plan by choosing to embark on a bottom-up approach. And we had good reasons, because we knew very well that trying to fundamentally change the way care is organised, if we want to do it in a [traditional] concerted way, we will never reach a national consensus; it's impossible. We are not going to get all the medical unions and all the hospital networks and everyone to agree ... Oh yes, yes, we are going to change. That's not how it works. So, the only way, the idea, and I still believe in it, is that we can change things through a bottom-up approach. If we do it in a sufficiently substantial and global manner [...], it is much better supported by [specific] needs or by a way of demonstrating that we succeeded in shifting the paradigm. This is change management, but by looking for the avant-garde in it. (Interview with a high-ranking official, 2017)

*Pilot projects are* [...] *less frightening than a change of law, regulation or financing mode.* (Interview with a high-ranking official, 2017)

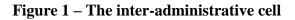
The important thing is really to set up a methodology so that all things are taken into account, and that it is also sufficiently participatory because the element of co-creation is really essential for me in this project, and I often stress this. Sometimes, more than the result to be achieved, it's the whole method to get there that is very important, the involvement of all the actors. (Interview with a coach, 2017)

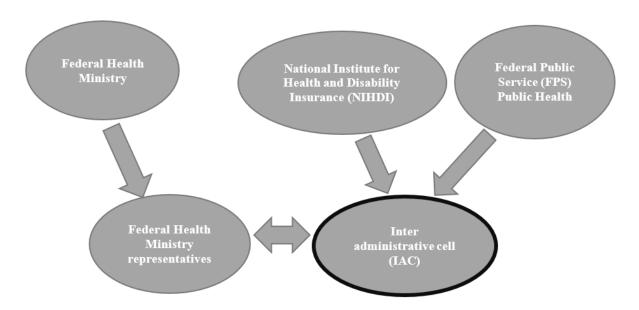
In these extracts, the interviewees expressed the advantages and the reasons that led to the choice of pilot projects as implementation instruments. The first interviewee explained that the traditional way of making decisions, at the level of the NIHDI bodies, would simply have

hindered finding an agreement on how to implement integrated care due to the diverging interests of the represented sectors. Such an agreement would, nevertheless, have been a prerequisite to any legal text intended to bring about structural changes in the way of working in the care sector. Therefore, the use of pilot projects was a way around this problem. The purpose was to show that some projects would succeed in implementing integrated care in their geographic area, hopefully serve as successful examples and produce a snowball effect in the areas in which no integrated care projects were implemented. The second interviewee stressed that the actions undertaken at a small scale, at the pilot project level, should be less frightening for hands-on professionals because they are more reversible than those that would have been directly implemented on a large scale to comply with the law. Finally, the third interviewee underlined the importance of working in co-creation with hands-on professionals. Professionals should be able to produce innovative propositions anchored in their day-to-day reality, including contextual elements that the authorities would not have considered.

#### 5.2. Integrated care pilot projects

At the federal level, the inter-administrative cell (IAC) was created pursuant to the Protocol of Understanding of the Inter-ministerial Conference of the 24th February, 2014 regarding the health policy for chronic patients. The IAC was assigned the role to manage and coordinate the operational implementation of the plan, and to help, guide and collaborate with the pilot projects as part of the iterative and incremental co-creation dynamic. This department gathered public officials of the NIHDI and of the Federal Public Service (FPS) Public Health. They also worked in close collaboration with representatives of the federal health minister's office (Belgian Ministry of Social Affairs and Public Health, 2015).





In January 2016, the Belgian health authorities published a guidance leaflet for future pilot projects in which they described the specific modalities of the implementation process. This leaflet specifically stated that it was meant to be evolutionary: the modalities were meant to be modified, if necessary, and new guidelines could be articulated by the authorities in the future, depending on the turn of events. This relates to the willingness of iterative and incremental cocreation expressed by the authorities in the plan.

The implementation process was divided into four main phases (Belgian Ministry of Social Affairs and Public Health, 2015):

- 1. The preparation phase (first phase of the selection procedure): the four-month preparation phase began in February 2016, when the authorities launched a call for expressions of interest. Hands-on professionals, interested in creating a pilot project, had to gather in multidisciplinary local consortia. They had to submit a joint expression of interest defining, approximately, their target groups, as well as the geographic area covered by their projects, by 31st May, 2016.
- 2. The conceptualisation phase (second phase of the selection procedure): between July 2016 and September 2017, the 20 selected pilot project consortia had to write a more detailed application file containing a 'loco-regional action plan'. This plan needed to describe their common vision and their strategic and operational objectives, as well as the actions they would implement to achieve their objectives if they were selected for the four-year execution stage. As from this

phase, each consortium had to appoint a local coordinator whose remit was to lead the process of creating the loco-regional action plan. The local coordinator was the main point of contact between the project and the authorities. During this phase, a lump sum funding of 40,000 euros, payable in two instalments, was provided to pay the coordinator's salary.

- 3. The execution phase: in January 2018, the twelve selected pilot projects entered the four-year execution phase and began to implement their loco-regional action plan.
- 4. The expansion phase: after the execution phase, the successful pilot projects were expected to evolve to cover the entire Belgian population.

It is clear that the two first phases were dedicated to designing the experiments that would be carried out in the field during the third phase. The third phase was actually both an implementation and experimentation phase. The expansion phase is intended to implement actions identified as best practices at a wider scale.

#### 5.3. A continuous co-construction process

Achieving co-creation required regular contacts between the parties involved. During the preparation and the conceptualisation phases, several meetings ("kick off meetings", information and plenary sessions and "intervisions") bringing together the IAC members, some representatives of the federal health minister's office, the coordinators and some pilot project members were organised to this end. The first three types of meetings were more formal and less regular than the intervisions, which were organised on a monthly basis.

Intervisions were key moments of discussion between the authorities, the coordinators and the pilot projects' key stakeholders who accompanied them. The authorities gave presentations on specific topics, provided additional instructions and new guidelines and answered coordinators' questions. The coordinators also had the opportunity to relay the difficulties, fears, disagreements and requests of their respective pilot project consortium and ask for clarification regarding some elements or procedures. They also communicated with their peers and discussed their respective practices.

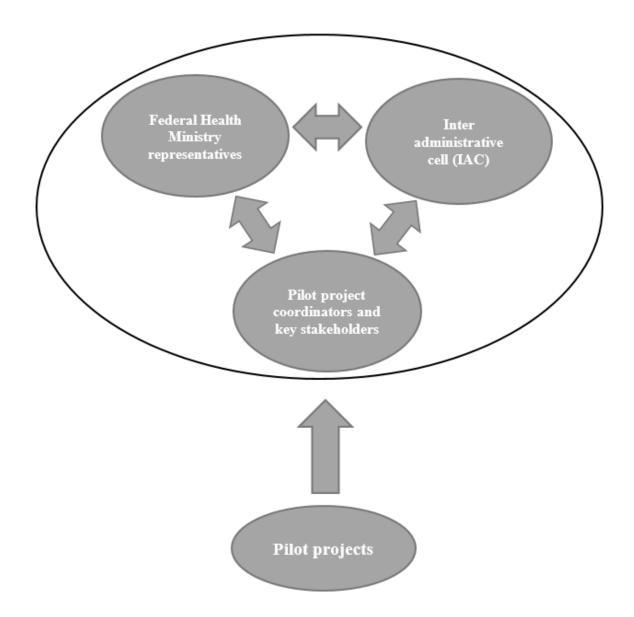


Figure 2 – Stakeholders' interaction during intervisions

Intervisions were not often peaceful due to the frequent divergence of opinion regarding several matters between the authorities and the pilot project members, whose opinions were relayed by the coordinators. For instance, one disagreement pertained to financial aspects and, more precisely, to the notion of 'bundled payment'.

Actually, in July 2011, the Belgian Health Care Knowledge Centre (KCE), a research centre that provides scientific advice on topics related to health care, was asked to produce a position paper related to future health care for chronic diseases. This scientific report, published in December 2012, summarised the challenges in this field through eighteen integrated care components (see Appendix 3), based on a consultation with experts and a thorough international

literature study regarding integrated care (Belgian Ministry of Social Affairs and Public Health, 2015). The IC4BH plan is an attempt to put into practice these recommendations.

One of the 20 KCE recommendations, which became the 12th of the 20 components of the IC4BH plan, referred to the adaptation of financing systems. As a reminder, the majority of physicians are self-employed and remunerated on a fee-for-service basis; however, the federal authorities expressed their intention to move from a fee-for-service system to a bundled payment model, at least for certain types of medical services, justifying their choice by reference to the international scientific literature regarding this topic.

In this literature, one can read that fee-for-service rewards volume instead of quality of care (Borgermans & Devroey, 2017; Hirsch et al., 2015) and can therefore hinder the implementation of integrated care based on a global patient-centred approach. A bundled payment system would seem more appropriate according to the scientific literature (Quinn et al., 2017). Bundled payment actually refers to, "a fixed payment that includes the prices of a group of services that would typically treat an episode of care in a defined period of time" (Quinn et al., 2017, p. 114). Using bundled payments could help neutralise expenses, enhance value of care and, consequently, enhance the system's sustainability at the macro-level.

As a result, during the conceptualisation phase, the authorities encouraged the pre-project consortia to include actions in their loco-regional action plans that would help develop and test bundled payment at the local project scale. However, professionals in the field quickly opposed this request for several reasons, which surprised the authorities given all the advantages of this payment model identified in the literature.

In an atmosphere of mistrust and suspicion, professionals argued that the concrete implementation modalities of such a transition were not clear enough. They did not have sufficient guarantees of support from the authorities to achieve this economic transition. Here is an interview extract illustrating this idea: *"It is like buying a car. But, when you drive it, you realise that they are still building the car while you are driving it and you cannot get out of it anymore."* (Interview with a coordinator, 2017).

Furthermore, this would require a huge cultural change at every level of the Belgian care production chain. They stressed that the authorities wanted to impose things and put the cart before the horse regarding this matter, arguing that Belgium is not yet ready for bundled payments: *"I cannot prevent myself from thinking that it is pretending to be bottom-up and is* 

*really top-down. They are going to compel us to work in a certain way.* "(Interview with a pilot project member, 2016).

While this choice is understandable at the macro level given that it could help reduce health expenditure, at the micro level, the professionals were worried, particularly the doctors, because their remuneration mode and their income would probably be impacted. As such, what would be a saving for the government would be a loss of income for medical professionals. Indeed, bundled payment transfers the risk from payers to providers, sometimes even resulting in financial losses for the latter (Quinn et al., 2017). Some GPs even threatened to leave their respective projects, which would have simply prevented the other stakeholders from submitting the application at the end of the conceptualisation phase: GPs were, indeed, mandatory project members.

At the request of those in the field (not only GPs), several additional meetings were set up to discuss the matter. This, among other factors, contributed to lengthening the conceptualisation phase, which was supposed to finish at the end of January 2017, but which actually ended mid-September 2017. Both parties tried to convince the other of the validity of their vision based on different types of arguments, i.e., scientific- (authorities) or experience-based (field workers). In the end, despite the authorities' insistence, no project complied with the request of designing actions to test actual bundled payment during the execution phase. Actually,

[the authorities] adapt, they are open to discussion with the projects but in this case, they [simply] had no choice. [They] felt that if GPs blocked the integrated care pilot projects, there would not be any integrated care pilot project anymore. [Dealing with] chronic diseases without GPs is not feasible. (Interview with a pilot project coordinator, 2018)

This empirical example illustrates the strong interdependence between the different hierarchical levels of the health care system. Here are some other interview excerpts confirming this assertion:

*Obviously, the powerful argument of pilot project professionals is to say: 'anyway, without us, what do you want to do? If no one wants to participate in your pilot projects, what are you [the authorities] going to do?' (Interview with a pilot project member, 2018)* 

Could they compel [us to do what they want us to do]? No [...], but what is the alternative? If we [hands-on professionals] do not comply voluntarily, we may be compelled. That is the threat. [The authorities could say]: 'if you do not want it, then, we will see if we cannot pass a Royal Decree'. (Interview with a pilot project member, 2018)

Change is frightening. [...] We [the authorities] know that there is a lot to do in the field. It is for this reason that it seems essential to take action at several levels and with hands-on professionals, because we cannot impose change alone. We can write a Royal Decree but ... (Interview with a high-ranking official, 2017)

*If we want to change things, dialogue [is a compulsory step].* (Interview with a pilot project member, 2018), people from all the levels have to gather and negotiate.

#### 6. Discussion

In an explorative context, workers in the field were delegated the task to both design and test new actions intended, if successful and identified as best practices, to develop integrated care for chronic patients on a national scale. The Belgian authorities chose to use pilot projects and mobilise hands-on professionals' experience and expertise:

- to avoid the problems that the traditional way of doing things could have caused;
- due to the contextual nature of integrated care (Amelung et al., 2017; Minkman, 2020) and the resulting lack of knowledge regarding the way integrated care could/should be implemented in the Belgian context; and also
- to benefit from the professional experience of field workers.

In the literature on policy making and policy design, this "co-creation" approach relates to the notions of "collaborative innovation" (Torfing, 2019, p. 4) and "process inclusivity" (Compton et al., 2019, p. 124), which both refer to the degree to which diverse interests are represented in the decision-making process, *inter alia* those of the directly affected stakeholders.

Including the latter in decision-making is considered desirable for several reasons. Given their experience and proximity with the field, they are expected to know the local context better, allowing them to produce tailored solutions and, as a result, solutions that are supposedly better. Furthermore, bottom-up collaboration between these stakeholders is also viewed as an advantage enhancing the legitimacy of the policy and helping build trust. Eventually, given that

they will have a role to play in the implementation of the decisions made (Compton et al., 2019; Lee, 1999), it is also expected to enhance the acceptance of these decisions (Vreugdenhil & Ker Rault, 2010).

In the context of the IC4BH plan, the use of pilot projects was a way to achieve inclusivity by including workers in the field in the process and work of "co-creation" to benefit from their respective experience (Gouillart & Hallett, 2015). Nevertheless, if this inclusive co-creation approach leading to multi-actor collaboration (Torfing, 2019) may be seen as a key facilitating factor (Compton et al., 2019), especially in a context of innovation (Torfing, 2019), an important lesson to draw from this research is that this alone does not guarantee the achievement of the desired outcome or that events unfold as planned. This research actually suggests that it also brought with it new issues to address, as detailed below.

#### 6.1. New collaboration modalities

The co-creation approach called for regular meetings between the different stakeholders, creating new collaboration modalities. The meetings of the IAC members, representatives of the federal health minister's office, the coordinators and key pilot project members, i.e., GPs, nurses, social workers, etc., contributed to progressively create a new dynamic of vertical interactions and vertical communication between stakeholders at the macro and the meso levels and, in this way, to alleviate the vertical organisational fragmentation between these levels. Gathering these different types of people on a regular basis is quite unusual in Belgium. As already mentioned above, health matters are normally discussed in the decision-making organs of the NIHDI, in which all the sectors involved in the pilot projects are not represented.

These specific meetings, which were particularly crucial throughout the process, had a goal to sustain the iterative and incremental co-creation process by providing the coordinators with support for the needs they had expressed. While these meetings were initially meant to be mostly informative, the participants appropriated the encounters, viewing them as a venue for expression, as opportunities to negotiate their participation in the projects or even call into question the content of the authorities' guidelines, which surprised the authorities.

The IC4BH plan is the result of a long reflection process in which, "knowledge [played] a fundamental justification function" (Radaelli, 1995, p. 174): the guidelines were built on the basis of scientific expertise on integrated care. Indeed, several Belgian public officials and policymakers took a closer look at successful cases of integrated care abroad; they attended scientific conferences abroad on the topic and relied on the KCE position paper.

Accordingly, "The relationship between expertise and politics has traditionally been described in terms of science speaking truth to power" (Pellizzoni, 2011, p. 765). Nevertheless, the recommendations and the guidelines designed by the authorities did not always seem relevant to the pilot projects' stakeholders, as shown in the empirical example above pertaining to bundle payments. Their diverging opinions led to a cultural clash (Moran & Rau, 2016) and heated negotiations to deal with the controversy (Callon, 1984). Hands-on professionals openly questioned and negotiated the authorities' guidelines built on scientific expertise, the legitimacy of which they put into question by justifying their opinion on the strength of their place-based knowledge of the health care system at the local level (Moran & Rau, 2016) related to their practice and their experience (Wagenaar & Cook, 2011).

This example illustrates that, "instruments at work are not neutral devices: they produce specific effects, independently of the objective pursued (the aims ascribed to them), which structure public policy according to their own logic" (Lascoumes & Le Gales, 2007, p. 3). Indeed, the use of pilot projects in a context of co-creation allowed their members to question and renegotiate the framework set by the authorities, which the latter did not expect. Pilot project stakeholders took advantage of these moments of interaction to define, clarify or redefine their respective roles and responsibilities. They sometimes even refused to achieve what was expected of them, arguing that the authorities were imposing autocratic top-down measures (O'Riordan et al., 2015) based on de-contextualised scientific knowledge (Moran & Rau, 2016), which was irrelevant in the Belgian-specific context. Not all of this would have been possible if the authorities had passed a law to implement the IC4BH plan. In this case, hands-on professionals would have been considered passive implementers who would have had to comply with the law, under the pain of sanctions.

In the case of integrated care pilot projects, implementers (pilot project stakeholders) were involved in a decision-making process at the local level: they were responsible for building and implementing their own loco-regional action plans. They were supposed to be active and to be involved voluntarily in the co-creation process initiated by the authorities, which they were, but not always in the manner expected by the latter, as illustrated in the example of bundled payments. This situation gave power to pilot project stakeholders who had the opportunity to influence the course of events, bringing significant unpredictability to the process.

Indeed, the result of local people's reflections was often different from the authorities' expectations and wishes. They were able to question everything and even leave the process at any time without sanction if they chose to do so, something the authorities feared given that

they were depending on them to implement integrated care in Belgium. On the other hand, the local professionals feared that the authorities might pass a law to impose their framework without taking their opinion into account if they left the process, which explains why, even if some stakeholders threatened to give up and leave the process, few actually carried out this threat. Through their regular interactions, IAC members, health ministry representatives, as well as pilot project coordinators and key stakeholders (see Figure 2) transformed the IC4BH plan implementation modalities. In this way, they transformed the public policy itself, creating a tripartite, "crossed-regulation" (Crozier & Thoenig, 1975). This means that each of the three parties involved was regulating the others and was also regulated by them in return: they were actually interdependent (Crozier & Thoenig, 1975, p. 12) and each held power.

Eventually, a serendipitous observation lies in the fact this process was neither completely bottom-up, as the authorities argued, nor entirely top-down, as several pilot project stakeholders put it. The authorities set the initial framework for action and determined the general aim, i.e., the metaproject (Lascoumes & Le Galès, 2005) (implementing integrated care), which was non-negotiable. They articulated guidelines and took the initiative to launch the call for pilot projects to materialise this metaproject. This gave pilot project members the impression that the process, which was supposed to be bottom-up, was actually disguised top-down, and that this was not "real co-creation". Nevertheless, as explained in the example above, pilot project stakeholders actually did have the opportunity to make proposals, negotiate things and influence the unfolding implementation process. Accordingly, if this was not co-creation, as pilot project stakeholders put it, it was at least a process punctuated by constant interactions, discussions and negotiations, probably inherent in iterative and incremental innovation. Therefore, in general, the achieved result would never be completely what the authorities or the pilot project stakeholders anticipated, but would rather be the outcome of successive mutual adjustments between them (Lascoumes & Le Galès, 2005).

#### 6.2. Becoming representatives

According to Lascoumes and Le Galès (2007), "Every instrument constitutes a condensed form of knowledge about social control and ways of exercising it" (Lascoumes & Le Gales, 2007, p. 3). Using pilot projects to implement the plan has been reshaping, "the relationship between the governing [the usual decision-makers] and the governed [the usual implementers]" (Lascoumes & Le Galès, 2007, p. 7) and has had consequences in terms of citizenship. It has begun to blur

the lines between these two statuses, creating a new intermediary local level at which people gather to design joint projects and make important decisions.

Indeed, pilot project stakeholders (corresponding to the governed in Lascoumes and Le Galès's framework) have been increasingly involved in the decision-making process. They have acquired a certain capacity for influencing things and questioning the authorities' framework by acting as representatives of their profession and of their project, a role to which they were not accustomed. Progressively, they have learned to assume this new role by taking part in pilot projects, exchanging ideas, and defending their interests and opinions. On the other hand, those at the macro level were put in a position in which they had to listen to the field workers' demands and consider them in order to orient their future decisions and provide them with support.

As a result, one can argue that the use of pilot projects supported the development of a "negotiated governance" (Lascoumes & Le Galès, 2005, p. 23). This observation denotes a transition from a social guardian state, which commands and controls, towards a mobilising state (Lascoumes & Le Galès, 2007), which sets the general framework for action, provides general direction, mobilises local people by delegating some tasks to them, and lets them take concrete action to achieve the general aim, in this case achieving integrated care in Belgium.

#### 6.3. An uncomfortable and risky endeavour

In an iterative regime of innovation involving constant confrontation of opinions, the project approach generates discomfort, immersing stakeholders at every level in a climate of (sometimes huge) uncertainty. Setbacks and changes of direction are frequent, which provokes anxiety and fatigue. As Segrestin (2004, p. 244) puts it, "they have embarked on projects as one would have on a risky expedition", betting on the future without completely knowing what would be asked of them and to what this would actually lead, such as, for example, bundled payments.

Except for the coordinators, no additional human resources were financed: pilot project members took part voluntarily in pilot project meetings as representatives on a regular basis. This additional task required massive time investment, making their workload heavier and heavier and reducing the amount of time left to achieve their other tasks, for which some receive subsidies from the Belgian federate entities. This created a situation in which they had to deal with several workloads (and sometime incompatible guidelines) attributed by different levels of power (federal level, federate entities).

As a result, field workers were put under pressure to take innovative initiatives, but had simultaneously to deal with many constraints (institutional, financial, organisational, legal, etc.), which reduced their flexibility. Incidentally, some interviewees stressed the psychological costs related to the process due to the heavy workload and the constant uncertainty inherent in the project's approach.

#### 7. Conclusion

This paper addressed the following research question: how does the use of multidisciplinary pilot projects as experimentation and implementation instruments reshape modes of public governance in the Belgian health sector in a context of transition and ongoing devolution? Actually, the use of pilot projects was a way to include workers in the field in the process in order to work in "co-creation" to benefit from their respective experience, and in this way achieve process inclusivity. If process inclusivity is recognised in the scientific literature as a success factor, this research suggests that it is also important not to view it as something "magical" that alone can erase all uncertainties or guarantee the peaceful implementation of a policy. Instead, it also brings with it new issues and controversies to address.

Indeed, one could have imagined, for example, that this new inclusive way of working would have resulted in a simple and peaceful transfer of tasks to the members of the pilot projects, the main task delegated being the design of innovative concrete actions to implement integrated care in Belgium. Instead, it seems that the use of pilot projects was progressively reshaping modes of public governance by transforming the roles of both the authorities and the actors involved in such projects, which were new roles that had to be learnt. The new authorities 'role was to offer support, which, in this case, led to the creation of a new department, the IAC, dedicated to this support mission. On the other hand, pilot projects stakeholders still shouldered the role of implementers as they would have traditionally; however, in this scenario, they had to implement actions that they themselves had designed, not actions designed by the authorities in collaboration with scientific experts. As such, in a certain way, they were both implementers and decisions-makers given that they had to make decisions about what should be done in the field. Therefore, the use of pilot projects, with an initial purpose of experimentation and implementation, also led to blurring the line between the roles of decision-maker and implementer.

Importantly, this role transformation required new modalities of collaboration between the authorities and pilot project consortia. It led to the emergence of new practices: regular meetings

between people who usually did not meet. Indeed, the iterative and incremental transition towards integrated care required that the authorities and local professionals collaborate closely. To that end, they met on a regular basis, notably during monthly intervisions. This led to building bridges between the different levels of the care production chain, notably between ministry representatives, public officials (IAC members) and pilot project stakeholders, resulting in the emergence of vertical collaboration, and one can even suggest the emergence of the early stages of an organisational vertical integration (Axelsson & Axelsson, 2006). In this context, the local professionals progressively learned to assume the new role of representatives of their project and profession, which is symptomatic of a more negotiated governance (Lascoumes & Le Galès, 2005).

Nevertheless, given that these different stakeholders each had their own logic of action (expertise-based vs. practice-based), some unexpected controversies emerged during the process, e.g., regarding financial aspects. This example shows that pilot project members succeeded in influencing the process and calling into question the framework set by the authorities, which the latter did not expect. Accordingly, they all entered a non-linear and sometimes conflictual process of constant interactions, discussions, negotiations and successive mutual adjustments as part of a tripartite crossed-regulation (Crozier & Thoenig, 1975), symptomatic of process inclusivity concretely put into practice.

The lesson to be drawn here is that interacting is a first, but not a sufficient, step to achieve real co-creation, which should result in vertical integration. Real co-creation requires that all stakeholders, regardless of their position in the care production chain (so, policy-makers included), interact regularly and expect controversies or even cultural clashes to emerge. Overcoming these differences of opinion involves making the effort to stand in the shoes of others to understand their respective day-to-day realities by really listening to what they have to say, which does not seem to be a natural practice at present. The research therefore underlines that the project approach also has its limitations: the additional workload, the inherent constant (sometimes conflictual) confrontation of opinions and changes of direction creating an uncomfortable climate of uncertainty, all of which raise questions in terms of well-being at work.

In conclusion, the results of this research might be of interest to policy makers who wish to use pilot projects to test and implement policies, in the health sector but also in other sectors. Nevertheless, further research is needed to establish the generalisability of the findings presented in this paper regarding the pilot project phenomenon. They should be put into perspective with the results of other research, such as, for example, similar research focusing on other pilot projects, both in Belgium and abroad, in the health sector or even in sectors such as education, employment and social action, among others. This would help identify what is specific for each sector regarding the use of pilot projects and what are common characteristics of the instrument pilot project, whatever the sector in which it is used.

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## 9. Appendices

Appendix 1 – Distribution of health	competencies in Belgium
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Belgian Federal State	Flemish, Walloon and Brussels- capital regions
Managing the compulsory health insurance	Prevention and health promotion
Defining care professions as well as the required associated skills and qualifications	Organising front-line care and services
Setting medical fee standards for doctors, nurses, midwives, physiotherapists, dieticians, dentists, etc.	Developing new instruments to support front-line care providers, apart from that which is related to health insurance matters
Defining and allocating admitted medical acts between the different professions mentioned above	Financing general practitioners' associations and defining the rules related to their governance
Managing medical on-call services.	Managing the multidisciplinary local networks, the integrated home care services, the palliative care associations, the multidisciplinary palliative teams and the "Impulseo fund", which is a specific fund for general medicine created to provide general practitioners with financial help regarding their settlements

### **Appendix 2 – Research Methods**

Type of information source : written documents		
Data	Additional information	
collection		
methods		
Literature	A literature study was conducted regarding the following topics: integrated	
study	care, chronic diseases, pilot projects and public policy instruments.	
(scientific		
literature)		
Documentary	Several political, legal and operational documents were read, notably the	
analysis	joint plan itself and the documents available on the website	
(political, legal	http://www.integreo.be/fr/documentation. This website is a	
and	communication tool created by the public authorities on which documents	
operational	relating to the IC4BH implementation plan were published, including	
documents)	political and legal documents, fact sheets, templates and application	

	guidelines, and PowerPoint presentations. Analysis of these documents provided an overview of the issues authorities sought to communicate and the information they wished to be explicitly known. The researcher also read and analysed the documents produced by the pilot projects she focused on throughout her fieldwork. <b>Type of information source : actions and interactions</b>	
Data     Additional information		
collection method		
Direct observation	The researcher attended several types of meetings as an external observer and took field notes for every one of those. In total, she attended 67 meetings, which correspond to 148 hours of observation. She spent 105 hours observing the meetings of two pilot projects (e.g., preparatory meetings during the conceptualisation phase, follow-up meetings during the execution phase): 35 hours for the first project and 70 hours for the second. The researcher also attended specific meetings, called plenary sessions and "intervisions", organised by the public authorities (43 hours). Regarding the analysis of the collected information, the notes taken were read several times to have a precise and global understanding of the course of events and also in order to put into perspective the qualitative data collected with those gathered during the interviews.	
	Type of information source : discourses	
Data collection method	Additional information	
Semi- structured interviews	<ul> <li>Twenty-four semi-structured interviews were conducted by the researcher with different categories of actors identified thanks to the snowball effect.</li> <li>These were people with whom the researcher had no prior relationship: <ul> <li>policy-advisers and public officials involved in devising and implementing the new policy (n=9)</li> <li>pilot project coordinators (n=8)</li> <li>different pilot project stakeholders, e.g., general practitioners, nurses, social workers, etc. (n=7)</li> </ul> </li> <li>The purpose of meeting these people was to identify, through their discourse, their formal and informal roles, the way they personally experienced the process, their knowledge (what they knew, but also what they did not know) and their feelings about it. A new interview guide was written for each of them. These interviews lasted between 33 and 98 minutes; they were all fully recorded, transcribed, read several times and then analysed manually through open coding, again by the researcher working alone. Open coding is a method of analysis from grounded theory methodology that allows the emergence of <i>ad hoc</i> core categories identified in the empirical material through repeated successive readings (Bryant &amp; Charmaz, 2011).</li> </ul>	

18 components of integrated care	
1.	Empowerment
2.	Support for caregivers
3.	Case-management
4.	Maintenance at work as well as educational, professional and social reintegration
5.	Prevention
6.	Dialogue and coordination
7.	Care continuity (extramural, intramural and transmural)
8.	Accenting the experience of patients and families' organisations and of
	mutual health insurances
9.	Integrated electronic health records
10.	Multidisciplinary guidelines
11.	Development of a quality culture
12.	Adaptation of financing systems
13.	Risk stratification and resources mapping
14.	Change management
15.	Training for professionals regarding empowerment and multidisciplinary
	collaboration
16.	Continuing training regarding integrated care
17.	Evaluation of the system performance
18.	Attractiveness of professions

## Appendix 3 – Integrated care components

Reference: Belgian Ministry of Social Affairs and Public Health, 2015, p. 10