



RAPID RESPONSE REPORT

CASE MANAGEMENT MODEL DRIVEN BY PATIENTS' ASSOCIATIONS

15 JANUARY 2026

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■ LIST OF ABBREVIATIONS

ABBREVIATION

DEFINITION

ALS	Amyotrophic Lateral Sclerosis
ASBL	Association Sans But Lucratif
CM	Case management
FTE	Full-time equivalent
GP	General practitioners
HD	Huntington's disease
KCE	Belgian Health Care Knowledge Centre
MS	Multiple Sclerosis
NIHDI	National Institute for Health and Disability Insurance
PD	Parkinson's disease
SSMG	Société Scientifique de Médecine Générale
VZW	Vereniging Zonder Winstoogmerk
WHO	World Health Organisation

RECOMMENDATIONS

Rationale

Over the past two decades, case management in Belgium has evolved progressively, but in a fragmented manner, through a multitude of initiatives. Some of these initiatives have been launched by institutional actors (e.g. the *Vlaams Agentschap Zorg en Gezondheid*), others by federal authorities (e.g. NIHDI has launched the Protocol 3 project), and still others by hospitals, sickness funds or regional organisations (e.g. the *Zorgproeftuinen* in Flanders or Brusano in Brussels). Recently, a new model of case management driven by patients' associations representing four neurodegenerative diseases has been launched for a three-year pilot project under a NIHDI convention.

All these case management initiatives aim to support individuals with complex health and social care needs, people often affected by multiple chronic conditions, psychosocial vulnerability, and/or a high risk of decompensation (sudden deterioration of a medical or mental condition). They therefore target patients requiring the most intensive, coordinated, and integrated interventions.

The Interfederal Plan for Integrated Care provides a national framework to strengthen coordination and continuity across health and social sectors. Case management is already included in this plan, and while its current operational focus is on perinatal care, people in vulnerable situations, and childhood and adolescent obesity, the intention of the Plan is to implement case management more broadly.

For (pilot) initiatives that start off without a thought-out evaluation protocol (which stipulates among others, primary and secondary objectives, outcome measures and targets, mechanisms of change) impact evaluation and to some extent also process evaluation become very difficult or even impossible. Hence, no (or only limited) conclusions on value for money can be drawn to inform future policy decisions.

An upcoming KCE study (process note for the evaluation of (complex) health policy interventions) will provide guidance on how to evaluate policy initiatives in a methodologically sound way.



RECOMMENDATIONS TO THE NIHDI AND THE FEDERAL PUBLIC SERVICE FOR PUBLIC HEALTH, FOOD CHAIN SAFETY AND ENVIRONMENT

1. We recommend **integrating all people with complex needs into the Interfederal Plan for Integrated Care**, including those affected by rare diseases or not represented by a patients' association, to ensure equitable access to case management services based on individual needs. As such, eligibility for case management services should not only be based on patients' diagnosis or specific disease but also on the level of complexity (see next point) and associated needs.
2. We recommend **applying a common working definition of "complex needs"**, recognising that complexity may arise from medical, psychosocial, functional, family and/or environmental factors.
3. We recommend **launching a research project to define possible options for case management models in Belgium**. This should enable selecting options that ensure **access to a case management for all people with complex needs (see recommendation 1 and 2)**. Different models can co-exist, **depending on various factors** (e.g. the needs of the populations, the most appropriate way to integrate it into the healthcare system, the cost-effectiveness of the implementation strategy).

The study on options for case management models in Belgium should at least:

- **identify the key characteristics of case management models** (goals, competencies, intensity of support, interprofessional coordination, institutional anchoring, etc.);
 - **map the relevant stakeholders** (authorities, NIHDI, health insurance funds, associations, professionals, patients) and their respective roles;
 - **develop several alternative models illustrating different organisational and institutional options** (e.g. a model integrated within primary care, a hospital-based model, a community-based model, a hybrid model);
 - **analyse the implementation and sustainability conditions of these options across different regional and institutional contexts.**
4. We recommend **planning for the evaluation of any new case management initiative *before* launching or implementing a new case management model**. The evaluation protocol should be developed according to the methodological standards which will be elaborated in the upcoming KCE process note for the evaluation of (complex) health policy interventions.

■ ABSTRACT



BACKGROUND

While many patients successfully manage their health care needs on their own or with the help of informal carers, those faced with more challenging situations (e.g. high risk patients, complex or fluctuating disease and therapeutic needs, instability, multiple coexisting conditions...) may need professional help navigating the system. Case management is one possible approach to provide this kind of support to patients, families, and other stakeholders.

Case management can be defined as a collaborative process of assessment, facilitation, care planning and coordination, evaluation, monitoring and advocacy that aims to **help individuals with complex health needs and their families identify and access the right services and resources, make optimal use of them and, ultimately, achieve the best possible health.**

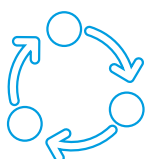
In other words, case management is a way of achieving **integrated care at the level of an individual patient**: it facilitates the appropriate delivery of health care services, and helps overcome fragmentation between services and providers. This support in managing care is not required for all patients: its relevance and importance relative to self-management increases with the complexity of the clinical situation and also the vulnerability of the patient.

Over the last 20 years, **numerous initiatives involving case management have been developed in Belgium** at various levels (federal or regional government, hospitals, sickness funds...), in various settings and for various population groups. Notable examples include the Protocol 3 convention for vulnerable older adults, the article 107 pilots in mental health care, and crisis units integrating case management for individuals in acute psychological or substance-related crises.

In July 2023, the NIHDI launched a **new pilot convention** (running until 2026) for the development of a **case management model driven by patients' associations** for four neurodegenerative diseases: multiple sclerosis (MS), Parkinson's disease (PD), amyotrophic lateral sclerosis (ALS) and Huntington's disease (HD). KCE has been tasked with the assessment of this new model based on the pilot project. If it would prove effective, it could be extended to other health conditions.

However, KCE could only evaluate the practical implementation, barriers and facilitators of patients' association-driven case management. Its effectiveness as a case management model could not be assessed, as the available data did not allow for it.

More on this in Section 1: Background and research section.



METHODS

Two research questions were formulated:

1. How is case management driven by patients' associations **implemented** in Belgium?
2. What are the **barriers and facilitators** to integrating case managers managed by patients' associations for these diseases into the broader case management ecosystem?

These questions were investigated through a pragmatic literature review, data from the activity reports of the seven patients' associations involved and scoping interviews with stakeholders. Due to time constraints, the research team chose to deliver a rapid response report relying on accelerated methods.

More on this in Section 2: Methods



RESULTS

Our pragmatic literature search yielded very limited information on patients' association-driven case management, with only one Canadian study tackling this specific topic in one of the four diseases i.e. ALS.

However, it allowed us to retrieve useful information on **existing case management models**. The various models in literature typically share elements of patient support, orientation and, often, coordination. **These models show considerable variation** in e.g. the level of training required of case managers, their clinical involvement and their interactions with other professionals, the eligibility criteria for patients, the degree of integration of care.

More on this in Section 3: Overview of the literature

The **implementation** of patients' association-driven case management in Belgium includes two main aspects: the overarching, strategic missions entrusted to the patient organisations, and the concrete implementation of case management.

On a **strategic** level, the patients' associations included in the convention were entrusted with missions such as information and outreach, alignment and integration within the existing care ecosystem, quality assessment and monitoring, reporting and data collection. Their obligations in this respect were fulfilled with varying success, and a number of difficulties were encountered. Notably, **coordination with existing services and integration in the wider care ecosystem** often seemed challenging. Also, while they all collected the required administrative and quantitative data, none of the involved patient organisations reported developing a **protocol for assessing the quality of the follow-up of care** (e.g. through PROMs/PREMs to capture the patients' perspective).

The **missions of case managers** as per the convention include an advisory and mediation role, collaboration and shared decision-making, developing a global and integrated approach to care, monitoring and evaluation, support and facilitation, and ensuring coordination of care.

Some aspects of this role were well-documented through a **common registration tool**. **Challenges** mostly relate to limited staffing (e.g. struggles to ensure adequate geographic coverage or perform home visits, having to decide how to prioritise patients in case of service overload...). Nonetheless, the patients' associations felt that the introduction of specialised case managers **enhanced their capacity to support patients in a variety of ways and strengthened collaboration with health care providers**.

More on this in Section 4: Practical implementation of patients' association-driven case management



DISCUSSION

Based on the information collected, the research team highlighted a number of **issues, as well as crucial considerations** that should be taken into account when deciding on the continuation or discontinuation of the current convention.

Regarding the implementation

- It would be worthwhile considering not only **what resources (full-time equivalent (FTE)) should be allocated and how**, but also how they should be **distributed** across regions, taking into account the prevalence and clinical trajectories of the diseases concerned. Sufficient resources and coverage to ensure the possibility of home visits, at least for an initial evaluation, is important to ensure a safe home environment.
- It might be advisable to ensure case management specifically targets **patients vulnerable and/or with a high degree of dependency and/or complex needs**.

Regarding the place of case management in relation to the broader health care system

- The **profile, role and position** of case managers relative to the multidisciplinary care team and to other professionals need to be clarified (e.g. what knowledge do they need to possess? Is a clinical background required? Should they be part of the care team or not?).
- On a related note, the **transferability of case management competences** (e.g. can they be taught, or are they bound to personal experience?) is an important consideration with regard to scalability.
- The patients' association-driven model has certain **advantages**, such as disease-specific experiential expertise, its advocacy function and a perceived neutrality/independence from existing health care structures.
- However, it also presents **challenges** in terms of e.g. coverage (some patients might not be adequately reached or be reluctant to engage with these organisations), recognition by health care professionals, and sustainability (no structural funding).
- Patients' association-driven case management needs to be **correctly positioned** within the health care system to avoid fragmentation and duplication of services.
- **Embedding case management within broader structures for chronic and/or integrated care** might be preferable to a patients' association-driven (and therefore disease-specific) approach, to ensure coherence across policy initiatives, provide a stronger foundation for effective implementation and ensure equitable access to all patients who need this kind of support (not least because a patients' association does not exist for all diseases). At the very least, overarching mechanisms are needed to establish cross-disease infrastructures and pool resources.
- More generally, case management should rely on a clear vision and explicit objectives. **It should not be treated as a short-term quick fix**, but be part of a broader transformation towards a sustainable healthcare system in Belgium to address and cope with vulnerable patients with chronic diseases and highly complex needs.

Regarding evaluation

- Proper evaluation of the patients' association-driven case management model requires a robust **study design**. The set of data that the associations are currently required to collect is too limited to allow for a comprehensive assessment of this care management model.
- **Data collection ought to be standardised** (to ensure comparability) **and expanded** beyond the administrative information and process measures that are currently required under the convention, to include perspectives from patients, informal caregivers, and frontline professionals.
- On a more general note, to allow for a sound evaluation of case management as an intervention, a robust evaluation protocol should be developed prior to data collection. It should comprise, among others, primary and secondary objectives, outcome measures and targets, the basic elements of process evaluation (i.e. implementation, mechanisms of change and context evaluation).

More on this in Section 5: Reflections on patients' association-driven case management in Belgium

■ REPORT

Box 1 – Note about the used terminology

In the Belgian context, there is no uniform definition of case management. Moreover, its interpretation varies internationally, sometimes overlapping with functions referred to as care management or care coordination. To better reflect the reality of practice, the emphasis was placed in this report on the roles and activities actually carried out rather than on professional titles. Consequently, this report includes scientific articles in which these notions provide relevant insights into the model under study, being case management driven by patients' associations.

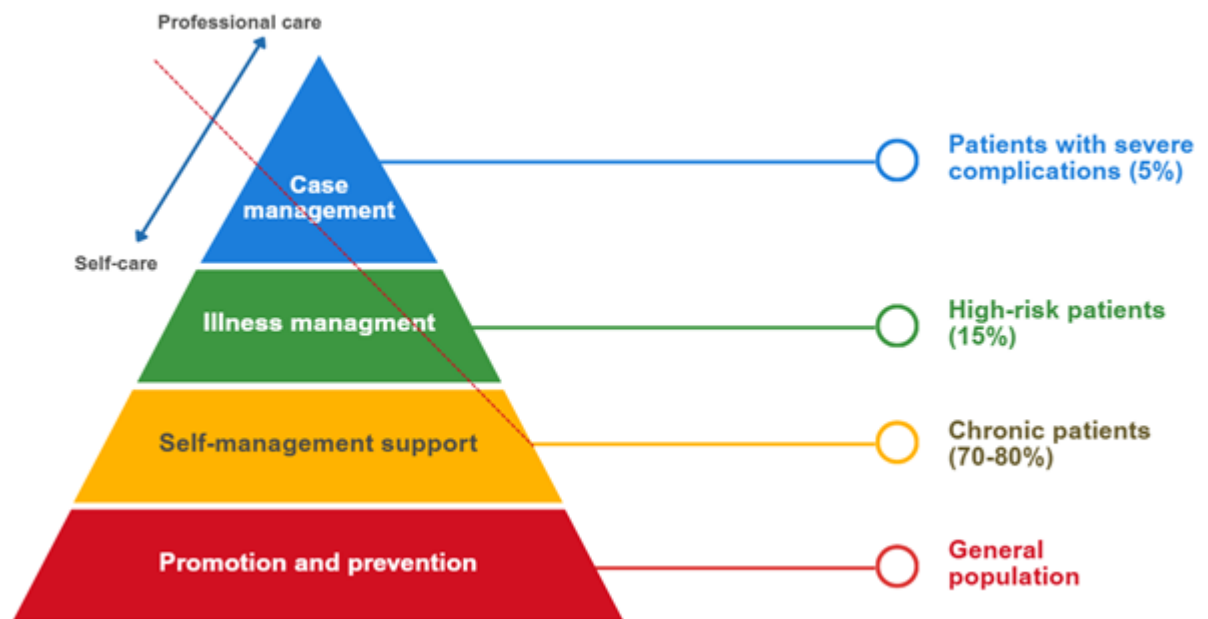
1 BACKGROUND AND RESEARCH QUESTIONS

Case management (CM) is defined by the Case Management Society of America (CMSA) as “a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality, cost-effective outcomes”.¹

Case managers are professionals who work with patients, families, and other stakeholders to help them navigate healthcare systems, to achieve optimal health, access to care and appropriate utilisation of resources, while balancing this with the patient's right to self-determination.² According to the World Health Organisation (WHO) 2016 report, the primary tasks of a case manager are therefore to assess the patient's and carer's needs, develop tailored care plan, organise and adjust care processes accordingly, monitor quality of care and maintain contact with the patient and carers.² In Belgium, these tasks are also reflected in the Interfederal Protocol Agreement on Integrated Care of 8 November 2023, which describes the expected role of case managers.³

Case management is categorised as ‘an individual model of integrated care’ aiming to facilitate the appropriate delivery of health care services and overcome fragmentation between providers. It is concerned with individual coordination of care for high-risk patients and/or patients with multiple conditions and their carers. It is especially applied to complex biopsychosocial needs, i.e. situations where multiple interrelated physical, mental, and social problems (can) occur simultaneously. By comparison, as seen in Figure 1, the “Kaiser Permanente Pyramid” (a population-based integrated care model) stratifies populations according to complex needs, stability, and associated focus for healthcare support. The base encompasses the general population, where the focus is on health promotion and prevention. For chronically ill patients with less complex needs, self-management is the major contributor to overall disease management. Self-management support is an essential component of good healthcare. Patients with long-term conditions require proactive disease management, and the top tier (+/- 5%) individuals, i.e. patients with complex interactions among physical, mental and social needs require case management.² The more complex individual needs become, the smaller becomes the relative contribution of self-management in comparison to professional management. The higher the relevance of professional management becomes, the more important becomes professional management support by, for example, case managers.⁴

Figure 1 – Extended Kaiser Permanente Pyramid



Adapted from *Integrated care models: an overview*. Copenhagen: WHO Regional Office for Europe; 2016.

Due to their overarching and coordinating role, case managers are present in various settings, including healthcare (especially aiming at coordinating care for individuals with complex biopsychosocial needs), social services (focusing on assisting homeless people, poverty, or other social challenges), legal settings, forensic science, etc. In this report, we focus on case management for patients with chronic neurodegenerative diseases.

Over the past two decades, case management has been progressively implemented across various health care initiatives in Belgium. The Protocol 3 convention for vulnerable older adults (since 2009), the article 107 pilots in mental health care (since 2011), and crisis units integrating case management for individuals in acute psychological or substance-related crises (since 2002) are among the main examples. Brusano, a Brussels-based non-profit organisation supporting integrated care, has also established dedicated case management functions, and the Flemish Zorgproeftuinen (2014–2017) tested new approaches to help frail elderly people remain at home in good conditions.^{5,6}

Following budget discussions in 2023, the General Council of the National Institute for Health and Disability Insurance (NIHDI) decided to allocate an earmarked budget of 2 million euro on a convention for specialised multiple sclerosis (MS) care coordinators and multidisciplinary^a MS consultations. As states in the words of the convention, these measure *can be rolled out in collaboration with the MS League and hospitals specialising in MS. A similar measure should be taken for people with Parkinson's disease (PD)*. The NIHDI also stated that *a need for support also appears to be evident in the short term for amyotrophic lateral sclerosis (ALS) and Huntington's disease (HD)*. After several consultations with stakeholders, they decided to expand the group and *to include the patients' associations for HD and ALS*. The convention according to art. 56 was launched in July 2023 with a budget secured until August

^a In the activity reports of patients' associations, the term *multidisciplinary team* refers to specialised teams involved in the follow-up of the person, typically organised within hospital-based reference settings. The term is also used in the scientific literature to describe care structures that bring together several types of expertise relevant to a specific condition. In addition, the NIHDI convention (e.g. the section referring to the specialised care coordinator and multidisciplinary consultation for multiple sclerosis) also employs this term when describing coordinated care practices.

2026. During this period, the NIHDI aimed to assess the value of patients' association-driven case management through this initiative.

The NIHDI asked KCE to evaluate the case management model driven by patient associations based on the four pilots in PD, ALS, MS and HD.

Given the novelty of the NIHDI initiative and the existing case management experiences in Belgium, KCE researchers formulated the following research questions:

1. How is case management driven by patient associations implemented in Belgium?
2. What are the barriers and facilitators to integrating case managers managed by patient associations for these diseases into the broader case management ecosystem?

This report is not an evaluation of the effectiveness of patients' association-driven case management, because the data did not allow for such an assessment.

2 METHODS

The convention was already in place before the launch of this study (December 2024). Considering the convention ends in August 2026, it was decided to deliver a rapid response report. The applied methods should therefore be seen in the light of the KCE process note for Expedited Scientific Research and Reporting (ESRO) reports which describes a more pragmatic way to conduct research in a fast manner with the same scientific rigor.⁷

We used the following methods:

Scoping interviews were conducted in December 2024 (+/- 1.5 years after the start of the convention) to explore perspectives on the initiation phase and current state of implementation, and to receive input on facilitators and barriers influencing its implementation. Nine semi-structured scoping interviews (with representatives of the seven patient associations, one representative from the neurology department at a university hospital, and one academic expert) were conducted by two KCE researchers (C.PdJ. for the French speaking interviews, and J.C. for the Dutch speaking interviews). A topic guide (see Appendix 1) was used covering facilitators and barriers (of the initiation phase), raising awareness on the existence of case managers in patient associations, onboarding of patients and case managers, roles, specificities of the disease, communication (between healthcare providers and across care lines), and perceptions. All interviews were conducted via videoconferencing and audio-recordings were transcribed verbatim using an in-house tool combining Whisper for speech recognition and Pyannote.audio for speaker segmentation.^{8,9} Data from the transcriptions were subsequently managed and analysed in NVivo by one researcher (J.C.). A content analysis approach was applied. Codes were inductively generated during the iterative review of the transcripts, enabling themes to emerge directly from the data. The emerging themes were then reviewed with the researchers involved in the interviews to ensure they reflected what was heard during the discussions. The results of the qualitative analysis were used to illustrate specific findings from the analysis of the activity reports (chapter 4) and to nourish the discussion section (chapter 5), rather than as solid qualitative evidence because we cannot be sure that we covered the full spectrum of perspectives amongst the interviewees. A more extensive qualitative design would not have been appropriate, given that the study addressed the initiation phase of the projects, intended to capture early insights rather than assess performance.

A pragmatic **literature search** was conducted to identify relevant studies published over the last ten years across three major databases: Medline, Embase, and Cochrane. The search strategies are detailed in Appendix 2. The review aimed at identifying models of case management and their key components.

A combination of controlled vocabulary (MeSH terms) and free-text keywords was used for the literature search. Figure 2 in Appendix 2 illustrates the interconnections between the concepts integrated into the search strategy. To better reflect the reality of the Belgian context, we focused more on roles and activities than on professional titles. Therefore, we used keywords such as case or care

manager/management, care coordinator/coordination, as well as patient navigation, for example. The search strategy was developed in collaboration with the KCE medical information specialist (N.F) to optimise sensitivity and specificity and was adapted to each database. The date of the last search was 19 March 2025. Retrieved references were imported into Covidence for records' management.

Given the large number of references identified through our search strategy, we applied specific inclusion and exclusion criteria to refine the selection. Our literature review included both primary studies and reviews focusing on models of case management, with special emphasis on those driven by patient associations or conducted in Belgium. The eligible population comprised frail populations, such as the elderly or patients with complex health conditions and care needs, while the eligible settings encompassed outpatient and community-based care. Papers on case management in hospital only were excluded. We also paid specific attention to studies addressing diseases covered by the convention (see Table 3 in Appendix 2 for a complete overview of the inclusion and exclusion criteria).

This literature review was supplemented by a pragmatic Google search to identify experiences of case management in patient associations, Belgian documents, examples of case management in neurology, and documents from professional associations of case management.

This review was not designed to cover the full extent of available literature.

An analysis of the annual activity reports submitted by the patient associations was conducted between March and June 2025.¹⁰⁻¹⁷ Under the convention, patient associations are required to collect and report specific data in their annual activity reports.

The data are encoded directly by the case managers into the reporting tool developed for this purpose. In the annual activity reports, these data are compiled and presented in aggregated form to provide a comprehensive picture of the activities carried out, while also ensuring patient anonymity and data protection.

In addition, the reports also include the patient associations' own analysis of their first year of implementation including lessons learned, successes achieved, and difficulties encountered.

The objective of our analysis was to examine the extent to which the requirements set out in the convention were effectively implemented by the patient associations and to assess whether the planned actions were carried out in practice.

3 OVERVIEW OF THE LITERATURE

3.1 Case management models from the pragmatic literature review

The literature search strategy resulted in 1591 unique records. After applying the inclusion and exclusion criteria, four papers were retained.¹⁸⁻²¹ This was supplemented by two additional papers identified through a Google search^{b, 22, 23}. One of the six papers focuses on case management driven by patient associations; the other presents models of case management in Belgium or abroad.

Ahmad et al. investigated case management for ALS within patient associations.¹⁸ This study took place in Canada, where published guidance on communicating an ALS diagnosis recommends that health professionals refer patients and families to ALS health charities (also known as patients' associations) for support. Indeed, the Canadian best practice recommendations for the management of ALS (updated in 2020) mentioned in its section about communication of diagnosis that "discussion about ALS treatments and ALS research should occur. Patients should be provided with written information about ALS resources (paper- or Internet-based) and encouraged to register with their local and national ALS society".²⁴ This recommendation was based on expert consensus, meaning that is a minimal level of evidence. In Canada, charities are involved in advocacy, direct support for people living with ALS, research and often act as funders or collaborators. Findings from Ahmad et al., based on interviews with 78 patients and family caregivers, highlight the role of charities as integral to the healthcare system. Interviewees viewed them as system navigators who facilitated access to care, clarified medical information, and addressed service gaps (particularly in psychological support) through information provision, referrals, and programmatic assistance.¹⁸ We can consider these activities as similar to the ones performed by patient associations in Belgium, but the main difference remains in the referral to charities in Canada, as part of the recommended patient's pathway after ALS diagnosis. This study is based on perception of the interviewees and, to our knowledge, this model of case management inside patient associations has not been evaluated.

In Belgium, Van Durme et al. analysed case management within the Protocol 3 project. They identified three distinct types of case management²³:

- the first, described as a "**social approach with low collaboration and clinical integration**", is largely a social support strategy with minimal clinical involvement. It lacks proper feedback mechanisms to general practitioners (GPs), shows little to no collaboration with them, and is characterised by high case turnover and weak inclusion criteria. Despite the use of multidisciplinary protocols, the teams often do not include nurses or social workers, relying instead on occupational therapists or psychologists;
- the second type, termed a "**social approach with integrative components**", incorporates elements of integrated care. It involves more structured coordination and skilled professionals, though clinical responsibilities are sometimes delegated. Feedback to GPs remains limited, and there is little monitoring of care plans or protocol use. However, this model benefits from strong inclusion criteria, well-trained staff with external supervision, and the use of supportive software tools. Teams typically include social workers alongside psychologists or occupational therapists;
- the third type, "**clinical integrative case management**", represents a more advanced and medically integrated model. It features robust monitoring of care plans, active peer support among professionals, and systematic feedback to GPs. Coordination is supported through formal partnerships and digital tools. Nonetheless, the model has weaker inclusion criteria and limited financial accessibility, especially for older patients who may face out-of-pocket costs.

^b Not retrieved by the search strategy: Van Durme et al. (2015) (partially indexed in Medline, not in Embase); Lukersmith et al. (2023) (excluded based on indications in the search strategy).

Four papers explore case management models outside Belgium.¹⁹⁻²² Although none of these models specifically address the neurodegenerative diseases targeted by the NIHDl convention, they provide valuable insights into different approaches to case management implementation. They were developed either through a comparative analysis of case management programs²⁰ or by applying existing theoretical frameworks to case management interventions^{19, 21, 22}. Providing an integrate overview of these models is challenging, as the papers used different methods to identify them, and their components vary considerably. This issue was also acknowledged by the authors themselves, highlighting the heterogeneity of methods, target populations, interventions, and, where applicable, outcomes.^{19, 20} Nevertheless, we consider these models relevant to illustrate the diversity of case management approaches.

Table 1 – Case or care management models from publications outside of Belgium

First author, year of publication	Categories	Characteristics
Hewner et al., 2021 ¹⁹	4 types of care management involving complex interventions led by professionals guiding care transitions: - integrated behavioural health and primary care, - embedded care management, - centralised care management, - transitional care management	Focusing on transitional care for high-need patients. Key components included discharge assessments, self-management education, behavioural health, medication management, and community resource access.
Longhini et al., 2021 ²⁰	4 models emerged from the scoping review: - complex integrated care models (often grounded on the Chronic Care Model framework), - case (or care) management, - involvement of pharmacist role, - involvement of community health worker role	The first three models included at least one strategy to ensure coordination and/or quality of care. Use of protocols and guidelines were retrieved in the first two models. In the case (or care) management model, there was always care coordination and almost often by a professional who was part of a multidisciplinary team and gave self-management support.
Lukersmith et al., 2023 ²²	Used the generalist/broker model and the person-centred community-based model (based on case manager taxonomy)	The generalist model emphasises meeting practical needs through a structured, administrative brokerage approach (arranging rather than providing services). The Person-centred model builds on this with a proactive, preventive focus on individual motivations and goals, emphasising participation planning, leveraging personal strengths, and managing contextual barriers or supports to help achieve goals.
Van Mierlo et al., 2016 ²¹	Examination of the two most prominent care management models in the Netherlands: the linkage and integrated care forms	COMPAS (Collaborative dementia care for patients and caregivers) study: Both models <u>share</u> features: a specialist dementia case manager, new patient referrals via GPs or specialists to a central contact point and a multidisciplinary team. <u>Differences</u> arise in the diagnostic pathway and service provision (independent services within a shared network in the linkage model versus a single organisation in the integrated model). In the linkage model, multidisciplinary teams are external to the case

		manager's team but can be contacted if needed; in the integrated model, all multidisciplinary activities occur within the institution.
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3.2 Additional contextual literature

This section summarises five papers that did not meet the inclusion criteria for our literature review (as they do not address case management models) but that nonetheless provide useful insights for our research questions.²⁵⁻²⁹ These papers were selected to provide illustrative examples.

In their paper, Van Halteren et al. describe an integrated and personalised care management model to tailor to the needs and preferences of individuals with Parkinson's disease. This model was based on five main components: care coordination, patient navigation, information provision, early detection of signs and symptoms through proactive monitoring, and process monitoring. The authors built it on the chronic care model; this is why the two models share characteristics such as self-management support, integrated decision support, proactive care delivery, mobilisation and use of available community resources. To implement personalised care in Parkinson's, the authors acknowledged to first identify the unmet needs and prioritise with input from patients, caregivers, and providers; regular evaluations are needed to ensure progress and long-term sustainability.²⁸

Integrated care as a broader approach

A broader approach to case management for people with neurodegenerative diseases is integrated care, including a dedicated and specialised HCP. For example, in Parkinson's disease, several programs and initiatives highlight the importance of trained HCPs or Parkinson's nurse specialists, particularly due to their coordinating role.²⁵ As a central point of contact for patients, they play a crucial role in coordinating care, liaising with various stakeholders, ensuring continuity of care, and addressing the complex needs of patients.²⁶ The coordinator can be a nurse, a social worker, or another professional trained in the specific aspects of the disease. Their titles and responsibilities may vary, but their core functions consistently include care coordination, referrals to the multidisciplinary team, and providing information to help patients and carers manage the disease.^{26, 29}

In their review, Thomas et al. outline the diverse roles of Parkinson's nurse specialists:²⁷

- care coordination: care planning, collaboration, referrals;
- education, advice, and support: psychological support, educating generalist HCPs, patient/carer education, goal setting;
- specialist clinical skills: monitoring and assessment, non-medical prescribing, non-pharmacological symptom management, and guiding patients toward research opportunities.

During our Google search, we also encountered this example of networking: ParkinsonNet is a specialised network providing care to patients with Parkinson's disease developed in the Netherlands and later exported internationally. Its goal is to improve care quality by creating a network of healthcare professionals specialised in Parkinson's disease. It is based on two key principles: developing the expertise of HCPs and collaborating as a multidisciplinary team around the patient. The care manager acts as a central contact point for patients and the multidisciplinary team, promoting continuity of care^c.

^c <https://www.parkinsonnet.com/>

4 PRACTICAL IMPLEMENTATION OF PATIENTS' ASSOCIATION DRIVEN CASE MANAGEMENT

This chapter discusses the provisions of the convention, which are presented in English translation (quoted verbatim in italics), and then assesses the extent to which these provisions were implemented by patient associations in practice.

During the summer of 2023, the NIHDI concluded conventions with seven associations representing patients with neurodegenerative diseases, i.e. MS, PD, ALS or HD.

The conventions were signed^d respectively with:

- in July 2023: Vlaamse Parkinson Liga vzw^{e30}, Ligue Belge de la Sclérose en Plaques – Communauté Française asbl^{f31} and MS-Liga Vlaanderen³²
- in August 2023: Ligue Huntington Francophone Belge (LHFB) asbl³³ and Huntington Liga vzw³⁴
- and in September 2023: ALS Liga België vzw – Ligue SLA Belgique asbl³⁵ and Association Parkinson asbl³⁶.

The convention aims *to create and evaluate a case management model operated by different patient associations*. The purpose of case management is, among other things, *to restore and stabilise the patient's care situation and to coordinate care so that the care process can once again proceed in a qualitative manner. The case manager acts as an external support line and point of contact both for the individual and their informal network, as well as for members of the interdisciplinary care team^g, and may initiate care coordination if it has not yet been established.*

4.1 Provisions foreseen

The convention is temporary and runs for a period of three years, *from 1 July 2023 to 31 August 2026*. Table 2 presents the provisions concerning the number of full-time equivalents (FTEs) and the annual budget allocated to staff, operations, and, where applicable, coordination.

The funding allocated to patient associations under the convention is primarily based on the number of FTEs and varies between patient associations. Patient associations with fewer FTEs were challenged by geographical coverage, limiting their capacity to provide home visits and therefore most contact with patients were held by telephone or email. Furthermore, it limits constructing locoregional contacts with healthcare providers and organisations.

^d As contracts require the signature of two parties who cannot always sign simultaneously, the date retained here is that of the last signature affixed.

^e vzw = Vereniging Zonder Winstoogmerk

^f asbl = Association Sans But Lucratif

^g In the NIHDI convention, the interdisciplinary care team refers to the group of individuals involved in the ongoing care and support process surrounding the person. This team represents those with whom the person and their informal context interact throughout the continuity of care and support. It is explicitly stated that the case manager is not a member of this team, but functions as an external point of contact for the person, their informal context, and the members of the interdisciplinary care team (ref NIHDI Convention).

Table 2 – Overview of the resources allocated per patients' association as stipulated in the convention

Patient association	Number of FTE Case Managers	Staff cost (Case Manager expenses)	Functioning (15%) cost	Coordination cost	Total per year
ALS Liga België vzw – Ligue SLA Belgique asbl	2	137 322€	20 598€	NA	157 920€
Ligue Huntington Francophone Belge (LHFB) asbl	1	68 661€	10 299€	NA	78 960€
HUNTINGTON LIGA VZW	1	68 661€	10 299€	NA	78 960€
Association Parkinson asbl	6	411 966€	61 795€	51 496€	525 257€
Vlaamse Parkinson Liga vzw	6	411 966€	61 975€	51 496€	525 257€
Ligue Belge de la Sclérose en Plaques – Communauté Française asbl	5	343 305€	51 496€	42 913€	437 714€
MS-Liga Vlaanderen	6	411 966€	61 795€	51 496€	525 257€

NA: not applicable

4.2 Overall missions and duties of the patient associations

Patient associations were expected to *integrate case managers into their organisational structures, either by recruiting new staff or by reassigning existing positions*. Case management is defined as *a dedicated function, meaning that it is the sole main task of the staff member*. The position is filled by *someone who is not part of the interdisciplinary team*.

In practice, only one patients' association reassigned 40% of the workload of each social worker to case management activities while the others recruited new staff.

Beyond this initial organisational requirement, *patient associations are also entrusted, within the framework of the convention, with the following missions: (i) information and outreach, (ii) analysis of the liaison function, (iii) quality assessment and monitoring, (iv) reporting and data collection and (v) integration within the care ecosystem*.

Information and outreach: patient associations are required to *inform all patients in the relevant provinces about the pilot project, the services offered by the patient association, and the eligibility conditions*.

In practice, they implemented a broad range of actions to increase the visibility and understanding of the new case management function among diverse stakeholders.

Patients, their families, and the general public represented a primary target group, particularly individuals potentially eligible for the pilot project and their informal caregivers. Beyond their existing members, the associations also sought to raise awareness among patients affected by the four targeted diseases and, through specific communication channels, the wider public.

Healthcare professionals and care institutions represented another key target group. The associations reached out to a broad range of professionals, including neurologists, GPs, pharmacists, nurses, and other frontline providers. These professionals were approached either individually or within the structures in which they work, such as specialised hospital departments (neurology, rehabilitation, genetic clinics), hospitals more broadly, primary care zones, public social welfare centres (OCMW-CPAS), and sickness funds. In parallel, professional networks and sectoral associations, such as Zorgnet Icuuro, Domus Medica, and the Société Scientifique de Médecine Générale (SSMG), were involved in disseminating information and creating relays. Public and associative bodies, such as local authorities or primary care councils, and umbrella organisations were also involved.

To reach these diverse audiences, the associations adopted a combination of complementary strategies. A first strand consisted in the production and dissemination of communication materials (brochures, leaflets, infographics, business cards, and digital content) distributed through hospitals, neurology practices, GPs' waiting rooms, pharmacies, public social welfare centres (OCMW-CPAS), and via professional and sectoral networks.

In addition, direct engagement with professionals and institutions was actively pursued. Presentations were organised in hospital departments, primary care networks, training sessions, and multidisciplinary platforms, while bilateral meetings with hospitals, sickness funds, social services, and professional associations facilitated the exchange of information, the identification of contact persons, and the establishment of partnerships. In several regions, case managers also took personal initiative to approach neurologists, GPs, social workers, and hospital teams to strengthen referral channels.

Finally, wider information campaigns targeted patients, their relatives, and the general public. These involved articles in association magazines, newsletters, and municipal bulletins; press releases sent to local authorities and scientific societies; and contributions to public health events such as fairs, patient forums, and regional conferences. Such efforts were reinforced through websites, social media, and appearances in mainstream media, thereby broadening the visibility and understanding of the new service.

Analysis of the liaison function: Throughout the convention, patient associations were required to *analyse the existing liaison function* financed through B4 contracts (*Budget Financiële Middelen/Budget des Moyens Financiers* (BMF/BFM)), in collaboration with partner hospitals (see Box 1). The results of this work had to be *submitted to the* (NIHDI health care) *Service* and presented in a report to the *Steering Committee*.

The convention further states that the (case management) *services provided under these agreements must take into account the target group already defined in the B4 contracts (agreements between the FPS Public Health and various hospitals)*. This requirement implies that activities had to be aligned with the population criteria used by hospital-based B4 liaison teams. The case management function was therefore expected not to duplicate hospital services but rather to complement them.

In theory, such liaison functions currently exist for three of the four neurodegenerative diseases involved in the convention, i.e. MS, ALS and HD. According to the FPS Public Health, these liaison functions are second-line hospital-based services designed to support **patients with advanced-stage conditions who still live at home**, by providing specialised guidance to both patients and their informal caregivers.

In practice, experience with these liaison agreements varied considerably:

- In some cases, historical agreements co-signed with hospitals had limited or no operational impact, being largely managed by hospital teams themselves. In other contexts, long-standing operational involvement within B4 conventions enabled associations to adapt their practices, clarify respective roles with hospital teams, avoid overlaps, and ensure coordinated patient follow-up. Case managers were generally not expected to intervene with patients already under the care of a hospital liaison team, except at the explicit request of liaison staff or families, while regular coordination meetings

were organised to review patient trajectories and anticipate transitions. In addition, certain associations progressively developed similar collaborative frameworks with hospitals not originally involved in the B4 conventions, with the aim of strengthening continuity of care and establishing new partnerships.

- In other cases, some associations concerned by the convention made no reference to liaison functions in their activity reports.

Box 1 – B4 Contracts and Liaison Function for Advanced Neurodegenerative Diseases

According to the official Belgian health portal (www.health.belgium.be), since July 1, 2014, *liaison functions* have been in place for patients in an advanced phase of neurodegenerative diseases (specifically MS, ALS, and HD) who live at home. These liaison functions are second-line services jointly managed by patient associations of these three neurodegenerative diseases and reference hospitals. Six such functions are financed full-time through the *Budget Financiële Middelen/Budget des Moyens Financiers* (BFM / BMF) in hospitals: one French-speaking and one Dutch-speaking liaison function for each of the three diseases.

The objective of these functions includes offering appropriate support and information to patients and their relatives, as well as to care providers, to help maintain continuity of care and ensure that the care provided remains well suited to each patient's situation. They also involve responding to complex individual issues through specialised advice to care providers.

Source: <https://www.health.belgium.be/fr/huntington>

Quality assessment and monitoring: patient associations must participate in the *development of a protocol to evaluate the quality of improved follow-up within the framework of the convention*. This protocol may rely on *Patient Reported Outcome Measures (PROMs)* and/or *Patient Reported Experience Measures (PREMs)*.

In practice, none of the activity reports made any reference to the development or implementation of such a quality evaluation protocol, nor to the use of PROMs or PREMs for this purpose.

Reporting and data collection: patient associations must *submit an annual report* to the *insurance committee of the NIHDI*, following its presentation to the steering committee. This report must include the following data:

3. Administrative data:
 - one code per beneficiary (to anonymise the data)
 - beneficiary's month and year of birth
 - date of diagnosis
 - reason for case manager intervention
4. Data on the number of new beneficiaries supported by the partner during the reference year
5. Qualitative data:
 - How long does it take between the patient's initial contact and the first appointment with the case manager?
 - How many patients have abandoned the case manager's support? And why?
 - How many different care or support providers have been involved in the case manager's support?
 - On average, how many contacts does the CM have with a patient?

All collected data are presented in Appendix 3.1.

In practice, all associations complied with the convention's requirements by systematically collecting the mandatory set of data. These core variables were registered and collected in a case management tool (see example in Appendix 3.2) developed by the patient associations. These data are supposed to be annually reported in the activity reports.

The number of new beneficiaries supported during the reference year varied considerably. The time between the patient's initial contact and the first appointment with a case manager was generally short, ranging from less than a week to a maximum of 20 days, depending on the association. Reported drop-out rates also differed, with some associations explaining withdrawals by a transfer to another convention or by the fact that the coordination of care was taken over by another provider.

Some data retrieved in the activity reports highlight issues of comparability across associations. Regarding the involvement of health and social care providers, the figures referred either to the total number of professionals contacted or to the total number of contacts with professionals throughout the year. This ambiguity complicates interpretation. Concerning case manager/patient interactions, the activity reports also diverged: some associations indicated the overall number of contacts made during the year (e.g. phone calls, e-mails, home visits), while others presented the average number of contacts per patient. This lack of standardisation in data reporting underlines the need for clearer guidelines to ensure meaningful cross-association comparisons.

Integration within the care ecosystem: the activities of the patient associations must be *harmoniously integrated into the existing case management ecosystem, in particular with the social services of the sickness funds, the home care coordination centres in Brussels and Wallonia, and the coordination of care of specialised hospital teams*. This link with existing initiatives must be *described in detail in the annual activity report*.

In practice, several associations reported developing structured collaborations with **specialised hospital teams**. These included regular coordination meetings with multidisciplinary hospital teams, the extension of collaborative approaches to additional neurology departments and hospital networks, and frequent exchanges aimed at ensuring continuity between hospital-based and community-based care. Sustained interactions with neuromuscular reference centres and hospital-based social workers were also described, with an emphasis on continuous communication as a prerequisite for optimal patient support.

Associations have also worked to integrate their activities within community-based home care coordination centres. In some cases, case managers proactively contacted local coordination teams to present their services, which led to collaborative arrangements such as joint meetings and regular exchanges of information about patient situations. According to the patient associations, the coordination teams valued the disease-specific expertise of case managers, often requesting their involvement as a complement to their own services, and even expressing interest in receiving further training on pathology-related support.

In addition, several associations reported collaborations with the social services of the sickness funds. These services are frequently involved in patient trajectories, providing practical support or assuming coordination tasks, making regular communication essential. In certain cases, patient associations also participated in consultation meetings with generalist case management teams to improve mutual understanding of roles and promote coordinated interventions.

Finally, some associations engaged in broader networking initiatives to foster synergies within the wider care and support ecosystem. These included frequent exchanges with multidisciplinary hospital teams,

as well as consultations with organisations experienced in case management to align their activities with existing chronic care structures.

4.3 Patient target group

As specified in the convention, case management services are offered to *all beneficiaries* (with ALS, MS, PD or HD) *who require the assistance of a case manager, either at their request or with their consent*.

In practice, target populations have been defined according to both the specificities of each disease and the complexity of patients' needs, leading to heterogeneous approaches to eligibility and prioritisation. While some associations apply prioritisation criteria only in situations of service overload or when waiting lists arise, others have developed more systematic frameworks based on predefined patient profiles, indicators of case complexity, or internal assessment tools such as structured referral forms. Three categories of criteria arise:

1. The first category of criteria relates to **acute care needs and deterioration**. Priority is given to individuals presenting rapid disease progression or approaching end-of-life. Some associations also consider the stage of the disease, paying particular attention to newly diagnosed individuals, especially at diagnosis disclosure, or to those experiencing relapses or other critical transitions that require intensified support.
2. A second category concerns **psychosocial vulnerability and environmental fragility**. In this group, patients living alone, lacking informal or professional support networks, experiencing social isolation, or refusing available help are prioritised. This category also includes situations marked by financial precarity, low health literacy or difficulties navigating complex care systems, which can hinder access to appropriate services without dedicated guidance.
3. A third category refers to **indicators of case complexity**. These include signals such as the accumulation of health and social problems, the multiplicity of care providers involved, triggering life events (such as the loss of a caregiver or relocation), the presence of cognitive or psychiatric symptoms or the absence of regular professional follow-up.

4.4 Case managers' background and skills

The convention stipulates the case manager *has a background in care or welfare which is not limited to the professions included in the coordinated law on the practice of healthcare professions (Belgian Act on the Practice of Healthcare Professions³⁷)*. Furthermore, the case manager must have the *necessary knowledge to navigate the healthcare and welfare landscape, possibly linked to a specific pathology*.

In practice, patient associations have operationalised these stipulations in diverse ways. The educational backgrounds of case managers vary widely spanning psychology, law, social work, nursing, occupational therapy, speech therapy and dietetics.

When recruiting for case managers, patient associations have emphasised several key competences and skills for case managers:

- **Knowledge of the disease:** some conditions are rare and complex, with highly variable trajectories (cognitive, behavioural, physical problems, symptom evolution, life expectancy). Patient associations consider that case managers should understand these differences and adapt their support accordingly.
- **Knowledge of the care landscape and patient rights:** given the complexity of healthcare and welfare system, patient associations consider that case managers should be able to guide beneficiaries through available services and rely on a broad collaborative network.

- **Communication skills:** patients and informal caregivers often cope with illness differently and may lack insight into their situation. Patient associations consider that case managers therefore need to conduct sensitive and sometimes difficult conversations with patients, caregivers, and health professionals often within limited time periods.

The case managers entered the function with diverse professional backgrounds and experiences, often rooted in healthcare (e.g. hospitals, primary care) or social services (especially when patient associations choose to convert existing positions into case managers). During onboarding, they received (an) educational course(s), developed by the patient association, spanning topics such as pathology-specific knowledge and skills (tailored to the complexity of the disease concerned), the care landscape, patients' rights, and communication skills. Associations also stress the value of peer learning, as case managers continuously exchange practices (e.g. regular intervision sessions organised within each language community) and lessons through collaborative platforms.

4.5 Assignments in the convention - Services delivered by case managers

Advisory and mediation role: *the case manager serves as advisor and mediator between the beneficiary and the informal caregiver, and acts as the reference person for them as well as for the members of the care team. In this capacity, (s)he is the facilitator and supervisor of the process (within the limits of their legal professional boundaries and expertise) concerning both the care team and the care situation.*

In practice, the organisational model of patient associations ensures that each beneficiary is supported by a single case manager who acts as their reference person. Given the very small teams, typically one case manager per province, or in some instances one for the entire Flemish region and another for Wallonia–Brussels, the issue of continuity does not arise: patients, families and care teams consistently interact with the same professional throughout the care trajectory.

At the same time, the limited staffing capacity and resources available make it difficult for some associations to guarantee systematic home visits. This constraint does not imply, however, that follow-up is lacking. Case managers adapt by prioritising the most urgent or complex cases for in-person visits, while ensuring regular monitoring through telephone calls, digital communication, or coordination with other professionals. In this way, they are able to maintain their function as facilitator and supervisor of the care process, even when the intensity or format of direct home-based support must be adjusted to resource limitations.

Collaboration and decision-making: *all decisions are taken in consultation with the beneficiary, the informal caregiver, and the other actors of the care team. The case manager always works in close consultation with the health care providers of the care team and with the person currently or recently responsible for care coordination.*

In practice, the implementation of collaboration and shared decision-making is reflected in the diversity and intensity of contacts maintained by case managers with health and social care professionals. Data encoded in the case management tool shows that these interactions vary considerably depending on the individual situation and the resources available.

Case managers frequently engage with hospital-based multidisciplinary teams and social services of the sickness funds, which often represent the primary interlocutors in complex care pathways. In some cases, the absence of a formal care coordinator meant that case managers had to assume responsibilities that extended beyond advisory or mediation, ensuring continuity of support across fragmented services. Contacts are also established with a wide range of community actors (including general practitioners, physiotherapists, speech therapists, palliative care services, municipal social

services, sickness funds, and specialised associations) illustrating the breadth of partnerships required to adequately support patients with neurodegenerative diseases.

However, the frequency of interactions is influenced by contextual constraints. For instance, the scarcity of neurologically trained allied health professionals and their limited capacity for home visits represent significant barriers, particularly for patients with severe mobility impairments. Geographic dispersion of professionals further complicates timely coordination. In addition, some associations reported the difficulty of convening more than two professionals simultaneously around a patient, which limits the effectiveness of formal case conferences and obliges case managers to rely instead on sequential bilateral exchanges.

Mediation also emerged as a central part of the case manager's function, extending beyond health care teams to intrafamilial settings, hospitals, and residential facilities. Case managers act as intermediaries to resolve conflicts, facilitate communication, and ensure that the voices of patients and their relatives are adequately represented in decision-making processes.

The activity reports highlight strong variation in the number of professional contacts per patient, largely explained by differences in social and family networks. Individuals with limited or absent support networks tend to generate a higher volume of interactions, as case managers must temporarily compensate for missing professional or informal structures until more durable support systems are established.

Global and integrated approach to care: the case manager *never limits his or her intervention to specific aspects of follow-up* but acts in a *comprehensive and integrated manner*. This includes ensuring that:

- *a global evaluation of the situation is carried out where necessary,*
- *a care plan is developed and correctly implemented, and*
- *the function of care coordination is exercised* whenever this is not yet in place but proves necessary for the proper progress of the care process.

In practice, the information relating to these three dimensions is systematically documented in the registration tool common to all associations (see screenshot in Appendix 3.2):

- **Global evaluation of the situation:** Case managers systematically start with an intake assessment to map the medical, psychosocial, and environmental needs of the beneficiary. Reports show that this first step is crucial to identify hidden vulnerabilities such as isolation, financial precarity, or mental health issues that would otherwise remain unnoticed. The registration tool allows case managers to record these multidimensional assessments and to categorise cases according to urgency or complexity, thereby structuring follow-up and justifying prioritisation decisions.
- **Development and implementation of a care plan:** Based on this evaluation, case managers work with the patient and their relatives to set realistic care objectives and identify appropriate professionals or services. The activity reports indicate that case managers play a central role in liaising with both hospital-based specialists and community providers. The registration tool is used to track the agreed objectives, document the involvement of each professional, and follow progress over time, which ensures that the care plan is not only defined but also effectively implemented. However, in practice, it remains unclear to what extent the information recorded in this tool is shared with other care providers within the "interdisciplinary care team." If this information is not systematically shared, it raises an important question regarding the actual level of care integration achieved through this model.

- **Function of care coordination:** When no other coordinator is available, case managers assume this role temporarily to guarantee continuity of care and coherence of interventions. The reports show that this situation arises frequently, as existing coordination mechanisms are often fragmented or absent. In such cases, case managers act as reference persons for the patient and family, while facilitating communication between providers. Once a suitable coordinator is formally designated within the care system, the case manager withdraws from this coordinating role but remains involved to provide pathology-specific expertise.

Monitoring and evaluation: at the end of each evaluation period, the case manager assesses the results obtained with the other actors, maintaining an objective stance towards the beneficiary, the informal caregiver and relatives, and the (health)care providers.

In practice, the extent to which these monitoring and evaluation activities are systematically documented remains uncertain. While the case management tool theoretically provides a space for recording such follow-up, it is not clear whether case managers consistently encode the results of evaluation meetings or patient outcomes. Among the associations, only one has explicitly developed and formalised a detailed process for monitoring the patient pathway, from intake to follow-up and closure. The others did not present such structured frameworks in their activity reports. This heterogeneity can be explained by the fact that the convention did not explicitly require associations to document monitoring and evaluation procedures in their annual reporting, thereby leaving room for variation in implementation and documentation practices.

Support and facilitation: the task of *adjusting/repairing the ongoing process (coordination of care and support)* is broadened to include serving as *an external helpdesk and point of contact for the beneficiary*, the informal caregiver, and the interdisciplinary team. This involves:

- providing *guidance in navigating the health and social support system* in line with the person's needs (person-centred and goal-oriented), and
- improving *communication and cooperation within the interdisciplinary team*, including the organisation of multidisciplinary meetings when appropriate.

In practice, the available data confirms that case managers maintain ongoing contact with beneficiaries through various channels (such as telephone calls, email exchanges, and home visits) which are systematically recorded in the registration tool. These records allow for a quantitative overview of the intensity and continuity of follow-up. However, information on the organisation of multidisciplinary meetings is not systematically captured. Instead, reporting is limited to the number and diversity of professional contacts established by case managers, both medical (e.g. neurologists, general practitioners, rehabilitation specialists) and non-medical (e.g. social workers, welfare services, home care providers). This information illustrates the facilitation role of case managers in fostering communication across the care network, but it does not provide detailed evidence on the extent to which formal multidisciplinary meetings were convened.

Ensure good coordination: The case manager *ensures that the care coordination function is carried out, if this function has not yet been assumed and still appears necessary for the smooth running of the care process.*

In practice, the activity reports confirm that case managers frequently assume a temporary coordinating role when no formal coordinator is yet in place, ensuring continuity of follow-up and preventing fragmentation of care. Once a dedicated coordinator emerges (whether through hospital teams, home care coordination services, or sickness funds) the case manager is expected to transfer responsibility while maintaining a supportive function.

However, the reporting remains incomplete. None of the activity reports provide systematic information on the appointed care coordinator such as, professional background, or date of entry into service. As a result, while the registration tool captures the number and diversity of professional contacts established by case managers, it does not document the concrete process of transferring coordination responsibilities, nor does it allow verification of whether coordination was effectively assumed by another designated professional.

The tasks listed in the convention were all retrieved in the activity reports. Despite some operational difficulties, associations reported that the introduction of dedicated case managers enhanced their capacity to support patients and strengthened collaboration with healthcare providers. They feel case managers are seen as coordinators rather than care providers. They maintain an overview of available services, connect networks around patients, and build safety nets in complex situations. Their scope goes beyond healthcare, addressing financial or employment issues, e.g. guiding patients to debt mediation services, liaising with institutions or supporting return-to-work discussions with employers. Case managers aim to function as a feedback loop between home and institutional care, ensuring continuity and integration across care levels. By empowering patients and supporting self-management throughout the disease trajectory, the case managers feel they help individuals navigate difficult circumstances while strengthening collaboration among professionals and informal caregivers.

5 REFLECTIONS ON PATIENTS' ASSOCIATION-DRIVEN CASE MANAGEMENT IN BELGIUM

This chapter contains mainly critical reflections regarding the current patients' association-driven case management convention, based on the findings described in this report and previous KCE research.³⁸ The limited scientific evidence on case management models and the lack of solid data to make a full assessment precludes drawing strong conclusions. Nevertheless, we highlighted crucial questions to consider if the continuation of the convention is envisaged.

In this section, we first reflect on the implementation of case management driven by patient associations for neurodegenerative diseases. Then, we discuss patient-association driven case management in relation to the broader health care system in Belgium. Finally, we outline important limitations in this evaluation and provide suggestions for future directions.

5.1 Implementation of case management driven by patient associations in neurodegenerative diseases

The convention allocated €2 million to initiate patients' association-driven case management for four neurodegenerative diseases, with most resources directed toward workforce development or reconversion. Based on these allocated resources, the **number of full-time equivalents (FTEs)** differed between associations, i.e. PD and MS received five to six FTEs each, while HD and ALS associations received one FTE per region. These differences invite reflection on how resources are allocated.³⁹ The four conditions included in the convention are all chronic, progressive, and complex neurodegenerative diseases, having multiple subtypes, including rare variants. Moreover, they differ in **prevalence** (estimated rates from high to low: PD > MS > ALS ± HD)⁴⁰ and in their **clinical trajectories** (e.g. ALS progresses rapidly, which may require more intensive, anticipatory coordination whereas PD involves long-term, fluctuating needs). Currently, the convention does not address these differences.

Resource allocation (and consequently workforce) also relates to **geographical coverage**. We observed that patient associations with several FTEs could position case managers more locally (e.g. at provincial level) assuming consequent shorter travel distances and allowing a more comprehensive knowledge of available regional services and networks. In contrast, associations with only one FTE per region might face challenges to cover larger territories with different services providers. From a previous report³⁸ we learned that initial assessment of the patient by the case manager in his/her home situation was important for creating a safe home environment. Follow-up visits could be, in certain situations, converted into telephone calls. For this, conducting (initial) **home visits**, which were considered highly valuable by the interviewed patients' associations and their case managers, might be hampered by geographical imbalances. As illustrated in the report on Protocol 3 projects, case managers will most often take up the role of point of contact for patients and informal caregivers during the period of the interventions.³⁸ Fragile organisational anchoring, the temporary aspect of the convention, and uneven allocation of resources might jeopardise this. **It is worthwhile considering not only how and how many FTEs should be allocated, but also how they should be distributed across regions, considering prevalence and clinical trajectories of neurodegenerative diseases.**

The convention targets all patients with PD, ALS, MS or HD who request case management, irrespective of their degree of psychosocial complex needs and level of dependency (see Figure 1). The intervention is particularly disease driven, while within their disease patients may have still a large degree of self-management. What makes it even more complex is that case managers' services from the convention are expected not to duplicate those from hospital-based B4 liaison teams (for advanced stages patients with ALS, MS, and HD) but rather complement them. Therefore, it is questioned whether provided case management effectively targets the group of patients at the top tier of the Kaiser pyramid, i.e. those with the greatest dependency and most complex needs. In the example of Protocol 3 the targeted patient population was described based on five dependency categories. Each of these dependency profiles was linked to scores evaluated by the BelRAI screener (i.e. IADL, CPS, ADL) categorising the patient population. Along with this categorisation, there was a discrepancy made in conditions and reimbursed units for beneficiaries of low-intensity case management and high-intensity case management. Therefore, questions remain on whether – and if so which – characteristics of patients with neurodegenerative should be targeted. This includes questions such as: 'How to describe the target population better to ensure case management is provided to the patients with the most complex needs and highest dependency?' 'Should case management be delivered throughout the entire disease course, or focused on specific phases such as diagnosis, rapid decline, or crisis?' 'Should home visits be inherent to the care pathway or might teleconsultations deliver similar outcomes?' 'Should there be differentiation between intensity of case management delivery throughout the patients' trajectory, e.g. high or low intensity?' 'Should the case manager be the reference person (i.e. the same person) throughout the patients trajectory?' 'Do certain patients with a diagnosis benefit more of case management delivery?' etc. It is important to implement accurate case-finding to ensure interventions target patients with defined care needs as well as having a single point of access for assessment and a joint care plan.³⁹

A persistent design question in case management is *who* should assume the role of case manager, *what* should be performed in case management, and should the function be embedded within or external to the multidisciplinary team? Internationally, case managers are often specialised nurses embedded within multidisciplinary teams, as illustrated by ParkinsonNet in The Netherlands, where nurse specialists combine care coordination, patient and caregiver education, psychological support, and symptom monitoring^h. Applying Hudon et al.'s framework to the Belgian convention highlights that case management should encompass a structured yet flexible set of core functions: comprehensive assessment, collaborative care planning, facilitation of interprofessional collaboration, navigation support, monitoring and evaluation.⁴¹ Both Protocol 3 and the current convention converge on these principles, positioning case managers as mediators, advisors, coordinators and external to the

^h <https://www.parkinsonnet.com/>

multidisciplinary team. The role of the case managers relative to the multidisciplinary teams, first-line healthcare providers, and care coordinators is, however, often puzzling. Locating case managers outside multidisciplinary teams may strengthen patient advocacy and facilitate system navigation, but risks detachment from day-to-day decision-making and communication delays. Embedding case managers in the teams can strengthen integration and continuity of care, but it risks narrowing their focus to biomedical tasks. *Whether a case manager is better placed internal or external to the multidisciplinary healthcare team remains unanswered.*

In Belgium, the Protocol 3 convention required that at least half of case managers be nurses or GP's, supplemented by social workers. In practice, GPs rarely took up this role, largely due to time and workload constraints, and the vast majority of case managers were nurses. These restrictions left other (health care) professions such as occupational therapists and psychologists out of the loop and unable to fill the role of case manager. By contrast, the NIHDI convention on neurodegenerative diseases allowed patient associations to recruit or reconvert staff from diverse healthcare and social welfare backgrounds. Consequently, one association reconverted its existing social workers into case managers, while the others hired new staff. The patient associations said in the recruitment of new case managers they **emphasised disease knowledge/experience**, familiarity with the care landscape, and communication/advocacy skills. This also raises questions about *to what extent (clinical) background is important? and can experiential knowledge substitute or complement professional training?* It creates uncertainty about **whether case management competences are transferrable** and trainable within professional curricula, or whether they remain bound to personal experience which is an important consideration for scalability. This is further hampered by (i) the absence of a clear definition of case management (e.g. are their structural differences with care coordinators as case managers are required to fulfil this role temporarily), (ii) a formal curriculum and (iii) accreditation of case managers. Patient associations tried to act proactively by offering onboarding and disease-specific training, yet training was largely developed in-house by the patient associations. The organised intervision sessions with the case managers of the different patient associations within the convention may have fostered peer learning.⁴²

5.2 Patients' association-driven case management in relation to the broader Belgian health care system

The convention required patient associations to fit their activities harmoniously into the existing case management ecosystem, particularly with the social services of health insurance funds and home care coordination centres in Brussels and Wallonia, as well as with the care coordination of specialised teams in hospitals. This illustrates the intention of the NIHDI to support the integration of patient-association-driven case management into the Belgian case management ecosystem. Patient associations already had certain partnerships in place, while other partnerships had to be initiated. For the latter, awareness-raising activities and initial contacts were made.

Patient associations may bring **certain advantages** to this model such as their perceived neutrality vis-a-vis established healthcare structures (hospitals, sickness funds, etc.), advocacy functions, and their disease specific experiential expertise, which was often seen by the patient associations as a facilitator for case management. Patient associations also reported stronger links with underserved and disadvantaged groups, suggesting a potential role in reducing inequities, and their policy connections may position them to signal unmet needs at a systemic level. The patient associations endeavoured to meet the requirements of the convention, which required substantial additional efforts on their part, and the sustainability of these efforts is uncertain due to the temporary aspect.

At the same time, **several challenges** appear. Not all patients value patient associations very highly. Some are sceptical about not-profit organisations or about the value of experiential expertise. Others, particularly those with rapidly progressing diseases, may find it confronting to engage with patient associations. As a result, some patients will avoid and hence remain unaware of available services. Concerning scalability of the patient-association driven model, it should be considered that several chronic or rare diseases do not have a formal patient association. This may result in unequal treatment

for patients. Moreover, healthcare providers may perceive patient associations as ‘outsiders’ to the health care system, which may limit collaboration. Traditionally, patient associations rely largely on grants, donations or project-based funding, which may constrain sustainability, integration in the health care system, and limit long-term planning, unlike hospitals or community health services, which are financed through recurrent health budgets. If patient associations do not receive sustainable resources their services delivery (such as case management) remain vulnerable. If funding stops or remains project-based, this will likely undermine sustainability compared to structures embedded in recurrent health budgets.

Traditionally, patient associations focus on advocacy, awareness, and peer support, with only limited involvement in direct service delivery within the health care system.¹⁸ With this convention, formal responsibility for case management delivery to MS, PD, ALS and HD was piloted. This marks a **possible paradigm shift** in the Belgian healthcare organisation. International evidence in this regard is sparse. One example comes from Canada, where ALS charities and similar organisations provide navigation and psychosocial support, though systematic evaluations are lacking.¹⁸

If these patient-association-driven case management models are pursued further some **considerations should be taken into account**.

First, services delivered by sickness funds, hospital-based reference centres, Brusano and others are already not fully aligned. Therefore, without clear coordination mechanisms, positioning patient-association-driven case management within the health care system risks adding another layer of complexity rather than enhancing integration. Moreover, it should also be clarified how this intervention relates to other integrated care models such as Protocol 3 and Art. 107 in Belgium. The latter also integrate the case management function, however, not driven by patient-associations. It should be carefully weighed if adding another model to already complex systems will not lead to more fragmentation. Moreover, in case of expansion of patient-association-driven case management structured alignment and long-term institutional recognition, clearly defining roles and responsibilities, greater visibility of case management roles and stable funding should be taken into account.^{39, 42}

Second, in-line with the Kaiser Pyramid framework, case management is generally positioned at the top tier, reserved for individuals with highly complex needs. The current convention targets specific chronic and/or rare diseases, i.e. PD, ALS, MS, and HD for which a patients’ association exists in Belgium. Disease-specific organisations necessarily restrict their reach, while the principles of case management such as care coordination, navigation, and psychosocial support are relevant across many chronic and rare conditions. When considering to roll out this model to other diseases, it needs to be taken into account that for many diseases no such associations exist. Moreover, there is a large variability in the patients’ association landscape. Some associations have very little resources, rely on very few individuals and have several other missions. Without mechanisms to pool resources or establish cross-disease case management infrastructures, the scalability of association-driven models will remain limited. This may raise also questions on access, equity and in general the sustainability of the model. Taking into account sustainability measures, as stated above, it will be key to define a target population within the disease in order to provide case management to those with the greatest dependency and most complex needs (top tier of Kaiser pyramid). To accurately identify these individuals (i.e. patients with the highest and most complex needs) and understand the exact nature of their needs (particularly those not met by the current system), a structured methodological framework like the NEED framework⁴³, could be used. This framework describes dimensions, criteria and indicators that can be used for assessing unmet health-related needs in various diseases, including healthcare services-related unmet needs. Although the NEED framework is not designed to directly identify patients who should benefit from case management, it provides valuable tools for gaining a comprehensive understanding of unmet needs within a given population. By assessing unmet needs related to various aspects such as impact on autonomy, impact on physical and psychological burden, treatment burden, access to care, continuity of care and social support, a NEED study can help define the overall priorities and areas for action in case management. However, patients’ needs may change over time and

throughout the course of the disease. It is therefore necessary to develop complementary approaches to assess this variability and its implications for the implementation of case management.

Third, insights from other chronic and integrated care models described in literature show that case management appears to be more beneficial when embedded within broader chronic care frameworks^{38, 39} (see chapter 3). For example, Dutch initiatives such as COMPAS in dementia care and the ParkinsonNet model position case managers within multidisciplinary networks, supported by structured protocols, shared records, and self-management support. Similarly, Longhini²⁰ and Lukersmith²² highlight the value of situating case management as a core component of the chronic care model. These examples suggest that long-term effectiveness is likely to depend on clear integration with structured care pathways, stable governance, and system-level alignment.

Finally, the aim of the current convention remains ambiguous. The convention was set up “*to create and evaluate a case management model operated by different patient associations*”, where case management aims to “*restore and stabilise the patient’s care situation and to coordinate care so that the care process can proceed in a qualitative manner*”. Whereas in the convention on Protocol 3³⁸, the objective was explicitly formulated as “postponing or avoiding residential care for vulnerable elderly patients”, which is in theory measurable by the number of residential admissions, the present convention did not specify concrete outcomes, targets, or expected impacts. This challenges the evaluation of this new case management model. From a previous KCE study on Protocol 3, we know that the absence of a clear governmental vision might create a sense of job insecurity and negatively affect wellbeing amongst healthcare professionals. Considering experiences from chronic care and integrated care frameworks and considering the importance of a **clear governmental vision** for long-term sustainability, it could be valuable to align the objectives of this convention more explicitly with the broader **Interfederal plan for integrated care**ⁱ. Such alignment would help ensure coherence across policy initiatives on complex and chronic care and is likely to provide a stronger foundation for effective implementation.

5.3 Limitations in evaluation and future directions

This evaluation was necessarily constrained by its context and methodological options. The convention operated under a temporary article 56 framework, requiring results within a short timeframe and leaving little possibilities for longitudinal follow-up or iterative evaluation cycles^{j, 23, 28, 44}.

Available data were limited to the mandatory registration of certain process measures and supplementary self-reported information from patient associations through their annual activity reports. To register these mandatory data, patient associations relied on a self-constructed case management tool, whereas in other integrated care projects in Belgium the BelRAI tool is often used to track among others the agreed objectives, to document the involvement of each professional, and to follow the process over time which provides important information on the definition of the care plan and its implementation. It allows the sharing of information among the care providers of the multidisciplinary team. The absence of standardised instruments thus prevented the collection of key information on variables such as patient characteristics, care planning, triage, timing and referrals, and interprofessional collaboration and communication.³⁸ In literature, the necessity of using information systems to support communication is highlighted, as is the use of data to pro-actively drive quality improvements when operating in a multidisciplinary teams within the case management ecosystem.³⁹ It is worth noting that the integration of BelRAI screener was initiated in June 2025, but it is unclear whether this will solve all the above issues.

The primary data sources used in this evaluation consisted of annual activity reports (delivered in May 2025 and covering the initiation phase of the convention) and scoping interviews with mainly delegates

ⁱ <https://www.riziv.fgov.be/nl/professionals/info-voor-allen/het-interfederaal-plan-voor-geintegreerde-zorg>

^j Appendix 4 provides a comparative table of factors for monitoring the implementation of case management.

from patient associations. While these provided some valuable insights into how case management was implemented in practice and how closely it aligned with the stipulations in the convention (as described in chapter 4), they were largely self-reported and descriptive in nature. This restricted the depth of analysis and left key perspectives unaddressed (e.g. those of healthcare professionals in first-line, reference centres, and patients). Moreover, the literature review faced its own challenges as many articles covering heterogeneous topics were identified, and only one peer-reviewed article covered a similar patients' association-driven case management model.¹⁸ Of note, differences in health system organisation abroad may reduce direct transferability.

Although requested in the convention, patient associations had not yet developed standardised tools to collect information on patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) during the evaluation period. Due to the aforementioned time constraints (e.g. ethical commission approval), no direct data from patients (e.g. surveys or interviews) illustrating their perspectives could be collected during this research. Consequently, necessary information on patient characteristics, care planning, outcomes, and experiences could not be captured. Perspectives of frontline healthcare professionals, including GPs, physiotherapists, and allied health providers, were also not collected due to the short time since initiation and due to the heterogeneity in work processes (different networks, different diseases, different geographical coverage). Their views on collaboration, workload, adherence to care plans and satisfaction with case management services would be valuable to get insights into feasibility, the care coordinator role, integration and sustainability. Therefore, we recommend in future evaluations to include perspectives from patients, informal caregivers, and frontline professionals such as GPs and allied health professionals to provide insight into acceptability and perceived impact.

The process measures required by the convention (e.g. time to inclusion, frequency of follow-up and exchanges with professionals) were relevant but not accompanied by benchmarks or thresholds. Without such reference points, it is unclear whether observed values reflect adequate practice, suboptimal performance, or normal variation across contexts.

This report did not assess the effectiveness of case management. As illustrated above, evaluating the effectiveness of case management initiated by patient associations requires approaches that go beyond simple process measurement, acknowledging the interplay of governance, financing, data infrastructure, professionals, and patient engagement. To understand under which conditions such interventions work, and to identify both enabling and hindering factors, more robust study designs are needed. At a minimum, this would involve the use of a comparator (e.g. a baseline measurement without case management) and a clear objective.

Case management in itself is an overarching concept for which the intervention is characterised by several components for which effectiveness depends on clearly defining its core components, distinguishing it from general care coordination, and conducting process evaluations to ensure fidelity, sustainability, and interpretability of outcomes across settings.⁴⁵⁻⁴⁷ Lambert et al. (2019) even suggested to reconsider the evaluation approach by moving away from viewing case management as an intervention and rather to consider it as a process of interconnected actions taking place within a complex system.⁴⁶ To enable a sound evaluation of the intervention, a first step would be to unravel this 'black box' and to describe clearly what case management entails. It is important to make these components measurable, ideally through a combination of qualitative and quantitative methods.⁴⁸ Without this level of specification, rigorous evaluation remains difficult. Indeed, case management takes place within complex adaptive health systems, where multiple actors, institutions, and processes interact dynamically. In such settings, case management for people with (complex) chronic or rare conditions is not linear but shaped by interdependencies, feedback loops, and evolving patient needs. This requires more advanced (resourceful and time consuming) interaction between quantitative and qualitative research methods applied in implementation and evaluation research such as process evaluations. In this way, evaluations can capture whether patients' association-driven case management works and, if so, how and under what conditions it can generate value for patients, professionals, and the health system as a whole. On the other hand, a study on options for case management models in Belgium is

also a feasible method in this manner to select options that ensure coverage for all people who need case management (i.e. people with complex needs). This study on options for case management models in Belgium should at least: identify the key characteristics of a case management model, map the relevant stakeholders, develop several alternative models illustrating different organisational and institutional options, and analyse the implementation and sustainability conditions of these options across different regional and institutional contexts. This approach would provide policymakers with a comparative and evidence-informed basis for selecting the most appropriate strategic direction, aligned with the objectives of consistency, equity, and sustainability within the system. Different models can co-exist, depending on various factors (e.g. the needs of the populations, the most appropriate way to integrate it into the healthcare system, the cost-effectiveness of the implementation strategy).

It is important for policymakers in Belgium to take into account that case management should not be treated as a short-term quick fix. Rather, it requires a broader transformation towards a sustainable healthcare system in Belgium to address and cope with (vulnerable) patients with chronic diseases and highly complex needs. An essential question for case management is also how to prevent individuals from needing such intensive support in the first place, shifting the focus from reactive to proactive, sustainable care.

■ APPENDICES

APPENDIX 1. SCOPING INTERVIEW TOPIC GUIDE

- Which facilitators and barriers did you encounter during the start of the convention?
 - Were the requirements stipulated in the convention text clear?
 - How did you recruit case managers? Which skills were required?
 - How did you train case managers?
 - Did the patient associations work together and how?
 - How was awareness raised on the existence of case managers in patient associations?
- Which facilitators and barriers did you encounter during the implementation period?
 - How could patients sign up for case management?
 - Did you provide case management to all patients who signed up?
 - In general, how many sessions case management per patient are necessary?
 - In case the number of requests for case management would exceed the available resources, how would that be handled? Are there criteria (target population)?
 - What was the strategy applied to build the ecosystem (first line healthcare providers) around the patient?
 - Which organisations did you contact?
- Do you feel that case management has an added value? If yes, how? for who?

APPENDIX 2. SEARCH STRATEGY AND INCLUSION AND EXCLUSION CRITERIA FOR THE PRAGMATIC REVIEW OF THE LITERATURE

Appendix 2.1. Search strategies

Appendix 2.1.1. Medline

Date	March 17, 2025	
Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to March 17, 2025>		
Search strategy		
1	exp *"Delivery of Health Care, Integrated"/	11316
2	(integrat* adj1 (care or pathway* or service* or delivery or healthcare or program* or approach* or model*)).ti,kf.	15804
3	(deliver* adj1 (care or healthcare or service*)).ti,kf.	12223
4	((system or systems) adj1 (care or healthcare or service*)).ti,kf.	17978
5	((organis* or organiz*) adj1 (care or healthcare or service*)).ti,kf.	5324
6	((interprofessional or multidisciplinary) adj3 coordinat*).ti,kf.	93
7	2 or 3 or 4 or 5 or 6	50207
8	1 or 7	58124
9	*patient care planning/	14315
10	care plan*.ti,kf.	8334
11	((coordinat* or co-ordinat*) adj2 (care or healthcare or service* or program* or approach* or management or team care or team treatment* or team assessment* or team consultation*)).ti,kf.	4337
12	goals of care.ti,kf.	883
13	action plan?.ti,kf.	1898
14	coordinat* care.ti,kf.	500
15	10 or 11 or 12 or 13 or 14	15152
16	9 or 15	27877
17	*case management/	6781
18	((case? or care) adj2 manag*).ti,kf.	24567
19	case manage*.jw.	4276
20	(care adj2 coordinat*).ti,kf.	3402
21	Care facilitator?.ti,kf.	29
22	Case? coordinat*.ti,kf.	13
23	Client? management.ti,kf.	5
24	Clinical case management.ti,kf.	55
25	Patient? navigation.ti,kf.	842
26	Service coordination.ti,kf.	57
27	Health navigator?.ti,kf.	47
28	(social work* adj5 (collaborat* or integrated or program? or team?)).ti,kf.	299
29	discharge planning.ti,kf.	1498
30	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29	33272

31	17 or 30	35050
32	*comprehensive health care/	3769
33	(comprehensive adj2 (healthcare or care or health)).ti,kf.	3860
34	32 or 33	6812
35	8 or 16 or 31 or 34	120202
36	limit 35 to yr="2015-2025"	54422
37	Amyotrophic Lateral Sclerosis/	25413
38	amyotrophic lateral sclerosis.ab,ti,kf.	33489
39	(charcot adj2 disease).ab,ti,kf.	177
40	(gherig? adj2 disease).ab,ti,kf.	1
41	(guam adj2 disease).ab,ti,kf.	36
42	38 or 39 or 40 or 41	33676
43	37 or 42	37977
44	Huntington Disease/	14390
45	huntington.ab,ti,kf.	4704
46	progressive chorea.ab,ti,kf.	70
47	45 or 46	4768
48	44 or 47	16359
49	exp Multiple Sclerosis/	74741
50	multiple sclerosis.ab,ti,kf.	100372
51	disseminated sclerosis.ab,ti,kf.	650
52	50 or 51	100753
53	49 or 52	108508
54	Parkinson Disease/	89458
55	parkinson*.ab,ti,kf.	162963
56	54 or 55	170824
57	43 or 48 or 53 or 56	320208
58	complex care.ti,kf.	496
59	complex diseases.ti,kf.	939
60	((complex care or care management or patient? management) adj5 (model? or framework? or setting? or system? or program?)).ab,ti,kf.	2605
61	((complex care or care management or patient? management) adj5 navigat*).ab,ti,kf.	48
62	58 or 59 or 60 or 61	3982
63	36 and 57	397
64	36 and 62	495
65	63 or 64	888
66	(case management* adj2 (evaluat* or effectiveness or model? or program? or setting? or system? or framework?)).ti,kf.	548
67	case manage*.jw. and (evaluat* or effectiveness or model? or program? or setting? or system? or framework? or pathways).ti,kf.	538
68	66 or 67	1010
69	limit 68 to yr="2015-2025"	245
70	63 or 64 or 69	1130

71	((systematic review or systematic literature review or systematic scoping review or systematic narrative review or systematic qualitative review or systematic evidence review or systematic quantitative review or systematic meta-review or systematic critical review or systematic mixed studies review or systematic mapping review or systematic cochrane review or "systematic search and review" or systematic integrative review).ti. not comment.pt. not (protocol or protocols).ti. not medline.st.) or (Cochrane Database Syst Rev.ja. and review.pt.) or systematic review.pt.	345055
72	meta-analys*.ti.	227426
73	meta-analysis.pt.	214042
74	exp Technology Assessment, Biomedical/	12651
75	health technology assessment.ti,kf.	3305
76	HtA.ti,kf.	1020
77	71 or 72 or 73 or 74 or 75 or 76	478349
78	70 and 77	41
79	randomized controlled trial.pt.	633903
80	controlled clinical trial.pt.	95678
81	randomized.ti,ab.	749248
82	placebo.ti,ab.	264641
83	clinical trials as topic/	204597
84	randomly.ti,ab.	457970
85	trial?.ti.	438583
86	79 or 80 or 81 or 82 or 83 or 84 or 85	1723047
87	exp animal/ not humans/	5318862
88	86 not 87	1591004
89	70 and 88	123
90	(belgium or belgie or belgique or brussel* or bruxelles or leuven or gent or antwerpen or hasselt or liege or namur or louvain* or mons or uantwerpen or vub or ugent or uhasselt or uclouvain or uliege or unamur or umons or vlaanderen or wallonia or flanders or flemish or walloon?).ti,kf,af,ot.	440327
91	70 and 90	19

Appendix 2.1.2. Cochrane

Date	19/03/2025 07:25:39	
Database: Cochrane		
Search strategy		
#1	[mh "Delivery of Health Care, Integrated"[mj]]	296
#2	(integrat* NEAR/1 (care or pathway* or service* or delivery or healthcare or program* or approach* or model*)):ti	908
#3	(deliver* NEAR/1 (care or healthcare or service*)):ti	400
#4	((system or systems) NEAR/1 (care or healthcare or service*)):ti	484
#5	((organis* or organiz*) NEAR/1 (care or healthcare or service*)):ti	114
#6	((interprofessional or multidisciplinary) NEAR/3 coordinat*):ti	16
#7	#2 or #3 or #4 or #5 or #6	1897
#8	#1 or #7	2106
#9	[mh "patient care planning"[mj]]	765
#10	(care NEAR/1 plan*):ti	869
#11	((coordinat* or co-ordinat*) NEAR/2 (care or healthcare or service* or program* or approach* or management or team)):ti	376
#12	"goals of care":ti	74
#13	(action NEAR/1 plan?):ti	185
#14	(coordinat* NEAR/1 care):ti	249
#15	#10 or #11 or #12 or #13 or #14	1489
#16	#9 or #15	2084
#17	[mh "case management"[mj]]	296
#18	((case? or care) NEAR/2 manag*):ti	2049
#19	(case NEAR/1 manage*):so	46
#20	(care NEAR/2 coordinat*):ti	308
#21	(care NEAR/1 facilitator?):ti	1
#22	(Case? NEAR/1 coordinat*):ti	1
#23	(client? NEAR/1 management):ti	4
#24	"clinical case management":ti	9
#25	(patient? NEAR/1 navigat*):ti	313
#26	"service coordination":ti	7
#27	(health NEAR/1 navigator?):ti	17
#28	((("social work" or "social worker" or "social workers") NEAR/5 (collaborat* or integrated or program? or team?)):ti	16
#29	"discharge planning":ti	123
#30	#18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29	2835
#31	#17 or #30	2927
#32	[mh "comprehensive health care"[mj]]	5313
#33	(comprehensive NEAR/2 (healthcare or care or health)):ti	311
#34	#32 or #33	5600
#35	#8 or #16 or #31 or #34	10857
#36	#35 with Cochrane Library publication date Between Jan 2015 and Dec 2025	7362

#37	[mh ^"Amyotrophic Lateral Sclerosis"]	892
#38	"amyotrophic lateral sclerosis":ab,ti	1545
#39	(charcot NEAR/2 disease):ab,ti	10
#40	(gherig? NEAR/2 disease):ab,ti	0
#41	(guam NEAR/2 disease):ab,ti	0
#42	#38 or #39 or #40 or #41	1555
#43	#37 or #42	1710
#44	[mh ^"Huntington Disease"]	348
#45	huntington:ab,ti	849
#46	"progressive chorea":ab,ti	0
#47	#45 or #46	849
#48	#44 or #47	879
#49	[mh "Multiple Sclerosis"]	5286
#50	"multiple sclerosis":ab,ti	12298
#51	"disseminated sclerosis":ab,ti	2
#52	#50 or #51	12300
#53	#49 or #52	12691
#54	[mh "Parkinson Disease"]	6170
#55	parkinson*:ab,ti	13829
#56	#54 or #55	14166
#57	#43 or #48 or #53 or #56	28887
#58	"complex care":ti	33
#59	"complex diseases":ti	2
#60	((("complex care" or "care management" or "patient management" or "patients management") NEAR/5 (model? or framework? or setting? or system? or program?)):ab,ti	453
#61	((("complex care" or "care management" or "patient management" or "patients management") NEAR/5 navigat*):ab,ti	6
#62	#58 or #59 or #60 or #61	482
#63	#36 and #57	55
#64	#36 and #62	121
#65	#63 or #64	173
#66	(case management* NEAR/2 (evaluat* or effectiveness or model? or program? or setting? or system? or framework?)):ti	94
#67	case manage*:SO and (evaluat* or effectiveness or model? or program? or setting? or system? or framework? or pathways):ti	73
#68	#66 or #67	160
#69	#68 with Cochrane Library publication date Between Jan 2015 and Dec 2025	105
#70	#63 or #64 or #69	277
#71	#70 in Cochrane Reviews	0
#72	#70 in Trials	277

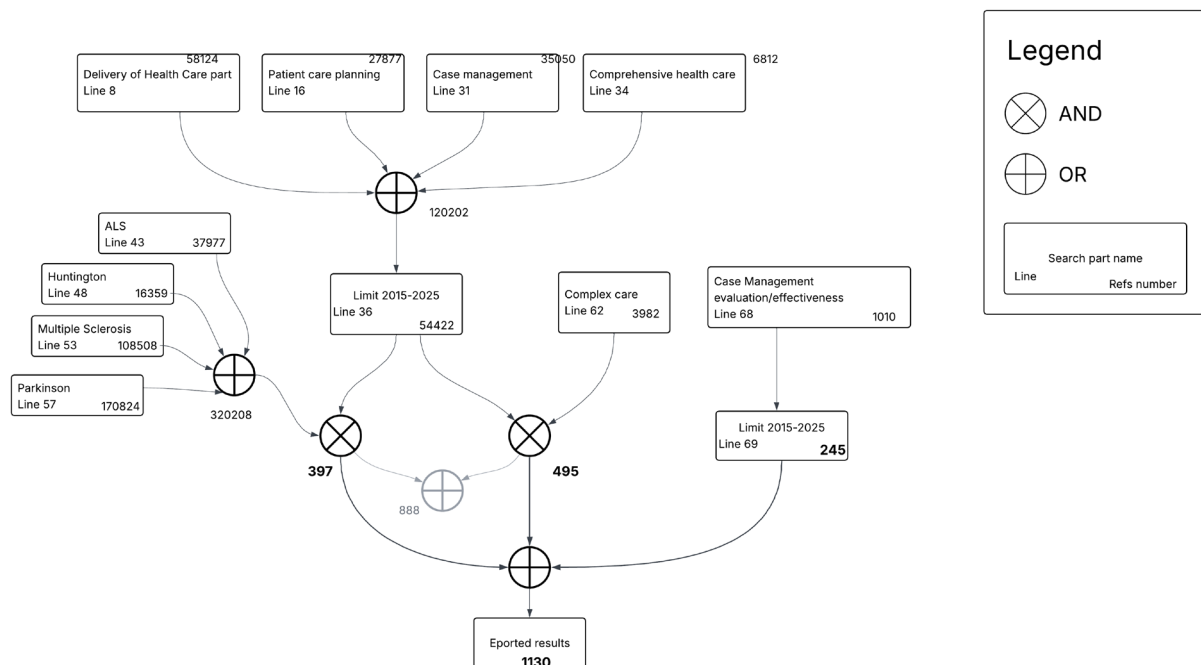
Appendix 2.1.3. Embase

Date	19/03/2025	
Database: Embase		
Search strategy		
#1	'integrated health care system'/mj	7186
#2	(integrat* NEAR/1 (care OR pathway* OR service* OR delivery OR healthcare OR program* OR approach* OR model*)):ti,kw	18240
#3	(deliver* NEAR/1 (care OR healthcare OR service*)):ti,kw	15256
#4	((system OR systems) NEAR/1 (care OR healthcare OR service*)):ti,kw	22982
#5	((organis* OR organiz*) NEAR/1 (care OR healthcare OR service*)):ti,kw	6213
#6	((interprofessional OR multidisciplinary) NEAR/3 coordinat*):ti,kw	155
#7	#2 OR #3 OR #4 OR #5 OR #6	61248
#8	#1 OR #7	72165
#9	'patient care planning'/exp/mj	9944
#10	(care NEAR/1 plan*):ti,kw	11359
#11	((coordinat* OR 'co ordinat*') NEAR/2 (care OR healthcare OR service* OR program* OR approach* OR management OR team)):ti,kw	5512
#12	'goals of care':ti,kw	1265
#13	(action NEAR/1 plan\$):ti,kw	2523
#14	(coordinat* NEAR/1 care):ti,kw	3440
#15	#10 OR #11 OR #12 OR #13 OR #14	20321
#16	#9 OR #15	29032
#17	'case management'/exp/mj	5862
#18	((case\$ OR care) NEAR/2 manag*):ti,kw	30662
#19	(case NEAR/1 manage*):jt	6303
#20	(care NEAR/2 coordinat*):ti,kw	4312
#21	(care NEAR/1 facilitator\$):ti,kw	31
#22	(case\$ NEAR/1 coordinat*):ti,kw	17
#23	(client\$ NEAR/1 management):ti,kw	19
#24	'clinical case management':ti,kw	63
#25	(patient\$ NEAR/1 navigat*):ti,kw	1599
#26	'service coordination':ti,kw	73
#27	(health NEAR/1 navigator\$):ti,kw	59
#28	('social work*' NEAR/5 (collaborat* OR integrated OR program\$ OR team\$)):ti,kw	317
#29	'discharge planning':ti,kw	1824
#30	#18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29	43326
#31	#17 OR #30	44385
#32	'health care'/mj	37175
#33	(comprehensive NEAR/2 (healthcare OR care OR health)):ti,kw	4911
#34	#32 OR #33	41542
#35	#8 OR #16 OR #31 OR #34	171054
#36	#35 AND [2015-2025]/py	77449

#37	#36 NOT [medline]/lim	29103
#38	#37 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)	16137
#39	'amyotrophic lateral sclerosis'/de	54100
#40	'amyotrophic lateral sclerosis':ab,ti,kw	45025
#41	(charcot NEAR/2 disease):ab,ti,kw	341
#42	(gherig\$ NEAR/2 disease):ab,ti,kw	1
#43	(guam NEAR/2 disease):ab,ti,kw	39
#44	#40 OR #41 OR #42 OR #43	45353
#45	#39 OR #44	60359
#46	'huntington chorea'/de	35871
#47	huntington:ab,ti,kw	31565
#48	'progressive chorea':ab,ti,kw	104
#49	#47 OR #48	31624
#50	#46 OR #49	41624
#51	'multiple sclerosis'/exp	174801
#52	'multiple sclerosis':ab,ti,kw	157674
#53	'disseminated sclerosis':ab,ti,kw	638
#54	#52 OR #53	158165
#55	#51 OR #54	191271
#56	'parkinson disease'/exp	215300
#57	parkinson*:ab,ti,kw	234281
#58	#56 OR #57	274830
#59	#45 OR #50 OR #55 OR #58	528922
#60	'complex care':ti,kw	591
#61	'complex diseases':ti,kw	1184
#62	((('complex care' OR 'care management' OR 'patient management' OR 'patients management') NEAR/5 (model\$ OR framework\$ OR setting\$ OR system\$ OR program\$)):ab,ti,kw	3937
#63	((('complex care' OR 'care management' OR 'patient management' OR 'patients management') NEAR/5 navigat*):ab,ti,kw	75
#64	#60 OR #61 OR #62 OR #63	5652
#65	#38 AND #59	211
#66	#38 AND #64	77
#67	#65 OR #66	285
#68	('case management*' NEAR/2 (evaluat* OR effectiveness OR model\$ OR program\$ OR setting\$ OR system\$ OR framework\$)):ti,kw	672
#69	'case management*':jt AND (evaluat*:ti,kw OR effectiveness:ti,kw OR model\$:ti,kw OR program\$:ti,kw OR setting\$:ti,kw OR system\$:ti,kw OR framework\$:ti,kw)	591
#70	#68 OR #69	1192
#71	#70 AND [2015-2025]/py	421
#72	#71 NOT [medline]/lim	204
#73	#72 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)	140

#74	#67 OR #73	423
#75	#74 AND ('meta-analysis'/exp OR 'meta-analysis' OR 'systematic review'/exp OR 'systematic review')	21
#76	#74 AND (random*:ab,ti OR placebo*:de,ab,ti OR ((double NEXT/1 blind*):ab,ti))	26
#77	#74 AND (belgium:ti,kw,ad OR belgie:ti,kw,ad OR belgique:ti,kw,ad OR brussel*:ti,kw,ad OR bruxelles:ti,kw,ad OR leuven:ti,kw,ad OR gent:ti,kw,ad OR antwerpen:ti,kw,ad OR hasselt:ti,kw,ad OR liege:ti,kw,ad OR namur:ti,kw,ad OR louvain*:ti,kw,ad OR mons:ti,kw,ad OR uantwerpen:ti,kw,ad OR vub:ti,kw,ad OR ugent:ti,kw,ad OR uhasselt:ti,kw,ad OR uclouvain:ti,kw,ad OR uliege:ti,kw,ad OR unamur:ti,kw,ad OR umons:ti,kw,ad OR vlaanderen:ti,kw,ad OR wallonia:ti,kw,ad OR flanders:ti,kw,ad OR flemish:ti,kw,ad OR walloon*:ti,kw,ad)	6
#78	#74 NOT (#75 OR #76 OR #77)	373

Figure 2 – Concepts and their relationships applied in the literature review (Medline search strategy)



Appendix 2.2. Inclusion and exclusion criteria

Table 3 – Inclusion and exclusion criteria for the literature review

	Inclusion criteria	Exclusion criteria
Populations	Patients with Parkinson's disease, amyotrophic lateral sclerosis, multiple sclerosis, Huntington's disease; frail populations (e.g. elderly or patients with complex health conditions and care needs)	Paediatric population, patients with cancer
Concepts	Models (<i>referenced as such by the authors</i>) of case management* Special attention to case management* driven by patients' association or in Belgium	
Settings	Outpatient and community-based care	Only in-hospital
Designs	Primary studies and reviews	
Languages	English, French, Dutch	
*Case management = roles and activities more than job function		

APPENDIX 3. DATA COLLECTED BY THE PATIENT ASSOCIATIONS

Appendix 3.1. List of data collected

The list below corresponds to the list that each association has provided to the KCE. This is the data encoded by the case managers in a reporting tool specific to each association (see example in Appendix 3.2)

Table 4 – Data collected by the patient associations

Data collected	ALS Liga België vzw – Ligue SLA Belgique asbl	Ligue Huntington Francophone Belge (LHFB) asbl	Huntington Liga vzw	Association Parkinson asbl	Vlaamse Parkinson Liga vzw	Ligue Belge de la Sclérose en Plaques – Communauté Française asbl	MS-Liga Vlaanderen
Administrative/qualitative data							
Anonymous code	X	X	X	X	X	X	X
Date of birth	X	X	X	X	X	X	X
Date of diagnosis	X	X	X	X	X	X	X
Purpose of the missions	X	X	X	X	X	X	X
If interrupted, why?	X	X	X	X	X	X	X
Contact delay	X	X	X	X	X	X	X
Other	a	b	c		d		e
Quantitative data							
Month	X	X	X	X	X	X	X
Number of calls (patient/other)	X	X	X	X	X	X	X
Emails/WhatsApp (patient/Other)	X	X	X	X	X	X	X
Number of Home Visits	X	X	X	X	X	X	X

Number of professionals involved	X	X	X	X	X	X	X
Other	a1	b1	c1				

Legend:

a: Number of interventions (geographical distribution); Number of contacts with professional caregivers; End of the process

a1: Number of network meetings, Number of multidisciplinary consultations

b: Patient, at risk of MH+, Province, case manager, method (method of receiving the request), date of request, requester (name of the client making the case management request), status of the mission, date of the first meeting, worker/network partners

b1: Number of network meetings, primary network, secondary network.

c: Code of residence (province), Case Manager, Method, Requester, Time to first appointment (days)

c1: Number of network meetings, Number of multidisciplinary consultations

d: KEY2, Case manager, Date of application, RR Nr, Year of birth, Residence, Zone, Gender service user, Date Diagnosis, Diagnosis, Referrer, Method of registration, Reason for intervention, Answered Date, Inform Consent, Network consultation, Other, Date of discontinuation, Date multidisciplinary consultations, Period, Total Contacts, Stop?, Duration of response, Duration of the first home visit, Duration of the process from the first home visit, Duration of the trajectory from Answered, Month Unique caregivers, Total contacts with healthcare providers, Aftercare contact with the service user, Aftercare Contact Care/Care Providers, Points of attention, Knowledge of one's own condition.

e: Area, Requester, Applicant's date of birth, Care Coordinator Present, Applicant's email, Method, Request or case status (e.g. ongoing, closed, ongoing), Case Manager, National Registry Number, Consent, Date of First Contact, Completion/Termination Date, Duration (End of Orientation), Days (End of Orientation)

Appendix 3.2. Example of a case management reporting tool

Beschrijving van Velden en Keuzelijsten – Casemanagementtool

Schermafbeelding Casemanagement tool MSLV

Registraties

Aanmelding door: Casemanager:

Datum: [Terug naar hoofdmenu](#)

Reden van aanmelding:

Zone:

Vraagsteller: Rijksregisternummer:

Vraagsteller geboortedatum: Datum diagnose:

ZorgCoordinatorAanwezig: ☒

Vraagsteller e-mail:

Methode:

Status:

Consent: ☒

Datum eerst contact: Duur: Dagen

Datum voltooid/stopgezet: Duur: Dagen

Voltooid/stopgezet: RedenVroegtijdigSt:

Logboek Doorverwijzingen:

Datum	Activiteit	Opmerking	Doorverwezen	Doorverwezen naar	DoorverwezenNaam	DoorverwijzingOpmerking	Duur
*			☒				

Record: 14 1 van 1 H Zoeken

APPENDIX 4. POSSIBLE DIRECTIONS IN EVALUATING AND IMPLEMENTING CASE MANAGEMENT

Examples of implementation assessment were retrieved in the literature, to guide us through illustrative indicators to monitor case management programmes. Hudon et al.⁴⁴ and Van Durme et al.²³ stress the importance of organisational, professional, patient-level, and system-level factors, including workload, training, use of evidence-based protocols, patient experience, and monitoring of care plans. Their analysis frameworks were built as follows:

- In the Protocol 3 project, Van Durme et al.²³ collaborated with stakeholders to identify 23 requirements (in eight domains) to be assessed in the implementation analysis of case management interventions², informed by the chronic care model. They also reported nine “soft” outcomes;
- In their paper on six Canadian experiences of case management, Hudon et al.⁴⁴ identified characteristics of these programs and the contexts in which they were implemented. This was guided by two conceptual frameworks: Chaudoir et al.’s model to assess the implementation of CM programs and the National Collaboration for Integrated Care and Support model to evaluate patient experience in integrated care.

Table 5 compares the factors used in both studies, based on the categories from Hudon 2022 that we adapted.

Table 5 – A comparison of implementation factors for monitoring, as proposed by Hudon et al. 2022 and Van Durme et al. 2015

Level of factors	Hudon et al. ⁴⁴	Van Durme et al. ²³
Organisational-level	• Staff turnover and healthcare teams’ instability • Information access/No information access • Manager support	• Staff: recruitment of adequate professionals, turnover • Workload: number of beneficiaries by equivalent full-time case manager, achievement of the case load
Case manager	• Case manager leadership: skills, attitudes and personal qualities, previous experience, networking • Provider engagement	• Skills of the case manager relate to the service provided, training • Use of results of research in decision-support • Use of evidence-based multidisciplinary protocols
Patient (and caregiver)	• Anxious patient • Patient with self-management skills • <i>Communication (patient experience)</i> • <i>Access to information</i> • <i>Transitions between professionals (patient experience)</i>	• <i>Patient’s and informal caregiver’s satisfaction with care</i> • <i>Improved health and healthcare literacy (including about the project’s functioning)</i> • <i>Patient facilitated access to the relevant information</i> • <i>Increased sense of security</i> • <i>Increased sense of belonging to a community</i> • <i>Increased coping abilities and sense of control</i> • <i>Decreased sense of social isolation</i> • <i>Lower threshold for help seeking behaviours</i>
Care-level and decision-making*	• Individualised service plan • Consideration of patient and family needs	• <i>Self-management and support addressing concerns of beneficiaries and informal caregivers</i>

	• Self-management support approach • Case manager access to information • <i>Care planning</i> • <i>Patient involvement in decisions</i> • <i>Consideration of patient and family needs</i>	• Use of quality or performance indicators • Monitoring of the care plan • Shared decision process • <i>Better detection and anticipation of crisis situations</i> • Work process: adequacy of the inclusion/exclusion criteria
Other HCPs and collaboration*	• Inter-professional collaboration • Relatives' participation in decision-making/relatives support	• Feedback to the GP • Presence of reflective discussion among peers • Existence of a structural link with organisations that can refer beneficiaries (community linkages) • Partnership with coordination centres and community organisations (community linkages) • Professional caregiver's satisfaction with care • <i>Care providers' facilitated access to the relevant information</i>
Use of tool*		• Use of a registry/list of beneficiaries • Reminders and prompts to organise the care
Financial*		• Financial accessibility to the programme (viewed by beneficiaries) • Adequacy of the financing of the project • Financial incentives to engage the GP
Structural and environmental-level*	• Proximity between providers	

*added to or adapted from the categories proposed by Hudon et al.⁴⁴

In italic: the key dimensions to evaluate patient experience of care from Hudon et al.⁴⁴ and the "soft" outcomes from Van Durme et al.²³

We observe that, although not perfectly overlapping, several key themes are addressed in both papers, including:

- the organisational level, with elements related to the workforce (e.g. training/skills, workload, staff turnover),
- professional practices and the care process (e.g. care planning, shared decision-making, collaboration),
- the patient-level, including access to information, self-management, satisfaction,

The system or policy level, which encompasses financing aspects, is included in the implementation monitoring model by Van Durme et al., such as the use of tools to assist in the practice. In this comparison, it should be noted that the framework of Van Durme et al., based on a Belgian experience provides a higher level of detail, as it reports variables and their studied modalities (and thus their direction: e.g. improved/increased characteristics).

Both frameworks emphasize that evaluating case management requires more than merely counting activities; it must incorporate clear criteria, contextual benchmarks, and attention to qualitative outcomes. Without such anchors, metrics such as the number of care plans or multidisciplinary meetings cannot reliably indicate whether case management is effectively achieving its core objective of stabilizing and improving patients' care situations.

This also illustrates the complexity and richness of monitoring case management, whether or not initiated by patient associations. Together, these two contributions underscore that robust evaluation must go beyond counting processes to include organisational, professional, and experiential dimensions.

Van Halteren et al. provide another example related to a proposed care management model for people with Parkinson's disease. They emphasize that implementing such a model should follow an iterative process, supported by regular evaluation, going beyond traditional metrics (like health outcomes and cost savings) and include patient and professional experiences, using qualitative and quantitative data²⁸. Nonetheless, evaluation of case management programs was mentioned as challenging by several authors, due to diversity in programmes, settings, beneficiaries, healthcare organisation. Moreover, case management itself is a complex intervention making it difficult to identify the underlying mechanisms of an effective intervention, but it's crucial to understand what is carried out and how.^{23, 28, 46}

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Colophon



The Rapid Response Reports aim to answer urgent questions from decision-makers. They apply expedited methods to produce timely evidence-based recommendations.

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