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Transforming care and support for patients with kidney insufficiency in Belgium

Discussion paper

SHARED
PATIENT EXPERIENCE

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Glossary

ACR: Albumin-Creatin ratio

APD: Automated Peritoneal Dialysis

CAPD: Continuous Ambulatory Peritoneal Dialysis

CKD: Chronic Kidney Disease

ESKD: End Stage Kidney Disease

eGFR: estimated Glomerular Filtration Rate

GP: General Practitioner

HAI: Health care-associated infections

HD: Hemodialysis

HHD: Home Hemodialysis

KRT: Kidney Replacement Therapy

ICHD: In-center Hemodialysis

LCHD: Low care Hemodialysis

MRSA: Methicillin resistant Staphylococcus aureus

NCDs: Noncommunicable diseases

PD: Peritoneal Dialysis

PREMs: Patient Reported Experience Measures

PROMs: Patient Reported Outcome Measures

SDM: Shared Decision Making

1. Executive summary

Chronic kidney disease (CKD) affects an estimated 1.1 million people in Belgium and represents a growing public health challenge (Mark et al., 2025). Despite major advances in treatment, many patients are still diagnosed too late, receive insufficient information about their treatment options, and face important psycho-social and organisational barriers throughout their care journey.

As there is currently no cure for CKD, early-stage management focuses on slowing disease progression and alleviating symptoms through pharmacological and dietary interventions. In advanced stages, when kidney function declines to stage 5, also referred to as kidney failure, renal replacement therapy becomes necessary. This may take the form of kidney transplantation or dialysis.

Living with CKD is often a gradual and exhausting process: as the disease progresses, patients must adapt to increasingly restrictive treatments, with dialysis imposing demanding routines that structure their daily lives. Persistent fatigue further limits their ability to participate in advocacy or even to articulate their experiences. As a result, the patient's voice is often underrepresented. Moreover, existing analyses, including the recent INAMI audit, tend to focus on how care is organised and delivered, but provide only limited insight into how patients actually live through and navigate their care journey.

In this context, this report aims to better understand how people living with renal insufficiency in Belgium can be supported in their daily and professional lives. It adopts a patient's perspective, complementing existing institutional analyses by focusing on the full care pathway and living experience. More specifically, this report is conceived as a discussion paper: rather than providing definitive answers, it seeks to highlight key challenges, identify gaps, and open the debate among stakeholders. By bringing forward patient perspectives and experiences, it aims to inform reflection, support dialogue, and contribute to the development of more inclusive and responsive care models.

Recognising the financial, organisational and workforce constraints facing the Belgian healthcare system, the objective is not to advocate for the implementation of every proposal, but to support informed discussions on how available resources can best improve the quality and experience of CKD care.

To bring this perspective to the forefront, the project was conducted by Shared Patient eXperience (SPX), an international non-profit association active in more than ten countries. Through its international network and established methodologies, SPX specializes in capturing and translating patient perspectives into actionable insights for healthcare providers, policymakers, and health system stakeholders. The organization develops action-oriented initiatives through research projects, training programs, webinars of exchanges, an annual international congress, and a yearly award recognizing best practices in patient experience.

The project was led by Shared Patient eXperience (SPX), an international non-profit organisation specialised in patient experience, with technical support from Antares Evidenze Health Consulting. Vantive supported the initiative but had no influence on the design, analysis or conclusions of this report.

Overall, the findings show that important gaps remain throughout the entire CKD journey, despite the high quality of Belgian nephrology care. These gaps are not limited to medical treatment and also concern information, psychosocial support, coordination of care and the organisation of daily life.

Key challenges include:

- **Chronic kidney disease remains insufficiently detected and recognised.**
  CKD often progresses silently and many patients are diagnosed only at advanced stages, sometimes during emergency admissions. Patients and professionals alike highlighted the need for stronger prevention efforts, improved health literacy, wider screening initiatives, and earlier referral pathways to nephrology care.
- **Patients report important unmet needs regarding information and shared decision-making.**
  Many patients feel insufficiently informed about treatment options, particularly home-based dialysis modalities and transplantation. Educational support remains highly variable across centres, and patients frequently describe treatment choices as being influenced by local practices rather than fully informed personal preferences.
- **Psycho-social support remains fragmented despite its importance throughout the care pathway.**
  Access to psychological support, social workers, dietary counselling and peer support varies considerably between centres. Yet these services are often identified by patients as essential to maintaining quality of life and treatment adherence.
- **Important organisational barriers continue to affect patients' daily lives.**
  Transportation difficulties, insufficient continuity of follow-up, and workforce shortages create additional burdens for patients already living with a demanding chronic condition.

To address these challenges, this discussion paper proposes a series of pragmatic actions structured around six priority areas:

1. Strengthening prevention, screening, and early diagnosis
2. Developing a more structured and multidisciplinary pre-dialysis pathway
3. Improving patient education, shared decision-making, and access to support services
4. Enhancing dialysis care through better coordination, transportation, and personalised care pathways
5. Improving information, preparation, and support throughout the transplantation journey
6. Addressing workforce shortages and adapting reimbursement mechanisms to reflect patient needs

2. Context: Chronic Kidney Disease

2.1. CKD represents a major public health and societal challenge in Belgium

Chronic kidney disease (CKD) is defined according to KDIGO guidelines as a persistent reduction in kidney function, reflected by an estimated glomerular filtration rate (eGFR) below 60 ml/min/1.73 m², and/or evidence of kidney damage lasting for at least three months (ISN-KDIGO, n.d.).

The eGFR is a key indicator used to assess how efficiently the kidneys filter waste from the blood. CKD is further stratified according to albuminuria levels, which reflect kidney damage. Together, eGFR and albuminuria help assess the risk of progression to end-stage kidney disease (ESKD) and guide clinical management.

				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30–300 mg/g 3–30 mg/mmol	>300 mg/g >30 mg/mmol
GFR categories (mL/min/1,73 m²) Description and range	G1	Normal or high	≥90	Low risk (if no other markets of kidney disease, no CKD)	Moderately increased risk	High risk
	G2	Mildly decreased	60–89	Low risk (if no other markets of kidney disease, no CKD)	Moderately increased risk	High risk
	G3a	Mildly to moderately decreased	45–59	Moderately increased risk	High risk	Very high risk
	G3b	Moderately to severely decreased	30–44	High risk	Very high risk	Very high risk
	G4	Severely decreased	15–29	Very high risk	Very high risk	Very high risk
	G5	Kidney failure	<15	Very high risk	Very high risk	Very high risk

Figure 1. Prognosis of CKD by eGFR and albuminuria categories (adapted from ISN-KDIGO, n.d.)

Although there is currently no cure for CKD, early management can slow disease progression and reduce the risk of kidney failure as well as cardiovascular complications such as myocardial infarction, stroke, and heart failure. KDIGO recommends a comprehensive approach combining lifestyle measures, dietary adaptation, and pharmacological treatment when indicated. In practice, this includes supporting patients in adopting a balanced, more plant-based diet, maintaining regular physical activity, stopping smoking, and controlling blood pressure and lipid levels through appropriate medication (ISN-KDIGO, n.d.). When CKD progresses to end-stage kidney disease (ESKD), or kidney failure, kidney replacement therapy becomes necessary, either through kidney transplantation or dialysis. Patients may also prefer comprehensive conservative care.

When it comes to numbers, data on epidemiology of CKD in Belgium are scarce. Nevertheless, according to a Belgian model-based analysis, CKD is a highly prevalent condition in Belgium, affecting an estimated 14.2% of the population (Vadia et al., 2023).

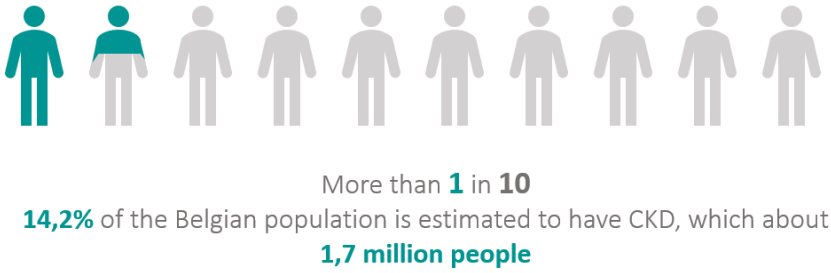


Figure 2. CKD prevalence in Belgium, 2022 (based on estimates reported by Vadia et al., 2023)

The disease burden is unevenly distributed across stages. CKD prevalence, including both diagnosed and undiagnosed cases, is highest in stages 1 and 3a, while stages 4 and 5 account for only a small proportion of total cases (Inside CKD, n.d.).

In recent years, new and effective treatments have appeared that have slow CKD progression, with already visible effects from therapies such as SGLT2 inhibitors (Correa-Rotter et al., 2024). In addition, for many rare kidney diseases, several promising treatments have proven to stabilise kidney function and could prevent progression to dialysis.

Because CKD is often asymptomatic in its early stages, a large proportion of patients remain undetected: it is estimated that 2 out of 3 patients (9.7%) of the prevalent Belgian CKD patients (14.2%) has undiagnosed CKD (Vadia et al., 2023). Moreover, while diagnosed CKD cases are projected to decrease between 2022 and 2027, the number of undiagnosed cases is expected to increase. As a result, unless CKD detection pathways are strengthened, most people living with CKD will likely remain undiagnosed by 2027 (Inside CKD, n.d.).

Beyond its epidemiological importance, CKD imposes a substantial burden on patients and society. Symptom severity and quality of life vary according to disease stage and treatment modality, with dialysis patients generally reporting the poorest quality of life, while transplant recipients report fewer and less severe symptoms (Fletcher et al., 2022). Fatigue, poor mobility, pain, drowsiness, and sleep disorders are among the most frequently reported symptoms. These physical burdens, presented in Appendix 2, are often compounded by important emotional and social impacts, including anxiety, depression, and limitations in daily and professional life.

At a broader level, CKD represents a major public health challenge and must be understood within the wider burden of noncommunicable diseases (NCDs)[1], which are the leading causes of death worldwide and account for an estimated 86% of deaths in Belgium (WHO, 2018; WHO, 2025).

Within the broader NCD landscape, CKD represents a significant contributor to mortality, with approximately 3,000 deaths amongst people with the disease in Belgium in 2023, corresponding to 2.7% of all deaths nationwide (Mark et al., 2025; Statbel, 2024).

Beyond its direct health impact, CKD is strongly associated with cardiovascular disease, which represents the leading cause of death among dialysis patients (Zoccali et al., 2023). Patients with advanced CKD, particularly those undergoing in-center haemodialysis (ICHD), are also exposed to healthcare-associated infections (HAIs), such as MRSA.

[1] Non communicable diseases (NCDs), also called chronic diseases, are long-lasting, non-infectious conditions resulting from a combination of genetic, physiological, environmental, and behavioral factors. These include cardiovascular disease, cancer, diabetes, and other chronic conditions such as CKD (WHO, 2025).

Importantly, MRSA colonization rates[2] are significantly higher among inpatients (14.2%) compared to outpatients (5.4%) and substantially increase the risk of developing infections (Zoccali et al., 2023; Zacharioudakis et al., 2014).

2.2. Limited evolution can be observed in the use of treatment modalities over time

When chronic kidney disease reaches end-stage kidney disease (ESKD), patients need kidney replacement therapy (KRT) that consists of either kidney transplantation or dialysis.

In practice, the two main options of dialysis in the hospital setting are:

- **In-center hemodialysis (ICHD):** Hemodialysis performed in a hospital or specialized dialysis center, providing full-care (high-care) treatment with continuous support and supervision by nephrologists and nursing staff.
- **Low care hemodialysis (LCHD) or hemodialysis in a satellite unit:** Hemodialysis is delivered in satellite dialysis centers where patients perform part of the required procedures themselves (sometimes referred to as self-care hemodialysis). Satellite dialysis centers may be located within a hospital or in a separate facility, but they are always linked to and supervised by a main dialysis center.

In terms of home-based dialysis modalities, these are the two available options:

- **Home hemodialysis (HHD):** hemodialysis at the home of the patient, with the patient mainly in charge of necessary manipulations.
- **Peritoneal dialysis (PD):** PD uses the peritoneal membrane as a semi-permeable membrane, instead of an artificial membrane. There are two main categories of PD: continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). CAPD uses, in contrast to APD, no machinery for the delivery and drainage of the dialysis fluids.

In Belgium, in-center hemodialysis has remained the predominant dialysis modality over the 2022-2025 period, consistently accounting for approximately 60% of treatments. Low-care HD represents 29-31%, while home-based dialysis modalities remain limited, hovering around 10% of patients. Within this segment, home hemodialysis increased modestly from 2.9% in 2022 to 3.2% in 2025. Peritoneal dialysis, traditionally the main home modality, edged up from 7.0% to 7.4%.[3]

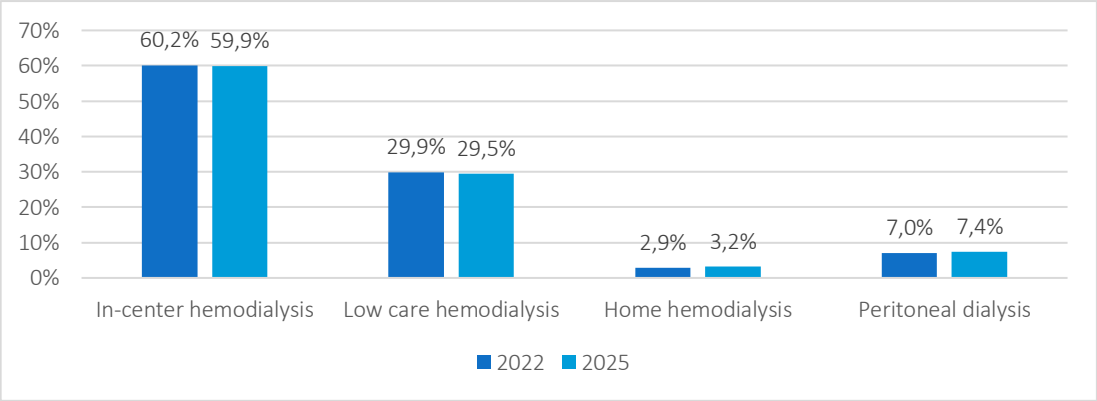


Figure 3. Evolution of dialysis modality distribution in Belgium (2022-2025)

[2] Colonization rates are defined as the proportion of patients carrying MRSA without necessarily presenting an active infection.
[3] This data has been provided by beMedtech. The 2025 figures reflect the data from trimester 1 to 3 only, as trimester 4 data was not available at the time of the report.

Longer-term trends reported by the Belgian nephrology societies (GNFB and NVBN) point in the same direction. Their 2020 national report, which excludes home hemodialysis patients[4], shows that the overall distribution of dialysis modalities evolved only gradually between 2011 and 2020 (Collège de médecins pour le centre de traitement de l'insuffisance rénale chronique, 2020). During this period, the proportion of patients treated with high-care in-centre hemodialysis decreased from 65.5% to 59.6% of all dialysis patients. Conversely, low-care hemodialysis delivered in satellite units increased from 25.5% to 33.1%, suggesting a gradual shift towards more autonomous forms of care within the hemodialysis pathway. In contrast, the proportion of patients receiving peritoneal dialysis declined slightly, from 9.3% in 2011 to 7.4% in 2020.

Overall, these findings suggest that while some redistribution has occurred within hemodialysis modalities, the uptake of home-based dialysis remains limited in Belgium, despite its recognised benefits in terms of patient autonomy, quality of life, and healthcare system sustainability.

Belgium also appears to remain behind several neighboring countries regarding the uptake of home dialysis modalities. A European comparison published in the Clinical Kidney Journal showed that home dialysis prevalence reached only 9.4%[5] in Belgium in 2022, compared with 26.7% in Denmark and 22.4% in the Netherlands (Lundström et al., 2025).

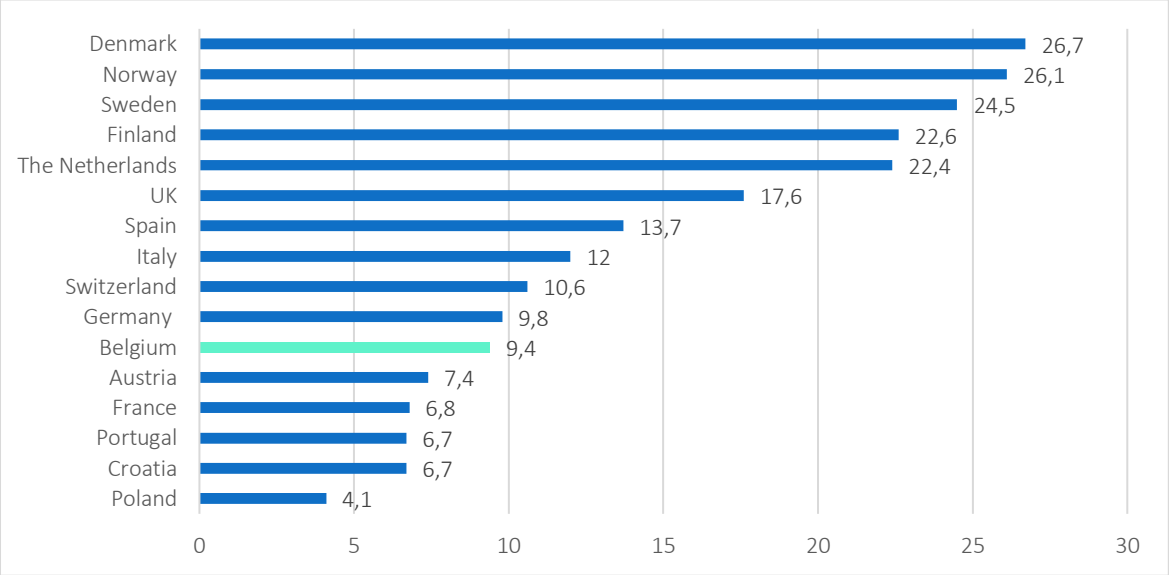


Figure 4. Home dialysis prevalence in percentage amongst comparable European countries, 2022 (adapted from Lundström et al., 2025).

In an effort to encourage alternative dialysis modalities and to improve the choice left to patients, several policy measures have been introduced over recent years. The latest dialysis convention (2024) notably introduced:

A "patient information fee" for nephrologists: a fee per new patient starting dialysis from 2024, to inform patients about the different treatments and to train them in the type of dialysis of their choice.

A "home dialysis support fee" for nephrologists: an annual fixed fee per home dialysis patient (peritoneal and haemodialysis) to inform, train and motivate patients to continue home dialysis.

[4] Consequently, the total number of dialysis patients and the distribution of dialysis modalities presented for 2011-2020 exclude home hemodialysis patients.

[5] In terms of the figures, these data come from the ERA report, whereas the temporal evolution in Belgium was shown thanks to bemedtech data. This explains the slight observed data differences.

The maintenance of the 40% "alternative dialysis" quota initially introduced in the 2016 convention: Hospitals must treat at least 40% of patients with alternative dialysis (non-ICHD) to maintain full hemodialysis funding. If the hospital treats less than 40% of patients with alternative dialysis, professional fees and the hospital rates for daytime haemodialysis are reduced by a calculated percentage (malus).

However, the practical impact of these measures appears limited. One major issue is that self-care dialysis is included within the definition of "alternative dialysis." As a result, part of the observed shift mainly reflects a transition from conventional in-centre hemodialysis toward self-care dialysis rather than a substantial expansion of home dialysis modalities such as PD or HHD (INAMI & SPF Santé Publique, 2025). This finding appears even more paradoxical knowing that the burden of treatment and the conditions of patients in hospital hemodialysis and those treated in self-dialysis centres are largely similar (INAMI & SPF Santé Publique, 2025).

Audit findings further highlighted important gaps in access to home dialysis modalities. Notably, 4 out of 24 audited hospitals (or 1 out of 6) were not offering peritoneal dialysis, despite this being a legal accreditation requirement.

2.3. CKD represents a major and growing financial burden for the Belgian healthcare system

The economic burden of chronic kidney disease in Belgium is substantial and is expected to remain high over the coming years. According to the Inside CKD microsimulation study, total annual healthcare costs directly associated with diagnosed CKD and its complications are projected to reach approximately €2,15 billion per year by 2027 (Vadia et al., 2023).

These estimates include costs related to CKD management, cardiovascular complications, and kidney replacement therapies, including hemodialysis, peritoneal dialysis, and kidney transplantation. It is important to note that the study only estimated direct healthcare costs for diagnosed CKD stages 3 to 5. Costs associated with CKD stages 1 and 2 were not included because they are more difficult to isolate from costs related to other chronic conditions commonly present at these earlier stages.

One of the key findings of the study is that CKD stage 3 represents the largest share of CKD-related healthcare expenditure. Although individual costs per patient remain lower than for advanced CKD or dialysis, the very high prevalence of stage 3 CKD results in a major cumulative economic burden.

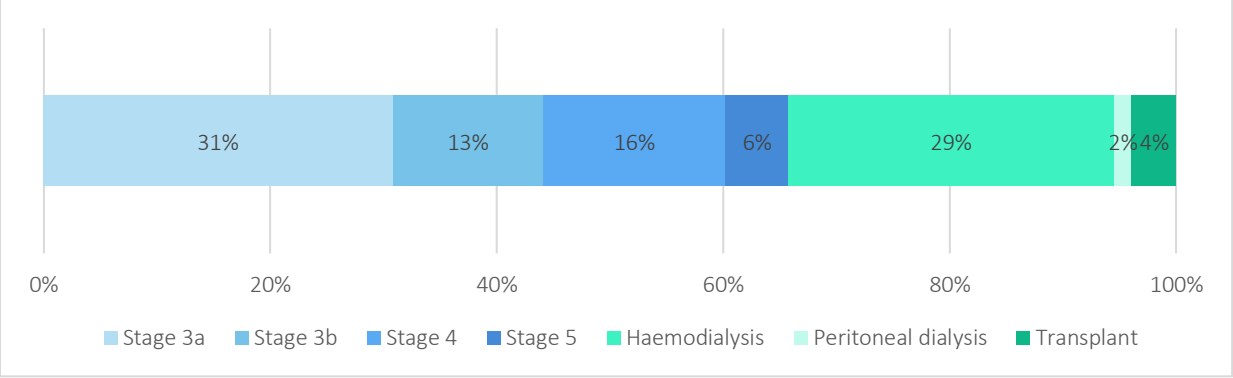


Figure 5. Distribution of healthcare costs associated with diagnosed CKD in Belgium, 2022 (Adapted from Vadia et al., 2023 & Inside CKD, n.d.)

The evolution of healthcare expenditures between 2022 and 2027 also illustrates that, without additional screening interventions, annual costs for diagnosed CKD remain broadly unchanged.

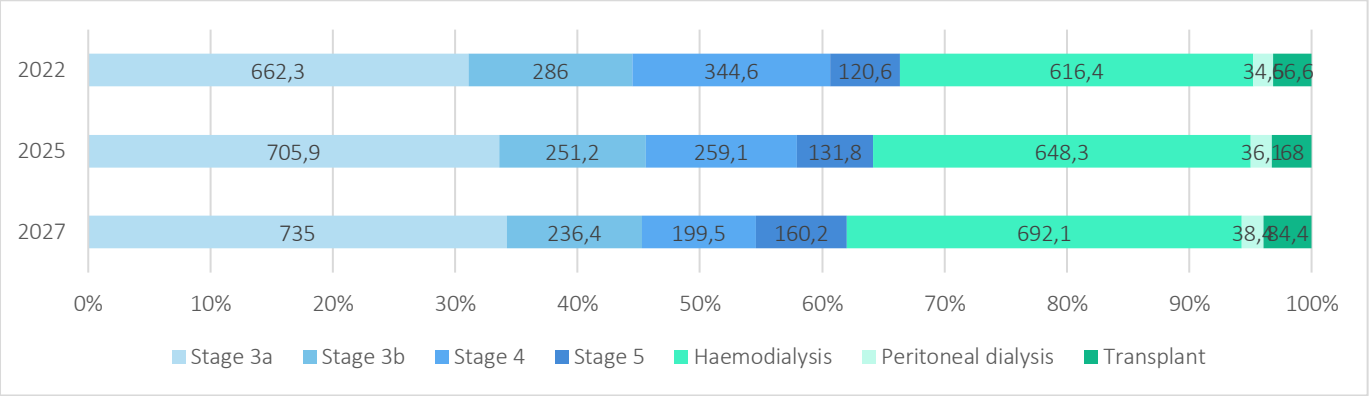


Figure 6. Healthcare costs (in millions) associated with diagnosed CKD without implementation of screening strategies, in Belgium (2022-2027) (Adapted from Vadia et al., 2023 & Inside CKD, n.d.)

3. Why focus on patient experience?

The Belgian healthcare system is under increasing pressure from a changing patient population. On the one hand, the population is ageing: the share of people aged over 65 is expected to rise from 20% in 2024 to 26% by 2050 (OECD et al., 2025). On the other hand, more people are living with chronic conditions. Today, around 40% of individuals aged over 65 in Belgium report having more than one chronic disease (OECD et al., 2025), a figure slightly below the EU average. Importantly, this is no longer only an issue of ageing. Multimorbidity is also increasing among younger adults aged 25-44 and 45-64, reflecting a broader shift in disease patterns (Sciensano, 2025). Together, these trends mean that healthcare systems are treating more patients with complex, long-term conditions that strongly affect daily functioning and quality of life.

At the same time, the role of patients in healthcare is changing. Patients are more informed, more engaged, and increasingly expect to be active participants in decisions about their care. In this context, systematically ignoring patient experience is becoming harder to justify, both ethically and in terms of care quality.

This shift towards greater patient involvement in healthcare is particularly important in chronic kidney disease. CKD is a lifelong, progressive condition that requires continuous and often demanding care, especially in the case of dialysis. Yet in Belgium, the lived experience of CKD patients remains largely under-documented. This underrepresentation is partly due to the progressive and fluctuating nature of the disease, the intensity of treatment and the high prevalence of fatigue, which can limit patients' ability to actively advocate for their needs and preferences.

Recent analyses have significantly improved our understanding of how CKD care is organized and delivered. For instance, the recent INAMI[6] audit offers valuable insights into the organization and functioning of dialysis services. This paper complements these findings by bringing forward the testimonies of several patients and shedding light on how care is experienced in practice. CKD affects more than just the body: it touches every aspect of patients' daily lives; it disrupts routines, limits work capacity, and imposes significant emotional and social burdens. Capturing patient experience helps make these impacts visible.

A widely cited definition was proposed by the Beryl Institute, which defines patient experience as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care" (Wolf, 2018).

Importantly, involving patients more actively in their care is a matter of action. Approaches such as shared decision-making (SDM), where clinicians and patients jointly make decisions based on clinical evidence and patient preferences, have been shown to improve patient satisfaction, increase treatment adherence, and have positive associations with improved quality of life and patient outcomes (Hoque, 2024).

Recognizing and measuring patient experience is therefore increasingly seen as essential to delivering high-quality, patient co-built care - especially in chronic conditions such as CKD, where care is long-term, complex, and deeply embedded in patients' everyday lives.

[6] The INAMI audit consisted of two components. First, in June 2024, an online survey was sent to all hospitals with an accredited dialysis centre, covering 51 hospitals operating a total of 52 centres (100% response rate). Second, an on-site audit was conducted in a randomly selected sample of hospitals with accredited dialysis centres. A stratified random sampling approach was applied, resulting in visits to 24 hospitals (8 in Wallonia, 4 in Brussels, and 12 in Flanders), all operating accredited dialysis centres.

4. Ongoing initiatives to improve patient experience in kidney care

These developments highlight the need for complementary SDM research to better understand the lived experience of people affected by kidney insufficiency. To bring this perspective to the forefront, the project was conducted by Shared Patient eXperience (SPX), an international non-profit association that regularly collects patient and caregiver testimonies across countries, with the aim of capturing perspectives as closely as possible to lived experiences and integrating them into healthcare improvement efforts.

To address this need, SPX launched several initiatives in Belgium, including this project, to collect and structure the perspectives of patients living with CKD and their caregivers:

The creation of a patient community	A collective space where patients, and sometimes their caregivers, can share their experiences, identify strengths and gaps in the care pathway, and highlight practical opportunities for improvement. Importantly, this is not a traditional patient association, but a structured participatory group focused on systematically capturing and using insights to improve care pathways.
The implementation of a nephrology-specific PREMs pilot project	A structured approach to capture patients' experiences across different stages of care, enabling systematic assessment of the quality and impact of CKD care from the patient's perspectives. This initiative is a first in Belgium, and currently, the pilot project runs for one year (with an initial start early 2026) in the following participating hospitals: Cliniques universitaires Saint-Luc, CHU Brugmann, Universitair Ziekenhuis Antwerpen, Cliniques universitaires de l'Europe and Hôpital Citadelle[7]. As the project is still ongoing, results are not included in this position paper.[8]
The redaction of a discussion paper	A document that brings together patient insights on CKD care in Belgium, existing Belgian and international evidence, together with healthcare professionals' perspectives, with the aim of identifying key gaps, highlighting priority areas for improvement, and informing future patient-centered initiatives.

[7] The start and end dates vary across participating hospitals. The first PREMs collection at Cliniques universitaires Saint-Luc and CHU Brugmann took place in March 2026, while Universitair Ziekenhuis Antwerpen and Cliniques universitaires de l'Europe will start in May 2026.

[8] Further information about the context, purpose, implementation and future ambitions of the nephrology-specific PREMs pilot project is included in Appendix 1.

4.1. Building a patient community

Context and purpose: The patient community was launched with the ambition of progressively creating a collective space where people living with kidney insufficiency and their caregivers can share their experiences and perspectives. Its primary goal is to provide a safe environment for patients and their relatives to voice their experiences, ultimately identifying both the strengths and gaps of the current care pathway while highlighting practical opportunities for improvement.

Implementation and functioning

The initial outreach began in 2025 through the *Ligue des Usagers des Services de Santé (LUSS)*, which then contacted several of their patient associations that could be relevant for the context of the subject (ADIR, LIR, ADEMAR, and Guerrière en Pyjama). In parallel, Belgian dialysis centers were also informed of the initiative. From this starting point, the community grew organically through a snowball effect, with participating patients inviting peers to join and share their voices.

Today, the group brings together a diverse range of participants, including patients undergoing dialysis (both in-center and at home), transplantation recipients, individuals at different stages of the disease and across age groups, as well as family caregivers.

As the initiative aims to identify both the strengths and limitations of the current care pathway and highlight concrete opportunities for improvement, monthly meetings were planned as of early 2026. These sessions provide a structured forum for discussion and collaboration, enabling participants to share experiences and insights. As a starting point, discussions explored in depth the five areas that patients of the community had identified in 2025 as key priorities for improvement: trust, patient involvement, support and communication, informed decision-making, and reimbursement. Conversations were also engaged with, but were not limited to, the key recommendations of the INAMI report.

It is important to note that the perspectives expressed through this initiative, and reflected in this discussion paper, represent the views of the participating patients and caregivers and should not be interpreted as positions of SPX.

Future ambitions

From the start, the initiative has aimed to build a Belgian patient community that reflects both French- and Dutch-speaking perspectives. In the course of its development, contact was established with NierNet, an emerging patient association in Flanders. It was subsequently agreed to pursue the development of each initiative at the regional level, while maintaining a shared ambition to converge over time towards a more integrated, national patient voice. It is important to note that NierNet primarily operates as a patient association, whereas Shared Patient exPerience has developed more as a patient community centred around peer exchange and shared lived experiences.

At this stage, the community primarily operates in French, but initial contributions from three Flemish patients have already been incorporated. This first step illustrates both the relevance and feasibility of progressively broadening participation across linguistic regions.

The community continues to develop progressively. Expanding participation remains a long-term objective, although careful attention is required given the fragility and fatigue frequently experienced by people living with advanced kidney disease. Ultimately, the goal is to support the emergence of a structured and representative patient voice capable of contributing to discussions on the future of kidney care in Belgium.

4.2. Developing a discussion paper

Context and purpose: The objective of this discussion paper is to explore how patients with kidney insufficiency in Belgium can be better supported in their personal and professional lives and more effectively considered throughout their care pathway. Centered on patient experience, the paper seeks to confront patients' lived experiences with the perspectives of healthcare professionals to formulate a set of concrete actions to improve patient care in Belgium.

Implementation and functioning

The discussion paper was developed through a three-step approach combining patient insights, professional perspectives, and international benchmarking.

- **Step 1 – Engagement round:** The first step consists of gathering real-world insights from multiple sources. This includes:
    - Patients living with kidney failure: in-depth, open discussions facilitated by SPX, allowing patients and caregivers to share their full care journey, priorities, and unmet needs in a qualitative and structured way
    - International analysis: Insights from more advanced countries (e.g., Scandinavian countries, the Netherlands, Germany) and from countries currently adapting their models (e.g., France) have been collected.
- **Step 2 – Align patient perspectives with Belgian professionals' insights:** To balance patient perspectives, structured exchanges were organized with healthcare professionals including nephrologists and nurses. These focus groups helped identify operational constraints, clinical priorities and practical opportunities for improvement within current care pathways.
- **Step 3 – Synthesis and alignment:** All insights were then consolidated into a single report, this document, that brings together patient experiences, professional perspectives, and international benchmarks to identify key gaps and translate them into clear, actionable areas for improvement.

Future ambitions

The discussion paper is intended as a starting point rather than a final output. It aims to support ongoing dialogue between patients and professionals and to inform future improvements in kidney care delivery in Belgium. In the longer term, it will contribute to embedding patient experience more systematically into care design, evaluation, and policy discussions, ensuring that care pathways better reflect what matters most to patients

5. Key areas of improvement related to the CKD patient journey

Identified needs and targeted actions were structured around the main stages of the CKD care pathway, from early screening and diagnosis to dialysis and long-term follow-up. This approach helps identify where gaps emerge in practice and highlights targeted opportunities for improvement at each stage of the patient journey.

Prevention, screening and (early) diagnosis	Advanced kidney disease	Dialysis	Transplantation
Focuses on the early stages of the care pathway, before or at the start of CKD, including prevention initiatives, screening practices, and timely diagnosis to enable early referral and slow disease progression.	Refers to the later stages of CKD, when most patients are already diagnosed with CKD and approaching kidney failure, and focuses on preparing them for future treatment through education, multidisciplinary care, and shared decision-making.	Explores the delivery of dialysis care, covering aspects related to experience of different modalities, transportation, safety and coordination of care.	Examines access to kidney transplantation, including pre-transplantation preparation, donor availability, and its integration within the overall care pathway.
Transversal aspects			
Education and workforce shortages Analyses cross-cutting issues related to the training, education, and awareness of nurses which influence care quality across all stages of the pathway.			
Reimbursement Addresses reimbursement mechanisms and access to financial support which impacts patients throughout the care pathway.			

It is important to note that the present analysis primarily focuses on patients receiving either dialysis treatment or transplantation. Although conservative care represents an important component of the CKD pathway, particularly for frail or elderly patients who do not pursue dialysis or transplantation, this population was not included in the current patient interviews.

For each stage, the analysis brings together three complementary perspectives:

- **Contextual elements,** describing how care is currently organized in Belgium, complemented, if relevant, by an international perspective providing best practices.
- **Insights from the field,** including patient experiences and healthcare professionals' feedback, highlighting concrete gaps in care delivery.
- **Identified targeted actions,** outlining actionable initiatives to address these gaps.

The following table summarizes the key targeted actions identified throughout this report. Actions are structured by area of intervention, strategic objectives, and proposed initiatives. To facilitate navigation, the table also allows readers to directly access the corresponding sections for each area of intervention.

Area	Strategies	Initiatives
Prevention, screening and (early) diagnosis	Increase public awareness and health literacy on kidney disease	Develop long-term educational approaches
		Expand GNFB and NVBN initiatives (World Kidney Day campaigns)
		Strengthen hospital-based prevention initiatives
		Integrate peer patient supporters into prevention initiatives
		Further involve patient associations in prevention efforts
		Use social media and risks calculators to amplify impact
	Improve early CKD detection through screening and structured referral pathways	Implement broader population-based screening strategies
		Use combined UACR and eGFR screening to improve early CKD detection
		Implement structured CKD risk stratification tools and clear referral pathways to nephrology care
	Reinforce the role of general practitioners in CKD detection	Strengthen CKD-related training in primary care
		Strenghten referral pathways and transmurral coordination between primary and nephrology care
Advanced kidney disease	Develop and formalize the role of nephrology educators	Define the key competencies and coordination role of nephrology educators
		Develop an accredited training pathway
		Systematically integrate nephrology educators into pre-dialysis pathways across dialysis centers
	Approve a national framework for the pre-dialysis pathway	Define minimum multidisciplinary requirements for pre-dialysis care
		Standardize patient assessment and care planning practices
		Strengthen coordination with primary care actors
	Redesign the CKD announcement conversation	Implement dedicated nephrologist-led CKD announcement consultations:
		Develop dedicated multidisciplinary consultation settings outside traditional hospital wards
	Strenghten multidisciplinary patient education and support	Implement a multidisciplinary follow-up consultation
		Provide structured and accessible educational resources
		Systematically offer stage-adapted peer-support opportunities
		Include psychological support conversations
		Facilitate access to social support servcies
		Establish dedicated helplines
		Implement guided visits of dialysis units
		Implement dedicated vascular access consultations

Area	Strategies	Initiatives
Dialysis care	Improve flexibility and quality of patient transportation	Strengthen patient support for transportation organization
		Improve coordination and flexibility of dialysis transportation scheduling
		Improve quality standards for grouped dialysis transportation
		Promote and expand volunteer-based transportation options
	Strenghten care coordination and more personalised dialysis pathways	Strengthen interoperable communication and transmural coordination
		Strengthen continuity and quality of nephrology follow-up
		Improve coordination and patient involvement in appointment scheduling
		Structure transitions from paediatric to adult nephrology care
Transplantation	Improve awareness and communication on transplantation and living donations	Train healthcare professionals in patient-centred transplantation communication
		Develop information sessions involving patient associations and nephrologists
		Develop and disseminate patient educational tools
		Systematically involve relatives in discussions on living donation
		Promote and further develop Belgium's Living Donor Exchange Program (LDEP)
	Improve pre-transplant assessment and post-transplantation follow-up	Establish centre-level targets for timely pre-transplantation assessment
		Introduce systematic psychological assessments before transplantation
		Strenghten psychological support after transplantation
		Organise peer-support sessions within transplantation centres
Education and workforce shortages	Adress nursing workforce shortages	Adjust the list of activities reserved for nursing assistants
		Reduce administrative workload for nurses
	Strenghten CKD education and specialized training for nurses	Strengthen initial training for dialysis nurses
		Implement tests and certification of dialysis training
		Develop a recognized role for dialysis educators (mentionned earlier)
		Strenghten structured continuing education and send protocol updates
		Strengthen training for home-care nurses
Reimbursement	Improve post-transplantation financial protection	Introduce a gradual phase-out of dialysis-related benefits after transplantation
		Reassess post-transplantion transportation reimbursement mechanisms
	Strenghten accessibility and financial support of transportation	Promote and expand municipal taxi voucher schemes for dialysis and transplanted patients
		Maintain third-party payment systems for transportation reimbursement
		Improve patient guidance regarding reimbursement and insurance procedures

5.1. Prevention, screening and (early) diagnosis

Contextual elements

In Belgium, as elsewhere, the prevalence of CKD is expected to increase further due to population ageing and the growing prevalence of risk factors such as diabetes, hypertension, obesity, and cardiovascular diseases. Despite this growing burden, CKD often remains underdiagnosed because the disease frequently progresses silently and without symptoms. Moreover, although clinical recommendations emphasize the importance of screening individuals at higher risk of CKD, systematic screening remains limited in Belgium. As a result, many patients are diagnosed only at advanced stages of disease.

Some key figures illustrate the extent of underdiagnosis and late referral in Belgium:

- Only 20% of at-risk individuals are aware of their kidney function (NierNet, 2026).
- In 2011, nearly 50% of patients are referred to nephrology care only at the stage of end-stage kidney disease (ESKD) or after less than three months of prior outpatient nephrology follow-up (Collart F., 2011).

Timely referral to nephrology care therefore remains a key determinant of patient outcomes. Early nephrology involvement improves disease management, facilitates preparation for dialysis or transplantation, and gives patients more time to consider available treatment options, including home dialysis modalities.

However, late referral remains a persistent challenge and has been documented for decades (Baer et al., 2010). Addressing this issue requires stronger collaboration between nephrologists and general practitioners, as well as greater coordination with other hospital-based specialists, including cardiologists, diabetologists, general internists, and urologists, given the close links between CKD and other chronic conditions (Nortier et al., 2017).

In an effort to address this issue, the Belgian Government introduced the care pathway for chronic kidney insufficiency in 2009. This initiative aimed to promote earlier detection and improve coordination between general practitioners, specialists, and patients through a formal care trajectory contract signed by the three parties. The pathway was expected to reduce late referrals and increase the number of patients entering a structured pre-dialysis process. However, as illustrated by the figures above, these objectives remain largely unmet.

One important limitation lies in Belgium's current screening approach, which remains relatively restrictive. In practice, screening mainly relies on eGFR testing among high-risk patients, whereas KDIGO guidelines recommend combining eGFR with albuminuria testing (UACR). UACR testing provides important additional prognostic information regarding kidney damage and cardiovascular risk and can help identify CKD at earlier stages, including in patients whose eGFR is still preserved. It also allows for a more accurate stratification of disease progression risk and follow-up needs.

However, UACR screening remains limited in Belgium, notably because reimbursement is largely restricted to patients with diabetes. As a result, only 11.1% of Belgian patients with evidence of CKD are estimated to have received a UACR test (Vadia et al., 2023).

Internationally, the United Kingdom is often cited as an important example of large-scale CKD detection in primary care through the Quality and Outcomes Framework (QOF). By integrating CKD indicators into financial incentives for general practitioners, the program contributed to increased kidney function and urine protein testing in primary care settings (Feakins et al., 2019).

Frontline insights

Patients frequently report late CKD diagnosis, leading to limited time to prepare for future treatment

Patient feedback indicates that chronic kidney disease is often diagnosed at a late stage, frequently when symptoms have already become severe. In some cases, patients reported that the disease was first identified in the emergency room. This late diagnosis is associated with significant emotional stress, leaving patients with little time to fully understand their condition, explore available treatment options, and prepare for future care. Patients consistently expressed a desire for earlier detection, which would provide more time for education, psychological preparation and lifestyle adjustments for the next stages of treatment.

Professionals highlight late nephrology referral and insufficient CKD screening in primary care

Healthcare professionals shared these concerns, highlighting that referrals to nephrologists often occur too late. They pointed to delays in recognition and referral across medical disciplines, suggesting that kidney disease is not always identified early enough in the patient's pathway.

More particularly, professionals identified several challenges at the level of primary care. Overall, they perceived general practitioners as not yet fully leveraged in the early detection of CKD, despite their central role in patient follow-up. For instance, routine urine testing in patients with diabetes is perceived as not being consistently implemented. Professionals also highlighted the need to strengthen awareness of key diagnostic markers in primary care, particularly serum creatinine and albuminuria.

Professionals pointed to a lack of public awareness regarding kidney health

Several professionals noted that many individuals have limited knowledge of their kidney function. They highlighted that kidney disease does not receive the same level of attention and resources as other conditions, such as cancer, despite having a comparable impact on the population.

Targeted actions

1. Increase public awareness and health literacy on kidney disease

Lead actors: SPF Santé publique, nephrologists' associations (GNFB, NVBN), Hospitals and nephrology departments, Patient associations

Objectives and outcomes: Strengthen public awareness and health literacy regarding kidney health in order to promote earlier detection of CKD, improve understanding of kidney function and risk factors, and encourage timely screening among high-risk populations.

Suggested initiatives:

- **Develop long-term educational approaches:** Kidney health awareness should progressively be integrated into school curricula and broader preventive health education programs.

- Further expand GNFB and NVBN initiatives such as World Kidney Day campaigns: Organizations such as the NVBN and GNFB already conduct awareness activities during World Kidney Day. Initiatives such as the the NVBN campaign "Zorg voor je nieren!", in 2025, involving almost all Flemish hospitals and offering information sessions and free urine screening tests, either at the hospital or later via their general practitioner (NVBN, 2025), should be increased and even nationalized.
- Strengthen hospital-based prevention initiatives: Belgian hospitals already organize local awareness activities such as screening stands, prevention campaigns, and patient information events. These initiatives could be further expanded and harmonized across centers. Examples include the "awareness morning" organized by Hôpitaux Iris Sud, combining discussions on kidney failure and dietary prevention, and the free kidney risk screening and information stands implemented by Hôpital Erasme.
    - Integrate peer patient supporters into prevention initiatives: Building on hospital initiatives, peer patient supporters could be systematically integrated into hospital-based prevention activities. To ensure impact, this role would require structured training, clear governance within hospital programs, and formal recognition within the healthcare system.
    - Further involve patient associations in prevention efforts: Patient associations can play a complementary role in prevention and awareness campaigns, as they already serve as trusted sources of information and peer-oriented support for patients and families.
- Use social media and risks calculators to amplify impact: To broaden engagement, mentioned actors can leverage social media to disseminate accessible information on CKD, raise awareness of risk factors, and encourage early screening among high-risk groups. In addition, interactive tools such as online kidney risk calculators can help identify individuals eligible for further testing, as illustrated by platforms such as kidneyquiz.theisn.org and info.zorgvoorjenieren.be.

2. Improve early CKD detection through screening and structured referral pathways

Lead actors: SPF Santé publique

Objectives and outcomes: Without changes to current clinical practice, the burden of chronic kidney disease in Belgium is expected to remain substantial in the coming years, highlighting the need to strengthen early detection and timely diagnosis. In line with KDIGO recommendations, implementing a more systematic CKD screening approach combining UACR and eGFR measurements, followed by appropriate treatment and monitoring, could improve early identification of CKD while remaining cost-effective.

Suggested initiatives:

- Implement broader population-based CKD screening: In line with KDIGO-ISN recommendations, CKD screening should primarily target high-risk individuals including those with hypertension, diabetes, cardiovascular disease, a family history of kidney disease, or a history of acute kidney injury. Screening should also be extended to other vulnerable groups, such as patients with conditions affecting kidney function (e.g., systemic lupus erythematosus, HIV, obesity, or genetic predisposition), individuals with occupational or environmental exposure to nephrotoxins, and populations facing socioeconomic disadvantages or limited access to healthcare.

  However, as a substantial proportion of individuals with hypertension or diabetes remain undiagnosed, screening strategies may therefore not be limited only to patients with known

hypertension or diabetes. Broader population-based screening, for example above a targeted age, could also be considered.

- **Use combined UACR and eGFR screening to improve early CKD detection:** In line with KDIGO recommendations, the possibility is to implement a CKD screening program involving UACR and eGFR measurements followed by treatment. A Belgian clinical study assessed the cost-effectiveness of a CKD screening program involving one UACR measurement and two eGFR measurements, which proved to be cost-effective in the studied population (Vadia et al., 2023).
- **Implement structured CKD risk stratification tools and clear referral pathways to nephrology care:** Promote the systematic use of the KDIGO Heat Map to classify CKD risk, guide monitoring frequency, and support timely referral to nephrology care. The framework, presented in Appendix 3, proposes follow-up frequencies ranging from 1 to 4+ assessments per year depending on CKD severity. While KDIGO recommendations provide a robust international framework, implementation should remain flexible and adapted to Belgian clinical realities, local organization of care, and individual patient complexity.

3. **Reinforce the role of general practitioners throughout the CKD care pathway**

Lead actors: SPF Santé publique, INAMI

Objectives and outcomes: Strengthen the role of general practitioners in the early detection, monitoring, and referral of CKD patients in order to improve timely diagnosis and reduce late referral to nephrology care. Given their central role in long-term patient follow-up, primary care physicians represent a key entry point for earlier identification of CKD, particularly among high-risk populations.

Suggested initiatives:

- **Strengthen CKD-related training in primary care:** Develop targeted educational initiatives for general practitioners on CKD identification, interpretation of eGFR and albuminuria results, recognition of CKD progression risk factors, and timely referral criteria to nephrology care.
- **Strengthen referral pathways and transmural coordination between primary and nephrology care:** Clarify care coordination responsibilities throughout the CKD pathway and improve communication between healthcare professionals. Examples of initiatives could include strengthening interoperability between IT systems or introducing automatic notifications within shared electronic patient records when new information is uploaded by general practitioners or nephrology teams. Those actions are further discussed in the “Dialysis” section.

5.2. Advanced kidney disease

Contextual elements

As CKD progresses, patients enter a structured multidisciplinary phase of care designed to prepare them for future treatment. During this period, patients receive information on dialysis and transplantation options and are supported medically, psychologically, and socially (Goovaerts et al., 2005; Goffin, 2014).

Access to interdisciplinary pre-dialysis care is increasingly recognized as a cornerstone of patient-centered CKD care. As Bear and Stockie (2014) note: *"Ensuring that patients with advanced CKD have access to interdisciplinary pre-dialysis care is almost a precondition for patient centered care, since it is in such environments that patient and family education can best be achieved, and joint decision making employed."*

Moreover, the quality of pre-dialysis education has been shown to strongly influence treatment choices. In fact, when comprehensive education programs are effectively implemented, more than 50% of patients requiring kidney replacement therapy opt for an autonomous dialysis modality (Goovaerts et al., 2005). Better-informed patients are also more likely to choose PD over conventional HD (INAMI & SPF Santé Publique, 2025), allowing in-center care to be reserved for patients requiring more intensive medical or nursing support (Goovaerts et al., 2005). In addition, patient education plays an important role in improving treatment adherence.

International experience further illustrates this impact. Aarhus University Hospital in Denmark has implemented a highly standardized approach combining "kidney schools," formal shared decision-making consultations, and structured decision aids[9]. This model is associated with a strong orientation toward home-based dialysis modalities: a Danish cohort study found that 68% of patients chose home-based dialysis following a shared decision-making intervention (de-la-Motte et al., 2025), while internal data showed that only 2% of patients remained undecided after the decision-making process.

When shifting the lens from individual hospitals to country-level systems, evidence shows that national guidelines for patient education are strongly linked to higher rates of home dialysis (Lundström et al., 2025). In countries without national guidelines for advanced kidney care patient education, home dialysis adoption is generally much lower. The data are striking: the prevalence of home dialysis is more than twice as high in countries with national guidelines compared to those without (20.9% versus 7.9%; odds ratio 1.398; 95% confidence interval 1.115-1.754; P = 0.004) (Lundström et al., 2025). These findings highlight the critical role of coordinated national guidance.

In Belgium, the absence of a national framework defining how pre-dialysis care should be organized may therefore contribute to the relatively low uptake of home dialysis modalities. The 2025 INAMI audit highlighted important structural gaps in the current organization of pre-dialysis care. Although 81% of centers (n = 52) [10] reported having a multidisciplinary pre-dialysis pathway, major variability between centers remains. Several important gaps were identified:

[9] Additional information is present in Appendix 4.

- **Multidisciplinary involvement remains uneven and largely nurse driven**. In 20 of 24 hospitals, educational sessions were organized individually, usually led by one or more specialized nurses. While nephrologists, dietitians, psychologists, social workers, and patient support staff were frequently involved, the participation of vascular surgeons, renal care coordinators, and patient-experience experts remained only occasional.
- **Patient assessment and care planning practices also present important gaps.** Only 8% of centers (n=52, or 4 centers) systematically use validated tools to assess comorbidities, quality of life, and functional status in patients over 70 years old, while only 18% use formal prognostic assessment tools. In addition, only half of centers consistently implement Advance Care Planning (ACP) for patients over 70.
- **Collaboration to establish the pre-dialysis pathway appears limited**. Only 16 out of 24 hospitals reported consulting or presenting the pathway to general practitioner associations or networks, only half reported engaging dietitians and just 8 out of 24 hospitals involved patients or patient associations.

Beyond education itself, access to treatment modalities also remains uneven across centers. Most importantly, 4 out of 24 audited hospitals did not offer peritoneal dialysis, considerably limiting access to home-based treatment options and restricting informed patient choice. The audit also identified the need for validated training for nurses and professionals involved in patient education to ensure consistent and high-quality patient education.

Frontline insights

Overall, patients highlight four main areas requiring improvement in pre-dialysis care. Those areas were also discussed with healthcare professionals.

A more personalized and respectful approach

First, patients express the need for a respectful approach adapted to individual circumstances and clinical trajectories. Many patients report encountering a relatively standardized, “one-size-fits-all” approach that insufficiently considers their individual circumstances. They share that important factor such as the context of diagnosis (routine detection versus emergency), clinical profile (for instance transplantation candidates versus non-eligible patients), or personal situation, including age, family structure, and professional life are not always adequately integrated into the decision-making process.

Linked to this lack of personalization, time constraints during consultations represent another important challenge. Patients frequently report that the time allocated for explanations and discussion is limited, particularly in diagnosis of announcement. This hinders their ability to fully understand the implications of different treatment options and to reflect on their preferences.

Healthcare professionals confirm these challenges, noting that the moment of diagnosis is inherently difficult to manage. Patients are often in a highly emotional state, which makes it unrealistic to expect full understanding in a single consultation. They further emphasize that patients vary significantly in their readiness to receive information, requiring communication to be adapted to individual emotional and cognitive capacity. In addition, the uncertainty of disease progression limits what can appropriately be communicated at each stage. Overall, professionals underline the need to balance structured information delivery with clinical judgment and interpersonal sensitivity.

Access to clear, comprehensive and comparable information on all treatment approaches

Patients report several limitations regarding information provision and shared decision-making throughout the CKD care pathway.

Key concerns regarding dialysis modalities raised by patients include:

- Information on treatment options is perceived as insufficiently transparent and not consistently comparable across treatment modalities.
- Most patients perceive treatment choices as oriented rather than fully open and patient led.
- Treatment options are not always proactively presented early in the care pathway.
- Patients have the sense that clinical habits and socio-cultural biases influence access to certain treatment modalities, which contributes to a perception of "pseudo-choice."
- In-center hemodialysis is often perceived as being presented as the default dialysis modality.

Moreover, decisions regarding vascular access (catheter versus fistula) are occasionally perceived as imposed rather than discussed collaboratively. Patients also report that kidney transplantation is not always introduced early enough in the patient's journey.

To support informed decision-making, patients further highlight that informational materials are often too generic and insufficiently discussed or emphasized by clinicians. Healthcare professionals corroborate these perceptions while also highlighting several structural constraints affecting information provision:

- The absence of a centralized information platform makes it difficult to provide patients with comprehensive and consistent information.
- Some Belgian hospitals still lack a clearly defined pre-dialysis care pathway. This creates uncertainty regarding which information should be communicated, by whom, and at which stage of the disease trajectory. Healthcare professionals consider that a more formalized step-by-step pathway could help ensure that key information is delivered at the appropriate time, for example based on eGFR thresholds. At the same time, professionals emphasize that any standardized pathway should remain sufficiently flexible to adapt to individual patient readiness, preferences, and needs.

Structured, personalized and accessible psycho-social and dietary support

Patients express a clear need for effective access to psychological support, social assistance, and dietetic counseling. However, they report that key consultations are sometimes missing or not systematically offered.

Psychological support

For many patients and families interviewed, psychological support is largely absent during the critical period between diagnosis and treatment initiation despite the important emotional burden associated with announcement and treatment decisions. Patients emphasize that psychological follow-up should be prioritized after emergency dialysis initiation. However, access to nephrology-specific psychologists remains limited. On the other hand, professionals note that psychological support depends on local resources and remains less systematically integrated in dialysis care than in fields such as oncology.

Dietary counseling

Even though patients actively seek concrete guidance to help preserve residual kidney function and prevent complications, they report that dietary counseling is sometimes lacking in the pre-dialysis phase.

Professionals largely confirm this gap, noting that while dietitians are often part of the care pathway, their involvement is often limited to a one-time consultation rather than a continuous follow-up. In addition, professionals highlight that dietary advice is sometimes perceived as too theoretical, limiting its practical applicability for patients.

Social support

Patients report rarely being referred to social workers, even though assistance with transportation or administrative procedures could be highly relevant before dialysis initiation.

Referrals to patient associations and peer patient supporters

Referral to patient associations and peer patient supporters remains limited, partly because healthcare professionals are not systematically trained to guide patients toward these resources. While professionals acknowledge their value, they also note that some pre-dialysis patients may feel overwhelmed by information early in the disease trajectory and prefer to engage later once treatment has started.

Recognition and empowerment of informal caregivers

Caregivers often feel insufficiently involved in discussions and decision-making despite their central role in the patient journey. They express a need for earlier involvement and better support throughout the transition to dialysis.

Targeted actions

1. Develop and formalize the role of nephrology educators

Lead actors: SPF Santé publique, INAMI, nephrologists' associations (GNFB, NVBN)

Objectives and outcomes: Strengthen, professionalize and better coordinate patient education throughout the pre-dialysis pathway through the development of a formalized nephrology educator role, inspired by the existing diabetes educator model.

Suggested initiatives:

- **Define the key competencies** and coordination role of nephrology educators within multidisciplinary pre-dialysis teams.
- **Develop an accredited training pathway** combining theoretical and practical training similarly to the Belgian diabetes educator framework. Beyond clinical and technical knowledge, training should also include communication and patient-announcement skills. Simulation-based approaches could serve as inspiration, as illustrated by the SimLabS programme, where healthcare professionals are trained through simulated consultations with actors playing patients, filmed announcement exercises, and collective debriefings focusing on verbal and non-verbal communication, tone, and the use of medical jargon.
- **Systematically integrate nephrology educators into pre-dialysis pathways** across dialysis centers.

2. Approve a national framework for the organization of the pre-dialysis pathway

Lead actors: SPF Santé publique, INAMI

Objectives and outcomes: Strengthen and standardize the multidisciplinary pre-dialysis pathway across Belgium to ensure more consistent, patient-centered, and coordinated care for patients with advanced CKD.

Suggested initiatives:

- **Define minimum multidisciplinary requirements for pre-dialysis care:** National guidance should define the minimum professionals and services systematically included within the pre-dialysis pathway across all dialysis centers. The INAMI recommends that all dialysis centers should implement a structured multidisciplinary pre-dialysis pathway involving, at minimum, a nephrologist, a specialized nurse, a dietitian, and psychosocial support services. Opportunities to mutualize certain multidisciplinary resources or support functions across centers couldbe welcome.
  Belgium could also draw inspiration from recent reforms implemented in France. In April 2026, the French Ministry of Health introduced a national framework requiring dialysis centers to ensure structured multidisciplinary patient information and education (composed of dietetic, psychological, social support) with mandatory traceability in the electronic medical record as a condition for maintaining authorization to provide dialysis care.
- **Standardize patient assessment and care planning practices**: Validated scales (such as Mini-Mental State Examination, the Katz Index of Independence, and the Clinical Frailty Scale), should better be used to assess comorbidity, quality of life, and functional status in patients over 70 years old, alongside prognostic scores for patients over 75 (such as the (a)REIN score). Advance Care Planning (ACP) discussions should also be implemented to support shared treatment decisions, particularly for older patients.
- **Strengthen coordination with primary care actors:** The pre-dialysis pathway should be better coordinated with general practitioners and other primary care actors through the addition of a dedicated pre-dialysis trajectory within the existing CKD pathway introduced in Belgium in 2009.

Once a clearer national framework for pre-dialysis care and dedicated educational roles are established, hospitals could further redesign their pathways based on insights and recommendations shared by both patients and healthcare professionals. A proposed redesigned pathway is presented in the following pages.

Two clinical trajectories must be distinguished: most patients (approximately 70-80%) receive a diagnosis sufficiently early to allow a planned pre-dialysis pathway before dialysis initiation and a smaller group (approximately 15-20%) requires urgent dialysis initiation, where clinical stability takes precedence[11].

The next suggested initiatives specifically refer to the non-urgent, planned pre-dialysis pathway, where sufficient time allows for a structured, multidisciplinary, and progressive preparation process. In urgent cases, however, selected elements of this pathway should still be systematically implemented once the patient's condition has stabilized.

3. Redesign the CKD announcement conversation

Lead actors: Hospitals and nephrology departments

Objectives and outcomes: Improve the quality of CKD diagnosis announcement consultations to better support patients during a highly sensitive and emotionally challenging moment in the care pathway.

[11] The Belgian literature does not provide a clear national estimate distinguishing between urgent and planned dialysis initiation; the most explicit figure identified comes from a French study, in which 16.2% of patients started dialysis in an emergency context (Fages et al., 2020).

Suggested initiatives:

- **Implement dedicated nephrologist-led CKD announcement consultations:** The care pathway should begin with a dedicated consultation of at least 40 minutes led by a nephrologist in order to provide sufficient time for explanation, emotional support, and discussion of treatment options. This is particularly important as the announcement of CKD is often experienced as a traumatic moment by patients, while current consultation times remain highly constrained. Belgium already introduced in 2024 a one-time nephrologist fee (€445.31) covering the first information session and initial training for all new dialysis patients, regardless of dialysis modality. However, this financing mechanism currently functions as a lump-sum educational fee rather than a specifically regulated consultation code, with limited guidance regarding the expected content, structure, or quality of the information provided. One option could therefore be to introduce a dedicated INAMI/RIZIV consultation code specifically linked to CKD announcement and treatment education consultations.
    - This consultation should provide a personalized explanation of the diagnosis, clarify end-stage kidney disease and introduce dialysis as a treatment option. The attention should be more on the personal aspects of dialysis rather than the technical ones.
    - Initial questions should be addressed and a second multidisciplinary appointment scheduled.
    - Communication must be adapted to patient readiness, cognitive function and health literacy, as patients differ in how much detail they wish to receive.
    - Before this consultation, patients should also be informed of their right to be accompanied and, if possible, to record the consultation.
- **Develop dedicated multidisciplinary consultation settings outside traditional hospital wards:** Expand consultation models bringing together nephrologists, nurses, psychologists, and other trained professionals in calmer and less institutional environments designed to facilitate communication and emotional processing. Patients highlighted that such settings could reduce anxiety and create a more supportive atmosphere. Several Belgian initiatives already move in this direction. For example, in Verviers, CKD announcements may be conducted at the patient's home by a nephrologist accompanied by two nurses, while at CHU Brugmann, the second consultation can also take place at home, combining medical explanations by the nephrologist with educational support from nurses, including videos presenting dialysis techniques. Similar multidisciplinary outpatient CKD consultation models have also been developed internationally, including in Ireland, where they are perceived as facilitating more coordinated and comprehensive care.

4. Strenghten multidisciplinary patient education and support

Lead actors: Hospitals and nephrology departments, peer patient supporters, patient associations

Objectives and outcomes: Strengthen patient education and shared decision-making through a structured multidisciplinary consultation during the pre-dialysis pathway.

Suggested initiatives:

- **Implement a multidisciplinary follow-up consultation:** Systematically organize a multidisciplinary education consultation involving, at minimum, a nephrologist, a dialysis nurse, and a dietitian to answer patient questions and present dialysis settings, treatment modalities, transplantation options, and dietary requirements. At the end of the consultation:

- **Provide structured and accessible educational resources:** Offer patients and caregivers videos, patient testimonials and take-home decision-support tools and dietary guidance. International examples such as the Aarhus University Hospital leaflet could serve as inspiration. Another option would be to develop a Belgian platform similar to Germany's *Nieren-Navi*, presenting the different kidney replacement therapy options, their principles, advantages, and limitations in a clear and accessible manner. Educational resources could also include practical tools such as kidney-friendly recipes developed with dietitians.
- **Systematically offer stage-adapted peer-support opportunities:** Strengthen patients' understanding of lived experiences across the CKD pathway by facilitating exchanges with peer patient supporters and patient associations. Different formats and activities should be developed to better reflect the diverse needs of patients at different stages of the disease trajectory, including pre-dialysis, dialysis, transplantation, and post-transplantation follow-up. Consideration could also be given to developing more stage-specific peer-support structures in order to provide more targeted support and shared experiences.
- **Include psychological support consultations:** Provide space for patients and caregivers to express concerns and emotional distress related to diagnosis and treatment decisions.
- **Facilitate access to social support services:** Help patients and caregivers navigate financial and administrative challenges such as transportation options.

- **Establish dedicated helplines:** Provide continuous access to guidance for patients and caregivers throughout the care pathway.
- **Implement guided dialysis unit visits :** Familiarize patients and caregivers with the dialysis environment before treatment begins. Ensure that visits are led by specialized dialysis nurses (preferably technician nurses) who are able to explain unit organization, schedules, machine functioning, and practical aspects of dialysis care.
- **Implement dedicated vascular access consultations:** Organize consultations with vascular surgeons to explain and plan the placement of a catheter or arteriovenous fistula, including the associated procedures, risks, benefits, and practical implications.

5.3. Dialysis care

Contextual elements

Experience of dialysis care

The experience of dialysis care is largely shaped by the chosen treatment modality as it affects patients' physical condition, psychological well-being and social life. Evidence suggests that patients undergoing peritoneal dialysis (PD) generally report a more favorable care experience than those receiving in-center haemodialysis (ICHD) and are also less likely to consider switching treatment (Juergensen et al., 2006; Rubin et al., 2004).

Transportation

The organization of transportation poses significant challenges to the quality of life of dialysis patients[12]. Patients often face long waits, overcrowded or unhygienic vehicles (with no separation for infectious patients), and restricted service on weekends. The centralization of transportation through MUTAS was not perceived as

[12] Transportation is also perceived a major source of financial concern, which is explored in the section "Transversal aspects – Reimbursement".

an improvement. On the contrary, grouped transportation resulted in long trips and extended waiting times, with patients spending up to 8.5 hours away from home for a 4-hour dialysis session, even when living relatively close to the hospital (SPF & INAMI, 2025). However, the CO2 fooprint of single patient transportation has to be considered.

Care coordination between dialysis patients and healthcare providers

Care coordination remains limited despite the high burden of comorbidities among dialysis patients. The on-site audit revealed that nearly half of centers (10/24) reported having no formalized coordination arrangements in place. The most common practices were periodic follow-up with endocrinologists (10/24 centers) and annual cardiology check-ups (8/24 centers), while systematic collaboration with general practitioners was reported in only 3 out of 24 centers. Coordination with other specialists such as ophthalmologists, oncologists, vascular surgeons, or geriatric services remained exceptional (SPF & INAMI, 2025).

In practice, follow-up coordination relied mainly on nursing staff and communication tools such as liaison notebooks or written correspondence. In some hospitals, information could also be shared through the "CoZo" electronic network used by hospitals, home care organizations, and general practitioners. However, no specific notification is sent to specialists when new information is uploaded, meaning that important updates were read too late or not accessed at all.

To address these persistent coordination gaps, a new nomenclature number (103994) was introduced in 2024. Concretely, nephrologists are now required to document and share with the general practitioner a comprehensive multidisciplinary care plan covering key aspects of CKD management, including dietary recommendations, advance care planning, kidney replacement therapy options, and justification when treatment modality is temporarily or permanently not feasible. The report must also be integrated into the electronic patient record and transmitted to the general practitioner.

In practice, however, the effectiveness of this measure depends on the existence of active collaboration with general practitioners and interoperable communication systems. The audit highlighted that many dialysis centers still lack formal agreements with GP networks and continue to rely on liaison notebooks or fragmented information exchanges.

Frontline insights

Patients reported different life experiences depending on their modality treatment

Patients describe the initiation of dialysis as a turning point, marking a transition from a relatively "normal" life to one associated with significant physical and emotional burdens linked to treatment sessions. In this context, dialysis modalities are not perceived as mere clinical options, but as key determinants of social inclusion, educational continuity, and personal autonomy.

In-center haemodialysis, often perceived as the default option, is described as significantly structuring daily life around fixed treatment schedules and repeated hospital visits. Patients report physical fragility, including recurrent physiological "crashes" such as blood pressure drops, as well as a sense of confinement that limits educational and professional opportunities.

In contrast, testimonies highlight the added value of home-based modalities, particularly peritoneal dialysis (PD). A caregiver whose child experienced different treatment modalities emphasized that home dialysis and PD "allow opening up to new projects and avoid being too restricted, whereas ICHD makes, for example, travelling impossible." She further reported that PD enabled them to travel abroad for ten days and maintain a social circle, illustrating how these modalities can support a more active and socially integrated life.

Patient feedback highlights several logistical and organizational challenges related to transportation

Patient feedback highlights some positive local practices, such as the involvement of volunteers in organizing transportation for paediatric patients at the Hôpital Reine Fabiola, which was perceived as well coordinated. However, patients also identified several areas for improvement.

First, patients pointed to a lack of structured support for transportation organizations among adults. Unlike in paediatric settings, adult patients are often left to navigate transportation arrangements on their own.

Second, logistical constraints within hospital infrastructure were highlighted. In some facilities, parking areas are located far from dialysis units, which can be particularly challenging for patients in a fragile condition (e.g. hypotension), making even short distances physically demanding.

Then, organized transport services (via mutual health funds or the CPAS) were perceived as insufficiently adapted to patient's frailty. Patients reported long waiting times after dialysis sessions, as drivers often transport multiple individuals, leading to delays of up to an hour or more. In some cases, drivers may leave if the patient is not ready at the exact scheduled time.

Finally, patients point out that the STIB TaxiBus service, a door-to-door transportation option designed for individuals with reduced mobility, requires advance booking. This is not well suited to the unpredictable duration of dialysis sessions, which can lead to scheduling mismatches and additional costs.

Patient feedback point to limited and fragmented care coordination in practice

Reduced involvement of general practitioners

The role of general practitioners appears significantly reduced in the dialysis pathway. Many patients report no longer having an active relationship with a GP, with care being almost entirely centered around the nephrologist. In some cases, general practitioners themselves prefer not to intervene due to the perceived complexity of dialysis care, even for basic procedures such as blood tests. When involved, their role is often limited to administrative support (for example prescriptions). However, patients pointed out their added in more accessible explanations and in offering longer consultations than nephrologists, who are perceived as more time constrained.

Limited privacy and continuity in nephrology consultations

Patients reported that in several centers, nephrology consultations do not take place in a dedicated setting but occur chairside during dialysis sessions, which limit privacy. In addition, they reported that rotating schedules where different nephrologists follow the patient each week were frequent, even though they disrupt continuity of care and weaken the patient-physician relationship. Patients reported greater satisfaction when follow-up was provided by the same physician over time.

Insufficient coordination of follow-up appointments and examinations

According to patients, the coordination of periodic examinations and appointments remains suboptimal. Routine follow-ups (e.g. vascular access imaging, cardiology assessments, regular blood tests) are often scheduled without sufficient patient involvement.

This lack of coordination with patients may also generate cascading delays when appointments are scheduled immediately before dialysis sessions, postponing the start of dialysis and disrupting the schedule of other patients in the unit. Patients also reported that communication channels used (e.g. email notifications) are not always adapted to the needs of less digitally connected populations.

Abrupt transition from nephrology paediatric to adult care

Overall, the transition from paediatric to adult nephrology care is described as particularly abrupt, with limited coordination between teams. In one case illustrated by a caregiver, the absence of proper handover has led to serious clinical consequences, highlighting the need for more gradual and coordinated transition pathways.

Need for more personalized care approaches

Some patients reported that care approaches were not adapted to their specific needs. They described a paternalistic approach where clinical interpretations overlook individual factors (e.g. attributing biological changes solely to non-adherence). Younger patients also felt that their active lifestyles and personal aspirations were insufficiently considered. This points to the need for more personalized care approaches.

Targeted actions

1. Improve flexibility and quality of patient transportation

Lead actors: Mutual health funds, CPAS, mobility operators, hospitals and nephrology departments

Objectives and outcomes: Improve transportation services in order to reduce waiting time and organizational stress for dialysis patients.

Suggested initiatives:

- **Strengthen patient support for transportation organization:** Provide more structured guidance for adult patients navigating transportation arrangements, inspired by the more coordinated support often available in paediatric settings.
- **Improve coordination and flexibility of dialysis transportation scheduling:** Strengthen coordination between dialysis centres and transport providers (e.g. CPAS, mutual health insurance funds, adapted transport services) to better synchronise patient arrivals, dialysis session timing, and return journeys after treatment. Transportation systems should also become more flexible in order to accommodate the unpredictable duration of dialysis sessions, for example by reducing rigid advance-booking requirements for services such as the STIB TaxiBus. The flow management system implemented at the Jolimont Clinic was identified as a positive example of efficient organisation.
- **Improve quality standards for grouped dialysis transportation:** Develop clearer quality requirements regarding hygiene conditions, vehicle overcrowding and separation of infectious patients.
- **Promote and expand volunteer-based transportation options:** Support models such as “Coup de Pouce” in Walloon Brabant, where volunteer drivers provide individual patient transport with costs limited to mileage reimbursement. Those offers greater flexibility than shared transportation services, enabling reducing waiting times after care, while remaining relatively low-cost for patients. However, its scalability is constrained by the limited availability of volunteer drivers.

2. Strenghten care coordination and more personalised dialysis pathways

Lead actors: SPF Santé publique, Hospitals and nephrology departments

Objectives and outcomes: Improve transmural coordination, continuity of follow-up, and personalization of dialysis care pathways.

Suggested initiatives:

- **Strengthen interoperable communication and transmural coordination:** Develop a national plan to standardize communication and follow-up arrangements between dialysis centers, hospitals, general practitioners, specialists, primary care, and home care services. This should reduce reliance on liaison notebooks and fragment written communication by improving interoperability between IT systems, introducing automatic notifications within shared electronic patient records, and supporting the effective implementation of the multidisciplinary care plans introduced through nomenclature 103994[13]. Existing digital tools such as Vaccinnet could also be more broadly integrated and accessible to specialists.
- **Strengthen continuity and quality of nephrology follow-up:** Promote more stable patient-physician relationships, for example through the designation of a referent nephrologist or assistant. Dedicated consultation slots outside dialysis sessions should be encouraged to improve privacy, continuity, and the quality of interactions, instead of relying on ad hoc chairside discussions during dialysis.
- **Improve coordination and patient involvement in appointment scheduling:** Avoid planning specialist consultations immediately before or after dialysis start to avoid cascading delays. Scheduling should take patient availability more systematically into account, while communication methods should be adapted to less digitally connected populations.
- **Structure transitions from paediatric to adult nephrology care:** Implement formalized handover processes including joint consultations between paediatric and adult nephrologists and temporary co-management periods after transfer to ensure continuity of care and reduce clinical risks.

5.4. Transplantation

Contextual elements

When it comes to kidney transplantation, Belgium is among the best-performing countries within the Eurotransplant system[14]. In 2025, it recorded the second-highest kidney transplantation rate in the network, though not in Europe, with 46.1 transplantations per million population, just behind the Netherlands (57.3 per million) (Eurotransplant, 2025).

[13] As explained earlier, this code requires nephrologists to document and share a structured multidisciplinary CKD care plan with the patient's general practitioner and integrate it into the electronic patient record.

14 Belgium is part of Eurotransplant, an international foundation aimed at facilitating the allocation and cross-border exchange of deceased-donor organs. Eurotransplant collects medical and immunological data from patients listed for transplantation across eight European countries: Germany, Austria, Belgium, Croatia, Hungary, Luxembourg, the Netherlands, and Slovenia.

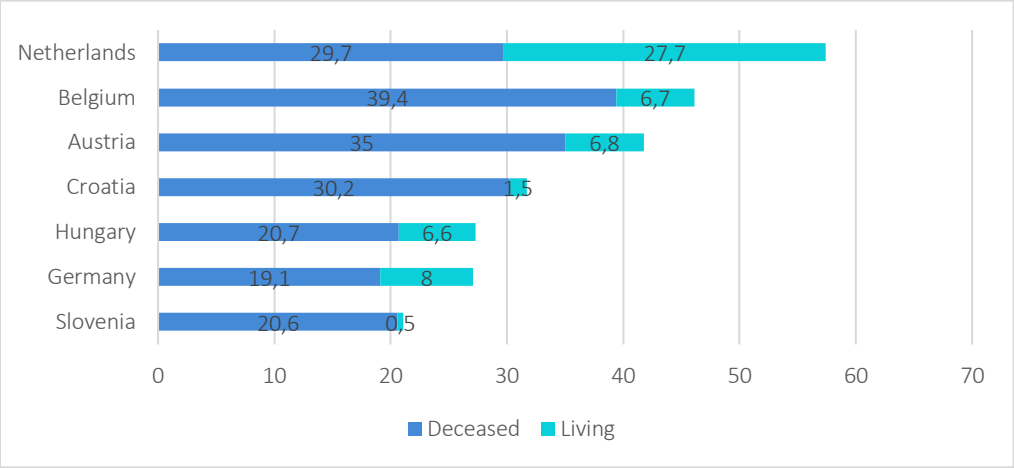


Figure 7. Kidney transplantations per million population in 2025 in the Eurotransplant group, by donor type (Adapted from Eurotransplant, 2025)

Belgium operates under an opt-out organ donation system: anyone registered in the population register is automatically considered a potential donor unless they have explicitly objected during their lifetime (e.g. through an official declaration or via the government health services website). Family members may, however, also report a known objection. This system may partly contribute to Belgium's comparatively high transplantation rates, especially when contrasted with countries such as Germany, where individuals must actively register as organ donors during their lifetime (opt-in system). However, the impact of opt-out systems should be interpreted with caution, as transplantation activity also depends on many other organisational, cultural, and healthcare system factors. Spain, for example, remains by far the most active transplantation country in Europe despite not relying solely on an opt-out approach.

In clinical practice, among patients under 65 years old, more individuals are now living with a functioning kidney transplantation than there are receiving dialysis treatment (INAMI & SPF, 2025), further illustrating the strong performance of the Belgian transplantation system. The distribution of prevalent KRT patients by age group and treatment modality is presented in Appendix 5.

Despite these strong outcomes, demand remains substantial, with around 1,100 patients on the national waiting list in 2023 (Medisphere, 2023), and an average waiting time for transplantation of approximately two years (AIRG, 2020).

Moreover, and as can be seen on figure 7, Belgium has relatively few living kidney donors. Only 14% of kidney transplantations in Belgium come from living donors (6.7 per million population), compared with substantially higher rates in the Netherlands (47%; 27.1 per million population) and Germany (30%; 8 per million population) (Eurotransplant, 2025; INAMI & SPF Santé publique, 2025). Compared with Belgium, these two countries rely more strongly on living donation and public awareness around it (INAMI & SPF Santé publique, 2025).

In Norway, medical teams also play a more active role in informing relatives about living donation opportunities (Renaloo, 2009). This difference is particularly notable given the well-documented advantages of living donation. It allows transplantation to be planned, often before dialysis is required, thereby improving quality of life. Living donor transplantation also preserves organ quality and reduces rejection risk, leading to higher success rates compared to deceased donor transplantations (Murray et al., 2025).

Beyond its direct clinical benefits, timely transplantation (whether from living or deceased donors) also shapes the broader dialysis landscape. It influences the proportion of patients treated with peritoneal dialysis as peritoneal dialysis is often used as bridge therapy before transplantation (Nardelli et al., 2022).

A final issue concerns the timing of pre-transplantation assessments, a comprehensive evaluation designed to determine a patient's suitability for kidney transplantation, which remains suboptimal in Belgium. According to the INAMI audit, assessments are most often initiated at the start of the pre-dialysis pathway (27%), but still frequently occur only at dialysis initiation (21%). In addition, 17% of hospitals reported variations in practice depending on the nephrologist within the same unit, highlighting inconsistencies in access and timing (INAMI & SPF, 2025).

Frontline insights

Patient feedback highlights important gaps in information regarding access to transplantation

Several patients report not being informed of the possibility of being listed for transplantation, or only at a very late stage in their care pathway. In this context, some patients also describe communication around transplantation as overly focused on worst-case scenarios, without sufficient contextualization or reassurance. One patient, for example, recalled being told that surgeons would "operate the day before to assess whether the organ is suitable and then proceed with the transplantation the next morning." This type of communication reportedly discouraged her from pursuing transplantation altogether for several years, until she was eventually listed in another center.

Regarding living kidney donation, one patient reported only learning about this option through someone in the Netherlands rather than from his Belgian care team. Although clinicians later confirmed the possibility, it had not been proactively discussed.

Regarding deceased donor transplantation, the functioning of the Eurotransplant allocation system remains poorly understood by patients. Limited explanations are provided regarding allocation criteria (e.g. waiting time, compatibility, geographical factors), leading many patients to perceive the process as opaque and unpredictable. Patients describe the system as a "black box", where the part of the process governing organ allocation appears random. In fact, some patients perceive a degree of subjective medical judgement in the final allocation decision, further reinforcing feelings of uncertainty and lack of transparency.

Patients report issues in pre-transplantation evaluation and preparation

Some patients report that pre-transplantation assessments are often done too late or not done at all, even though they point out variation between centers. Several patients also indicate that no psychological assessment was conducted, and that structured education regarding the procedure, associated risks was insufficient or absent.

Patients need more support in post-transplantation follow-up

Patients acknowledge some improvements in the management of treatment-related side effects but still report limited structured psychosocial support after transplantation. In particular, peer support initiatives remain insufficiently developed, with no systematic approach to connecting newly transplanted patients with experienced recipients who could provide reassurance and practical guidance. In addition, patients describe graft failure and the return to dialysis as a highly distressing experience, and they often feel that this transition is not sufficiently supported in hospital follow-up.

Targeted actions

1. Improve awareness, information and communication on transplantation and living donations

Lead actors: Hospitals and nephrology teams, transplantation centers, INAMI

Objectives and outcomes: Ensure that patients receive earlier, clearer, and more systematic information on transplantation options, including both deceased donor transplantation and living kidney donation.

Suggested initiatives:

- **Train healthcare professionals in patient-centered transplantation communication:** Provide formations to nephrologists in communicating transplantation risks, benefits and procedures in a reassuring and accessible way.
- **Develop information sessions involving patients associations and nephrologists:** Integrate structured transplantation information sessions as a routine component of the CKD patient education pathway. These sessions could combine medical explanations provided by nephrologists with testimonies from transplanted patients to offer both clinical information and lived experience perspectives.
- **Develop and disseminate patient educational tools:** Provide accessible and patient-friendly educational materials, such as the transplantation guides developed by centers like Saint-Luc (Cliniques universitaires Saint-Luc, 2020). Educational resources could also include simplified explanations of the Eurotransplant allocation system, covering aspects like waiting time, geographical factors, and the role of medical judgement in allocation decisions.
- **Systematically involve relatives in discussions on living donation:** Family members and close relatives should be systematically included in discussions on living donation, as living donation most frequently occurs within family relationships (53%) or close emotional relationships (41%) (Belgian Transplantation Society, 2024).
- **Promote and further develop Belgium's Living Donor Exchange Program (LDEP):** This national cross-donation program enables incompatible donor-recipient pairs to exchange kidneys anonymously through coordinated surgeries between Belgian transplantation centers. Following interruptions during the COVID-19 period, renewed INAMI funding for four annual matching campaigns represents an opportunity to accelerate exchanges, increase living donation, and reduce waiting lists (INAMI & SPF, 2025).

2. Improve pre-transplantion assessment and post-transplantion follow-up

Lead actors: Hospitals and nephrology teams, transplantation centres, INAMI

Objectives and outcomes: Facilitate earlier listing and increase opportunities for pre-emptive transplantation by standardizing earlier pre-transplantation assessments. In parallel, strengthen psychological evaluation before transplantation to assess patients' readiness for transplantation and their understanding of the importance of long-term treatment adherence in preserving graft function.

Post-transplantion follow-up should also be reinforced through improved psychosocial support and peer-support initiatives in order to help patients adapt to post-transplanted life, long-term treatment adherence, and potential complications.

Suggested initiatives:

- **Establish center-level targets for timely pre-transplantation assessment:** Require transplantation centers and heads of nephrology departments to complete pre-transplantation assessments 6 to 12 months before anticipated dialysis initiation, in line with KDIGO recommendations (Chadban et al., 2020), while ensuring coherent practices across nephrologists within the same unit.
- **Systematically integrate psychological assessment in pre-transplantation assessments:** Include psychological evaluation within standard pre-transplantation assessments to assess emotional readiness and understanding of post-transplantation treatment adherence.
- **Strengthen psychological support after transplantation:** Provide access to psychological counselling before and after transplantation in order to support emotional preparation, address fears and uncertainties, and help patients adapt to post-transplanted life and potential complications.
- **Organize peer-support sessions within transplantation centers:** Facilitate group discussions involving patients with lived transplantation experience.

5.5. Education and workforce shortages

Contextual elements

The quality and sustainability of CKD care depend heavily on the availability, training, and retention of healthcare professionals throughout the care pathway. Belgium currently faces several workforce and training-related challenges, particularly regarding renal nurses, who play a central role across all stages of CKD care, from pre-dialysis education to dialysis treatment, home care, and transplantation follow-up.

The following sections therefore mainly focus on nursing staff. Challenges and recommendations concerning other healthcare professionals, including nephrologists, general practitioners, psychologists and dietitians, are addressed in the previous thematic sections whenever relevant issues were identified.

Workforce shortages and retention challenges among dialysis nursing staff

During the on-site audit, dialysis center managers were asked to identify the two most urgent challenges at a higher policy level. The shortage of nursing staff was identified as the main issue in 75% of centers (SPF & INAMI, 2025). Several factors contribute to this situation, including difficulties in recruiting new nurses, strong competition between hospital departments, demanding working conditions (weekend shifts and on-call duties and high staff turnover). In addition, regulatory restrictions on the scope of practice of nursing assistants limit their involvement in certain dialysis-related tasks, thereby increasing the workload and responsibilities placed on dialysis nurses.

Limits in nephrology nursing education

Initial training for dialysis nurses also remains insufficiently structured across Belgian centers, despite the technical complexity of dialysis care and the recognized importance of specialized nephrology training for patient safety and quality of care.

In fact, as reported by the INAMI audit, in most centers (17/24) initiation training mainly consisted of on-the-job learning at the patient's bedside during the first two weeks, only half of the time supported by a mentor (12/24). In rare cases, this training period was extended to one month or even six months. Moreover, only 14 out of 24 hospitals reported that nurses attended the ORPADT basic course (2-3 days).

Other training formats included self-learning modules (7/24), industry-provided training (9/24), or postgraduate nephrology programs offered by institutions such as Haute École Condorcet and Odisee. Overall, the audit identified a major issue regarding initial training: this training course was rarely mandatory, and only one center reported a formal assessment of acquired competencies.

Continuing education for nurses also appears insufficiently structured. Updates regarding new guidelines or protocols are mainly communicated through emails, team meetings or through the head nurse. In some cases, information is disseminated through newsletters, intranet platforms, or informal discussions with nephrologists. No center reported having a formal system ensuring that all nurses, including those returning from long absences, systematically review and acknowledge updated protocols.

At the same time, Belgium has started to develop more formal frameworks for specialized nursing practice. Specialized nephrology and dialysis training programs already exist in several Belgian institutions, and the legal framework for Advanced Practice Nurses (APNs/IPA) was recently introduced at national level in April 2024. APNs are nurses with advanced clinical training and extended responsibilities who can play a more autonomous role in patient follow-up, patient education, and clinical decision-making. To obtain accreditation as an APN in Belgium, nurses must hold a master's degree in nursing sciences and complete at least 3,000 hours of clinical practice. Accreditation is not permanent and must be maintained through 80 hours of continuing education every four years and an additional 1,500 hours of clinical practice. However, the integration of APNs into the Belgian healthcare system remains at an early stage of implementation. Unlike general nursing activities, which are clearly defined by existing legislation, the broad scope of APN practice still requires further clarification regarding responsibilities, integration into care pathways, and practical implementation across healthcare settings.

Consequences for home dialysis and residential care nurses

In turn, training gaps limit the expansion of home dialysis and dialysis in residential care facilities.

In fact, one of the main barriers identified for the expansion of home dialysis is the shortage of home-care nurses specifically trained in dialysis techniques and patient monitoring. As a result, many patients cannot be adequately supported with essential tasks such as connection and disconnection from dialysis equipment, limiting the possibility of transferring part of the care from the hospital to the home environment. This comes in addition to the fact that home dialysis remains financially less attractive within the current home nursing reimbursement framework.

The implementation of peritoneal dialysis in residential care facilities is also considered extremely difficult in practice as nurses working in these facilities are generally unfamiliar with peritoneal dialysis techniques. Due to high staff turnover in residential care settings and intense working schedules, providing continuous training by hospital teams is perceived as costly, time-consuming, and difficult to sustain over time.

Frontline insights

Patients' perspectives on nursing staff

Patients generally describe nursing staff as highly committed and essential to the daily functioning of dialysis care. However, they also perceive increasing pressure on nursing teams, reflected in limited time available for patient interaction. Patients also highlight the central role nurses play beyond purely technical care, as nurses are often perceived as the main point of contact for practical explanations and daily coordination.

Regarding home dialysis, patients report that support from specialized dialysis nurses is generally highly valued when available, particularly for initiating treatment at home or managing complications.

However, many home-care nurses outside dialysis centers are perceived as insufficiently trained or experienced in dialysis-specific procedures, especially arteriovenous fistula puncture. Patients explain that this procedure requires repeated practice and regular exposure to maintain proficiency and ensure safety.

Targeted actions

1. Adress workforce shortages and retention challenges among nephrology nurses

Lead actors: SPF Santé publique, Hospitals and nephrology teams

Objectives and outcomes: Strengthen the attractiveness, retention, and availability of specialized nursing staff in nephrology and dialysis care in order to preserve dialysis capacity and ensure continuity and quality of care. Without targeted action, Belgium risks facing major dialysis capacity shortages in the coming years.

Suggested initiatives:

- **Adjust the list of activities reserved for nursing assistants:** Reassess regulatory restrictions to allow appropriately trained nursing assistants to perform selected dialysis-related tasks under supervision.
- **Reduce administrative workload for nurses:** Strengthen dedicated secretarial support to manage tasks such as scheduling appointments, organizing transport, monitoring vaccinations, and handling patient calls.

2. Strenghten CKD education and specialized training for nurses

Lead actors: SPF Santé publique, Hospitals and nephrology teams

Objectives and outcomes: Improve the quality and recognition of specialized nephrology and dialysis training for nursing staff across hospital, homecare, and residential care settings.

Suggested initiatives:

- **Strengthen initial training for dialysis nurses**: Expand or make compulsory the ORPADT basic course (2-3 days) and encourage participation in self-learning modules or postgraduate nephrology training programs.
- **Implement testing and certification of dialysis training**: Establish mechanisms to formally test and certify the knowledge and competencies acquired during dialysis training.

  Certification could progressively serve as a bridge toward advanced nephrology nursing roles, creating clearer professional pathways for nurses developing specialized expertise in CKD care. As Belgium introduced the legal framework for Advanced Practice Nurses (APN/IPA) in April 2024, further actions are now needed to clarify authorized clinical activities, integration into multidisciplinary teams, reimbursement mechanisms, and implementation across care settings. To remain attractive and meaningful, these advanced roles should also be associated with clearly defined responsibilities, extended competencies, and appropriate remuneration.

- **Develop a recognized role for dialysis educators:** Create a specialized role of "nephrology educator", supported by a formal and accredited training curriculum, modeled on the existing diabetes educator framework in Belgium. This recommendation is further detailed in the "Pre-dialysis" section.
- **Strengthen structured continuing education and send protocol updates**: Implement formal systems to ensure that all nurses regularly review and acknowledge new or revised protocols, including after long absences from clinical practice.
- **Strengthen training for home-care nurses:** Provide specific training for nurses who support patients undergoing home dialysis or dialysis in residential care facilities. Build on pilot projects such as the initiative developed by the Institut Marie Curie (CHU Charleroi-Lodelinsart), where dialysis machines were installed in a residential care facility and nurses and nursing assistants received dedicated training through the ORPADT/Condorcet program (130 hours of theoretical and practical training on fistula puncture and dialysis monitoring).
- **Develop specialized hospital-based mobile nursing teams:** Create specialized hospital-based mobile nursing teams able to intervene in patients' homes and residential care facilities in order to support dialysis patients and local care teams.

5.6. Reimbursement

Contextual elements

Reimbursement of healthcare costs

The direct medical costs related to dialysis treatment are largely covered through Belgium's compulsory health insurance system. However, patients may still face important out-of-pocket expenses, particularly for medication co-payments, laboratory tests, or complementary care. As a result, many patients rely on complementary insurance provided by mutual health insurance funds to cover part or all the remaining costs

Reimbursement of transportation costs

The overall reimbursement framework is the following:

- Compulsory health insurance reimburses transportation costs for non-hospitalized dialysis patients at €0.37 per kilometer (indexed amount), calculated based on the shortest distance between the patient's official residence and the dialysis center, regardless of the mode of transportation used.
- Complementary insurance schemes provided by mutual health insurance funds may intervene in transportation costs to dialysis centers, as well as nephrology consultations.

However, several structural issues were identified, generating important financial pressure for vulnerable populations.

- Reimbursement conditions vary substantially between health insurance funds. According to the INAMI audit, one mutual health insurance fund introduced annual reimbursement ceilings beyond which no additional transportation costs were covered (INAMI & SPF, 2025).
- Certain mutual health insurance funds are considering abandoning the third-party payment system, which would require patients to advance transportation costs themselves (INAMI & SPF, 2025).

- Transportation costs also vary considerably depending on patients' mobility status and the transportation provider used.

Disability recognition and social allowances

Dialysis patients may benefit from official disability recognition through the Federal Public Service Social Security. Depending on the recognized disability level, income, and family situation, patients may obtain income replacement allowances, integration allowances, and additional social benefits such as parking cards, social tariffs for utilities and telecommunications, or reductions for public transportation

Reimbursement of home dialysis

Patients performing home dialysis receive financial compensation intended to cover additional household costs for increased water, electricity, and phone use:

- Home hemodialysis: €8.43 per session
- Peritoneal dialysis: €0.76 per dialysis day

Frontline insights

Patients report that dialysis treatment costs are well covered financially

Dialysis patients report that dialysis is well covered financially, with essentially no out-of-pocket costs for the treatment itself. However, they also highlight that many patients experience multiple comorbidities, such as cardiovascular or neurological conditions, leading to additional consultations and hospital-related expenses that can become substantial over time. Patients nevertheless note that these costs are often mitigated through broader social protection mechanisms, including disability-related entitlements. Some also mention that the possibility of spreading payments over several months helps reduce immediate financial pressure.

Patients highlight gaps in information and understanding of reimbursement systems

In home-based peritoneal dialysis, one patient was unaware of the daily allowance of €0.76 intended to cover increased water, electricity, and telephone costs. In addition, there is some confusion regarding insurance eligibility, with one case illustrating incorrect information provided to a family about hospitalization insurance being impossible due to a neonatal diagnosis. Overall, patients stress that navigating insurance and mutual health fund procedures largely depends on their own initiative, with limited structured guidance provided.

Patients point out that transportation reimbursement can be uneven and burdensome

Regarding transportation reimbursement, patients report that it is overall adequate and considered fair, particularly when they drive themselves. In such cases, out-of-pocket costs remain limited. Parking costs appear to be well managed: all interviewed patients report that parking is either free or reimbursed (e.g. dedicated parking spaces or access badges for dialysis patients).

For patients unable to drive, alternative transportation solutions exist, such as CPAS-supported services, mutual health insurance fund arrangements (e.g. transportation to and from home or care facilities) or dedicated driver services. However, these are paid services and patients report that costs can be significantly higher than reimbursements. Patients also report that dedicated driver services are frequently saturated.

Other solutions include "STIB Taxi arrangements", but these often require a predefined return time, and additional charges may apply if the hospital stay is longer than expected, resulting in the return trip being billed.

Kidney transplanted patients point out a mismatch between reimbursement and clinical reality

From a social protection perspective, patients point out that they rapidly lose disability-related benefits after transplantation because they are administratively considered "cured". However, in practice, kidney transplant recipients remain chronically ill patients requiring lifelong immunosuppressive therapy and close medical monitoring. In the early post-transplantation period, patients report having weekly consultations for blood tests to adjust and monitor immunosuppressive medication levels and ensure optimal dosing. After the first year, follow-up appointments are usually spaced out to approximately every two months, depending on clinical stability.

Patients also report important transportation-related difficulties after transplantation. While transportation reimbursement is often well covered during dialysis, coverage may decrease after transplantation because patients move from a "dialysis/severe chronic disease" reimbursement category to a standard "post-operative/non-urgent medical transportation" framework, which is subject to lower reimbursement conditions. As a result, some transplanted recipients face substantial out-of-pocket transportation costs despite the high frequency of follow-up visits. Patients also warn that these financial barriers may have clinical consequences, as reduced access to follow-up care can contribute to poorer adherence and, in some cases, graft loss.

Targeted actions

1. **Improve post-transplantation financial protection**

Lead actors: SPF Santé publique, INAMI

Objectives and outcomes: Better align reimbursement with the long-term clinical reality of kidney transplantation recipients to reduce financial vulnerability, improve continuity of follow-up care, and support long-term graft outcomes.

Suggested initiatives:

- **Introduce a gradual phase-out of disability-related benefits after transplantation:** Avoid abrupt loss of disability-related entitlements immediately after transplantation by introducing transitional reimbursement periods reflecting the continued medical and social needs of transplanted recipients.
- **Reassess post-transplantation transportation reimbursement mechanisms:** Adapt transportation reimbursement frameworks to better reflect the high frequency of follow-up consultations after transplantation, particularly during the first post-transplantation year.

2. **Strengthening accessibility and financial support of transportation**

Lead actors: SPF Santé publique, INAMI, municipalities, mutual health insurance funds

Objectives and outcomes: Reduce financial and organizational barriers related to transportation for dialysis and transplantation patients to facilitate regular follow-up care and reduce the risk of missed consultations.

Suggested initiatives:

- **Promote and expand municipal taxi voucher schemes for dialysis and transplantation patients:** Existing systems such as the Brussels "taxi ticket" scheme already provide subsidized transportation through partnerships between municipalities and taxi providers. Dialysis centers could play a more proactive role by systematically informing eligible patients and supporting them in accessing these schemes.

In parallel, similar models could be extended beyond Brussels and explicitly include dialysis and transplanted patients among eligible populations. Currently, eligibility mainly targets older adults, individuals with disabilities, and low-income groups (e.g. BIM status).

- Maintain third-party payment systems for transportation reimbursement: Prevent mutual health insurance funds from discontinuing third-party payment mechanisms for dialysis and transplantation-related transportation, as requiring vulnerable patients to advance high transportation costs may create barriers to follow-up care and treatment adherence.
- Improve patient guidance regarding reimbursement and insurance procedures: Provide clearer and more structured information regarding mutual health insurance procedures, complementary insurance eligibility, disability-related entitlements, and reimbursement rights throughout the CKD and transplantation pathway.

6. Appendices

6.1. Appendix 1 – Launching a nephrology-specific PREMs pilot project

Context and purpose

As PREMs are currently the most appropriate tool for measuring patient experience, a pilot project has been launched to adapt the Kidney PREMs to the Belgian context. Since no such tool is yet in routine use in Belgium, SPX is implementing a pilot adaptation to collect structured data on the experiences of patients living with kidney insufficiency. Its primary objective is to better understand perceived quality of care by assessing patients' experiences, including their interactions with healthcare staff, respect, clarity of communication, waiting times, and overall satisfaction. Unlike PROMs (Patient-Reported Outcome Measures), which measure health status and clinical outcomes, PREMs focus on the patient's lived experience throughout the care pathway.

Implementation and functioning

The project, the first PREMs initiative specifically designed for kidney insufficiency in Belgium, was launched and developed from 2025 onwards. Its design followed a collaborative approach involving patients, caregivers, and nephrologists to ensure both engagement and relevance of the results. Its implementation followed a clear stepwise approach:

I. **Methodology validation by professionals (2025):** Working groups with the teams at CHU Brugmann to co-design and validate the proposed methodology.
II. **Pilot testing with patients and professionals (2025):** Testing the questionnaire with a small group of kidney insufficiency patients, alongside consultations with healthcare professionals from participating institutions, to assess clarity and relevance.
III. **Data collection and presentation (2026 - 2027):** PREMs are collected in three distinct one-month waves via tablets, QR codes and e-mail links. This structured approach allows monitoring of changes in patient experience, identification of potential seasonal variations, and ensures data representativeness. This quantitative analysis aims to identify trends and areas for improvement. Results are then shared individually with each partner institution.
IV. **Intermediate results presentation (end 2026):** Aggregate results are presented at an event organised by SPX.

Currently, the pilot project runs for one year (from early 2026 to 2027) in participating hospitals Cliniques universitaires Saint-Luc, CHU Brugmann, Universitair Ziekenhuis Antwerpen and Cliniques universitaires de l'Europe et l'Hôpital de la Citadelle[15]. Other hospitals are expected to join the project over time.

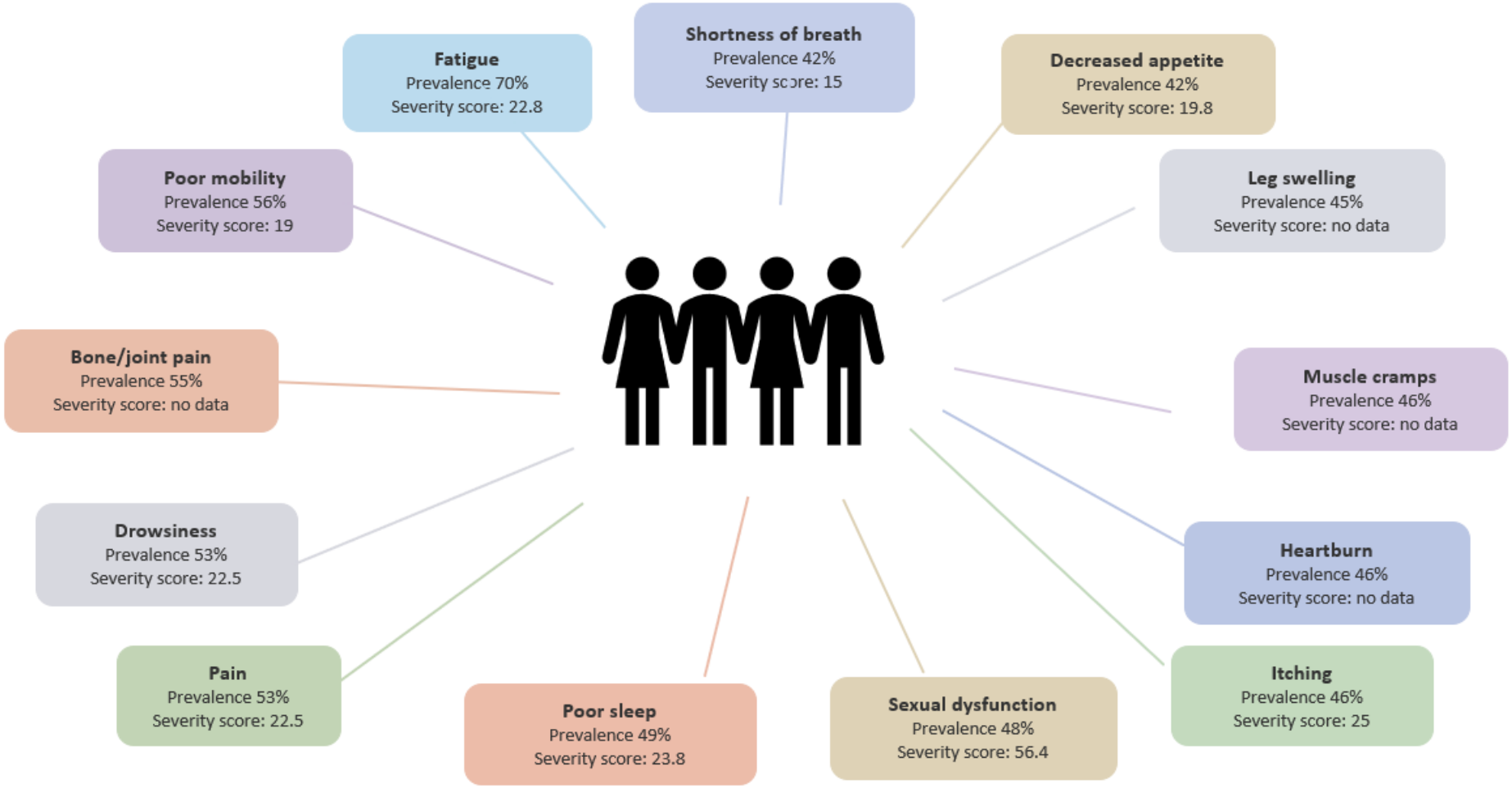
The tool selected for this project is an adaptation of the UK Kidney PREM, internationally validated and recognized, translated, modified, and tailored to the Belgian context to cover all treatment modalities: in-centre or home hemodialysis, peritoneal dialysis, kidney transplantation, and conservative care.

Future ambitions

Beyond the pilot phase, the initiative also aims to establish a sustainable and reusable model that hospitals could continue to use and potentially extend to other chronic conditions. Ultimately, the ambition is to integrate PREMs into institutional dashboards so that patient experience becomes a practical tool for continuous quality improvement.

[15] The start and end dates vary across participating hospitals. The first PREMs collection at Cliniques universitaires Saint-Luc and CHU Brugmann took place in March 2026, while Universitair Ziekenhuis Antwerpen and Cliniques universitaires de l'Europe started in May 2026.

6.2. Appendix 2 – CKD symptom burden (KDIGO, n.d.)



6.1. Appendix 3 – Guide to frequency of assessment for CKD progression and timely referral to nephrology service (Goderis et al., 2016).

GFR categories (mL/min/1,73 m²) Description and range				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30–300 mg/g 3–30 mg/mmol	>300 mg/g >30 mg/mmol
	G1	Normal or high	≥90	Screen 1	Treat 1	Treat and refer 3
	G2	Mildly decreased	60–89	Screen 1	Treat 1	Treat and refer 3
	G3a	Mildly to moderately decreased	45–59	Treat 1	Treat and refer 2	Treat and refer 3
	G3b	Moderately to severely decreased	30–44	Treat and refer 2	Treat and refer 3	Treat and refer 3
	G4	Severely decreased	15–29	Treat and refer 3	Treat and refer 3	Treat and refer 4+
	G5	Kidney failure	<15	Treat and refer 4+	Treat and refer 4+	Treat and refer 4+

The numbers 1, 2, 3, and 4+ within parentheses suggest the measurement frequency for eGFR and albuminuria (number of times per year).

At "*", consultation with nephrology service should take place as needed depending on local arrangements regarding frequency of monitoring and timing of referral.

6.2. Appendix 4 – Pre-dialysis education in Denmark

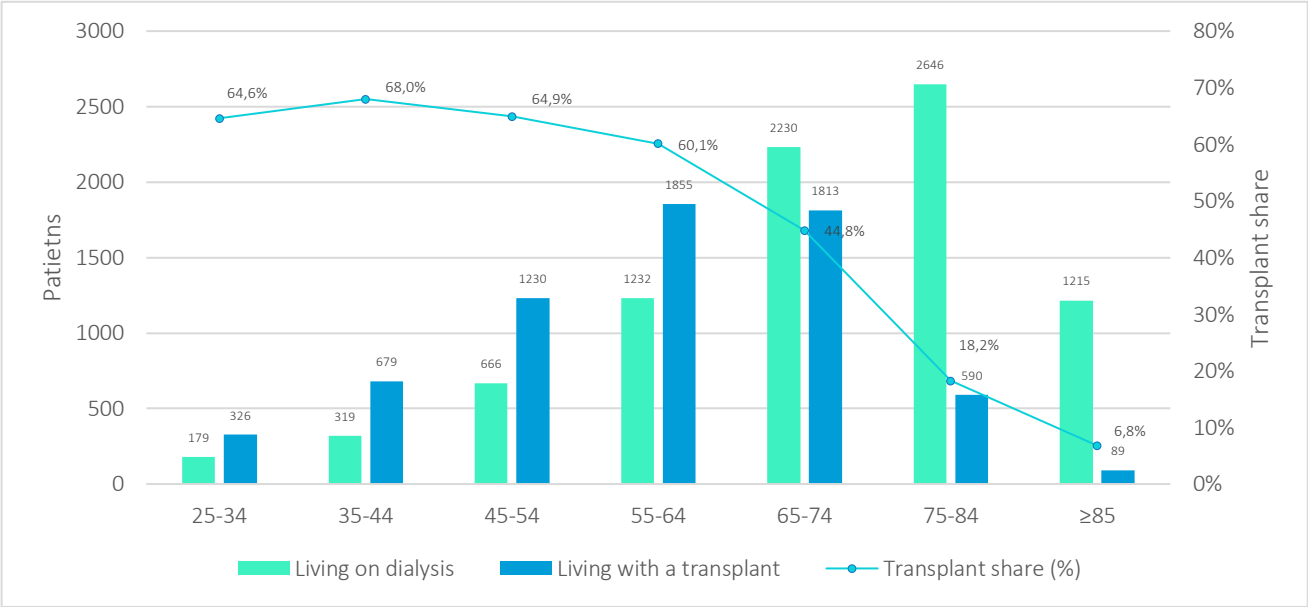
Aarhus University Hospital in Denmark illustrates a highly structured and operationalized approach to pre-dialysis education and shared decision-making, where modality choice is fully embedded within the clinical pathway rather than handled as an isolated step. At this institution, the model relies on two main pillars:

- **Structured patient education ("kidney school"):** Once referred to nephrologists, all patients and relatives are invited to participate in group-based kidney schools covering CKD progression and all treatment modalities. These sessions are delivered by trained nurses and physicians, with the involvement of experienced patients to reinforce peer-to-peer learning.
- **Standardized shared decision-making consultations:** Following education sessions, patients engage in structured discussions with trained nurses using dedicated (and systematically used) decision aids developed for patients, families, and healthcare professionals. The decision aid, which is a leaflet of dozen pages that patients can take home, is organized in three steps: first, it explains why a decision is needed and clarifies the choice to be made; second, it presents the available options in detail, including peritoneal dialysis without help, peritoneal dialysis with help, home hemodialysis, and in-hospital

hemodialysis; and third, it supports the actual decision through a guided reflection on knowledge, values, certainty, and the support needed.

This structured approach has a measurable impact: internal data from the last five years indicate that only 2% of patients remain undecided after the SDM process. It is also associated with a strong orientation toward home-based modalities: a retrospective Danish cohort study (n=484; 2018-2023) at Regional Hospital Gødstrup and Aarhus University Hospital found that, after a shared decision-making intervention, 68% of patients chose a home-based modality versus 32% for centre-based care (de-la-Motte et al., 2025).

6.1. Appendix 5 – Age distribution of prevalent KRT patients by treatment modality, 2020 (INAMI & SPF, 2025).



7. Bibliography

AIRG Belgique. (2020). *La greffe*. https://www.airg-belgique.org/fr/la-greffe/

Belgian Transplantation Society. (2024). Le don d'organes: État des lieux scientifique, juridique et éthique. In *Le don d'organes: État des lieux scientifique, juridique et éthique*. https://ieb-eib.org/pdf/2024/le-don-organes-etat-des-lieux-scientifique-juridique-et-ethique.pdf

Bear, Robert Allan, and Suzanne Stockie. 2014. "Patient Engagement and Patient-Centred Care in the Management of Advanced Chronic Kidney Disease and Chronic Kidney Failure." *Canadian Journal of Kidney Health and Disease* 1 (1): 24. https://doi.org/10.1186/s40697-014-0024-7.

Collège de médecins pour le centre de traitement de l'insuffisance rénale chronique (2020). *Rapport national du GNFB et du NBVN à la commande du Collège de médecins pour le centre de traitement de l'insuffisance rénale chronique Janvier 2011 – Janvier 2020.* Microsoft Word - Rapport College 2020 - rapport national.docx

Correa-Rotter, R., Wheeler, D. C., & McEwan, P. (2024). The broader effects of delayed progression to End-Stage kidney disease: delaying the inevitable or a meaningful change? *Advances in Therapy*, *41*(10), 3739–3748. https://doi.org/10.1007/s12325-024-02950-6

Cliniques universitaires Saint-Luc. (2020). *Guide du patient candidat à une greffe rénale*. https://www.saintluc.be/sites/default/files/2020-09/commu-dsq-108-guide-patient-candidat-greffe-renale_0.pdf

de-la-Motte, P., Jensen, V.B.J., Bergum, M.H. *et al.* Shared decision making and dialysis choice: an observational longitudinal cohort study. *BMC Nephrol* **26**, 282 (2025). https://doi.org/10.1186/s12882-025-04220-1

Eurotransplant. (2025). *Kidney transplants per million population, by year, by country, by donor type;* Eurotransplant Statistics Report Library. Eurotransplant - Statistics

Fages, V., De Pinho, N. A., Hamroun, A., Jacquelinet, C., Frimat, L., Foucque, D., Combe, C., Massy, Z., Boucquemont, J., & Stengel, B. (2020). Déterminants sociaux et organisationnels du démarrage de la dialyse en urgence chez des patients suivis en néphrologie – Une étude de cohorte prospective. *Néphrologie & Thérapeutique*, *16*(5), 252. https://doi.org/10.1016/j.nephro.2020.07.015

F. Collart (2011). *The follow-up of chronic renal failure*. EPREUVE 1.pmd

Feakins, B., Oke, J., McFadden, E., Aronson, J., Lasserson, D., O'Callaghan, C., Taylor, C., Hill, N., s, R., & Perera, R. (2019). Trends in kidney function testing in UK primary care since the introduction of the quality and outcomes framework: a retrospective cohort study using CPRD. *BMJ Open*, *9*(6), e028062. https://doi.org/10.1136/bmjopen-2018-028062

Goderis, Geert, Gijs Van Pottelbergh, Kathleen Claes, Erika Vanhauwaert, Eefje Van Nuland, Annelies Vantieghem, and Paul Van Royen. (2016). "Multidisciplinaire richtlijn Chronisch nierlijden (CNI)," December.

Goffin (2014). *Implementation and maintenance of a successful home hemodialysis programme: A 40-years experience [Conference presentation].* Université catholique de Louvain, Brussels, Belgium. sympo_DEH_2014_-_Eric_Goffin_-_40_ans_HHD-avec-compression.pdf

Goovaerts, T., Jadoul, M., & Goffin, E. (2005). Influence of a Pre-Dialysis Education Programme (PDEP) on the mode of renal replacement therapy. *Nephrology Dialysis Transplantation*, *20*(9), 1842–1847. https://doi.org/10.1093/ndt/gfh905

Hoque, F. (2024). Shared Decision-Making in Patient Care: Advantages, barriers and potential solutions. *Journal of Brown Hospital Medicine*, *3*(4), 13–15. https://doi.org/10.56305/001c.122787

Fletcher, B. R., Damery, S., Aiyegbusi, O. L., Anderson, N., Calvert, M., Cockwell, P., Ferguson, J., Horton, M., Paap, M. C. S., Sidey-Gibbons, C., Slade, A., Turner, N., & Kyte, D. (2022). Symptom burden and health-related quality of life in chronic kidney disease: A global systematic review and meta-analysis. *PLoS Medicine*, *19*(4), e1003954. https://doi.org/10.1371/journal.pmed.1003954

INAMI & SPF Santé Publique (2025). *Audit sur le traitement de l'insuffisance rénale chronique terminale*. Audit sur le traitement de l'insuffisance rénale chronique terminale

Inside CKD. (n.d.). *Belgium.* https://www.insideckd.com/explore-the-data/belgium/prevalence-of-diagnosed-and-undiagnosed-ckd

ISN-KDIGO (n.d.) *CKD early identification & intervention toolkit; ISN-KDIGO early screening booklet.* ISN_KDIGO_EarlyScreeningBooklet.indd

Juergensen E, Wuerth D, Finkelstein SH, Juergensen PH, Bekui A, Finkelstein FO. Hemodialysis and peritoneal dialysis: patients' assessment of their satisfaction with therapy and the impact of the therapy on their lives. Clin J Am Soc Nephrol. 2006 Nov;1(6):1191-6. doi: 10.2215/CJN.01220406. Epub 2006 Aug 30. PMID: 17699347

KDIGO. (n.d.). *Top 10 Takeaways for People Living with CKD from the KDIGO 2024 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease*. https://kdigo.org/wp-content/uploads/2025/01/Key-Takeaways_KDIGO-2024-CKD-Guideline_People-Living-with-CKD.pd

Lundström, U. H., Meeus, G., Aronsen, T., Clause, A., Finderup, J., Finne, P. J., Kampmann, J. D., Lange, J., McCarthy, K., Nohra, R., Stompòr, T., Wood, E., Lichodziejewska-Niemierko, M., & Jacobson, S. H. (2025). Increasing the adoption of home dialysis through improved advanced kidney care patient education: a call for action. *Clinical Kidney Journal*, *18*(4), sfaf087. https://doi.org/10.1093/ckj/sfaf087

Mark, P. B., Stafford, L. K., Grams, M. E., Aalruz, H., ElHafeez, S. A., Abdelgalil, A. A., Abdulkader, R. S., Abeywickrama, H. M., Abiodun, O. O., Abramov, D., Abrar, M. M., Abreu, L. G., Abubakar, B., Aburuz, S., Addo, I. Y., Adegboye, O. A., Adegoke, N. A., Adeyeoluwa, T. E., Adnani, Q. E. S.,. . . Coresh, J. (2025). Global, regional, and national burden of chronic kidney disease in adults, 1990–2023, and its attributable risk factors : a systematic analysis for the Global Burden of Disease Study 2023. *The Lancet*, *406*(10518), 2461-2482. https://doi.org/10.1016/s0140-6736(25)01853-7

Medisphere (2023). *Plus de 1.500 Belges attendent un don d'organe.* *Plus de 1.500 Belges attendent un don d'organe - Medi-Sphere*

Murray, J., Luke, A., Wallace, D., Callaghan, C., & Sharples, L. D. (2025). Comparison of outcomes after living and deceased donor kidney transplantation : UK national cohort study. *British Journal Of Surgery*, *112*(8). https://doi.org/10.1093/bjs/znaf162

National Kidney Foundation. (n.d.). *Stage 5 chronic kidney disease (CKD)*. Retrieved April 20, 2026, from https://www.kidney.org/kidney-topics/stage-5-chronic-kidney-disease-ckd

Nardelli, Luca, Antonio Scalamogna, Piergiorgio Messa, Maurizio Gallieni, Roberto Cacciola, Federica Tripodi, Giuseppe Castellano, and Evaldo Favi. 2022. "Peritoneal Dialysis for Potential Kidney Transplant Recipients: Pride or Prejudice?" *Medicina* 58 (2): 214. https://doi.org/10.3390/medicina58020214.

NierNet (2026). *NierNet Vlaanderen en NBVN slaan de handen in elkaar voor meer bewustwording, preventie en vroegtijdige opsporing.* NierNet Vlaanderen en NBVN slaan de handen in elkaar voor meer bewustwording, preventie en vroegtijdige opsporing - Niernet : Niernet

Nortier, J., Plennevaux, V., Nolf, A., Hougardy, J.-M., & Petit, A.-D. (2017). *Le trajet de soins de l'insuffisance rénale chronique : développement et perspectives / Clinical care pathway for chronic kidney disease: Development and perspectives*. Service de Néphrologie, Dialyse et Transplantation rénale, Hôpital Erasme, Université Libre de Bruxelles. *2017-RMB 4 - NORTIER_p.271-278.pdf

NVBN. (2025). *World Kidney Day 2025*. NBVN - World Kidney Day 2025

OECD, World Health Organization, European Observatory on Health Systems and Policies, European Commission, Health Systems and Policy Monitor, OECD Health Committee, & EU Expert Group on Health Systems Performance Assessment. (2025). State of Health in the EU | Profil de santé par pays 2025: Belgique: Profil de santé par pays 2025 [Report]. In *State of Health in the EU*. https://eurohealthobservatory.who.int/docs/librariesprovider3/country-health-profiles/chp2025pdf/2025_translations/soheu-2025-belgium-french-native-language-final-web.pdf?sfvrsn=9685d47_1

Rubin HR, Fink NE, Plantinga LC, Sadler JH, Powe NR: Patient ratings of dialysis care with peritoneal dialysis vs hemodialysis. JAMA 291: 697–704, 2004

StatBel (2024). *0.6% fewer deaths in 2023.* https://statbel.fgov.be/en/news/06-fewer-deaths-2023

Sciensano. (2025). *Résultats de l'Enquête de santé 2023–2024 – Santé et qualité de vie : Maladies et affections chroniques*. https://www.sciensano.be/fr/resultats-de-lenquete-de-sante-2023-2024/sante-et-qualite-de-vie#maladies-et-affections-chroniques

Vadia R, Vandendriessche E, Meeus G, Mahieu E, Jouret F, Van Pottelbergh G, Maris M, Retat L, Jadoul M, Vankeirsbilck A, Garcia Sanchez JJ (2023). *Inside CKD: predicting the Clinical and Economic Burden of Chronic Kidney Disease in Belgium.* posterepiburden130348-pdf.pdf

Van Westrum, E. S., Hoogeveen, E. K., Broekman, B. F. P., Siegert, C. E. H., Keurhorst, D., Annema, C., Hemmelder, M. H., Bos, W. J. W., Dekker, F. W., Meuleman, Y., Group, T. P. S., Van Westrum, E. S., Dekker, F., Hemmelder, M., Broekman, B., Siegert, C., Abrahams, A., Hoogeveen, E., Annema, C., . . . Meuleman, Y. (2025). Fatigue across different chronic kidney disease populations: experiences and needs of patients. *Clinical Kidney Journal*, *18*(5), sfaf118. https://doi.org/10.1093/ckj/sfaf118

WHO (2025). *Non communicable diseases*. Noncommunicable diseases

WHO (2018). *Noncommunicable diseases country profiles 2018. Belgium*. Noncommunicable diseases Belgium 2018 country profile

Wolf J.A. 2018. *PRENDRE SOIN D'AUTRUI EST HUMAIN : les facteurs qui influencent l'expérience de soins aujourd'hui.* From The Beryl Institute. *influence_paper_fr.pdf*

Zacharioudakis, I. M., Zervou, F. N., Ziakas, P. D., & Mylonakis, E. (2014). Meta-analysis of methicillin-resistant Staphylococcus aureus colonization and risk of infection in dialysis patients. Journal of the American Society of Nephrology : JASN, 25(9), 2131–2141. https://doi.org/10.1681/ASN.201309102

Zoccali, C., Mallamaci, F., Adamczak, M., De Oliveira, R. B., Massy, Z. A., Sarafidis, P., Agarwal, R., Mark, P. B., Kotanko, P., Ferro, C. J., Wanner, C., Burnier, M., Vanholder, R., & Wiecek, A. (2023). Cardiovascular complications in chronic kidney disease: a review from the European Renal and Cardiovascular Medicine Working Group of the European Renal Association. Cardiovascular Research, 119(11), 2017–2032. https://doi.org/10.1093/cvr/cvad083