



Takeda

Every transplant matters



Recommendations on improving post-transplant care **in Belgium**

This report was initiated, organised and funded by Takeda with insights from key experts with an interest in transplant.

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C-ANPROM/BE/CORP/0060 – October 2024



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Introduction

Every year, more than 70,000 people across Europe & Canada undergo life-changing transplantations in the hope of more years living in better health.^{1,2} The phase that follows these life-saving interventions, holds the key to unlocking the full potential of transplantation. Throughout this pivotal post-transplant care period, both transplant recipients and medical professionals face challenges that demand meticulous attention and dedication.

The field of transplantation encompasses two primary modalities: solid organ transplantation (SOT) and hematopoietic stem cell transplantation (HSCT).³ These life-transforming interventions, which hold profound life-saving potential, hinge upon the invaluable altruistic provision of either an organ or stem cells.

Optimal post-transplant care plays an essential role in enhancing the value of transplant interventions. To achieve long-term survival and a high quality of life for all transplant patients, it is paramount for stakeholders involved to foster clinical and multidisciplinary care, scientific research, an optimal organization of healthcare. Advancements in preventive and antiviral therapies, along with the implementation of international best practice guidelines, have significantly improved the management of post-transplant infections. Nevertheless, some patients still experience serious consequences from infections in their recovery journey, both physically and mentally, underscoring the need for continuous improvement in post-transplant care, with special focus on preventing post-transplant virus infections.⁴

Initiated by Takeda, a patient-focused global biopharmaceutical company committed to improving healthcare worldwide, this report builds upon the analysis of post-transplant recommendations conducted by an international expert working group at the European and Canadian levels. This collaborative effort resulted in the **'Every Transplant Matters' report**, which puts forth ten policy recommendations to guide decision makers in supporting post-transplant care.

With this present policy memorandum, Takeda Belgium leads the adaptation of these international recommendations to the concrete situation in Belgium. It aims to advise and inform policymakers and stakeholders on enhancing post-transplant care considering the specificities of local actors. This stems from a comprehensive landscape analysis and discussions with expert clinicians and patients in SOT and HSTC, focusing the discussion on post-transplant care services, instead of a broader discussions surrounding medication accessibility.



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Every Transplant Matters

A briefing and recommendations
for decision makers on
improving post-transplant care

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If you would like more information about this initiative or Takeda's work in post-transplant care **Please email us on: be-info@takeda.com**



Methodology and Recognition of Expert Contributions

This policy memorandum was developed based on 1) extensive desk research through, among others, a review of relevant published literature, and 2) input from experts in the fields of SOT, HSCT, and transplant patient advocacy – gained during two roundtable discussions and reviews of content.

The first roundtable discussion on post-transplant care in HSCT took place on 16 January 2024. It consisted of the following participants: Prof. Dr. Frédéric Baron (CHU Liège), Prof. Dr. Tessa Kerre (UZ Gent), Prof. Dr. Dimitri Breems (ZNA), Prof. Dr. Xavier Poiré (CU Saint-Luc), and patients Mr. Joël V. and Ms. Aude V. (Transplantoux). The second roundtable was held on 23 January 2024 and focused on post-transplant care in SOT. The following experts participated: Prof. Dr. Christiane Knoop (HUB Erasme), Prof. Dr. Patrick Evrard (CHU UCL Namur), Prof. Dr. Karl Martin Wissing (UZ Brussel), Prof. Dr. Dirk Kuypers (UZ Leuven), along with patients Mr. Raf D. (Transplantoux) and Ms. Patricia C. (AIRG Belgique). We extend our grateful thanks to the experts who contributed their unique insights to this report.

Overview policy recommendations



1. Fostering research, innovation and data sharing

- 1 Strengthen accurate transplant data collection for Eurotransplant in the case of SOT and for EBMT in the case of HSCT by enhancing hospital support with dedicated funding and trained personnel.



2. Enhancing post-transplant care delivery

- 2 Develop clear conventions for multidisciplinary care in all transplant fields for patients to receive high-standard qualitative care.
- 3 Invest in the psychological follow-up of patients throughout their transplant journey.
- 4 Recognize training and development of specialized transplant coordinator nurses to support the patients during their transplant journey through a unique professional designation.
- 5 Increase awareness of post-transplant infections among HCPs in emergency care.

For SOT, in particular:

- 6 Establish a universally recognized “transplantation card” for individuals who have undergone SOT, enabling emergency responders to promptly identify the transplant history of a patient and remain attentive to post-transplant risks.

For HSCT, in particular:

- 7 Implement an exception for ambulances to transfer HSCT patients to the transplant hospital instead of the closest hospital for the first 6 months after the transplant.



3. Elevating patient engagement and empowerment

- 8 Develop a clear and concise post-transplant care path for various transplants in both SOT and HSCT, outlining scheduled appointments with the multidisciplinary team to guide patients in their recovery.
- 9 Establish an accessible online platform offering comprehensive and user-friendly information on post-transplant care.
- 10 Identify and support ‘patient-partners’ to facilitate multidisciplinary support to vulnerable patients who are less reachable due to their socio-economic and/or mental-cognitive background.
- 11 Develop comprehensive tools to identify and address medication non-adherence among post-transplant patients, encompassing individualized barriers and targeted interventions.

Transplants: a life-saving opportunity

1. What is a transplant?

For many patients with a condition, a transplant is a life-saving intervention that allows the person to live a healthier and longer life. There are two main types of transplants:



The first type of transplant is the **solid organ transplant (SOT)** primarily considered as a final alternative for patients with a malfunctioning organ. Patients suffering from end-stage organ failure require a SOT, which involves the replacement of their failing organ with a donated one from a deceased or living donor. The most performed SOTs from deceased donors are kidney transplants, followed by liver and heart transplants. Other organs such as lungs and pancreas can also be transplanted. However, due to a shortage of available donated organs and the challenge of finding suitable matches for every patient, the demand for organs exceeds the supply. For patients on a waiting list, receiving an organ transplant represents their final hope for a healthier life.⁵



Secondly, **hematopoietic stem cell transplantation (HSCT)**, also known as bone marrow transplant, is a procedure where stem cells are given to patients who have impaired or insufficient bone marrow function. This procedure can be categorized into two types, namely autologous and allogeneic HSCT. **Autologous HSCT**, is intended to allow for the administration of very high dose of chemotherapy. To protect the bone marrow, it is harvested from the patient prior to chemotherapy and then reintroduced afterward. For **allogeneic HSCT**, the transplanted bone marrow comes from a donor. HSCT is most often performed with patients with certain cancer types, such as leukemia. Infections are a major complication of HSCT, and the procedure is only reserved for patients with a life-threatening disease.⁶ The discussion on HSCT will be limited to allogeneic HSCT in this report.

A potential risk following a SOT is organ rejection, which makes the use of immunosuppressant medications pivotal in post-transplant care as they aim to prevent transplant rejection. However, taking immunosuppressants weakens the immune system leading to a risk of developing common infections, like Cytomegalovirus (CMV), which may not cause any symptoms for healthy adults, can (re)activate, and may become a serious problem for some transplant patients. The challenge lies in finding the optimal dosage of immunosuppressants that maintains the

stability of the transplanted organ while minimizing the negative impact on the patient's immune system.⁷

For patients undergoing HSCT, the concern of getting an infection becomes significant due to their compromised immune system. Managing and mitigating this risk of infections is of significant concern for these patients.⁸



2. Transplants in Belgium

2.1 Solid organ transplantation

Following the EU Directive 2010/53, the European Union (EU) aims to guarantee the quality and safety of human organs intended for transplantation.⁹ In Belgium, Eurotransplant is entrusted by the Belgian authorities with the task of allocating organs from deceased donors, while coordinating the organ donations from living donors lies with the 9 SOT transplant centers officially designated by the Belgian government.¹⁰ Additionally, Eurotransplant maintains a comprehensive record of all living donor transplants conducted within its member states.¹¹

Data of Eurotransplant shows that (see figure 1 in annex), in 2023, in the countries where Eurotransplant is active, 10,099 patients were added to the active waiting list for an organ totaling the number of total patients on the waiting list to 13,498.¹² **In Belgium, 1,453 patients** were on the active waiting list for a donor organ and transplantation as of 1 January 2024, of which the large majority of 1.186 patients are waiting for a kidney transplant. The number of patients on the active waiting list in Belgium has shown a fluctuating trend starting at 1,248 patients in 2013. Notably, there was an uptick in 2021, with a significant rise from 1,350 to 1,514 patients on the waiting list.¹¹

1,453
patients

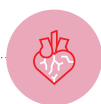
**on active waiting list for a donor organ
and transplantation**
(as of 1 January 2024¹¹)

1,060
transplants
conducted

**using organs from deceased donors
in the Belgian transplant centers**
(in 2023¹⁴)



453 KIDNEYS



49 HEARTS



228 LUNGS



310 LIVERS

The figure (see figure 2 in annex) illustrates the total number of SOTs performed in Belgium from 2014 up until the latest available data in 2023. In 2023, 1,060 transplants were conducted using organs from deceased donors in the Belgian transplant centers with 453 kidney transplants, 49 heart transplants, 228 lung transplants and 310 liver transplants.¹⁴ Notably, the figures demonstrate the discernible impact of the COVID-19 epidemic on the health-care sector, with a slowdown in recent years and a gradual recovery in 2022 for SOT from a deceased donor. The effects of the COVID-19 crisis for SOT with a living donor were only predominantly evident in 2020.

The Belgian Transplant Society (BTS) acts as an intermediary between healthcare professionals (HCP), patients, and competent authorities in Belgium, fostering collaboration among all stakeholders in the field of SOT. Currently, the BTS is in the process of setting up the transplantation library, a valuable resource for educational content.¹⁶

Three main international organizations develop detailed guidelines namely the ISODP (International Society of Donation and Transplantation), the ESOT (European Society for Organ Transplantation), and the American Society of Transplantation. These medical guidelines are valuable on a high level. At the national level, compliance with those international/European guidelines is jeopardised/complicated by external factors such as the reimbursement of medicines. Every SOT center develops an internal procedure that takes the different guidelines into account. These procedures are adapted frequently as new studies and guidelines are published.

“A transplant is not coming back to your previous life, it is entering a new life.” Patricia C. - SOT patient

2.2 Hematopoietic stem cell transplantation

Hematopoietic stem cells used for transplantation can be derived from various sources, including the bone marrow, peripheral blood or umbilical cord.¹⁷ The Marrow Donor Program Belgium (MDPB) is part of the Belgian Red Cross and is responsible for maintaining a donor registry of potential marrow donors in Belgium as defined by the Royal Decree of 7 November 2011, under the supervision of the Federal Agency for Medicines and Health Products (FAGG). As part of the umbrella organization World Marrow Donor Association (WMDA), the Belgian Bone Marrow Registry collaborates with other national stem cell registries, as well as individual cord blood banks, adhering to international standard for HSCT donor registries.¹⁸

The accreditation of the Joint Accreditation Committee-ISCT & EBMT (JACIE) recognizes the transplantation center in relation to rigorous quality measures and thorough inspection. Within Europe, these accredited JACIE centers have achieved a level of ‘excellence’. This leads in Belgium to **the recognition of 17 HSCT centers**, all of which offer autologous HSCT, and 11 centers which additionally offer allogeneic HSCT.¹⁹ Remarkably, Belgium, alongside Switzerland and the Netherlands, ranks among the top countries in the highest percentage of accredited centers performing both autologous and allogeneic HSCT relative to the total number of centers per country. In total, there are 22 HSCT centers recognized by the EBMT (European Society for Blood and Marrow Transplantation).²⁰

According the most recent data from the EBMT, the 11 allogeneic HSCT centers in Belgium performed altogether a total of 422 transplantations in 2018. Additionally, there were 524 autologous HSCT transplantations performed. This contributed to a total of 946 HSCT transplants in 2018 in Belgium. **Calculations of Eurostat show that there were consequently 8.4 HSCTs per 100.000 inhabitants in Belgium, reflecting the prevalence of these procedures within the population.**²¹

8.4 / 100.000

HSCT's / inhabitants in Belgium²¹

In the field of HSCT, **the Belgian Hematology Society (BHS)** plays a major role. The scientific society shares information about stem cell transplantation, particularly complications associated with it, such as infections and rejection. The platform also shares HSCT guidelines and information on clinical trials carried out by the BHS and other scientific players in Belgium. In collaboration with the Belgian Cancer Registry, the BHS has set up the Belgian Transplant Register (BTR) in 2012, which consolidates all vital data concerning HSCT activities conducted in Belgium. The information contained within the registry facilitates the execution of retrospective clinical studies and prospective clinical trials on patients, as well as foster international collaboration, primarily with the EBMT.^{22,23} EBMT sets out guidelines, however as not all medicines are (fully) reimbursed in Belgium, it is often difficult to follow these guidelines. This is why the BHS formulates alternatives.

2.3 Patient organizations

In addition to hospitals, not for profit patient organizations, such as Transplantoux, vzw Nierpatiënten, Hepatotransplant, Oxygène Mont-Godinne asbl,... enrich the landscape by representing the voice of transplant patients and providing additional support to patients. The landscape of patient organizations in the transplant field is scattered due to the wide range of transplant types and the presence of underlying conditions leading to the transplantation such as leukemia, kidney failure or cystic fibrosis.

Many patient organizations originate from transplant centers or focus on a specific organ. For example, Hépatotransplant asbl for liver transplants with the Saint-Luc University Hospital in Brussels²⁴, Dialaug vzw for kidney transplants with the University Hospital of Antwerp (UZA)²⁵ and Lotuz for allogeneic HSCT patients in Flanders.²⁶



Post-transplant infections

In the year 2018, a total of 2,123 patients underwent either a SOT or HSCT in Belgium.^{27,28} Nevertheless, the journey does not stop there. Of the patients that receive a transplant, many afterwards face infections jeopardizing a successful transplant. While transplants are well-advanced and well-performed in Belgium, there is still an unmet need in current policy to focus on the importance of post-transplant care. This unmet need was recently recognized by federal Minister for Social Affairs and Public Health Frank Vandenbroucke (Vooruit) in his 2023 policy note as he stated **the need for a care path for the patient** for the pre- and post-abdominal organ transplantation including pre-transplantation medical preparation, and post-transplantation focus on maximizing physical and mental well-being to enhance overall quality of life and reduce mortality and morbidity.²⁹



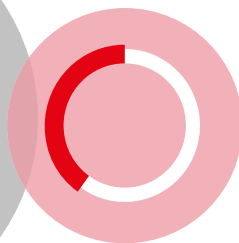
After transplantation, each patient faces different risks and complications. As every transplant is different, so is every follow-up care path. For patients who receive a SOT transplant, the lifelong intake of immunosuppressant medicines is the patient's best chance to prevent their organ from being rejected. At the same time, it also reduces the resistance to infections.

Among those viral infections, the cytomegalovirus (CMV), is one of the most frequent infections³⁰ as between **60-100% of adults will contract CMV at some point in their lives.**³¹ Many people will not even realize they have it, while others may have cold-like symptoms such as sore throat, swollen lymph nodes, fatigue or fever. Once you have the virus it stays in your body for life.

In most cases of post-transplant CMV infection, the dormant virus reactivates in the patient's system while their immune system is suppressed by their post-transplant medications. It is also possible for CMV to be transferred from a positive donor to a negative patient through the donated organ or stem cells; careful pre-testing occurs to prevent this from happening wherever possible. Certain types of transplants carry a higher risk of CMV.³²

60-100%

Between 60-100% of adults will contract CMV at some point in their lives.¹⁷



30-70%

30-70% of stem cell transplant patients will experience an active CMV infection.^{18,19}





Transplant patients with CMV are 2-9 times more likely to have poor transplant function than those without CMV.^{33,34}

Although CMV may not cause any problems for healthy adults, it can still have serious consequences. Transplant patients with CMV are 2-9 times more likely to have poor transplant function than those without CMV. This not only adversely affects patients' physical and emotional well-being but also has a considerable impact on their overall quality of life.^{33,34}

Transplantation teams diligently strive to proactively manage and prevent CMV and other viral infections. Nevertheless, a notable percentage of patients, ranging **between 16% and 56% of SOT patients, experience CMV infection.**^{35,36} This occurrence often gives rise to substantial complications, including but not limited to organ rejection, disease relapse, and, in severe cases, fatality.^{37,38}

Between 30% to 70% of patients who have received a stem cell transplant will experience an active CMV infection.^{39,40} Patients who undergo an allogeneic transplant will need to take immunosuppressants to prevent graft-versus-host disease (GvHD), a condition where the transplanted donor cells perceive the patient's body as foreign and launch an attack against it. However, these immunosuppressants also weaken the immune system leading to an increased risk of infection. Studies on risk factors for CMV have shown that the treatment of GvHD through immunosuppressants can trigger CMV replication.⁴¹ Additionally, there is evidence indicating that patients undergoing CMV replication face a notably higher risk of developing acute GvHD.⁴²



Patient testimonial from an HSCT patient - Aude V.

“At the age of fifteen, I had an HSCT and received care at a pediatric hospital. The pre-transplant care involved a team of specialists - surgeons, psychologists, and dieticians - who provided holistic support. The period of isolation after the transplant was very challenging due to minimal social interaction. To cope with the fact of having to stay isolated, I invested in a new electric violin that could be sterilized, allowing me to play music during this time.

Moving from pediatric to adult hospital care was a big step in my post-transplant journey, requiring me to take a more active role in managing my health more independently. Adjusting to a new medical team, direct communication aimed at me rather than my parents and the need to gather information independently became immediate priorities. Regular medical check-ups and necessary administrative tasks became part of my routine.

Going through the adjustment phase made me realize that getting a transplant is not just about the transplant itself. It's about embracing a whole new way of living, with the constant support of a caring team who always had my back.”



Patient testimonial from a SOT patient - Patricia C.

"My solid organ transplantation journey has been life-altering, impacting me physically, emotionally, and psychologically. From the start, a multidisciplinary team guided me through a comprehensive care plan, crafting a tailored pathway that spanned years before and after the transplant itself. The pre-transplant care extended over three years, a much too long period that I nevertheless used to stay in relatively good shape & prepare myself for the transplantation.

After the first months of transplantation, the responsibility to coordinate the care journey falls on the patient's shoulders, depending on the symptoms/side effects that he encounters. This transition can be challenging, requiring the patient to manage all aspects of their recovery. Many patients encounter difficulties in organizing their appointments and medication regimens. Moreover, the responsibility of maintaining comprehensive records of their health information and medical history rests with the patient when visiting other specialists than the one following the transplant. The significance of this journey extends beyond the medical procedures to embody a complete lifestyle change. Providing patients with tools to aid in managing these responsibilities would be a great support in their new way of living.

My experience underscores the critical role of integrated, patient-centered care in the field of transplantation, highlighting the shift towards a more informed, empowered, and supported patient experience. Taking care of the level of education, comprehension & autonomy of the patients is also a must as not all are equal on these."



The policy landscape for transplant and post-transplant care

The three main pillars, listed below, should be considered when formulating policy recommendations. These are interconnected and therefore need to be read in combination, as improvements in one lead to progress in the others. Indeed, a holistic approach should be favored, whether when considering the transplant pathway in the field or the policy considerations attached to it.

1

Fostering research,
innovation and
data-sharing

2

Enhancing
post-transplant
care delivery

3

Elevating patient
engagement and
empowerment

The following policy recommendations stem from an analysis of the current situation in Belgium, as well as potential improvements discussed with healthcare professionals (HCPs) in the field. They are aligned with the overarching recommendations outlined in the international 'Every Transplant Matters' report and, where needed, tailored to the Belgian context.





1. *Fostering research, innovation and data sharing*

A supportive policy environment is crucial, as it fosters research, development and the effective implementation of emerging technologies into clinical care. All this starts with the accurate and qualitative collection of data. Transplant registries and scientific societies at regional and national levels are committed to improving patient outcomes in transplantation, through research, education, and partnerships. Experts argue against the need for another registry at the Belgian level solely for post-transplant care data collection, as European entities like Eurotransplant and the EBMT already gather data from SOT and HSCT, respectively. Instead, the focus should be on optimizing data collection, ensuring consistency, and maintaining high standards across these existing data repositories.

Policy recommendations

1. Strengthen accurate transplant data collection for Eurotransplant in the case of SOT and for EBMT in the case of HSCT by enhancing hospital support with dedicated funding and trained personnel.

1. **Strengthen accurate transplant data collection for Eurotransplant in the case of SOT and for EBMT in the case of HSCT by enhancing hospital support with dedicated funding and trained personnel.**

For HSCT, it is important to share enough data with EBMT in time for the transplant center to be part of the benchmark. This benchmark is necessary to position the center with other centers and learn from it. It is challenging for transplant centers to submit all the data in time in the transplant registries. For Eurotransplant, the field notes that even simple data is missing.





2. Enhancing post-transplant care delivery

The cost of transplantation, whether HSCT or SOT, carries a significant burden on the healthcare system. In 2020, the estimated cost for a single transplant ranged **between €30.000 - €100.000** accounting for factors such as the transplant type and the costs for medicines, personnel, and procedures, among others.^{46,47,48} These estimates exclude any additional costs, such as costs of psychological support as these are very personally variable. The significant benefits derived from a well-structured post-transplant care plan become even more apparent when considering the substantial financial commitment made by the healthcare system for each transplant.

Infections acquired during the post-transplant care phase pose **a dual risk**: they threaten the success of the transplant and the significant healthcare investment, while also adding to the burden on public expenditure, including lost patient income due to their inability to work and additional treatments required to prevent a transplant failure. Emphasizing infection prevention and enhancing post-transplant care is crucial, not only for the well-being of patients, but also as a safeguard for the substantial investment made in the patient's renewed life. It is **crucial to take every possible measure to prevent any infections or complications** that could jeopardize the success of the transplant. The initial investments related to transplantation cannot reach their full potential if post-transplant care is inadequately managed, considering the complications, infections and side effects that can arise.

Policy recommendations

2. Develop clear conventions for multidisciplinary care in all transplant fields for patients to receive high-standard qualitative care.
3. Invest in the psychological follow-up of patients throughout their transplant journey.
4. Recognize training and development of specialized transplant coordinator nurses to support the patients during their transplant journey through a unique professional designation.
5. Increase awareness of post-transplant infections among HCPs in emergency care.

For SOT, in particular:

6. Establish a universally recognized "transplantation card" for individuals who have undergone SOT, enabling emergency responders to promptly identify the transplant history of a patient and remain attentive to post-transplant risks.

For HSCT, in particular:

7. Implement an exception for ambulances to transfer HSCT patients to the transplant hospital instead of the closest hospital for the first 6 months after the transplant.

2. Develop clear conventions for multidisciplinary care in all transplant fields for patients to receive high-standard qualitative care.

In lung transplants, for example, not all multidisciplinary care is reimbursed for patients. Some hospitals choose to provide support services with their own financial means. However, this puts the hospitals under financial pressure.

In January 2024, a convention specifically for abdominal organ transplantation has been put in place that aims to reimburse a multidisciplinary approach. This is the first step of the government in recognizing the importance of a pre- and post-transplant multidisciplinary approach to support patients with liver, kidney, and liver-pancreas transplants. The exercise to translate this convention from guidelines and the contract to reality within the hospital is currently being made.⁶⁰

For example, in the field of cystic fibrosis, a convention with RIZIV/INAMI facilitates reimbursement for patients in all multidisciplinary facets.⁶¹ Cystic fibrosis serves as an example of a condition where multidisciplinary care is comprehensively reimbursed. This is not the case in lung transplantations for example. For patients in all types of transplants to have equal access to qualitative care, the development of clear conventions is an absolute must. The participants to the roundtables identified additional needs for a more optimal transplant care.

3. Invest in the psychological follow-up of patients throughout their transplant journey.

Ensuring robust proactive psychological support for transplant patients is paramount for their overall well-being and recovery. Transplantation can have a profound psychological impact, evoking a range of psychological reactions from the moment it is announced. These psychological challenges persist long after the transplant is completed, potentially lasting several years or even the remainder of the patient's life. For instance, in the case of HSCT, the patient must remain isolated in a sterile room for up to 6 weeks after the transplant, unless complications extend the period of isolation.^{49,50} This period of isolation is accompanied by extensive drug treatment, which can cause undesirable effects such as behavioral disorders, mood swings, depression, and even psychotic reactions. Professionals in the field emphasize the importance of the role played by the patient's family and partner in supporting them in their new lifestyle.

Establishing a standardized support structure is challenging, due to varied reactions experienced by patients and the significant mental impact of the procedure. Furthermore, it is not uncommon for certain patients to decline seeing a psychologist, as it could potentially reveal anxiety or be perceived as unnecessary.⁵¹ Nevertheless, it should be noted that such consultations are often crucial for providing a new perspective on certain issues that the patient experiences.⁵² This approach not only contributes to improved mental health outcomes but also positively influences physical health. Patients equipped with diverse coping mechanisms are likely to adhere more closely to their treatment plans, reducing the risk of complications and enhancing overall recovery.

Despite its importance, **psychological support for transplant patients is not standardized and not always reimbursed in Belgium.** Due to this constraint, many hospitals choose to offer this support with their own means according to the experts in the field. However, due to an overload both financially and in terms of workload, psychologists are not able to proactively engage with all patients. In many cases, patients need to request psychological care themselves which is a potential barrier for seeking support. Standardizing reimbursed psychological support services can ensure that transplant patients not only navigate the medical aspects of their journey but also their recovery and post-transplant life.

4. Recognize training and development of specialized transplant coordinator nurses to support the patients during their transplant journey through a unique professional designation.

The complexity of transplant procedures necessitates the involvement of a diverse and multidisciplinary team. This approach has already been implemented in several transplant centers. The implementation of multidisciplinary care has demonstrated improved patient outcomes and reduced morbidity and mortality rates in both SOT and HSCT transplants.^{53,54,55,56}

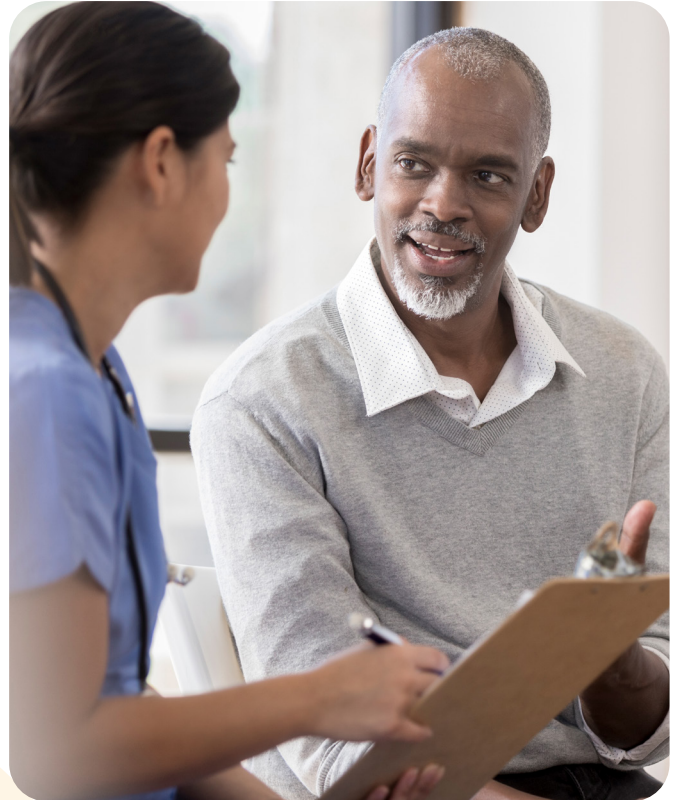
According to experts participating in the roundtables, investing in **specialized transplant coordinator nurses** is crucial in delivering qualitative post-transplant care to patients. Patients receive a lot of valuable information through the experience of the nursing staff. The nurse plays a crucial role in supporting patients as they navigate the numerous challenges following transplantation, which encompass complications as well as the enduring physical and psychosocial effects.⁵⁷ Specialized nurses in transplant care who are well-trained and have sufficient resources are essential in guaranteeing appropriate and in-depth support to transplant patients, both in HSCT and SOT. Studies show, although not specifically linked to post-transplant care, that investing in nursing staff has a strong correlation between improved patient care outcomes with lower rates of hospital-acquired infections, medication errors, and mortality rates.⁵⁸

With this, the possibility of establishing a unique professional designation for transplant coordinator nurses (similar to nurses in oncology) should be explored with recognized training.

5. Increase awareness of post-transplant infections among HCPs in emergency care.

SOT and HSCT patients face a lifelong risk of infections due to long-term immunosuppressant medications. Unlike healthy individuals, their bodies may not exhibit classic signs of infection like fever and inflammation. This makes timely diagnosis challenging, especially in emergency care settings where quick decisions are crucial. Insufficient awareness among emergency healthcare professionals (HCPs) can lead to delays in diagnosing and treating infections in transplant patients. These delays can significantly impact patient outcomes. By enhancing awareness of post-transplant infections among HCPs in emergency care, early recognition of infection can be ensured since educated HCPs can identify subtle signs that might be overlooked otherwise. This early recognition enables timely interventions, leading to faster diagnosis and prompt treatment, thereby enhancing the likelihood of a successful recovery and improving patient outcomes by minimizing complications and potentially life-threatening situations for transplant patients.⁵⁹





For SOT, in particular:

- 6. Establish a universally recognized “transplant card” for individuals who have undergone SOT, enabling emergency responders to promptly identify the transplant history of a patient and remain attentive to post-transplant risks.**

As emergency departments are not always instantly aware of a patient’s transplant history and the associated risks, the transplant card presents a solution for rapid recognition, especially if a patient does not live close to a transplant hospital. This is already the case in the UK for patients who have undergone a kidney transplant. This facilitates timely access to personal information such as organ type, transplant date, and contact details of the transplant team. Moreover, the card serves as a medical alert, indicating the patient’s possible immunosuppressed status and post-transplant risks, ensuring heightened vigilance and appropriate precautions. It fosters improved management of post-transplant care during emergencies as well as raises awareness within emergency care. Ideally, this card should be connected to the patient’s health records and accessible to all healthcare professionals who need to view the patient’s information.

For HSCT, in particular:

- 7. Implement an exception for ambulances to transfer HSCT patients to the transplant hospital instead of the closest hospital for the first 6 months after the transplant.**

In Belgium, currently the law prescribes that in case of an emergency, ambulances need to take the patient to the closest hospital, irrespective of the patient’s previous medical records/ treatments. However, for the first months after a transplant. For the first months after the transplant, a patient must be closely monitored by the transplant specialist. Transferring patients directly to a transplant center in case of emergency can gain crucial time as experts can directly take the condition of the patient and the associated post-transplant risks into account. After six months, the criticality of the immune system lowers.



3. Elevating patient engagement and empowerment

Empowering patients to actively participate as equal partners in their post-transplant care journey is paramount. Decision makers play a pivotal role in shaping health systems that prioritize patient engagement and foster a patient-centric approach. By encouraging and supporting patients and their caregivers, decision makers contribute to an environment where informed decisions about the transplant journey can be made collaboratively, ultimately leading to improved outcomes and a more responsive healthcare system.

Policy recommendations

8. Develop a clear and concise post-transplant care path for various transplants in both SOT and HSCT, outlining scheduled appointments with the multidisciplinary team to guide patients in their recovery.
9. Establish an accessible online platform offering comprehensive and user-friendly information on post-transplant care.
10. Identify and support 'patient-partners' to facilitate multidisciplinary support to vulnerable patients who are less reachable due to socio-economic or other barriers.
11. Develop comprehensive tools to identify and address medication non-adherence among post-transplant patients, encompassing individualized barriers and targeted interventions.

8. **Develop a clear and concise post-transplant care path for various transplants in both SOT and HSCT, outlining scheduled appointments with the multidisciplinary team to guide patients in their recovery.**

After hospitalization, the patient must become the coordinator of his/her own care path. For many patients, it is not easy to keep track of every appointment or all information that they need to take into consideration. By structuring the post-transplant care path, accompanied by a dedicated HCP, the aim is to empower patients by providing a **roadmap for their recovery journey** including scheduled appointments, medication schedules and an online information platform.

9. **Establish an accessible online platform offering comprehensive and user-friendly information on post-transplant care.**

This online information platform can offer a range of resources, including **educational materials, support groups, and tools to monitor and track post-transplant progress**. Combining these elements, a sense of control and confidence is fostered in the patients during the post-transplant period. This online platform is not solely aimed at the patient but also informs the families about the possible post-transplant risks.

This platform could be best facilitated by a collaborative effort involving healthcare authorities, transplant centers, patient organizations, and digital health experts to ensure that it is tailored to meet the needs of both patients and healthcare providers. The online platform of the SFGM-TC (French-speaking Society for Marrow Transplant and Cellular Therapy) in France can provide inspiration here. The Society unites over 500

organizations active in HSCT and developed online accessible material (booklets, videos...) that help patients and their families to understand the transplant and risks.⁴³

Additionally, developing an information platform needs to ensure that it is designed with accessibility and inclusivity in mind. This involves making the information available in multiple languages, considering various literacy levels, and incorporating features that accommodate individuals with different abilities.

10. Identify and support 'patient-partners' to facilitate multidisciplinary support to vulnerable patients who are less reachable due to their socio-economic or other barriers.

A large proportion of patients, especially in larger cities such as Brussels, have culturally diverse backgrounds and may face language barriers. Many patients, particularly in Brussels, encounter difficulties accessing and understanding complex health information due to cultural and linguistic differences.

By leveraging 'patient-partners' – individuals who accompany and support fellow patients on their journey towards self-care – we can bridge gaps and enhance health literacy. **Encouraging peer interactions** among patients from similar linguistic and cultural backgrounds is proven to be beneficial according to the experts in the field. This approach facilitates mutual support among community members, offering a valuable complement to traditional health-professional interactions.

11. Develop comprehensive tools to identify and address medication non-adherence among post-transplant patients, encompassing individualized barriers and targeted interventions.

Non-adherence poses a significant risk to patient health and can lead to complications in post-transplant care for both SOT and HSCT.^{44,45} By developing effective tools (e.g. through a checklist for patients, personalized reminders, survey, etc.), HCPs can promptly identify non-adherence and implement targeted interventions. **Understanding individual barriers to adherence** is crucial, as it enables tailored support strategies, ultimately improving medication adherence rates among transplant patients and ensuring better long-term outcomes for transplant patients.



Annex: Figures

Figure 1: Active waiting list in Belgium, by year, by organ¹³

Belgium	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Kidney	878	871	797	849	824	914	952	1108	1189	1186
Heart	89	11	117	103	111	91	110	111	83	75
Lung	82	104	122	143	143	163	106	106	111	77
Liver	187	188	174	201	189	172	181	193	130	128
Pancreas	70	68	65	61	57	51	48	45	34	31
Total patients	1248	1288	1217	1292	1269	1341	1350	1514	1504	1453

Figure 2: SOT in Belgium, by year, by donor type, by organ¹⁵
ORGANS TRANSPLANTED IN BELGIUM, BY YEAR, BY DONOR TYPE, BY ORGAN

Deceased donor	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Kidney	416	475	453	485	474	389	326	359	427	453
Heart	82	82	70	79	76	84	54	52	63	49
Lung	203	224	255	239	228	222	182	184	186	228
Liver	221	247	255	260	266	250	210	234	267	310
Split liver	10	4	1	9	9	12	4	13	2	4
Pancreas	11	9	11	14	16	11	9	8	15	9
Pancreatic islets	24	57	32	17	18	16	9	7	10	7
Total	967	1098	1077	1103	1087	984	794	857	970	1060
Living donor	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Kidney	67	57	67	63	57	45	37	59	55	80
Liver	2	1	3	3	-	-	-	-	-	1
Split liver	38	32	43	33	33	27	21	21	28	26
Total	107	90	113	99	90	72	58	80	83	107
Total all donors	1074	1188	1190	1202	1177	1056	852	937	1053	1167

Statistics.eurotransplant.org : 2082P_Belgium : 07.02.2024 : counting each individual organ (lung/kidney/split liver)

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Recommendations for decision makers

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C-ANPROM/BE/CORP/0060 – October 2024