



Come Together

Organ donation after medical assistance in dying: how to honour patient's wishes

Martine Bouchard, Executive Director of Transplant Québec

Marie-Josée Lavigne, executive director advisor and Head of the Hospital Teaching and Development
Department of Transplant Québec





TRANSPLANT
QUÉBEC

*Ensemble pour
le don d'organes,
pour la vie
depuis 50 ans*

Organ donation after medical assistance in dying: how to honour patient's wishes

Canadian College of Health Leaders | June 2024

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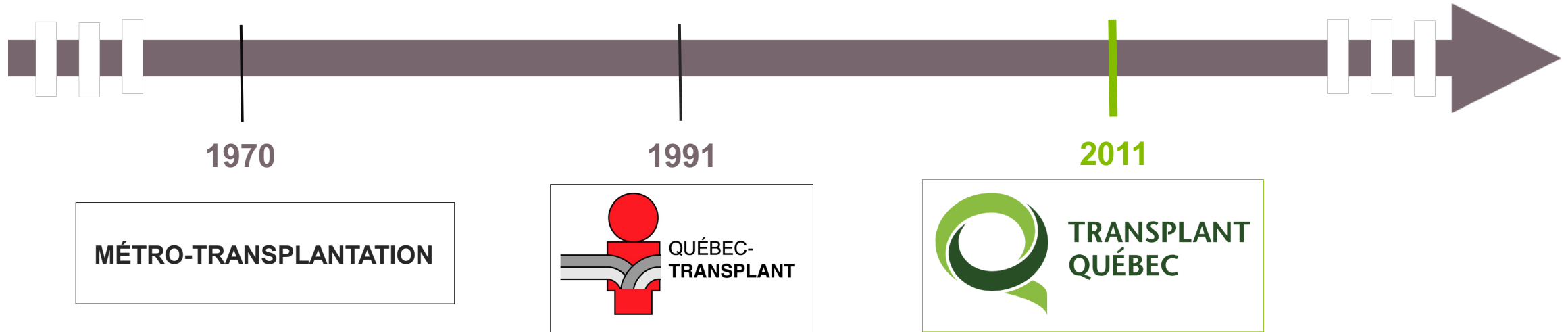
Objectives

- Explain the importance of participative leadership in the development and innovation of organ donation in Québec.
- Understand the importance of all key actors working together to implement new practices.

Summary

- Transplant Québec: History and mission
- Organ donation in Québec
- Strategic plan by Transplant Québec
- The notion of the patient-partner
- Passage through a parliamentary committee
- Giving consent to organ donation in Québec
- Perceptions and knowledge of organ donation in June 2023
- Magnet hospital and transformational leadership
- MAID law in Québec
- MAID: What do we know? What was the potential? Key points and potential issues
- Recommendations from the ethics committee
- MAID-related organ donation in Québec and what it entails
- The different actors
- Support for families and patients in a MAID context
- First five years of MAID in Québec
- Next steps and future development

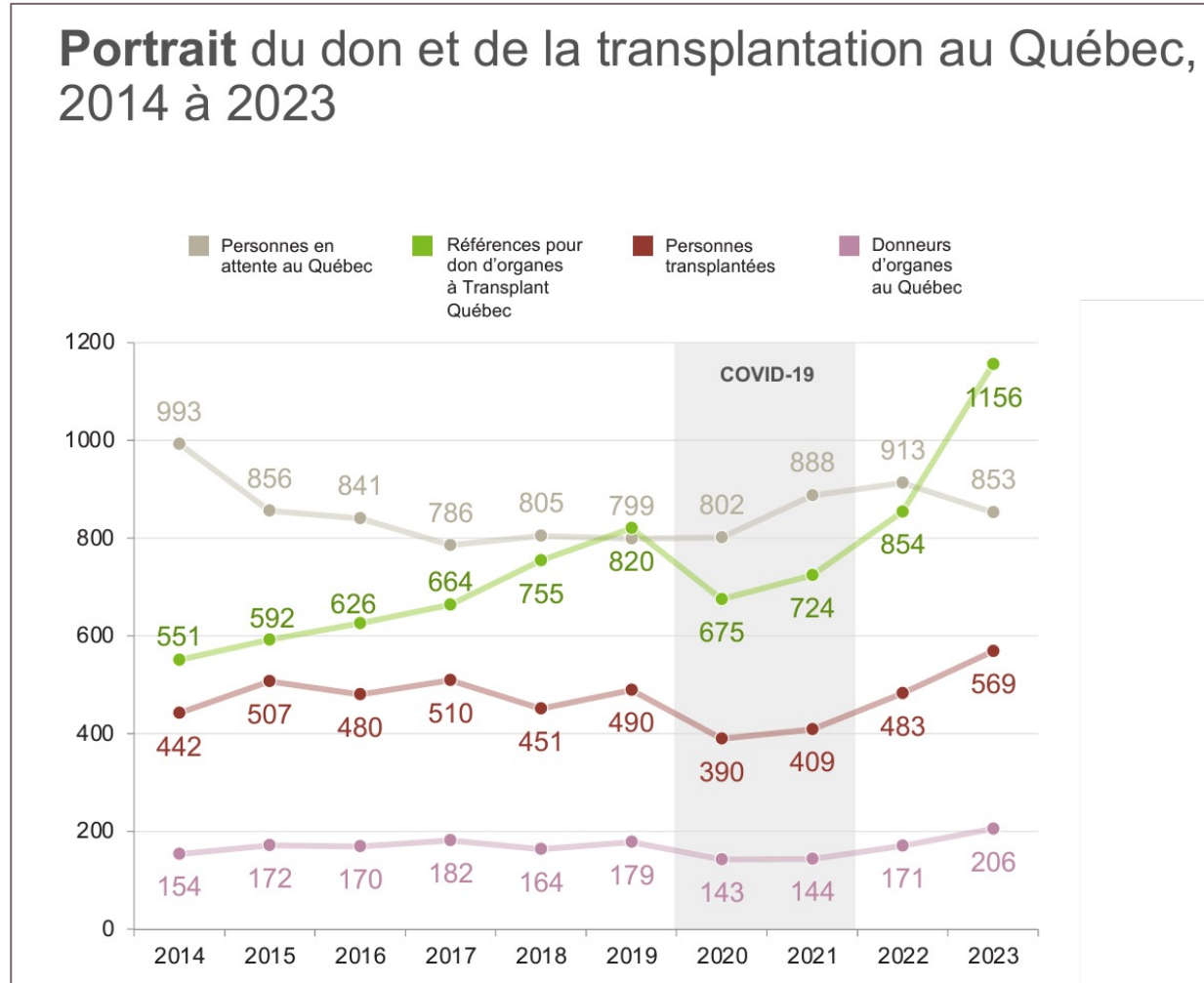
Transplant Québec



Our mission

Transplant Québec helps **save lives** through the **efficient and equitable coordination of the organ donation process** and the **promotion of a donation culture** in **society** and across the **health care network**, while **contributing** to **research** and **training**.

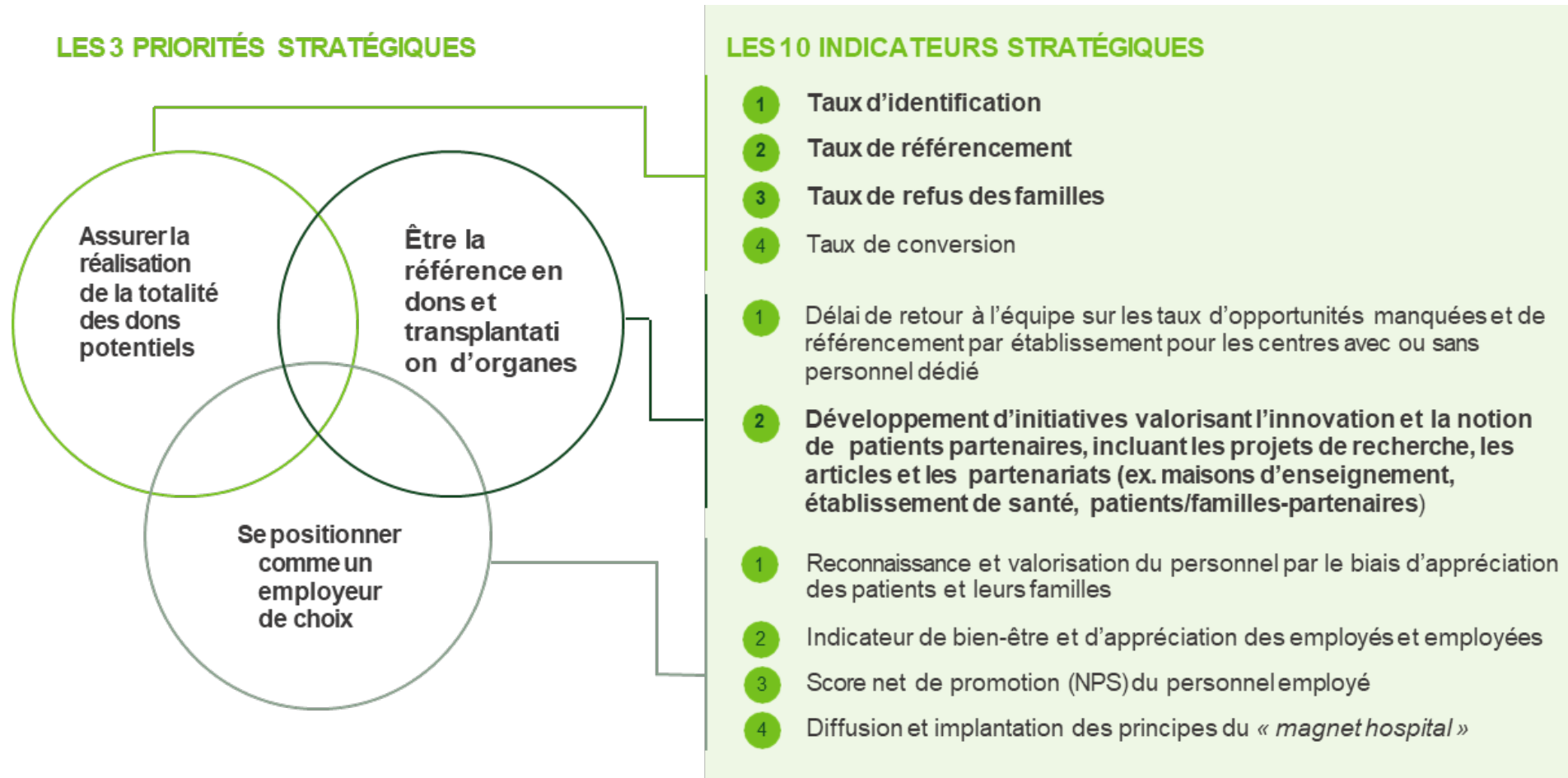
Organ donation in Québec in 2023:



Transplant Québec: Strategic Plan 2024 - 2027

3 strategic priorities

10 strategic indicators



Transplant Québec: Strategic Plan 2024 - 2027

4 axes tactiques 17 initiatives tactiques

TACTICAL AREAS

OBJECTIVES

TACTICAL INITIATIVES

1 Promote a culture of donation among health professionals

Ensure that the culture of donation is shared by all health professionals and results in the systematic adoption of organ donation standards and protocols by all Québec establishments.

1. Standardize the normative framework for organ donation across all establishments in the health network by appealing to management teams in health establishments
2. Pursue and increase training and teaching activities for professionals
3. Consolidate the performance evaluation structure for establishments

2 Engage the public with regard to donation and transplantation

Educate the public so that the importance of donation and transplantation is shared, the realities of donation are understood, the role of Transplant Québec is recognized, and stakeholders are collectively engaged in a change of culture.

4. Be proactive with political stakeholders and lead them to align themselves with Transplant Québec Q's ambitions
5. Hold public awareness campaigns on organ donation and the importance of making your intentions explicit
6. Cultivate a community of ambassadors to support organ donation and transplantation awareness efforts as well as Transplant Québec's visibility
7. Leverage partnerships to increase Transplant Québec's scope of action
8. Launch targeted organ donation awareness initiatives for groups from diverse ethnocultural backgrounds

3 Invest in the development of Québec Transplant's operational and functional capacities

Give Transplant Québec the human and technological resources required to process a greater number of organ donations across the province and deal with the increasingly complex work of coordinating its activities.

9. Attract, retain and develop talent at Transplant Québec
10. Improve the well-being of Transplant Québec employees
11. Emphasize staff training and improve internal knowledge-transfer practices aimed at improving skills
12. Implement high-performance technological and organizational tools and pursue the development of the Organ donation information system (SIDO)
13. Continue optimizing operations through the efficient use of resources and collaboration tools

4 Promote a culture of quality and performance within the donation and transplantation system

Mobilize the health ecosystem to align with Québec's ambition to be a high-performing and exemplary jurisdiction in terms of organ donation and transplantation, and oversee public communications concerning the progress made by each establishment in Québec

14. Improve and sustain data- and information-sharing to make the donation and transplantation system more effective
15. Further develop the support structure for the loved ones of donors
16. Participate in research on donation and transplantation
17. Develop provincial guidelines

Transplant Québec : planification stratégique 2024 - 2027

AXES TACTIQUES

OBJECTIFS

INITIATIVES TACTIQUES

1 Promote a culture of donation among health professionals

Ensure that the donation culture is shared by all health professionals and leads to the collective adoption of organ donation standards and protocols by all Québec establishments

1. Standardize the normative framework for organ donation across all establishments in the health network by appealing to management teams at health institutions
2. Carry out and increase training and teaching activities for professionals
3. Consolidate the performance evaluation structure for establishments

2 Engage the public in donation and transplantation

Educate the public to share the importance of donation and transplantation so that the reality of donation is understood and the role of Transplant Québec is recognized, and get stakeholders involved in changing the culture

4. Be proactive toward political stakeholders and encourage them to align themselves with TQ's ambitions
5. Carry out public awareness campaigns on organ donation and the importance of making one's intentions known
6. Cultivate a community of ambassadors in support of efforts to promote awareness of donation and transplantation as well as Transplant Québec's visibility
7. Draw on partnerships to expand Transplant Québec's scope of action
8. Launch targeted organ donation awareness activities for diverse ethnocultural groups

4 Promote a culture of quality and performance within the donation and transplantation ecosystem

Mobilize the health ecosystem to share Québec's ambition to be a well-performing and exemplary jurisdiction in regards to organ donation and transplantation, and oversee public communications on progress made by each Québec establishment

14. Promote and sustain data- and information-sharing to improve performance across the donation and transplantation system
15. Develop the support structure for the loved ones of donors
16. Participate in research on donation and transplantation
17. Develop provincial guidelines

Development of innovation and the notion of the patient-partner

Foster a patient-loved one experience

- A patient-loved one experience is:
 - A set of facts experienced by patients and their loved ones
 - A perception, interactions, an organizational culture

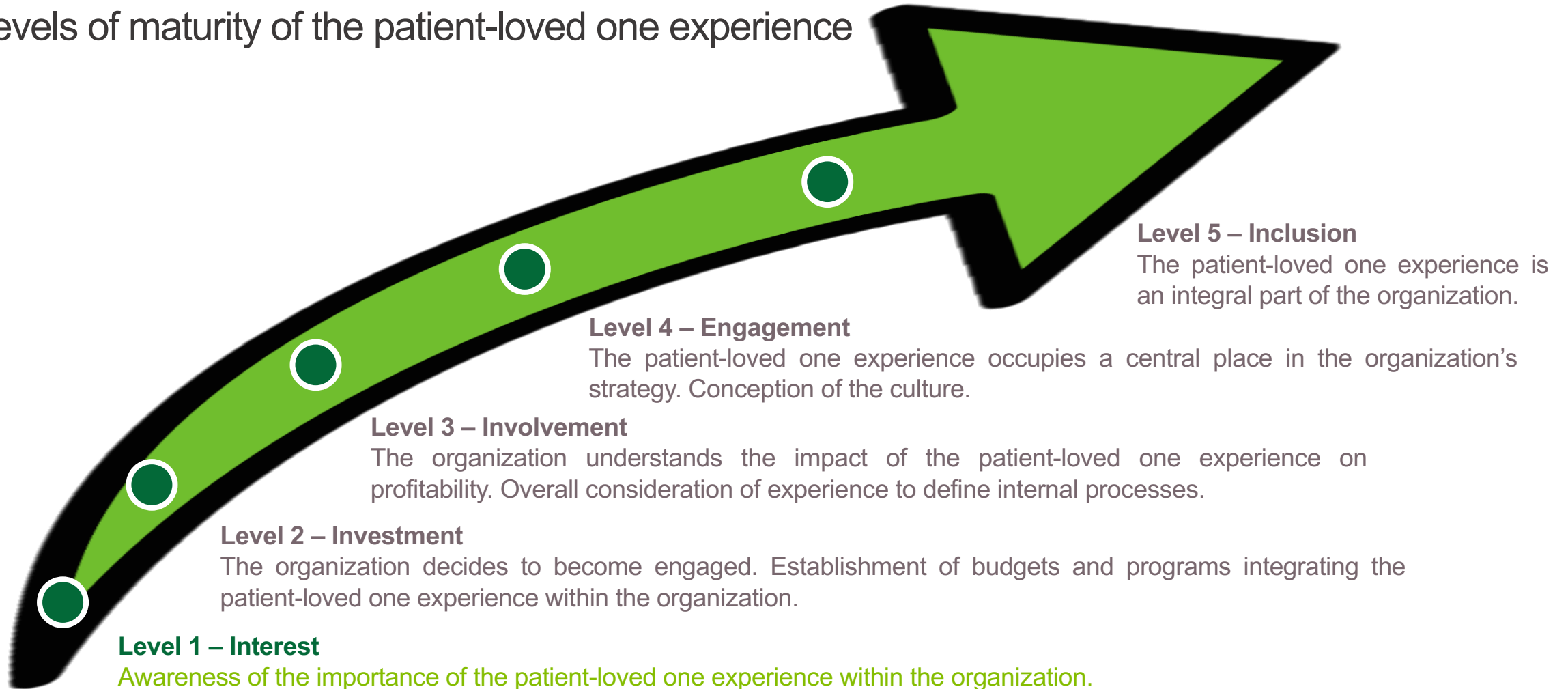
- The patient-loved one experience occurs throughout the care and services trajectory.

- The patient-loved one experience leaves an impression that can be:
 - Positive
 - Negative
 - Neutral

- The patient-loved one experience involves:
 - Engaged employees
 - An environment that fosters a positive experience
 - A systematic approach to quality

Development of innovation and the notion of the patient-partner

Levels of maturity of the patient-loved one experience



Development of innovation and the notion of the patient-partner

Creation of a patient-partner

- This concept is based on the idea of building “with” the user rather than building “for” to the user.
- Three different approaches:

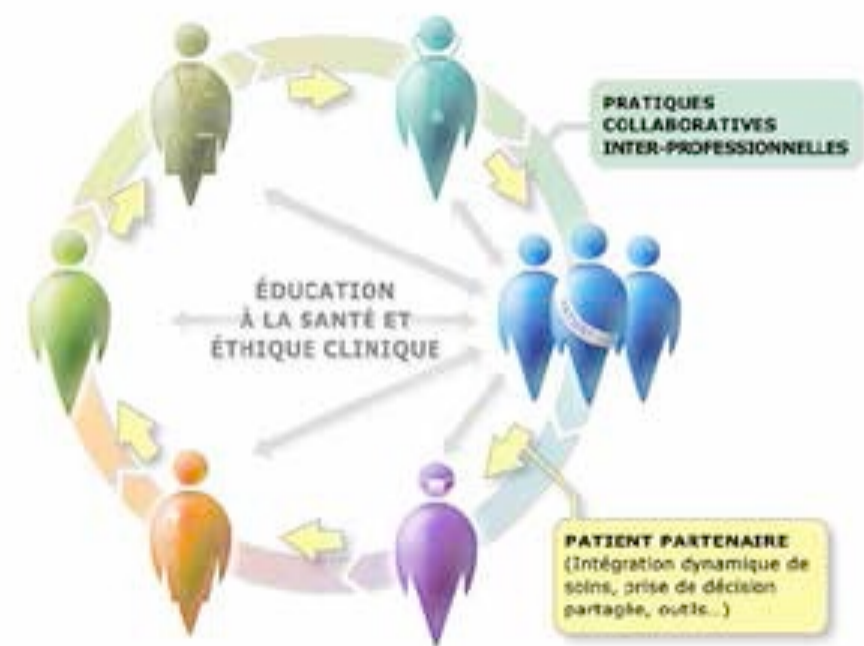
Paternalism (caregivers decide)



Patient-centered approach (response to needs identified by the user decided by caregivers)



Care partnership (the user is a member of the team)



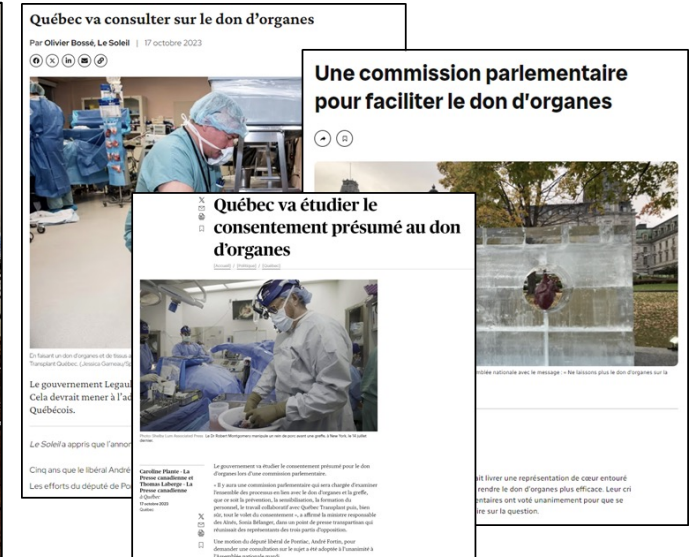
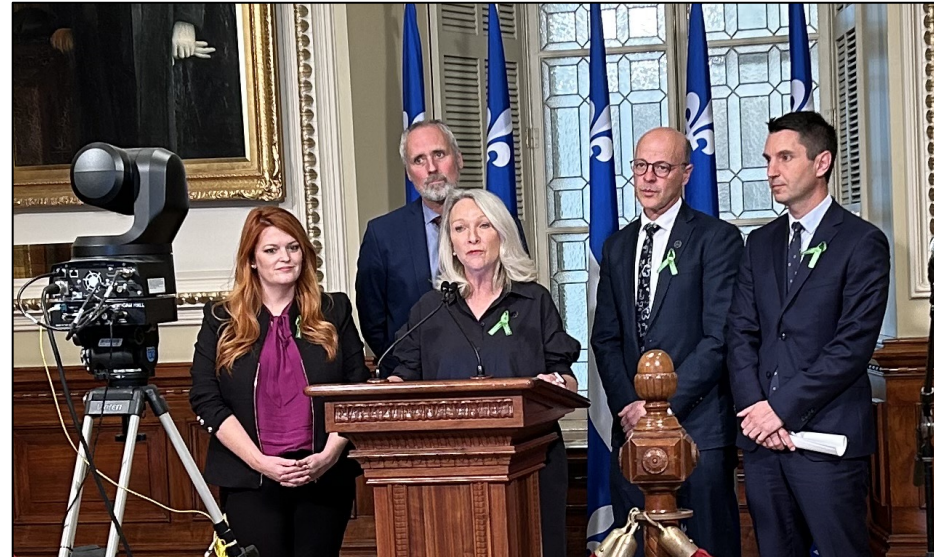
Development of innovation and the notion of the patient-partner

The resource patient-loved one acts in various spheres:



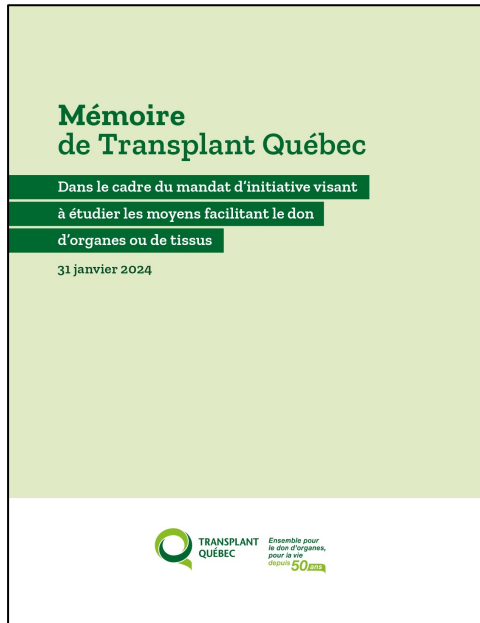
Parliamentary committee

- **Public action** before the **National Assembly**
- **Unanimous adoption of a motion** on organ donation at the National Assembly of Québec.
- The minister tabled a private order of initiative before the **Committee on Health and Social Services** aimed at studying **means to facilitate organ and tissue donation**, notably through the establishment of **presumed consent**.



Parliamentary committee: Filing of the brief

12 recommendations:



Legislative measures

1. Specific and comprehensive law on organ donation and transplantation
2. Designation of the organization in charge
3. Provide for adequate financing
4. Human, material and financial resources available
5. Presumed consent on the condition that public buy-in is demonstrated
6. Provide a user-friendly single online window accessible to everyone

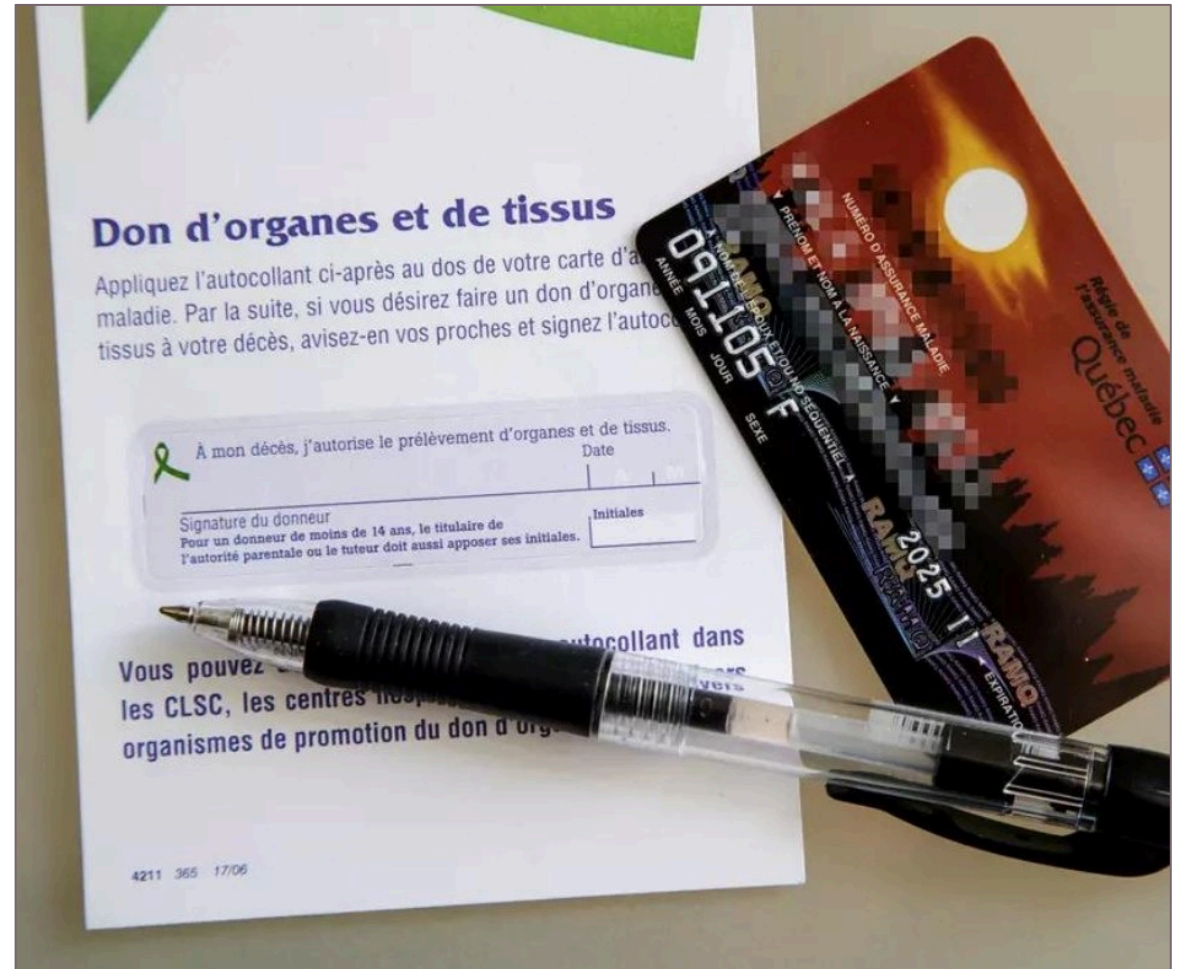
7. Reinforce the obligation to notify Transplant Québec of the imminent or recent death of all persons.
8. Specify the reasons for not following up on the final wishes registered by a person before their death.



Consent to organ donation in Québec

There are three ways to give consent to organ and tissue donation:

- Registration in the Registre des consentements de la Régie de l'assurance maladie du Québec (RAMQ).
- Registration in the Registry of Consents to Organ and Tissue Donation of the Chambre des notaires du Québec.
- Signature on the sticker on the back of the health insurance card



Consent to organ donation in Québec



Sont favorables
au don d'organes

92%



Connaissent les
démarches pour faire
connaitre leurs volontés

55%



42%

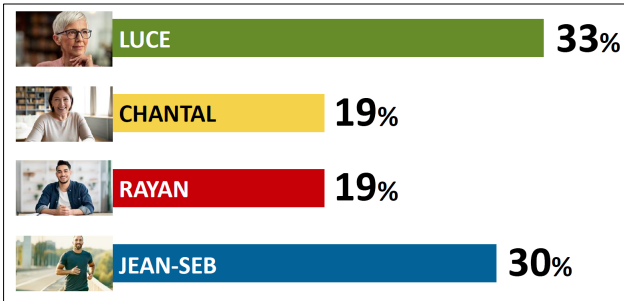
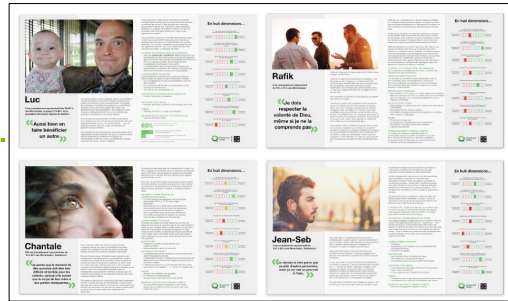
des **Québécois** souhaitent
garder le consentement
explicite



43%

des **Québécois** souhaitent
changer pour le
consentement présumé

Personas: Perceptions and knowledge related to organ donation in June 2023



Luc
« Aussi bien en faire bénéficier un autre. »
Il est représentatif de 82% de la population du Québec.

Louise
« Je suis bien trop âgée et plus assise en bonne santé pour faire don de mes organes. »
Elle est représentative de 19% des Québécois.
75% des Québécois ne sont pas prêts à faire un don d'organes.
45% des Québécois ne sont pas prêts à faire un don d'organes.

Chantale
« Je n'aime pas penser au moment de mourir, de perdre ce qui nous a, aborder ce moment. »
Elle est représentative de 19% des Québécois.

Organ donation in Québec

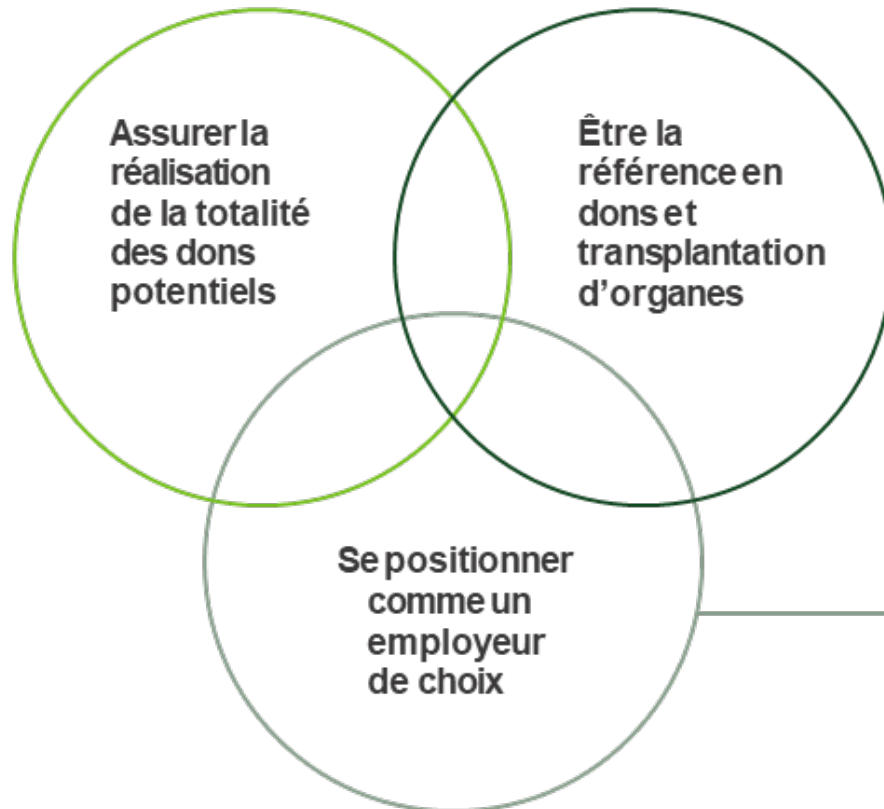
- One donor can save eight lives and help up to 20 people by donating their tissues.
- The following organs can be transplanted:
 - Heart
 - Lungs
 - Liver
 - Kidneys
 - Pancreas
 - Face
- Donors account for only 1.4% of people who die in hospital: maximum of 450 people
 - Neurological determination of death (NDD): all organs
 - Determination of cardiac death (DCD): all organs except the heart



Magnet hospital philosophy and transformational leadership

Transplant Québec: Strategic planning with three strategic priorities

LES 3 PRIORITÉS STRATÉGIQUES



Diffusion et implantation des principes du « *magnet hospital* »

Magnet hospital philosophy and transformational leadership

The bases of the magnet hospital philosophy

 A **culture of care** centered around the **needs of the patient or their family**

 **Expert caregivers**

 **Strong support** for **staff training** from the **institution**

 **Transformational nursing leadership**

 **Participatory management** favouring the empowerment of caregivers

 **Autonomy of caregivers** in their **clinical decision-making** sphere

 **A collegial relational climate**

 Adequate **staff management**, **adapted** to **workloads** and **patient needs**

In your view, organ donors in a MAID context accounted for what percentage of the total number of organ donors in Québec in 2023?

A

Close to 5%

B

Close to 10%

C

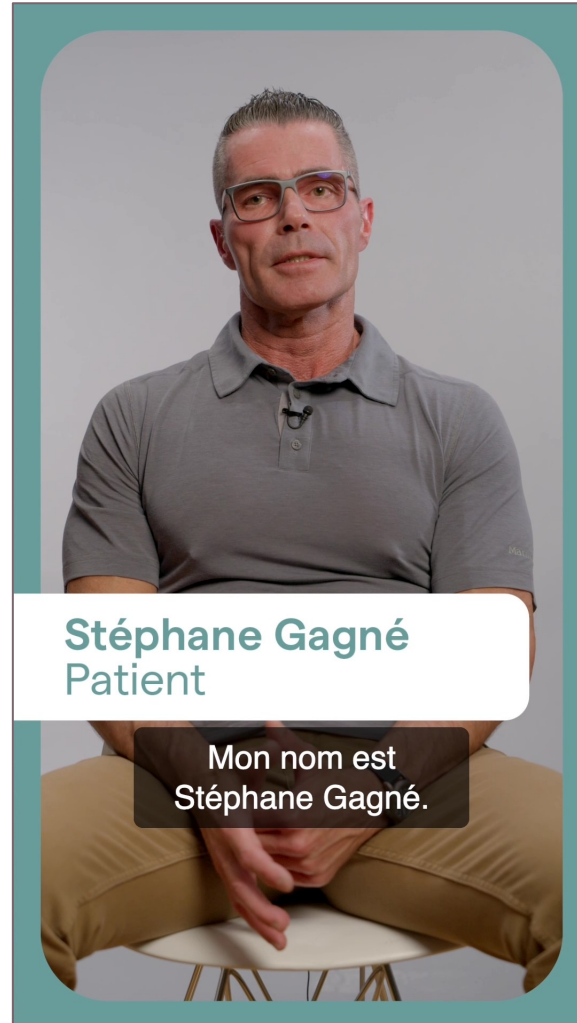
Close to 25%



Amendments to MAID legislation in Québec

- The entry into force of the Act respecting end-of-life care in December 2015:
 - Quebecers given recourse to MAID, based on their health condition.
- Person deemed incapable:
 - The law waives the obligation to provide final consent immediately before receiving MAID.
 - Written agreement with the physician allowing them to receive medical assistance in dying if they become incapable
- The Institut national d'excellente en santé et en services sociaux (INESSS):
 - Consultation with people living with a neurocognitive disorder (NCD) and informal and family caregivers (IFC)
 - Explore the care and services experience of these users in Québec
 - One of the significant needs expressed by participants: access to anticipated medical assistance in dying so that people can die with dignity

Testimonial from a patient who donated organs in a MAID context

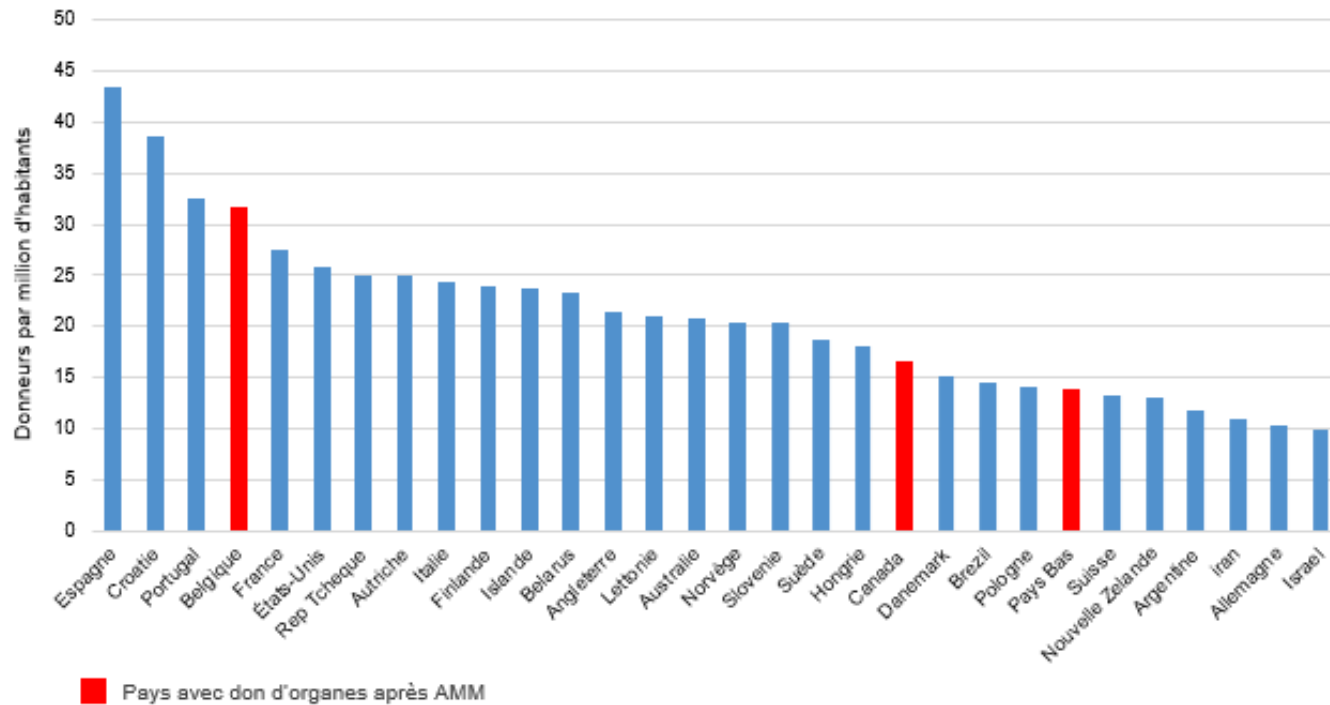


Stéphane Gagné
Patient

Mon nom est
Stéphane Gagné.

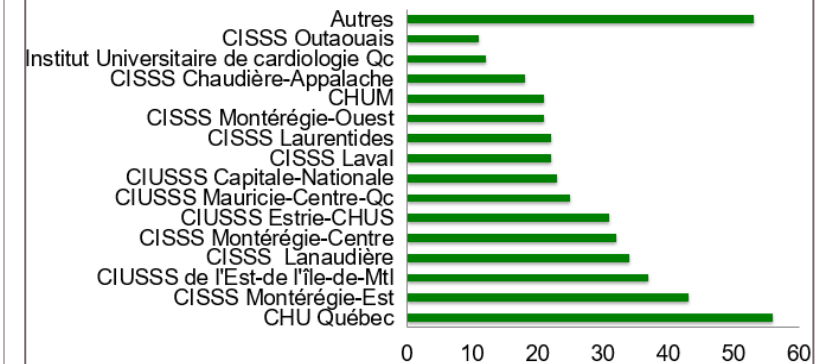
Establishment of a new practice: What do we know?

Situation dans le monde



	Pays-Bas (N=6672)	Belgique (N=1807)	Suisse (N=421)	USA (N=71)	Canada (N=1300)
Année publication	2015	2011	2004	2013	2017
Âge:					
<65 ans (%)	23	16.5	33	44	72 (moyenne)
Cause (%):					
Néoplasie	66	69	38	65	57
Maladie CV	4.5	6	12	N.R	10.5
Maladie neurologique	9	7	24.5	N.R	23
Maladie pulmonaire	7	4	N.R	10	
Autres	13		24.5	17	9.5

AMM au Québec 2015-2016



Key points

- Transplant Québec has no role to play in the decision concerning medical assistance in dying.
- The two processes, notably the MAID decision and the donation, must remain completely separate from one another.
- Under no circumstances must the organ donation process prevent or delay a MAID process initiated by a person.



What was the potential?

- 450 X 23 % eligible = **103** potential cases
- 103 X 25 % referrals = **25** cases
- 17 donors confirmed = increase of **~10%** in the number of annual donors, with the potential to save **17-51 lives**



Potential issues

- Capacity for consent;
 - How much can/should medical professionals ask for?
 - How much can we approve?
- Information vs solicitation
 - Transplant Québec recommends that treating physicians can (or should) inform the patient of donation possibilities
 - Solicitation remains prohibited
 - Principles of equity and autonomy
- Dead donor rule
 - Death by Donation is illegal in Canada
 - Confirmation of death: Absence of circulation must be confirmed by clear and objective criteria
- Protection from conflicts of interest:
 - Transplant team should have no role in MAID decision or death determination
 - There should be no health care professional initiated discussion of donation prior to final MAID decision



Recommendations of the ethics committee

Transplant Québec:

- Gets involved only when the two MAID notices are signed (Transplant Québec not involved)
- Before undertaking any approach, must ensure that the person qualifies for the donation (eligibility).
- Must ensure that the person's intention to donate is not what is motivating their application for MAID.
- Must ensure that the person fully understands the implications of the donation process.
- Must ensure that the person is not pressured into their decision to donate their organs.
- Must ensure that the teams are comfortable with the decision.
- Explains that the family must be informed about the MAID-donation.
- Must follow the current DCD protocol.



What organ donation in a Québec MIAD context entails

- An adapted approach:
 - The process is initiated only after eligibility for MAID is confirmed.
 - After the MAID decision is accepted and formalized, the care team informs the patient about organ donation.
 - Importance of free and informed consent
 - After consent, determination of eligibility as an organ donor
 - The person decides which of their organs and tissues can be procured.
 - The person has the right to withdraw their consent at any time during the process.



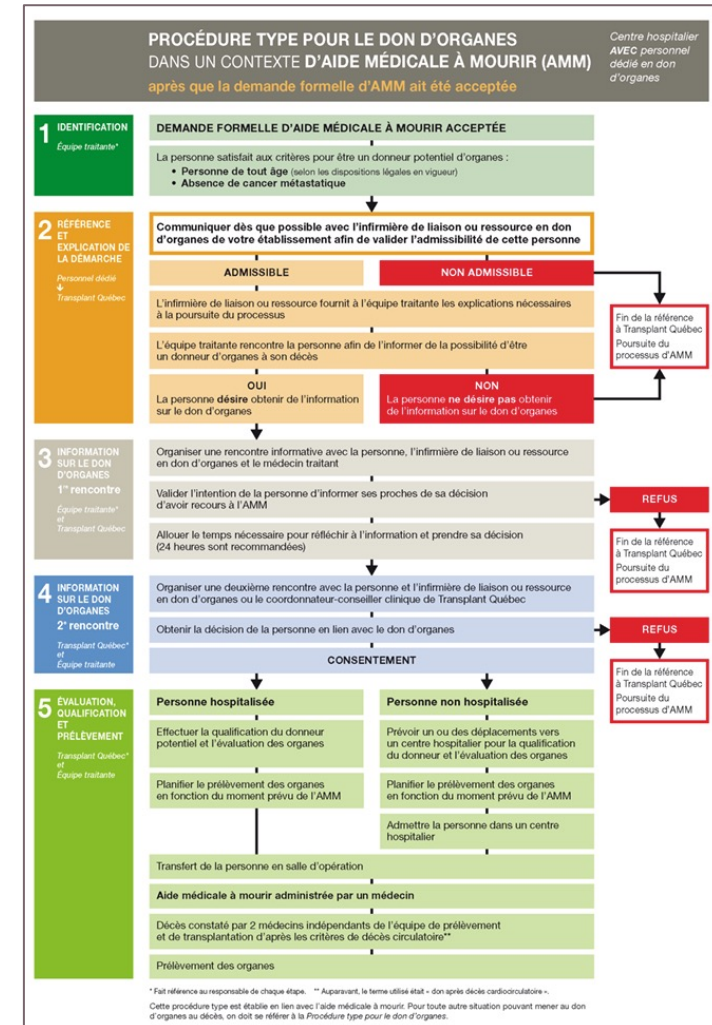
Free, informed, and revocable consent

Determining if organs are eligible for transplant

- MSQ (medico-social questionnaire)
- Review of medical file
- Half-day hospitalization (the week preceding MAID)
 - Blood tests
 - Medical imaging
 - Physical examination

MAID and organ donation: specifics

- Confidentiality and anonymity
- In a hospital setting, ceremony possible
- Possible exclusion of organs (final examination in OR)
- Heparin
- Limited time with their loved ones



Conditions that may affect or even prevent organ donation

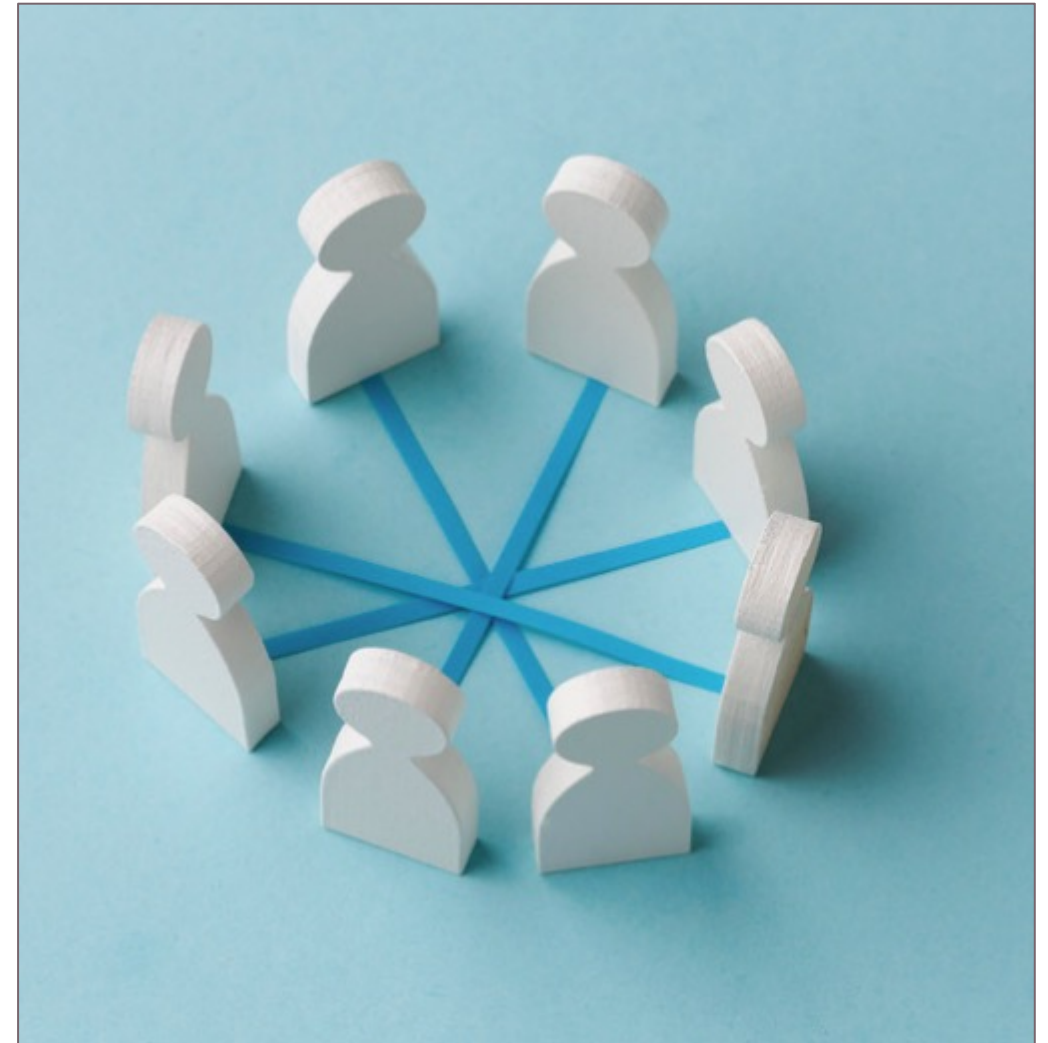
The person may...

- Change their decision regarding MAID
- Lose their capacity to consent to treatment
- Wish to receive palliative sedation rather than MAID
- Wish not to inform loved ones
- Withdraw consent to organ donation
- Wish to die at home



Mobilizing all actors

- Draw on the expertise of each team member:
 - Ethics committee
 - Clinical coordinator/advisor
 - Nurse with expertise in family support
- Consult our partners:
 - Medical federations
 - Professional orders
 - Health establishments
- Work in partnership with other ODOs in Canada
- Take part in formulating CBS guidelines
- Respect the comfort levels of clinical staff and facilitate exchanges
- The first cases occurred at the end of 2017:
 - Two years after the entry onto force of medical assistance in dying legislation
 - As requested by individuals at the end of life



Support for families and patients in a MAID context

- Facilitate the development of a relationship of trust
- Ensure that the expectations, needs, and end-of-life project of the individual are respected
- Strengthen the patient's sense of autonomy and empowerment during the process
- Guide them through their decision-making regarding organ evaluation and qualification
- Help the individual and their loved ones reach a decision regarding an end-of-life ceremony
- Prepare the person and their loved ones for the various stages in the process
- Provide support to loved ones after the process



Our first five years

Research

Organ donation after medical assistance in dying: a descriptive study from 2018 to 2022 in Quebec

Matthew J. Weiss MD, Mathilde Dupras-Langlais BScInf, Marie-Josée Lavigne BScInf, Sylvain Lavigne BScInf MSc, Annie-Carole Martel BComm, Prosanto Chaudhury MD MSc

■ Cite as: *CMAJ* 2024 January 29;196:E79-84. doi: 10.1503/cmaj.230883

Abstract

Background: Since the implementation of medical assistance in dying (MAiD), deceased organ donation after MAiD has been possible in Quebec. We sought to describe organ donations after MAiD in the first 5 years after this practice was implemented in Quebec.

Methods: We reviewed all cases referred for donation after MAiD from January 2018 to December 2022. We presented all data descriptively with no comparison statistics.

Results: Transplant Québec received 245 referrals for donation after MAiD, of which 82 were retained (33.5%). Of

the 163 nonretained referrals, 152 (93.2%) had a recorded reason, including 91 (55.8%) for medical unsuitability on initial screen (e.g., organ dysfunction, medical history), 34 (20.8%) for patient refusal and 21 (12.9%) instances where patients withdrew from the MAiD process entirely. Six patients died before MAiD. Eighteen of the 82 retained cases were cancelled later in the process, almost all ($n = 17$, 94.4%) because of medical contraindication discovered during detailed donor evaluation. Sixty-four patients became actual donors after MAiD, increasing from 8 in 2018 to 24 in 2022. The total conversion rate from referral

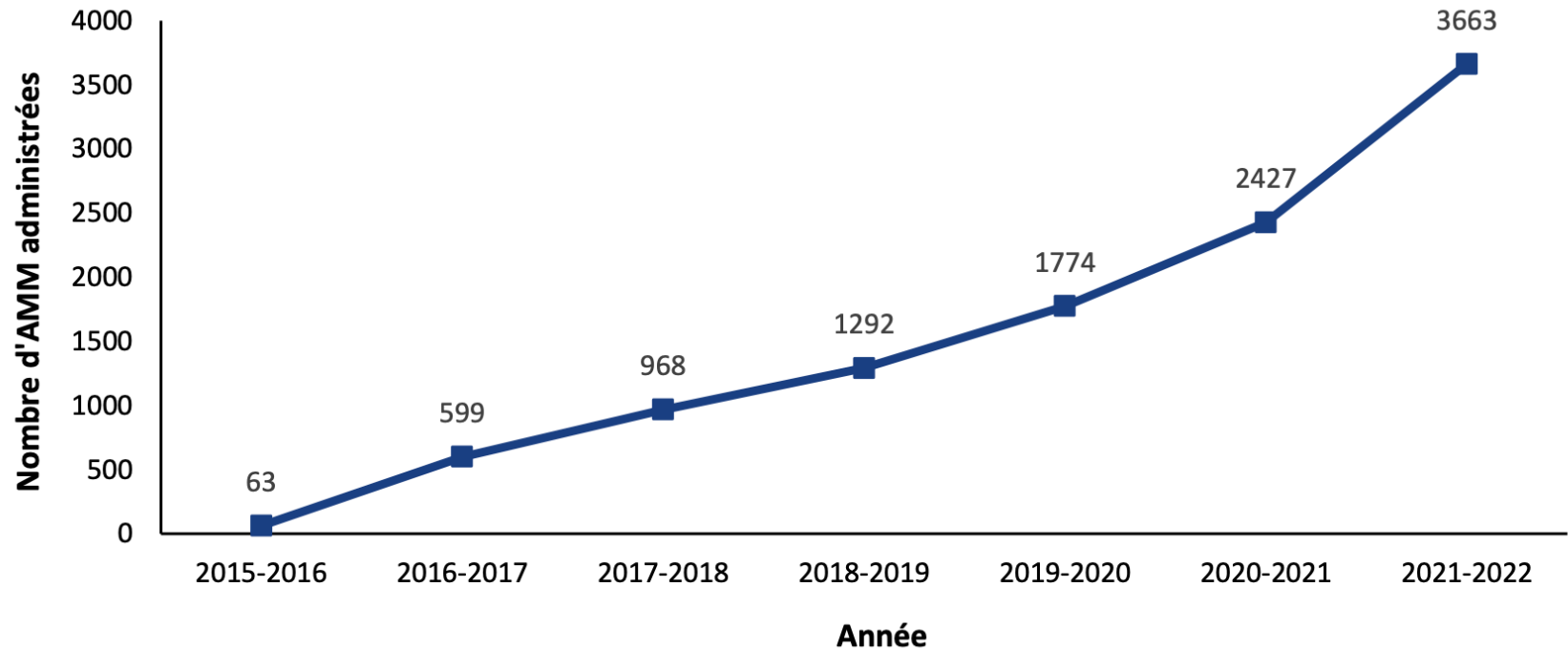
to an actual donor was 26.1% (64/245). A total of 182 organs (116 kidneys, 20 livers and 46 lungs) were transplanted after MAiD. During the study period, MAiD donors represented 8.0% (64/803) of total deceased donors, increasing from 4.9% (8/164) in 2018 to 14.0% (24/171) in 2022.

Interpretation: These data describe a substantial increase in deceased donation after MAiD in the first 5 years of implementation in Quebec. Future studies should focus on how to optimize systems to ensure these requests are treated in the most ethical and medically effective way.

MAID in Québec

Figure 3.2

Nombre d'AMM administrées entre le 10 décembre 2015 et le 31 mars 2022



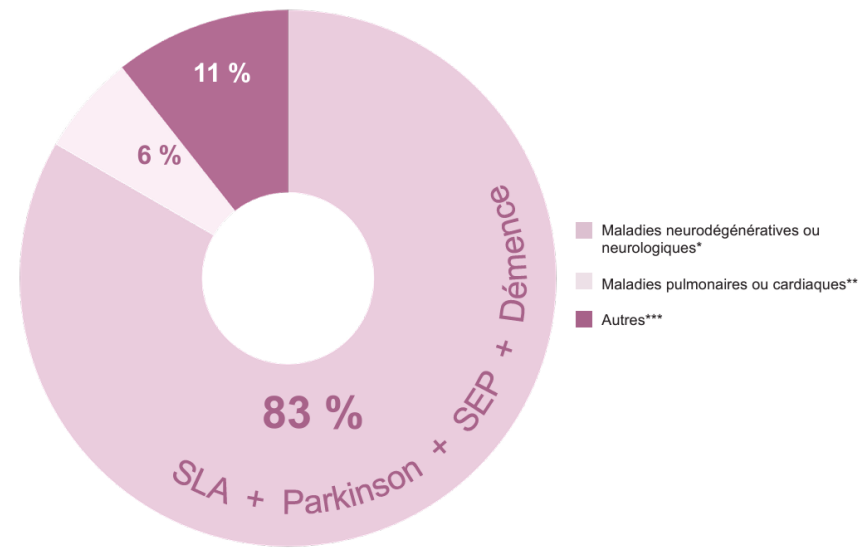
Commission sur les soins de fin de vie, rapport sur la situation des soins de fin de vie, 2022

Donors after MAID in Québec

	Donors	Organs
2018	8	19
2019	13	36
2020	8	26
2021	11	35
2022	24	66
Totals	64	182

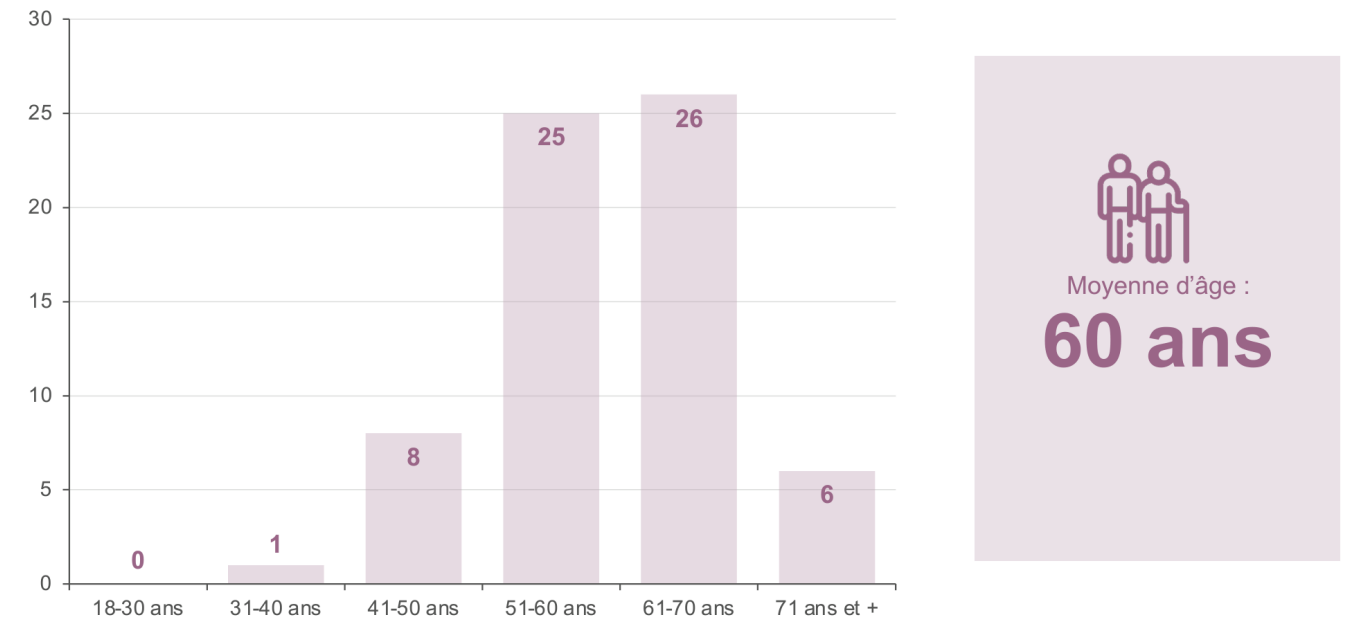
Overview of MAID-related organ donation in Québec, 2017 to 2022

Diagnostiques prépondérants des donneurs en contexte d'AMM au Québec, 2017 à 2022



* Ex. : Sclérose latérale amyotrophique (SLA), Parkinson, sclérose en plaques (SEP), démence et autres maladies
 ** Ex. : Maladie pulmonaire obstructive chronique (MPOC) et autres maladies
 *** Syndrome de douleur intractable, polyarthrite rhumatoïde, fibromyalgie, blessure du système nerveux central

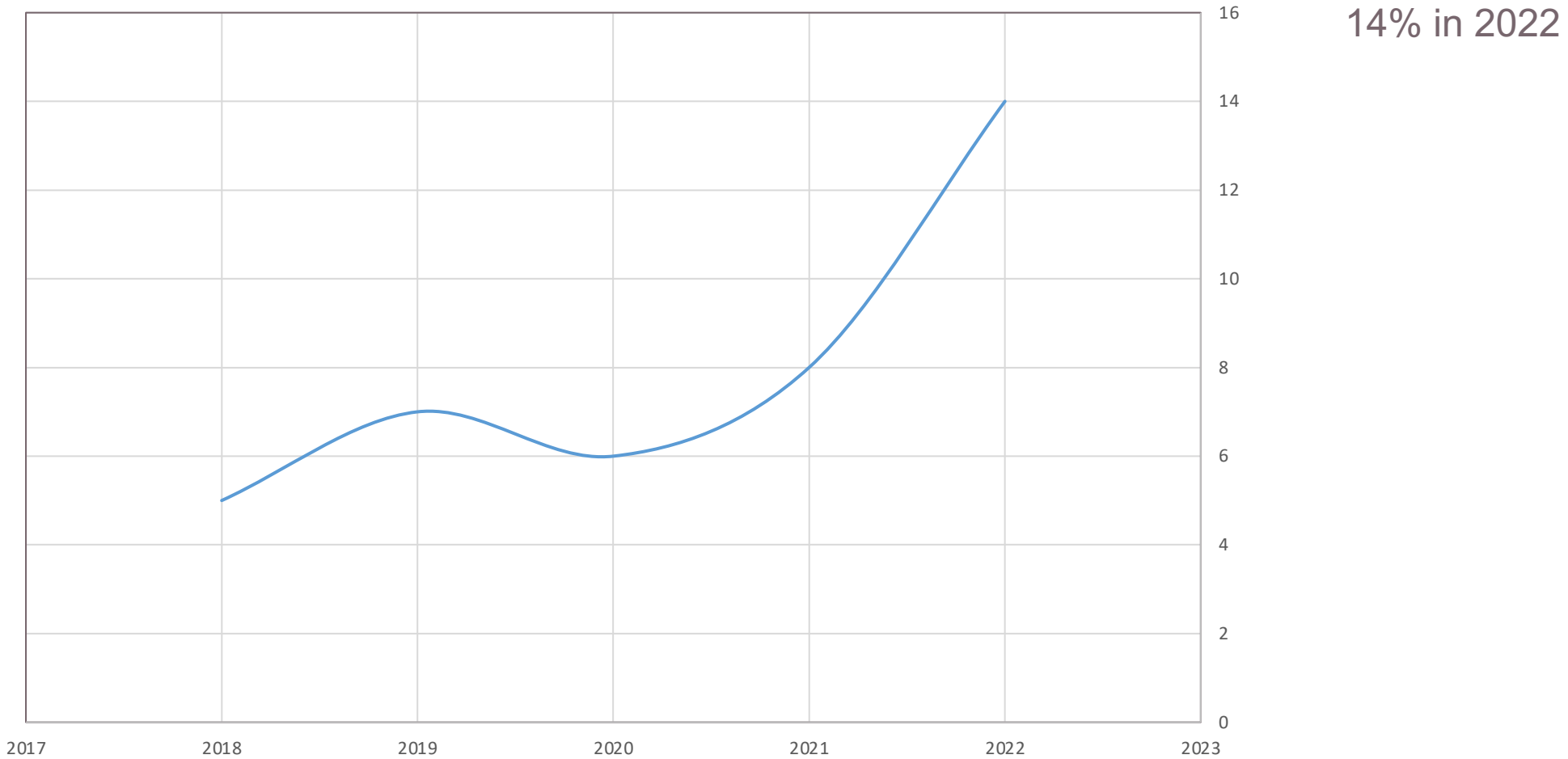
Donneurs d'organes en contexte d'AMM au Québec, par groupe d'âge, 2017 à 2022



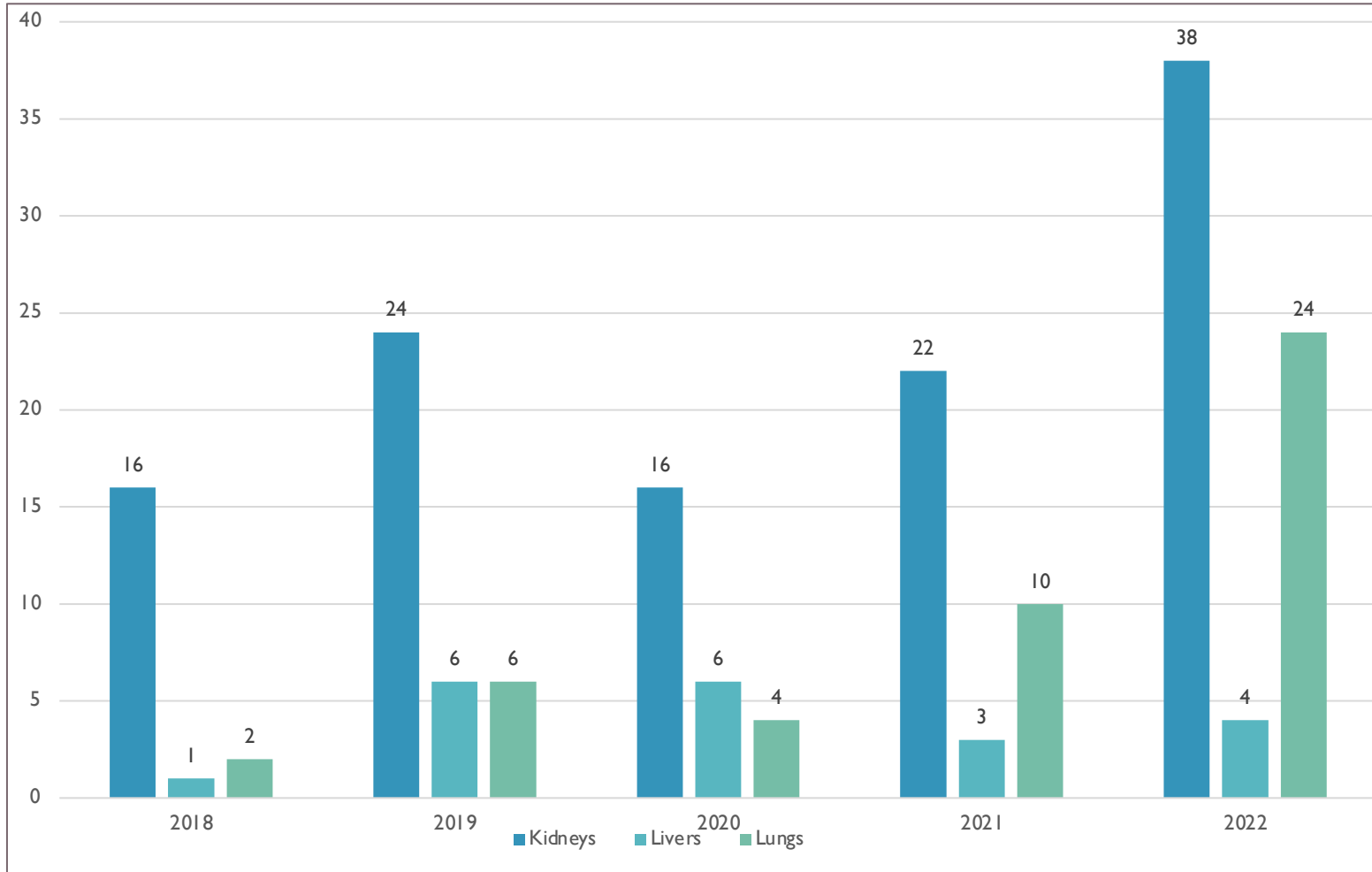
Demographics of MAID donors 2018-2022

Sex	Male	41
	Female	23
Age (Avg 60 y/o)	40-49	9
	50-59	23
	60-69	26
	70 and +	6
Diagnosis leading to MAID	Neurodegenerative disorders	54
	Terminal cardiopulmonary disorders	4
	Other	6

Deceased donation as a percentage of total activity

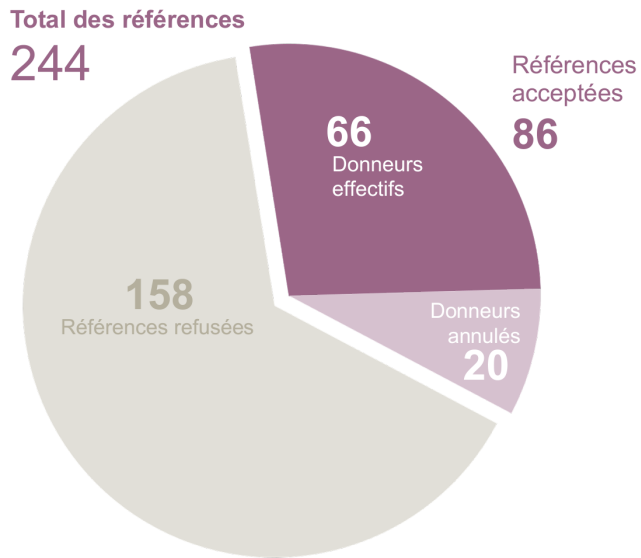


Transplants from Donors after MAID



Overview of MAID-related organ donation in Québec, 2017 to 2022

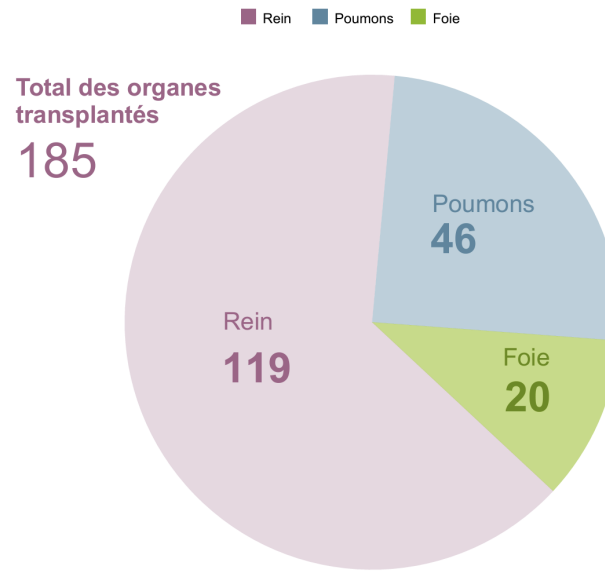
Traitement des références par Transplant Québec en contexte d'AMM, 2017 à 2022



Références acceptées
86


Des 244 références pour don d'organes faites à Transplant Québec, plus de **35 %** ont pu être retenues.

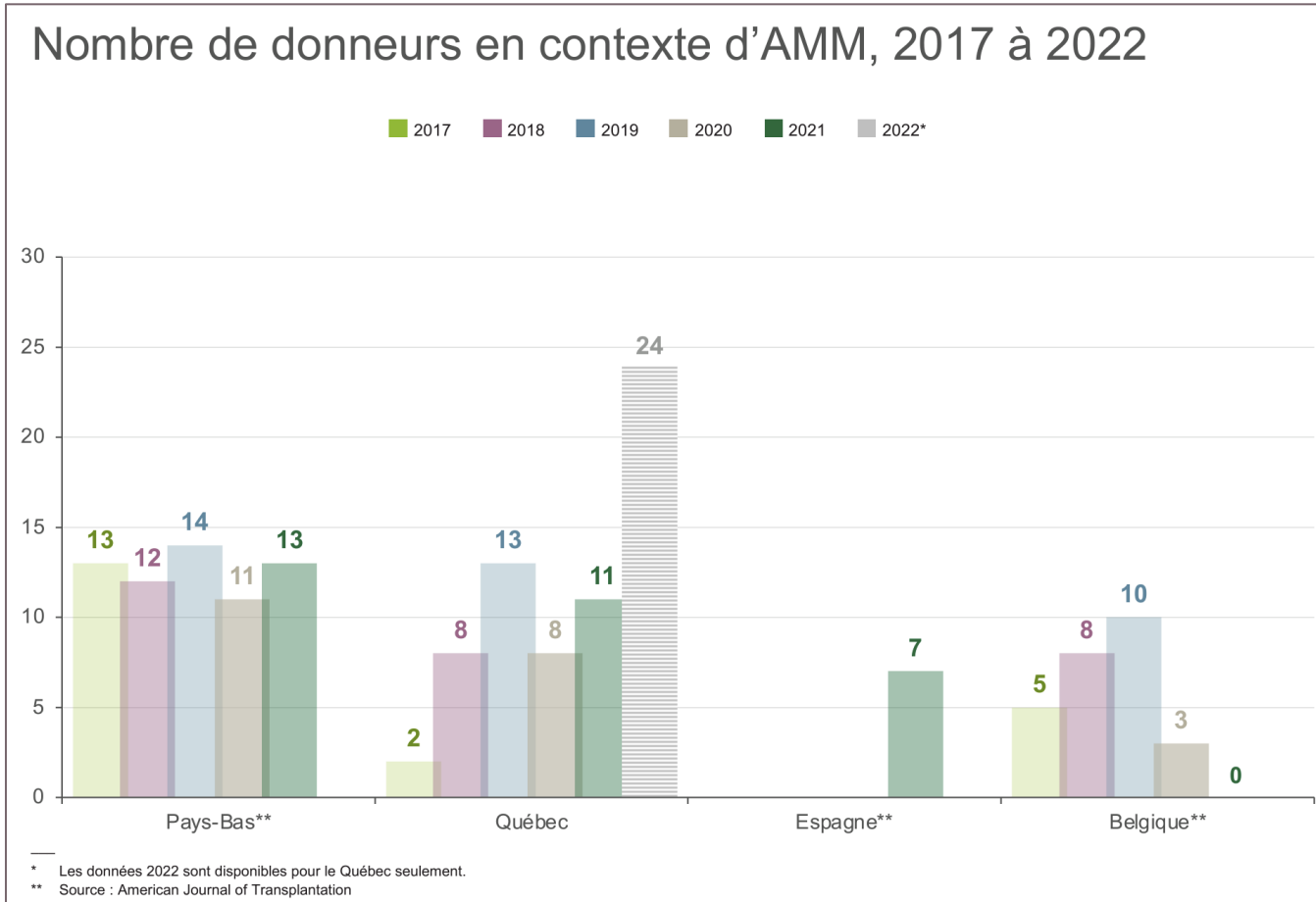
Organes transplantés provenant des donneurs du Québec en contexte d'AMM, 2017 à 2022




En moyenne, **2,8 organes** par donneur ont été transplantés depuis la mise en vigueur de la Loi*.

* Loi concernant les soins de fin de vie

Overview of MAID-related organ donation in Québec, 2017 to 2022



Next steps

- Study the outcomes of organs retrieved post-MAID
- Study the impact of the process on patients and their loved ones
- Continue legal and ethical analysis of emerging issues:
 - Patient having lost the capacity to consent
 - What do we do with patients who can no longer consent?
- How to make sure that all patients who have entered the MAID process are given the option of donating their organs
- Procure the heart/pancreas
- Patient partners and resource:
 - Personas
- Dying at home and MAID-related organ donation
- Correspondence program
 - Direct contact
 - Video of recipient



Future development

FUTURE LOADING



- Giving a voice to the loved ones of donors and recipients
 - Invaluable source of ideas for improvement
 - Taking their suggestions into consideration helps alleviate grief
 - Favours a more positive experience
- The “patient-loved one” experience
 - Each experience is personal
 - Hard to replicate due to individual nature
 - A rich and multi-faceted perspective can be gained through testimonials:
 - Emotional experience
 - Physical experience
 - Intellectual experience
 - Spiritual experience
- Guiding the experience:
 - Benchmarks and metrics based on the perceptions of the loved ones of donors and recipients
 - Yearly analysis of the organization’s level of maturity

Future development

Questions:

- How do we include the voices of the loved ones of donors when they're going through the grieving process?
- What approach should professionals favour when dealing with the donor's loved ones?
- At what stage in the grieving process should the donor's loved ones be contacted?
- How do we help professionals include the voices of the loved ones of donors and recipients?
- Who is best suited to approaching the loved ones of donors and recipients? Professionals, or someone who's already been through the same experience?
- What training programs exist for patient-partners?

Courses of action :

- Create an internal committee on including the voices of the loved ones of donors and recipients.
- Have the discussion group gather testimonials from the families of donors and recipients.
- Mobilize patient-partners who've been through the same experience and have them gather testimonials from recipients and from the donor's loved ones during phone interviews.
- Evaluate the possibility of a research project focused on ways to include the voices of the loved ones of donors and recipients.
- Get guidance from Marie-Pascale Pomey at the Université de Montréal.

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