Appendix 1: Summary of Original and New/Updated Recommendations

Deceased organ donation in conscious and competent patients
Medically suitable, conscious, and competent patients who provide first-person consent to end-of-life procedures should be given the opportunity to donate organs and tissues. Patients who seek MAiD or WLSM should not be prohibited from donating organs and tissues.
Before consenting to WLSM or MAiD, patients should carefully consider all end-of-life options with their physician or health care professional.
Referral to an organ donation organization
Referral to the organ donation organization should occur as soon as is practical after the decision to proceed with WLSM or determination of eligibility for MAiD. Preliminary evaluation of the patient's eligibility to donate should be performed before the donation approach, if possible. This avoids the potential distress of making a request or obtaining consent for donation only to have to inform the patient that they are medically or logistically ineligible.
All Track Two Patients should be referred to the provincial organ donation organization for information-sharing if a patient initiates a discussion on donation, regardless of when this discussion occurs within the 90-day assessment period. (New Recommendation)
Conversations about donation*
The decision to proceed with MAiD or WLSM must be separate from, and must precede, the decision to donate.
Treating physicians, MAiD providers and MAiD assessors should be educated on how to respond to inquiries concerning organ donation. This should include how the decision to donate may affect the end-of-life care process and options, and when to refer patients to the organ donation organization. The organ donation organizations should develop checklists or discussion guides to facilitate donation conversations to ensure patients are consistently well informed.
All eligible, medically suitable patients should be given an opportunity to consider organ and tissue donation, consistent with provincial or territorial required referral legislation, regional policy and ethical principles of respect for autonomy and self-determination. However, this must be reconciled with regional values and health care culture. Initially, some jurisdictions might prefer to begin with systems that respond only to patient-initiated requests.
Donation coordinators will have to tailor their conversations to ensure the patient remains the centre of the MAiD or WLSM and organ donation process, to ensure patient autonomy.
When an approach is to be made, discussions should happen early to allow individuals time to consider the options, ask questions and plan accordingly.
Patients and their families should be provided with standardized information resources, such as

online material or pamphlets, to help guide responses to donation inquiries. The decision to proceed with MAiD or WLSM must precede discussions about donation.
Consent
The patient must have the ability to provide first-person consent to MAiD or WLSM as well as to organ and tissue donation.
Physicians, MAiD assessors, and WLSM or MAiD providers should be cognizant of the risk of coercion or undue influence on patients to donate their organs; however, the patient's altruistic intentions should not be discouraged.
Donation discussions must respect patient autonomy, and first-person consent should be obtained and upheld. Although it is welcomed and encouraged that family members are included in donation conversations, consent must be obtained from the patient and conversations should be focused on them.
The individual should be informed and understand that they may withdraw consent for MAiD or donation at any time, and that withdrawal of consent for donation does not affect their consent for, or access to, MAiD or WLSM.
The donation team should make every effort to resolve conflict, through dialogue, between the patient's expressed wishes to donate and a family's disagreement. First-person consent should direct all subsequent decisions unless consent was revoked.
Under circumstances in which a Track One Patient has provided first-person consent for MAiD, including completion of a waiver of final consent and first-person consent for donation, but loses the capacity to reaffirm consent before death, first-person consent for donation should be upheld and next steps to facilitate donation should be coordinated with the substitute decision maker (SDM). (Updated Recommendation)
Under circumstances in which Track One Patient has provided first-person consent for MAiD, including completion of a waiver of final consent but loses capacity before first-person consent for donation, the SDM should be approached to 1) reaffirm consent for registered donors and those in jurisdictions with opt-out legislation or 2) discuss and obtain consent for patients without registered consent if consistent with the patient's wishes. (Updated Recommendation)
All Track Two Patients who are potentially eligible fordonation should be approached for first-person consent for donation after MAiD once MAiD eligibility has been confirmed, regardless of when their eligibility for MAiD is confirmed within the 90-day assessment period. (New Recommendation)
The donation team must understand and abide by the laws and policies of their jurisdiction with respect to reporting of MAiD deaths (e.g., coroner, special committee). To facilitate donation, these parties should be contacted before the MAiD procedure, in accordance with the current laws and policies.
Donor testing and evaluation*

Primary care physicians, staff of organ donation organizations, MAiD providers and transplant teams should work to minimize the impact and inconvenience to the patient of donating their organs. This could include scheduling home visits for blood draws and coordinating investigations (e.g., x-rays, ultrasound) to minimize hospital visits and inconvenience to the individual.
Transplant teams and surgeons should work with the donation team to determine the minimum necessary investigations, to avoid the burden of excessive assessments and testing.
Donor teams should routinely discuss the potential impact of unanticipated results from the donor investigations, including previously undiagnosed infectious diseases, and their impact on public health reporting and contact tracing.
MAiD procedures
Consent for MAiD must be reaffirmed before the MAiD procedure. The health care team or MAiD provider should reaffirm consent before relocation to the hospital and before beginning any antemortem interventions for the purposes of facilitating donation. This may reduce the momentum of the donation process and reduce the potential for patients to feel pressured to continue with MAiD in the interest of ensuring donation.
For Track One Patients receiving MAiD after loss of capacity who require admission to the hospital for donation, transfer and admission to the hospital should be coordinated with the SDM. (New Recommendation)
Track Two Patients must provide first-person consent immediately before the MAiD procedure. As such, first-person consent should be obtained before transfer and admission to hospital for donation. (New Recommendation)
Further work is needed to assess the potential for donation after MAiD at home in Canada. In the interim, patient-initiated requests for donation after MAiD at home warrant consideration on a case-by-case basis, where feasible. (New Recommendation)
Determination of death*
The dead donor rule must always be respected. Vital organs can be procured only from a donor who is already deceased; the act of procurement cannot be the immediate cause of death.
Protection for patients
Separation of decisions*
To avoid any real or perceived conflict of interest, health care practitioners should separate the decision regarding WLSM or MAiD from discussions concerning donation. Providers who are assessing eligibility for MAiD should not be involved in donation discussions. Discussions concerning donation should happen only after WLSM decisions are made, or patients have been found eligible for MAiD by 2 independent assessments.

The primary health care team should acknowledge patient inquiries concerning donation that are made before a decision to proceed with MAiD or WLSM. General information on deceased organ and tissue donation may be provided. However, specific discussion and decisions pertaining to donation should wait until the decision to proceed with MAiD or WLSM has been finalized.
Patients may wish to postpone their MAiD procedure, owing to a temporary improvement in their health or an event they wish to experience before their death. The freedom of the patient to postpone their MAiD procedure must be reinforced and preserved, and every effort should be made to honour their wishes to donate their organs should their MAiD procedure be rescheduled.
Directed and conditional donation
Living donation before death from patients considering MAiD or WLSM should be neither offered nor encouraged. Should a patient insist on living donation before death, the request should be considered on a case-by-case basis.
Organ donation organizations and transplantation programs should develop a policy on directed deceased donation for patients pursuing MAiD, in alignment with the directed donation principles and practices that are in place for living donation in their jurisdiction. (New Recommendation)
Separation of roles*
Consistent with current guidelines and practice regarding donation after death determination by circulatory criteria, separation should be maintained between the end-of-life care, donation and transplant teams. Surgical recovery and transplant teams should not be involved in the patient's end-of-life care or MAiD or WLSM procedure. The only exception is insofar as they may provide guidance for minimal requirements for donor investigations or premortem interventions.
Patients who wish to donate their organs after MAiD or WLSM, but who request that their decision to pursue MAiD or WLSM remain confidential, should be informed of the risk that their family members may discover incisions associated with surgical retrieval of organs. They should be encouraged to disclose their decision to family members; however, there is no obligation to stop the donation process should the patient wish to maintain the confidentiality of their MAiD or WLSM procedure.
That an organ donor received MAiD should not be disclosed to the potential recipient during allocation; however, medically relevant information regarding their underlying disease may be disclosed according to guidelines for exceptional distribution, where applicable.
Supports for patients and families*
Specially trained professionals, such as donation physicians and coordinators, patient navigators or social workers, must be available to answer the patient's questions and facilitate the coordination of their MAiD or WLSM and donation. This may take place over a period of many weeks. The patient and their family must be provided with specific instructions on how to access these resources.
Support should be available in an optimally convenient location and setting for the patient, such as home visits or coordination with visits to clinics. For patients in remote locations, video-based

technologies may be of assistance.
The donation team should work with the patient, their family and the MAiD or WLSM provider to develop a plan and best possible options for the MAiD or WLSM procedure that accommodates the wishes of the patient, preserving the opportunity to donate and reconciling coordination of hospital logistics.
Ongoing access to support for patients and their families is critical. Despite patient consent, donation might not proceed, owing to failure to find a suitable recipient, deterioration of health that compromises medical eligibility to donate, surgical findings during organ recovery, or withdrawal of consent by the patient. These patients and their families must continue to receive support even if donation does not proceed.
Continued support must be available to family members after the patient's death. Processes need to be developed to ensure families are given the opportunity to provide feedback on their experience, which may help with their grieving process and may help inform quality improvement measures.
ALS and neurodegenerative diseases*
People with ALS and patients with other nontransmissible neurodegenerative diseases should be offered the opportunity to donate organs after their death.
Organ donation organizations should exercise caution regarding allocation of organs from donors with undiagnosed or rapidly progressive neurodegenerative diseases, as these may pose elevated risks to recipients. Organ allocation in this context should follow existing exceptional distribution policies and practices.
Transplant professionals must balance the benefits of the transplant against any potential for harm of receiving a transplant of an organ from a donor with a neurologic illness. Transplant professionals must use their discretion to help the transplant candidate navigate the decision. The surgeon may wish to consult the donor's neurologist to help inform their advice to the transplant candidate.
All cases of ALS or other neurodegenerative diseases that arise in transplant recipients should be reported to Health Canada, to determine potential associations with donor illness and the baseline risk of neurodegenerative illness in transplant recipients (e.g., whether transplant recipients, in general, have rates of ALS that differ from the general population).
Physicians who follow organ recipients should be aware that the donation was by a patient with neurodegenerative disease such as ALS; aware of theoretical transmission risk of neurodegenerative diseases; and cognizant of symptoms or complaints that warrant further investigation by a neurologist to determine if a neurodegenerative disease is present.
Active monitoring (i.e., regular visits to a neurologist) is not recommended for transplant recipients who have received an organ from a donor with a neurodegenerative disease. Neurological monitoring would impose a substantial burden on the recipient and present no benefit to the recipient, particularly as there is currently no value in early detection of these illnesses.

Information resources should be available for transplant candidates and for transplant professionals to help with the decision regarding whether to accept or refuse an organ for transplant. A means of obtaining a consult from a specialist neurologist in neurodegeneration may also be useful in helping the potential recipient make an informed decision. This information should also be available to organ donation organizations and the donation professionals responsible for assessing the eligibility of the patient who is considering donation.
Health care professionals
Health care professionals may exercise a conscientious objection to MAiD or WLSM specifically, but they should strive to accommodate the wishes of the donor by ensuring that their objection to MAiD or WLSM does not impede the ability of the patient to donate.
Health care professionals should act in accordance with provincial and territorial requirements as well as professional and regulatory college requirements for effective referral.
Health care professionals responsible for the care of conscious, competent patients who have requested WLSM or MAiD and donation should be briefed so they are familiar with the patient's end-of-life plan and relevant policies and procedures.
Debriefing after the procedure (i.e., MAiD or WLSM with or without donation) should be offered every time to all members of the health care team who participated. Debriefing by an external resource may be beneficial so that team members feel comfortable sharing their experience.
Psychological support, such as that offered through employee assistance plans, should be accessed when required. Staff of employee assistance plans may benefit from additional training and education regarding MAiD with or without donation to adequately meet the needs of these health care professionals.
Hospitals must ensure that staff are available who are willing and able to honour the patient's wishes to donate after their death or have an effective referral plan in place.
Participation of health care professionals in MAiD and in organ donation by patients who received MAiD should be voluntary, when possible, without interfering with the patient's access to care. The health care team should be well informed and well briefed so they understand the patient's wishes and the outcome they are working toward, as well as relevant policies and procedures.
Health-care professionals involved in donation after MAiD require specialized education, training, and support. (New Recommendation)
Reporting
Clinicians must be aware of the reporting and documentation requirements for MAiD and WLSM and for donation in their jurisdiction.
Records pertaining to organ donation after MAiD, as well as donation and transplant outcomes, should be reported federally and be accessible to clinicians, researchers and administrators.

Transplant outcomes should be easily cross-referenced with the underlying illness of the MAiD donor.
Efforts to formalize the collection and reporting of data specific to donation after MAiD should be prioritized by organ donation organizations. (New Recommendation)
* Recommendations in these sections were not explicitly reviewed as part of the 2023 guidance update but remain valid. Note: MAiD = medical assistance in dying, SDM = substitute decision-maker, Track 1 patients = patients whose natural death is reasonably foreseeable, Track 2 patients = patients whose natural death is not reasonably foreseeable. These recommendations replace or supplement recommendations from the original 2019 guidance.[2]