

Interprovincial organ sharing national data report:

National Organ Waitlist

2012–2018

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**For more information, please contact:
Organ and Tissue Donation and Transplantation**

Canadian Blood Services

1800 Alta Vista Drive
Ottawa, ON K1G 4J5
Canada

Email: transplantregistry@blood.ca

This report is accessible online at
<https://professionaleducation.blood.ca>

Report development

Annual data reports are developed to provide a comprehensive set of results about critical metrics for national patient registries (National Organ Waitlist (NOW), Highly Sensitized Patient (HSP), Kidney Paired Donation (KPD), and the reports are shared with our partners, key stakeholders, the donation and transplantation community, and the general public.

Data sources

Data has been extracted from the Canadian Transplant Registry (CTR). This is the information technology system developed and maintained by Canadian Blood Services in which patient data is stored and matching algorithms are run. Additional data has also been provided directly by provincial organ donation and transplant programs and provincial human leukocyte antigen (HLA) laboratories.

Unless otherwise stated, data in this report covers the period of 2012–2018, from the establishment of the NOW to the end of 2018.

Acknowledgements

Canadian Blood Services acknowledges, with gratitude, the commitment of the Kidney Transplant Advisory Committee, the Living Donation Advisory Committee, the National HLA Advisory Committee, the Heart Transplant Advisory Committee, the Liver Transplant Advisory Committee, the Organ Donation and Transplantation Expert Advisory Committee, and all those whose advice supports the continued growth and achievements of Canadian Blood Services' interprovincial organ sharing programs.



Foreword from Canadian Blood Services
Amber Appleby, RN, BScN, MM

Director, Organ and Tissue Donation and Transplantation

Canadian Blood Services manages and operates clinical programs that support interprovincial sharing of organs and operates the national technology platforms essential to the success of these programs.

The National Organ Waitlist (NOW) is a web-based program maintained and operated by Canadian Blood Services and used by provincial donation and transplantation programs to identify patients in urgent need of an organ transplant across Canada. The NOW is accessible 24/7, meaning transplant programs are able to list and update the status of patients in need in real-time. Provincial Organ Donation Organizations (ODOs) use the NOW as a first step in the organ allocation process to identify patients in most critical need of an organ anywhere in Canada.

The NOW is supported by the Canadian Transplant Registry (CTR), a sophisticated technology platform operated by Canadian Blood Services. The CTR matches available donor organs with potential waitlist recipients anywhere in the country. This national web-based technology is currently used by more than 400 health professionals coast-to-coast.

This year we are pleased to share individual reports for each of the national patient programs, which is an evolution from previous reports that combined annual data for the NOW, the Kidney Paired Donation (KPD) program and the Highly Sensitized Patient (HSP) program. These new individual data reports also offer greater insights into the growth of each program by reporting on longer periods of data collected.

Collaboration is an essential component of a high performing organ donation and transplantation system and Canadian Blood Services is committed to working together with provincial ODOs and other system stakeholders to continue to lead national data collection, collation and reporting about CTR and NOW activity.

Canadian Blood Services remains committed to delivering a better future for Canadian patients. Together, we are Canada's lifeline.



Amber Appleby, RN, BScN, MM

Director, Organ and Tissue Donation and Transplantation
Canadian Blood Services

Executive summary

Canadian Blood Services operates three national patient programs which serve to maximize transplant access for patients most in need by facilitating interprovincial organ sharing. These programs include the National Organ Waitlist (NOW), as well as the interprovincial organ sharing programs for Kidney Paired Donation (KPD) and Highly Sensitized Patients (HSP). These programs operate on the Canadian Transplant Registry (CTR) web-platform, which is maintained by Canadian Blood Services.

The NOW enables 24/7, web-based access to immediately view, list, and update the status of patients waiting for non-renal organs in Canada, as well as to update the medical urgency of patients as their status changes. Organ Donation Organizations (ODOs) use the NOW to match and allocate available organs to 'high-status' transplant candidates and to identify nationally listed non-renal patients who may be a match for organs that cannot be transplanted in the donor's home province. ODOs register donors in their provincial donor management systems and use the NOW as a first step in the organ allocation process to identify patients in most critical need of an organ anywhere in Canada. The CTR sends alerts to ODOs to provide up-to-date information about organ availability and patient priority and enables transplant programs to update changes to patient urgency status any time of the day or night.

This report presents results for a cross-section of active candidates on the NOW as of the end of December 2018, as well as results for patients active during the year and historical information about the active candidate pool over time.

At the end of 2018, there were 851 active candidates on the NOW. These patients have been waiting for an average of 15 months from their respective list dates, with 65% having been listed in 2018. Approximately half of these active patients were waiting for a liver transplant, 14% in need of a heart transplant, 27% in need of a lung transplant, and 10% in need of a pancreas transplant. Beyond the 851 active candidates on the NOW, an additional 305 patients had an organ request which is on hold.

The NOW has improved the efficiency and safety of the system used for sharing organs for patients in most urgent need by automating the centralized national organ waitlist that enables patients' status to be continually updated, to the minute. The CTR and the services available to provincial programs are evolving to meet the interprovincial sharing needs of the organ and tissue donation and transplantation community in Canada.

National Organ Waitlist

Active patients

Results as of December 31, 2018.

Active transplant candidates by organ*

Candidates with one active request:

Heart	111
Lung	225
Liver	422
Pancreas (whole/islet)	33
Kidney–pancreas (combination)	50

Candidates with multiple active requests:

Heart & lung	2
Heart & liver	3
Liver & intestine	3
Other combinations	2

Total candidates active on waitlist 851

* Patients who are listed as requiring liver–kidney combination transplants are included in total for liver transplant candidates. Two patients who require a kidney–pancreas combination transplant for whom the kidney request is on hold are included in the kidney–pancreas (combination) category.

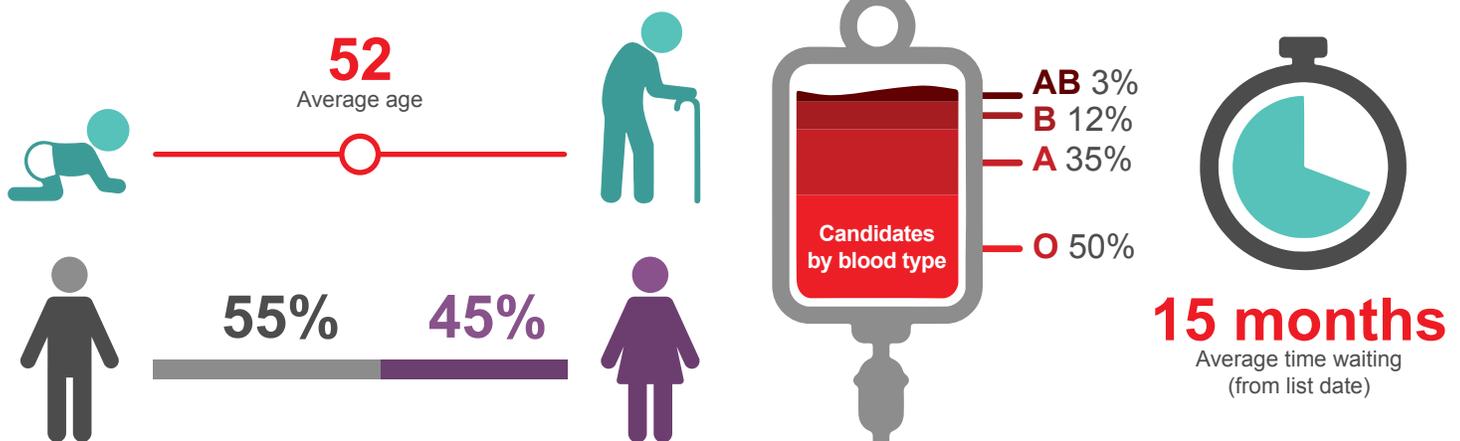
Active patients on the National Organ Waitlist (NOW) represent only the portion of patients for whom transplantation was determined to be an appropriate treatment and who are prepared to receive a transplant. Many patients who are experiencing organ failure or who have other organ-related medical issues are not candidates for transplantation.

Transplantation is considered to be major surgery that carries potential risks, including the potential for organ rejection and graft failure. In order to be eligible to receive a transplant, patients are required to meet certain criteria relating to their medical and psychological suitability for this procedure. Prior to being added to the waitlist, patients are assessed by medical professionals who conduct a thorough evaluation to determine whether transplantation would be an appropriate course of treatment and discuss treatment options with the patient.

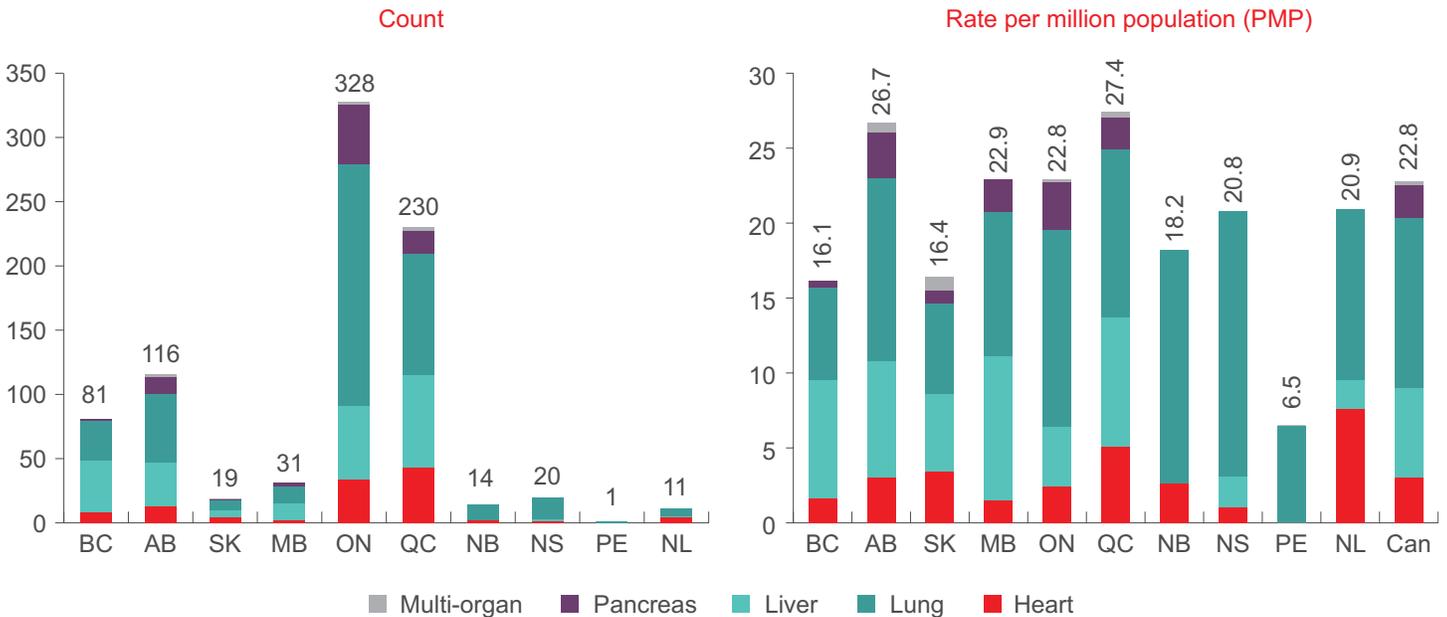
Since physiological and psychological factors can change over time, patients may also be removed from the waitlist temporarily or permanently. Many patients who are added to the waitlist will have their candidacy placed on hold while temporary issues that make them unsuitable for transplant are resolved.

For instance, in some cases a waitlist patient’s medical condition may improve to the point that a transplant is no longer required, while in other cases the patient’s medical or psychological condition may change in ways that make the patient unable to safely receive a transplant, in which case alternate courses of treatment may be pursued. As of the end of 2018, there were 305 transplant candidates on the national organ waitlist whose candidacy was on hold.

Active candidate demographics



Active candidates by province



Province determined by patient's provincial health number.

Population values used in rate calculations based on Oct. 1, 2018 estimates from Statistics Canada. Table 17-10-0009-01. Population estimates, quarterly, available online at <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000901>. Extraction date: Feb. 15, 2019. YT has been included in results for BC, and NU and NT have been included in the results for AB.

While the total number of patients active on the NOW has varied (a range of 725 to 815) for the past three years, a notable increase is apparent in the latter part of 2018. The number of transplant candidates listed increased from approximately 780 patients in the summer to 840 in the fall and ending the year with 851 active patients.

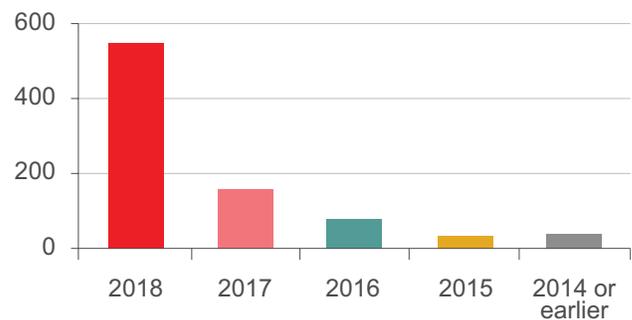
The waitlist is continually changing, and although the number of active patients fluctuates slightly, this number represents the balance between new transplant candidates being added to the list and those being removed from it because of temporary issues (i.e. being placed on hold), receiving a transplant, or becoming permanently ineligible for one (i.e. too sick to be eligible). Of the active candidates at the end of 2018, 65% were listed in the same year.

The average time waiting among active patients is generally inversely proportional to the number of patients on the waitlist¹; in periods where there is a minor surge in new patient listings, the newly listed patients cause the average wait time to go down in the short term while equilibrium is re-attained. For example, when the total waitlist climbed from less than 730 to more than 810 in a six-month period from October 2016 to March 2017, the average wait time saw a corresponding decrease from more than 480 days to less than 430 days.

¹ There is a strong correlation ($r = 0.52$) based on monthly waitlist extracts, 2016-2018 ($n=24$).

The demographic composition of the NOW has also seen gradual changes in recent years. The proportion of female patients relative to male patients has increased gradually from females representing 39% of active patients in the NOW at the start of 2016 to 45% of patients at the end of 2018. Conversely, the average age of active waitlist patients has been within the range of 49 to 52 years for the past two years, with recent results being at the high end of that range. It is projected that the average age will remain at approximately 52 years old into 2019.

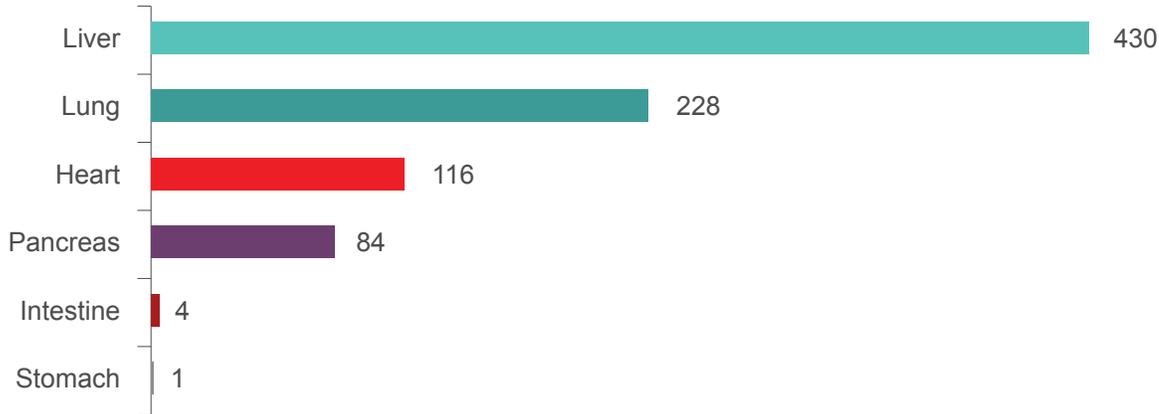
Year of listing for active transplant candidates



Organ requests

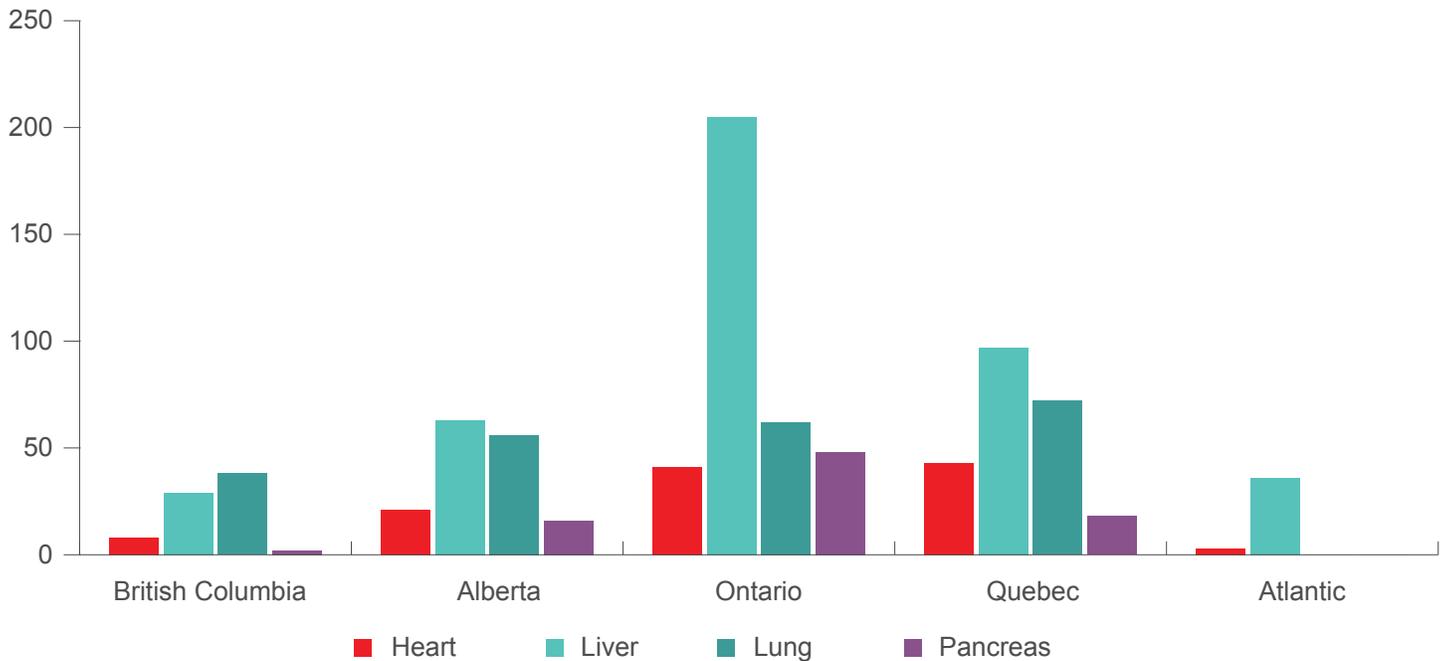
Results as of December 31, 2018.

Active requests



Of the 851 transplant candidates who were active at the end of 2018, 14% required a heart transplant, 51% required a liver transplant, 27% required a lung transplant, and 10% required a pancreas transplant. These proportions are typical for the NOW in general.

Active candidates by transplant program province and organ²



² The National Organ Waitlist does not contain centre level information for Quebec patients. Quebec patients are all listed under Transplant Quebec. The eight British Columbia heart transplant candidates are patients of St. Paul's Hospital and B.C. Children's hospital; the transplant program for all other B.C. candidates is Vancouver General Hospital. The transplant program for all Alberta patients is the University of Alberta Hospital, and the program for all Atlantic patients is Queen Elizabeth II.

Not all provinces have transplant programs for all organs. See Appendix 5 for breakdown of the active transplant candidates at year-end by province and transplant program, as well as notes concerning interprovincial patient registrations.

Among the 768 candidates who were in need of a heart, lung or liver transplant at the end of 2018, two-thirds (67%, n = 515) had been waiting for less than a year, with two-thirds (67%, n = 56) of candidates in need of a pancreas transplant having been waiting for less than two years. Many candidates have been waiting considerably longer, with 30 (4% overall) transplant candidates having been listed prior to 2014.

Time from listing to transplant for heart, lung, liver, and pancreas transplant recipients³, 2018



³ Results based on initiation of listing as recorded in CTR and date associated with the recipient's organ request being deactivated in CTR due to transplant. Results are limited to patients "transplanted" in 2018. While these results may provide insight into the transplant wait times in general terms, they are provided as a reference only; their accuracy as a representation of actual program activity is limited.

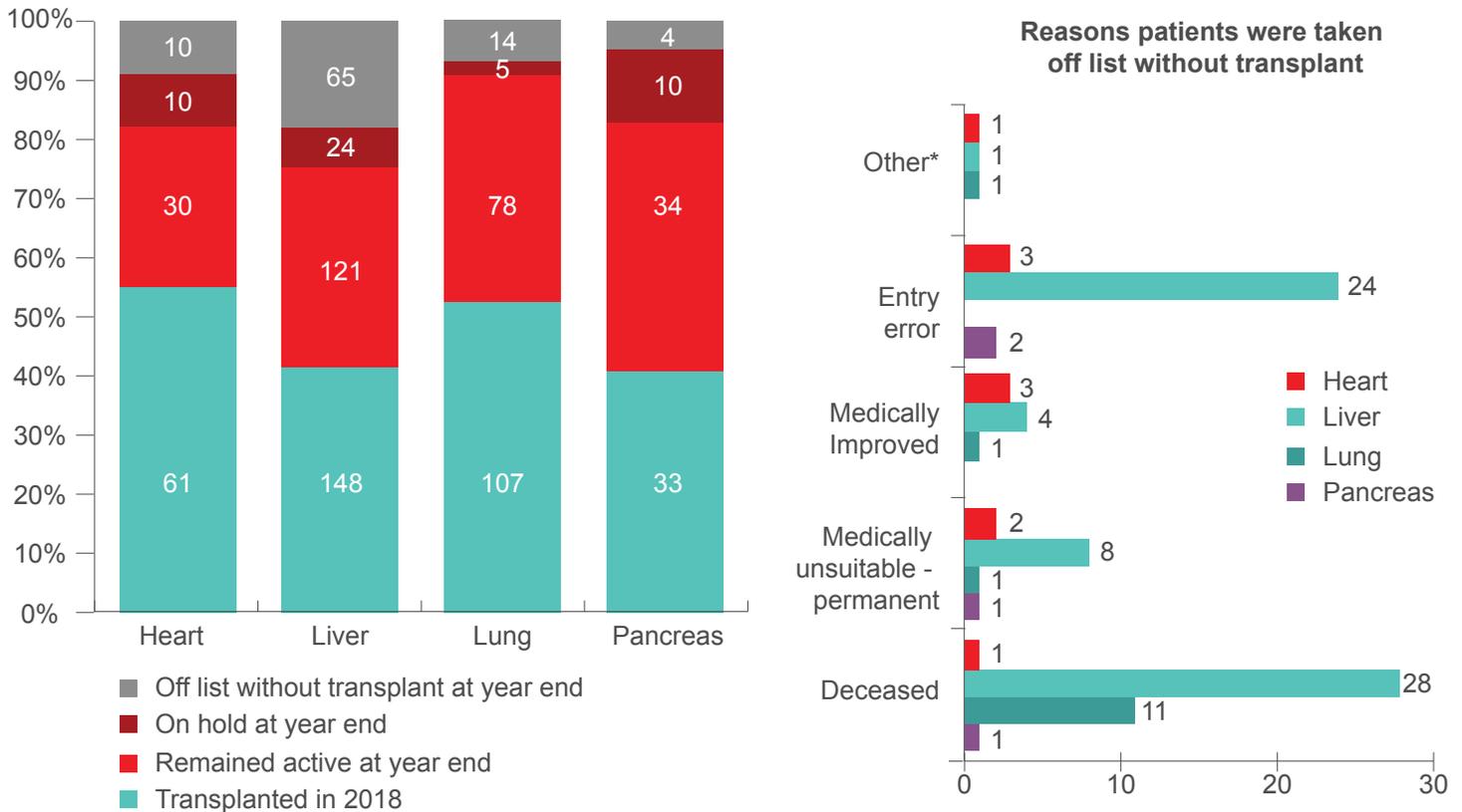
The NOW is primarily utilized to capture the critical information necessary to manage the national wait list for those in need of a heart, lung, liver, pancreas, intestine, or stomach transplant, with extremely little information available regarding transplant procedures themselves or post-transplant outcomes; nevertheless, CTR records relating to recipient activity can be used to estimate transplant wait times. It should be noted that there are known issues with respect to the precision and accuracy of relying on NOW data for this purpose, and these results are provided for reference only.

Based on a review of CTR records, 193 heart transplant cases, 362 liver transplant cases, 525 lung transplant cases, and 93 pancreas transplant cases were identified as having taken place in 2018 based on the dates associated with candidate organ requests being inactivated due to transplant.⁴ On the basis of this operationalization, the median times to transplant for heart, lung, and liver recipients in 2018 were 75 days, 71 days, and 95 days, respectively. The median time to transplant for pancreas recipients was 123 days, or just longer than four months.

⁴ Despite minor discrepancies, these totals are generally consistent with the total transplants reported nationally for these organ groups in 2018 as part of Canadian Blood Services' survey of Canadian organ donation organizations, conducted in cooperation with the Canadian Institute of Health Information's Canadian Organ Replacement Register. For validated results that more accurately reflect program activity, please consult Canadian Blood Services' 2018 System Progress Report.

One-year participation outcomes based on 2018 cohort: State of organ request at year end

In 2018, 223 transplant candidates died while on the waitlist. Additionally, transplant candidates can be taken off the list due to changes in their medical status, particularly in cases where the patient becomes too ill for transplant. Patients may be removed from the list for this reason in advance of death relating to organ failure rather than remaining on the NOW up until the point of death, and CTR records may not be updated to reflect patients' conditions after being taken off the list. As such, the reasons provided for being taken off the list will underestimate the actual number of patients who died without receiving a transplant. At present, there are no defined acceptable rates for entry errors in the Canadian Transplant Registry; however, the current amount of patient records entered in error is within generally accepted limits at less than 4%.



* Other category includes "Decision Not To Proceed at This Time - Patient Choice" (Heart), "Unsuitable for Transplant – Psychological" (Liver), and "Other" (Lung)

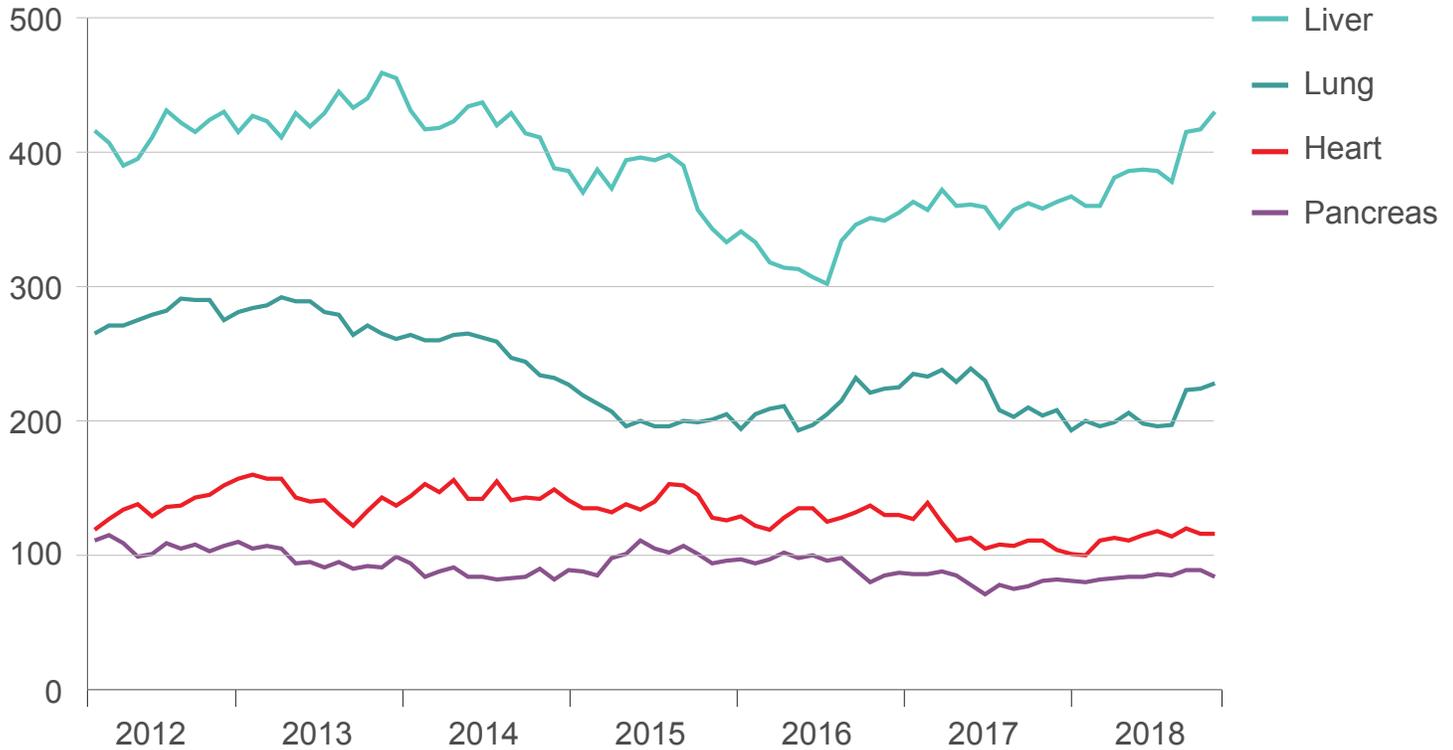
As of the end of 2018, the CTR had listed more than 10,000 organ requests (i.e. individual patients requesting one or more organ for transplant; subsequent listing for the same patient are counted as distinct requests). The results presented above are based on a sample of 752 heart, lung, liver, and pancreas transplant candidates who were active at the start of 2018 and shows the state of their organ request as of the end of 2018. An additional patient who was active at the start of 2018 received an intestine transplant (not included in the results above).

Based on CTR records of reasons patients were removed from the waitlist, 41% of both liver and pancreas candidates active at the start of 2018 received a transplant, more than half of heart candidates (55%) and of lung candidates (52%) received their respective transplants.

By the end of 2018, 262 (35%) of the cohort were still active on the waitlist, while an additional 48 (7%) changed their status to on hold. More than half of these patients (26) were placed on hold because of their availability, with the reason provided in the CTR for the request being on hold in most cases being temporary medical unsuitability or medical improvement.

The gap between transplants performed and persons on waitlist has narrowed significantly between 2008 (2,077 transplants performed and 4,380 people on the waitlist, for a difference of 2,303) and 2018 (2,829 transplants performed and 4,351 people on waitlist, for a difference of 1,522).

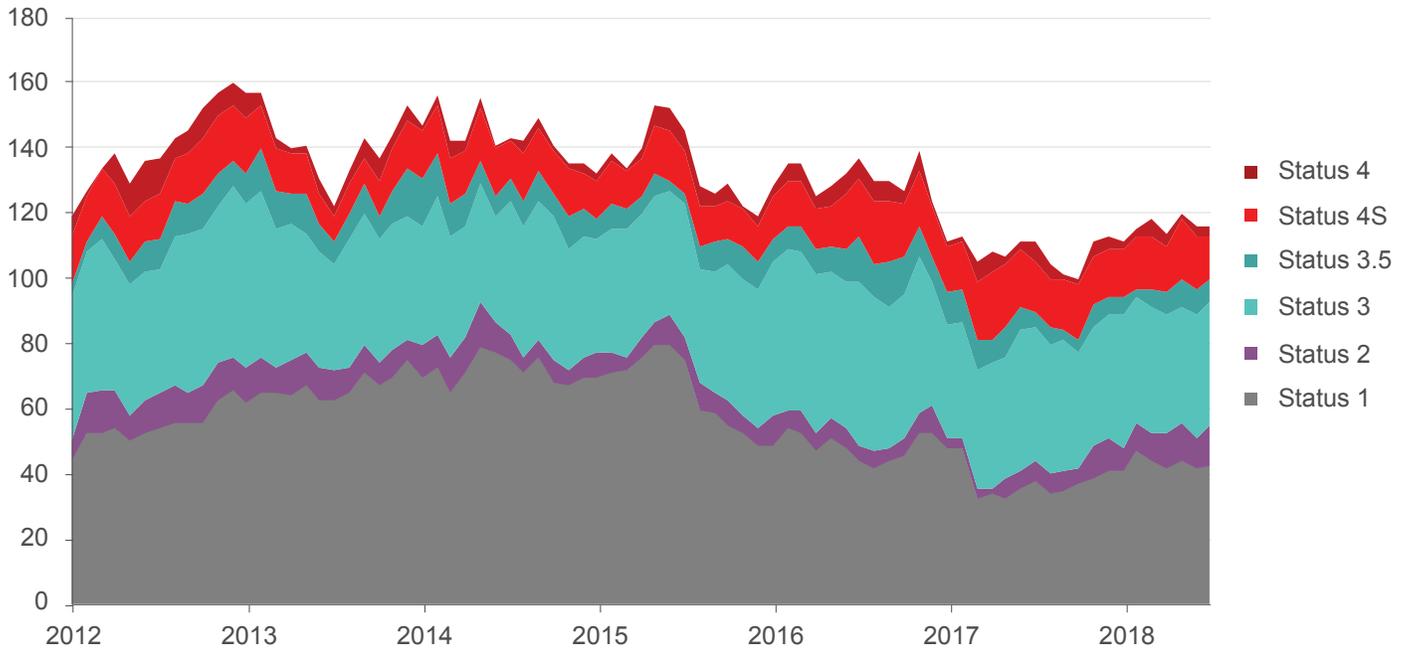
Active transplant candidates over time by organ



The number of transplant candidates with active requests for each of these organs increased between the start and end of 2018, most notably lung patients (a 13% increase) and liver patients (a 21% increase), although both remain at levels that are consistent with previous years.

Heart, lung, and liver transplant candidates are assigned a medical status rating to represent the condition of the patient and the urgency of their need for a transplant based on such factors as medical urgency, sensitization, treatments, and other related factors. In general, the higher the status number, the greater the level of priority that a transplant candidate is afforded. Descriptions of the medical status categories are provided in Appendix 2 (heart transplant candidates) and Appendix 3 (lung/liver transplant candidates).

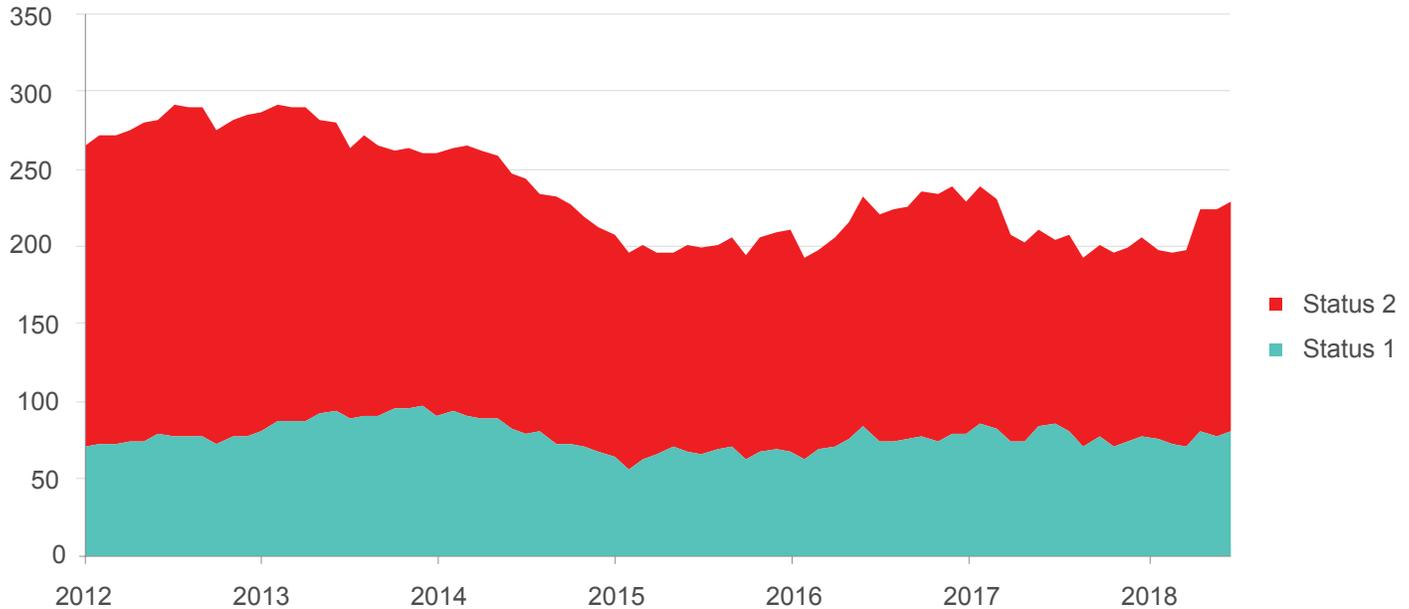
Active heart transplant candidates over time by medical status



Among heart patients, it is typical that 5% or fewer are assigned as Status 4, denoting the highest level of medical urgency. Patients who are given a rating of 4S due to their sensitization profile, which determines how difficult they are to match, had historically made up approximately 9% of heart candidates; however, since late 2016, 4S patients have made up 10% to 20% of active heart candidates.

Please see Appendix 2 for definitions of heart patient medical status ratings.

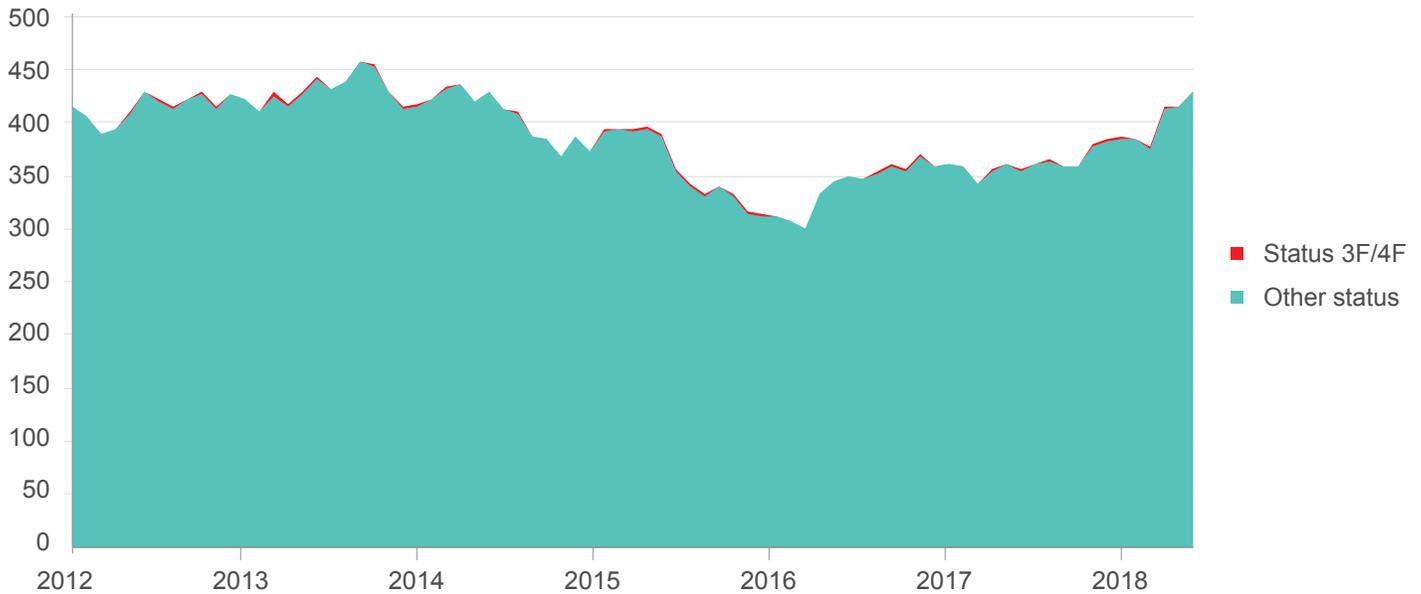
Active lung transplant candidates over time by medical status



The majority of active lung patients are assigned as Status 2, indicating that they are clinically deteriorating; however, the proportion of lung patients assigned a medical status of 1 (denoting clinical stability) has been increasing. Overall, the number of active lung candidates listed has declined over the last six years. Status 2 lung patients have seen the most significant drop. Status 2 listings have gone down 35% since 2013.

Please see Appendix 3 for definitions of lung patient medical status ratings.

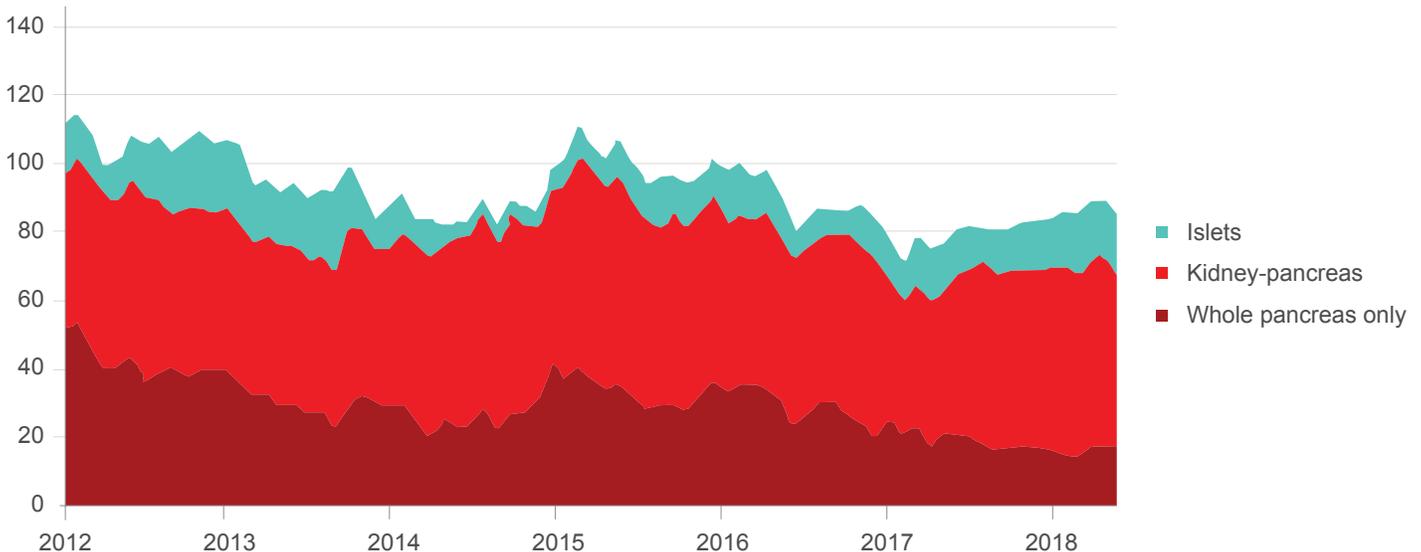
Active liver transplant candidates over time by medical status (3F/4F and other)



From the initiation of the registry until mid-2014, the number of active liver transplant candidates remained relatively stable with 425 ± 35 candidates active at any given time. The number of active patients then decreased to approximately 300 over the next 20 months, and from mid-2016 to the end of 2018 the number of active candidates increased to its former level with 430 active candidates at the end of 2018. In general there have been three or fewer candidates active at any given time with a medical status of 3F or 4F.

Please see Appendix 3 for definitions of liver patient medical status ratings.

Active pancreas transplant candidates over time by request type



At the initiation of the NOW, there were more than 50 transplant candidates listed for a whole pancreas transplant without a simultaneous kidney transplant; however, the number of these candidates who are active in the waitlist has decreased over time, with 2018 generally seeing 20 or fewer. Patients in need of other types of pancreas transplant are represented with greater consistency in the NOW. At any given time there are typically between five and 25 pancreas islet transplant patients active on the NOW and 50 ± 12 patients who are waiting for a multi-organ kidney pancreas transplant. Currently, the majority of active patients listed for a pancreas transplant require a kidney-pancreas multi-organ transplant (60%), with an additional 19% listed for pancreatic islets.

Appendix 1: Glossary

ABO (or Blood Group)

A term used interchangeably with “blood group”. For example, ABO-O refers to blood group O whereas ABO-B refers to blood group B.

Active

Any donor or candidate record that is ready for matching in the registry.

Blood Group

See ABO.

Canadian Transplant Registry (CTR)

A web-based database for interprovincial listing of donors and potential recipients and for allocating the donor organs to the recipients. It is operated by Canadian Blood Services and supports the Kidney Paired Donation (KPD) registry, the Highly Sensitized Patient (HSP) registry for high-cPRA kidney transplant candidates and the National Organ Waitlist (NOW) for non-renal transplant candidates.

Candidate (or Transplant Candidate)

A patient who needs a solid organ transplant and who is registered in the Canadian Transplant Registry (CTR).

Calculated Panel Reactive Antibody (cPRA)

A population-based estimate of the percentage of donors that will be incompatible with a given candidate due to the presence of antibodies.

Donor

A person, either living or deceased, who provides cells, tissues, or organs for transplantation.

List dates

The date at which a transplant candidate is added to the organ transplant waiting list of a provincial program for a given organ request.

Sensitization

The degree to which a transplant candidate has detectable circulating antibodies which will attack foreign tissue, such as a transplanted organ.

Ventricular Assist Devices (VAD)

A mechanical pump that supports heart function and blood flow for patients with weakened hearts by pumping blood from a lower heart chamber, simulating the natural action of a heart.

Waitlist

A list of patients who are qualified and registered by a transplant program and who are waiting to receive an organ transplant.

Appendix 2: Criteria for heart medical status ratings

Status criteria for adult cardiac transplantation (Canadian Cardiac Transplant Network, 2012)

Status 4

- 1) Mechanically ventilated patient on high-dose single or multiple inotropes ± mechanical support (e.g. Intra-aortic balloon pump, extra-corporeal membrane oxygenation (ECMO), abiomed BVS5000, or biomedicus), excluding long-term ventricular assist devices (VAD).
- 2) Patient with VAD malfunction or complication, such as thromboembolism, systemic device-related infection, mechanical failure, or life-threatening arrhythmia.
- 3) Patient should be recertified every seven days as a Status 4 by a qualified physician, if still medically appropriate.

Status 4S

- 1) High PRA (>80%).

Status 3.5

- 1) High-dose or multiple inotropes in hospital, and patients not candidates for VAD therapy or no VAD available.
- 2) Acute refractory ventricular arrhythmias.

Status 3

- 1) VAD not meeting Status 4 criteria.
- 2) Patients on inotropes in hospital, not meeting above criteria.
- 3) Heart/lung recipient candidates.
- 4) Cyanotic congenital heart disease with resting saturation <65%.
- 5) Congenital heart disease – arterial-shunt-dependent.
- 6) Adult-sized complex congenital heart disease with increasing dysrhythmic or systemic ventricular decline.

Status 2

- 1) In-hospital patient, or patient on outpatient inotropic therapy not meeting the above criteria.
- 2) Adult with cyanotic CHD: resting O₂ saturation 65-75% or prolonged desaturation to less than 60% with modest activity (i.e., walking).
- 3) Adult with Fontan palliation with protein-losing enteropathy.
- 4) Patients listed for multiple organ transplantation (other than heart-lung).

Status 1

All other out-of-hospital patients.

Appendix 3: Criteria for liver and lung medical status ratings

Lung status ratings

A Review of Listing and Allocation Criteria for Lung Transplantation, 2008 (Canadian Council for Donation and Transplantation Working Document)

Status 2

Actively listed and clinically deteriorating.

Status 1

Actively listed and clinically stable.

Note: Status 0 would denote a patient who is accepted for transplant/not actively listed.

Liver status ratings

2008 Listing and Allocation Practices for Liver Transplantation in Canada (Canadian Council for Donation and Transplantation Working Document)

Status 4F

Patient in an ICU and intubated due to FHF (includes primary graft non-function).

Status 3F

Patient in an ICU or equivalent care facility due to FHF, but not requiring intubation, and fulfills the King's College criteria for high mortality without transplantation.

Appendix 4: List of Canadian transplant programs

Information regarding Canadian programs reported by the Canadian Society of Transplantation.

	Transplant Program	Organs Transplanted
British Columbia	B.C. Children's Hospital	Kidney, Heart, Liver
	St. Paul 's Hospital	Kidney, Heart
	Vancouver General Hospital	Kidney, Liver, Lung, Pancreas/Kidney-Pancreas, Islet Cell
Alberta	Alberta Children's Hospital	Kidney
	Foothills Medical Centre Site	Kidney, Pancreas/Kidney-Pancreas
	University of Alberta Hospital	Kidney, Liver, Heart, Heart/Lung, Lung, Intestine/Multi-Visceral, Pancreas/Kidney–Pancreas, Islet Cell
Saskatchewan	St. Paul 's Hospital	Kidney
Manitoba	Children's Hospital of Winnipeg	Kidney
	Health Sciences Centre	Kidney, Heart/Lung, Lung
Ontario	London Health Sciences Centre	Kidney, Liver, Heart, Pancreas/Kidney-Pancreas
	St. Joseph's Health Care System	Kidney
	Hospital for Sick Children	Kidney, Liver, Heart, Lung
	St. Michael's Hospital	Kidney
	Toronto General Hospital	Kidney, Liver, Heart, Lung, Intestine/Multi-Visceral, Pancreas/Kidney–Pancreas
	Kingston General Hospital	Kidney
	The Ottawa Hospital	Kidney
	University of Ottawa Heart Institute	Heart
Québec	C.H. de l'université de Montréal, Notre Dame	Kidney, Lung, Pancreas/Kidney–Pancreas
	C.H. de l'université de Montréal, St.-Luc	Liver
	Hôpital Maisonneuve-Rosemont	Kidney
	Hôpital Ste-Justine	Kidney, Liver, Heart
	Institut de Cardiologie de Montréal	Heart
	Montreal Children's Hospital	Kidney
	Royal Victoria Hospital	Kidney, Liver, Heart, Pancreas/Kidney–Pancreas
	C.H. universitaire de Sherbrooke	Kidney
	C.H. universitaire de Québec	Kidney
Institut Universitaire De Cardiologie	Heart	
Atlantic	IWK Health Centre	Kidney
	Queen Elizabeth II Health Sciences Centre	Kidney, Liver, Heart, Pancreas/Kidney–Pancreas

Appendix 5: Active transplant candidates on the National Organ Waitlist as of year-end 2018

	Program	Heart	Liver	Lung	Pancreas	Intestine
British Columbia	B.C. Children's Hospital	1				
	St. Paul's Hospital	7				
	Vancouver General Hospital		29	38	2	
Alberta	University of Alberta Hospital	21	63	56	16	1
Ontario	London Health Sciences Centre	1	19		4	
	Ottawa Heart Institute	15				
	Hospital for Sick Children	14	18	1		3
	Toronto General Hospital	11	168	61	44	
Québec	All programs	43	97	72	18	
Atlantic	Queen Elizabeth II	3	36			
Total		116	430	228	84	4

Transplant candidates from Manitoba requiring a heart or lung transplant ($n = 15$) were referred to the University of Alberta Hospital in Edmonton or the Ottawa Heart Institute, while those requiring a liver transplant ($n = 13$) were referred to Toronto General Hospital or the Hospital for Sick Children as appropriate. Of the 19 patients requiring various organ transplants from Saskatchewan, almost all were referred to the University of Alberta Hospital. In some cases, patients were referred to the Ottawa Heart Institute. Heart patients from Newfoundland and Labrador were referred to the Ottawa Heart Institute, while Heart patients from Nova Scotia and New Brunswick remained as patients with the Queen Elizabeth II program in Halifax, and lung patients from these provinces were referred to the program at Toronto General Hospital.