

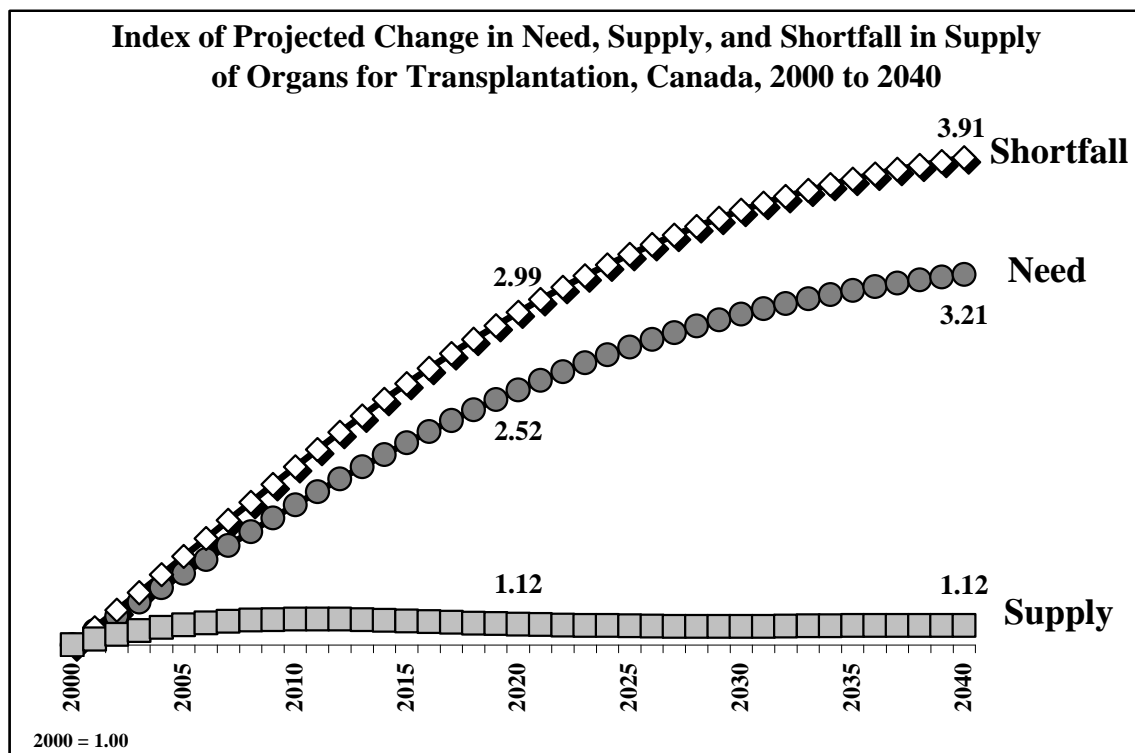
The Urban Futures Institute

Research on Population, Community Change and Land Use

Donation Matters:

Demographics and Organ Transplants in Canada, 2000 to 2040

by David Baxter and Jim Smerdon



The Urban Futures Institute Report 46

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2040**

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**June 2000
ISBN 1-894486-32-3**

The authors wish to thank the British Columbia Transplant Society for all of its assistance in providing data and information on solid organ transplants in Canada. All responsibility for the tabulation and analysis of the information, and the projections and conclusions based on it, is solely that of the authors.

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Donation Matters:

Summary

The continuation of current demographic trends (declining birth and death rates and an aging population) combined with the rapidly growing need for transplants and projected organ donation rates will lead to an ever widening shortfall between the need for, and supply of, organs for transplantation. This transplant gap will increase from this year's estimated 5,441 people whose transplant needs are unmet to 16,250 by 2020 (a 199% increase), and to 21,265 by 2040 (a 291% increase).

The aging of Canada's population, accompanied by continuing increases in non-demographic factors such as the incidence of diabetes and hepatitis C, will lead to an 152% increase in need over the next two decades (from 7,247 this year to 18,278 in 2020) and a 221% increase over the next 4 decades (to 23,280 in 2040). The rapid growth of Canada's older population and the slow growth of its younger population, combined with a continued decline in mortality rates to causes that permit organ transplantation and continued increase in live donation rates, will lead to a much slower growth in supply over the same period. Under this trend scenario, the number of organs donated for transplant will increase by 12% over the next two decades (from 1,806 in 2000 to 2,028 in 2020) and next four decades (to 2,015 in 2040). The result of a 221% increase in need and a 12% increase in supply will be a 291% increase in the transplant gap, widening it to a chasm.

If the gap is to be narrowed, rather than to widen, it will be necessary to significantly increase the effective rates of donation and to seek non-donor solutions. In the short term, the first strategy will be most important. This will mean implementing measures to ensure that all potentially transplant-viable mortalities flow into the transplant stream by giving greater emphasis to the development of a system of routine referrals of all mortalities, greater presence of dedicated in-hospital donation specialists, a broad and effective registration system for donation consent, and much greater public education about donation.

It will also mean significant additional effort to increase live donation rates. This will be a significant challenge, as the impressive growth in live donation that has occurred in the past decade must be accelerated beyond the level of growth already assumed in the trend projection. In the longer term, bio-medical technology will continue to provide options to a reliance on organ donors. While the promise of research is great, it must be put in the context of the fact that the greatest increases in demand, at least under current trends, will occur in the next fifteen years, while technological solutions often require decades.

To prevent the widening of the gap, and even more ambitious, to narrow it, will require a wide range of efforts to make today's good transplant system an ever better one. In doing so, it may be useful to consider the practice in other countries: this must be done with great care. Other countries' higher cadaveric donation rates may not be the result of a more efficient donation system, but rather may be due to unique pattern of mortality. For example, on the surface, Spain, with a cadaveric organ donor rate of 31.5 per million population, is the leader in per capita donation rates, with the United States (22.7) coming in a distant second, and Canada (13.7) in 13th place.

Considered in more detail, the difference is not as great. Canada's live donor rate is 12.0 live donations per million population, the 4th highest after Sweden (13.5), the USA (15.8) and Norway (17.6), and far above Spain's 0.5 per million rate. Considering factors that affect Canada's cadaveric donation rate, it must be noted that Canada has a relatively low mortality rate due to causes associated with cadaveric donation: its age standardized rate of 101.2 road deaths each year per million population is far below the 142.5 per million rate of Spain and the 156.8 per million of the United States; its age standardized rate of 45.6 deaths per year per million due to cerebrovascular disease is slightly below the 48.0 per million rate of the United States and well below the 75.4 per million rate of Spain; and its mortality rate due to gunshot wounds is 35 per million per year, compared to the 126 per million of the United States. Any improvements in Canada's transplant system must acknowledge the reality of both mortality rates and live donation in Canada.

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I. Introduction.

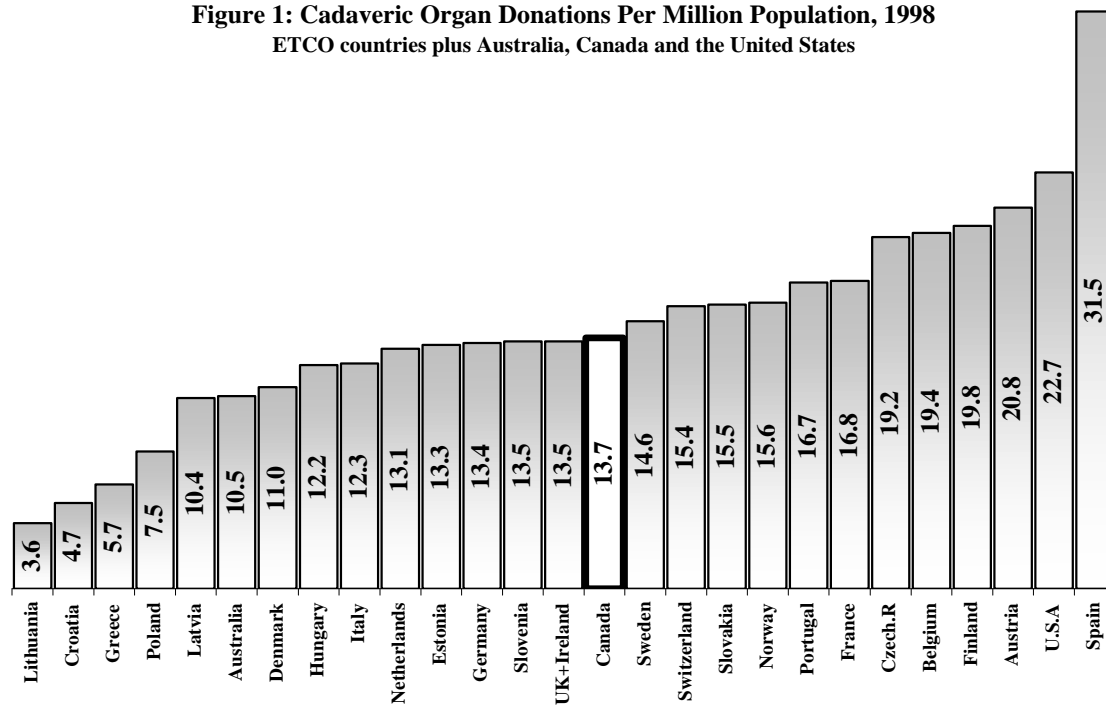
This report presents a demographically based projection of the change in the magnitude of the shortfall between the need for, and the supply of, solid tissue organs for transplants (the transplant gap) in Canada over the next four decades. From examination of current trends in organ transplant waiting lists, age specific recipient and donation rates, and the projected characteristics of Canada's population over the coming decades, it is apparent that, without major improvement in effective donation rates, the need will increase much faster than the supply. Within the next two decades, without significant increases in both the live donation rate and in the effective cadaveric donor rate, the gap will widen and deepen to become a chasm.

The report is organized into four sections, the last of which presents the projection of growth in the shortfall between the need for, and the supply of, organs for transplantation, with the first three providing the background for the projection. This first section considers data on organ transplantation rates in an international and national context. The second section reviews available data on age specific patterns of donation, receipt and need for organs for transplantation. The third section presents a summary of the population projection used in the estimation of changes in organ need and supply.

a. The International Context

It is common to use comparative statistics as the basis for judgment of the effectiveness of programs within a region. While the desire to compare is understandable, it must be done with caution and qualification, as fundamental differences socio-economic and demographic conditions between regions may invalidate conclusions drawn from simple comparisons.

Figure 1: Cadaveric Organ Donations Per Million Population, 1998
ETCO countries plus Australia, Canada and the United States



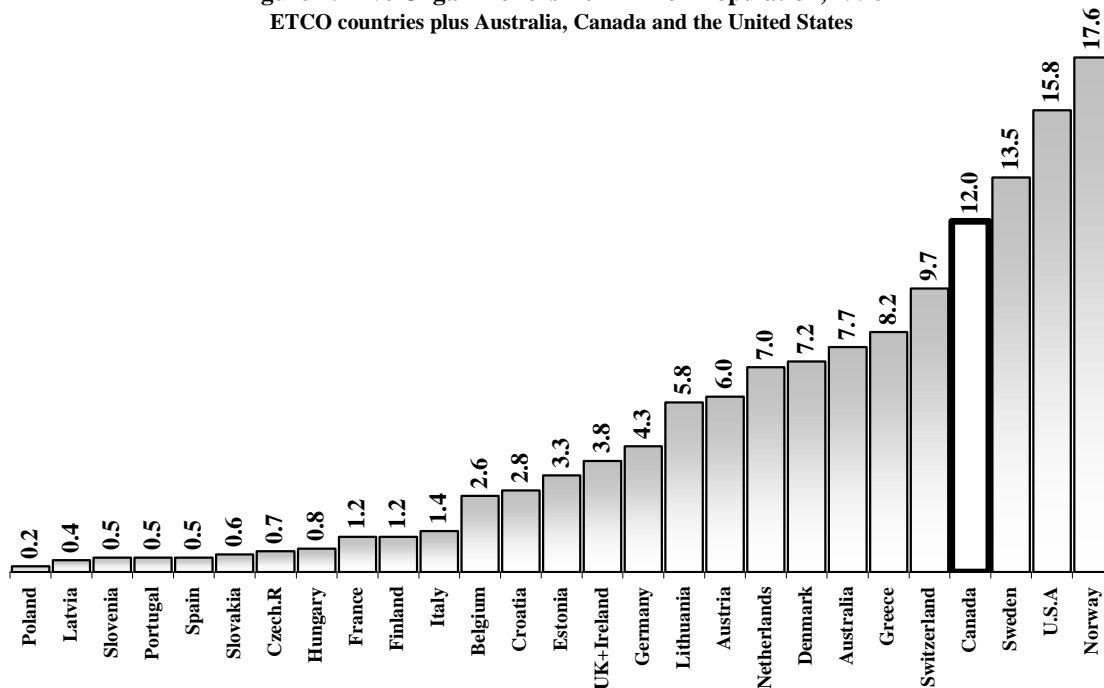
For example, recently, the organ donation rate in Canada has been compared unfavorably with those of other countries¹, with higher donor rate countries such as Spain cited as targets that should be aimed for and as a source of programs that should be emulated². Assuming that the same definition of a donation is used in all nations, Spain, with an organ donor rate of 31.5 per million population, is far and away the leader in per capita rates, with the United States (22.7) coming in a distant second, and Canada (13.7) in 13th place (Figure 1)³. While this fact may be uncontested, much in the way of qualification must be made before any judgment as to the superiority of Spain, or any other region, may be made from this data.

The first qualification is that the definition of donation used in the data is not the same for all countries⁴. The reference to Spain's superior rate is solely within in the context of cadaveric donation: the data for Spain include all instances where permission for a cadaveric donation is given, even if no transplant subsequently occurs, and hence is a nominal donor rate. The data for the United States includes those instances where permission is obtained and where an organ is recovered, regardless of whether or not a transplant subsequently occurs. The data for Canada includes only those instances where a transplant occurs: the rate for Canada is a transplant, or effective donor, rate. If, in Spain and the United States, all cases included in the data ultimately lead to a transplant, the definitions are effectively the same: anything less than 100% transplant to permission/organ recovery ratio will mean that the nominal donor rates for Spain and the USA are overstated relative to Canada's effective transplant rate.

The second qualification is that cadaveric donation is not the only source of organs for transplants: live donation is also an important source (Figure 2)⁵: in Norway, for example, the live donor rate is higher than the cadaveric rate. In this context, Canada ranks much higher than in the cadaveric donation context, ranking 4th with a donation rate of 12.0 per million, following Norway, The United States, and Sweden. [Note that the live donation rate in Spain, 0.5 per million, is one of the lowest in the data set. Combining live and cadaveric rates, Canada ranks in 6th place, with a total donation rate of 25.7 per million, following the United States (38.5),

Norway (33.2), Spain (32), Sweden (28.1), and Austria (26.8).]

Figure 2: Live Organ Donors Per Million Population, 1998
ETCO countries plus Australia, Canada and the United States

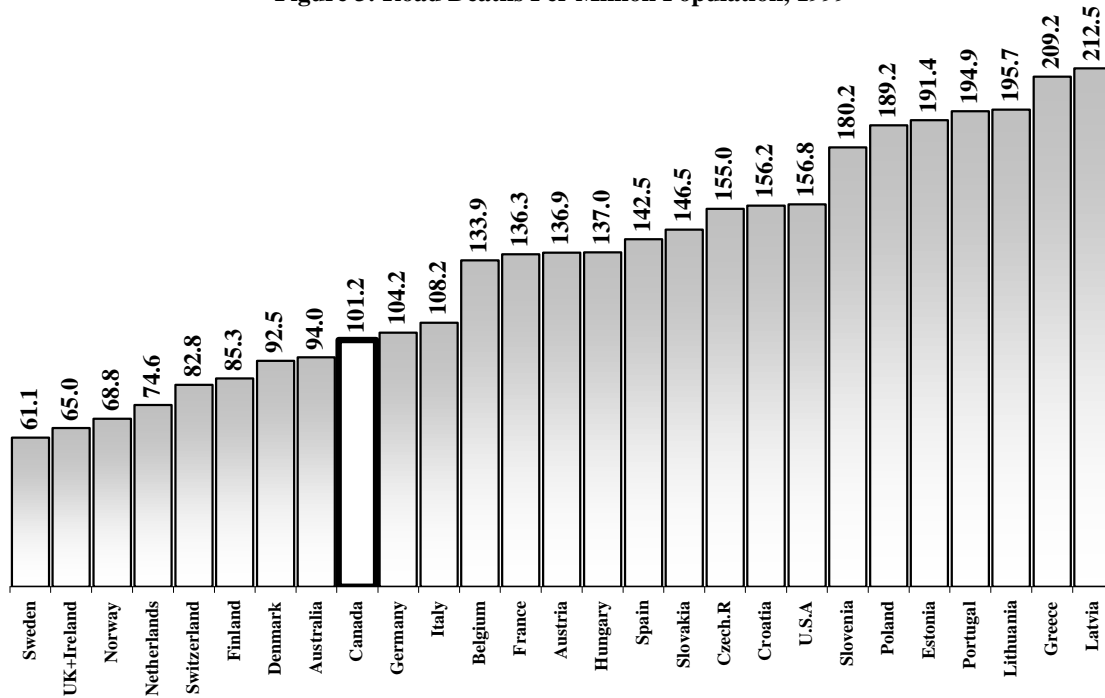


Live organ transplant rates are determined by many factors, including availability of medical infrastructure to carry out transplants, cultural attitudes, effectiveness of transplant awareness programs, family size, strength of kinship bonds, and strength of civic identity. As well, given the strong age specific pattern of organ donation (see Section II for detailed discussion), rates must be given on an age-standardized basis. Each of these factors must be considered before judgment as to the relative merits of any one program can be made: all other things equal, a nation with widespread availability of technology, strong marketing programs, large and strongly bonded families, strong civic culture, dense concentrations of population, and a relatively large young adult population will have a higher live organ donation rate than one that does not.

Cadaveric donation rates must also be qualified by the conditions that prevail in each country. The need for such qualification results from the particular requirements for cadaveric donation eligibility: for a solid organ to be used in a transplant, the donor must die on a ventilator in a hospital, must be certified as brain dead, and must be without contraindications. These medical requirements ensure that regional geographical, social, and economic conditions will result of differences in the relative size of the potential organ transplant pool regardless of the effects of organ recovery for transplantation programs. The relative size of the potential pool will have a significant impact on the magnitude of the donation and transplant rates.

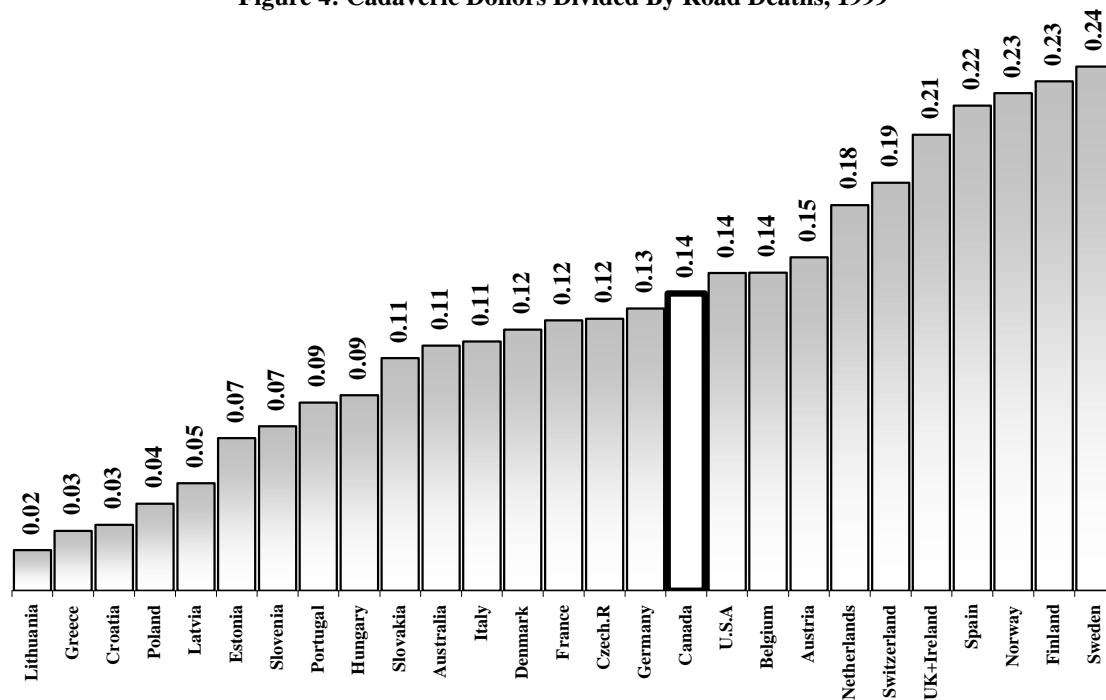
For example, consider one of the major causal factors for cadaveric donation, road accidents (Figure 3)⁶. The fact that road mortality rates in Spain (142.5 deaths annually per million) and the United States (156.8 per million) that are more than 40% higher than Canada's (101.2 per million population), certainly provides some indication that the relative size of the potential donor in these countries is much greater than that of Canada's: to the extent that this is the case, it is not surprising that they rank above Canada on a donations per population base.

Figure 3: Road Deaths Per Million Population, 1999



As an initial approach to standardization of cadaveric donation rates by country, the number of cadaveric donations per million can be divided by the number of road deaths per million to establish a ratio of cadaveric donations to road deaths (Figure 4). By this admittedly crude measure, it is generally the relatively small, highly urbanized countries of Sweden, Finland, Norway, the UK and Ireland, Switzerland, and the Netherlands, that have high ratios of cadaveric donation compared to road mortality: Canada is in the 11% to 15% range that characterizes the larger industrialized countries in the sample.

Figure 4: Cadaveric Donors Divided By Road Deaths, 1999



Spain still ranks relatively high in the list using this mortality-adjusted measure, which suggests further consideration of factors that may affect the size of the potential pool of cadaveric donors. One of these is the composition of causes of mortality in motor vehicle accidents. For example, given the significant risk of head injury in accidents involving two-wheeled transportation (bicycles, scooters, mopeds and motorcycles), the greater relative use of these forms of transportation, the greater the potential cadaveric donation rate. Of the countries included in the ETCO data, Canada has the lowest mortality rate involving two wheeled transportation (6.2 per million), almost half of the USA's 10.9 per million and a quarter of Spain's 25.8 per million (Figure 5)⁷. Canada sits roughly in the middle of the range in terms of deaths of drivers and passengers of cars, with 78.9 per million, compared to Spain's 76.1 and the United States 82.2 (Figure 6)⁸. Canada is 5th lowest in terms of pedestrian mortality, with 13.3 pedestrian deaths in road accidents per million population, compared to the USA's 19.8 and Spain's 24.6 (Figure 7)⁹. While it is not possible to prove using these data, the possibility that much of the difference between national cadaveric donation rates is the result of differences in the relative magnitude of supply rather than differences in system efficiency should not be ruled out.

A number of other factors will also affect the size of the potential supply of donors related to road accidents, including relative extent of longer distance, higher speed travel (accidents in rural areas have a higher fatality rate than those in urban areas¹⁰, but also occur at greater distance from hospitals), the age of the vehicle fleet (newer cars have more passenger safety features), fleet mix (the increasing proportion of SUVs and urban trucks in a fleet that has, in the recent past, been mainly comprised of lighter compact cars), infrastructure design, the relative proportion of trips on public transit and commercial carriers, and the age of the population. Unless all of these factors are taken into account, comparison between, for example, Spain's relatively high cadaveric donor rate and Canada's medium one or Lithuania's low one, cannot be used as the basis for identification of either a superior transplant system or an attainable donation rate.

**Figure 5: Road Cycle Deaths Per Million Population, 1999
(Bicycles, Mopeds, and Motorcycles)**

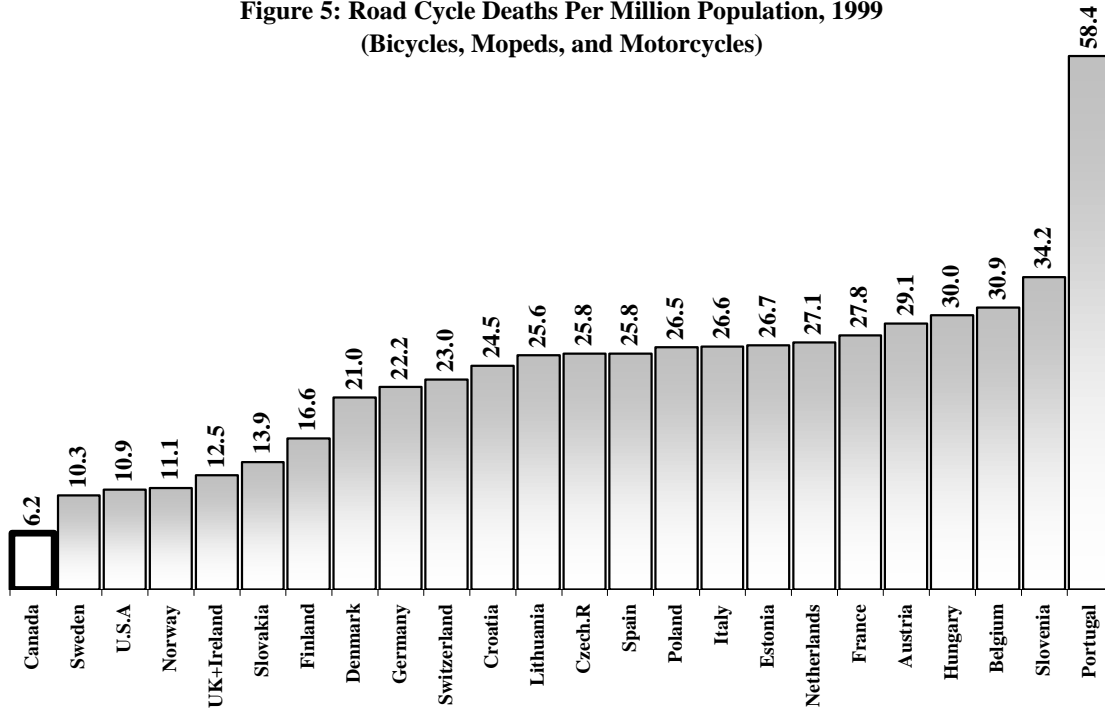
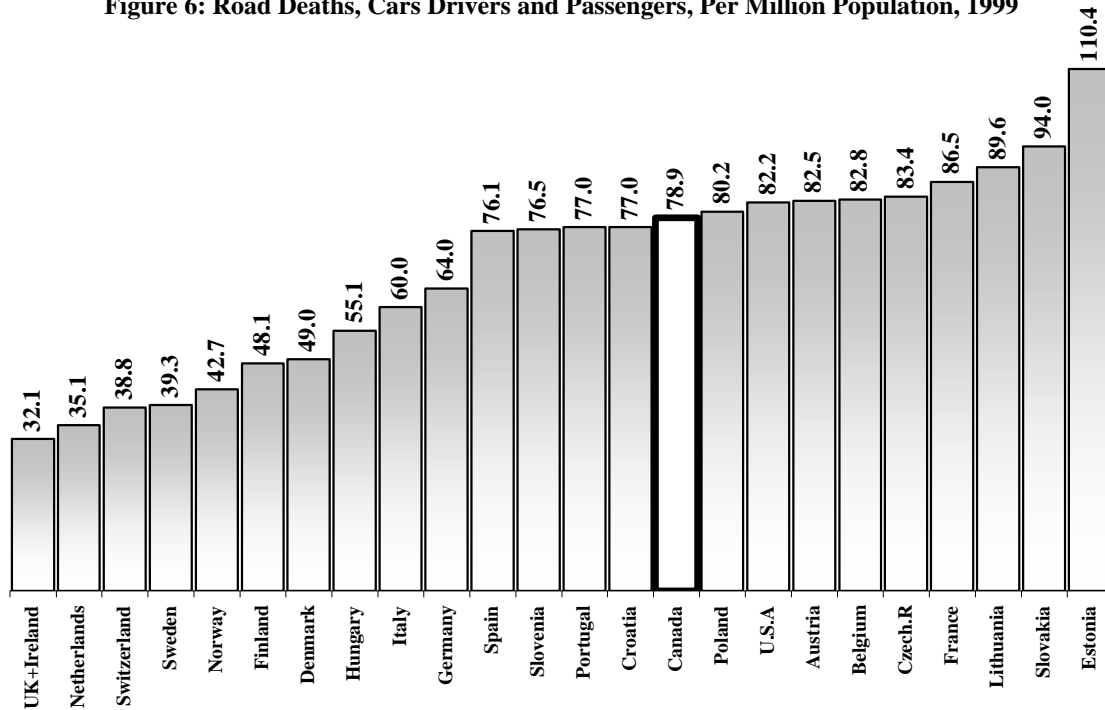
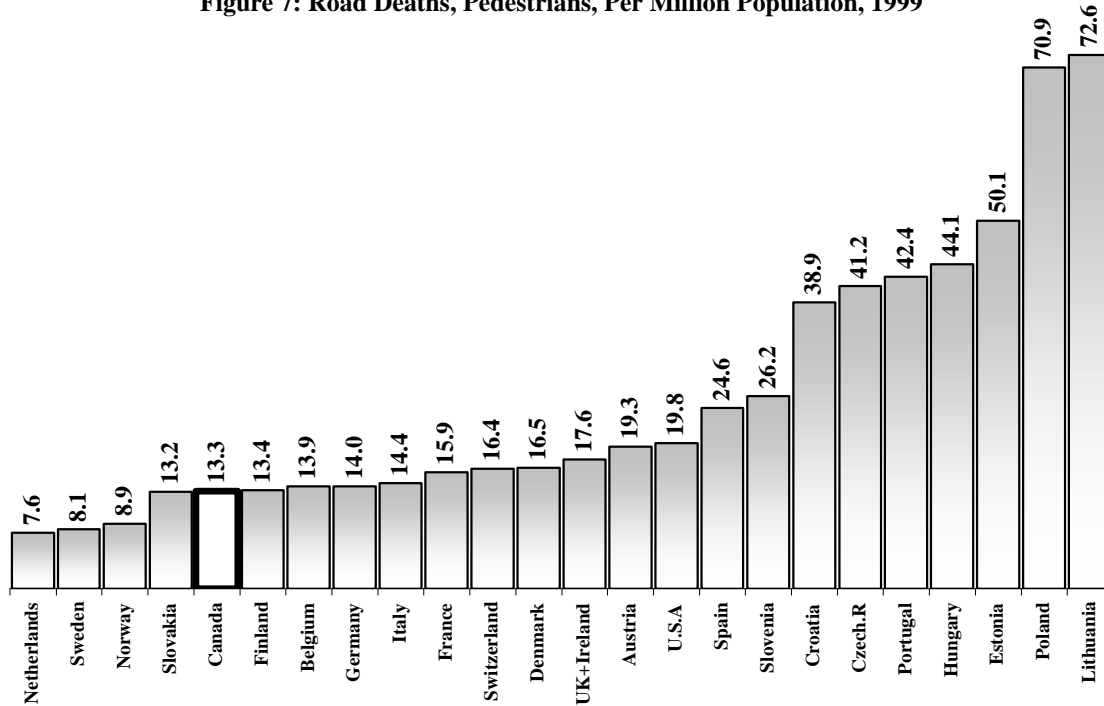


Figure 6: Road Deaths, Cars Drivers and Passengers, Per Million Population, 1999



The age composition of a population has been identified as a primary factor in both need for and supply of organs for transplantation, something that is considered in greater detail in Section II. It is useful here to briefly consider the role that age differences might play in explaining variance between cadaveric donor rates between countries.

Figure 7: Road Deaths, Pedestrians, Per Million Population, 1999



There is a common age pattern to motor vehicle accident mortality rates in almost all countries: relatively low in the under 15 age group, jumping to very high levels in the 15 to 24 age group, then gradually declining to medium levels in middle age before climbing again to high levels in the oldest age groups. This pattern is shown clearly in, for example, Spain, The United States and Canada (Figure 8)¹¹. From the perspective of organ donation, contraindications generally rule out organ donation from the 75 plus population: thus, all other things equal, when a country has a high proportion of its population in the young adult stage of the life cycle, there will be a greater number of motor vehicle mortalities than when the proportion in the high risk age group is small.

Similarly, a country with a high concentration of its population in young adult age groups will, all other things equal, have a higher motor vehicle accident mortality rate, and potentially a higher cadaveric donor rate, than one with a low concentration in these age groups. Spain, in the most recently available data (Figure 9)¹², did have a greater proportion of its population in the young adult age groups, 16% compared to Canada (14%) or the USA (14%). Noting that Spain has a much smaller proportion of its population in the under 15 population (17%, compared to 22% for the USA and 21% for Canada), it will be informative to observe the changes in the aggregate road mortality rate (per million) and the cadaveric donation rate in Spain as this smaller cohort ages into the high risk 15 to 24 age group over the next decade.

Having noted the impact that age composition will have on potential for cadaveric donation, note also that in every age group either the United States (0 to 24 and 75 plus) or Spain (25 to 74) had a higher age specific mortality rate due to motor vehicle accidents than Canada. As result, even with the same age profile as Canada, these countries would have a higher number of road mortalities per million in the population. This can be shown by using a standard population, together with national age specific mortality rates, to calculate age standardized mortality rates.

Figure 8: Male Age Specific Mortality Rate (per 100,000) Motor Vehicle Accidents, 1995

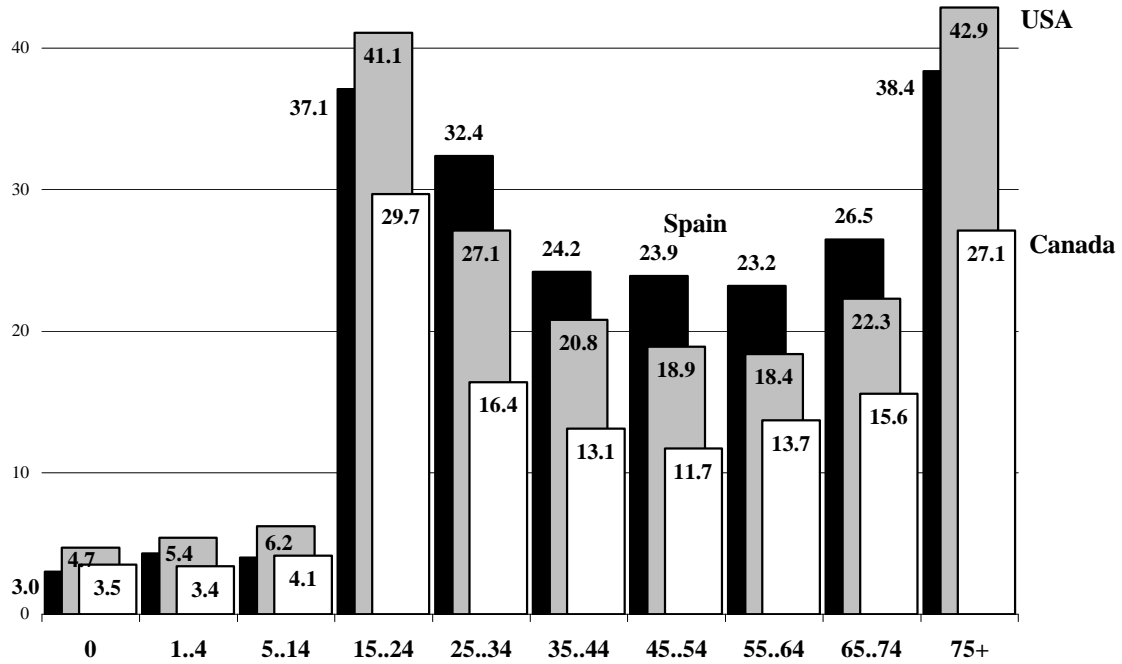
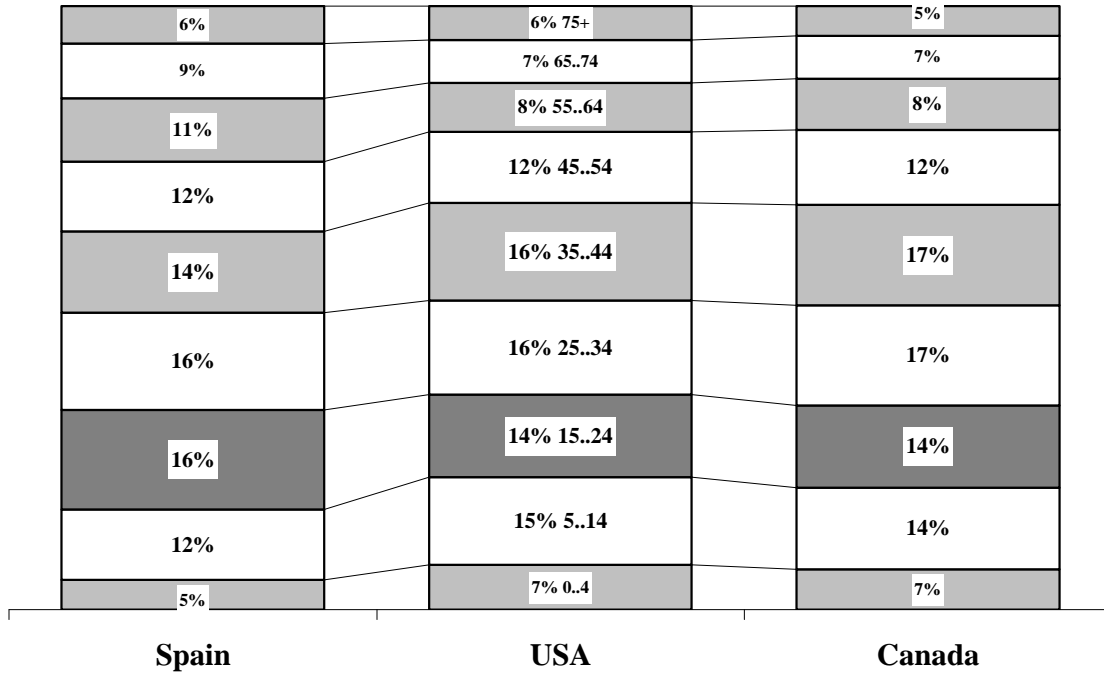
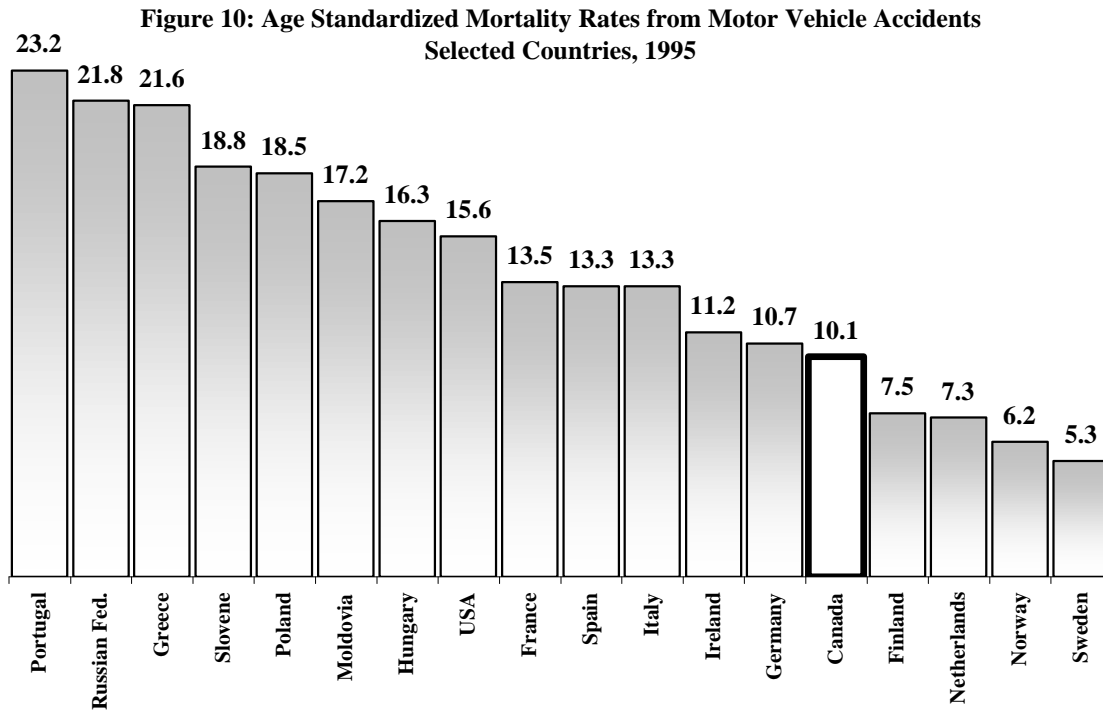


Figure 9: Population Age Composition, 1995





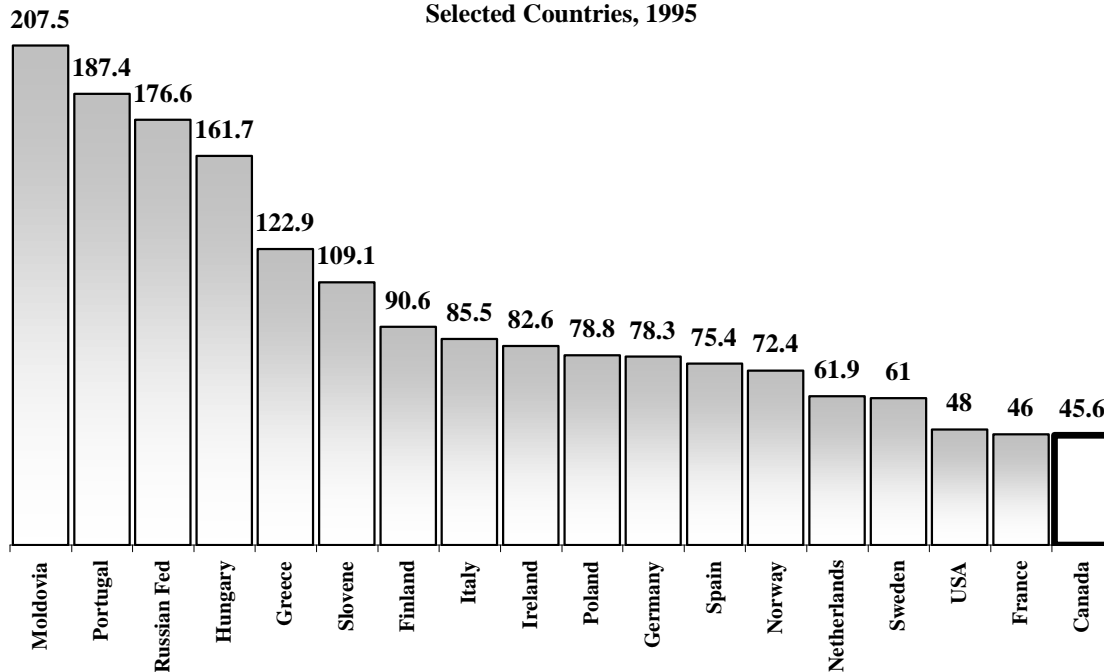
In 1995, Spain's age standardized mortality rate due to motor vehicle accidents was 30% above Canada's, and the USA's was 50% higher (Figure 10)¹³. All other things equal, it would be reasonable to presume that these countries would have a higher cadaveric donation rate than Canada. This suggests that Canada's lower cadaveric donor rate may have much to do with the relative size of the potential cadaveric donor pool: if this is the case, efforts that attempt to increase Canada's effective cadaveric donation rate to that of countries with relatively large potential donor pools will require a significantly higher level of resources and efficiency in organ donor registration, hospital notification and transplant system infrastructure.

The focus on motor vehicle mortality was to demonstrate that a wide range of factors underlies cadaveric donation rates, and that before comparison, and particularly before judgment, it is necessary to consider a wide range of factors not shown in the donation per million figures. Brief mention of three non-motor vehicle accidents causes serves to reinforce this point. The first is to note the wide range in mortality rates due to gun shot wounds that exists between countries. Eleven out of 436 cadaveric donors in Canada in 1997 were persons who died of gunshot wounds¹⁴. The mortality rate due to accidental gunshot wounds in Canada is in the range of 1.25 per million people, half of Spain's 2.5 per million, and a quarter of the USA's 5 per million¹⁵. In 1996, 34,040 people in the USA died from gunshot wounds, a rate of 126 per million: 1,067 people died of gun shot wounds in Canada in the same year, a rate of 35 per million¹⁶.

Mortality due to gun shot wounds illustrates the role that life style differences may play in the relative size of the donor pool. Another is shown in the relative incidence of mortality due to intra-cranial events (e.g., stroke, aneurysm). This is now the major source of cadaveric donation in Canada, accounting for 56% of donations compared to the 30% due to traumatic injury (e.g., motor vehicle accidents, gunshot wounds, head trauma)¹⁷. While international data at the level of strokes and aneurysm is not readily available, the data on the broader grouping of mortality due to cerebrovascular disease indicates that, again, Canada ranks relatively low on the scale of

countries with respect to mortality due to this general cause (Figure 11): its age standardized mortality rate of 45.6 per 100,000 places it 40% below Spain's 75.4 per 100,000 rate¹⁸.

Figure 11: Age Standardized Mortality Rates from Cerebro-Vascular Disease
Selected Countries, 1995



The third example relates to economic structure: the greater the degree to which a workforce is engaged in physical production, particularly in the resource industries, the greater the risk of accidental mortality. All other things equal, a country with a high proportion of its workforce engaged in farming, fishing, mining and forestry has the potential for a greater cadaveric donor rate than one with a small proportion. Having said this, the rural location of these resource-based activities may mean a greater difficulty in recovering organs from such industrial accidents.

The forgoing illustrated the wide range of factors that can affect the relative size of the potential organ donor pool, and hence donation rates. A low cadaveric donation rate per million population, in itself, indicates little: the only useful way national comparisons could be made would be in terms of the transplant rate per 1000 eligible potential donors. Given the pattern of mortality by cause in Canada, it does not seem likely that we will achieve the aggregate cadaveric rates per million population of countries such as Spain. The goal should be to have the highest possible rate per 1000 eligible donors, not merely the highest number per million population.

The fact that attaining Spain's 32 cadaveric donors per million population may not be possible in no way absolves us from striving to increase the ratio of transplants per 1000 eligible donors, particularly given the increasing shortage of organs for transplants projected for the future. If anything, while celebrating the low, and declining mortality rates due to accidents and adverse effects and due to intra-cranial events that Canada enjoys, we should do everything to ensure that the ratio of the number of transplants per 1000 eligible cadavers will increase: we must make the best possible use of a thankfully declining supply. This means continued pursuit of programs such as routine referrals of all mortalities, dedicated in-hospital donation specialists, increased public education, and registration of consent for organ donation will be increasingly important.

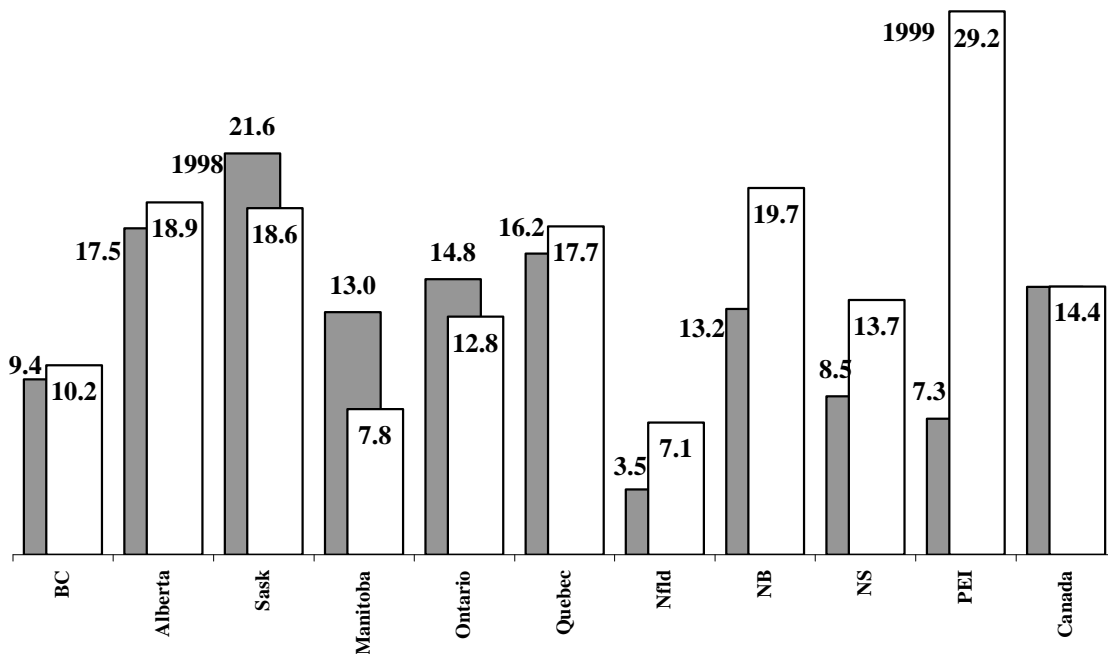
It will also mean that live donation will continue to become more important in the context of liver, kidney and lung transplants. Without denying the importance of cadaveric donation, and its paramount importance in heart transplants, it is apparent that live donation offers the potential of a growing pool of potential donors that cadaveric donation does not.

b. Provincial Comparisons

All of the caveats about comparisons of donor rates considered in the preceding section with respect to international data, plus one and minus one, must be applied in comparisons between provinces in Canada. The additional caveat for inter provincial comparisons is that the numbers of observations are so few that they are subject to significant annual variance and may not be statistically representative. The caveat that does not apply is the definitional one, as the same definition of an effective donation rate (a transplant) applies throughout the country.

The volatility that small numbers introduces is apparent even at the most aggregate level, that of total cadaveric donation (Figure 12)¹⁹. For example, over the past two years, while the national average rate per million remained relatively constant at 14.4 donors per million, the underlying rates for the provinces displayed significant variance. Saskatchewan, which had the highest rate in 1998 (21.6), dropped to 4th place behind PEI, New Brunswick, and Alberta in 1999. Clearly, when one is dealing in rates per million and provinces with a million or fewer residents, even the slightest change in number of donors becomes a significant change in the rate. Even when the population base is much bigger, such as in the provinces of Ontario and Quebec, the year to year variation is significant: Ontario's rate dropped from 14.8 in 1998 to 12.8 in 1999, while Quebec's increased from 16.2 to 17.7.

Figure 12: Cadaveric Donation Rates Per Million Population, Canada & Provinces, 1998 & 1999



When a small number of observations are involved, year-to-year change does not identify either a trend or a basis for comparison: even at the national level, swings of plus or minus 15% have been observed within the past decade (1991 to 1993). 1999's national rate of 14.4 per million falls in the middle of the range of 14.0 (1994) to 14.8 (1997) that has prevailed since 1993. With the absence of any trend in the annual rate at the national level, and given the variance that exists

at the provincial level, any comparisons should be of an average of a multiple of years.

Using 5 year moving averages (Figure 13) shows that cadaveric donor rates nationally and in Ontario have been essentially constant at 14.5 and 14.2 per million over the past decade. Rates in Alberta, Manitoba, recently in Quebec, and until recently in the Maritimes, have been above the national average, with rates in Ontario, Saskatchewan, British Columbia, until recently in Quebec, and recently in the Maritimes, below the national average. The five-year moving average rate in British Columbia has generally declined over the last decade, while those of Alberta and Quebec have generally increased.

Figure 13: Five Year Moving Average of Cadaveric Donor Rates, Canada and Regions, 1990 to 1999

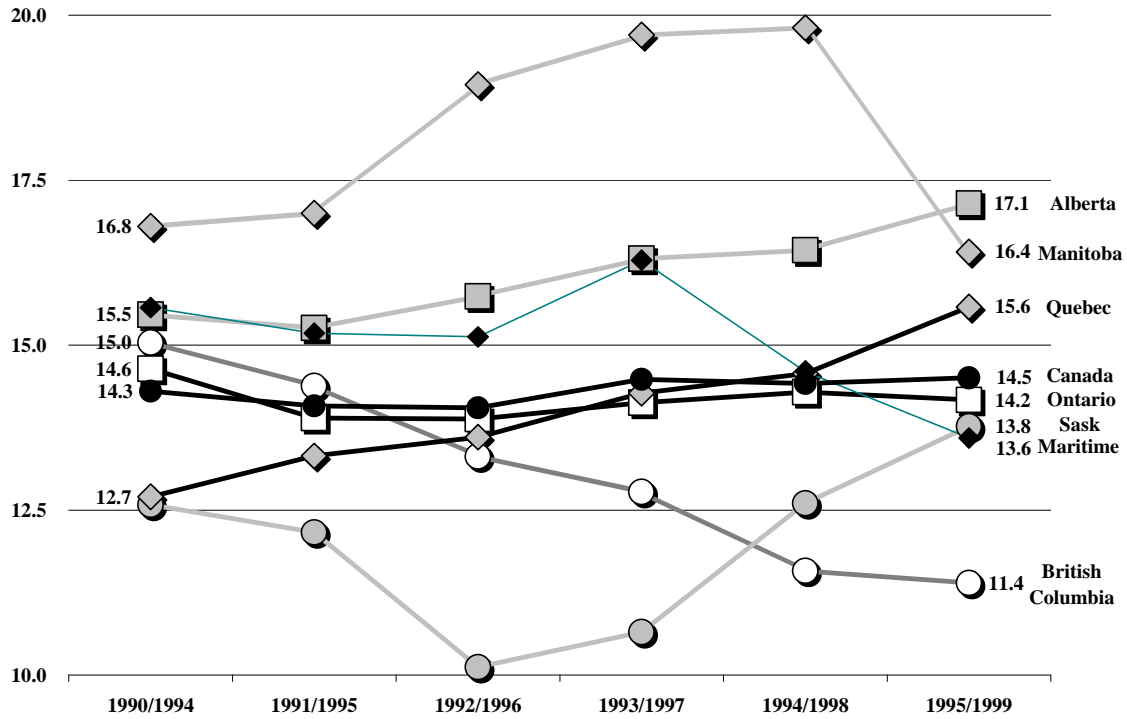
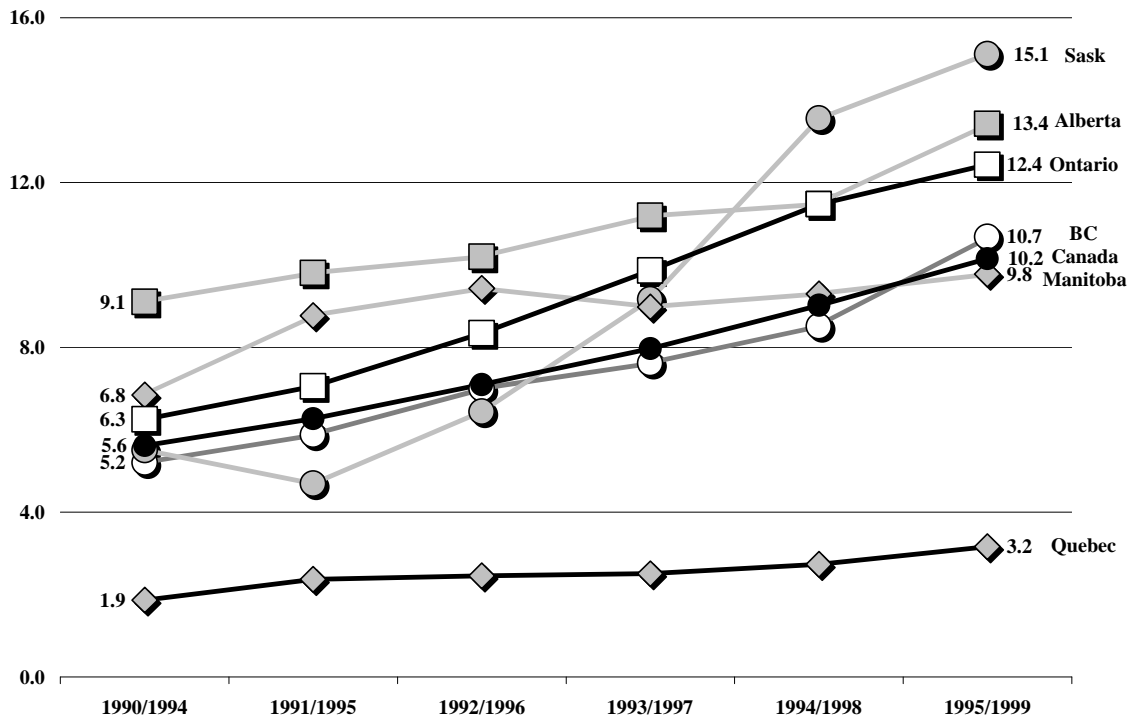


Figure 14: Five Year Moving Average of Live Donor Rates, Canada and Regions, 1990 to 1999



While the use of a moving average is also appropriate for the live donation rates, it is not necessary to spot the trends: over the past decade, in almost every year in almost every region of Canada (data not available for the Maritimes), live donor rates per million increased significantly (Figure 14). Using the five-year moving averages to remove year-to-year fluctuations shows the almost doubling of live donor rates over the past decade in Canada. Manitoba (with a 40% increase from 6.8 live donors per million average from 1990/94 to 9.8 per million in for 1995/99), Alberta (50%) and Quebec (70%) showed the smallest percentage increases in five year moving average live donor rates over the past decade, while Saskatchewan (170%), British Columbia (110%) and Ontario (100%) showed the largest percentage increases. Quebec remains with the lowest live donor rate per million (3.2), with Saskatchewan (15.1), Alberta (13.4) and Ontario (12.4) having the highest rates. British Columbia (10.7) and Manitoba (9.8) are currently at the national 10.2 average, although recent trends suggest that BC's rate is moving up faster than both the national average and Manitoba's.

As would be expected, the range between highest and lowest live donor rates between provinces within Canada is much smaller than it is between countries. Nonetheless, the same factors that cause differences in the size of the potential donor pool at the international level will affect it at the national level: factors to be considered include medical infrastructure, socio-economic differences at both the cultural and familial level, age structure of the population, and awareness of organ donation programs. Further research into these factors, and the extent to which they can be affected by policy, will be most important, as the future growth in need for organs for transplant in the face of continued declines in the potential supply of cadaveric donation will require that live donation rates be not merely maintained at their current level, but continue to grow as they have in the past. Given the law of diminishing returns is likely to apply to efforts to continue to expand live donation rates, the future level of effort in promotion of live donation will have to be significantly greater than that current expended.

As with live donation, a wide range of factors must be considered before drawing conclusions about inter-provincial differences in cadaveric donation. While most of these factors were discussed in the preceding section, brief consideration of data for Canada and its provinces is appropriate. First recall that for a mortality to hold the potential for a transplant, it must occur in a hospital on a ventilator, meet brain death criteria, and be the result of a cause of death that does not damage, or preclude the use of, solid tissues organs for transplantation. Thus geography itself will play a role in contributing to inter-provincial differences in the relative size of the potential donor pool, and hence to cadaveric donation rates: median distance to hospitals and regional characteristics of hospital infrastructure will affect the relative number of deaths that occur in hospitals. [If research funds were available, it would be useful to compare provincial rates of deaths in hospitals by cause and median distances to health facilities with ventilator capacity.]

As a proxy for direct data on hospital mortality by cause, the degree of concentration of population in metropolitan regions (Statistics Canada's Census Metropolitan Areas, CMAs) can be used (Figure 15)²⁰. Ontario (with 71.0% of its population living in CMAs), Quebec (65.7%) and Alberta (62.5%) have the greatest percentage of their populations in metropolitan regions, and hence have the greatest percentage in regions where speedy access to appropriate health care institutions prevails. The implication is that, all other things equal, higher rates of in-hospital deaths might be anticipated in Ontario, Quebec and Alberta, than in Saskatchewan, New Brunswick, and Newfoundland.

There is a range of rates of mortality due to cerebrovascular disease found in the provinces of Canada (Figure 16)²¹. Newfoundland ranks first in this regard (its age standardized annual rate of 63.9 deaths per 100,000 puts it 33% percent above the Canadian average) followed by Alberta (50.6), Manitoba (50.2), and Ontario (49.3). Quebec (44.0), Prince Edward Island (44.7) and Saskatchewan (45.4) rank lowest in terms of this rate: all other things equal, it could be reasonably anticipated that these three regions would have a lower number of eligible donors due to this cause than the top four.

Figure 15: Percent of Population in Metropolitan and Non-Metropolitan Places of Residence, Canada and Provinces, 1996

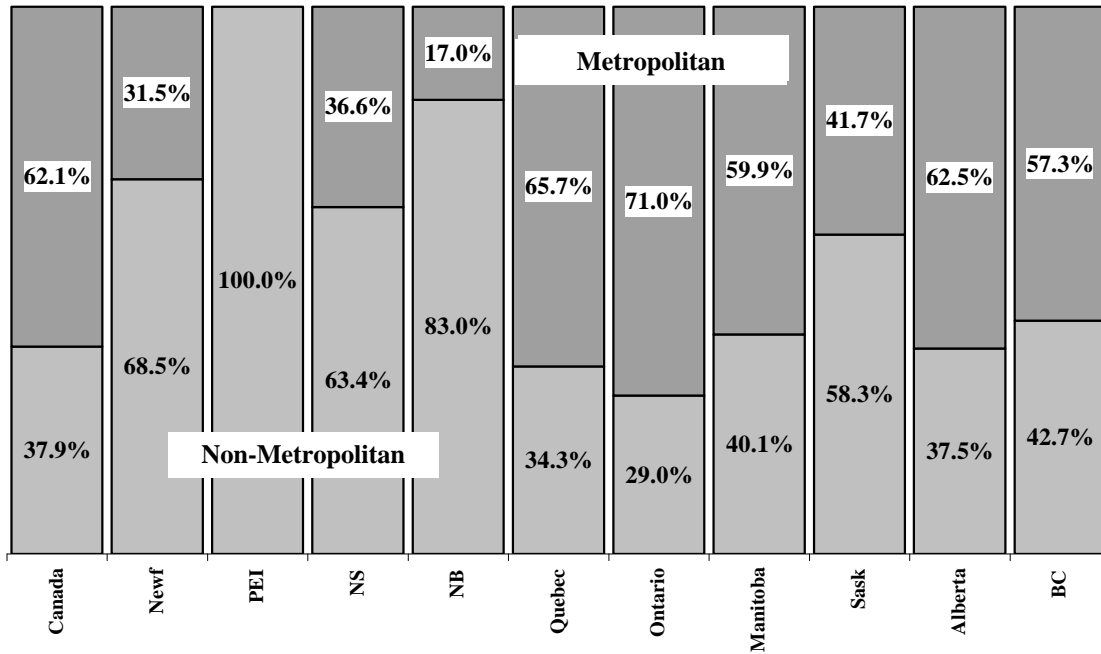
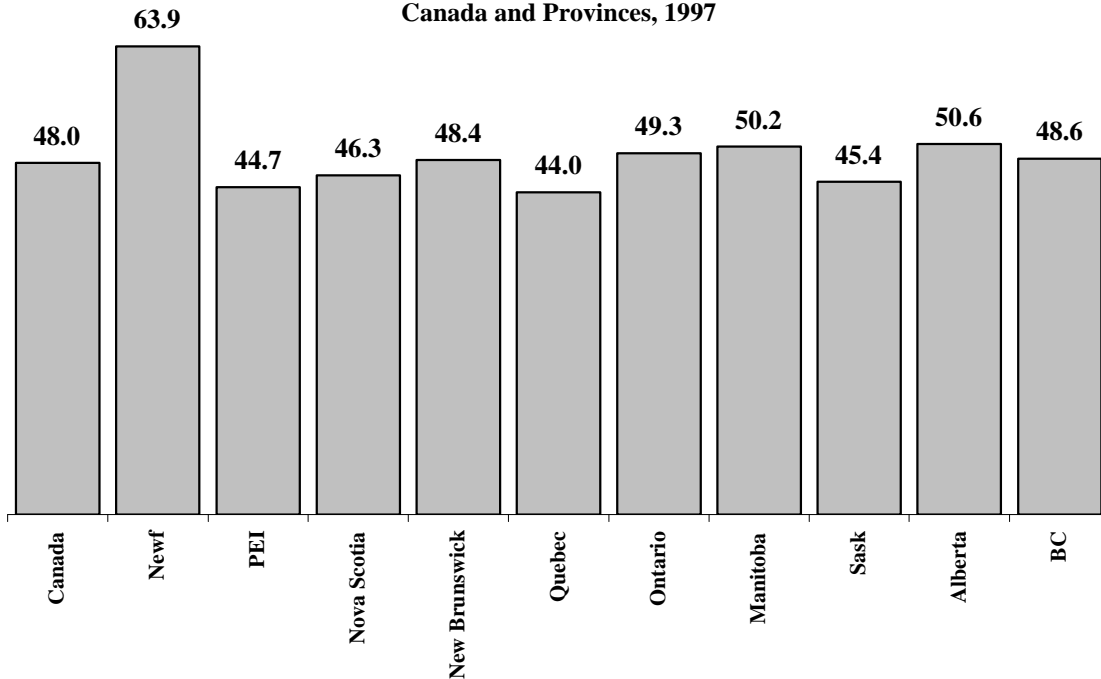


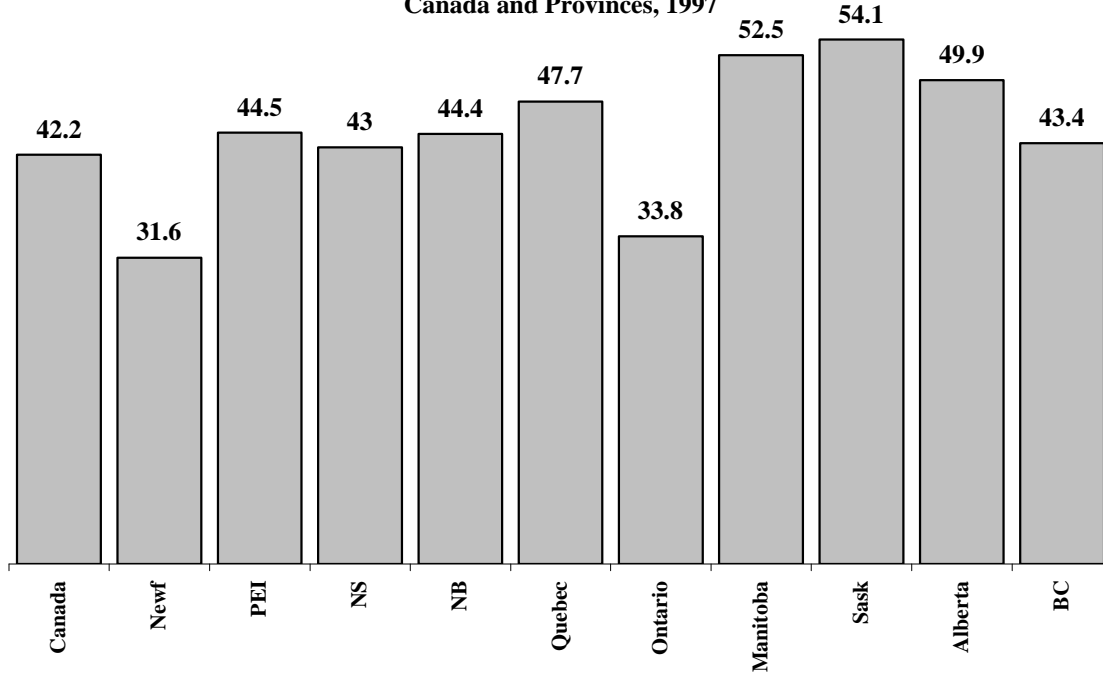
Figure 16: Age Standardized Mortality Rate per 100,000, Cerebrovascular Diseases, Canada and Provinces, 1997



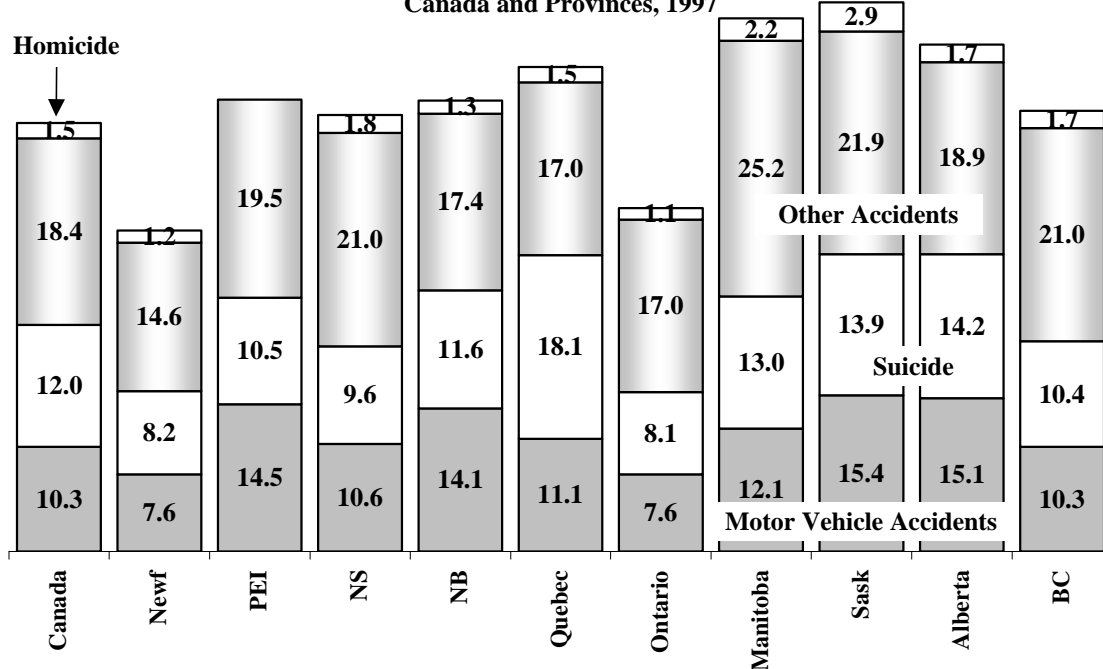
The second major cause of death that contributes to the pool of eligible cadaveric donors, mortality due to accidents and adverse affects, also demonstrates significant variations in mortality rates between provinces (Figure 17)²². On an age-standardized basis Saskatchewan (with an annual age standardized rate of 54.1 deaths per 100,000), Manitoba (52.5), Alberta (49.9) and Quebec (47.7) have the highest mortality rates for accidents and adverse affects. The lowest rates are found in Newfoundland (31.6) and Ontario (33.8), with the remainder of the

falling in the 43.0 to 44.5 range.

**Figure 17: Age Standardized Mortality Rate per 100,000, All Accidents and Adverse Effects
Canada and Provinces, 1997**



**Figure 18: Age Standardized Mortality Rate per 100,000, Type of Accidents and Adverse Effects
Canada and Provinces, 1997**

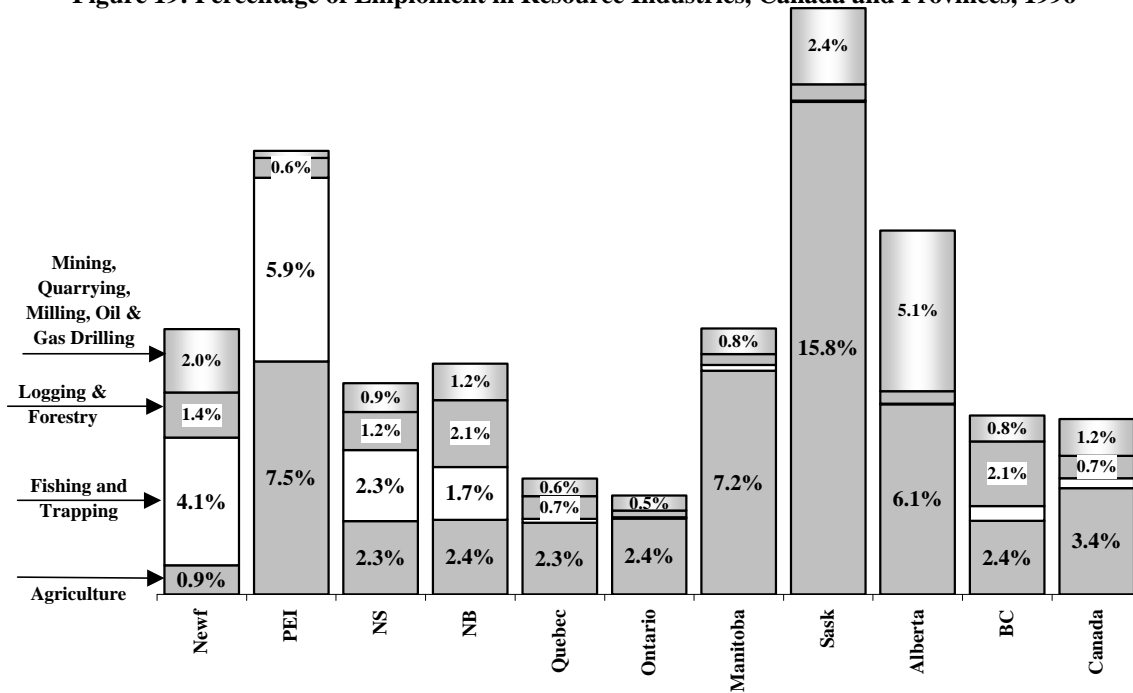


Saskatchewan (with an annual rate of 15.4 deaths per 100,000 population), Alberta (15.1) and Prince Edward Island (14.5) have the highest age standardized motor vehicle accident mortality rates (Figure 18)²³, with Newfoundland (7.6) and Ontario (7.6) having the lowest rates.

Excluding motor vehicle, homicide and suicide, the highest rates of mortality due to other accidents and adverse effects are found in Manitoba (25.1), Saskatchewan (21.9), Nova Scotia (21.0) and British Columbia (21.0): the provinces with the four lowest rates from these causes are Newfoundland (14.6), Quebec (17.0), Ontario (17.0), and New Brunswick (17.4).

Geography and economic structure affect both these rates and the probability that mortality due to these causes will be ultimately expressed in an organ donation. To the extent that mortalities due to other accidents and adverse effects include work related incidents, regions with relatively small shares of their work force in resource, and particularly resource extraction, industries will have relatively low mortality rates to these other causes: Ontario and Quebec have less than 4% of the their workforce in resource industries, compared to 19% in Saskatchewan, 14% in Prince Edward Island, and 12% in Alberta (Figure 19)²⁴. With the greater work place risk involved in these industries compared to the service sector, greater mortality rates might be anticipated: the fact that, by definition these workplaces are in rural and remote locations will reduce their potential for reasons of distance to hospitals. For example, the high percentage share of the workforce that is in logging and forestry in British Columbia (2.1%) and New Brunswick (2.1%) will create a different potential due to work related accidents than the negligible 0.2% share these activities have in the workforce of Ontario.

Figure 19: Percentage of Employment in Resource Industries, Canada and Provinces, 1996



The primary resource employment share is a reflection of, and is reflected in, the percentage of population living in rural and remote areas compared to metropolitan ones. It is also part of travel patterns, and the degree to which long distance and private vehicle travel occurs, which in turn is reflected in motor vehicle accident mortality rates. Three provinces in Canada have below average utilization rates of private passenger vehicles for the journey to work (Figure 20)²⁵. Ontario, Quebec, and Manitoba have less than 80% of journey to work trips in these types of vehicles: they also have the three highest public transit utilization rates (12.2%, 11.8%, and 9.8%, respectively). The relatively high percentage of bicycle and motorcycle use in British Columbia (2.1%), Saskatchewan (1.5%), and Manitoba (1.4%) will also create differences in the composition of trauma due to motor vehicle accidents: the extent to which the use of cycles is in

urban or rural areas will also have an impact on the extent of mortality in hospital.

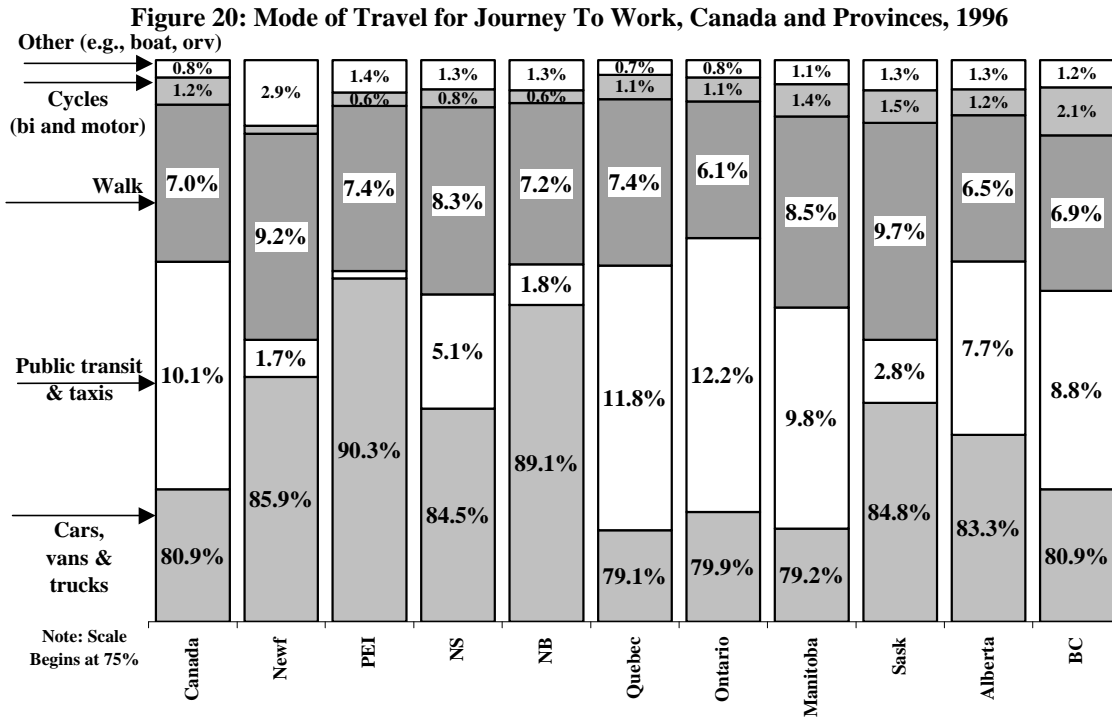
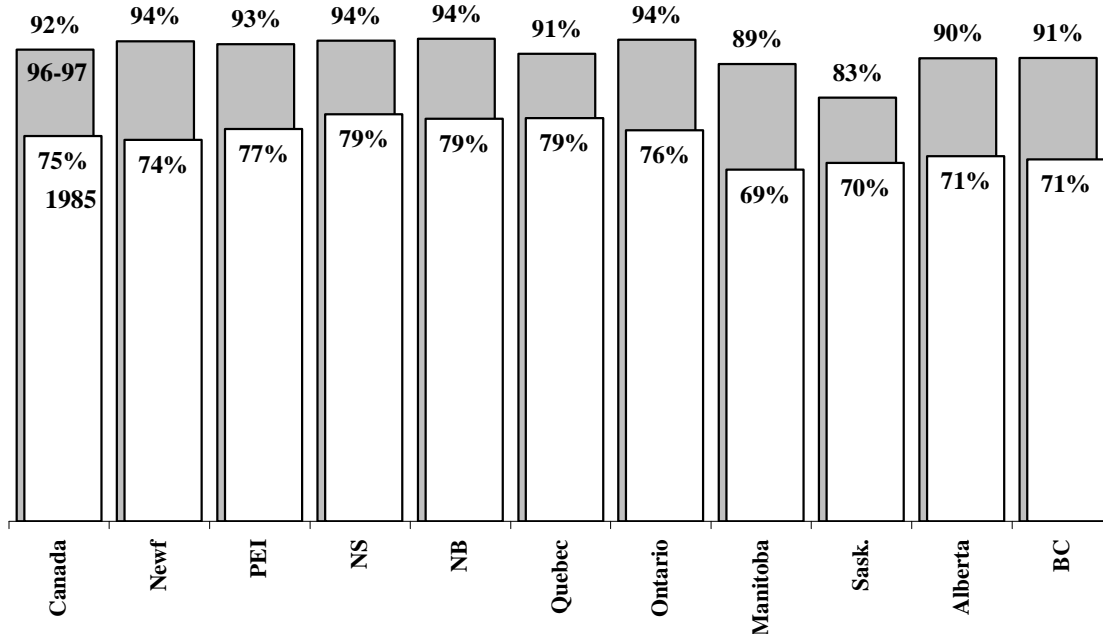


Figure 21: Percent of Respondents Who Reported No Occurance of Drinking and Driving In Previous Month, 1985 and 1996-97



There are other differences in travel behaviour that may affect the relative size of the potential cadaveric donor pool. For example, according to the results of the National Population Health Survey, Saskatchewan (17%) and Manitoba (11%) have the highest incidence of reported drinking and driving (Figure 21)²⁶. Manitoba (23%), Alberta (22%), and Saskatchewan (18%) have the highest incidence of reported driving without the use of seatbelts (Figure 21)²⁷.

Figure 22: Percent of Respondents Who Reported Always Using Seatbelts

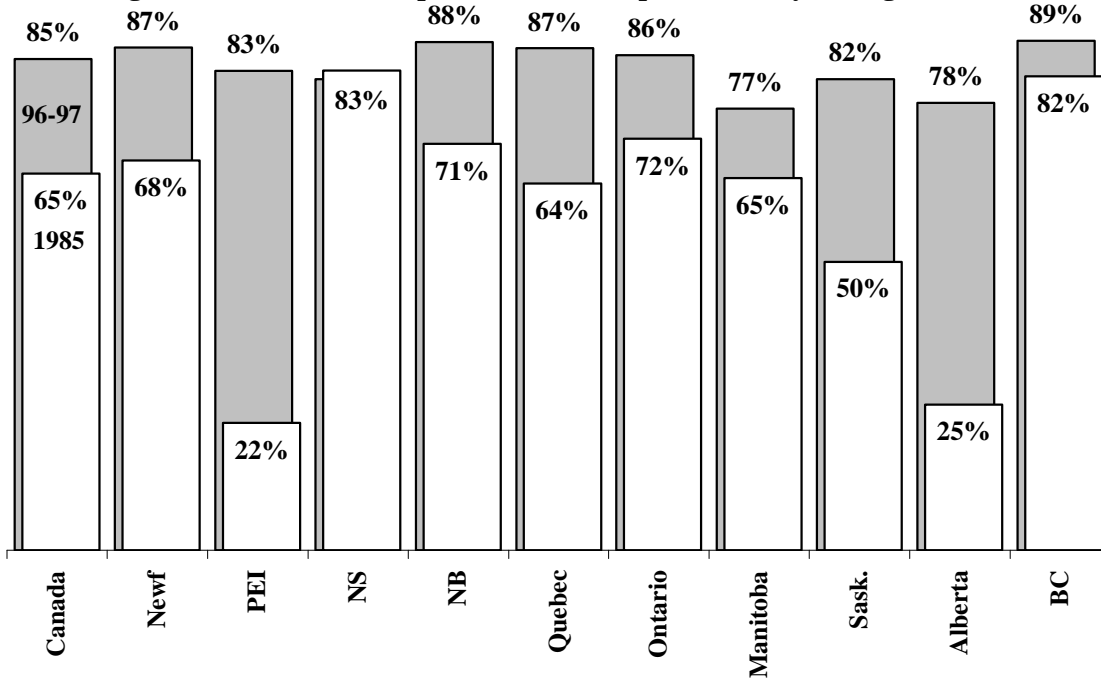
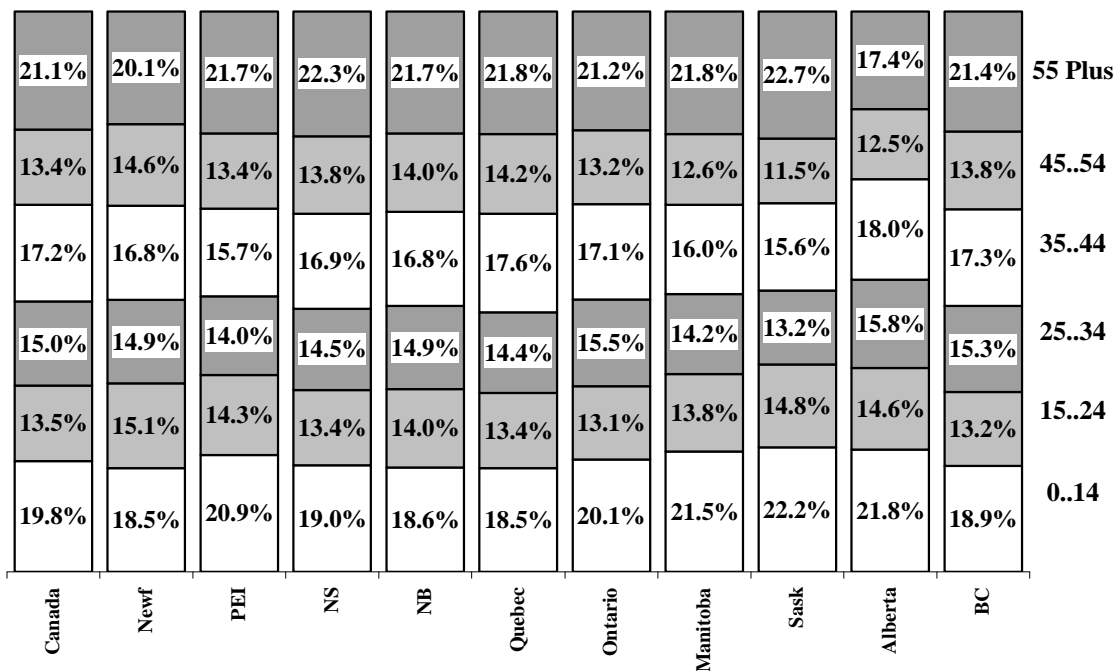


Figure 23: Age Distribution of the Population, Canada and Provinces, 1998



All of these geographical, economic, and behavioural factors will result in difference in both the potential and realized supply of cadaveric donation of organs for transplantation. Compounding these affects will be the age compositions of provincial populations. While there is a general correspondence in provincial age distributions (Figure 23)²⁸, Alberta is distinct in its younger than average age profile: only 17.4% of Alberta's population is 55 years of age or older, compared to the national average of 21.1%. Alberta has the nation's largest share of 0 to 14 year

olds (21.8%), the third largest share of the high-risk 15 to 24 year olds (14.6%, following Newfoundland's 15.1% and Saskatchewan's 14.8%), the largest share of 25 to 34 year olds (15.8%), and of 35 to 44 year olds (18.0%).

Figure 24: Annual Population Growth, Canada and Provinces, 1995 to 1999

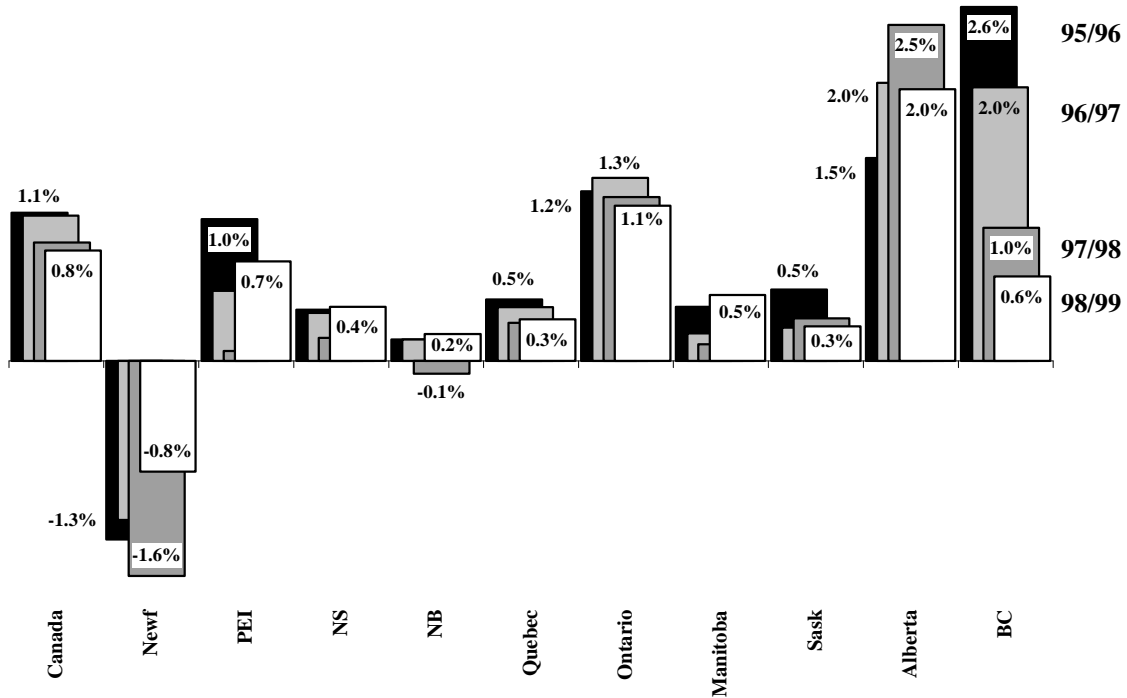
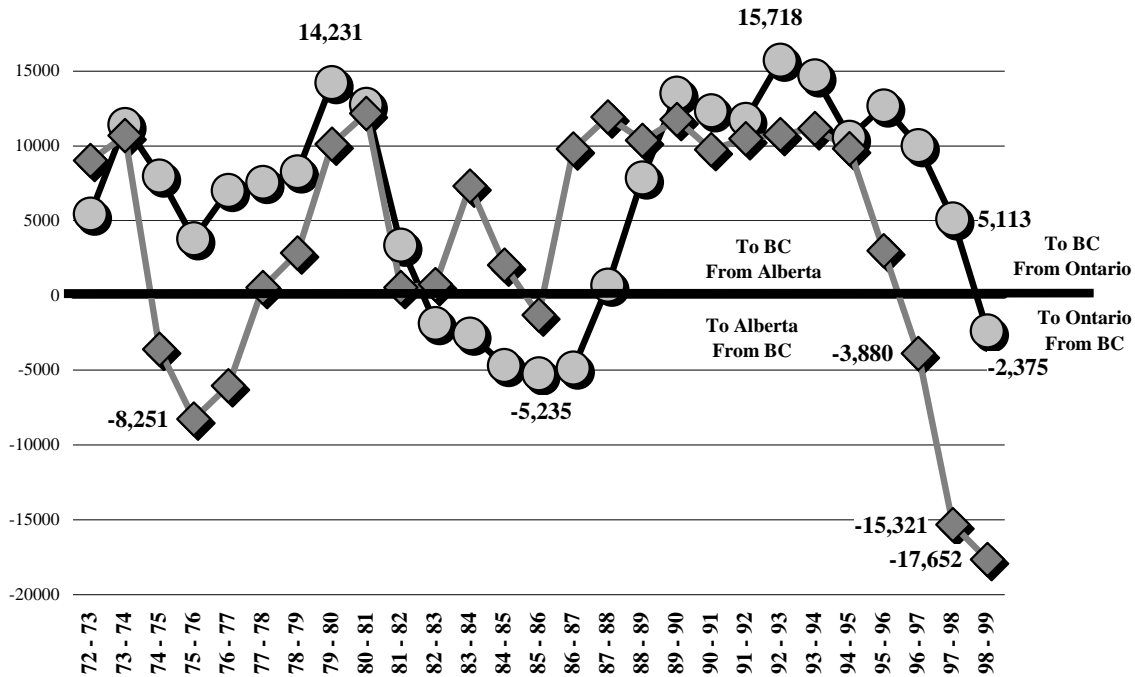


Figure 25: Ontario-BC-Alberta Net Inter-Provincial Migration, 1972 to 1999 (Fiscal)



This relatively youthfulness may explain some of Alberta's relatively high cadaveric donation rate: the forces that created this relatively young population may also have contributed to the

difference in the trends in cadaveric donation rates between Alberta and BC. Canada's population growth has slowed since 1995, the result of slowing immigration, increasing emigration, declining births and increasing mortality: in 1995/96 Canada's population grew by 1.1%, while it grew by only 0.8% in 1998/99 (Figure 24)²⁹. Most of the provinces generally maintained a steady annual growth rate throughout the period: the exceptions were the provinces of Alberta and British Columbia. British Columbia's population growth rate dropped steadily from 2.6% in 1995/96 through 2.0% in 1996/97 and 1.0% in 1997/98 to reach 0.6% last year. Alberta's population growth followed almost the opposite path, increasing from 1.5% in 1995/96 through 2.0% in 1996/1997 to reach 2.5% in 1997/98 before slowing to 2.0% in 1998/99.

One of the major factors explaining this change was net inter-provincial migration between the two provinces. From 1988/89 to 1994/95, BC was the net recipient of record high levels of net intra-provincial migration from both Alberta and Ontario (Figure 25)³⁰. Since 1995, this pattern has reversed, first with Alberta and more recently with Ontario. By 1996/97, British Columbia was a loser in the intra-provincial migration exchange with Alberta, losing a net of 3,880 people to Alberta in 1997/97, 15,321 in 1997/98 and 17,652 in 1998/99. For the first time in a decade, British Columbia also lost a net of 2,375 people through intra-provincial migration with Ontario.

These intra-provincial migrants are not typical of the population of the provinces: of 1998's total 21,000 person net loss of people from British Columbia to other provinces in Canada, 85% were people under the age of 35 and 41% were between the ages of 15 and 29; of Alberta's net gain of 31,000 people from other provinces in Canada, 80% were people under the age of 35 and 50% were between the ages of 15 and 29. Thus not only is Alberta's population growing, it is growing in the high-risk young adult age groups. Nor are inter-provincial migrants typical of their age group: as demonstrated by their willingness to move, these are the ones who will take a chance on the uncertainty of migration – they are the risk takers of their cohort.

c. Conclusions

This section has indicated the wide range of factors that underlie both live and cadaveric donation, and which, without a great deal of qualification, limit the usefulness of both international and inter-provincial comparisons of donor rates per million inhabitants. Significant unique factors will result in each region having a very particular pattern of mortality, by both cause and location with respect to health care infrastructure, which must be acknowledged in policies and programs with respect to organ donation. Rural and remote regions may never be able to approach the nominal donation rate of metropolitan regions.

This is not to suggest that programs should not be monitored or compared, but rather that the basis of comparison must be meaningful. Rather than attempt to adjust donor rates for all of the myriad of local and regional factors that will affect them, comparative measures should focus on how effective programs are given the pool of potential donors they have. For example, cadaveric donor rates could be compared on the basis of number of transplants achieved per 1000 eligible donors, rather than per million population. Eligible donors would be comprised only of deaths that a) occurred in hospitals, b) were from eligible sources (e.g., intra-cranial events and traumatic injury), c) met brain death criteria, and d) where there were no contraindications.

The data with respect to deaths in hospital by causes are available (at a cost) for both the current and historical periods for provinces in Canada: this measure could be introduced immediately. The result would be a comparative measure of how effective programs were given the external constraints of the location and causes of mortality.

II. Patterns of Organ Donation and Receipt

a. Trends in Mortality

In Section I, for introductory purposes, general mention was made of the sources of organs for donation: it falls to this section to consider in more detail the age specific patterns of need for, and supply of, organs for transplantation. On the need side, the waiting list for organ transplants in Canada is currently comprised of 78.2% waiting for kidney transplants, 10.1% for liver transplants, 3.3% for pancreas and kidney-pancreas, 3.8% for heart, 1.4% for single lung and 2.8% for double lung, and 0.3% for heart & lung transplants³¹.

The diseases that bring people to require such transplants are varied, and include:

- for kidneys, diabetes, glomerulonephritis, and hypertension;
- for livers, hepatitis C, alcoholic cirrhosis, and sclerosing cholangitis
- for hearts, coronary artery disease, cardiomyopathy; and ischemia; and
- for lungs, cystic fibrosis, idiopathic pulmonary fibrosis, and bronchiectasis.

To anticipate the need for organ transplants, it is useful to consider morbidity rates and, most significantly, trends in mortality rates as a result of these causes. In terms of morbidity, the example of the incidence of hepatitis C is informative: it has been estimated that there are 250,000 to 300,000 people in Canada infected with this virus, with up to 30% of these expected to damage the person's liver to the point that the disease will be fatal without an organ transplant³². The contingent liability that this disease poses medical and transplant resources is enormous.

The available data on patterns of mortality by major cause shows the basis for concern about both increasing need and decreasing supply of cadaveric donation of organs for transplantation. There has been a substantial and sustained decline in age standardized mortality rates in Canada in the post war era, with 1997's rate of 661 deaths per 100,000 population being almost half of 1950's 1,219 per 100,000 rate. Considering the causes that generally indicate the sources of both need and supply (and for which time series data are available), the general trend of decline is also apparent (Figures 26 and 27)³³. On the need side, ischaemic heart disease increased during the 1950s and 1960s, but has declined sharply since the 1970s, with the current rate of 131.7 deaths per 100,000 population being 60% of 1950's 216.0 per 100,000. Chronic liver disease has followed a generally similar path, increasing 2.5 times between 1950 and 1976, and then declining steeply since then: in spite of this decline, 1997's rate of 6.4 deaths per 100,000 to this cause is 20% above 1950's 5.5 per 100,000. Diabetes mellitus has shown quite a different path, increasing from 1950 to the mid-1979s, then declining to the mid-1980s, but increasing since then: 1997's rate of 17.4 per 100,000 is 10% above 1950's 16.2 per 100,000.

These patterns have been in the context of even greater declines in the two major source causes of mortality with potential for cadaveric donation. The age adjusted mortality rate for all accidents and adverse effects remained relatively constant from 1950 to the mid 1970s, and then declined rapidly, with 1997's rate of 42.2 per 100,000 being 60% of 1950's 75.4 rate. The steady decline in mortality due to cerebrovascular disease over the past 50 years has been even more dramatic: 1997's rate of 48 per 100,000 is 30% of 1950's 148 per 100,000.

Two issues are raised by these long run trends in age standardized mortality rates. The first is, generally speaking, that the causes that have traditionally been the source of cadaveric organ donation are declining faster than those that create the need for transplants. The second is that, while age standardization is useful to map long-term behavioural trends, projections of future need and supply must acknowledge their distinct age specific patterns, and that the future

population of Canada will be older than it is now or has been in the past.

Figure 26: Age Standardized Mortality Rates, Selected Causes, Canada, 1950 to 1997

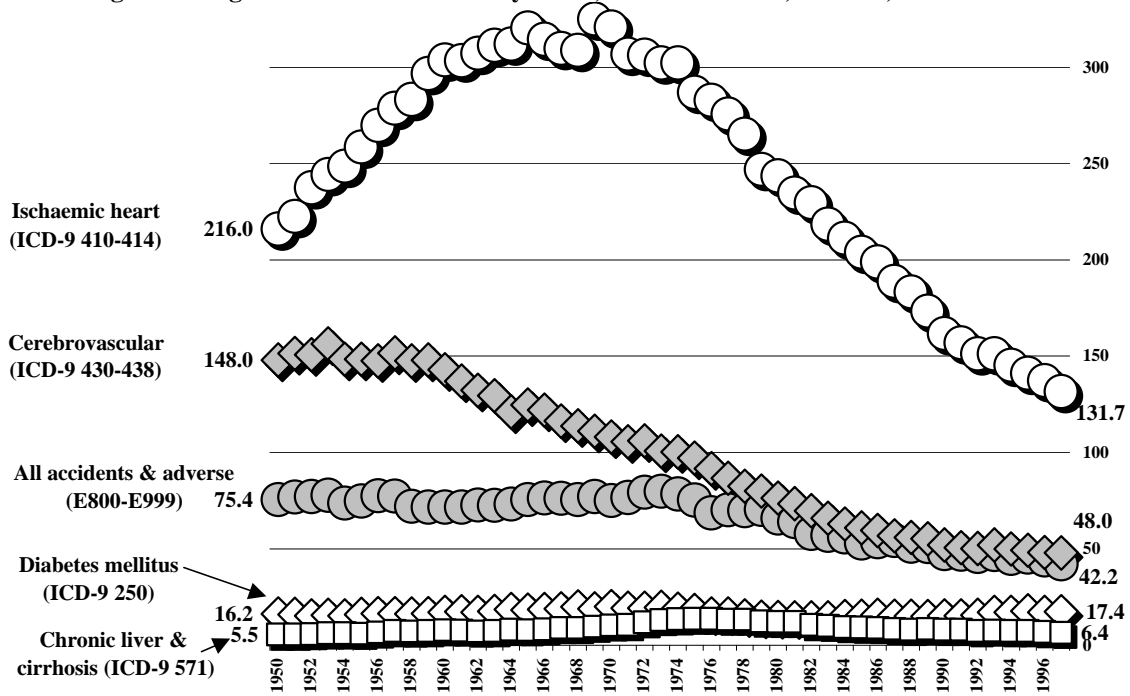


Figure 27: Change in Age Standardized Mortality Rates Selected Causes, Canada, 1950 to 1997, 1950 = 1.00



On the supply side, mortality due to accidents and adverse effects that is not contraindicated for transplantation occurs predominantly in the young population, with age specific mortality due to this cause in the range of 0.040% (40 deaths per 100,000) from ages 15 to 69 (Figure 28)³⁴: from age 15 to 44, this is the leading cause of deaths from males (and, from ages 15 to 39, for females). Cerebrovascular disease, in contrast, demonstrates the more common mortality pattern, with increases in rates occurring with increases age.

Projected demographic patterns for Canada (see Section III) indicate that in the future, the population under the age of 45 will remain relatively constant, while the 45 and older population will grow rapidly. In the context of cadaveric donation, the decline in the incidence of mortality due to accidents and adverse effects coupled with the constant number of people in the younger adult age groups portends an absolute decline in cadaveric donation from this cause. In contrast, the aging of the population into the older age group suggests an increasing role for donations due to cerebrovascular disease: continuing declines in mortality due to this cause may offset some of the growth that otherwise would occur due to the aging of the population. However, note that the cerebrovascular rate passes that of all accidents and adverse effects in the 60 to 64 age group: after this age, the risk of contraindications often preclude organ donation. Further, the contribution of mortality due to these two general causes to the potential donor pool is limited, to a great extent, by the requirement that mortality must occur on a ventilator in a hospital: both causes generally involve both sudden incidence in non-hospital locations.

The major diseases that generate the need for organ transplantation, in contrast, demonstrate very strong increasing-with-age patterns (Figure 29)³⁵: the mortality rate due to chronic liver disease and cirrhosis increases 20 fold, from 0.0016% in the 35 to 39 age group to 0.0332% in the 70 to 74 age group. Over the same span of years, the mortality rate for diabetes mellitus increases 73 fold (from 0.0012% of the people in the 35 to 39 age group dying from this cause each year to 0.0879% in the 70 to 74 age group), and that for ischaemic heart disease increases 37 fold (from 0.0065% to 0.5963%). To the extent that these mortality rates are indicative of an underlying need for transplants, when they are coupled with the aging of Canada's war and post-war baby boom generations into the 60 plus age groups over the coming two decades, the need for organs for transplantation will clearly increase faster than the supply: the projected magnitude of the widening of this gap is documented in Section IV.

Figure 28: Age Specific Mortality Rates, Canada 1996 & 1997 Average
Accidents and Adverse Effects & Cerebrovascular Effects, Log Scale

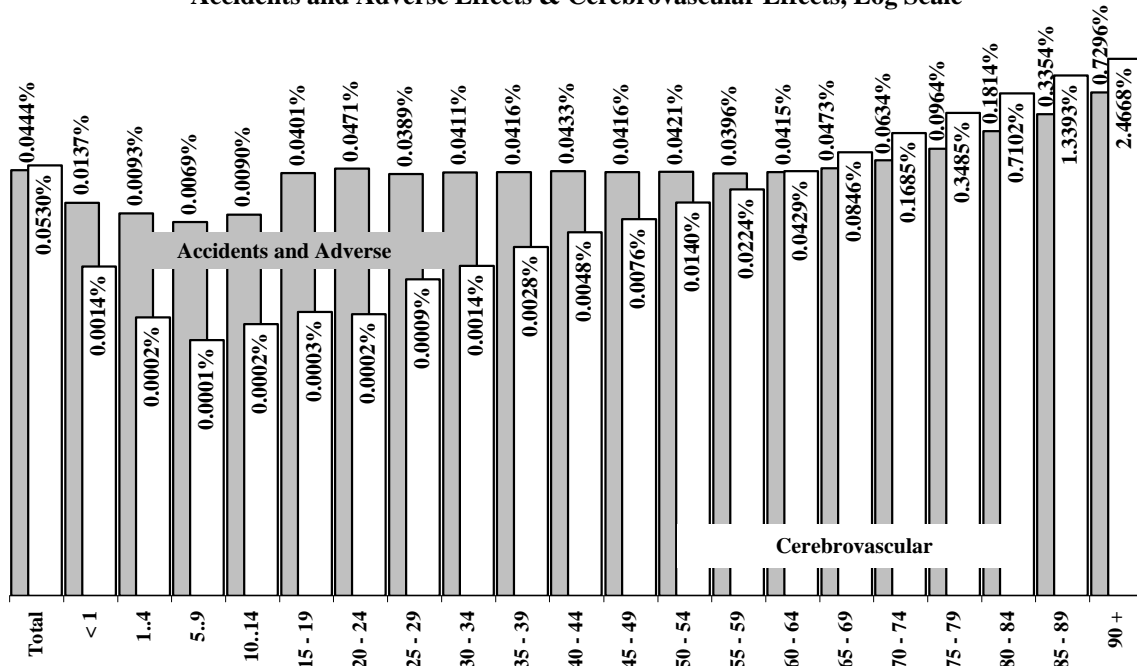
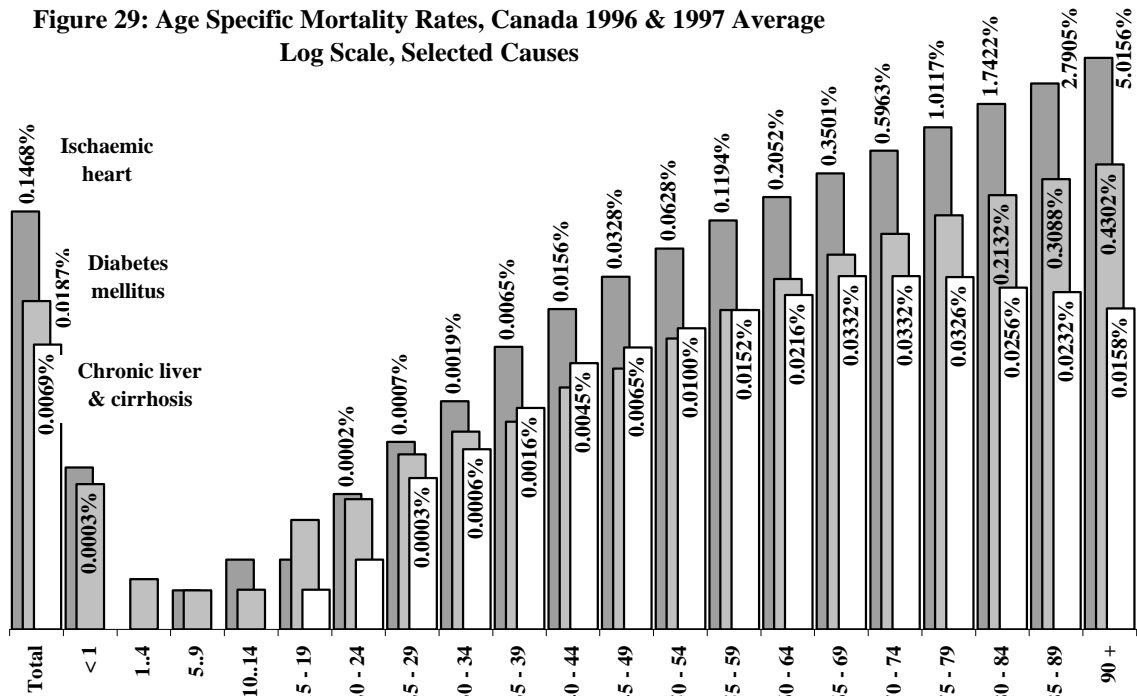


Figure 29: Age Specific Mortality Rates, Canada 1996 & 1997 Average
Log Scale, Selected Causes

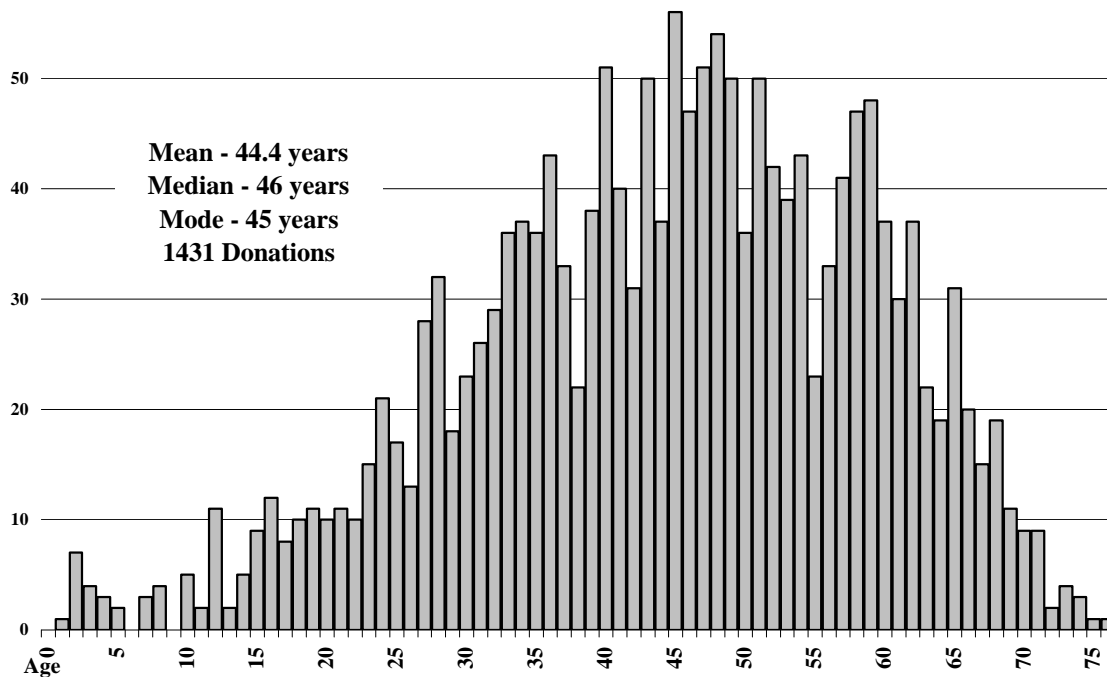


b. The Age Profile of Organ Recipients

In considering the specific characteristics of organ donors and recipients, single years of age data is required: this was supplied to this project by the BC Transplant Society, and hence the following analysis generally focuses on the BC experience. While this is likely to generally match the national average, and such is assumed here for projection purposes, if research funds are available it would be useful to carry out the same analysis at the national level.

Over the past decade in British Columbia, the age profile of the organ recipient population has demonstrated a skewed-to-the-right distribution, with the average age of recipients being 44.4 years, half of the recipients being 46 years of age or older, and the typical recipient being a 45 year old (Figure 30)³⁶. This age pattern understates the age pattern of organ reception, as it does not acknowledge either the number of people of each age or change in the age composition of the population over the decade. The average of the annual organ recipient rate (the number of people in the age group receiving an organ through transplantation per 100,000 people in the age group during the year) clearly identifies the high reception rate age groups (Figure 31). The highest rates are found in the 45 to 64 age groups, which are the age groups projected to experience the greatest absolute and relative growth over the next two decades.

Figure 30: Age Distribution of Recipients of Organ Donations, British Columbia, 1990 to 1999



The organ reception rate represents the effective need for organs, showing only the need has been met through transplants: it does not represent the total need. A first estimate of the full need is the number of people on waiting lists, or more broadly, the number of people on dialysis (as approximately 10% to 15% of people on the waiting list die each year)³⁷. If this latter measure is used, a pattern of exponential growth in need, well beyond demographic change, has been demonstrated in Canada. Between 1981 and 1998, the population of Canada increased by 22%, from 24,820,382 to 30,300,422: the number of people on dialysis increased by 1,178%, from 977 in 1981 to 12,487 in 1998 (Figure 32)³⁸. The greatest increases were in the 45 plus population. While the number of 45 to 64 year olds increased by 43%, the number of people in the age group on dialysis increased by 905%: there was a 2,495% increase in the number on dialysis in the 65

plus age group, compared to a 57% increase in the number of people of this age.

Figure 31: Average Of Annual Age Specific Organ Receipt Rates, British Columbia, 1990-1999

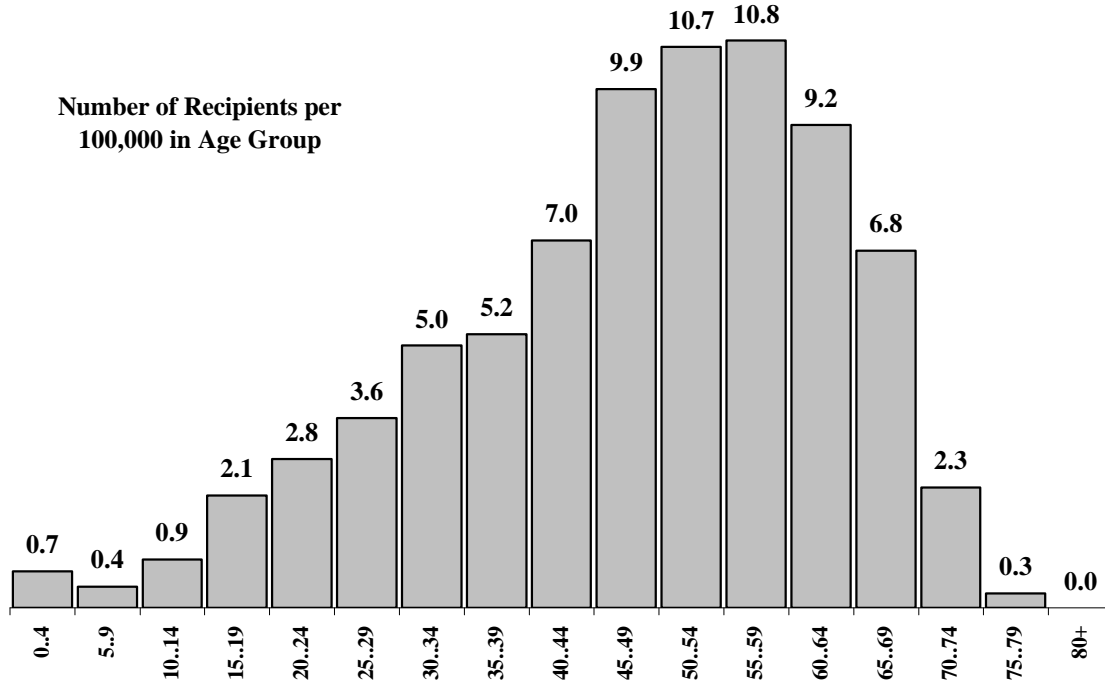
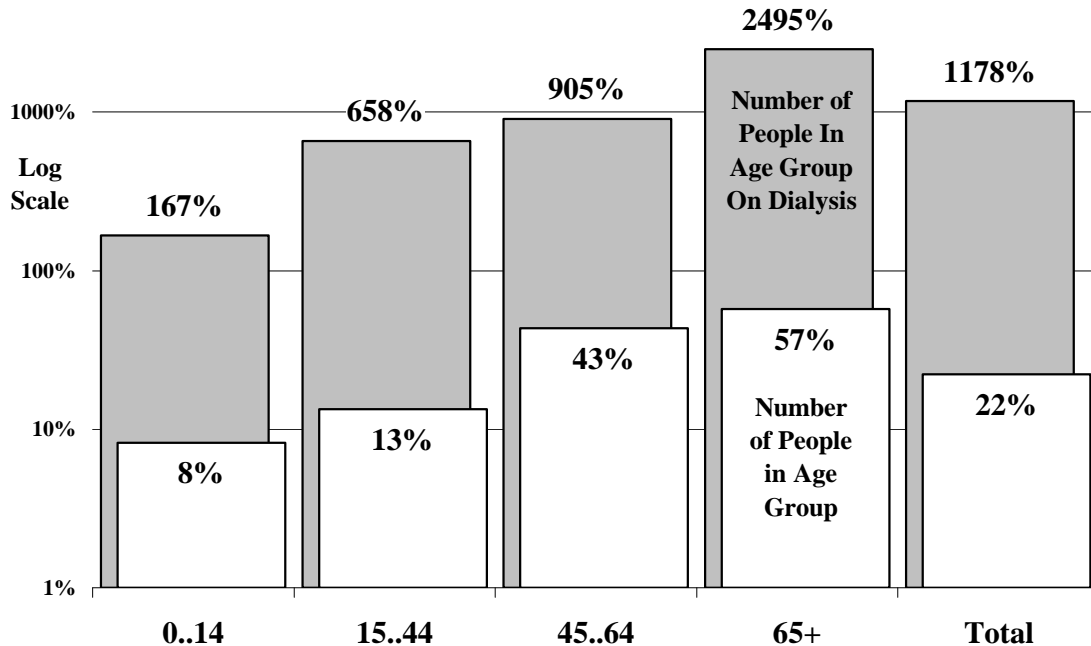


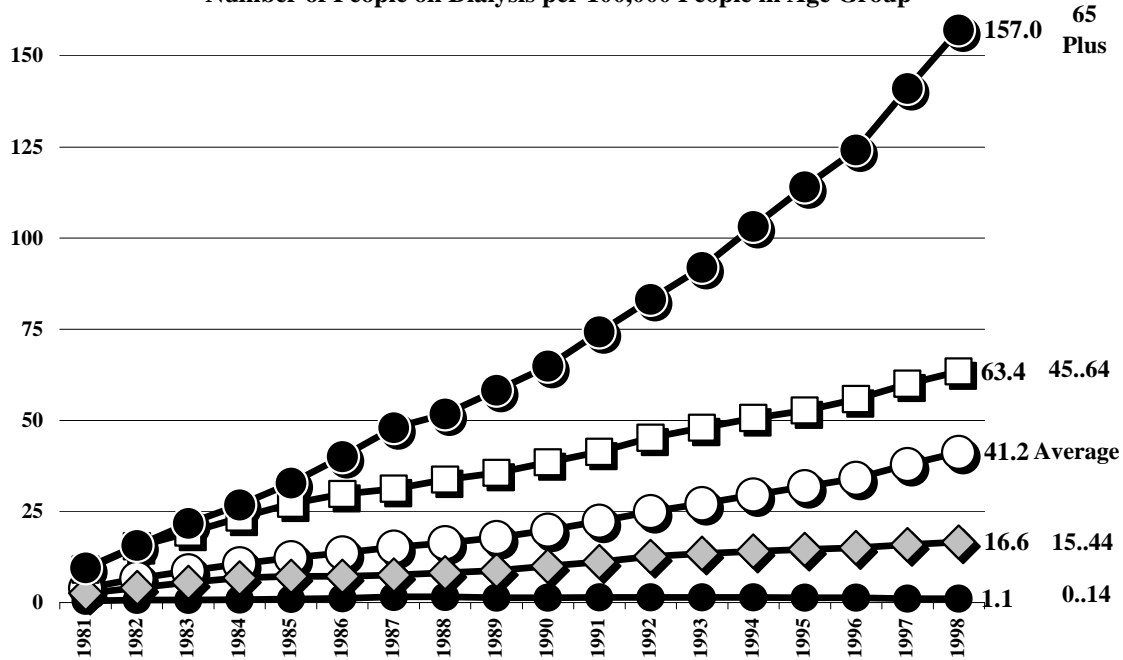
Figure 32: Increase in Population and Persons on Dialysis by Age Group, Canada, 1981 to 1998



The age specific dialysis treatment rates in all but the youngest age group have grown exponentially over the past two decades (Figure 33). The rate for the 65 plus age group has increased from 9.5 people on dialysis for every 100,000 people in the age group in 1981 to 157.0 in 1998, from 9.0 to 63.4 for the 45 to 64 age group, and from 2.5 to 16.6 for the 15 to 44 age group. The increase occurred through the period, and in the case 65 plus age group increased at

an increasing rate. The exception to this pattern is the 0 to 14 age group, where the rate increased from 0.4 per 100,000 in 1981 to 1.6 in 1988, and then declined to 1.1 in 1998. An aging population and an exponentially growing need rate in older age groups portends increases in the need for dialysis treatment, and for transplants, that will be much greater than the rate of increase in the population as a whole.

Figure 33: Age Specific Rate of Dialysis, Canada, 1981 to 1998
Number of People on Dialysis per 100,000 People in Age Group



c. The Age Profile of Organ Donation

i. Live Organ Donation

In the following discussion of the age pattern of supply of organs for transplantation, donations (transplants) as well as donors is used as the measure. The reason is that in many cases, specifically with respect to cadaveric donation, there are multiple transplants to several recipients from a single donor. The effective measure for donors, therefore, is the number of organs donated (the number of transplants) per 100,000.

The age specific pattern for live organ donation is shown in the data for British Columbia, although the very small number of live donations makes the graphs somewhat irregular (Figures 34a and 34b)³⁹. The age profile of live donations is significantly younger than the profile of all organ recipients (c.f., Figure 30), but there is a very close correspondence between the age profile of the live donation and the recipients of the donated organs. The average age of persons making live organ donations over the past decade in British Columbia was 39.61 years, with half of the donors under the age of 39, and a typical age of a person making a live donation being 42 years. The corresponding figures for recipients of live organ donations are slightly younger, with a mean of 39.41, a median of 38 and a mode of 40 years. The distribution of the ages of the recipients of live organ donations is, however, much wider than that of the donors (the range for donors most likely influenced by the legal age of consent). Live donations were from people

between the ages of 19 and 66, while recipients' ages ranged from 1 to 70.

Figure 34a: Age Distribution of Live Organ Donations, British Columbia, 1990 to 1999

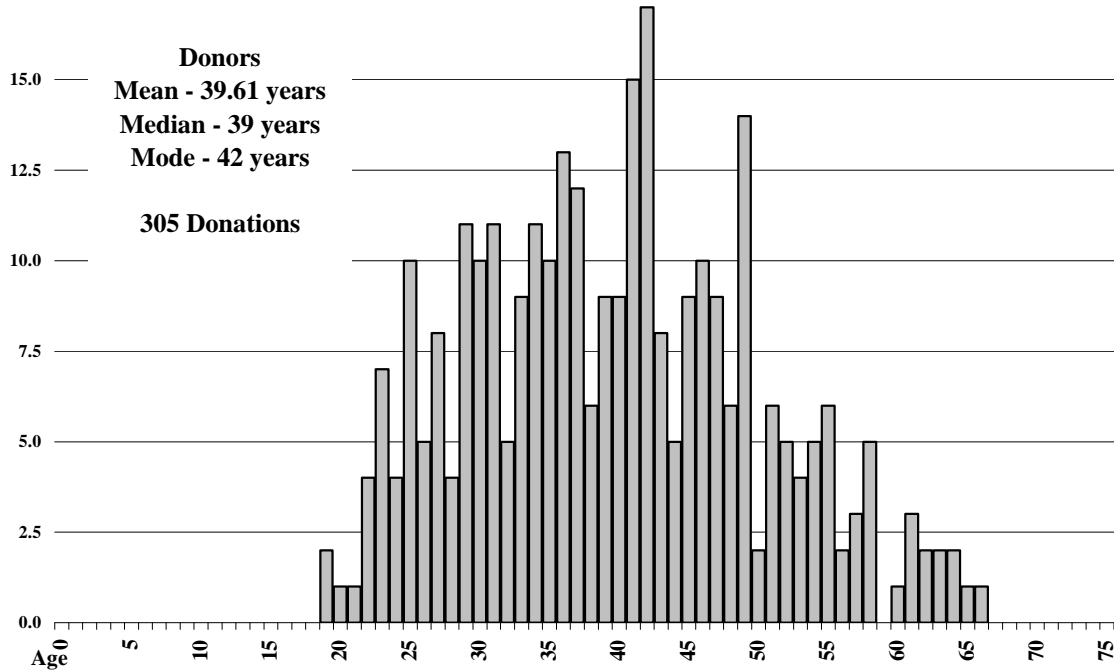
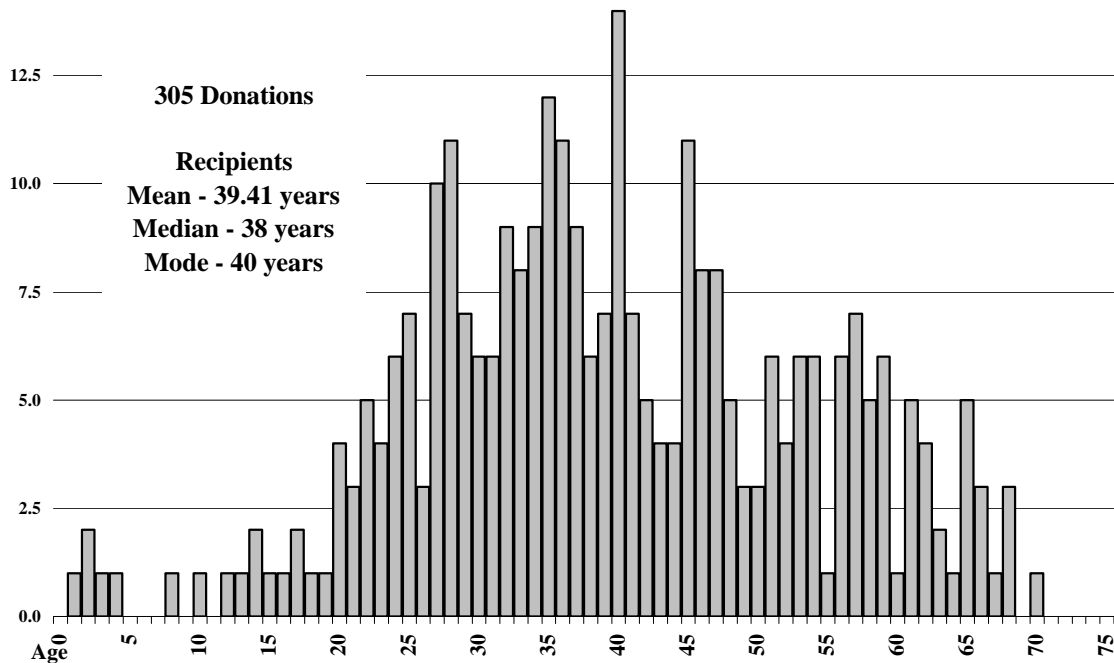


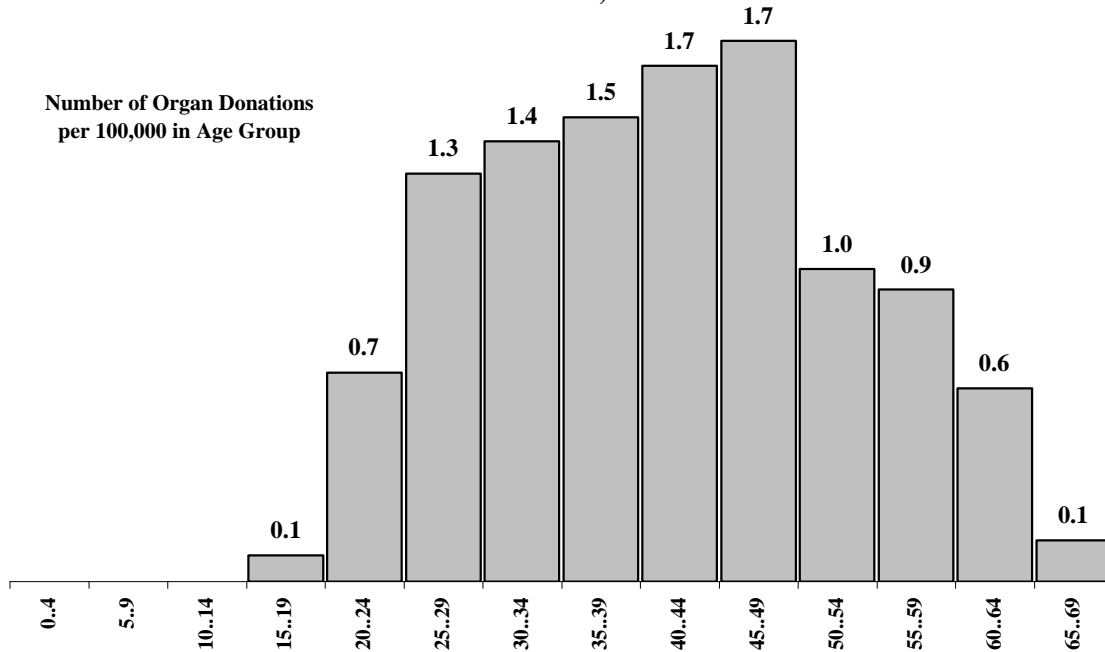
Figure 34b: Age Distribution of Recipients of Live Organ Donations, British Columbia, 1990 to 1999



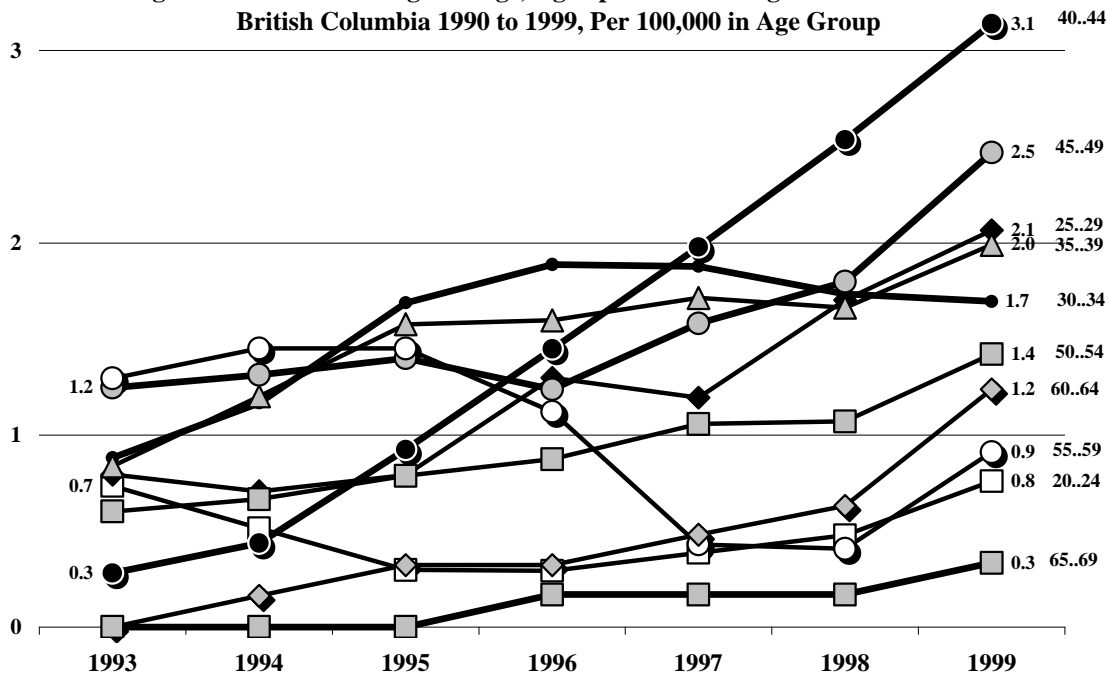
The distribution of the live donation rate centers on the population in their late 30s, the age group where the population was largest during the last decade. Expressing the live donation rate in terms of number of organs donated per 100,000 people in the age group shows that the highest propensity to be a live organ donor is between the ages of 40 and 50 (Figure 35). This brings a positive note to the discussion of live organ donation, as these are the age groups will increase by

a significant number of people over the next decade.

**Figure 35: Average of Annual Age Specific Live Organ Donation Rates
British Columbia, 1990-1999**



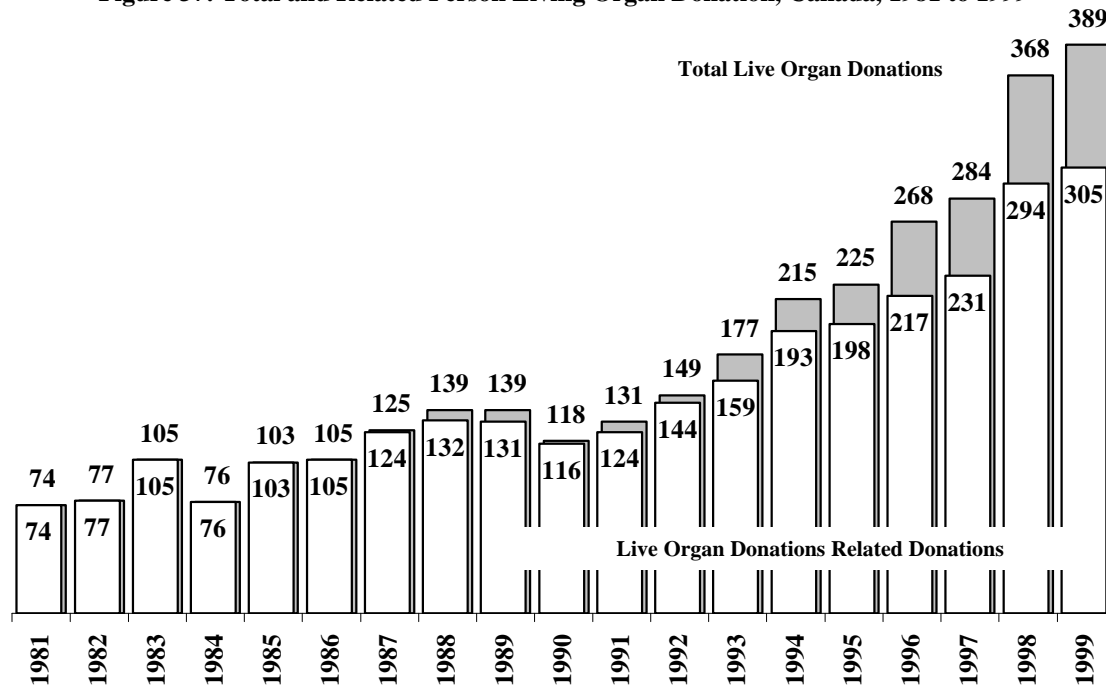
**Figure 36: 3 Year Moving Average, Age Specific Live Organ Donation Rates
British Columbia 1990 to 1999, Per 100,000 in Age Group**



An even more positive note is added by examination of the trends in the age specific live organ donation rate over the past decade: in British Columbia in every age group except the 30 to 34 year olds, the number of live organs donated per 100,000 people in an age group increase dramatically between 1990 and 1999 (Figure 36). For examples, the 3 year moving average of the live donation rate for the 40 to 44 age group increased ten-fold from 0.3 per 100,000 over the

1990 to 1993 period to an average of 3.1 per 100,000 for the past three years; for the 45 to 49 age group the rate doubled from 1.2 to 2.5, as it did for the 50 to 54 age group (from 0.7 to 1.4). The increase in live donation rates is doubly significant because much of the increase is due to a growth of living unrelated donors (Figure 37)⁴⁰. During most of the 1980s, live organ donation was exclusively between related persons: from 1987, the share of donations between unrelated persons increased gradually to reach 22% (84 donors) by 1999.

Figure 37: Total and Related Person Living Organ Donation, Canada, 1981 to 1999



ii. Cadaveric Donation

Cadaveric donation demonstrates an age profile that is quite distinct from that of live donation (Figures 38a and 38b)⁴¹. In British Columbia over the past decade, the distribution have been across the entire age span, from 1 year to 75, with a bi-modal distribution having local peaks in the mid 20s and mid 50s age groups. While its is not possible to discern this from the data available for this project, the pattern is likely the result of the two major causes of death involved in cadaveric donation, with the younger age group peak associated with accidents and adverse effects causes, and the older one related to the cerebrovascular causes.

The average age for cadaveric donations is 32.8, with a median of 31 years and a mode of 18 years. This is dramatically younger than the age profile of the recipients of cadaveric donations, who have an average age of 45.4 years, with half of the recipients 47 years of age or older, and a typical recipient aged 48. Figures 38a and 38b clearly show the inter-generation aspects of cadaveric transplants, and underscore the concern about a widening gap between the number of people needing transplants, which will grow rapidly as the population ages, and the number of organs available for transplant.

For continuity purposes, it is useful to consider cadaveric donation in terms of age specific donation rates. The bi-modal distribution of this source of donated organs is very strongly shown in the average of the past decade's age specific rates (Figure 39), with the 15 to 19 age group (7.6 organs donated per 100,000 people in the age group) and 50 to 54 age groups (7.1 per 100,000)

having the highest, and almost equal, rate of cadaveric donation per 100,000 people. The strength of this pattern begs for the data on cadaveric donation by cause and age.

Figure 38a: Age Distribution of Cadaveric Organ Donations, British Columbia, 1990 to 1999

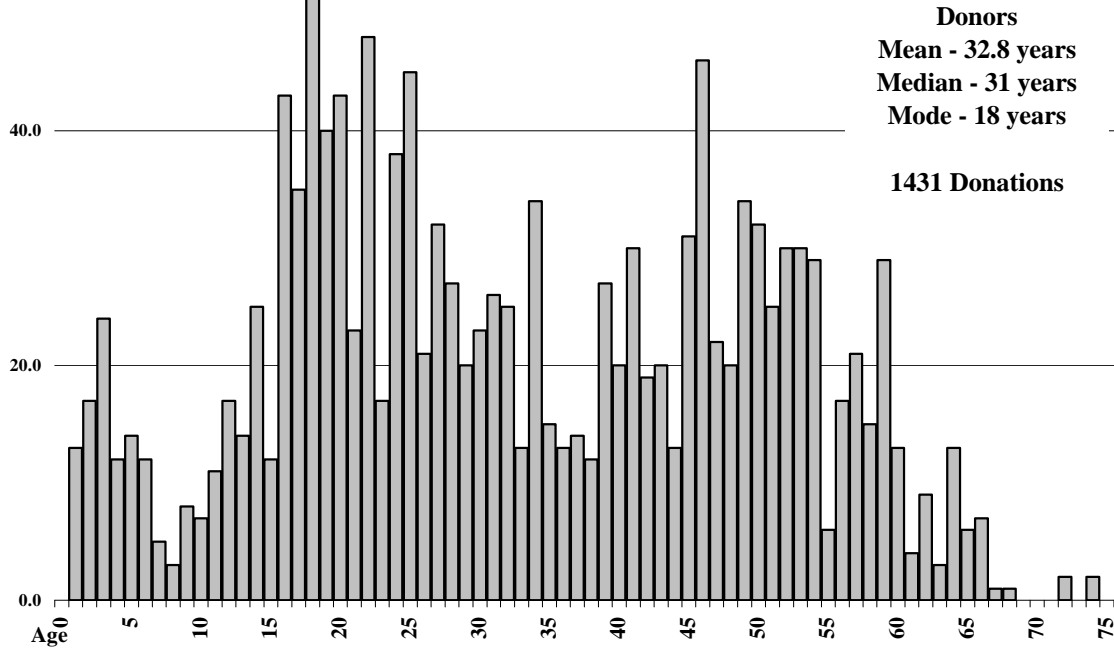
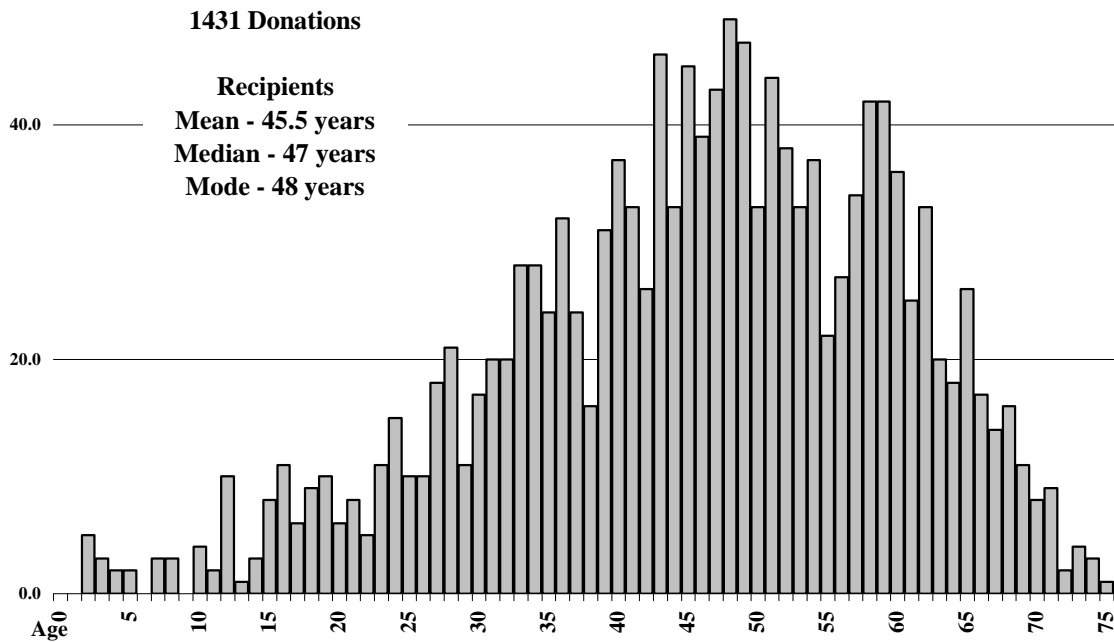
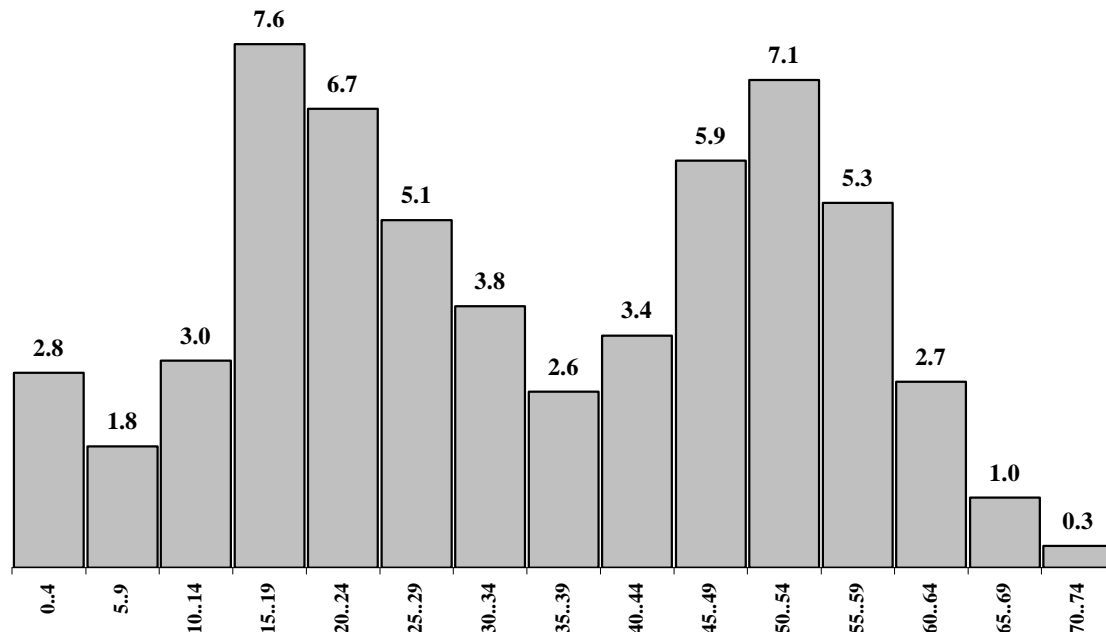


Figure 38b: Age Distribution of Recipients of Cadaveric Organ Donations, British Columbia, 1990-1999



**Figure 39: Average of Annual Age Specific Cadaveric Organ Donation Rates
British Columbia, 1990-1999, Per 100,000 in Age Group**



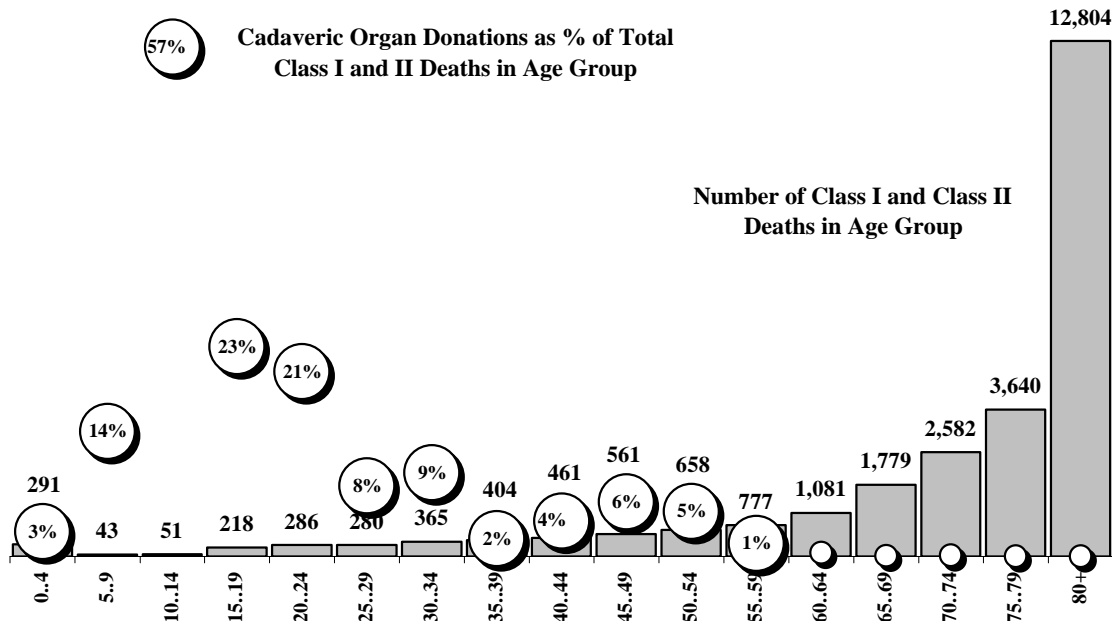
Given the long run trends of declining mortality rates, it is appropriate to explore cadaveric donation at a deeper level, that of cause and age. There are but a few specific causes of mortality that ensure the integrity of solid organs, and hence form the base for the potential cadaveric supply (see Section II.iii). These eligible causes are grouped as Class I (most frequent and ideal source of organs for transplant) and Class II (not ideal, but no contraindication for transplant): the rest of the causes of death do have contraindications and are definitely not considered as a source of organs for transplantation.

The total number of deaths due to these causes forms the widest possible potential supply of organs from cadaveric donation. Between this potential and the reality of an organ being transplanted lie a number of forces that reduce the potential pool dramatically⁴²: these forces all result from the requirement that solid organs for transplant must be continuously oxygenated, and hence the patient must die on a ventilator in a hospital and be certified as brain dead. This requirement means that many Class I mortalities are not a source of organs for transplant because the sudden nature of both accidents and adverse effects and cerebrovascular disease most often places these events outside of hospitals and away from ventilators. Of those that occur under acceptable external conditions, contraindications will mean that, while the mortality was due to a Class I cause, either diseases that rule out transplants were present or the violent nature of the trauma rendered the organs unusable for transplants. Further, brain death criteria may not be met in an otherwise qualifying situation.

Thus the actual potential supply of organs for transplantation is a very small fraction of the total of Class I and Class II deaths in a region. It is this smaller pool that should be the basis of measurement of effectiveness of transplant programs. The degrees to which transplant specialist are informed of the potential donation, to which consent is obtained, and to which, once consent

is obtained, the system by which the transplant procedure is engaged and the medical infrastructure is made available for use is the measure of the effectiveness of the process: the number of donations or transplants per million inhabitants is not. The data were not available to permit this project to create such a measure of effective donation rates. The best use of the available data did permit to measurement of the number of cadaveric organ donations as a percentage of the Class I and Class II deaths in an age group (Figure 40). The effect of contraindications on reducing the effective pool of organs for donation is clearly shown in the older age groups, with the greatest number of Class I and Class II deaths occurring in the 55 plus population: less than 1% of these deaths ultimately lead to an organ donation. The highest effective rates occur in the young age groups (from 14% in the 5 to 9 age group, to 57% in the 10 to 14 age group, and then to 8% and 9% in the 25 to 29 and 30 to 34 age groups): while these donation rates are high, there are not a lot of deaths involved. The lower 2% to 6% rates that prevail in the 35 to 54 age groups are compensated for, to some extent, by the larger number of mortalities that occur in these age groups.

Figure 40: Cadaveric Donation Rate, Number of Organ Donations as a Percentage of the Number of Class I and Class II Deaths in Age Group, British Columbia, 1996-1997 Average



iii. Eligible Causes

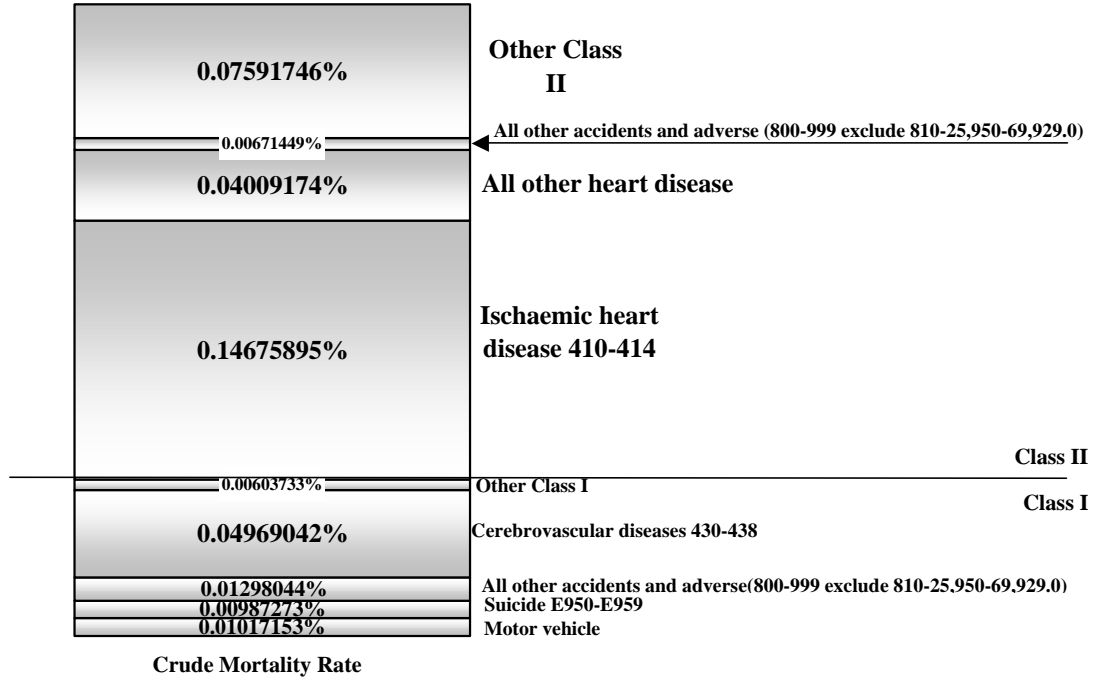
In 1996-1997, an average of 0.71832% (718 per 100,000) of Canada's population died from 2112 individual ICD-9 Causes. The average annual death rate for Class I causes was 0.08875%, and for Class II causes was 0.26277%: Class I and Class II deaths accounted for half (0.35152% of 0.71832%) of all deaths (Figure 41)⁴³.

The single largest group of Class I deaths was cerebrovascular disease (0.04949%); followed by accidents and adverse effects excluding motor vehicle accidents, suicide, and homicide (0.01298%); motor vehicle accidents (0.01017%); suicide (0.00987%) all heart disease excluding ischaemic (0.00415%); causes of perinatal mortality excluding stillbirth (0.00052%); homicide (0.00005%); and miscellaneous other causes (0.00134%).

The single largest group of Class II deaths was ischaemic heart disease (0.14676%); followed by

all other hearth disease (0.04009%); accidents and adverse effects excluding motor vehicle accidents, suicide and homicide (0.00671%); atheroclerosis (0.00475%), cerebrovascular diseases (0.00335%); congenital anomalies (0.00339%); homicide 0.00152%; suicide (0.00289%) and miscellaneous other causes (0.05330%).

Figure 41: Class I and Class II Crude Mortality Rates, Canada, 1996-1997 Average

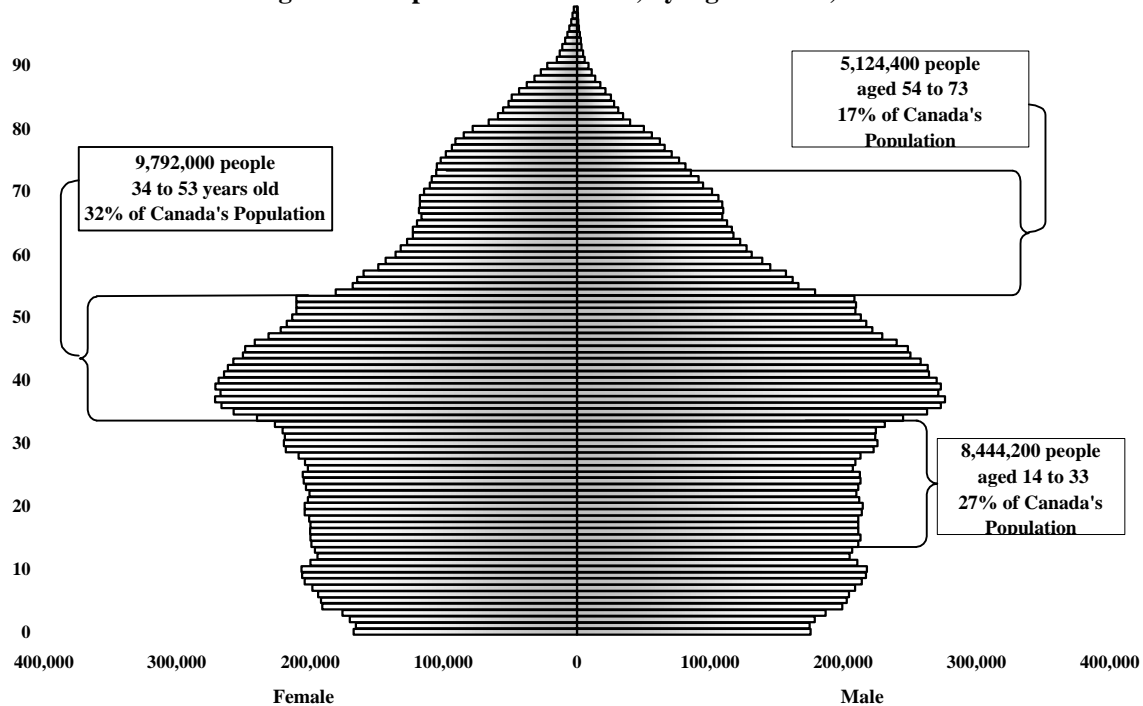


In the projections described in the last section of this report, age and sex specific mortality rates were calculated for all 2112 detailed 4 digit level ICD-9 causes observed in 1996 and 1997. These were then coded to Class I and Class II categories, then aggregated to the 20 major ICD-9 groups for which long-term mortality rate trend data are available. Appendix II of this report list all Class I ICD-9 causes of death observed in Canada in 1996 and 1997, together with their annual average mortality rate for 1997-1997, and their higher level aggregations.

III. The Population⁴⁴

Given the age specific pattern displayed in both donation and receipt of organs for transplantation, population dynamics will play a significant, but by no means exclusive, role in determining future levels of both the need for and supply of organs for transplantation. The starting point for the future population of Canada is its current population, with aging (the dominant factor), natality, mortality, and net immigration determining its future size and composition. The current age profile of Canada's population is characterized by its world war two and post world war two baby boom bulge (Figure 42).

Figure 42: Population of Canada, by Age and Sex, 2000



The number of people of each age in Canada increases significantly with decreasing age from the 240,650 people aged 63 in 2000 (those born in 1937) through the beginning of the post war baby boom generation (the 418,766 people aged 53 who were born in 1947), to reach the most typical Canadian and the typical baby boomer, the 548,059 people born in 1963 who are now 37 year olds. Under the age of 37, the age profile narrows rapidly to the 484,907 people aged 34 (born in 1966) who mark the end of the baby boom generation, then gradually tapers inwards to the 390,083 people aged 4. The base of the age profile then significantly narrows to the 343,254 people born in the past year, reflecting the significant decline in the annual number of births that have occurred since 1996.

There are fewer people of each age under the age of 34, and over the age of 63, than there are people of the intervening ages: of the 30,719,812 people in Canada today, 12,728,953 (41%) are between 34 and 63 years of age. The aging of this bulge will have significant impact on the future of every aspect of Canadian society, from the labour market⁴⁵ to organ donation. The post war baby boom generation (currently aged 34 to 53) accounts for 32% of the country's population, with the preceding generation, today's 54 to 73 year olds, accounting for 17%, and the subsequent generation, today's 14 to 33 year olds, accounting for 27%. Of the two thirds of Canada's population who are not post war baby boomers, 45% are under the age of 33 and 23%

are over the age of 54.

The challenge for transplantation is readily apparent from Canada's current age profile: if demographic forces alone shape the future (i.e., if today's age specific donation and receipt rates prevail in the future, and mortality rates continue to decline – see Appendix I for this constant rate scenario), the aging of the baby boom generation out of the high propensity to donate age groups into the high propensity to receive age groups will significantly increase the relative and absolute size of the gap between the number of organs available, and the number required, for transplants.

The most significant biological processes that will influence the size and composition of Canada's future population will be aging, which will shift the current population profile up into progressively older ages. Given the war and post war baby boom bulges to the population profile, this aging will cause rapid growth in the number of people in older age groups: offsetting these increases, to a greater or lesser extent, will be mortality. Age specific mortality rates also demonstrate a strong age related pattern (Figure 43): after age 9, the probability of dying in any one year increases steadily with increasing age.

Figure 43: Age Specific Mortality Rates, Males and Females, Canada 1998



The aging of 34 to 63 bulge will lead to an increasing number of deaths each year, as the bulge moves into successively higher mortality rate age groups: currently, it is still in a relatively low mortality rate stage of the life cycle, in the range of 200 to 1,000 deaths per 100,000 people in the age group. Within two decades, at current mortality rates, the bulge will have aged into the stage of the life cycle where rates of 1,000 to 10,000 per 100,000 prevail.

Current mortality rates, however, will not prevail in two decades, just as today's mortality rates did not prevail two decades ago: throughout the post-war period Canada has experienced a steady decline in the mortality rates (Figure 44). The age standardized mortality rate for males has declined from 1,375 deaths per 100,000 in 1950 to 848 in 1997, and that for females has declined from 1,089 to 524. For population projection purposes, it is necessary to assume that this trend will continue: a mathematical extension of the trend over the past decades indicates stabilization

of the rates at 694 per 100,000 for males and 473 per 100,000 within approximately 50 years. (Note: this aggregate projection is the sum of the projections for individual cause age specific mortality rates as is discussed in Section IV).

**Figure 44: Age Standardized Mortality Rates, All Causes, Canada
 1950 to 1997, Trended to 2040**

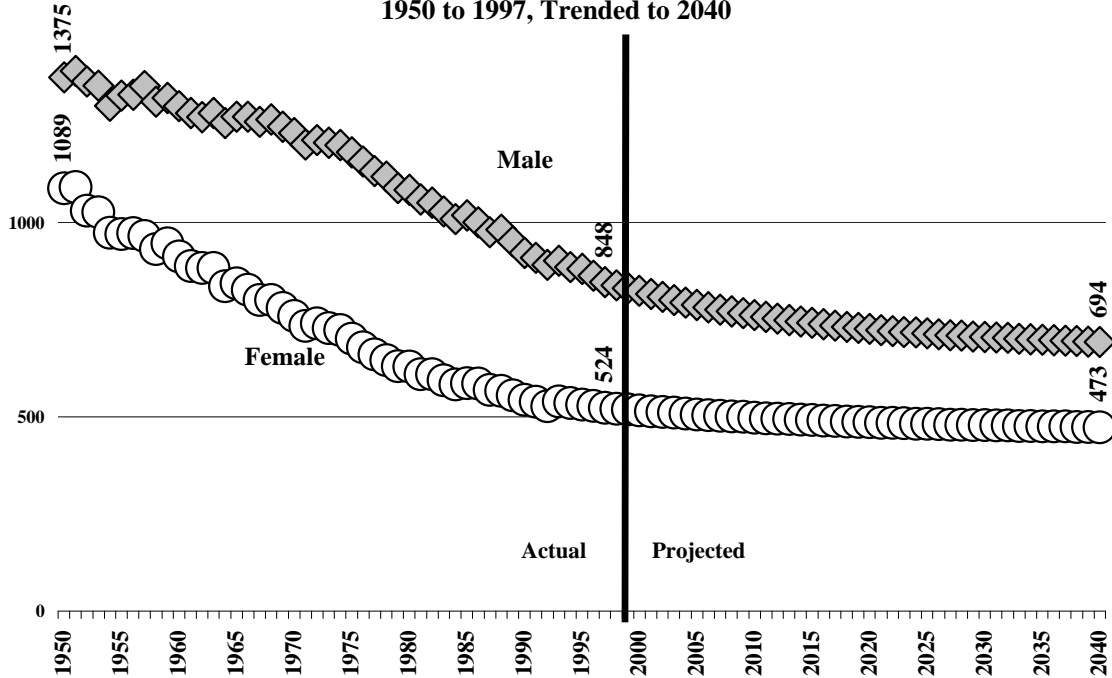
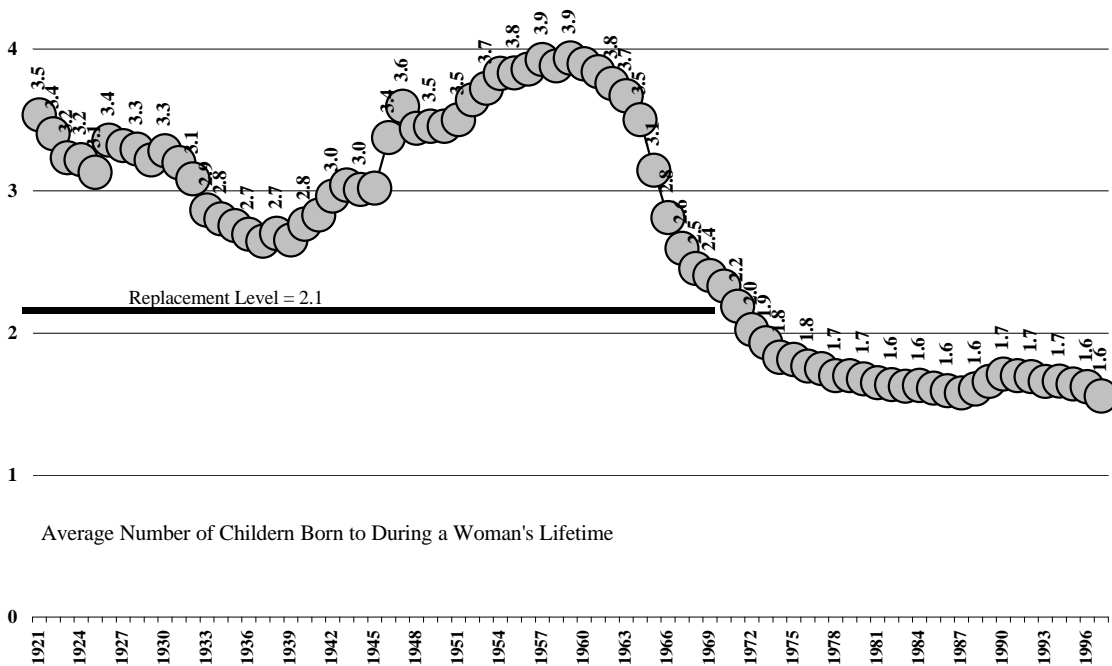


Figure 45: Canada, Total Fertility Rate, 1921 to 1997

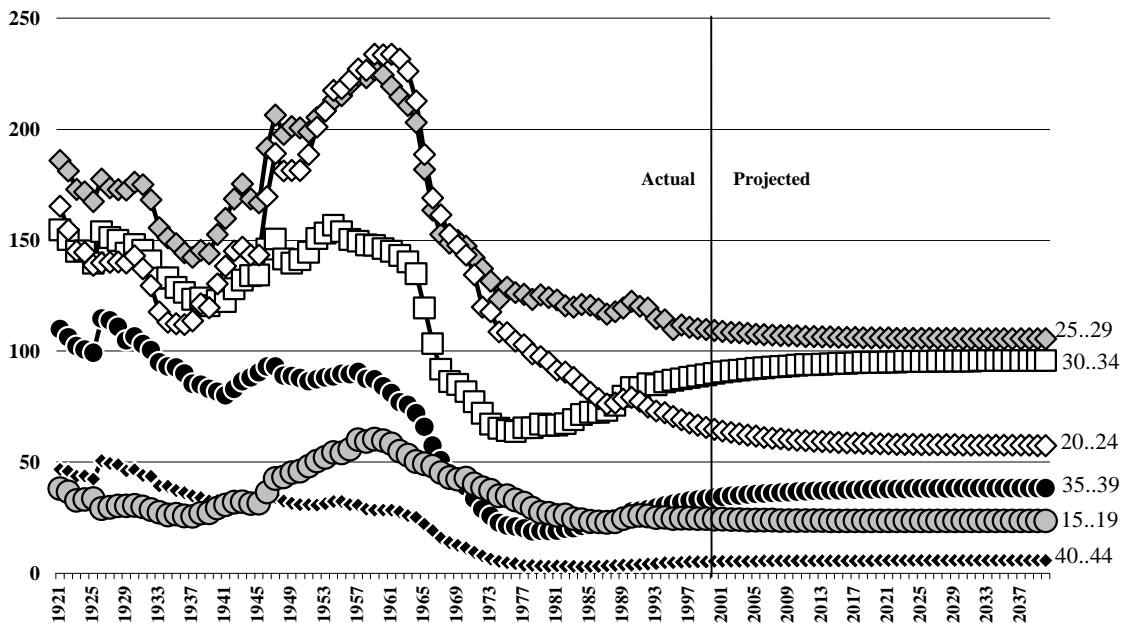


Over the past four decades, a similar trend of long run decline has been observed in birth rates (Figure 45). In the 1950s and early 1960s, there was an average of 3.5 to 3.9 children born per

woman in Canada during her lifetime (the total fertility rate). With the increase in female labour force participation rates, the urbanization of the Canadian population and the widespread use of reproduction planning, this rate fell significantly during the late 1960s, to reach an average of 2.1 children born per woman during her lifetime by 1969. This a critical rate in population dynamics, as it is the minimum average number of births during a woman's lifetime required for a population to grow by biological processes alone (the replacement rate). Since 1969, Canada has had a below the replacement level birth rate: since 1976, the rate has stabilized in the 1.6 to 1.7 births per woman range, with the current rate of 1.6 being at the lower end of the range. A below the replacement level means not only that a population does not replace itself (biologically) but also that each generation the median age of the population will increase as 2 older people contribute only 1.6 younger people to the population.

This stability in the average number of children women have during their lifetime should not be interpreted as indicating constancy in birth rates, as the age when women have children continues to change (Figure 46). Between 1961 and 1976, the number of births per 1000 women in every age group declined significantly, with the most noticeable decline occurring in the 20 to 24 age group (from 235 births per 1000 women in 1961 to 100 in 1976).

Figure 46: Canada, Age Specific Birth Rates, 1921 to 2021
(Number of Births Per Year Per 1000 Women in Age Groups)



From 1976 on, rates for women under the age of 30 continued to decline, but rates for women 30 and older changed course, increasing steadily between 1976 and 1997: the most noticeable change was for women aged 30 to 34, whose rate increased from 64 births per 1000 women in the age group in 1976 to 88 per 1000 in 1997. Mathematical projections of the trends observed over the past quarter century indicates a stabilizing of age specific birth rate trends by 2040.

The most common age at which women give birth to a child now is between 28 and 30 (Figure 47). The effect of the shifting of births from the early twenties to the late twenties and early thirties has increased the span of a generation from the 20 year age difference between mothers and children of 1961 to almost 30 years today. The increase in the age of mothers when children are born has compounded the effect of the decline in the average number of children a woman has during her lifetime on the relative number of children in our population. The stretching out

of the generation span from 20 to 30 years means that the we are taking longer to add a smaller number of people to our population, which in turn means that our population, in the absence of net immigration, will experience rapid increases in the share of its population that is in older age groups as the baby boom generation ages and the younger population declines. The demographic challenge that this raises is to find ways to support intergenerational transfers from younger working populations to older populations, ranging from the formalized transfers of health care, pension and income support, to informal family companionship and care.

Figure 47: Birth Rates by Age of Mother, Canada, 1997

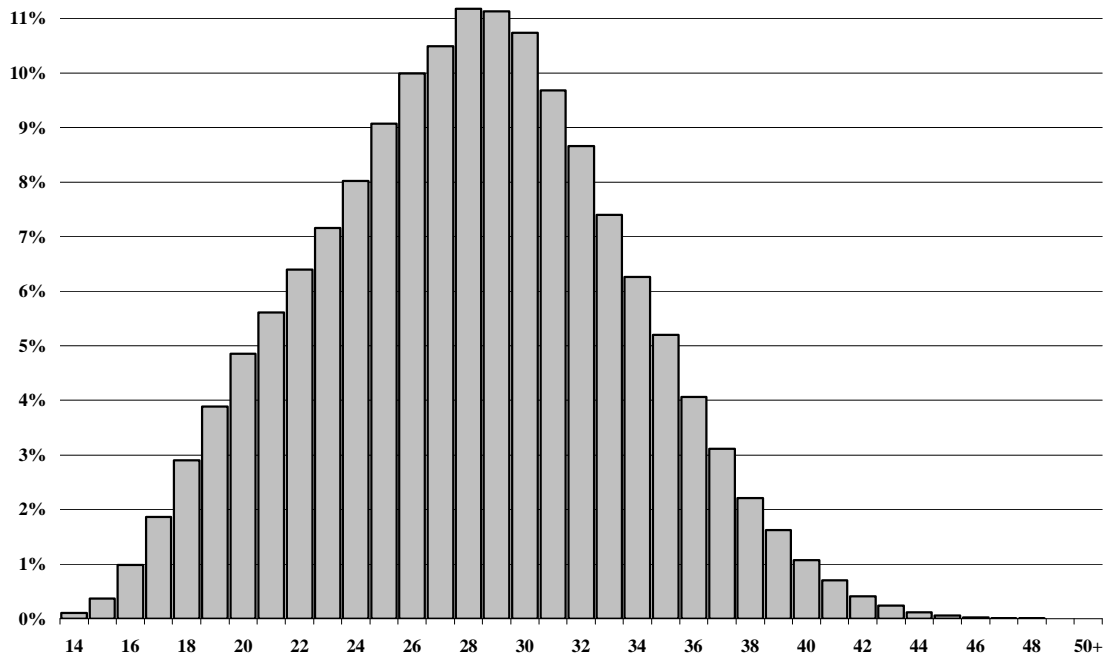
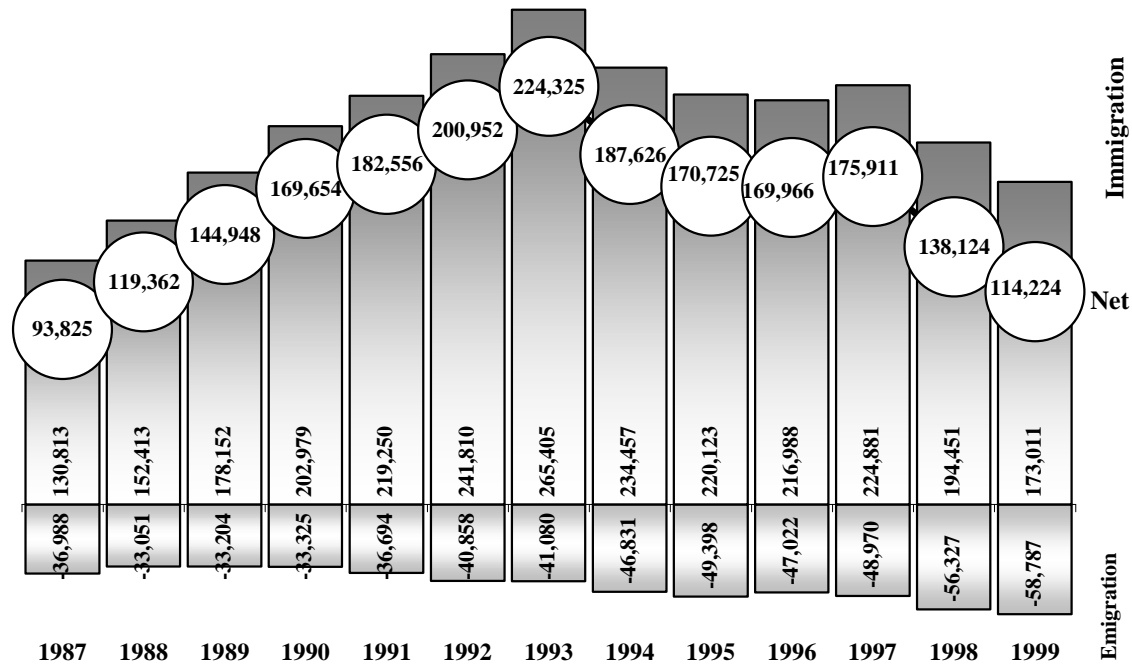


Figure 48: Immigration and Emigration, Canada, 1987 to 1999



Canada is fortunate in that it has been able to offset some of the effects of the aging of its population that would otherwise result from a below the replacement level birth rate through international migration. In the post war period, Canada has maintained a positive net immigration, with immigration exceeding emigration throughout the period. Recently released data for the past decade shows a changing direction of the net immigration flow (Figure 48)⁴⁶. Immigration grew significantly as a result of changes in immigration regulation in the late 1980s and early 1990s, from 130,813 in 1987 to 265,405 in 1993: it has declined substantially from this peak to reach 173,011 in 1999. From 1989 on there has been a sustained increased in the emigration from Canada, much of it the brain, talent and skills drain (come back, Shania) to the United States. In 1989, 33,051 people permanently emigrated from Canada: by 1999, the outflow had increased to 58,787.

The net result of these two flows of international migration was an addition of 114,224 people to Canada's population in 1999, down from the 224,325 net addition of 1993, and slightly below the 119,362 net addition of 1988. In 1999, there were 340,891 births in Canada (the smallest annual number since 1947), and 222,425 deaths, the largest annual number ever. The net biological increase in Canada's population in 1999 was 118,446, approximately the same number as the increase due to net immigration. Immigration in 1999 was 0.57% of Canada's population, down from 0.93% in 1993: emigration was 0.19%, compared to 0.15% in 1993. In total, Canada's population increased by 232,670 residents in 1999, a 0.76% increase, the smallest annual increase since the 1930s depression.

The term fortunate was used in the context of the historical net immigration flow to Canada because migration flows, whether inter-provincial (as discussed on page 19) or international, are comprised mainly of young people: 68% of the immigrants to Canada in 1999 were younger than Canada's baby boomers (i.e., under the age of 34), with 65% of the immigrants over the past 5 years being under 34 (Figure 49). The emigrant population also has an age profile younger than that of the resident population, with 52% of 1999's, and 48% of the past three year's⁴⁷, emigrants

under the age of 34: note that the emigrant age profile is slightly older than that of the immigrant profile (Figure 50). Net inward migration to Canada makes our population younger than it otherwise would be directly, by adding more post boomers to our population, and indirectly, by increasing the number of women of childbearing age which in turn increases the number of births.

Figure 49: Age Distribution of Immigrant and Resident Populations, Canada 1999

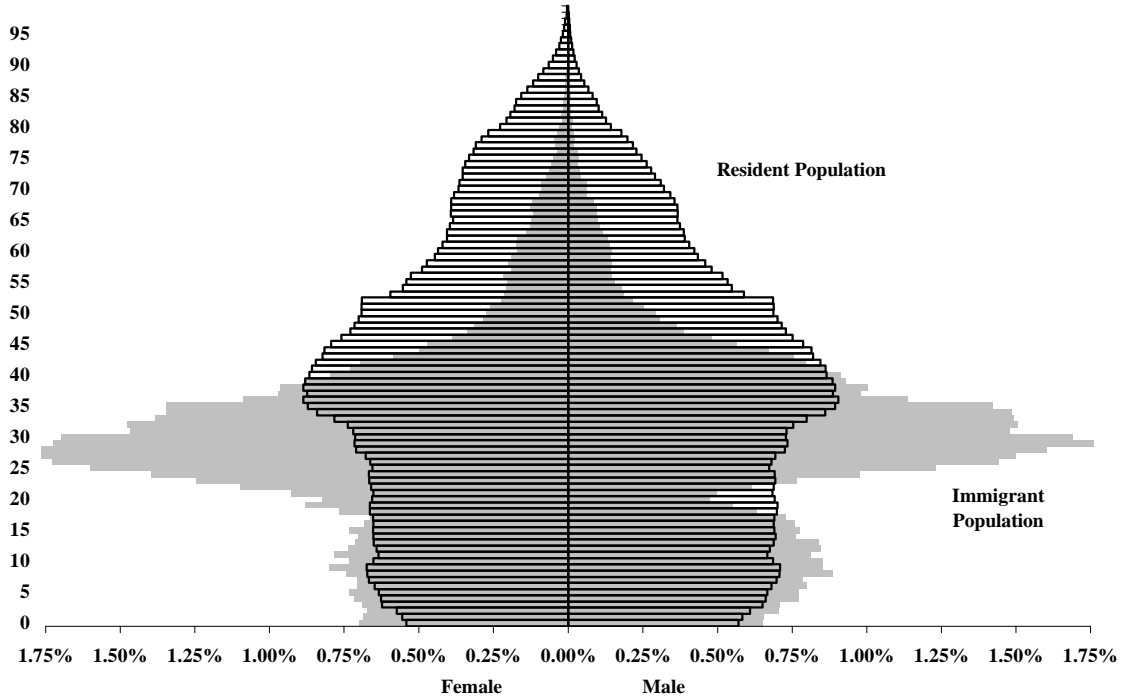
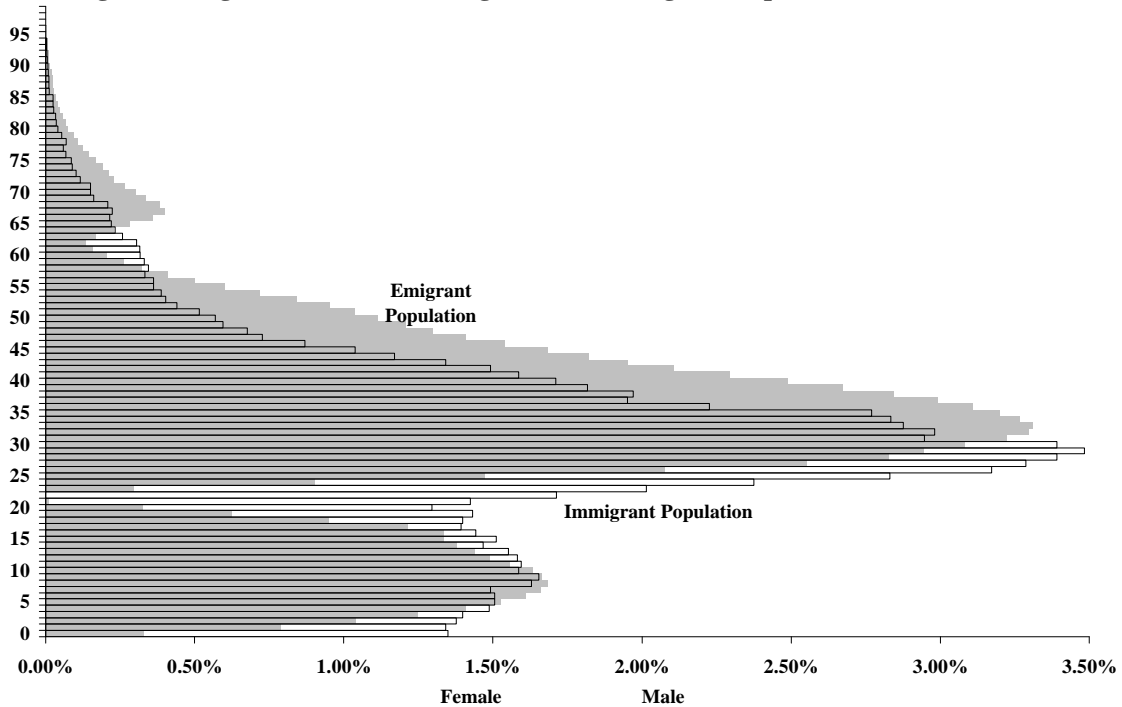


Figure 50: Age Distribution of Emigrant and Immigrant Populations, Canada, 1999



For purposes of projection of Canada's future population, it is here assumed that:

- a) mortality rates follow their historical trends, but at diminishing rate to stabilize by the middle of the century;
- b) birth rates follow their trends over the past 25 years, also stabilizing by mid-century;
- c) immigration reverses its recent decline and increases to reach 0.75% of Canada's population (the average of the 1990s) by 2010, and then remains at the 0.75% rate for the remainder of the forecast period;
- d) in spite of the strong increase in emigration rates over this decade, emigration rates do not increase beyond their current 0.19% of the resident population level;
- e) the age distribution of the immigrant population matches the age profile of its average for the past five years; and
- f) the age distribution of the emigrant population matches the age profile of its average for the past three years.

Given the current age profile of Canada's population, and these assumptions, the country's population will grow from its current 30,719,812 residents to 35,572,893 in 2020 and 38,402,360 in 2040 (Figure 51). This projection indicates a continuation of the slowing of population growth in Canada, from an 0.8% increase this year to a 0.6% increase in 2020 and a 0.2% increase in 2040. Slowing of population growth in Canada will occur even if the net immigration level to Canada increase from its current 0.57% to 0.75% by 2010, and remains at this level.

The projected increase in net immigration from 139,626 this year to 198,202 by 2020 and 213,967 by 2040 (Figure 52), will be to a large, and increasing, extent offset by the continuing decline of the contribution of biology to population growth (Figure 53).

Figure 51: Canada's Projected Population, Current Trends Scenario, 2000 to 2040

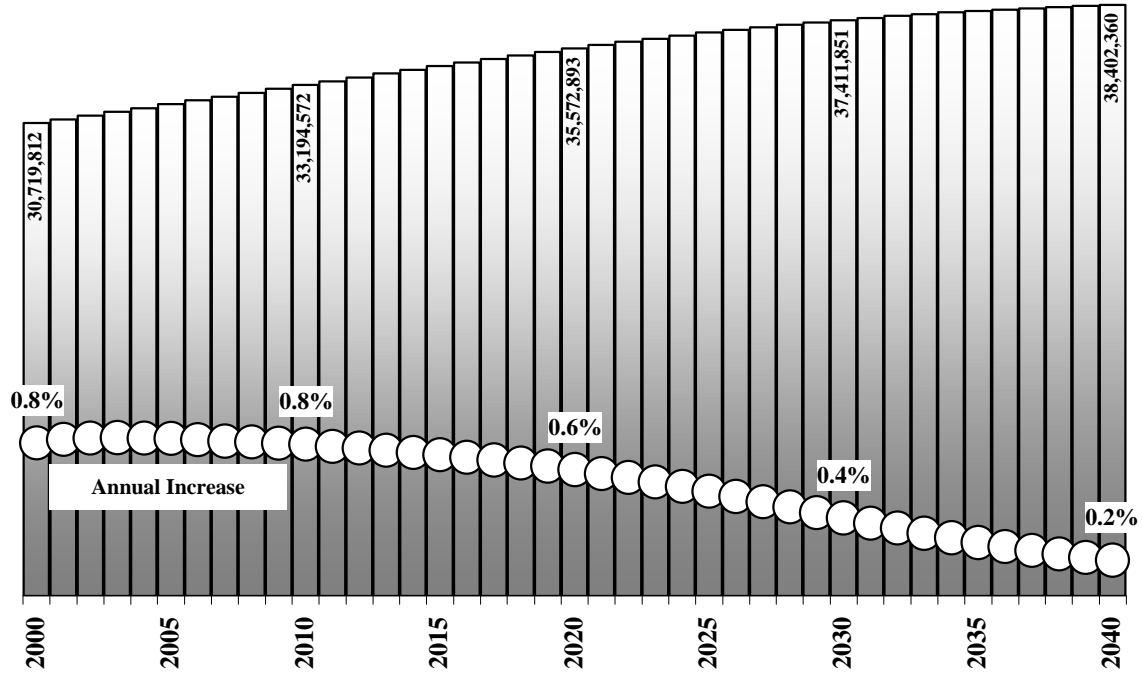
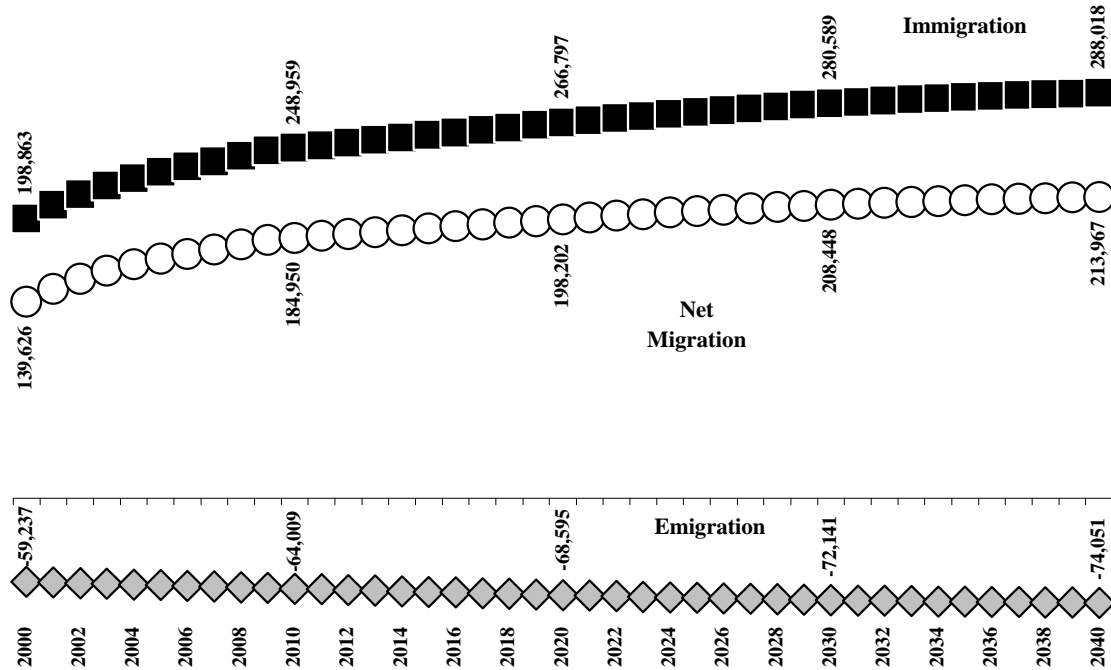
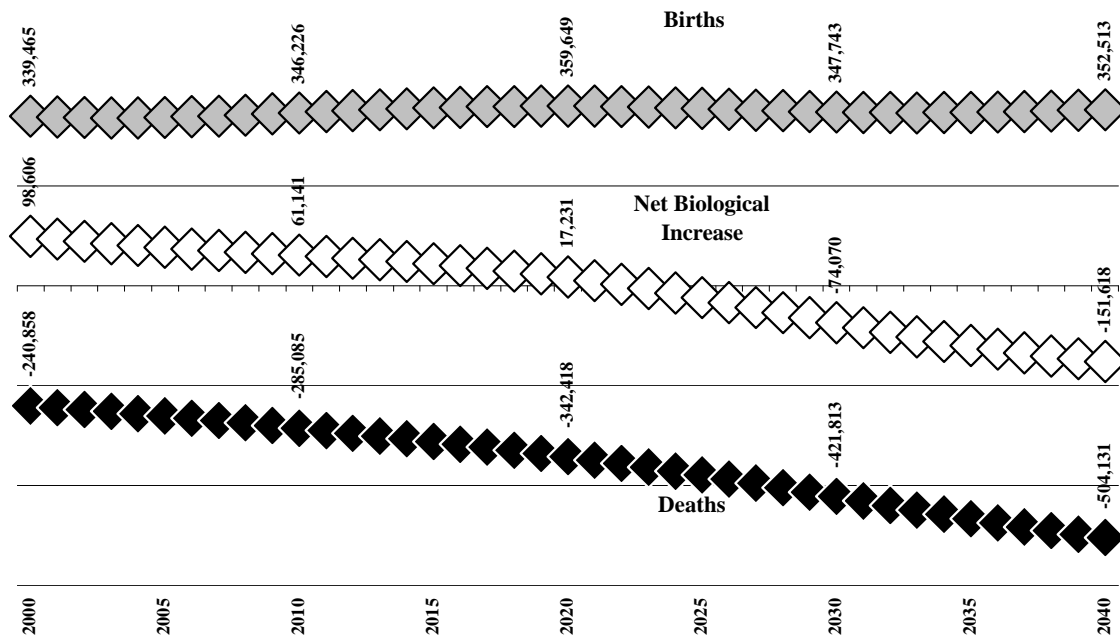


Figure 52: Projected Immigration, Emigration, and Net Migration, Canada, 2000 to 2040



Part of the reason for the slowing of the population growth rate is simply that the size of the base is increasing: the main reason is that the number of deaths will increase faster than the number of births (Figure 53). Between now and 2020, aging will take the war and post war baby booms into slightly higher mortality rate age groups, and hence, while the number of deaths each year will increase it will do so at a relatively constant rate. From 2020 on, however, even with the assumption of continuing declines in mortality rates, the number of deaths each year will accelerate as the bulge moves into the highest mortality rate age groups. With the number of births projected to remain relatively constant over the projection period, the contribution of biology to population change will be negative after 2020, with 151,618 more deaths than births occurring in Canada by 2040.

Figure 53: Components of Biological Change, 2000 to 2040



The reason the number of births will remain relatively constant is that the projected level of net migration to Canada will essentially maintain the size of the childbearing population while aging will increase the size of the older population. From today to 2020, the bulge of the age profile will shift up, with the typical Canadian of 2020 being 57 years old - today's typical Canadian plus 20 years (Figure 54). The net positive immigration that results from a projected immigration rate of 0.75% and an emigration rate of 0.19% will generally offset the decline in the under 34 age group that would otherwise result from a below the replacement rate birth rate.

Under these conditions, we can anticipate a slight decrease in the number of people in the high organ donation rate 0 to 24 age groups (426,413 fewer people, a 4% decrease) and a relatively constant 25 to 44 age group (64,634 more people, a 1% increase, Figure 55). Aging will ensure that the high organ recipient rate 45 to 64 age group will increase dramatically, adding 2,792,362 people (39%) more, and that the 65 plus age group will increase more in relative terms (63%) although by fewer people (2,422,498 more).

Any circumstances that would lead to higher than projected emigration rate, a lower than projected immigration rate, a lower than projected birth rate, or a lower than projected mortality

rate will increase the growth of the older age groups relative to younger ones.

Figure 54: Population of Canada, by Age and Sex, 2000 and 2020

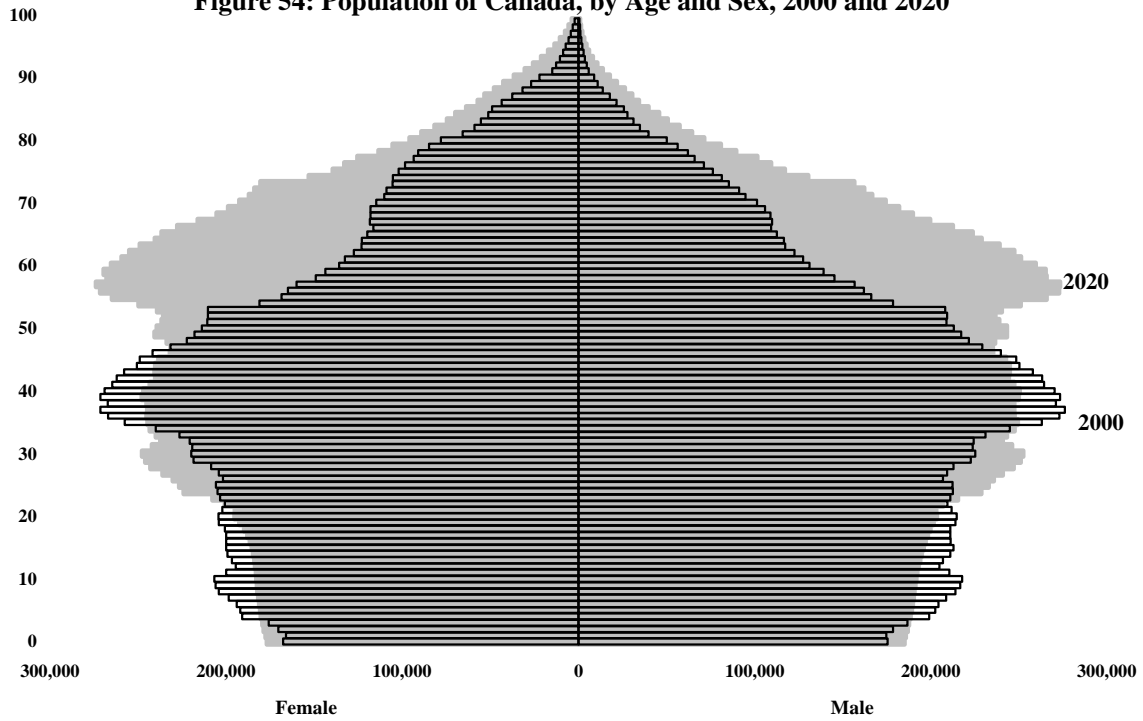
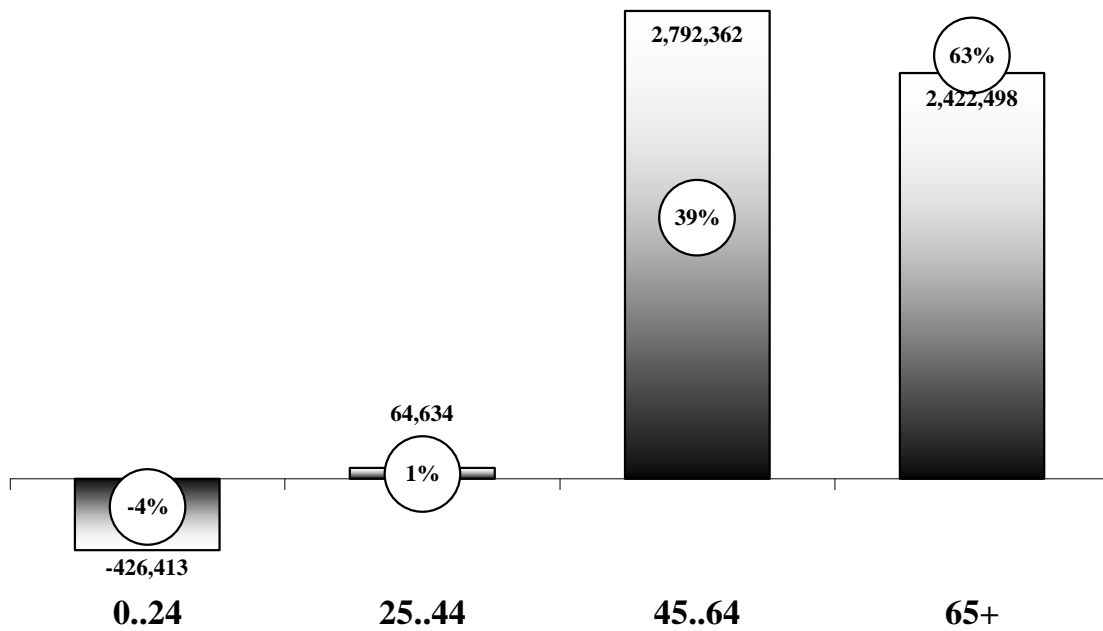


Figure 55: Population Change by Age Group, Canada, 2000 to 2020



While the picture over the longer run is similar, it is not identical (Figures 56 and 57). By 2040, mortality will have begun to narrow the war and post war baby boom bulge of the age profile, as the current typical Canadian will have reached age 77. Nonetheless, the sheer size of the bulge will mean that the most significant relative and absolute growth over the next four decades will be in the 65 plus age group, which will increase by 129%.

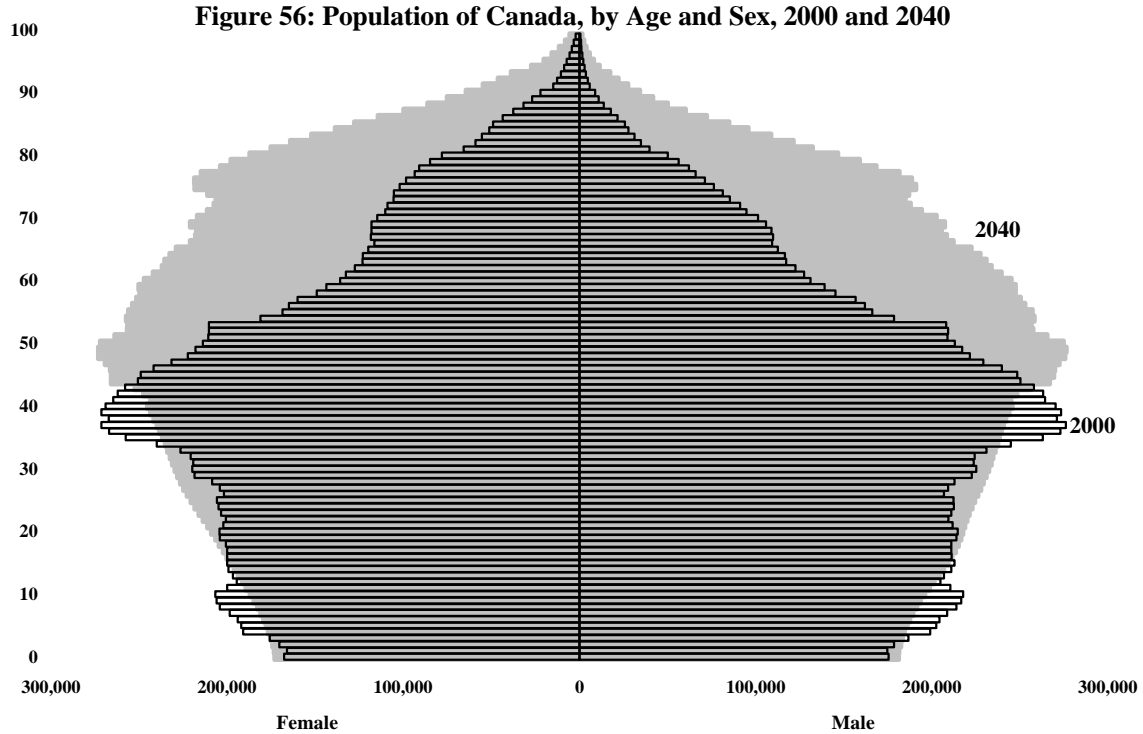
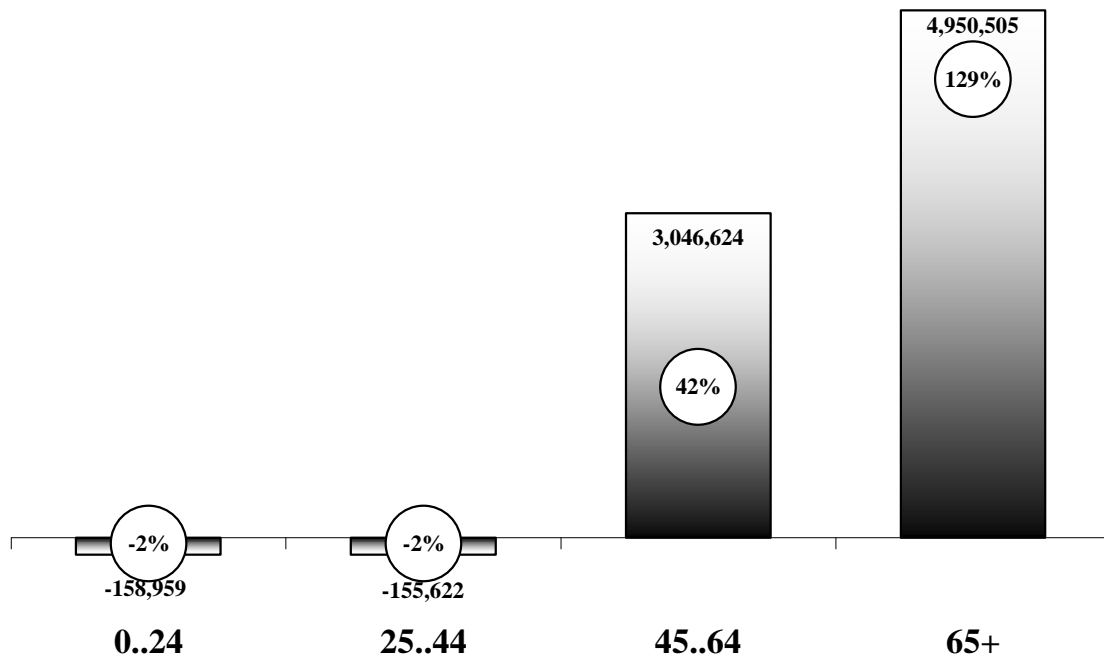


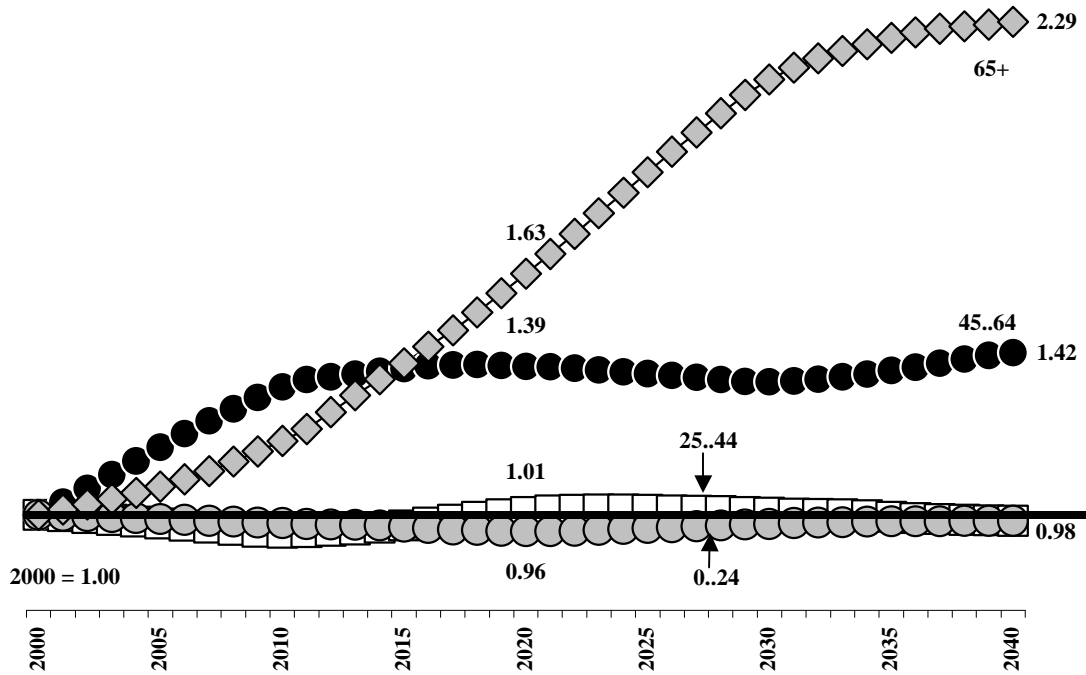
Figure 57: Population Change by Age Group, Canada, 2000 to 2040



The dynamics of Canada's population will trace a distinct pattern of change in the size of age groups over the coming decades (Figure 58). Over the next decade, the most rapidly growing age group will be the 45 to 64 age group, as the widest part of the baby boom bulge ages into it. In the following decade, as the front edge of the bulge ages into the 65 plus age group, it in turn will become the most rapidly growing, a status it will hold for the remainder of the period

In contrast, the pattern for the 0 to 24 and 25 to 44 age groups is essentially to remain at their current size. If immigration moves above the 0.75% level, emigration below the 0.19% level, the total fertility rate goes up, or if women start having children much earlier in their lives, the size of the younger age groups may increase slightly more than indicated here - for any of these to occur would require a dramatic change in trends observed to date. Even if they do, the rates for change for younger age groups will not approach those of the older age groups: the aging of the 41% of Canada's current population that is currently between the ages of 34 and 63 will dominate demographic change for the next half century.

Figure 58: Population Change by Age Group, Canada, 2000 to 2040



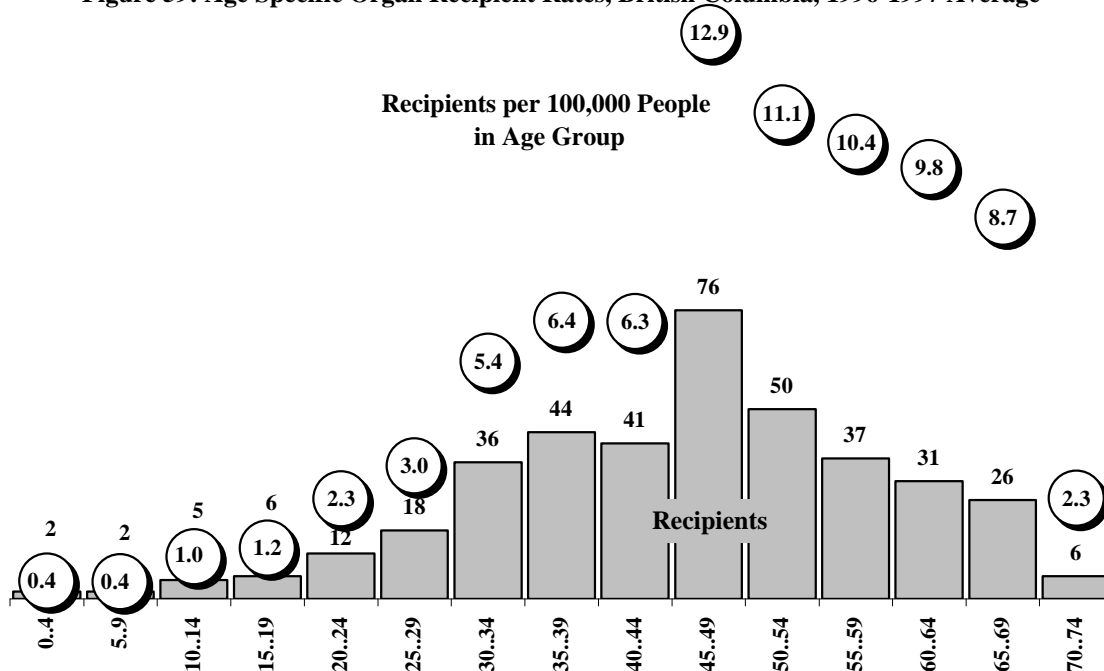
IV. Levels of Supply and Need of Organs for Transplantation

Given the trends and age specific pattern of organ donation and need documented in Section II, the challenges for transplantation can be readily inferred from Figure 58. In order to project the change in magnitude of both need and supply, and hence of the transplant gap, it is necessary to use more specific assumptions relating to donation and receipt patterns. As the most recent mortality data by detailed cause was available for 1996 and 1997, these are the reference years for the data used in the projection. Thus while Section II considered the data for the demographics of organ donation and receipt over the 1990 to 1999 period, the projections of organ need and supply are calibrated to the 1996 and 1997 reference years.

a. Need for Organs for Transplantation

In this projection of the future magnitude of the need for organs for transplantation, demographic and non-demographic trends are incorporated into the model separately. The demographic component is reflected in the use of age specific organ receipt rates, in this case using the data for the recipient rate that prevailed in British Columbia in the reference years (Figure 59).

Figure 59: Age Specific Organ Recipient Rates, British Columbia, 1996-1997 Average



In the model, these rates are multiplied by the number of people in the corresponding age group in the population projection for Canada to determine the base need from each age group. These are obtained from data on effective need, that is, from data on the need that was met by transplants: the data do not include the unmet need. As data on the detail age composition of those in need of organ transplantation are not currently available, it was assumed that the age profile of unmet need was identical to that of those who received transplants.

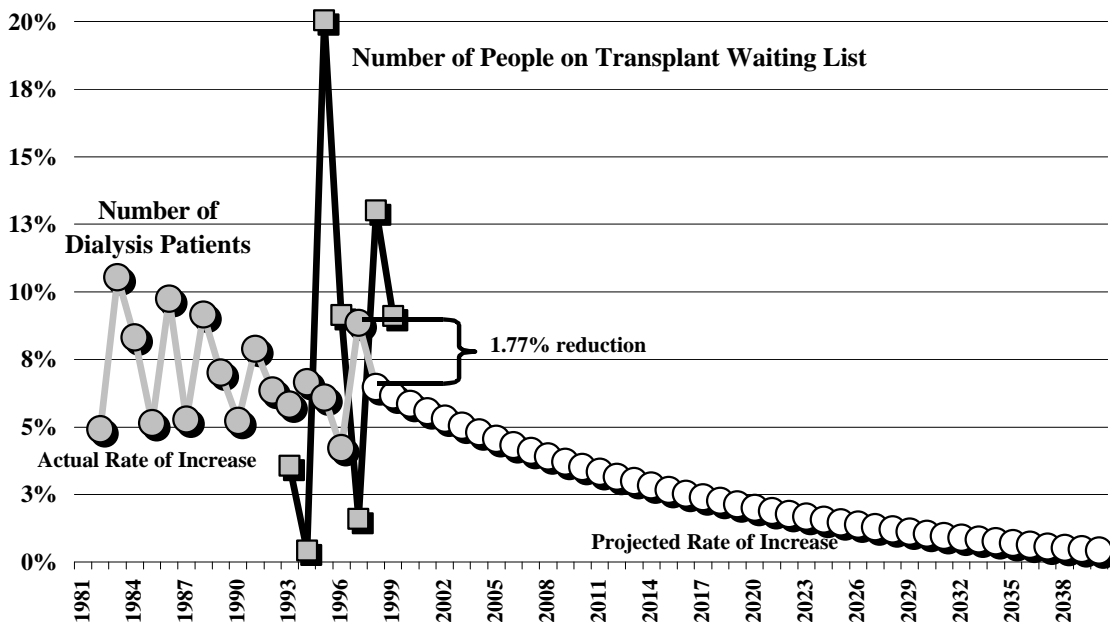
The estimate of total need can then be made by calibrating the base estimate of need to estimated total need in 1996 and 1997. There are a number of ways that this total need has been defined. One definition is that total need is equal to the number of people receiving transplants each year (met need) plus one-third of the people on dialysis during the year: this results in a total need estimate average for 1996 and 1997 of 5,160. Another definition is that the number of people on

the waiting list for transplants plus the number of transplants scaled by 10% to 15% to account for the number of people who die each year waiting for a transplant: this results in an estimated average of 4,970 for 1996 and 1997. To be conservative, the lower estimate was used.

To incorporate the non-demographic factors into the model, it is necessary to acknowledge that the reference years are points on a path of rapidly increasing age specific need for organs from transplantation. Over the past 15 years, the number of transplants in Canada increased by an average of 6.2% per year, the official waiting list for transplants has increased by an average of 7.9% per year over the past decade, and the number of persons on dialysis increased by an average of 8.1% per year over the past 15 years (8.24% per year over the past decade). If demographic factors alone (population growth and change) explained growth in need waiting lists and patients on dialysis would have increased at an average of only 1.77% per year.

It is necessary to consider how much longer non-demographic factors (such as the increasing incidence of diabetes and hepatitis C) will cause the need for organs for transplantation to increase at an average annual rate of 6.47% (8.24% - 1.77%). All evidence suggests that the 6.47% annual growth will continued well into the future: in spite of this evidence, in order to be conservative, it is here assumed that the non-demographic rate of increase in need for organs from transplantation will decline asymptotically to reach zero by 2040 (figure 60). This is a very optimistic assumption, but it is necessary to acknowledge the stabilizing of underlying factors that generally occurs in systems: 6.47% growth per annum over the next 40 years would lead to a 12-fold increase in need in addition to that which population growth and aging would bring. The projected downward growth in need due to non-demographic factors is added to that produced by demographic factors to arrive at an estimate of future need.

Figure 60: Historical and Projected Estimated Growth In Dialysis and Transplant Waiting List Adjusted For Demographic Change, Canada



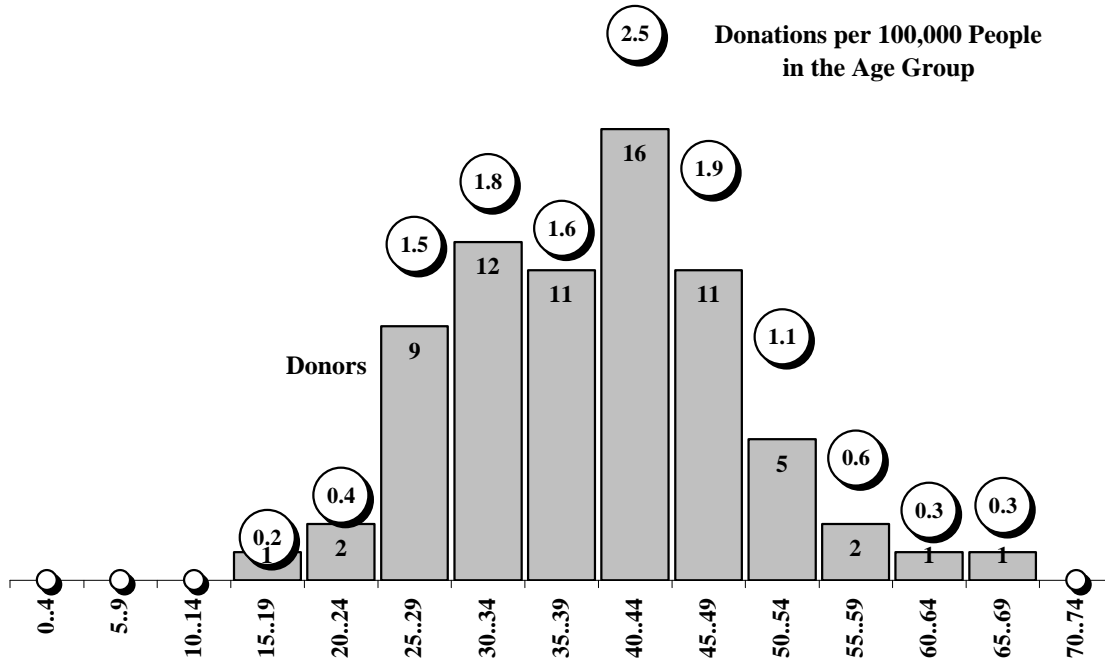
These assumptions are necessary because detailed long term data on the need for organ transplants by age and cause are not readily available. When they are, it will be possible to do trend projection of the change in the rate of need for organ transplants by age and cause, and use

the resultant demographically based vectors in the projection model.

b. Live Donation

As similar approach was taken to the estimation of live organ donation. The base of the live donation projection is the value estimated by applying the age specific propensity for live donation rates observed in British Columbia for the reference years (Figure 61) to the corresponding age groups in the projected Canadian population. This base value was then calibrated to the average of 275 living donors per year in Canada in the reference years.

Figure 61: Live Organ Donation, British Columbia, 1996 and 1997

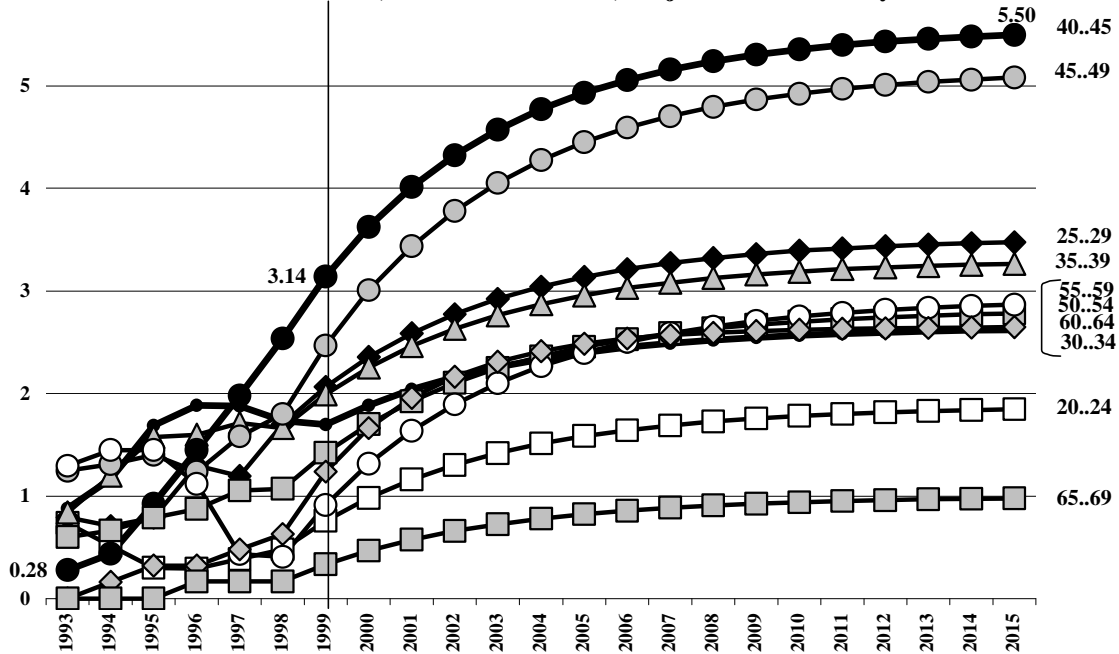


As with the number of people on waiting list, the number of live organ donors has increased faster than the country's population has changed. Between 1981 and 1997, the number of live donors in Canada increased by an annual average of 8.6% per year (see Figure 37): in British Columbia over the past decade the number increased by an annual average of 20.9% per year. Age specific live donation rates increased in every age group between 20 and 69 in British Columbia between 1990 and 1999: for example, the rate of 45 to 49 year olds increased from a three year average of 0.28 live donors per 100,000 in the age group for the 1990 to 1993 period to 3.14 per 100,000 for the 1997 to 1999 period (see Figure 36). For purposes of this projection, it was, again optimistically, assumed that these would continue to increase, albeit at a slowing rate (Figure 62), that would, for example, cause the rate for the 40 to 44 age group to stabilize at 5.5 per 100,000 by 2015. This pattern of change in age specific live donation rates, together with the age specific rates for the reference years, are used to project the number of live donors.

c. Cadaveric Donation

The projection of the rate of organ supply from cadaveric donors involves a different process, as it is necessary to project changes in mortality rates by cause of class of death. The following paragraphs documents this process using the example of mortality due to accidents and adverse effects other than motor vehicle accidents, suicide or homicide. The reason for selecting this other accidents cause as the example is that includes within Class I, Class Two and Not Used.

**Figure 62: 3 Year Moving Average of Age Specific Live Organ Donation Rates (Per 100,000)
British Columbia, Actual 1990 to 1999, Projected to Stabilize by 2015**



i. Aggregating Rates

This step is required because of the high cost of historical data on mortality at the detailed ICD-9 level. As was noted in Sections II.c.ii and iii, the 1996 and 1997 data at this level were categorized in Class I, Class II or Not Used. These data were divided by the population by age and sex to estimate detailed age and sex specific mortality rates by cause and class of death. Ideally, the projection of mortality rates would be done at this detailed level, as it would reflect the specific course of change that applies to each unique cause of death within each group. The data exist to do so, but their acquisition costs was too great for this project.

A less expensive alternative was identified, that of using trends in age standardized mortality rates by 20 summary causes available for the period 1950 to 1997. The detailed causes for were aggregated to match those in the age standardized data. For example, all accidents and adverse effects in the standardized data are in four summary categories: motor vehicle accidents; homicides; suicides; and other accidents. To match this last category, causes such as accidents involving vehicles other than cars, falling, drowning, industrial accidents, accidental death to fire arms, etc., were aggregated, resulting in an age group and sex tabulation of deaths due to other accidents allocated to Class I, Class II and Not Usable. As an example of this tabulation, Figure 63 shows that males in the 35 to 39 age group in 1996 and 1997 averaged 20.65 deaths per 100,000 due to other accidents: 7.7 were Class I, 12.9 were Class II, and 0.1 were Not Usable.

ii. Trends in Rates

The next step was to establish the trend line for age standardized mortality rates for each of the summary cause groups. For example, the trend for male mortality due to Other Accidents has been a steep decline from 62 deaths per 100,000 in 1950 to 25 per 100,000 in 1997: extending the past decade of change forward mathematically results in an estimate of a rate of 15 per

100,000 by 2040 (Figure 64). It was assumed that the projected change in the rate for each age group and class would be the same as that for the age standardized rate. In order not to be compelled to make this assumption, it will be necessary to acquire the historical annual ICD-9 four-digit mortality by age and gender data back for at least a decade.

Figure 63: Age Specific Mortality Rates by Class, Accidents and Adverse Affects Other Than Motor Vehicle Accidents, Homicide or Suicide, Canada, 1996-1997

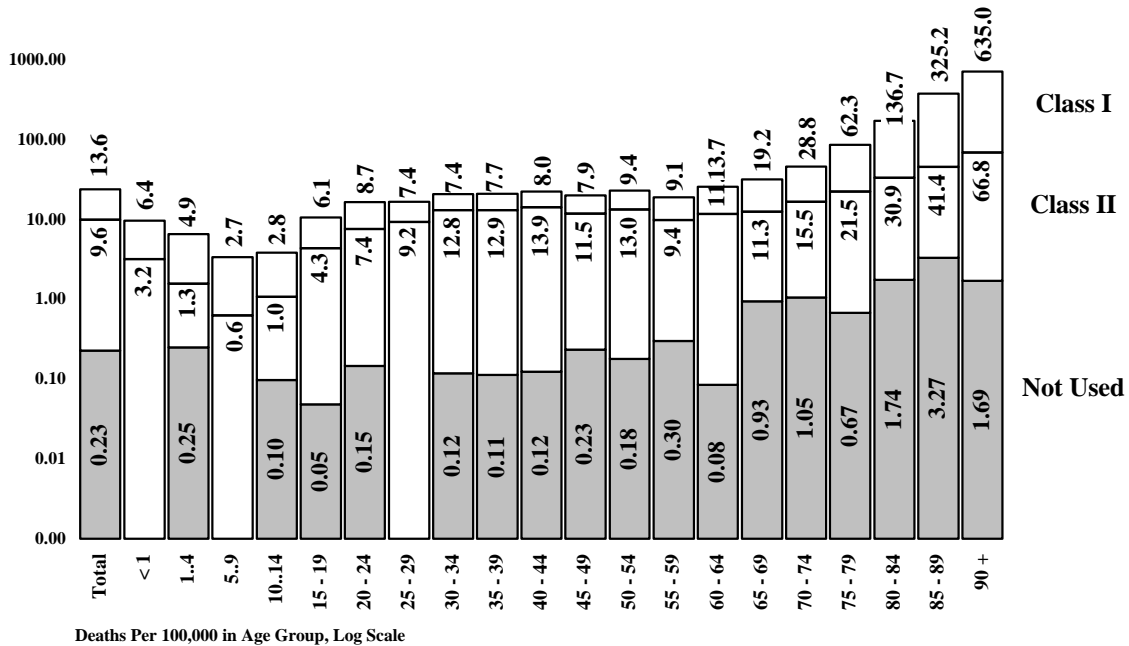
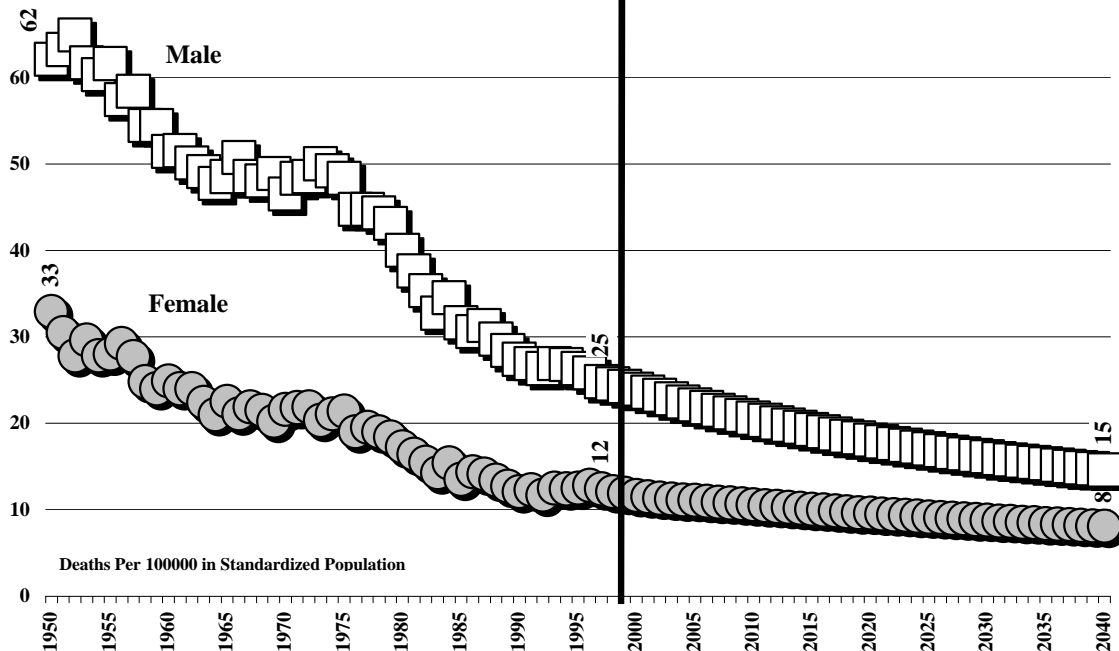


Figure 64: Age Standardized Mortality Rates, Accidents and Adverse Affects Other Than Motor Vehicle Accidents, Homicide or Suicide, Canada, 1950-1997, Trended to 2040



iii. Projected Age and Sex Specific Mortality and Cadaveric Donor Rates by Class

The procedure described in the preceding paragraph was applied to all 20 of the summary cause and 2112 detailed cause of death categories to generate a table of projected annual mortality rates by age, sex, summary cause and class of mortality for 1997 to 2040. These were in turn aggregated to age and sex specific mortality rates for Class I, Class II and Not Used.

Figure 65: Male Age Specific Mortality Rates, Class I Causes, 1997 and Projected 2040

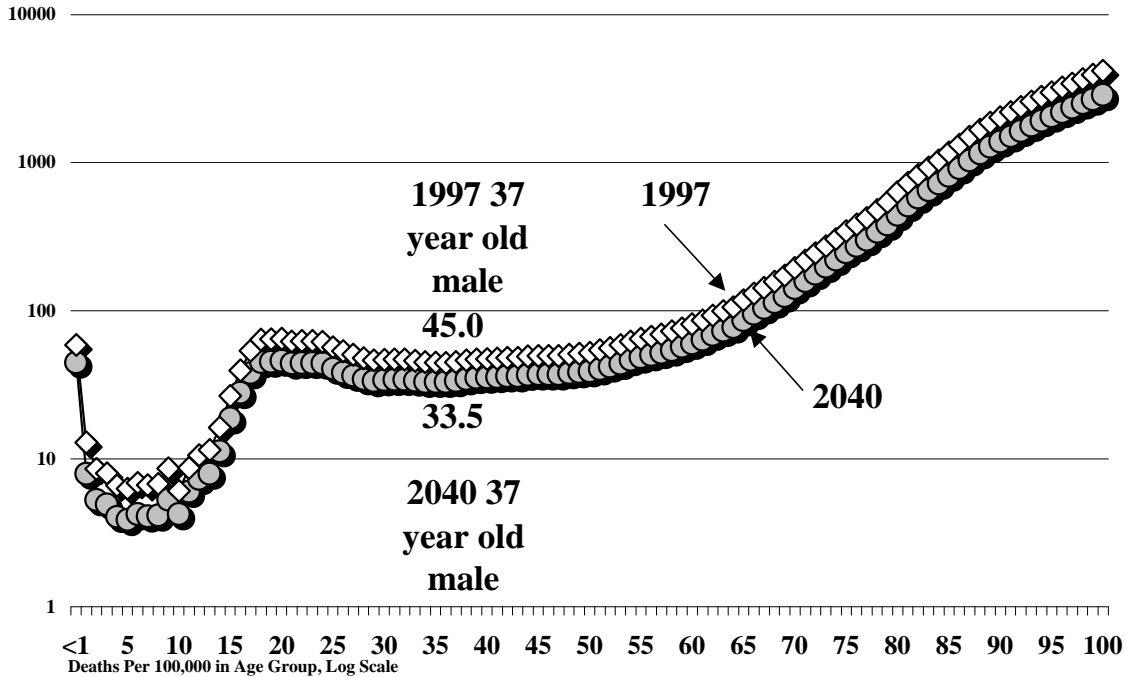


Figure 66: Cadaveric Donation Rate, Number of Organ Donations as a Percentage of the Number of Class I and Class II Deaths in Age Group, British Columbia, 1996-1997 Average

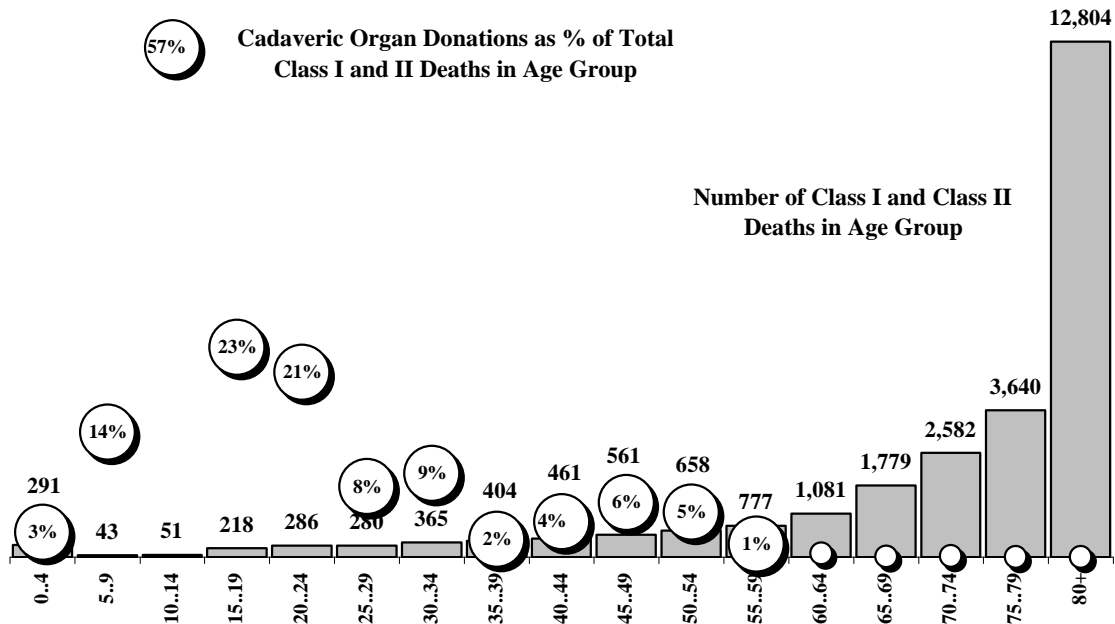


Figure 65 shows the resultant set of age specific rates for male Class I deaths in 1997 and 2040. While there appears to be little difference in the lines, note that a log scale is being used: the 37 year old male Class I mortality rate projected for 2040 is 33.5 per 100,000, representing a 25% decline over the next 40 years from the 1997 rate of 45 deaths per 100,000 males aged 37.

The final step is to estimate the percentage of the Class I and Class II deaths that will provide organs that will be used in transplants. The rate used was the average of the 1996 and 1997 ratios of cadaveric donation in each age group to the number of Class I and Class II deaths in the age group in British Columbia (Figure 66 which is Figure 40 repeated here for convenience). Again, please note the very low rates in the older age groups as a result of contraindication.

d. The Transplant Chasm: The Widening Gap Between Need and Donation

There is much that could be done to improve the robustness of the data and the model used to project the requirement for, and availability of, organs for transplantation in the future: the critical reader will have doubtless thought of many possible improvements already. Before embarking on any major effort to "improve" these forecasts, it is important to recall their purpose, which is to describe the direction of the changes that organ transplantation will face in the future, and identify the major reasons for this direction. The projections presented here are not intended to be seen as statements of what will happen, but rather to encourage discussion to find ways of avoiding the situation that would occur if current trends were followed. The specific values presented here are, in themselves, not represented as being either "right" or of great significance: what is important is the magnitude and direction of change they indicate. Hopefully, they will contribute to a process that will ultimately ensure that they are not right.

As such, it would be difficult to make a strong case for allocating substantial resources to improving the model and its data: they would be better allocated to dealing with the issues that the results of the model highlight. Please note that as the values are based on long run trends and the age specific rates that prevail in one region, a model-generated value may not precisely match that which will be observed in any one year. Also, please recall that need was defined to be larger than the sum of transplants plus the waiting list, giving consideration to both the number of people who die each year while waiting for a transplant and to the number of people on dialysis

What the projections show is that the continuation of demographic trends combined with the trends in the rate of success at obtaining organ donations from live and cadaveric donors will be an absolute and relative increase in the transplant gap (Figure 67). Following current trends, the difference between the number of transplants available for transplant and the number of people needing transplants, will increase from this year's estimated 5,441 people whose transplant needs go unmet to 16,250 by 2020 (a 199% increase), and to 21,265 by 2040 (a 291% increase).

The aging and growth of Canada's population, combined with continuing increases in non-demographic factors, will lead to an 152% increase in need over the next two decades (from 7,247 this year to 18,278 in 2020) and a 221% increase over the next 4 decades (to 23,280 in 2040). The rapid growth of Canada's older population and the slow growth of its younger population, combined with a continued decline in mortality rates of Class I and Class II causes being slightly more than offset by increasing live donation rates, will lead to a much slower growth in supply over the same period. Under this trend scenario, the number of organs donated for transplant will increase by 12% over the next two decades (from 1,806 in 2000 to 2,028 in 2020) and next four decades (to 2,015 in 2040).

The result of the projected 221% increase in need and the 12% increase in supply over the next four decades will be a 291% increase in the shortfall between need and donation, widening the transplant gap to a chasm (Figure 68).

Figure 67: Projected Supply and Need, Transplanted Organs, Canada, 2000 to 2040

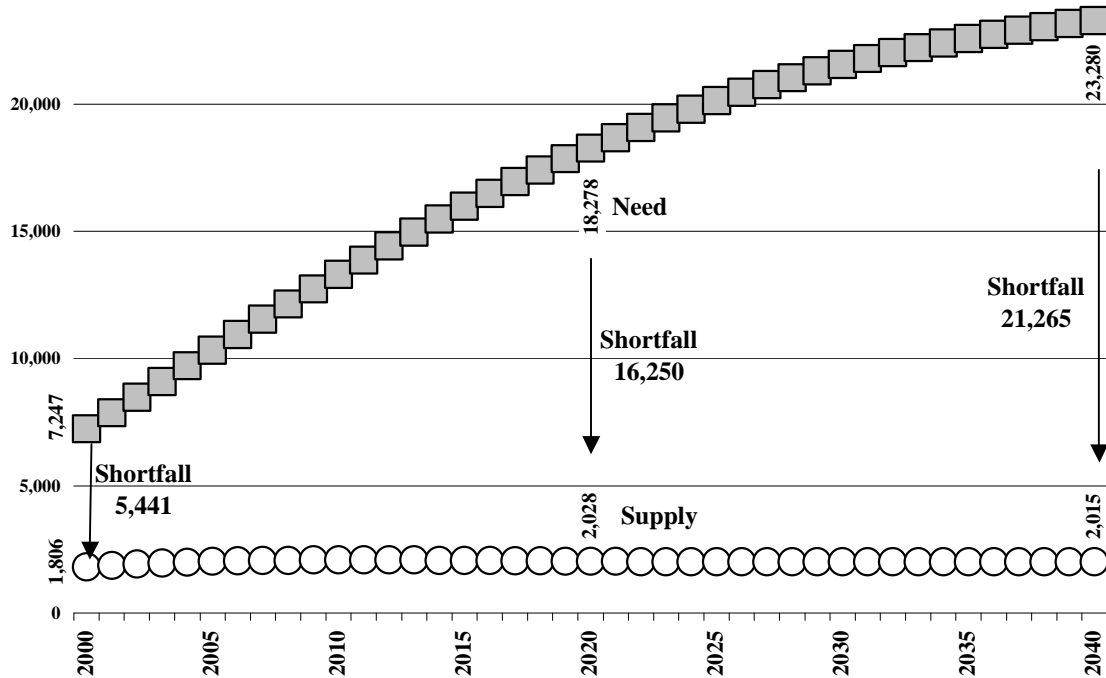
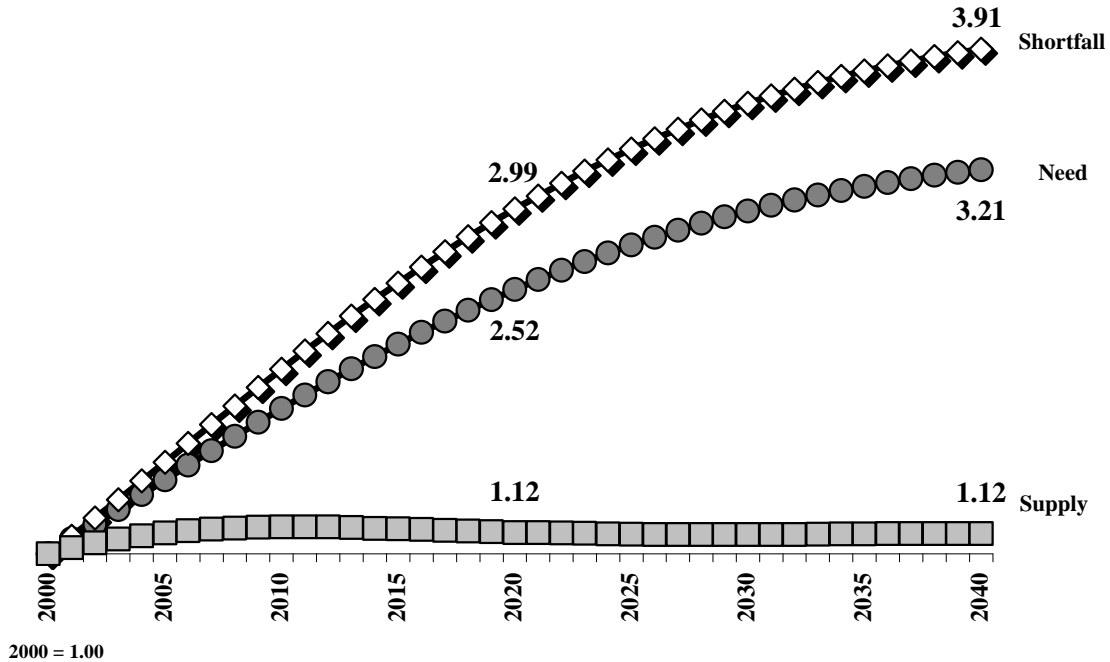


Figure 68: Index of Projected Change in Need, Supply, and Shortfall in Supply of Organs for Transplantation, Canada, 2000 to 2040



The increase in need, which will be greatest in the next two decades, will result from the rapid increase in the number of people aged 45 to 64 (the highest recipient rates) combined with the

projected increase (albeit at a slowing rate) due to non-demographic factors. The increase in supply will also be the greatest during the next two decades, driven by the assumed increase in live donation rates and the still declining mortality rates projected for the period.

Figure 69: Projected Supply of Transplanted Organs by Source, Canada, 2000 to 2040

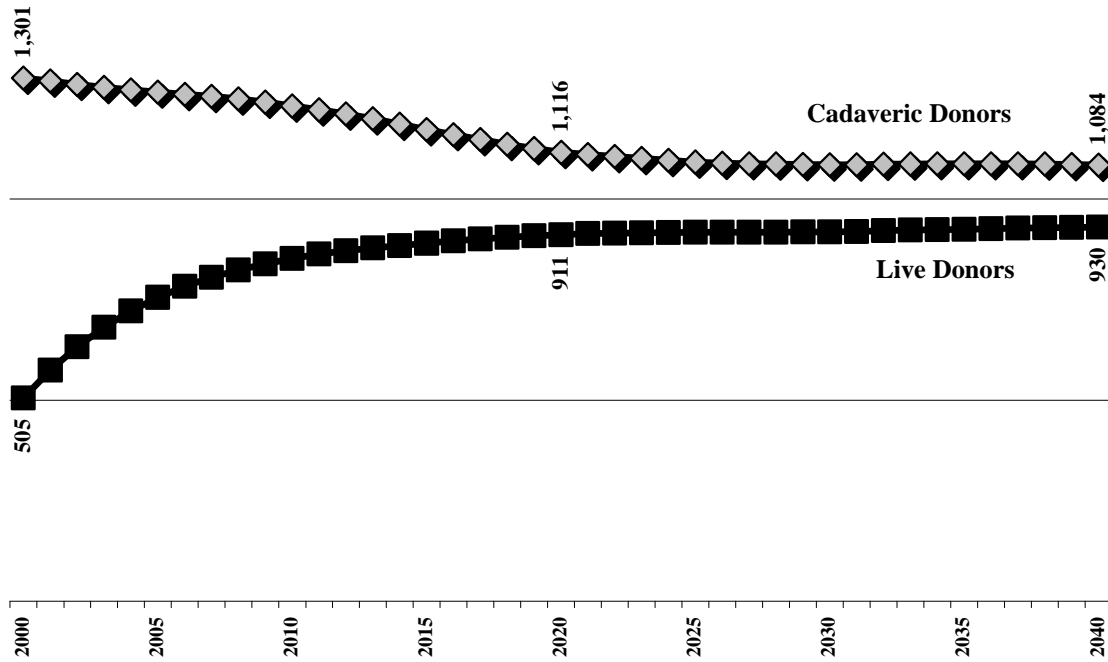
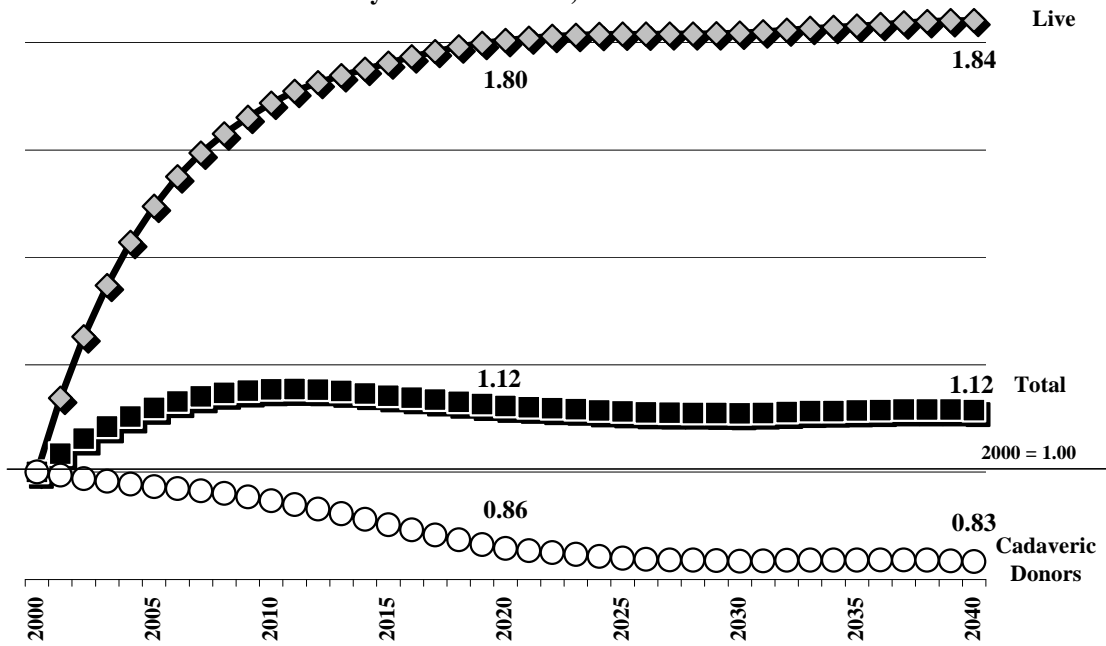


Figure 70: Projected Change in Supply of Organs for Transplantation
by Source Canada, 2000 to 2040



The impact of increasing live donor rates and declining mortality rates on organ donation will be more significant than is shown in total supply. The assumption of the gradual slowing of the increases in age specific live donation rates would result in an increase in the number of live donations from its current estimated 505 per year level to 911 by 2020 and to 930 by 2040 (Figure 69). This increase in live donation will slightly more than offset the decline in the number of cadaveric donations. An aging population and declining mortality rates will result in a decline in the number of organs available from cadaveric donation (assuming current recovery rates) from the current estimate of 1,301 to 1,116 in 2020, and to 1,084 in 2040.

An aging population and increasing live donor rates would result in an 84% increase in live organ donation (80% in the next twenty years and 84% over the next forty, Figure 70). This increase will slightly more than offset the 14% decline in cadaveric donation over the next twenty years and a 17% decline over the next forty. Demographics and current trends⁴⁸ will mean that the shortfall of donation of organs for transplant will increase over the coming decades.

e. Conclusions

The trend projection is, in a number of senses, an optimistic one, in that it assumes that live donation rates will continue to increase at a pace that will more than offset the decline of cadaveric donation that will result from the aging of the population and a continued decline in mortality rates. Nonetheless, the continued rapid growth of waiting lists and patients on dialysis, combined with the aging of the country's population out of the relatively high donation rate younger age groups and into the relatively high recipient age groups, will lead to a growth in need that will overwhelm the increases in supply. Under current trends and conditions, the transplant gap will widen rapidly and significantly in a transplant chasm.

If the gap is to be narrowed, rather than to widen, it will be necessary a) to significantly increase the effective rates of donation and b) seek non-donor solutions to transplant need. In the short term, the first strategy will be most important, as it can bring about immediate results. This will mean implementing measures to ensure that all potentially viable Class I and Class II mortalities flow into the transplant stream. There will be a continued, and overwhelming, public interest in reducing mortality due to Class I and Class II causes: it would not be prudent to rely on the current recovery rates to ensure transplant supply. This means a greater emphasis on development of routine referrals of all mortalities, greater presence of dedicated in-hospital donation specialists, a broad and effective registration system for donation consent, and much greater public education about donation.

It will also mean significant additional effort to increase live donation rates. This will be a significant challenge, as the impressive growth that has occurred in the past decade must not merely be continued, it must be accelerated beyond the level of growth already assumed in the trend projection. In the longer term, bio-medical technology will continue to provide options to a reliance on organ donors. While the promise of research is great, it must be put in the context of the fact that the greatest increases in need, at least under current trends, will occur in the next fifteen years. Technological solutions often occur over decades, not years.

Appendix I: A Constant Rate Scenario

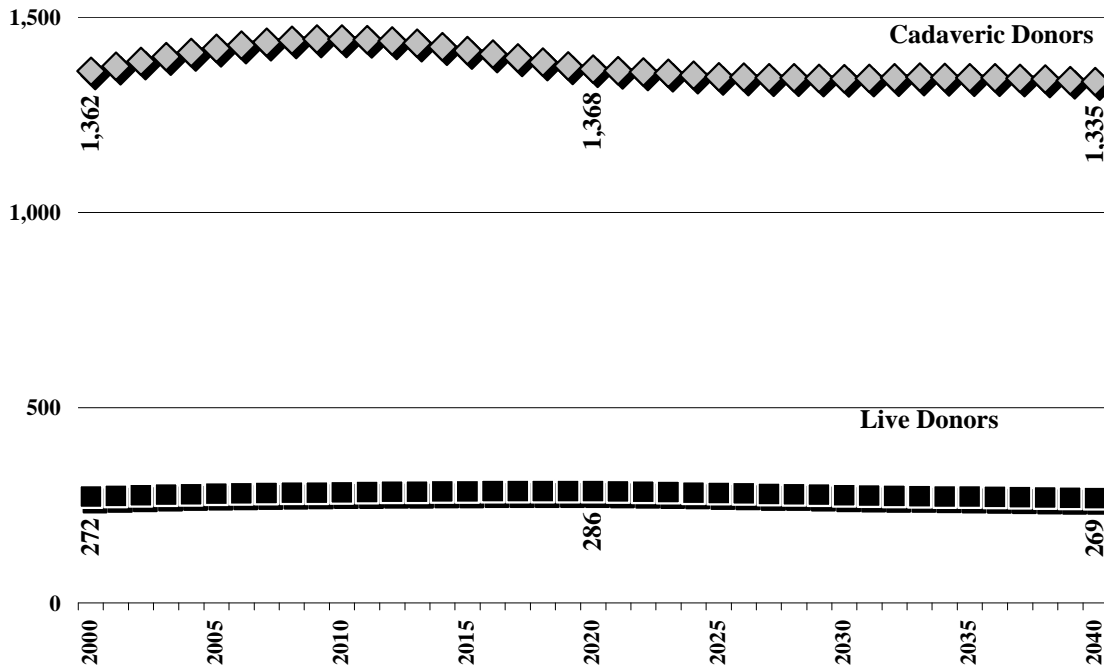
The trend projection of a widening transplant gap relied on a number of assumptions about continuation of patterns of change in need for organs for transplant, in live donor rates, and in mortality rates. All of the assumptions were based on the best available data, and are reasonable, yet there will always remain the question of how sensitive the fundamental conclusion, that the transplant gap in Canada will continue to widen, is to these assumptions. One way to test this sensitivity is to assume that all rates remain at the reference year level: if the same conclusion may be drawn from the results of such a constant rate scenario, even if the values it produces differ greatly from those of the trend scenario, then the conclusion is robust. Such a projection will be a demographic projection, as the only factors causing change in the need for, and supply of, organs for transplants are population related: aging, migration, natality, and mortality.

The implications of the current rate assumptions are:

- constant reference year age specific live donation rates will, all other things equal, increase the relative magnitude of the transplant gap, as they will result in a smaller future supply;
- constant mortality rates will reduce the relative magnitude of the gap, as they will result in a larger future supply of organs from cadaveric donors;
- constant age specific demand for organs will reduce the relative magnitude of the gap, as they will result in a low future demand;
- constant birth rates will reduce the relative magnitude of the gap, as they will increase the number of young people in the population in the future; and
- constant immigration and emigration rates will result in a larger relative transplant gap as they will result in a smaller younger population in the future.

Even with this unrealistic scenario, demographics would ensure that the transplant gap would widen in the future.

Figure 71: Constant Rate Projected Supply of Transplant Organs, Canada, 2000 to 2040



The assumption of constant rates would mean a much smaller, and relatively constant, number of live donations, ranging from 272 in 2000 to 269 in 2040, while the number of cadaveric donations would be higher, and also remain relatively constant throughout the next four decades (ranging from 1,368 in 2020 to 1,335 in 2040, Figure 71). The constancy of the two sources of supply would lead to a relatively constant total supply, ranging from 1,635 in 2000 to 1,604 in 2040 (Figure 72). Constant rates would also mean that need would be relatively lower, but would still increase as a result of the aging of the population: the need for 5,252 transplants in 2000 would increase to 6,265 by 2020 and 6,019 by 2040. A relatively constant supply and a growing need would mean an increasing shortage of organs for transplant, from a gap of 3,617 in 2000 to 4,611 in 2020, and to 4,415 in 2040 (Figure 72). The result of a 19% increase in need, and a 0.1% increase in supply between 2000 and 2020 would be a 27% increase in the transplant gap, with the 2% decline in supply and the 15% increase in need over the next 40 years leading to a long run increase of 22% in the gap (Figure 73).

Figure 72: Constant Rate Supply and Need, Transplant Organs, Canada, 2000 to 2040

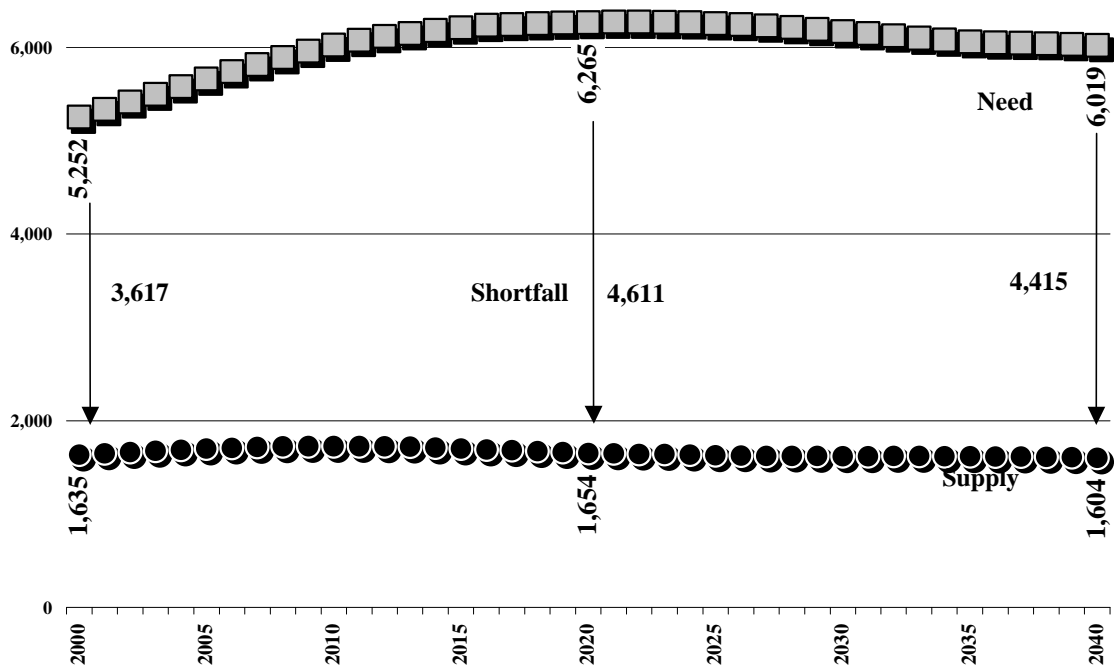
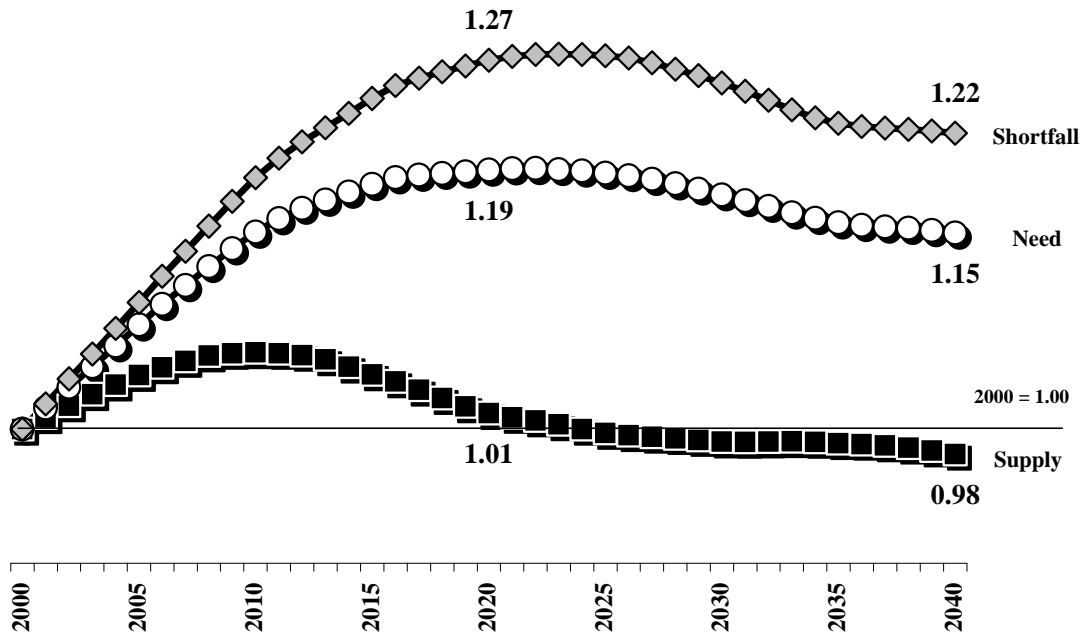


Figure 73: Constant Rates Index of Projected Change in Need, Supply, and Shortfall in Supply of Organs for Transplantation, Canada, 2000 to 2040



Removing the assumptions of trended rates, and replacing them with that of constant rates, still leads to a conclusion that the transplant gap will widen significantly unless actions are taken to increase the rate of donation faster than the aging of the population and non-demographic factors increase the need.

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Appendix II

ICD-9 Codes for Class I Mortalities

ICD-9	1996/97 average mortality rate
Class I Total	0.08875245%
000..099	
100..199	
200..299	0.00047749%
300..399	0.00086481%
400..499	0.05382558%
500..599	
600..699	
700..799	0.00051293%
800..899	0.02033678%
900..999	0.01273486%
All accidents and adverse	0.03307164%
Motor vehicle accidents, E810-E825, E929.0	0.01017153%
Suicide E950-E959	0.00987273%
Homicide E960-E969	0.00004693%
All other accidents etc	0.01298044%
All other heart disease 391,392.0, 393-398,402,404,410-416,420-429	0.00413516%
Cerebrovascular diseases 430-438	0.04969042%
Causes of perinatal mortality excluding still births 760-779	0.00051293%
All other causes	0.00134230%

Class II Total	0.26276815%
000..099	0.00000841%
100..199	0.00492516%
200..299	0.00689329%
300..399	0.00682991%
400..499	0.20578716%
500..599	0.01888310%
600..699	0.00039875%
700..799	0.00790935%
800..899	0.00327680%
900..999	0.00785621%
All accidents and adverse	0.01113301%
Suicide E950-E959	0.00289411%
Homicide E960-E969	0.00152442%
All other accidents and adverse(800-999 exclude 810-25,950-69,929.0)	0.00671449%
All other malignant neoplasms (140-208 exclude 152-3,159.0,162,174-5)	0.00492516%
Ischaemic heart disease 410-414	0.14675895%
All other heart disease	0.04009174%
Cerebrovascular diseases 430-438	0.00334836%
Atherosclerosis 440	0.00474751%
All other respiratory disease (460-519 exclude 480-487,490-493)	0.00033358%
Congenital anomalies 740-759	0.00338866%
Causes of perinatal mortality excluding still births 760-779	0.00131259%

Total Mortality	0.71832493%
Class I All Causes	0.08875245%
Class II All Causes	0.26276815%
Total All Causes Class I and Class II	0.35152060%

Class I Motor vehicle accidents, E810-E825, E929.0	0.01017153%
Suicide E950-E959	0.00987273%
Homicide E960-E969	0.00004693%
All other accidents and adverse(800-999 exclude 810-25,950-69,929.0)	0.01298044%
All other heart disease 391,392.0, 393-398,402,404,410-416,420-429	0.00413516%
Cerebrovascular diseases 430-438	0.04969042%
Causes of perinatal mortality excluding still births 760-779	0.00051293%
All other causes	0.00134230%
Class II Suicide E950-E959	0.00289411%
Homicide E960-E969	0.00152442%
All other accidents and adverse(800-999 exclude 810-25,950-69,929.0)	0.00671449%
All other malignant neoplasms (140-208 exclude 152-3,159.0,162,174-5)	0.00492516%
Ischaemic heart disease 410-414	0.14675895%
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Congenital anomalies 740-759	0.00338866%
Causes of perinatal mortality excluding still births 760-779	0.00131259%
All other causes	0.04672860%

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Endnotes:

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- ¹ Keith Martin, "Solutions needed for organ donor crisis", Victoria News, May 3, 2000.
- ² CIHI press release, "Organ Donations Drop, Waiting List Continues to Rise", April 19, 2000
- ³ Data from The European Transplant Coordinators Organization ETCO web site.
- ⁴ Definitions provided by The BC Transplant Society (BCTS).
- ⁵ Data from ETCO web site: 1998 Canada live donor rate provided by Canadian Organ Replacement Register (CORR) and BCTS.
- ⁶ Data from UN/ECE Transport Division Road Safety web site, The Australian Transportation Safety Board web site, and the UN/ECE Statistical Yearbook web site.
- ⁷ Data from UN/ECE Transport Division Road Safety web site and the UN/ECE Statistical Yearbook web site.
- ⁸ Data from UN/ECE Transport Division Road Safety web site and the UN/ECE Statistical Yearbook web site.
- ⁹ Data from UN/ECE Transport Division Road Safety web site and the UN/ECE Statistical Yearbook web site.
- ¹⁰ The Australian Transportation Safety Board web site.
- ¹¹ Data from the World Health Organization Information System; tabulation, analysis and interpretation by The Urban Futures Institute.
- ¹² Data from the World Health Organization Information System; tabulation, analysis and interpretation by The Urban Futures Institute.
- ¹³ Data from World Health Organization Annual Statistics 1996 web site.
- ¹⁴ Data supplied by BCTS form CORR/CIHI.
- ¹⁵ ¹⁵ Data from the World Health Organization Information System; tabulation, analysis and interpretation by The Urban Futures Institute.
- ¹⁶ Data from the Statistical Abstract of the United States web site and Statistics Canada, National Population Health Survey 1996-1997, Unpublished Data, Health Statistics at a Glance CDROM.
- ¹⁷ CIHI press release, "Organ Donations Drop, Waiting List Continues to Rise", April 19, 2000
- ¹⁸ Data from the World Health Organization Information System; tabulation, analysis and interpretation by The Urban Futures Institute.
- ¹⁹ From data supplied by British Columbia Transplant Society (BCTS).
- ²⁰ Data from Robert Mendelson and Ray Bollman, Rural and small town population is growing in the 1990s (Statistics Canada Agriculture Division Working Paper #36, 1998).
- ²¹ Statistics Canada Health Statistics Division, Unpublished Data, Health Statistics at a Glance CDROM
- ²² Statistics Canada Health Statistics Division, Unpublished Data, Health Statistics at a Glance CDROM
- ²³ Statistics Canada Health Statistics Division, Unpublished Data, Health Statistics at a Glance CDROM
- ²⁴ Statistics Canada, 1996 Census of Canada, The Nation Series CDROM
- ²⁵ Statistics Canada, 1996 Census of Canada, The Nation Series CDROM
- ²⁶ Statistics Canada, National Population Health Survey 1996-1997, Unpublished Data, Health Statistics at a Glance CDROM
- ²⁷ Statistics Canada, National Population Health Survey 1996-1997, Unpublished Data, Health Statistics at a Glance CDROM
- ²⁸ Statistics Canada, Annual Demographic Statistics 1999 CDROM
- ²⁹ Statistics Canada Website
- ³⁰ Statistics Canada, Annual Demographic Statistics and Quarterly Demographics CDROM
- ³¹ CIHI press release, "Organ Donations Drop, Waiting List Continues to Rise", April 19, 2000
- ³² BCTS, "British Columbia Transplant Society calls for national action to avert new hepatitis C crisis", press release, November 1999.
- ³³ Statistics Canada Health Statistics Division, Unpublished Data, Health Statistics at a Glance CDROM
- ³⁴ Statistics Canada Health Statistics Division, Unpublished Data, Health Statistics at a Glance CDROM, and custom tabulation of unpublished data.
- ³⁵ Statistics Canada Health Statistics Division, Unpublished Data, Health Statistics at a Glance CDROM, and custom tabulation of unpublished data.
- ³⁶ Data supplied by BCTS.
- ³⁷ Data provided by BCTS.
- ³⁸ Data provided by BCTS.
- ³⁹ Data supplied by BCTS.
- ⁴⁰ Data from CORR/CIHI supplied by BCTS.
- ⁴¹ Data supplied by BCTS.

⁴² See Lynn Stothers, The Potential Supply of Organ Donors for the Province of British Columbia (BCTS June 1995) for a detailed discussion of the myriad and magnitude of factors that reduce the potential pool to an effective supply of organs for transplantation, and on the definitions of Class I and Class II causes.

⁴³ Statistics Canada Health Statistics Division, Unpublished Data, Health Statistics at a Glance CDROM, and custom tabulation of unpublished data.

⁴⁴ This methodology for this projection is described in detail in The Urban Futures Institute publication Forty Million: Canada's population in the Next Four Decades (June 1999). The projection presented here has been updated with data from Statistics Canada's Annual Demographic Statistics, March 2000.

⁴⁵ For a detailed discussion of labour force implications, see Help Wanted: Projections of Canada's Labour Force Over the Next Four Decades (The Urban Futures Institute, July 1999).

⁴⁶ Statistics Canada, Unpublished Data

⁴⁷ Age profile data for permanent emigration from Canada is available for only the past 3 years.

⁴⁸ The effect of demographics alone on organ donation is shown in Appendix I of this report.