

The Burden of
Out-of-Pocket Costs for

**CANADIANS
WITH DIABETES**

The Issue:

Government coverage of diabetes medications, devices and supplies varies across jurisdictions, leaving some costs for these supports to be borne directly by people living with diabetes in order to effectively manage their disease.

- 57% of Canadians with diabetes say they do not comply with their prescribed therapy because they cannot afford their medications, devices and supplies, thus potentially compromising their diabetes management.
- Less access to public or private insurance means greater out-of-pocket expenses.
- These costs are particularly difficult for low-income Canadians, such as those who do not receive social assistance, seniors on fixed incomes, or those who have high drug costs but do not qualify for other forms of assistance.
- Lack of access to these diabetes supports can increase the risk for costly, life-threatening diabetes-related complications.

Since 2001, the Canadian Diabetes Association (the Association) has tracked out-of-pocket expenses for Canadians with diabetes using specific composite type 1 and type 2 case studies with low incomes, and compared them across provinces and territories.

These composite case studies have enabled the Association to compare and track public drug programs and their ability to support access to diabetes medications, devices and supplies for individuals with similar circumstances.

To reflect the diversity of individual circumstances faced by Canadians with diabetes across Canada, the Association commissioned new research to construct type 1 and type 2 composite case studies that reflected annual incomes of \$43,000 and \$75,000. In addition, out-of-pocket costs were calculated for people with type 1 diabetes who use an insulin pump at three income levels (<\$15,000, \$43,000 and \$75,000). This research reveals a complex picture of out-of-pocket costs across jurisdictions and income levels:

- **There are significant differences in out-of-pocket costs for diabetes both across jurisdictions and programs within**

Canada, and at each income level. However, the average costs across jurisdictions for people with diabetes, in most cases, is >3% of income or >\$1,500 for diabetes medications, devices and supplies – the threshold recommended by the Kirby and Romanow Commissions respectively to receive coverage for catastrophic drug costs. In many circumstances, people with diabetes pay far above these thresholds.

- Provinces with low or no out-of-pocket costs for people living with diabetes at very low incomes, have much higher costs for those living with diabetes at higher incomes.
- Conversely, some jurisdictions with higher out-of-pocket costs for people with diabetes with incomes <\$15,000 have lower costs for people living with diabetes at higher incomes.
- Generally, Canadians with type 1 diabetes who use an insulin pump face far higher out-of-pocket costs than those who do not use a pump, as well as those with type 2 diabetes. The high cost for pumps and pump supplies in most jurisdictions effectively renders them inaccessible for many Canadians with low incomes. Not surprisingly, people with type 1 diabetes who live in jurisdictions with the most enhanced public coverage for insulin pumps and supplies bear the lowest out-of-pocket costs.
- **People with lower incomes bear higher out-of-pocket costs in proportion to their income.**

To ensure that all Canadians with diabetes can optimally self-manage their disease, the Association recommends that all governments address out-of-pocket expenses by:

- **Enhancing financial assistance for people living with diabetes.**
- **Ensuring access and affordability of diabetes medications, devices and supplies.**

Out-of-pocket costs for people with diabetes

One of the biggest challenges for people with diabetes in Canada is the cost of the medications, devices and supplies they need to help manage their disease. Depending on where they live in Canada, some people have no costs due to government coverage, while others without access to coverage by government, employer or private insurance plans must spend thousands of dollars annually to manage their diabetes. This is particularly challenging since a person with diabetes can incur medical costs two to five times higher than a person without diabetes.¹ These costs can include:

- Diabetes management supplies, such as syringes, lancets, glucose testing meters, test strips and insulin pumps and supplies.
- Insulin and/or other diabetes-related medications.
- Medication to lower blood pressure and other medications to treat diabetes-related complications.
- Frequent medical visits and diagnostic tests.
- Specialized home care visits, and rehabilitation or permanent residential care should debilitating complications arise.

Most Canadians with diabetes are faced with these costs. Government coverage of diabetes supports varies across jurisdictions, leaving some costs to be borne by individuals, which many cannot afford: 57% of Canadians with diabetes say they do not comply with their prescribed therapy due to costs for the medications, devices and supplies they require,² thus potentially compromising their ability to manage their disease and increasing their risk for costly and life-threatening diabetes-related complications, such as heart attack, stroke, blindness, kidney failure and depression.

Calculating out-of-pocket expenses

Since 2001, the Association has tracked out-of-pocket costs for type 1 and type 2 diabetes based on specific composite case studies (“Janet” - type 1, and “Peter” - type 2). By using these composite case studies in successive diabetes reports, the Association has been able to compare whether provinces and territories have improved their ability to support access to diabetes medications, devices and supplies for individuals with similar circumstances.

While there are differences across jurisdictions and programs, there are also differences between Canadians based on income: low-income Canadians, such as those analyzed in the “Janet” and “Peter” case studies within successive reports, face a heavier financial burden given their inability to afford private insurance plans and reliance on government diabetes programs for support. As noted in *Diabetes: Canada at the Tipping Point - Charting a New Path*, generally, less access to public or private insurance means greater out-of-pocket expenses.³ These costs are particularly difficult for low-income Canadians who are not on social assistance, seniors on fixed incomes, or those who have high drug costs but do not qualify for assistance.⁴

“Janet” and “Peter” composite case studies

The “Janet” case study was first introduced in *Diabetes Report Card 2001*. The “Peter” case study was added in *Diabetes Progress Report 2003*. The circumstances governing these composite case studies have not changed since their introduction in 2001 and 2003: 1) their income levels have not been adjusted for inflation; and 2) their required therapies continue to be based on the most current *Canadian Diabetes Association Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada* (2008).

- *Janet is a 22-year-old female with type 1 diabetes.* She takes insulin four times daily and tests her blood glucose five times daily. She does not require additional medications to manage, treat or avoid complications. Janet lives alone with an annual income of <\$15,000. She has no private health insurance plan and relies on government assistance.
- *Peter is a 52-year-old male with type 2 diabetes.* He is self-employed. Neither he nor his wife Mary has private health insurance. Mary works full-time, earning \$25,000 annually. Peter earns \$30,000 annually. Peter’s only support for his medications and supplies is a government program (if available). He takes two antihyperglycemic medications to achieve required blood glucose levels, and two antihypertensive medications to regulate his blood pressure, including one to protect his kidneys from complications; he uses a statin to lower his lipids. He tests his blood glucose levels twice a day. Peter will also need multiple therapies and additional medications to prevent heart disease, stroke and kidney disease.

New research

To reflect diversity of individual circumstances faced by Canadians with diabetes across Canada, the Association commissioned new research to construct additional type 1 and type 2 composite case studies that reflected average and higher incomes:

- Out-of-pocket costs were calculated for both “Janet” and “Peter” at an average annual individual income of \$43,000⁵ and a much higher annual income of \$75,000.
- Additionally, for “Janet”, out-of-pocket costs were calculated for the use of an insulin pump and related supplies at annual individual incomes of <\$15,000, \$43,000 and \$75,000.
- All other aspects of these two cases studies remain the same under this new research.

The summary tables (on the opposite page) outline costs for:

- Type 1 diabetes with and without a pump at annual incomes of <\$15,000, \$43,000 and \$75,000.
- Type 2 diabetes at annual incomes of \$30,000, \$43,000 and \$75,000.

Trends

In the clear majority of circumstances, people with diabetes pay >3% of income or >\$1,500 out-of-pocket for the medications, devices and supplies they need to manage their disease. In many circumstances, people with diabetes pay far above these thresholds.

- When averages for costs are determined for provinces only⁸, people with diabetes pay >3% or more for out-of-pocket costs for all incomes across all provinces and incomes except for people with type 2 diabetes with family incomes of \$100,000.
- This is particularly true for people with diabetes who use pumps to manage their diabetes. **When examining averages across provinces, those who use pumps can pay anywhere from two to almost six times more than the 3% threshold.**
- The only circumstances where average costs are <\$1,500 are for those individuals with type 1 diabetes who have annual incomes of <\$15,000 who do not use a pump. For all other scenarios, costs are above this threshold for people with diabetes.

While AB has no out-of-pocket costs for people with type 1 diabetes earning <\$15,000,^{9,10} the province has among the highest costs for people earning higher incomes, whether they use a pump or not.

Conversely, some jurisdictions with higher out-of-pocket costs for people with type 1 diabetes earning <\$15,000 have lower costs for people with higher incomes.

- PEI has the highest costs for people with incomes of <\$15,000 and type 1 diabetes whether they use a pump or not. But PEI has the lowest provincial costs for those with type 1 diabetes with incomes of \$75,000 who do not use a pump.
- NS has among the highest costs for people with type 1 diabetes and incomes of <\$15,000 whether they use a pump or not. But among provinces, NS has the lowest costs for those with incomes of \$43,000 who do not use an insulin pump.

For those living with type 1 diabetes earning higher incomes, there are differences in regards to costs amongst the different jurisdictions. There is little change for costs for **type 2 diabetes: NL, NB and PEI have among the highest costs across all incomes, while QC, the territories and NIHB have the lowest.**

Low-income Canadians with diabetes bear the highest out-of-pocket costs compared to those with the highest incomes.

- While those with type 1 diabetes who do not use an insulin pump with an income of \$43,000 pay more than those with incomes of <\$15,000, those with incomes of \$75,000 pay less than both groups.
- Those with type 1 diabetes who earn <\$15,000 and use a pump pay far more of their income than those with annual incomes of \$43,000 and \$75,000. **The high cost for these devices and supplies renders them inaccessible for low-income Canadians for whom using a pump may be clinically appropriate.** This includes some jurisdictions where pump programs exist but have limitations.
- People with type 2 diabetes with incomes of \$30,000 pay more as a percentage of both their annual and family income than those who earn \$43,000 and \$75,000.

Table 1: Type 1 Diabetes Out-of-Pocket Expenses by Province/Territory, as of June 2011

Annual individual income of <\$15,000 ⁶			Annual individual income of \$43,000						Annual individual income of \$75,000								
Without a Pump			With a Pump			Without a Pump			With a Pump			Without a Pump			With a Pump		
P/T	\$CN	%II	P/T	\$CN	%II	P/T	\$CN	%II	P/T	\$CN	%II	P/T	\$CN	%II	P/T	\$CN	%II
PEI	1,564.58	10.8	PEI	5,673.01	39.1	NL	3,021.10	7.0	AB	6,823.76	15.9	NL	3,021.10	4.0	AB	6,823.76	9.1
ON	942.61	6.5	NS	4,428.35	30.5	AB	2,963.65	6.9	NB	6,819.64	15.9	AB	2,963.65	4.0	NB	6,819.64	9.1
QC	847.55	5.8	SK	4,414.35	30.4	NB	2,954.68	6.9	QC	5,681.42	13.2	NB	2,954.68	3.9	SK	6,473.00	8.6
NS	559.76	3.9	QC	3,945.70	27.2	PAvg	2,095.07	4.9	PEI	5,673.01	13.2	MB	2,848.10	3.8	NS	6,411.72	8.5
PAvg	531.39	3.5	NB	3,937.60	27.2	MB	2,051.10	4.8	SK	5,385.08	12.5	NS	2,722.75	3.6	QC	5,681.42	7.6
SK	499.20	3.4	PAvg	2,664.32	17.7	ON	2,010.61	4.7	NS	5,150.75	12.0	SK	2,550.00	3.4	PEI	5,673.01	7.6
BC	475.20	3.3	P/TAvg	1,910.23	13.2	BC	1,925.20	4.5	PAvg	4,689.94	10.9	PAvg	2,492.40	3.3	PAvg	5,264.56	7.0
MB	395.85	2.7	BC	1,805.28	12.5	QC	1,715.70	4.0	P/TAvg	3,357.10	7.8	BC	2,481.33	3.3	MB	4,957.50	6.6
P/TAvg	386.71	2.7	MB	1,655.85	11.4	PEI	1,564.58	3.6	MB	3,311.10	7.7	ON	2,102.19	2.8	BC	4,505.28	6.0
YK	100.00	0.7	ON	783.09	5.4	P/TAvg	1,503.63	3.5	BC	3,255.28	7.6	P/TAvg	1,787.43	2.4	P/TAvg	3,760.40	5.0
NB	29.20	0.2	YK	100.00	0.7	SK	1,462.00	3.4	NL	2,910.31	6.8	QC	1,715.70	2.3	NL	2,910.31	3.9
AB	0.00	0.0	AB	0.00	0.0	NS	1,282.16	3.0	ON	1,889.09	4.4	PEI	1,564.58	2.1	ON	2,290.00	3.1
NU	0.00	0.0	NU	0.00	0.0	YK	100.00	0.2	YK	100.00	0.2	YK	100.00	0.1	YK	100.00	0.1
NIHB	0.00	0.0	NIHB	0.00	0.0	NU	0.00	0.0	NU	0.00	0.0	NU	0.00	0.0	NU	0.00	0.0
NT	0.00	0.0	NT	0.00	0.0	NIHB	0.00	0.0	NIHB	0.00	0.0	NIHB	0.00	0.0	NIHB	0.00	0.0
NL	0.00	0.0	NL	0.00	0.0	NT	0.00	0.0	NT	0.00	0.0	NT	0.00	0.0	NT	0.00	0.0

Table 2: Type 2 Diabetes Out-of-Pocket Expenses by Province/Territory, as of June 2011

Annual individual income of \$30,000 ⁷			Annual individual income of \$43,000						Annual individual income of \$75,000					
P/T	\$CN	%II	%FI (\$55K)	\$ (CN)	% (II)	%FI (\$68K)	P/T	\$ (CN)	% (II)	%FI (\$100K)	P/T	\$ (CN)	% (II)	%FI (\$100K)
NB	3,426.99	11.4	6.2	3,426.99	8.0	5.0	NB	3,426.99	4.6	3.4	NB	3,426.99	4.6	3.4
NL	3,396.04	11.3	6.2	3,396.04	7.9	5.0	NL	3,396.04	4.5	3.4	NL	3,396.04	4.5	3.4
PEI	3,036.31	10.1	5.5	3,036.31	7.1	4.5	SK	3,066.37	4.1	3.1	SK	3,066.37	4.1	3.1
NS	2,868.39	9.6	5.2	2,974.53	6.9	4.4	PEI	3,036.31	4.0	3.0	PEI	3,036.31	4.0	3.0
MB	2,563.60	8.5	4.7	2,987.89	6.9	4.4	MB	2,987.89	4.0	3.0	MB	2,987.89	4.0	3.0
PAvg	2,529.95	8.4	4.6	2,715.51	6.3	4.0	PAvg	2,715.51	4.6	3.0	NS	2,974.53	4.0	3.0
AB	2,484.84	8.3	4.5	2,594.70	6.0	3.8	ON	2,594.70	3.8	2.9	BC	2,879.12	3.8	2.9
ON	2,073.50	6.9	3.8	2,484.84	5.8	3.7	AB	2,484.84	3.8	2.9	PAvg	2,868.41	3.8	2.9
BC	2,032.79	6.8	3.7	2,330.44	5.4	3.4	SK	2,330.44	3.8	2.8	ON	2,821.45	3.8	2.8
SK	1,870.50	6.2	3.4	2,312.79	5.4	3.4	BC	2,312.79	3.3	2.5	AB	2,484.84	3.3	2.5
P/TAvg	1,824.97	6.1	3.3	1,957.51	4.6	2.9	P/TAvg	1,957.51	2.8	2.1	P/TAvg	2,066.72	2.8	2.1
QC	1,546.58	5.2	2.8	1,610.58	3.7	2.4	QC	1,610.58	2.1	1.6	QC	1,610.58	2.1	1.6
YK	250.00	0.8	0.5	250.00	0.6	0.4	YK	250.00	0.3	0.3	YK	250.00	0.3	0.3
NU	0.00	0.0	0.0	0.00	0.0	0.0	NU	0.00	0.0	0.0	NU	0.00	0.0	0.0
NIHB	0.00	0.0	0.0	0.00	0.0	0.0	NIHB	0.00	0.0	0.0	NIHB	0.00	0.0	0.0
NT	0.00	0.0	0.0	0.00	0.0	0.0	NT	0.00	0.0	0.0	NT	0.00	0.0	0.0

Legend: P/T = Province/Territory \$CN = Canadian dollars %II = Percentage of Individual Income %FI = Percentage of Family Income
P/TAvg = Provincial/Territorial Average PAvg = Provincial Only Average NIHB = Non-Insured Health Benefits for First Nations (Federal)

Discussion

In 2002, the Romanow and Kirby Commissions made recommendations concerning out-of-pocket costs for medications in Canada.

- The Kirby Commission urged provinces and territories to ensure their residents **never pay out-of-pocket costs of >3% of their family income for prescription drugs**. This is in order for these jurisdictions to qualify for federal reimbursement of their drug plans.¹¹
- The Romanow Commission advocated that provinces and territories receive additional federal funds to help cover prescription drug plans costs to **protect Canadians against catastrophically high drug costs, defined at >\$1,500 per year**.¹²

In 2003, First Ministers agreed that all Canadians should “**have access to the drugs they need without undue financial hardship**”.¹³ To support this, the federal government committed \$16 billion over five years to provinces and territories to support health system enhancement, including expanding catastrophic drug coverage.¹⁴

BC, SK, MB, ON, QC, NS, NL, and NU have catastrophic drug coverage through capping drug costs at a fixed amount or a certain percentage of income. Some of these plans also extend coverage to specific low-income residents. AB has a universal catastrophic drug plan, but limits payouts to \$25,000 per year. PEI, NB, NWT, and YK offer coverage to specific populations. The NIHB also offers catastrophic drug cost coverage.^{15,16}

While some coverage for catastrophic drug costs exists to some degree across Canada, it is nonetheless estimated that **catastrophic drug coverage is available to only 25% of the Canadian population,¹⁷ leaving the clear majority of Canadians without any protection from excessive drug costs.**

Canada also has higher out-of-pocket costs than peer countries. **In 2007, 6% of Canadian families spent more than \$1,000 in out-of-pocket drug costs, higher than in Australia, New Zealand, Britain, Germany and the Netherlands.** Only the US had a higher percentage of respondents.

Lack of coverage for significant drug costs has implications for patient care and outcomes as well as overall health system sustainability.

- While a significant proportion of people with diabetes do not comply with their prescribed therapy due to costs, this situation is not unique. In fact, **10% of Canadians as a whole report not filling a prescription or skipping a dose due to cost.**¹⁸
- Increases in prescription drug costs have been shown to result in an increased likelihood of these prescriptions not being filled, and accompanying **increases in hospital admissions, emergency care, and physician visits.**¹⁹

¹ See Canadian Diabetes Association and Diabète Québec. *Diabetes Report 2005: The Serious Face of Diabetes in Canada*, 2005, p. 19.

² PSL Research, *Report on Survey of Canadians with Type 2 Diabetes*, February 2007, p. 60.

³ This report and supporting documents (2011) are available at: <http://www.diabetes.ca/advocacy/reports-and-information/diabetes-canada-at-the-tipping-point/>.

⁴ The detailed methodology regarding how out-of-pocket costs were calculated for *Diabetes: Canada at the Tipping Point* is available at www.diabetes.ca/dpr.

⁵ The average total income for unattached individuals in 2009 for unattached non-elderly males who earn a living was \$46,300 and for unattached non-elderly females who earn a living was \$40,200. (See Statistics Canada, *Average total income by economic family types, 2005 - 2009*.) So the 2 totals have been combined to provide average annual income of \$43,000.

⁶ The national average for out-of-pocket for type 1 diabetes at an annual income of <\$15,000 has changed slightly with this new research from the total of \$385.65 noted within *Diabetes: Canada at the Tipping Point - Charting a New Path* due to changes in some provincial deductibles and copayments. At the individual jurisdictional level, costs for QC and MB have increased by \$9 and \$5.80 respectively.

⁷ The national average for out-of-pocket costs across jurisdictions for type 2 diabetes at an annual income of \$30,000 has changed slightly with this new research from the total of \$1,797.51 noted within *Diabetes: Canada at the Tipping Point* due to changes in provincial premiums and deductibles, as well as refinements to the validation process with jurisdictions. These have resulted in a slight increase in the average costs for type 2 diabetes at \$30K, both in dollars, as well as a percentage of annual individual income. At the individual jurisdictional level, costs for AB, SK and MB have increased by \$432.00, \$16.05 and \$36.40 respectively. Costs for ON have decreased by \$100.00

⁸ If the populations of the territories are added together with the population eligible to receive benefits under the NIHB, this totals 941,934 people, or <3% of Canada's population. (Statistics Canada. *Quarterly Demographic Estimates*, January to March 2011, p. 14; and Health Canada, First Nations and Inuit Health Branch. *Non-Insured Health Benefits Program, Annual Report 2009/2010*, p. 7.) The data on out-of-pocket expenses from each program/ jurisdiction are not weighted (i.e., adjusted to represent the population from which samples were drawn). There are also significant Aboriginal populations within each territory who may also be eligible for benefits under the NIHB. (Statistics Canada. *2006 Census: Aboriginal Peoples in Canada in 2006: Inuit, Métis and First Nations*, p. 11.) Determining average costs across provinces only provides a form of adjustment concerning the influence of jurisdictions and programs with very small populations who may be eligible for more than one form of public coverage.

RECOMMENDATIONS

To ensure that all Canadians living with diabetes can optimally self-manage their disease, the Canadian Diabetes Association recommends that all governments address out-of-pocket costs by:

- **Enhancing financial assistance for people with diabetes.** Governments must enhance existing financial supports, such as the Disability Tax Credit.
- **Ensuring access and affordability of diabetes medications, devices and supplies.** The current drug review process results in too many Canadians not having equitable access to the medications, devices and supplies required for effective self-management. A review of international best practices can identify a more effective and efficient drug review system that better serves the health needs of all Canadians is required. Jurisdictions should also explore a common drug formulary to standardize access.

⁹ In 2005, AB's out-of-pocket costs for type 1 diabetes were \$2,359.34. "Janet" may have been eligible for the Alberta Adult Health Benefit at that time, but it was not noted by the AB government in its response to a survey that informed the findings of *Diabetes Report 2005*.

¹⁰ Several jurisdictions enhanced access to diabetes medications, devices and supplies following the release of *Diabetes Report 2005*.

¹¹ Senate Standing Senate Committee on Social Affairs, Science and Technology. *The Health of Canadians – The Federal Role. Final Report on the state of the health care system in Canada*, October 2002, p. 133.

¹² Commission on the Future of Healthcare in Canada. *Building on Values: The future of healthcare in Canada*, 2002, p. 197.

¹³ *First Ministers' Accord on Health Care Renewal*, 2003.

¹⁴ *Ibid.*

¹⁵ Karin Phillips. *Catastrophic Drug Coverage in Canada*. Library of Parliament, 2009, pp. 5-8.

¹⁶ Health Council of Canada. *Progress Report 2011: Health Care Renewal in Canada*, May 2011, pp. 9-10.

¹⁷ *Catastrophic Drug Coverage in Canada*, p.6.

¹⁸ *Progress Report 2011: Health Care Renewal in Canada*, p. 13.

¹⁹ *Catastrophic Drug Coverage in Canada*, p. 10.

About the Canadian Diabetes Association

Today, more than nine million Canadians live with diabetes or prediabetes. Across the country, the Canadian Diabetes Association is leading the fight against diabetes by helping people with diabetes live healthy lives while we work to find a cure. Our community-based network of supporters help us provide education and services to people living with diabetes, advocate for our cause, break ground towards a cure and translate research into practical applications.

For more information, please visit diabetes.ca
or call 1-800-BANTING (226-8464).