Submission to the Standing Committee on Health:

A call for Canada to uphold the rights of people living with diabetes at home and abroad

Universities Allied for Essential Medicines, T1International, Santé Diabète, 100 Campaign

October 22nd 2018

This brief outlines the domestic and international situation around access to insulin and other necessary diabetes supplies.

Solutions for improving the lives of people living with diabetes in Canada and abroad are proposed within.

Type 1 vs. Type 2 Diabetes

Type 1 diabetes is a condition in which the body no longer produces any insulin. Therapy for type 1 diabetes requires the administration of insulin and regular blood glucose (sugar) testing. **Without insulin, someone with type 1 diabetes will die in a matter of days**. With insufficient access to insulin, a person with type 1 diabetes will not be able to stabilize their blood glucose, leading to complications (e.g. blindness, amputation, kidney failure) and ultimately premature death. Type 2 diabetes is a condition where the body still makes insulin--but the insulin is insufficient for the person's needs. This means that the person needs to take medicines that make the insulin work more potently, or in some cases, people with type 2 diabetes will need to also administer insulin.

The Situation in Canada

Currently 57% of Canadians living with diabetes are non-adherent with a therapy because they cannot afford it.[1] Lack of access to treatment increases the risk of complications and the likelihood that a person with diabetes will need to access other health supports, such as the emergency department, long-term care facilities, hospital treatments, and medical appointments to manage their complications in the future.[2]

Out of Pocket Costs

Diabetes treatment costs vary by treatment option and region. The highest burden generally falls on individuals using an insulin pump with an annual income below $15,000.[3] Low-income (<$15,000) individuals living in Nova Scotia see among the highest costs for people with type 1 diabetes.[4] Individuals living in New Brunswick, Quebec, Saskatchewan, Nova Scotia, and PEI who use an insulin pump and have an income under $15,000 all spend more than 25% of their annual income on out-of-pocket diabetes expenses.[5] The highest burden is felt in PEI, where 39% of individual income is spent on out-of-pocket diabetes expenses.[6] Those living in Nunavut or the Northwest Territories, and individuals eligible for the NIHB program consistently spend

[1] Canadian Diabetes Association, "The Burden of Out-of-Pocket Costs for Canadians with Diabetes" (2011). Retrieved from: https://www.diabetes.ca/CDA/media/documents/publications-and-newsletters/advocacy-reports/burden-of-out-of-pocket-costs-for-canadians-with-diabetes.pdf
[2] CDA, "Burden"
[3] CDA, "Burden"
[4] CDA, "Burden"
[5] CDA, "Burden"
[6] CDA, "Burden"

0% out-of-pocket on their diabetes expenses.[7] The Yukon Territory sees similar low costs across the board, up to 0.5% of individual income for those with type 2 diabetes and an annual individual income of $30,000.[8] Both Nunavut and the Northwest Territories employ an Extended Health Benefits Full Coverage Plan for Chronic Health Conditions that covers the full cost of drugs listed in the NIHB formulary.

Canadians who use an insulin pump are burdened with higher out-of-pocket costs than those who do not use a pump.[9] This is especially true for the lowest-income Canadians who use a pump. This technology is out of reach for many who may benefit from the therapy.

The average Canadian spends more than 3% of annual income on out-of-pocket prescription drug costs, above the threshold recommended by the Kirby Senate Committee and Romanow Commissions.[10] Across all incomes in Canada, people living with diabetes spend well above this.[11] These Commissions proposed federal spending to offset high proportionate costs of prescription drugs to individuals, eventually incorporating prescription drugs into the *Canada Health Act*.[12]

<u>High costs of treating diabetes disproportionately affects low-income Canadians</u>

Low-income Canadians are disproportionately affected by the high costs of treating diabetes in Canada.[13] A recent study found that socially disadvantaged individuals with diabetes have a higher risk of CVD complications and death compared to individuals with higher SES.[14] This study also compared patients above and below 65 years of age in Ontario as a model of universal drug coverage.[15] The result was more pronounced between those under 65 who either paid out-of-pocket for their prescriptions, or who relied primarily on private insurance.[16] A recent study saw a decrease in mortality in a diabetic population between 1994 and 2005, however the decrease in the lowest income group was significantly smaller than that in the highest income group.[17] This study estimated that as many as 5000 deaths in Ontario alone could have been prevented by universal drug coverage for people with diabetes.[18] While one third of low-income

[7] CDA, "Burden"
[8] CDA, "Burden"
[9] CDA, "Burden"
[10] CDA, "Burden"; The Romanow Commission. November 28, 2002. "Building on Values: The Future of Health Care in Canada"; http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf [*Romanow Report*].
[11] CDA, "Burden"
[12] *Romanow Report.*
[13] *Romanow Report.*
[14] Gillian Booth et al, "Universal Drug Coverage and Socioeconomic Disparities in Major Diabetes Outcomes" (2012) 35:11 Diabetes Care 2257. [Booth, "Universal Drug Coverage"]
[15] Booth, "Universal Drug Coverage"
[16] Booth, "Universal Drug Coverage"
[17] Lorraine Lipscombe et al, "Income-related differences in mortality among people with diabetes mellitus" (2010) 182:1 CMAJ E1.
[18] Booth, "Universal Drug Coverage"

Canadians report cost-related nonadherence to medicines, currently only 25% are eligible for catastrophic drug coverage.[19]

The need for prescription drug coverage was introduced by the Royal Commission on Health Services. At this point in history, the Commission felt that the rising price of new life-saving prescription drugs, the unpredictability of determining who may require these drugs, and the disproportionate burden that rising costs would place on low income individuals and those living with chronic diseases required some intervention to relieve the burden on people who required essential medicines. It is now 2018, and still we see an increased burden on low income individuals living with diabetes, and ever-rising costs of prescription drugs and supplies to treat the condition.

Indigenous Peoples Living With Diabetes in Canada

Generally, there is a lack of available data about the burden of access to diabetes medications on Indigenous populations in Canada. It is well-documented that there is a disproportionate disease burden on Indigenous people, and these communities are less likely to receive care that meets recommended guidelines. Diabetes-related mortality is as much as three times higher for Indigenous populations as compared to non-Indigenous populations.[20] Overall, Indigenous peoples have greater difficulty with glycemic control, and have higher rates of complications such as kidney disease, hypertension, and high blood pressure. A recent policy roundtable found that these challenges can be linked to "*variability across the country in terms of public and private insurance coverage for medications and supplies for those managing their diabetes*".[21]

Irregular Migrants Living in Canada

In 1999, Nell Toussaint entered Canada as a visitor from Grenada. After finding employment, she remained in the country after her visa expired. While working and contributing to Canada's social security and tax systems, she tried to apply for permanent-resident status twice. Twice her applications failed, in part due to the cost barrier of the application. Nell Toussaint had diabetes, and despite applying to Canada's Interim Federal Health Program (IFHP), she was unable to access this program. Her health deteriorated, and she was diagnosed with multiple life-threatening health complications including pulmonary embolism and renal dysfunction. Nell unsuccessfully challenged this deprivation with the Federal Court of Canada and the Federal Court of Appeal before filing a complaint with the UN Human Rights Committee. The Committee found that Canada had violated her rights to life and equality under international law by denying her access to life-saving health care services.

[19] Michael Law et al, "The effect of cost on adherence to prescription medications in Canada" (2012) 184:3 CMAJ 297

[20] Diabetes care and management in Indigenous populations in Canada: *A pan-Canadian policy roundtable*. November 2017. https://www.ihe.ca/download/diabetes_care_and_management_in_indigenous_populations_in_canada_backgrounder.pdf [*A pan-Canadian policy roundtable*].

[21] *A pan-Canadian policy roundtable*

Canadian Solutions

1. Encourage all provinces and territories to lower out of pocket costs for Canadians living with diabetes. Make vital diabetes supplies, including insulin, injection devices, self-measurement of blood glucose test strips, ketone measurement sticks, free at the point of delivery at all pharmacies in Canada.
2. Incentivize generic production of generic insulins and diabetes medications and impose price controls on off-patent medicines.
3. Improve access to culturally appropriate diabetes care for Indigenous communities. Consider mobile screening clinics and telehealth to provide increased access to specialists and other care providers for Indigenous communities in rural and remote areas.
4. Follow the recommendation of the UN Human Rights Committee to review national legislation immediately to ensure that irregular migrants with diabetes have access to essential health care services.

The International Situation

Insulin: Canada's Gift to the World

Nearly 100 years ago University of Toronto researchers discovered insulin, a life-saving drug for people living with diabetes. The study team wished the world to benefit and sold their patent for $1. This miraculous discovery received the 1923 Nobel Prize and is on our $100 bill. It also led to CBC viewers to declare Dr. Frederick Banting, one of the members of the research team, one of the "10 Greatest Canadians".[22]

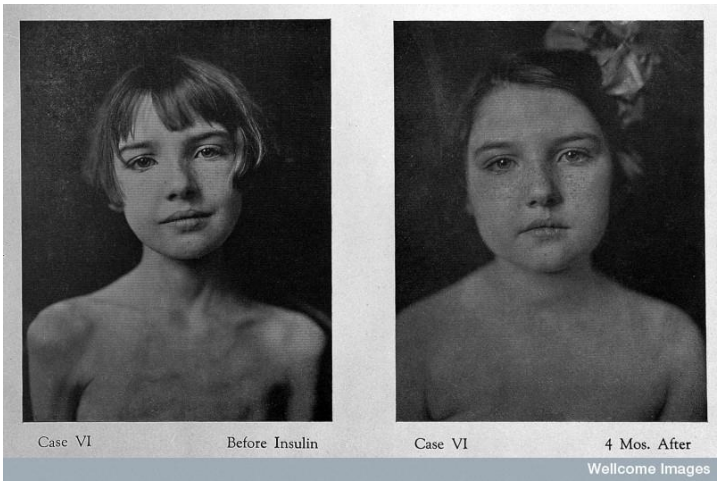

Figure 1: One of the first patients treated with insulin, before and four months after insulin therapy

[22] Guy Dixon, "The greatest Canadian". November 30, 2004. https://www.theglobeandmail.com/arts/the-greatest-canadian/article1144309/

Insulin: Too Often Out of Reach

Despite the fact that insulin was synthesized by Canadian researchers nearly 100 years ago, a lack of affordable insulin remains the leading cause of death for young people living with diabetes.[23] Today, one in two people who need insulin do not have reliable access to this life saving medication.[24] The reason for this lack of access is multifaceted, including import taxes and markups along the supply chain, but a major issue is that insulin is priced above the level that most people can afford in low and middle-income contexts.

The Price of Insulin is Too High

A major issue is that insulin is priced above the level that most people can afford. To this end, an annual insulin regime is often priced above median income, and insulin is priced between 2.5 and 4.5 times higher than any other non-communicable disease treatment regime.[25] The annual cost of purchasing insulin for health systems in Mali, Nicaragua, Vietnam, Kyrgyzstan, Mozambique, and Zambia makes up 40 times the annual per-person public sector expenditure on pharmaceuticals.[26] In the public sector, the lowest paid unskilled government worker would have to pay 2.5 days wages to purchase 10mL of human insulin, and 7.5 days to purchase 10mL of analogue insulin. In the private sector, those values jump up to 3.5 days and 9.5 days, respectively.[27] A recent study in the BMJ Global Health found that the cost to produce one vial of human insulin is estimated to be between $2.28 and $3.42 USD, and the cost of producing one vial of analog insulin is between $3.69 and $6.16 USD. Current list prices of analogs like Humalog and Lantus sit anywhere between $275 and $300 USD/vial. In Canada, one year's supply of Lantus, one half of a typical insulin regimen, costs about $1800 CAD. Researchers contended that the price for one year's supply of insulin could be as low as $78 per person—and insulin manufacturers would still make a profit.[28]

[23] Edwin Gale. Dying of diabetes. Lancet. 2006; 368(9548):1626-8. [Gale, "Dying of Diabetes"]
[24] Gale, "Dying of Diabetes"
[25] Fact Sheet 4: Insulin Prices. April 2016. Health Action International. http://haiweb.org/wp-content/uploads/2015/05/HAI_ACCISS_factsheet_insulinprices.pdf [ACCISS Fact Sheet 4]
[26] Fact Sheet 1: Inequities and Inefficiencies in the Global Insulin Market. November 2015. Health Action International. http://haiweb.org/wp-content/uploads/2015/11/ACCISS-Fact-Sheet-1-Inequalities-in-Insulin-Market.pdf [ACCISS Fact Sheet 1]
[27] Dzintars Gotham, Melissa Barber, and Andrew Hill. Production costs and potential prices for biosimilars of human insulin and insulin analogues. *BMJ Global Health* 2018; 3. https://gh.bmj.com/content/3/5/e000850.info [Gotham et al., "Production costs and potential prices"]
[28] Gotham et al., "Production costs and potential prices"

Insulin Access is a Woman, Child and Refugee Health Issue

Figure 2: A girl in Mali at the opening of a new clinic treating people with type 1 diabetes.
Photo courtesy of Santé Diabète

Diabetes and insulin inaccessibility hurt the most vulnerable. Women with diabetes are often subjected to stigma and discrimination, being passed over for marriage by people who believe they cannot have children or who do not want to pay for their treatment costs. This often condemns women and girls with diabetes to a life of isolation and desertion. Girls with diabetes are also often abandoned as families tend to invest more in boys, creating a double burden when girls are diagnosed with diabetes.

Canada is Well Positioned to Help

Canada is the birthplace of insulin, and can amplify the #insulin4all movement which is pushing for equal access to insulin and diabetes supplies worldwide. Canada has world-class diabetes expertise. Organizations like the TRANSNUT Centre and the International Health Unit (l'Unité de Santé Internationale -USI) of the University of Montréal, and as well as the Banting and Best Diabetes Centre of the University of Toronto, have experience in adapting Canadian best practices to low and middle income countries. Many international humanitarian NGOs keep offices in Canada, making it well positioned to save the lives of millions of people living with diabetes in low and middle income countries. Finally, we recommend Canada also listens to and supports organizations like Universities Allied for Essential Medicines (UAEM), T1International, and Santé Diabète who work with persons living with diabetes every day.

International Solutions

1. Use Canada's standing on the international stage to advance the cause of non-communicable disease treatment; and type 1 diabetes treatment in particular. This includes at the United Nations and related agencies (WHO, UNDP), and at high-level international forums

2. Instruct Development Canada to fund projects and programs that will improve access to insulin in low and middle income countries.

3. Reaffirm the rights and responsibilities of sovereign nations to provide their citizens with essential medications necessary for health, as set out in the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement and the Universal Declaration of Human Rights.

4. Support and consult with civil society groups working towards the rights of people living with type 1 diabetes, including the right to access insulin. These groups include T1International, Universities Allied for Essential Medicines (UAEM) and Santé Diabète.

For More Information:

UAEM – https://uaem.org

T1International – http://t1international.com

Santé Diabète – https://santediabete.org/en/

100 Campaign – http://www.100campaign.org/