Not-So Universal: Script

EPISODE 1

Did you know that over 300,000 Canadians live with type 1 diabetes and approximately 30,000 are children (JDRF Canada)? Type 1 diabetes (T1D) is an autoimmune disease, meaning that the body spontaneously self-destructs, and accidentally kills off the beta cells in the pancreas. These beta cells produce the hormone insulin which is important for allowing the body to take sugar from the food you eat and turn it into energy. Without insulin, the body has no way of converting the sugar into energy, leading to hyperglycemia, or high blood sugar. Type 1 diabetes requires lifelong management to maintain blood sugar levels in a healthy range (JDRF Canada). Since the pancreas doesn't produce insulin, it's taken externally, often through injections.

Insulin itself was discovered just 100 years ago by Sir Frederick Banting and Charles Best right here in Canada at the University of Toronto. Banting believed it was unethical to profit from a discovery that would save lives. He famously said, "Insulin does not belong to me, it belongs to the world" and sold the patent for just $1. But today, we have to ask: does insulin *really* belong to the world? Is it accessible to all who need it?

[Introduction music]

You're listening to *Not-So Universal*. This is a short, mini-series podcast where we'll be exploring the inequalities in diabetes healthcare that creates a divide in quality of life and health outcomes in Canada. Whether you know someone with T1D, are looking to become a more informed citizen, or are a policymaker, this podcast is for anyone interested in learning about the socioeconomic disparities in diabetes technology access, and exploring what we can do to support a more inclusive healthcare system that serves all Canadians.

[Transition music]

Insulin is typically administered through injections or from an insulin pump, which works like an artificial pancreas by continuously delivering insulin. Other advanced technologies, like Continuous Glucose Monitors, or CGMs, track blood sugar levels in real time. Some of the latest CGMs can even sync with insulin pumps to create a hybrid closed-loop system, which automatically adjusts insulin delivery based on live blood sugar data. It's super cool - it's almost completely hands off and it really shows just how far we've come in 100 years.

Research consistently shows that these advanced diabetes technologies, like insulin pumps and CGMs, improve health outcomes for people with T1D. For example, they help improve something called "time in range," which refers to the percentage of the day that a person's blood sugar is within a healthy target range. A1C is a blood test that measures your average blood sugar level over the past two to three months. A higher time in range and a lower A1C is evidence of better blood sugar control, and is associated with reduced complications, and an overall improved quality of life (Stefanac).

Now, this all sounds amazing, right? T1D used to be a death sentence, but now we've got all this cool technology that saves lives and improves health outcomes. Unfortunately, there's a catch: many of these technologies are incredibly expensive, and often not fully covered by insurance or public healthcare plans (Diabetes Canada). As a result, many Canadians with T1D face financial burdens or are unable to access the technology they need for effective management. This inequality creates a significant divide in health outcomes and quality of life, which is based primarily on socioeconomic status, but also potentially on other intersectional social factors, like race or gender.

To learn a bit more about this issue, let's talk to Layan Saleh, a pharmacy student at the University of Toronto who has also worked as a pharmacist assistant for the past 2 years.

[Transition music]

[Zainab]: When it comes to diabetes supplies and pharmacare, do patients have equal access?

[Layan]: Well, to preface, it's worth noting that Canada is the only country in the world with universal healthcare, but *not* universal pharmacare. This means that access to diabetes supplies and medications isn't equal across the country. Canada has this patchwork of public and private prescription coverage that depends on where you live, your income, and your employment, and that level of coverage that patients receive varies greatly. This creates systemic barriers for some patients, particularly those who may not have sufficient insurance or live in provinces with limited public coverage for their medications, such as diabetes supplies. In pharmacy school, we are constantly taught about the significant impact of social determinants of health, and medication coverage is a key example of how factors like income, employment, and geography can affect a patient's ability to manage chronic conditions such as diabetes. So when I was a pharmacy assistant, I worked for two years, and I've had many instances where some patients would be like, this insulin is too expensive, or they would ask us, is it okay if I pick this up at a later date so they could wait for their paychecks and possibly get the medication. Some patients, they're like, can we just not take this medication at all and tell us to cancel their prescription? And in this case, in these cases, it affects their health because they're not taking the necessary medications for their illnesses. So in some cases, the pharmacist on duty would come on and say, oh, we can ask your prescriber for possible alternatives.

[Zainab]: So in some cases, you're able to go and contact the provider, but in some cases, is that not possible?

[Layan]: Yeah, some cases, from my knowledge, from my experience, there are medications where you will need to pay a very hefty price, and just some patients aren't able to afford that, and some will choose to just not take the medication at all, which is incredibly sad because people should be entitled to the medication they need.

[Transition music]

Type 1 diabetes can be diagnosed at any age, but most diagnoses are in children. This makes most T1Ds a vulnerable population since they rely almost exclusively on their parents for care.

Unfortunately, this dependency creates a significant financial burden on families. Often, a child's health outcomes are directly tied to their parents' socioeconomic status and this inequality shows just how important it is that we address the disparities in access to diabetes technologies.

Let me share why I decided to explore this topic. I was diagnosed with Type 1 diabetes when I was just two years old. It was a complete shock for my family. I was in the hospital for 5 days on an insulin IV drip, and then on insulin injections for a year. I was about 4 years old when I switched to an insulin pump. I was lucky enough to have access to the best technology and have my parents take care of everything. While we didn't struggle financially, it still was expensive and a huge time commitment. My mom took time off work for many years because she was taking care of me. Let's hear a little bit about what she had to go through.

[Mother]: Thinking about those early days after my first child was diagnosed with type one diabetes, it's hard to believe how vivid it still is in my mind. As much as I was the one trying to keep her healthy, I was also the one that was doing the things that she was afraid of … having to poke my little girl's fingers and give her injections every few hours was impossible emotionally as a mother but there was no choice and she was so little. At the same time I also had a baby boy to take care of who had to kind of sit in the background patiently and wait while I tried to figure this out. My focus was entirely on my kids, but thank God I had my mother to help me, because I don't know how I would have done it without her. For the first few months after Zainab was diagnosed, she would wake up every night, and come running to me or call me to go to her. If she hadn't already called me, I was checking her blood sugar routinely at 2am just to make sure she was still okay. The night checks continued for many years afterwards. When Zainab started kindergarten, her little brother and I would go to her classroom twice a day at snack and lunch to check her blood sugar. Her school was very supportive and gave him a place to eat with all of the other children. I was volunteering there often, working with the teachers to make sure celebrations included snacks Zainab could have. When Zainab was grade 2, she asked me to come into the school with her and do a presentation for her class about her diabetes. What was supposed to be a triumphant moment for her ended up much different. A few of the boys and girls in the class decided to bully her because of her diabetes. We made the difficult decision to take her out of that school and send her to another school in Mississauga once we exhausted all of our other options. We were living in Georgetown at that time which was about an hour's drive from the new school. My infant and I would be at her school in the morning to check her blood sugar for snack time and stay in Mississauga to be available to check her again for her lunch in early afternoon and then wait for dismissal to bring her and her siblings home.

[Background music ends]

I am so grateful to have had my mother devote all of her time and attention towards making sure I stayed alive. But for most of my life, I didn't fully realise the sacrifices that she made. And I didn't think about how that level of care might not be possible for everyone. Expecting a parent to take time off work, while also paying for diabetes supplies that can cost up to $18,000 a year, is not realistic. It places an immense burden on families, one that has a direct impact on

children's health outcomes. It wasn't until I joined a community of students with type 1 diabetes that I realized not everyone had the privilege of accessing the best tech like I had.

Is that fair? Is it fair that right here in Canada, the health outcomes of children are tied to their parents ability to afford care?

[Transition music]

This podcast draws inspiration from the transformative framework of poet and activist Audre Lorde, particularly her advocacy for healthcare rights. Lorde wrote about healthcare injustice from her own lived experiences, including after her biopsy when she reflected on how silence around her health would not serve her or others. Though the tumour was benign, she would later discover she had breast cancer, a diagnosis she wrote about in *The Cancer Journals.* Lorde's work emphasizes moving from "silence to action" by speaking out against systemic inequalities and building personal, intersectional movements for change.

In the footsteps of Lorde's approach, this podcast seeks to amplify the voices of Canadians with type 1 diabetes who face barriers to accessing life-saving technology. Why is this connection important? Because, like Lorde, we know that sharing personal stories has the power to spark change. Diabetes care is often treated as an individual issue, tied to a person's ability to afford it—but we need to reframe this as a systemic problem that demands collective action. By bringing these stories to light, we can confront the inequalities in access to diabetes technology and work toward a future where care is truly universal.

Join us in the next episode of *Not-So Universal* as we explore the cost of care, and dive deeper into the experiences of people who have struggled with unequal access to diabetes technology and understand how it's affected them.

EPISODE 2

[Introduction music]

Welcome back to *Not-So Universal* where we're exploring the inequalities in diabetes healthcare that create a divide in quality of life and health outcomes.

Imagine this, you're in a grocery store filling your cart with essentials for the week: bread, cheese, milk, and you realize that you don't have enough money for both food and your life saving medication insulin. What do you do? How do you make the impossible choice between two things you need to survive?

For many Canadians, this is not a hypothetical situation. It's a harsh reality. In fact, a non-profit organization called T1International found that nearly one in five Canadians with type 1 diabetes have had to ration their insulin because they simply couldn't afford it. And it's not just insulin. The costs of the technology that help manage diabetes, such as insulin pumps and continuous glucose monitors, CGMs, add an even heavier financial burden.

In this episode, we'll listen to the experiences of people who have struggled with unequal access to diabetes technology and understand just how it's affected them.

[Transition music]

In 1923, Dr. Banting and his colleagues selflessly sold the patent for insulin for $1. Today however, according to the World Health Organization, "despite the goodwill of the early days and collective efforts from many sectors, the promise that insulin would belong to the world has not been kept" (World Health Organization).

Insulin alone can range from an average of $900 to $1,700 annually, depending on the type and the dosage. But that's just the starting point. To actually use that insulin, you need the technology — the needles, the pump, the CGMs. And that technology? Well, they can cost thousands of dollars a year. Out-of-pocket costs for the technology to administer the insulin is another hefty bill. In general, costs for adults are higher than those for youth and seniors. Out-of-pocket costs are lowest for people using injections, and the highest for people using insulin pumps and CGMs. Provincial average out-of-pocket costs can range from $870 to $7,700.

And the consequences of these high costs are devastating. According to a 2011 report by the Canadian Diabetes Association, 57% of Canadians with diabetes reported not adhering to their prescribed treatments because they simply couldn't afford them.

[Transition music]

Let's hear from Nathaniel who was diagnosed with type 1 diabetes in 2005 when he was 11 years old. After graduating from theatre school, he worked as an actor and arts administrator for seven years before pivoting careers. He now works in the non-profit space facilitating peer support programming for families of youth living with T1D.

Here he shares what the costs of diabetes were like for him.

[Nathaniel]: Those costs meant that I couldn't have access to this technology until I finally found it. And because I didn't have access to that technology, my numbers were what they were. And will see how that plays out down the line as I continue to age with diabetes. And I guess the way that I interacted with the financial barrier was, and again, it might have just been standing on principle, but also just means and access. And, I very quickly was like, it's hundreds of dollars every two weeks for a little dot on my arm. I can't do that. I don't know how anybody could do that. I'm not going to do that. So the way that I financially dealt with the burden was, I just I didn't. I was like, I won't, I won't engage with this. I can't, I can't. And morally, I won't, I won't pay into this out of pocket, because then I'm endorsing the system that is exploitative and broken.

[Transition music]

Nathaniel's story shows a reality that many people with diabetes face: the crushing financial burden of life-saving technology. For him, the cost of CGM — hundreds of dollars every two weeks — was simply too much. And it wasn't just a financial decision, it was also an ethical stance. Let's unpack this a bit.

Nathaniel is pointing to a broader issue here which is the commodification of health. CGMs are revolutionary tools that can transform diabetes management, offering better blood sugar control and reducing long-term complications. But their high cost creates a barrier that excludes many people who could benefit from them, leaving them to manage their condition with less effective tools, or worse, without the tools they need at all.

Without tools like CGMs, people like Nathaniel are at greater risk for long-term complications like kidney disease, neuropathy, or vision loss. This exclusion not only harms individuals but also creates systemic burdens on healthcare systems over time. A quote often attributed to Gandhi says, "the true measure of any society can be found in how it treats its most vulnerable members" (Elber). It's deeply troubling that we're taking advantage of those who can't afford the technology needed to manage their health effectively, forcing them to suffer serious health consequences in the long term.

Analyses by the Canadian Federation of Nurses Unions, estimate that cost related non-adherence to prescribed drug regimens in Canada contributes to, in the range of, *270 to 420* premature deaths of working-age Canadians with diabetes every year. Those are *hundreds* of people who could have lived longer, healthier lives — if only they had had access to the right tools.

[Transition music]

But the financial burden isn't the only issue here. There's also the mental and emotional toll of managing diabetes under these circumstances. Let's hear from Rav.

Rav Samra was diagnosed with type one diabetes when she was two years old. She received her bachelors in Occupational Health and Safety and an HR Management certificate. Rav is a

passionate advocate within the diabetes community. CBC interviewed her about the cost of insulin in Canada and she also helped author a paper with T1International.

[Rav]: being from the family that I'm from, I feel like it's a very common Asian mentality of like, if something goes wrong, or if something expires, or doesn't last as long as it should, there's kind of like this guilt associated with that. And so once you start applying like a price onto like each pump site or each CGM, anytime that you experience some type of failure, whether it's like, your sensor is keeps calibrating, it's like, girl, you got to change this or like, your pump tubing gets caught in the door. You feel one just annoyed because it's like, I have to go through this all over again, like, sooner rather than later. But then you like those kind of like initial hot thoughts happen, right? Like, I'm a failure. I'm a bad diabetic. And like, those things aren't true. They're not even real. There's no such thing as a bad diabetic. So it's definitely difficult when you apply that kind of cost. And like, you feel like you're wasting supplies, you feel like you're wasting medication, but it's, everything's finicky at the end of the day. So now that I'm like, fully independent, I don't, I've done the work to kind of make sure that that's not the mentality that I have.

[Background music ends]

Rav's story reminds us that the costs of managing diabetes aren't just financial — they're emotional and mental too. The constant pressure to maintain equipment, manage failures, and deal with feelings of guilt takes a real toll. It's like paying for new shoes and being hypervigilant about not getting them dirty. But when it comes to diabetes, we shouldn't have to be so concerned about taking care of the shoes or in this case the diabetes tech. The tech is supposed to take care of us.

And even though I come from a place of privilege and I don't have to worry about the cost of supplies, I still feel the emotional weight, just in a slightly different way. During the school year, I find it hard to balance everything. My CGM needs to be changed once a week, and in order to keep it working within that week, I need to calibrate it every 12 hours. But when things get hectic, like during exam season or when I'm recording a podcast, I sometimes fall behind. I don't calibrate on time, or I delay changing my sensor. And besides the fact that I have worse control of my blood sugar during this time, I feel really guilty. Because I know I have supplies that so many people don't have access to, and I'm not using them to their full potential.

This emotional burden adds another layer to an already heavy workload. Managing diabetes on top of daily life, on top of school or work, it's hard enough without the feelings of guilt or wasting supplies. And when you add to that the knowledge that only certain people have the privilege of taking care of their health like this, the burden feels even more unfair.

This emotional weight can spiral into bigger mental health challenges, like depression, anxiety, and burnout. A meta-analysis by researchers Reynolds and Helgeson found that young people with diabetes experience significantly more depressive symptoms and clinical depression than their peers.

This cyclical relationship between depression and diabetes is concerning. Depression can lead to poor self-care and diabetes management, which in turn can worsen physical health and exacerbate depressive symptoms. This vicious cycle shows how important it is that we address the multifaceted burdens that T1Ds have to go through.

For Nathaniel, these burdens were compounded by the challenges of accessing technology that could have significantly improved his diabetes management. He talked about the hoops that he would have to jump through to try and get access to a CGM that would better regulate his average blood sugar levels, or A1C. Here's what he had to say:

[Nathaniel]: Even though I had access to things that were covering my insulin, they weren't covering my access to this hot, new technology. And I remember applying to, through my clinic, different clinical studies, just trials for either medications, or just other stuff, because part of those studies would be that they would give you a CGM for the six months that you were on the studies. For me, the biggest draw was that for this six months, I don't have to worry about, like, I would feel like the kid staring at the window at that, like the brand new shiny red bike, being like one day I'll have that bike. But one day I'll have this life changing technology. But I would sign up for these, and I remember, I was on a road trip with some friend and we're driving to a cottage, and I got a call from the intake doctor. I think I missed the call, but I listened to the voicemail and the voicemail told me that for the study, because they need certain metrics to be in line, like they need you to have like a certain, BMI and be like, be a certain age, like all the things to fill the criteria for their study. And one of those things the A1C and my A1C was, I think, 0.2, too high outside of their constraints for the study. And they said, unfortunately, for that reason, we can't include you in the study. And I remember I was surrounded by my friends, we're gonna have an amazing weekend, I just broke down in tears on the way to what was in the end, a very fun weekend. But like, it was just, I put all my hope in like, I've found a way for this six month span of time, I'm gonna be okay, I'm gonna have better management. And I don't think I realized how much I'd invested into that hope until suddenly it was taken away from me. And what really galled me about that was that my A1C would be lower, if I had the technology. If I had had this thing that I was participating in the study to get access to, if I'd had it, then I would have been, it was weird, recursive loop, and it sent me down this very, just existential sort of spiral because it's beyond the financial burden. And then I sit there thinking, like, how is it in any way fair? And even with the privilege and the means that I have access to, and I don't have access to this, like, but knowing that there are people out in the world, because they can afford it, or because they have coverage, they're going to be healthier than me, and live a better, healthier life than me. And likewise, that I, with my access, will be healthier and will be living a better quality of life than people who don't have access to what I have access to. Like, that just, that level of inequity is just a manifestation of corporate greed. I don't know what you want to call it. Just, like, truly the most vile aspects of how we take care of our most vulnerable people. That's where it hit me, where it wasn't just financial, it was mental, and it was philosophical, and it was, like, down at my core of, like, I can't change this, I can't get rid of this, and I'm beholden to the system.

[Background music ends]

That feeling of powerlessness, the emotional weight of it all — it's enough to make anyone question the system. Nathaniel's frustration also points to this sense of moral outrage that resonates with many people living with chronic conditions. It's not just a question of whether or not the technology is available — it's a question of fairness and justice. Because Nathaniel is right: this is not just a financial issue. It's a *philosophical* one, a *moral* one. Why should someone's health be dictated by their ability to pay? Why should some people live healthier lives, with better access to care, simply because they have the financial means? This creates a two-tier healthcare system where the well-being of individuals is determined not by their needs, but by their ability to pay or their eligibility for coverage.

[Closing music]

In his 1966 speech, Martin Luther King Jr. was advocating for the rights of marginalized communities, particularly the poor and disenfranchised, to receive equal access to healthcare. He said, "Of all the forms of inequality, injustice in health is the most shocking and inhuman" (Galarneau). While King was focused on civil rights and healthcare access for African Americans, his words resonate today as we see how systemic inequality in healthcare continues to disproportionately affect people with chronic conditions like diabetes.

Join us in the next episode where we'll look at policies behind this issue and explore concrete ways we can take action to advocate for equal access to the care and technology that people with diabetes need to live healthy and fulfilling lives.

EPISODE 3

[Introduction music]

Welcome back to *Not-So Universal* where we're exploring the inequalities in diabetes healthcare that create a divide in quality of life and health outcomes.

In this episode, we'll be examining the roots of these health disparities by analyzing relevant government policies. We will then explore the concrete ways we can take action to advocate for equal access to the care and technology people with diabetes need to live healthy, fulfilling lives.

Canada, unlike the US, does have a few mechanisms in place that regulate drug prices. For example, the Patent Medicine Price Review Board, or PMPRB, sets a ceiling on the prices that drug manufacturers can charge for new medications, based on the price of the same drugs in comparable countries (Government of Canada). On paper, that sounds great, but there's a catch: the PMPRB only regulates the prices that patent holders charge wholesalers, hospitals, and pharmacies, not the price consumers—people like you and me—who actually pay at the pharmacy counter.

So, while the base cost for drugs may be set by the PMPRB, end-user prices can still vary greatly depending on factors like wholesaler and retailer markups, pharmacy filling fees, and insurance coverage. And here's the kicker: once a drug is on the market, its price is rarely reviewed again. So, the prices of existing drugs—like the insulin that people with T1D rely on—can continue to rise with no oversight or intervention. All of the insulins that Canadians currently use, their price is already set. There is actually no instance under which they have been reviewed to date.

This is where we see a gap: while we may have price ceilings at one stage of the supply chain, they don't protect the people who need these medications the most. And, we know that insulin isn't the only medication that people with diabetes need. Continuous glucose monitors, insulin pumps, and other devices are often out of reach for many people, either due to their high costs or a lack of insurance coverage.

So, what about Bill C-64, the recent piece of legislation aimed at creating a national pharmacare program? On February 29, 2024, the Government of Canada introduced Bill C-64, An Act Respecting Pharmacare, which lays out a framework for implementing national pharmacare. On the surface, this bill seems like a step in the right direction (Prime Minister of Canada). The government has committed to including diabetes medications and devices in the initial scope of the program, and it's promising improved access to life-saving treatments for Canadians living with diabetes. But there are some serious concerns from different sides, especially when it comes to how it could affect people with diabetes.

Diabetes Canada supports the idea of universal pharmacare in principle, but they have some big concerns about the details in the way its being implemented with Bill C 64. Specifically, they're worried that the list of diabetes medications and supplies that the bill will cover is too limited.

Right now, the bill includes some diabetes medications, but not all of them. And when you consider how complex diabetes is—every person has different needs—it's important that a wide variety of medications and devices are available.

For example, Rav explains how her insulin isn't fully covered.

[Rav]: Diabetes has so many wonderful health ailments associated with it, like I'm someone who has low thyroid, I have PCOS. So there are other medications I have to take. Because I have insulin resistance and things like metformin didn't really work out for me, I was constantly nauseous. I'm on a newer type of insulin called U200 insulin. So it's double the concentration. Most people are on U100. So I was flying through 300 units of insulin in like a day and a half. And that was just a lot in terms of insulin I was using, the cost, everything. So now that I'm on a U200 insulin, honestly, shout out to my pump trainer at the time for speaking to my endo to make sure I could have access to this insulin and get a prescription - was a game changer because now I use up the reservoir in my pump in like three, four days, instead of a day and a half. So the Humalog U200 is about $420 a month without insurance. And I do have insurance. So it's about $90 a month with that coverage.

Rav's insurance doesn't fully cover her insulin and it isn't covered under Bill C-64 either. This bill, without covering newer treatments leaves many Canadians who are already underinsured or uninsured still struggling to manage their condition. Limited coverage may only widen the gap between those who can afford the best care and those who can't, leaving many T1Ds without the tools they need to live a healthy life.

Kathy Megyery, a spokesperson from the Canadian Chamber of Commerce argues that Bill C-64 could disrupt the current workplace insurance plans that cover over 27 million Canadians. Right now, many Canadians, like Rav, have some sort of coverage through their employer's private insurance. This can include medications that may not be included in the public system. If the federal government moves to create a single-payer system, many employers might stop providing drug coverage to their employees. This could force people to switch from private insurance plans to government coverage, which may not cover the same medications or treatments, possibly forcing them onto older or less effective options.

What's more is that each province has to decide to join this program. BC has already signed an initial agreement with the federal government, and Manitoba, PEI, and Newfoundland have also said they will join. However, Alberta and Quebec have said they are opposed, while other provinces and territories are undecided.

This is where things get even more complicated: Big Pharma and the insurance industry are actively lobbying provinces to oppose national pharmacare, as they stand to lose profit if Canada moves to a universal system. This is a major threat to public health, as it would prevent more comprehensive coverage and access to necessary medications for people with diabetes and others who rely on prescription drugs.

Diabetes Canada has been very vocal about the need for a more comprehensive approach. The organization emphasizes that Bill C-64 must better reflect the individualized nature of diabetes care. They also advocate for robust consultations with all stakeholders—especially people with lived experience of diabetes—before any final decisions are made.

One major recommendation from Diabetes Canada is that the formulary, which is the list of medications covered, should be expanded to include more modern, effective treatments, as outlined in their Clinical Practice Guidelines. Additionally, they've called for a "do no harm" principle to ensure that people who currently have private coverage are not negatively impacted by the changes, and that no one is left behind.

A policy that resolves Canada's patchy drug coverage system could avert the premature deaths of many hundreds of Canadians each year and improve the quality of life for many, many more.

[Transition music]

As human rights activist Behrouz Boochani remarked, "It's not only awareness. Awareness is not enough. Instead, you challenge the language, and you create a different and transformative language" (Paik et al.). Boochani spent years in detention on Manus Island, where he used writing, filmmaking, and other forms of art to bear witness to the inhumane treatment of refugees. He called for a shift in how we talk about injustice. Similarly, we need to reshape the way we talk about diabetes care. It's not just about awareness—it's about transforming the systems that perpetuate inequality and harm. We have to challenge the structures that allow people with diabetes to suffer because of a lack of access to the care and technology they need. This perspective is important in the fight for better access to care. If we only focus on "awareness," the underlying inequalities in the healthcare system go unchallenged. But if we change the language to centre on "equal access," "human rights," and "justice," it transforms the conversation into one that demands systemic change.

Here's what Nathaniel thinks:

[Nathaniel]: I think there's a broader danger that our public healthcare system is in at the moment, where, just with a move towards privatizing services, and that that's tied to chronic underfunding of services, so that's, so that's one aspect of it, and so I'm just, I'm always cautious when it comes to talking about solutions, because it feels like it's such a bigger thing, like, recently the federal NDP pushed for the pharmacare bill to pass, but the way that Canada is structured is that healthcare is a provincial thing, so then the provinces need to opt into that, and you have provinces that are questioning whether they should opt into that, and, I mean, private interests have access to ears that you and I don't have access to, and it's easier for private interests to advocate for policy that makes health access inaccessible, and therefore more profitable, and they have a seat at the table, and we don't, or that we need to be louder, and it's more work for us to be louder, and to be organized as people in the healthcare community, and it's making our voices known on a federal level, and on a provincial level, and just making sure that provinces are able to opt into this, like, new pharmacare package, but also making sure that those policies, when they come out, that they have some teeth… And I think

conversations. I'm a big believer in talking about it. Because people, people see us and they see the things on our arms, they see the pumps, they see the pens, they think that we've got it sort of figured out. And there's this idea of, like, we're in Canada, so we've got it covered. Or at least we're not the states. That's just such a low bar.

Exactly. This is where Rav brings us back to the heart of the issue—how our current system prioritizes profit over patients and why access to technology should be considered a basic human right, not a privilege.

[Rav]: I would love for Canada to have universal pharma care. And that is a big ambitious goal, I know. And sometimes I wish other folks understood that Canada is like the only country that has universal health care without having universal pharma care. And it is very costly. And of course, having universal pharma care would be costly as well. But I think in the long run, it would be for the better. And we have seen that certain companies prioritize their profits over their patients. And having access to technology is a privilege when in all honesty, it should be a right. And I think having folks who have lived experience with diabetes, whether you know, there's so many different types, like across the board, we need that experience, where policies are being made and implemented. So whether it's diabetes caucuses, you need patients and patient advocates in there to help make these decisions, because they know how this is really going to impact wherever you fall in your life. So I know there was a diabetes caucus created, and I think Diabetes Canada, JDRF were asked to be a part of it. But like, they didn't want a group like Type 1 International there, because they are very much against pharma funded corporations.

What both Nathaniel and Rav highlight is that healthcare isn't just about treatment—it's about the policies and the structures that govern who gets access to treatment. This isn't just an issue of personal responsibility, or the idea that people with diabetes simply need to "manage their condition better." As Nathaniel puts it, the healthcare system has a bigger issue. That's where the conversation needs to shift—from awareness of the condition and the inequalities to transforming the systems that perpetuate these disparities.

Both Nathaniel and Rav are challenging us to look beyond the surface-level solutions to healthcare challenges—like the idea of simply raising awareness. Instead, they're asking us to engage with the deeper, structural issues that impact people with diabetes: privatization, corporate influence, and unequal access to the tools that people need to live healthy lives. This isn't just a healthcare issue—it's a social justice issue.

Lived experience in policy-making is a point that both Nathaniel and Rav stress. Rav emphasizes that people who face the daily challenges of managing diabetes should be at the table when policies are made. Groups that are critical of pharmaceutical interests, such as Type 1 International, should also be included in these discussions. Why? Because those who live with diabetes understand the realities—they know what works, what doesn't, and most importantly, what needs to change. Including lived experience in policy-making ensures that the resulting policies are truly patient-centered, rather than shaped by corporate interests that prioritize profit over patient care.

A review article by Agarwal et al., published in *Current Diabetes Reports,* highlights the disparities in access and use of diabetes care technologies among racial minorities and lower socioeconomic groups. Though the article is from the US, its findings are relevant to the situation here in Canada as well. The authors critique inequitable prescribing practices, the lack of support for social determinants of health, and the high costs of diabetes care as major contributors to ongoing disparities in access. One of their primary recommendations is the inclusion of underserved populations at every stage of the process—from the design and marketing of diabetes technologies to their implementation and dissemination. The authors advocate for user-centred design approaches and the use of stakeholder advisory boards.

So, what can we do?

Write to your Member of Provincial Parliament especially if your province hasn't yet signed on to the pharmacare program. If you have diabetes, share how it impacts your life and urge them to opt into and support the expansion of coverage under Bill C-64. Let them know that insulin pumps, continuous glucose monitors, and newer insulin should be included in the formulary.

Talk to people around you. Share what you've learned about diabetes care and the gaps in coverage. The more people understand the issue, the more likely we are to create change. Social media platforms like Twitter or Instagram can be great for spreading awareness. Share your story and tag politicians to highlight the need for expanded pharmacare coverage. Talk about it at town halls, with organizations, with institutions. You don't need to be a policy expert to speak up and talk about it. The more people that talk about it and learn, the more people can advocate and support changes.

Change doesn't happen overnight, but we have to keep pushing, and consistency is key. The more we make our voices heard, the more likely we are to get the changes we need.

If you're a policymaker, don't just hear our concerns—act on them. Support bills like Bill C-64 and push for universal pharmacare that is inclusive of all socioeconomic backgrounds. Listen to our lived experiences and involve us in all stages of developing and designing diabetes technology. Create policies that are truly patient centred and reflective of the realities that people with diabetes face.

As we wrap up this episode, it's clear that there's no one-size-fits-all solution to the challenges we face in improving healthcare for people with diabetes. We can't wait for someone else to solve this problem for us. The time to speak up is now. The more voices we have demanding change, the more likely we are to create the healthcare system we all deserve—one that prioritizes health over profit.

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