Out-of-Pocket Expenses and Rationing of Insulin and Diabetes Supplies:

Findings from T1International's 2024 Survey

THE INSULIN PRICE CRISIS:
IT'S NOT OVER

T1I INTERNATIONAL

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ABSTRACT

Introduction:

It's not over. Despite global attention and promises of action, the insulin price crisis continues—and for many, it's getting worse. This report compares self-reported data on insulin and glucose self-monitoring supply rationing, percentage of income spent, and access challenges against previous years' data, as well as World Health Organization (WHO) affordability metrics. Our findings make it clear: the crisis of access and affordability for people with type 1 diabetes is far from over.

Methods:

A global cross-sectional survey—conducted in Arabic, English, French, Spanish, and Swahili—was led by T1International's patient advocate network from November to December 2024. Participants shared data on household income, out-of-pocket expenses, rationing, budgeting sacrifices, access challenges, and personal experiences with insulin and glucose self-monitoring supplies.

Results:

People living with type 1 diabetes across the globe are rationing insulin and glucose self-monitoring supplies more often in 2024 compared to previous years' surveys. Globally, survey respondents are spending ca. 12% of their income on insulin and glucose self-monitoring supplies with high-income country survey respondents spending a smaller percentage of their income on insulin and glucose self-monitoring supplies compared to survey respondents in middle-income and low-income countries. Globally, 37.22% of respondents rationed their insulin and 79.38% of survey respondents reported difficulty accessing their insulin or glucose self-monitoring supplies (due to inventory concerns, prescription issues, or travel required), with similar trends by country economic classification.

Discussion:

This study demonstrates an increasing trend in how much people with type 1 diabetes are spending on insulin and glucose self-monitoring supplies. It highlights the impact of out-of-pocket expenses on diabetes care and their associations with rationing of insulin and glucose self-monitoring supplies. Access barriers to insulin and testing supplies persist across all countries, despite World Bank national economic classifications. These barriers reflect broader systemic challenges such as inefficiencies in the supply chain, regulatory hurdles, and market concentration. This report highlights the need for urgent global and national policy reforms. These findings aim to inform policymakers, public health agencies and advocates, and serve as a call to action for community-led change toward affordable, equitable, and quality diabetes care for all.

ACKNOWLEDGEMENTS

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The primary author of the report is Shaina Kasper,[1] T1International's Executive Director. Support reviewing survey data and responses was done, in alphabetical order, by Katarina Braune,[2] Sara Helena Pereira e Silva Gaspar,[3] Pilar Gomez[4], Yvonne Kamau[5] Campbell Mitchell,[6] Elizabeth Pfiester,[7] Maham Tahir,[8] and Chris Toavs.[9] Survey data support was by Josh Weinstein[10] and with pro bono support from the Analysis Group. Additional review was done by Ravjot Samra,[11] and Katie Souris.[12]

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Dissemination:

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Historic recognition:

This initiative was conceived by T1International's Founder, Elizabeth Pfiester. Former iterations of this report in previous years were done by Abishek Sharma, Axel Thieffry, Elizabeth Pfiester, Hanne Ballhausen, James Elliott, Katarina Braune, Katarzyna Anna Gajewska, Katherine Souris, Mridula Kapil Bhargava, Ravjot Samra, Saron Sauter, Shane O'Donnell, Shiva Raj Mishra, and Yanbing Chen.

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Content Warning

This report contains content relating to insulin rationing due to access and cost leading to complications and early mortality. This may be confronting and distressing to some readers. Please exercise caution and care when engaging with this content.

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INTRODUCTION

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Photo: Washington State #insulin4all Protest for World Diabetes Day 2024.

About

Over 9.5 million people live with type 1 diabetes across the globe. Persons living with type 1 diabetes need insulin to survive. Despite being discovered over a decade ago, it is estimated that half of all people who need insulin cannot because it is unaffordable, inaccessible, or both. High insulin costs and lack of access have led to rationing, which can cause consequential health impacts.

Access to affordable insulin and essential diabetes supplies remains a global crisis, disproportionately affecting individuals in low-income and middle-income countries and those with lower incomes in high-income countries.

The 2024 Out-of-Pocket Expenses and Rationing Survey builds upon previous findings, confirming that the financial burden on persons living with type 1 diabetes remains alarmingly high. This survey represents T1International's fifth survey of out-of-pocket expenses and builds on previous rationing and cost data surveys in different scales and contexts. Previous surveys found that persons with type 1 diabetes reported high out-of-pocket expenses and rationing of insulin and diabetes supplies. While past reports have documented the scale of the crisis, this survey provides updated insights into the financial strain people face in securing life-sustaining diabetes care.

We also share country-level analyses for Panama (Appendix 1) and the United States (Appendix 2). The survey also examines the World Health Organization's new insulin and glucose self-monitoring supplies affordability framework and the lived experiences of those who struggle with insulin access (Appendix 3).

Transparency and accessibility are values of T1International. We aim to provide clear background data and information to help every reader understand this report. We also aim to avoid complex language and to define our terms wherever possible to support this report's content to be as accessible as possible. Please let us know if you have any questions by emailing contact@t1international.com.

of people who need insulin cannot get it because it is inaccessible, unaffordable, or both

Background and Rationale

T1International is a global diabetes non-profit led by people with diabetes for people with diabetes, see www.t1international.com. T1International receives no funding from pharmaceutical companies, device manufacturers, or anyone who may influence the organization's advocacy efforts.

This survey builds on a decade of Out-of-Pocket Expenses survey research by T1International.

2016

The initial survey in 2016 included ca. 200 of participants from almost 40 countries, highlighting the financial burdens of diabetes management and rationing due to cost constraints. Out-of-pocket expenses were compared to average monthly wages in each country.

2018

The 2018 survey expanded to ca. 1,500 respondents over 90 countries and revealed that approximately 18% of participants had rationed insulin at least once in the previous year. It also noted that more than 66% of respondents received no financial coverage for their diabetes-related expenses.

2020

The 2020 survey was conducted in the height of COVID-19 supply disruptions, reporting more than 63% of participants with insulin supply disruptions and 25% facing price increases. This survey was conducted with ca. 1,000 participants from 64 countries and found that 25% of respondents underused insulin at least once in the last year due to cost. It also observed correlation between out-of-pocket expenses and household income, particularly among those with partial healthcare coverage.

2022

The 2022 survey consisted of ca. 1,000 survey respondents from 69 countries and compared data from Canada, India, Panama, Sweden, Germany, the United Kingdom, and the United States of America. The survey highlighted the Out-of-Pocket expenses that led to rationing, emphasizing the need for healthcare system improvements and price reductions to ensure equitable access to insulin.

In reaction to the high costs of insulin and glucose self-monitoring supplies, and high indications of rationing, T1International launched our Fight for Five Campaign in 2022. This campaign calls for a world where no one with diabetes has to spend any more than 5% of their income on insulin and glucose self-monitoring supplies. This campaign is a direct response to the WHO setting five global coverage targets which were adopted by Member States at the Seventy-Fifth World Health Assembly to strengthen the prevention and control of diabetes. The fifth Global Diabetes Coverage Target is that by 2030, 100% of persons with type 1 diabetes ought to have access to affordable insulin and blood glucose self-monitoring supplies. Recognizing that the World Health Organization (WHO) had never set an "affordability" metric like this before, T1International advocates fought across the globe to ensure that the global diabetes coverage target would set a bold enforceable standard for monitoring systems and guarantee affordable access to insulin and glucose self-monitoring supplies. See T1International's work highlighting the WHO's conflict of interest on this matter and our call for more meaningful patient engagement in this process.

Photo: Craig Miller speaking at the Global Day of Action for #insulin4all in Indianapolis, Indiana, March 2024.

Survey Design and Procedures

Ethics:

In line with T1International's Ethical Patient Engagement principles, patients were meaningfully involved in planning, leadership, and drafting the overall strategy of the survey including survey development, distribution, analysis and reporting.

A statement providing information on the type of data to be collected and explaining that the survey was completely voluntary was provided. Respondents were also informed that no identifiable information would be collected, and that they would receive no compensation or other financial reward for participating. To ensure data integrity and ethical standards, respondents were required to provide digital confirmation at multiple stages of the online survey. This included informed consent, confirmation that they were over 18 years old, and verification that they or members of their household were living with type 1 diabetes—excluding those using insulin or glucose self-monitoring supplies for other forms of diabetes or unrelated medical conditions.

Translations:

We translated the survey with volunteer translators from English into Arabic, French, Spanish, and Swahili according to T1International's Translation Standard Operating Procedure, which involves one person doing the translation and two different persons cross-checking the translation, ensuring that at least one translation volunteer has lived experience with type 1 diabetes, and ensuring regional diversity in translators. The same translators were used to translate the open-ended question responses from Arabic, French, Spanish, and Swahili into English.

Pilot Testing:

Prior to launching the survey, T1International piloted the survey with two persons in each language using a group of bilingual volunteers from every continent to refine the question structure and to ensure clarity and reader accessibility.

Data collection:

The survey questionnaire gathered information on:

- Monthly out-of-pocket expenses for insulin and diabetes management supplies
- Respondents' household income
- The percentage of income spent on diabetes care
- The frequency and reasons for insulin rationing
- Barriers to insulin access, regardless of affordability

In order to keep the survey concise and short (the average survey response time was 12 minutes), we did not collect data on the ages or genders of the persons in the household including the ages or the genders of the persons living with type 1 diabetes; the dosage forms or types of insulins used; the types of glucose self-monitoring supplies used; and more.

Distribution:

The 2024 Out-of-Pocket Expenses and Rationing Survey was conducted between November 1 and December 31 2024, collecting data from individuals with type 1 diabetes across the globe. The survey was disseminated using email, social media platforms, and through partner organizations. Some Partners or Advocates printed and, with consent, collected responses from patients who did not have access to the internet via printed survey, phone interview, or in-person interview, and then transcribed their responses into the online platform.

Data Analysis:

A total of 1,063 survey responses were collected from 55 countries. Of these, 14 were removed for lacking explicit consent and 55 for the respondent being under 18 years old. Additionally, 165 respondents were removed for responding “No” or “I don’t know” to the question “Has everyone in your family who uses insulin or glucose self-monitoring supplies devices been diagnosed with type 1 diabetes?”.

Additionally, after data collection was complete, we removed outliers and certain survey responses using a set threshold to ensure data accuracy and reliability. This included outliers who reported per person income ten times or more the monthly national Gross National Income (GNI) per capita (31), respondents with invalid household response patterns (such as reporting more people living with type 1 diabetes in the household than total household members) (40), those who reported insulin and glucose self-monitoring costs $5,000 USD or more monthly (6), and other invalid or inconsistent response patterns identified after manual curation (4). This left a total of 747 records representing 53 countries.

Respondents were categorized by income bracket and national economic classification based on the most recently available World Bank designations (high-income countries, upper-middle-income countries, lower-middle-income countries, and low-income countries), and using the most recently available World Bank exchange rates. The data were analyzed to identify trends in financial burden, disparities in accessibility, and the relationship between affordability and real-world access.

In addition to analysis of the total dataset, we also analyzed country-level data for all countries that had 11 or more qualified responses: Canada, Colombia, Costa Rica, Egypt, Ghana, Guatemala, India, Nigeria, Pakistan, Panama, South Africa, Tanzania, and the United States. The highest number of participants resided in the United States (n=197) and Panama (n=192). See Appendices 1 and 2 for a breakdown of these countries’ data, which includes categorization by most recent World Bank Gross National Income (0-50%, 51-100%, 101-150%, and 151% or greater).

T1International collected data on household income, size, and number of people with type 1 diabetes to calculate precise per-person costs and income. This allowed for more accurate comparisons of individual out-of-pocket expenses, rather than relying on country-level averages. We primarily used means, with medians included where relevant. Unless otherwise noted, all expenses data is reported in US Dollars (USD).

RESULTS

- **High costs of insulin and glucose self-monitoring supplies takes a large percentage of income**
- **The impact of high costs: Rationing is still prevalent**
- **Trends of rationing over time**
- **Budgeting adjustments**
- **Affordability does not mean accessibility**

High costs of insulin and glucose self-monitoring supplies takes a large percentage of income

Comparing the amount spent on insulin and glucose self-monitoring supplies to income accounts for purchasing power parity and the real cost of living—key factors in understanding access to essential diabetes care. T1International's Fight for Five campaign advocates for a world where the cost of insulin and glucose self-monitoring supplies represents no more than 5% of a person's income in any given country. Our survey results indicate that we are far from achieving this goal. According to self-reported data from individuals living with type 1 diabetes across the globe, the average percentage of income spent on these essential items was 11.77%.

Survey respondents spent on average

on insulin each month, more than the estimated annual cost of production for analogue insulins.

Additionally, survey respondents spent an average of

each month on glucose self-monitoring supplies in 2024.

However, this average alone does not fully capture the severity of the financial burden for many households, especially in low- and middle-income countries. That's why we also calculated the median percentage—representing the midpoint in the dataset—and found it to be higher at 29.33%. This discrepancy between the average and the median is particularly telling. It suggests a skewed distribution, where a smaller number of respondents may be spending relatively low percentages, pulling the average down, while a much larger portion of survey respondents are experiencing far higher costs.

By reporting the median, we highlight the more typical experience for our survey respondents. This is especially important in global health data, where income inequality and health system disparities can mask the struggles of those hit hardest by out-of-pocket expenses. The median figure of nearly 30% underscores the reality that for many, insulin and glucose monitoring supplies are not just unaffordable—they are financially devastating. It paints a far more accurate and urgent picture of the affordability crisis and reinforces the need for policies grounded in lived experience data, not only economic modeling.

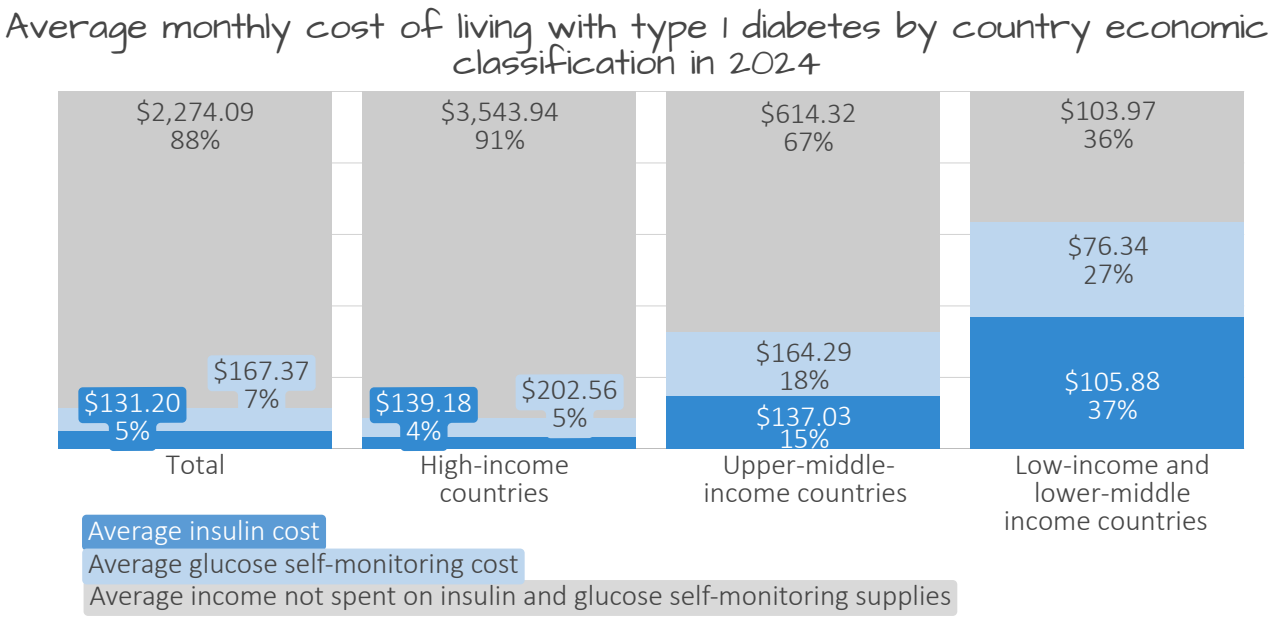
People with type 1 diabetes reported spending on average

of their income on insulin and glucose self-monitoring supplies in 2024.

Our goal is 5% or less.

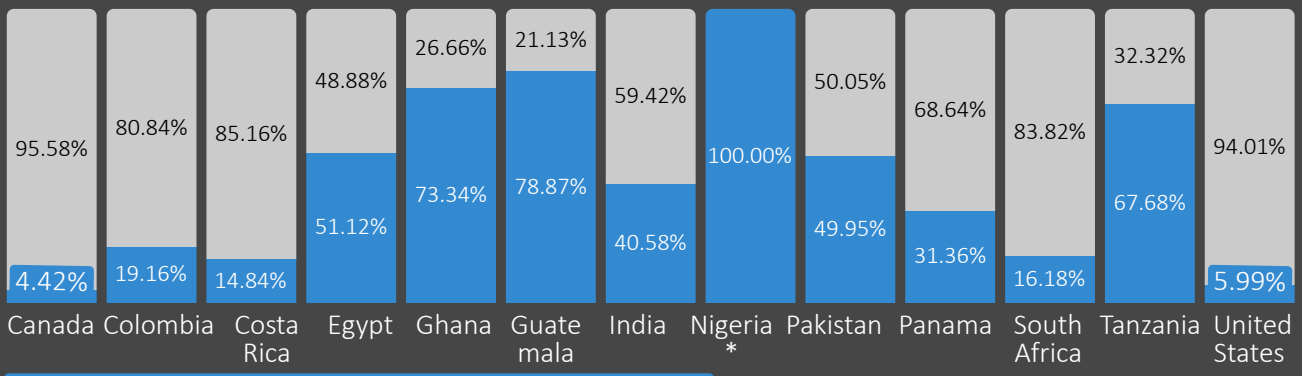
Of countries where we had 11+ responses (see Table 1), the average percentage of per person income spent on insulin and glucose self-monitoring supplies ranged widely from country to country. In Canada, survey respondents paid on average less than 5% of their income on insulin and glucose self-monitoring supplies (4.42%), while in Nigeria, respondents spent over 150% of their income (152.78%) on average.

Purchasing power, or the amount of goods and services that can be bought with the unit of local currency, is critical when looking at the costs of insulin and glucose self-monitoring supplies.[25] In Guatemala and the United States, respondents spent around $400 a month on insulin and glucose self-monitoring supplies ($392.68 and $410.64 respectively) but in the United States, that accounted for an average of 5.99% while in Guatemala, that accounted for 78.87%.[26] Affordability is not simply how much insulin and supplies cost, but how those costs compare to income; many respondents are spending far too much of their income on essential insulin and testing supplies.



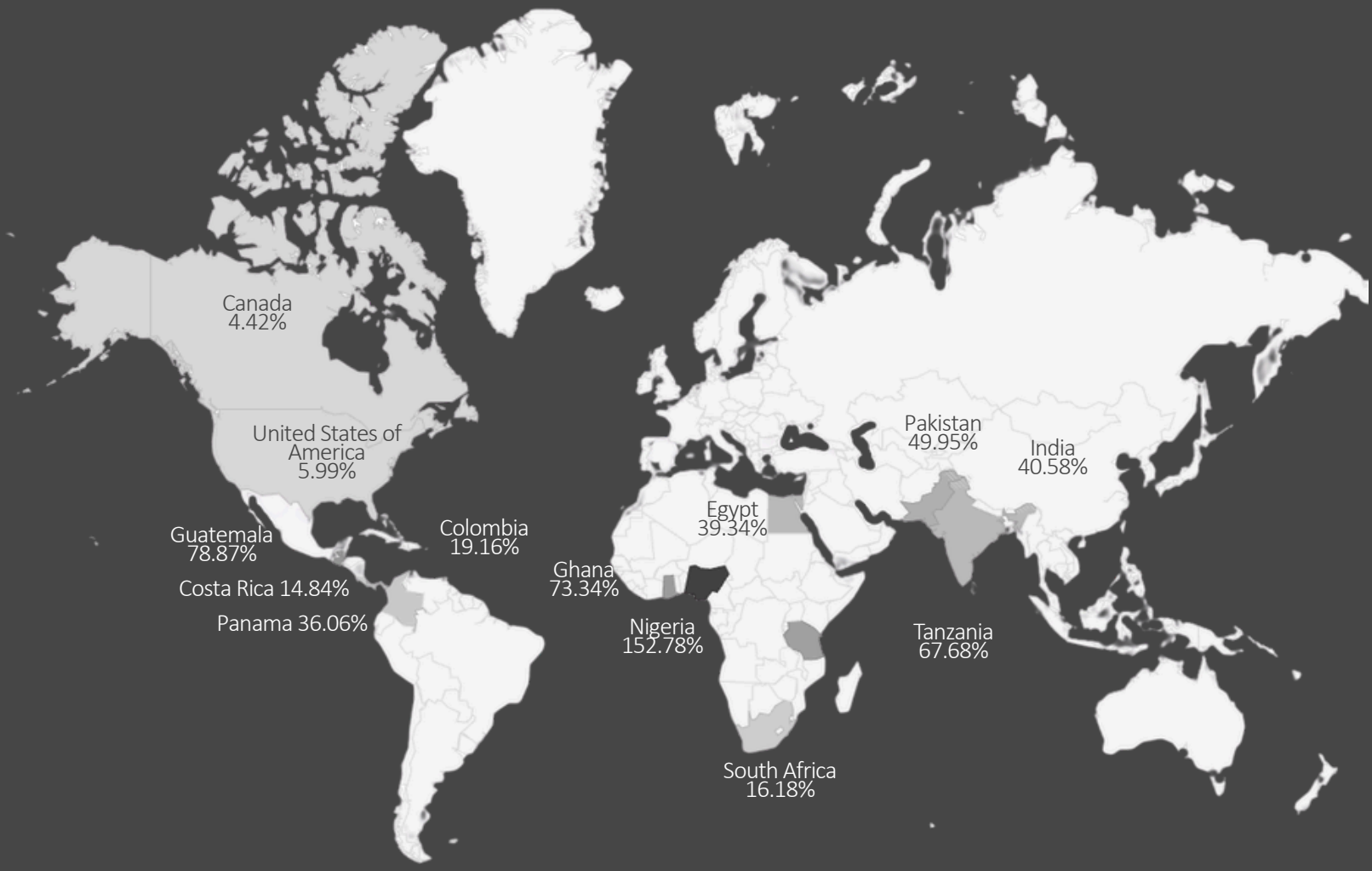
25. Purchasing power of local currency can also be represented in International Dollars (ID), for more, see Appendix 3.
26. In Nigeria, survey respondents spent an average above 100% of their income,potentially due to them being students or recent graduates with limited income; the average age of Nigerian respondents was 25 compared to an overall respondent age of 38.
27. Of these respondents reported spending more than 100% of their per-person household income on insulin and glucose self-monitoring supplies, many were likely taking a larger-than-their per-capita amount of their total household income for survival, with only 16 (2.28%) of total households spending 100%. Many spending such a high percentage of their income on insulin and glucose self-monitoring supplies are likely relying on support from people outside their households, borrowing from non-household members, or borrowing from institutions.

Percentage of average monthly cost of living with type 1 diabetes by country economic classification in 2024



* = This country had a reported average cost of insulin and glucose testing supplies more than the average monthly income per person

Average monthly out-of-pocket expenses percentage of income spent per person living with type 1 diabetes in certain countries



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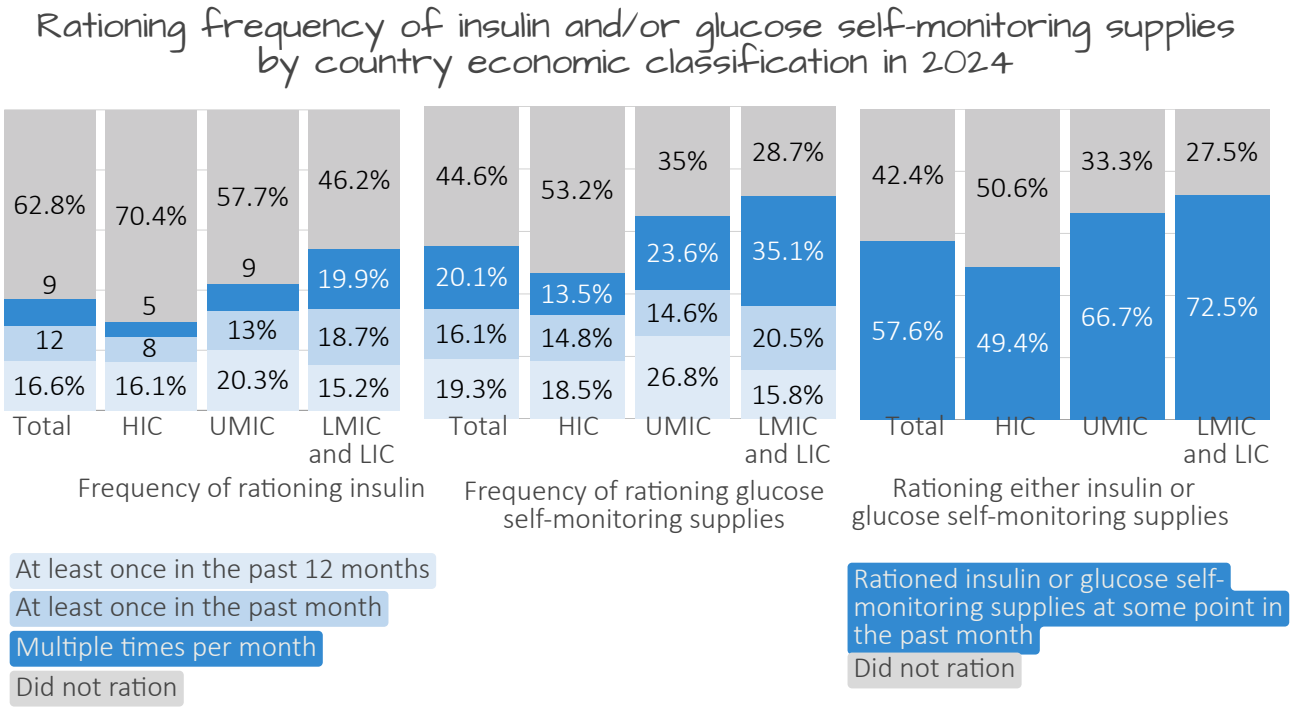
The impact of high costs: Rationing is still prevalent

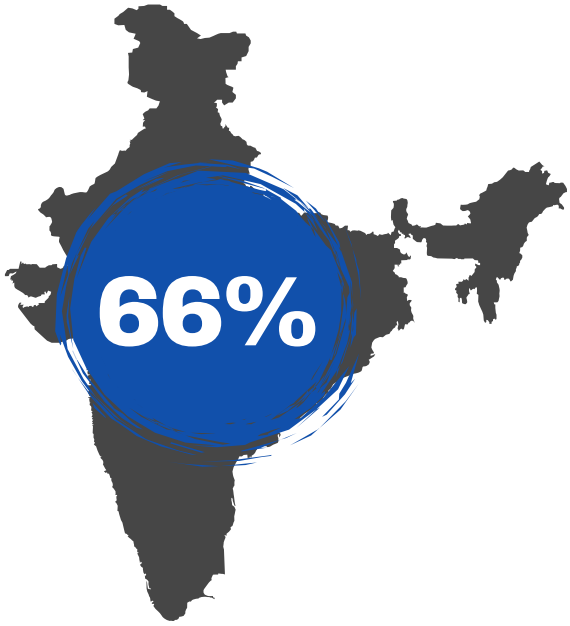
The high costs of insulin and supplies continue to force people living with type 1 diabetes to ration, leading to potentially serious health risks. In total, 37.22% of respondents reported having rationed insulin in the past year, 55.42% of persons rationed glucose self-monitoring supplies, and 57.56% rationed either insulin or glucose self-monitoring supplies (see Table 3).

The percentage of persons rationing is directly related to the country's World Bank economic classification. For example, about 30% of respondents in high-income countries reported rationing insulin at some point in the last year (29.58%), with 8.39% at least once in the past month and 5% multiple times per month. Insulin rationing is reported more frequently in lower-middle-income countries and low-income countries, with 53.80% of respondents rationing insulin due to cost at some point in the past year, but about 18.71% reporting rationing at least once in the past month (2.5 times those in high-income countries) and 19.88% rationing multiple times per month (about 4 times those in high-income countries).

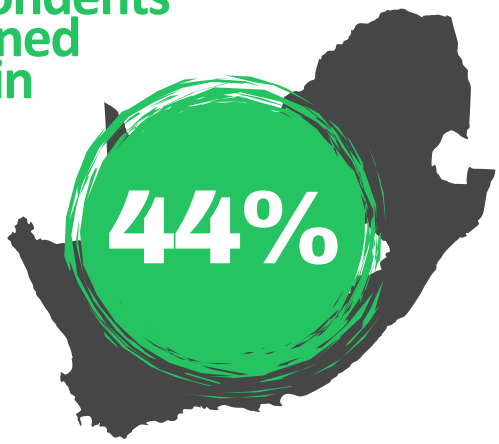


There is an alarming prevalence of rationing insulin and glucose self-monitoring supplies in countries with sufficient responses enabling reports on national-level data (see Table 4).

In India, 66% of respondents rationed glucose self-monitoring supplies



In South Africa, 44% of respondents rationed insulin



In India and Pakistan, around 65% of survey respondents reported rationing either insulin or glucose self-monitoring supplies in the last year. In Pakistan 39.47% of survey respondents rationed insulin, likely due to widespread shortages due to rupee devaluation and lack of imports over 2024. In India, 34.21% of survey respondents rationed insulin, echoing insulin availability rates by other researchers. In India, 65.79% of survey respondents rationed glucose self-monitoring supplies and in Pakistan, 63.16% of survey respondents rationed. These high rates reflect systemic affordability barriers in these countries, where public coverage is inconsistent and out-of-pocket expenses remain high for life-sustaining treatment.

Panama also shows that World Bank income classification alone does not ensure access: 58.85% of survey respondents reported rationing, driven largely by difficulties affording test strips and supplies. Notably, even in the United States, a high-income country with advanced healthcare infrastructure, half of all survey respondents (50.76%) reported having to ration their insulin or testing supplies—likely due to high list prices, insurance designs, and gaps in emergency access.

Meanwhile, South Africa, which did not have sufficient data on glucose self-monitoring supply rationing, showed the highest insulin rationing rate (44.44%) of all reportable countries, likely due to the human insulin pen discontinuation in the country in 2024.

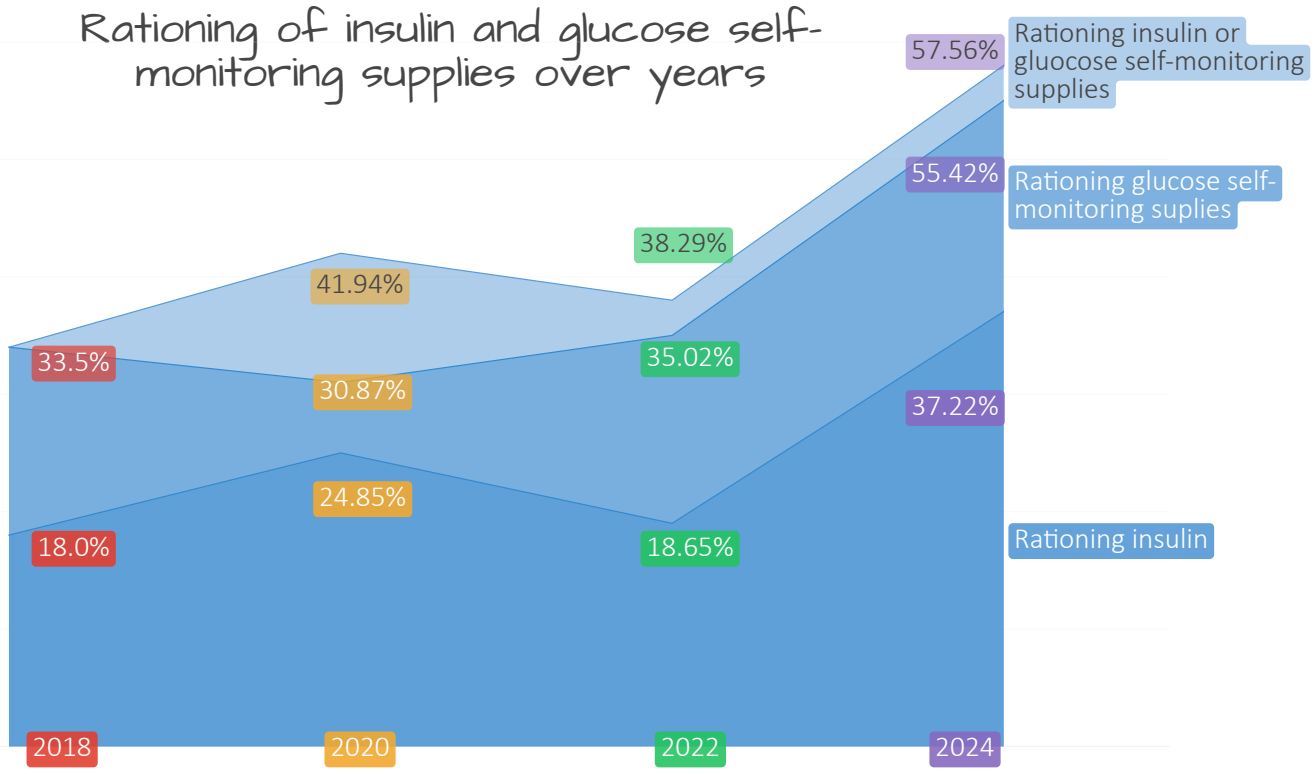
These numbers point to a critical conclusion: rationing is not limited to low-resource settings. Instead, it is a widespread outcome of unjust systems that prioritize pharmaceutical profit over patient survival. Whether caused by high out-of-pocket expenses, insurance exclusions, broken public procurement systems, or market shortages, the need for urgent, systemic reform is clear across every region and income level.

Trends of rationing over time

Because this is the fifth iteration of T1International's Out-of-Pocket Expenses and Rationing Survey, we are uniquely positioned to observe how rationing trends have evolved over time (see Table 5). Note that each year, survey respondents were different individuals in each survey iteration. Although our earliest survey in 2016 did not collect data on rationing, the four subsequent surveys (2018, 2020, 2022, and 2024) reveal an alarming upward trajectory.

Insulin rationing has doubled, rising from 18.0% of survey respondents in 2018 to 37.22% in 2024. The rationing of glucose self-monitoring supplies has also surged, increasing from 33.5% to 55.42%—a 1.6-fold increase. These results show a dangerous pattern of deteriorating access and affordability, even as awareness of the insulin crisis has grown globally.

In the eight years we have been tracking this data, insulin rationing has doubled.



An exception to this trend occurred in 2022 when insulin rationing rates briefly declined: just 18.65% of survey respondents reported insulin rationing, compared to 24.85% in 2020. This temporary drop may have been influenced by a range of factors, including shifts in survey participation, pandemic-era public health interventions, or temporary policy expansions like emergency access programs. However, the 2024 data signal a return to a rising trend. These trends are especially concerning given the known consequences of rationing, including preventable hospitalizations, complications, and early death.

This long-term trend data underscores the need for sustained, systemic solutions, rather than one-time policy fixes or temporary funding boosts.

It also highlights the importance of recurring, community-led data collection efforts to ensure that the global diabetes community is not left behind in future affordability and access assessments.

T1International's survey remains one of the only global, independent data sources capturing these realities

—and it paints a clear and urgent picture.

Photo: Pakistan #insulin4all advocate Yahya Ur Rehman holds a sign

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Survey respondent from Mexico:

Tenemos que recortar gastos de comida, gasolina, en ocasiones no llevar al médico a otro miembro de la familia para poder comprar insulina.

We have to cut expenses on food and gasoline and sometimes not take another family member to the doctor to be able to buy insulin.

Survey Respondent from France:

Je n'ai jamais eu de problèmes pour accéder à de l'insuline. Ma pharmacie m'en fournit toujours. Je ne rencontre pas non plus de difficultés pour accéder aux capteurs de glycémie qui me sont envoyés directement par La Poste à mon domicile. Les seules dépenses que je fais pour mon diabète sont pour m'acheter des stickers pour ma pompe ou des trousses pour le matériel de diabète. N'est-ce pas injuste face aux autres réalités du monde?

I've never had any problems accessing insulin. My pharmacy always provides it. I also have no trouble accessing the blood glucose sensors that are mailed directly to my home. The only expenses I incur for my diabetes are to buy stickers for my pump or kits for diabetes equipment. Isn't that unfair compared to other realities in the world?

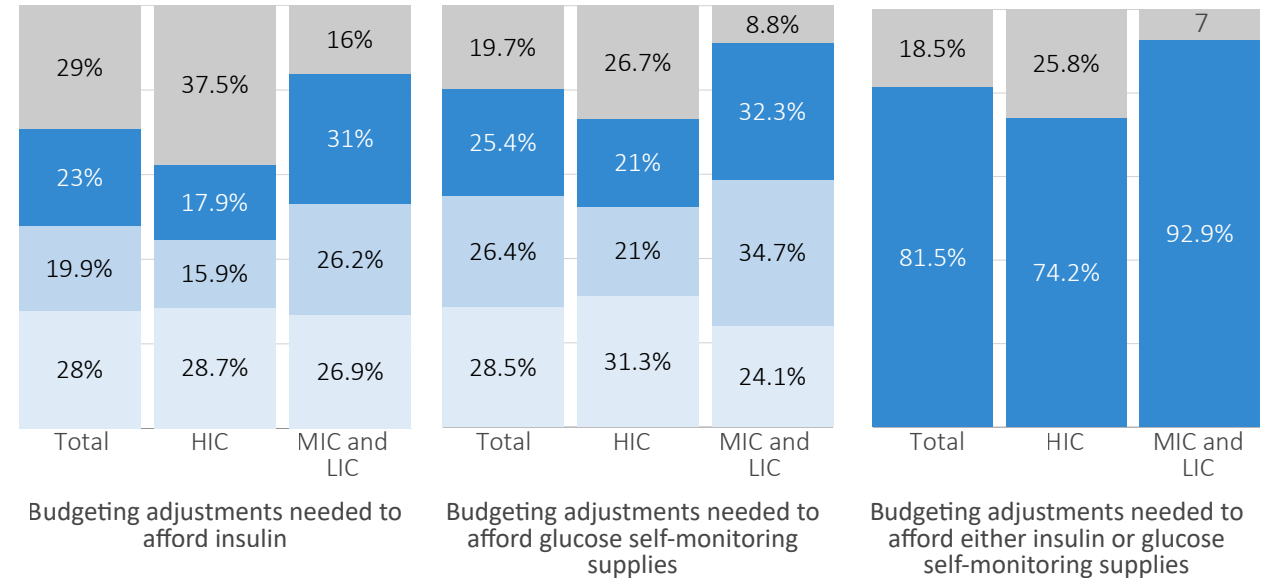
Budgeting Adjustments

For the first time in our decade of our Out-of-Pocket Expenses and Rationing Survey, T1International's 2024 iteration asked respondents about the budgeting adjustments they make in order to afford insulin and glucose self-monitoring supplies (see Table 6). These budgeting decisions may include skipping meals, delaying rent, reducing other medical care, or forgoing education costs, and they underscore the cascading consequences of high prices of essential medications and supplies. The findings are striking: 70.95% of all survey respondents reported having to adjust their household budget to afford insulin, and 80.32% had to do so to afford glucose self-monitoring supplies. When combined, 81.53% of survey respondents indicated they had to make budgeting adjustments to afford either insulin or supplies, underscoring the widespread financial burden of diabetes.

The data also show a clear correlation between a survey respondent's World Bank country income classification and the likelihood of making these budgeting adjustments. In high-income countries, 74.17% of survey respondents reported adjusting their budget to afford insulin or monitoring supplies. That figure rises sharply in middle-income and low-income countries, where up to 92.86% of survey respondents reported making budgeting sacrifices—indicating both a greater cost burden and fewer economic safety nets.

Perhaps most sobering, 100% of survey respondents in several countries reported making budgeting adjustments to afford their insulin and/or glucose self-monitoring monitoring supplies: Costa Rica, Guatemala, India, and Tanzania (see Table 7).

Budgeting adjustments needed to afford insulin and/or glucose self-monitoring supplies by country economic classification in 2024



Budgeting adjustments are a powerful signal of economic stress—they may occur before patients begin to ration, but still reflect serious tradeoffs that erode quality of life and wellbeing. These findings suggest that even among those not currently rationing, the burden of diabetes care is disrupting daily life and household stability. Investments in improving access to medicines and health technologies yield significant returns for health systems and household budgets. These results reinforce the call for policies that go beyond simply preventing death, and instead aim to ensure that people with diabetes can live healthy, dignified, and economically secure lives. Affordability must not be defined solely by survival—it must reflect true accessibility without financial harm.

Affordability does not mean accessibility

Even when insulin and glucose self-monitoring supplies are theoretically affordable, cost alone does not ensure access. T1International's 2024 survey included new questions on access barriers, and the findings reveal that systemic and logistical challenges prevent many people with diabetes from getting the medications and supplies they need to survive. These barriers include inventory shortages, difficulty obtaining prescriptions, limited pharmacy availability, and the need to travel long distances to access care. These concerns have been echoed in past surveys and media reports, confirming that access breakdowns are a global issue affecting high- and low-income settings alike.

Across all survey respondents, 68.81% reported difficulty accessing insulin, and 70.82% reported difficulty accessing glucose self-monitoring supplies.

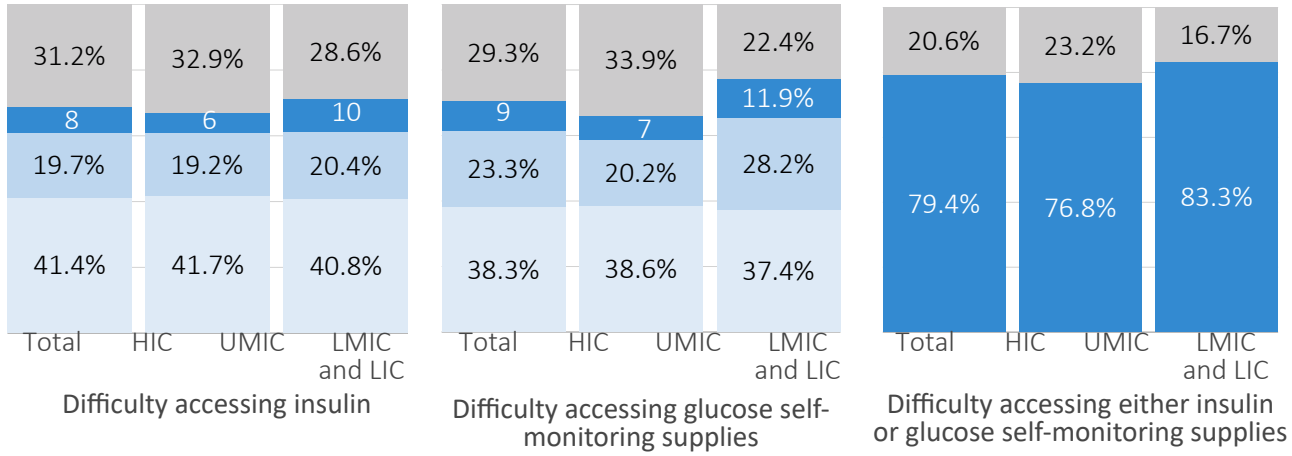
When combined, 79.38% of people surveyed experienced some level of access difficulty for one or both critical diabetes resources (see Table 8).

Notably, access challenges were not limited to low-income and middle-income countries. In fact, the proportion of survey respondents reporting some level of insulin access difficulty was similar across World Bank income classifications, with consistently slightly higher access difficulty in lower-income countries: 67.11% in high-income countries and 71.43% in middle-income and low-income countries. The same trend emerged for access to glucose self-monitoring supplies, with 66.45% of high-income country survey respondents and 77.55% of middle-income and low-income country survey respondents reporting difficulty.

While extreme access issues—defined as frequent inventory shortages, routine prescription barriers, or recurring travel to distant pharmacies—were slightly more prevalent in middle-income and low-income countries (10.20% for insulin and 11.90% for monitoring supplies), they still affected over 6.18% and 7.28% of survey respondents in high-income countries, accordingly. This underscores that geographic proximity to wealth does not equate to equitable access, especially in the absence of robust healthcare infrastructure or responsive public supply systems.

Data from individual countries reveal even starker patterns (see Table 9). In India, over half (56.89%) of survey respondents experienced barriers to insulin access, and two-thirds (67.57%) reported trouble accessing glucose self-monitoring supplies. In South Africa, over half of survey respondents had difficulty accessing insulin (55.56%), likely due to the human insulin pen discontinuation in the country in 2024. Alarmingly, 100% of survey respondents in Egypt reported difficulty accessing insulin —indicating a meaningful breakdown of access among our survey respondents there and echoed in policy where local manufacturing capacity has been delayed.

Ranked difficulty accessing insulin and/or glucose self-monitoring supplies by country economic classification in 2024



These findings highlight the need for stronger supply chain management, decentralized distribution, prescription reforms, and emergency access policies —especially in public health systems and fragile markets. Policymakers must treat both cost and access as dual crises in the fight for insulin justice. Without urgent investment in accessibility solutions, people living with diabetes will continue to face life-threatening delays, regardless of their ability to pay.

of people in low- and middle-income countries experienced extreme difficulty accessing glucose self-monitoring supplies

Listen to patients

Not to Big Pharma

Survey respondent from Colombia:

Soy [padre] soltero, [de un niño] de 10 años con diabetes tipo 1 y tengo [otros hijos], vivo en un municipio muy pobre sin acceso a nada y [aveces de] sentirme tan abrumada he pensado en [tirarme a] un carro.

I am a single [parent] of a [child] … with type 1 diabetes, and I have .. other children. I live in a very poor neighbourhood with no access to anything, and sometimes, feeling so overwhelmed, I have thought about throwing myself in front of a car.

DISCUSSION

- **Policy Recommendations**
- **Case Studies**
- **Limitations**
- **Future Research**

This study highlights the devastating financial burden, persistent access barriers, and systemic inequities faced by people living with type 1 diabetes across the globe. Our findings clearly demonstrate that those in low-income and middle-income countries are disproportionately affected, with survey respondents in these countries reporting the highest rates of rationing, budgeting adjustments, and percentage of income spent on essential diabetes care. In lower-middle-income and low-income countries, survey respondents spend 63.67% of their income on insulin and glucose self-monitoring supplies, compared to 8.93% in high-income countries (see Table 10).

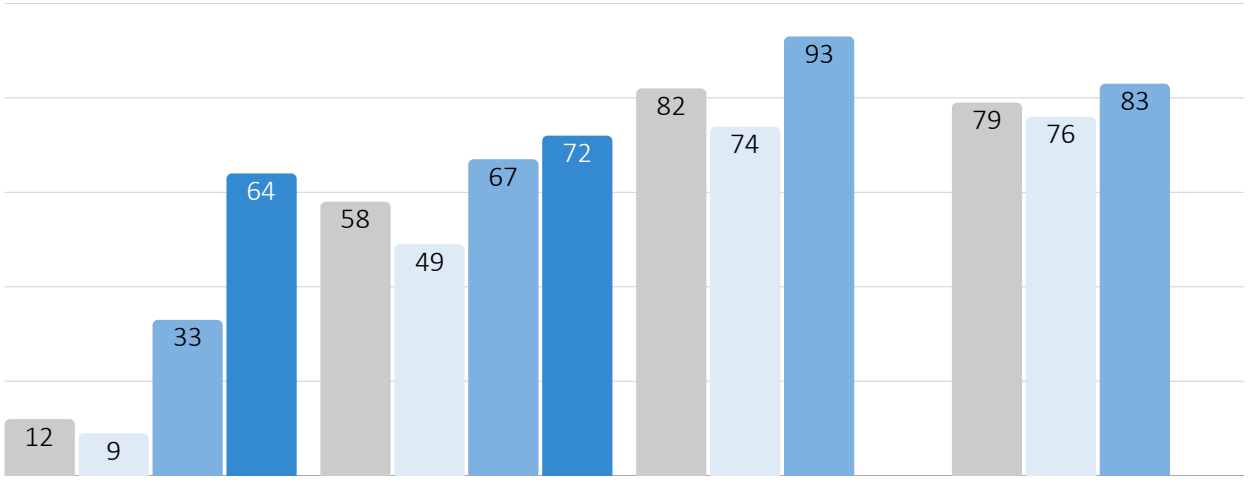
Where you live determines whether you can afford to stay alive.

Yet, importantly, our data also show that access barriers are not bound by World Bank income classification, illustrating that the root causes of inaccessibility—pharmaceutical industry greed and lack of government accountability leading to issues like broken supply chains, restrictive prescription practices, and insufficient provider availability—are systemic and global. Governments must demand lower prices for insulin and testing supplies for their people. Pharmaceutical manufacturers must put patients' lives over profits. Affordability, while critical, does not necessarily equal access. Governments, global health institutions, and manufacturers must understand that price regulation alone will not solve the problem. They must also take responsibility for structural improvements to healthcare infrastructure, procurement systems, and policy enforcement to address these urgent access crises.

While pharmaceutical companies often emphasize recent price reductions and donation programs, people living with diabetes continue to face significant barriers to insulin access and affordability. These real-world experiences highlight the gap between public messaging and patient reality.

It's time to center the voices of those who rely on insulin to survive.

Average access and affordability burden for people living with type 1 diabetes by country economic grouping in 2024



Policy Recommendations

Survey responses call attention to an urgent need for local, national, and global policies that address the root causes of high out-of-pocket expenses for insulin and glucose self-monitoring supplies. Current solutions being offered are stop gaps. We call on governments to adopt universal pricing caps on the list price of insulin to ensure everyone, regardless of insurance status, has affordable access. Governments should also expand public pharmaceutical production to reduce reliance on monopolistic manufacturers.

Global health bodies, particularly the World Health Organization (WHO), must revise affordability metrics to reflect lived realities and ensure data transparency. The current WHO Affordability Index often misclassifies countries as "affordable" despite survey respondents reporting costs exceeding 30 to 70% of income. We recommend refining the Affordability Index in consultation with affected communities, using transparent data sources and accountability mechanisms.

Finally, manufacturers must be held accountable. The tactics of product hopping, patent evergreening, and pay-for-delay must be outlawed, and pricing negotiations must be made public and tied to the cost of goods. We call on the Big Three insulin manufacturers, as well as glucose self-monitoring supplies supply manufacturers, to lower their prices and conduct transparent pricing negotiations. Insulin and device manufacturers must be held accountable to make their products affordable and accessible to all: we call for governments to promote competition by reforming patent laws and regulations, and support public pharma initiatives.

Below are several case studies of recent advocacy activities leading to policy change that could meaningfully lower insulin and glucose self-monitoring supplies, increase access, and reduce rationing and budgeting adjustments needed for those with type 1 diabetes to survive and thrive.

Case Studies:

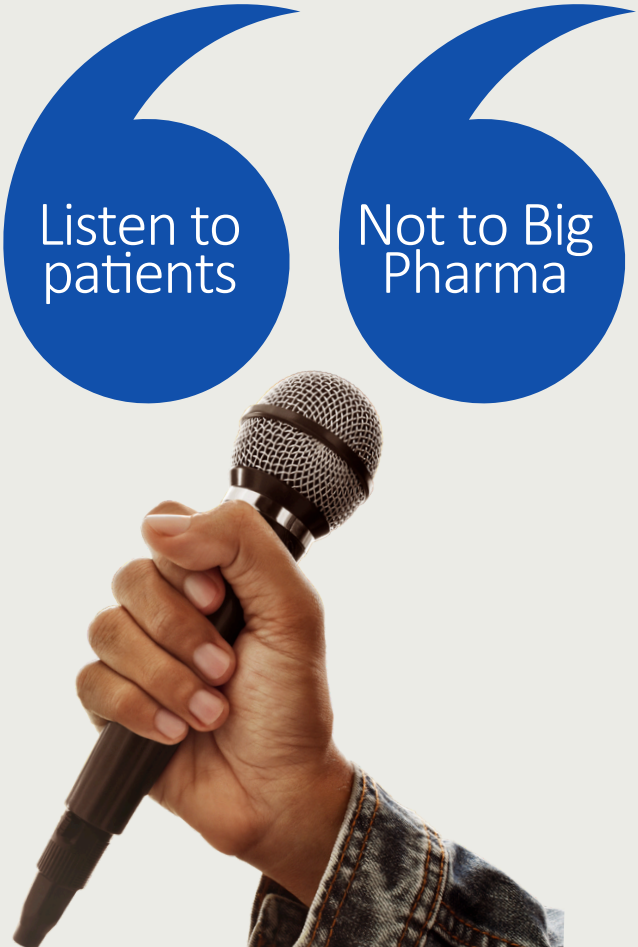
Advancing Insulin access in Pakistan Through Local Manufacturing and Government Action

The Alec Smith Insulin Affordability Act – Emergency Access in Minnesota and the Push for National Reform

Brazil's Success in Government Negotiation and Local Production of Insulin

Anti-Competitive Lawsuit in South Africa

Winning easier importation of insulin and diabetes supplies in Panama



Survey respondent from Burkina Faso:

Je pense qu'un plaidoyer doit être proposé afin qu'on puisse facilement [accéder] au matériel et à l'insuline gratuitement que ce soit pour Les enfants ou [pour] Les personne[s] adultes

I think that people should advocate so that we can easily access insulin and supplies for free, no matter if someone is a child or an adult.

Case Study: Advancing Insulin Access in Pakistan Through Local Manufacturing and Government Action

Photo: Global Day of Action for #insulin4all Roundtable participants in Pakistan, March 2024. Photo Credit: Meethi Zindagi

In response to increasing scarcity and cost of insulin from multinational manufacturers, Pakistan has taken a significant step forward with the local production of human insulin, marked by the launch of a new product in August 2024. This milestone follows coordinated advocacy efforts led by T1International's Advocacy Partner, Meethi Zindagi, which convened key stakeholders during the March Global Day of Action for #insulin4all Roundtable. While public pharmaceutical production remains a long-term goal, domestic manufacturing offers a critical pathway to reduce reliance on costly imports and address ongoing supply shortages.

Building on this momentum, the Punjab government announced the Chief Minister Insulin for All program, which will deliver insulin directly to children with type 1 diabetes in three major districts of Punjab. The program draws on Meethi Zindagi's successful Promise of Insulin home delivery model and reflects a growing recognition of community-driven advocacy in shaping public health solutions. With local production underway and government commitment growing, this case exemplifies how grassroots leadership can drive systemic change to improve insulin access.

Case Study: The Alec Smith Insulin Affordability Act – Emergency Access in Minnesota and the Push for National Reform

Photo: Nicole Smith-Holt and James Holt Jr speaking outside of Eli Lilly's headquarters in Indianapolis, Indiana.

In 2017, Alec Smith, a 26-year-old Minnesotan with type 1 diabetes, died after rationing his insulin due to its unaffordable price. His tragic death became a rallying cry for insulin affordability advocates and spurred the passage of the Alec Smith Insulin Affordability Act in 2020. The law established Minnesota's Insulin Safety Net Program, which includes an Urgent Need Program that provides a 30-day supply of insulin for no more than $35 to those in crisis, and a Continuing Need Program to help eligible patients afford insulin for up to 12 months. For years, #insulin4all advocates, including Nicole Smith-Holt, Alec's mother and T1International's Ambassador, pushed tirelessly for the law, which was upheld despite legal challenges from pharmaceutical companies. It stands as a powerful example of community-led policy change making a life-saving difference.

While over half of U.S. states have now passed insulin copay cap laws, these caps typically apply only to state-regulated insurance plans—impacting just about one in five people. That means most people—including those on federally regulated plans, employer-sponsored plans, or uninsured—still face unmanageable costs. Copay caps are also a limited solution: they reduce out-of-pocket expenses for some, but do not lower the overall list price of insulin. That's why national action is urgently needed. We need a federal insulin price cap that applies to everyone, including those without insurance or in emergency situations. The Alec Smith Act shows what's possible when people advocate for bold solutions—but it also shows why state laws alone are not enough to meet the scale of the crisis. A nationwide policy is necessary to ensure no one is forced to ration insulin—ever again.

Case study: Brazil's Success in Government Negotiation and Local Production of Insulin

Photo of Brazilian President Luiz Incácio Lula da Silva at the opening of the Biomm recombinant human insulin-producing plant. Photo credit: Merco Press

Brazil has taken bold, proactive steps to ensure affordable access to insulin by combining strong government negotiation power with public production strategies. In recent years, the Brazilian government successfully negotiated the price of newer, more effective types of insulin, enabling broader access through the country's universal public health system (SUS). This negotiation reduced the cost burden for the national health system and ensured that people living with diabetes could access insulin at no cost at the point of care. In doing so, Brazil demonstrated how leveraging state power can shift the balance away from monopolistic pharmaceutical pricing and toward public health equity.

In addition to price negotiations, Brazil has also invested in local production of insulin glargine. Through public-private partnerships and strategic licensing agreements, Brazil has strengthened its pharmaceutical sovereignty and reduced its dependence on imported insulin from multinational corporations. Local production helps stabilize supply, avoid price shocks, and ensure continuity of care—especially critical during global disruptions like the COVID-19 pandemic. Brazil's approach offers a powerful model for other low-income and middle-income countries seeking to expand insulin access. It illustrates how strong public policy, aligned with the right to health, can challenge corporate control and ensure that essential medicines are accessible and affordable to all who need them.

Case study: Anti-Competitive Lawsuit in South Africa

Photo: T1International South Africa #insulin4all Chapter leader Janice Barnes protests at a protest to Novo Nordisk on World Diabetes Day, 2024. Photo Credit: Bloomberg

In response to widespread protests over the high cost of insulin and the discontinuation of human insulin pens, the South African government is investigating major insulin manufacturers for potential anti-competitive practices such as price-fixing. The protests highlighted the unaffordability of insulin for many South Africans, especially those from lower-income backgrounds, who were struggling to access this life-saving medication. The investigation seeks to examine whether these practices are being used to exclude competition and prevent entry of alternative suppliers that could potentially lower insulin prices by increasing competition in the market. If successful, it could improve access to affordable insulin for South African patients, set a precedent for legal actions globally, and push for greater transparency and affordability in the pharmaceutical industry.

Case study: Winning easier importation of insulin and diabetes supplies in Panama:

Photo: DiabetesLATAM and the Ministry of Health signed a MOU, signaling a partnership on behalf of those with type 1 diabetes, in September 2023. Photo Credit: DiabetesLATAM

In Panama, systemic barriers such as high tariffs and bureaucratic red tape had long hindered access to donated insulin and diabetes supplies. Recognizing these challenges, DiabetesLATAM launched a comprehensive advocacy campaign focused on both direct care and structural change. In August 2022, the organization began providing care to 30 children with type 1 diabetes, which soon expanded to over 280 participants in March 2025. Working with direct aid organizations, DiabetesLATAM supplied essential insulin and diabetes supplies while offering ongoing education, medical consultations, and patient empowerment programs. To strengthen their advocacy, DiabetesLATAM collected patient testimonies and advocated to their health ministry, calling for more change.

These community-driven efforts led to a groundbreaking milestone in September 2023 when DiabetesLATAM signed a memorandum of understanding with Panama's Ministry of Health. The agreement simplified the process for importing donated insulin, reducing bureaucratic hurdles and paving the way for broader systemic impact. Since then, the program has seen improved insulin availability, stronger relationships between patients and the public health system, and growing momentum for continued reforms. DiabetesLATAM's model is a replicable example of how local organizations can lead national change.

Limitations

We note that this survey encountered several limitations. Many people, particularly those who are otherwise marginalized, were likely under-represented due to the requirement for internet access. While in some cases, survey responses were collected by printed survey rather than electronic collection, or via interview, the vast majority of survey responses were completed by desktop, laptop, or smartphone device. Similarly, only survey respondents engaged with some level of online diabetes activities or organizations would have been aware and invited to participate in the survey. This means that intra-country income disparity was less representative and likely favored higher income households; those with support for their diabetes management and care may be over-represented in the data. Despite these challenges, our data compared to the IDF's diabetes atlas's estimate of diabetes-related expenditures being so similar to our out-of-pocket expenses survey response data country-to-country affirms that our data collection is relatively accurate (see Appendix 3).

The survey was only disseminated in five languages, limiting its reach. Additionally, our data collection did not account for additional costs such as lab work, syringes, and emergency care, which can represent a financial burden for people living with diabetes worldwide.

We recognize using the World Bank country income classification is flawed and superficial. These classifications are based solely on Gross National Income per capita which does not reflect wealth distribution or economic inequality within countries. For example, "high-income" countries may still have large populations living in poverty or with limited access to healthcare and other resources. Using data metrics such as the Gross National Income per capita does not tell us whether a country has robust public health infrastructure, universal healthcare, or insulin access programs. Different countries with the same World Bank income classification can have radically different health outcomes and access to medicines. These classifications also do not account for conflict zones, displacements, sanctions, or other political realities that impact healthcare delivery, access, and regulations.

We also acknowledge the inherent biases present in survey responses, including those introduced through question design, language framing, and response options. Certain questions may have been interpreted differently across cultural or healthcare contexts, leading to variations or inconsistencies in responses. In some cases, this resulted in incomplete or unusable data, particularly when survey respondents misunderstood definitions, skipped required fields, or provided conflicting answers. As with any self-reported survey, there is the possibility of recall bias, social desirability bias, and response fatigue, all of which could influence the accuracy and completeness of responses.

Future research

Much more research is needed related to global out-of-pocket expenses, rationing, and impacts on the lives of people with diabetes. Financing for this research should be prioritised for patient-led organizations and institutions. Here we suggest several avenues for future research. First, more data needs to be collected on people living with diabetes, including those with other types of diabetes such as type 2 diabetes, gestational diabetes, LADA, MODY, type 5 diabetes, and more. Secondly, more qualitative data from open-ended survey responses should be collected and thematically analyzed to capture the emotional, logistical, and relational toll of insulin insecurity. Third, future surveys should collect useful disaggregated demographic data, including age and gender of those with type 1 diabetes, and type of insulin and glucose self-monitoring supplies devices used, to better understand intersectional barriers to care. Fourth, more country-specific data is needed, particularly in underrepresented regions, to understand within-country inequalities and advocate for targeted national policies. Fourth, the survey should be translated and available in more languages. Lastly, research is needed to measure the health outcomes of insulin rationing over time, such as hospitalization rates and diabetes complications, to strengthen the evidence base for urgent policy reform intervention.

Photo: Demonstrators outside of Eli Lilly's headquarters in Indianapolis, Indiana, 2022.

Listen to patients

Not to Big Pharma

Survey respondent from Egypt:

الخدمة الصحية سيئة للغاية ولا تهتم بمرضى السكر، ونشعر بأن السكر ذنب علينا اقترفناه [وتشعر] بالإرهاق الدائم من ذلك. الإنسولين[أسعارها] غالية جدا[وشريط] القياس غالية جدا [و ليست] دائما متوفرة في الصيدليات.. الانسولين] والشرائط] دايما اسعارهم[اغلى] وهذا يجعلنا نشعر بعدم [الأمان] بشكل دائم . علاوة على ذلك الاسعار غالية جدا جدا جدا ولا يوجد تأمين صحي يكفلنا

The healthcare service is very poor and does not care for people living with diabetes (diabetes patients). We feel as if having diabetes is a fault we have committed, and we constantly feel exhausted from it. Insulin prices are high, and so are the prices for test strips, which are not always available in pharmacies. The prices of insulin and strips are always increasing, making us feel perpetually insecure. Moreover, the prices are extremely and incredibly high, and there is no health insurance that covers us…

CONCLUSION

Closing

The 2024 Out-of-Pocket Expenses and Rationing Survey confirms that financial and access-related barriers to insulin and diabetes supplies remain a global crisis, with devastating implications for health, equity, and survival. Despite years of activism and increased visibility, many people living with type 1 diabetes still face impossible choices between life-saving care and basic necessities. Though our survey did not cover other types of diabetes, we know that people with type 2 diabetes, and other health conditions and disabilities, are facing similar challenges accessing the medicines and care they need. The findings affirm that affordability metrics must be redefined, supply chains must be strengthened, and the right to insulin must be treated as a non-negotiable human right.

At T1International, our response is rooted in grassroots leadership, global collaboration, and strategic pressure. We act in three primary ways:

1. We run strategic advocacy campaigns that build power at the local, national, and global levels, including support for patent reform and public production of insulin.

2. We build coalitions with partners and allies, amplifying the voices of those most impacted through community-led research, trainings, and narrative-shifting media.

3. We support and train advocates—especially in low-resource settings—to lead campaigns, influence policy, and foster community solidarity for long-term change.

Above all, we believe in patient leadership. We believe that those most affected by injustice must be at the forefront of the fight for change. Having patient-led research ensures that questions that matter to patient needs are centered.

Pharmaceutical companies may claim the insulin crisis is behind us, but people who rely on insulin are still facing high costs and limited access every day. The reality doesn't match the headlines. It's time to stop the public relations spin and start taking real action—by listening to the voices of those who live with diabetes and need insulin to stay alive.

Calls to Action:

This crisis is not just a policy issue—it is a matter of public ethics and equity. T1International calls on everyone—whether you are a person with diabetes, a caregiver, a health worker, or an ally—to join the movement for #insulin4all. There are several ways to get involved:

Join us in calling for a future where insulin and glucose self-monitoring supplies are not luxuries, but guaranteed rights.

1. Join T1International's Fight for Five campaign to build a world where no one with diabetes has to spend more than 5% of their income on insulin and glucose self-monitoring supplies.
2. Write to your policymakers in support of legislative and administrative changes including patent reform, price caps, and public pharma.
3. Support grassroots organizations with advocacy strategies through volunteering or donating to sustain our community-led research and advocacy.
4. Share your story of insulin rationing to build public and political pressure.

T1INTERNATIONAL

OUT-OF-POCKET EXPENSES AND RATIONING OF INSULIN AND DIABETES SUPPLIES: FINDINGS FROM T1INTERNATIONAL'S 2024 SURVEY

Appendix 1:

Panama Fact Sheet

Introduction

An estimated 3,925 people are living with type 1 diabetes in Panama. Panama, classified as a high-income country, is facing rising rates of diabetes and a growing demand for insulin and glucose self-monitoring supplies. Yet access remains out of reach for many. An estimated 920 people living with type 1 diabetes are “missing” as they died early due to complications.

T1International’s 2024 survey shows that people living with diabetes in Panama experience high out-of-pocket expenses and frequent supply shortages. This fact sheet explores the realities of living with type 1 diabetes in Panama, highlighting affordability gaps and systemic shortcomings in the public health system. About 84% of the population is covered by the Caja de Seguro Social, a public institution responsible for managing and providing healthcare services to insured members. This may indicate comprehensive coverage. However, this survey has revealed that the lack of consistently available and affordable insulin and glucose self-monitoring supplies leads to high out-of-pocket expenses and impacts.

Panama received 192 qualified survey responses, an estimated 4.89% of total people living with type 1 diabetes. We were able to do this work because in 2020, DiabetesLATAM was founded and in response to a lack of type 1 diabetes data in the country, they invested in the design and development of a database linked to membership of the charity. For any person to participate in DiabetesLATAM’s online or in-person programmes, they must register in the database. This has given DiabetesLATAM the ability to reach 1,800 members in 15 countries online, with 63% of members living in Panama, and collect data like in this survey.

Photo: DiabetessLATAM volunteers. Photo Credit: DiabetesLaATAM

Listen to patients

Not to Big Pharma

Survey respondents from Panama

No todo el tiempo es posible tener tiras y tampoco alcanza para un sensor.

It is not always possible to get testing strips and even harder to afford a sensor.

Demasiadas caras en Panamá , viajó a otro país [para] adquirirla más barata.

They are too expensive in Panama; I travel to another country to purchase them at a lower price.

Hasta el momento las insulinas las conseguimos mediante el minsa. En casos que estos están desabastecidos la.compra en farmacia privada sale del presupuesto quincenal.

So far, we get the insulin through the Ministry of Health (MINSA). In cases where they are out of stock, purchasing from a private pharmacy comes out of our biweekly budget.

En estos momentos no tengo trabajo. Dependemos de CSS y un patrocinio de sensores del Gobierno anterior

At the moment, I don't have a job. We depend on CSS and a sensor sponsorship from the previous government.

Costs and its impacts

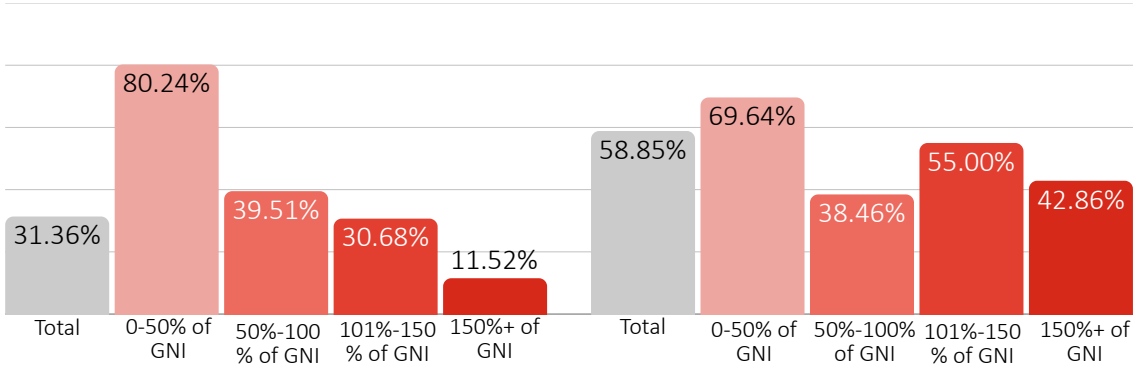
In Panama, survey respondents living with type 1 diabetes are spending, on average, $151.95 per month on insulin and $186.50 on glucose self-monitoring supplies. This totals $338.45 per month, which is about double of the IDF's estimated expenditure per person ($180.18) likely due to this just accounting for expenses per person with type 1 diabetes rather than other types of diabetes. The average monthly income is $938.67, meaning that individuals with type 1 diabetes are spending about 36% of their monthly income just to afford insulin and supplies.

However, the impact of these costs is not the same for everyone. Lower-income households in Panama are disproportionately affected. While high-income households spend an average of $544.60 per month on insulin and glucose self-monitoring supplies, low-income households (those earning between 0-50% of Gross National Income) spend $244.82 on average. But when adjusted for income, the disparity becomes clear: low-income survey respondents are spending nearly double the percentage of their income on these essential supplies compared to high-income. Specifically, low-income survey respondents are spending 80.24% of their income on insulin and glucose self-monitoring supplies, while high-income individuals are spending 11.52% (see Table 11).

Survey respondents in Panama are spending about

of their income on insulin and glucose self-monitoring supplies

Affordability burden for people living with type 1 diabetes by percentage of country Gross National Income in Panama in 2024



Percentage of income spent on insulin and glucose self-monitoring supplies

Percentage who rationed insulin or glucose self-monitoring supplies

This heavy financial burden has real consequences for people's health. The data shows that 58.85% of survey respondents in Panama have had to ration their insulin or glucose self-monitoring supplies over the past year, and an alarming 93.75% had to adjust their household budgets to afford these life-sustaining supplies. The struggle to afford basic necessities like insulin and glucose self-monitoring supplies affects the very core of daily life and puts people's health at risk.

What's more concerning is the trend over time. Looking at data from previous years, we see that while survey respondents are spending slightly less on insulin and glucose self-monitoring supplies in 2024 ($338.46) compared to 2022 ($434.30), rationing has increased dramatically. In 2022, 18.18% reported rationing insulin; by 2024, this number had jumped to 66.67%. Similarly, the percentage of survey respondents rationing glucose self-monitoring supplies has nearly doubled, from 31% in 2022 to 55.21% in 2024.

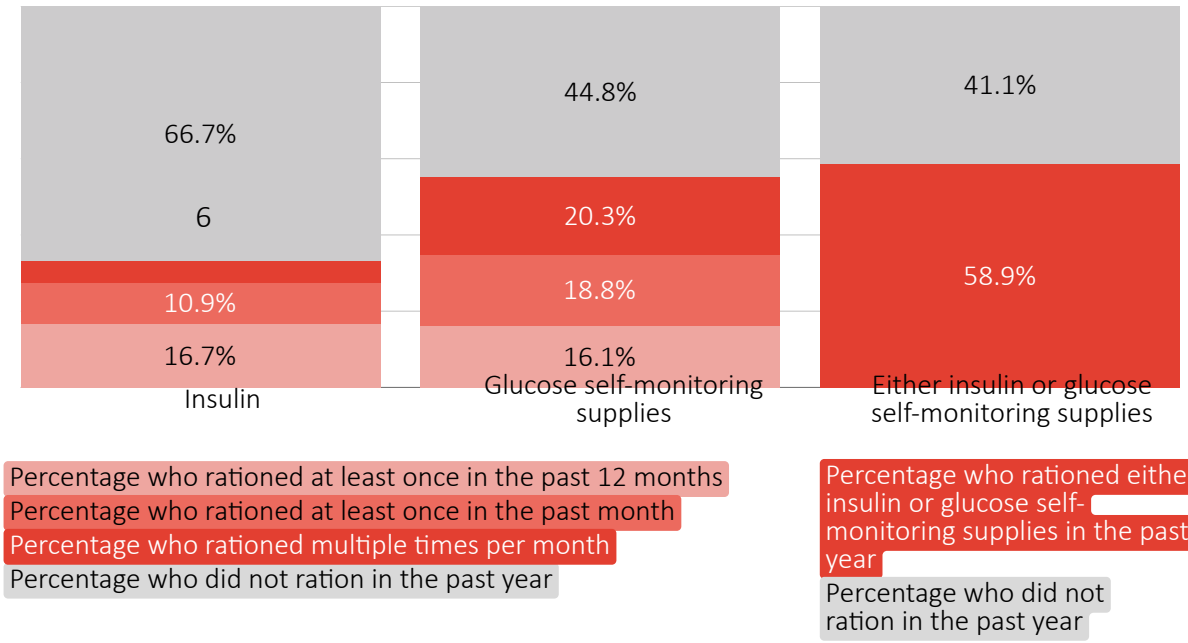
59%

of people in Panama reported having to ration either their insulin or glucose self-moniotring supplies in the past year

Rates of rationing insulin went up from 18.18% in 2022 to 66.67% in 2024

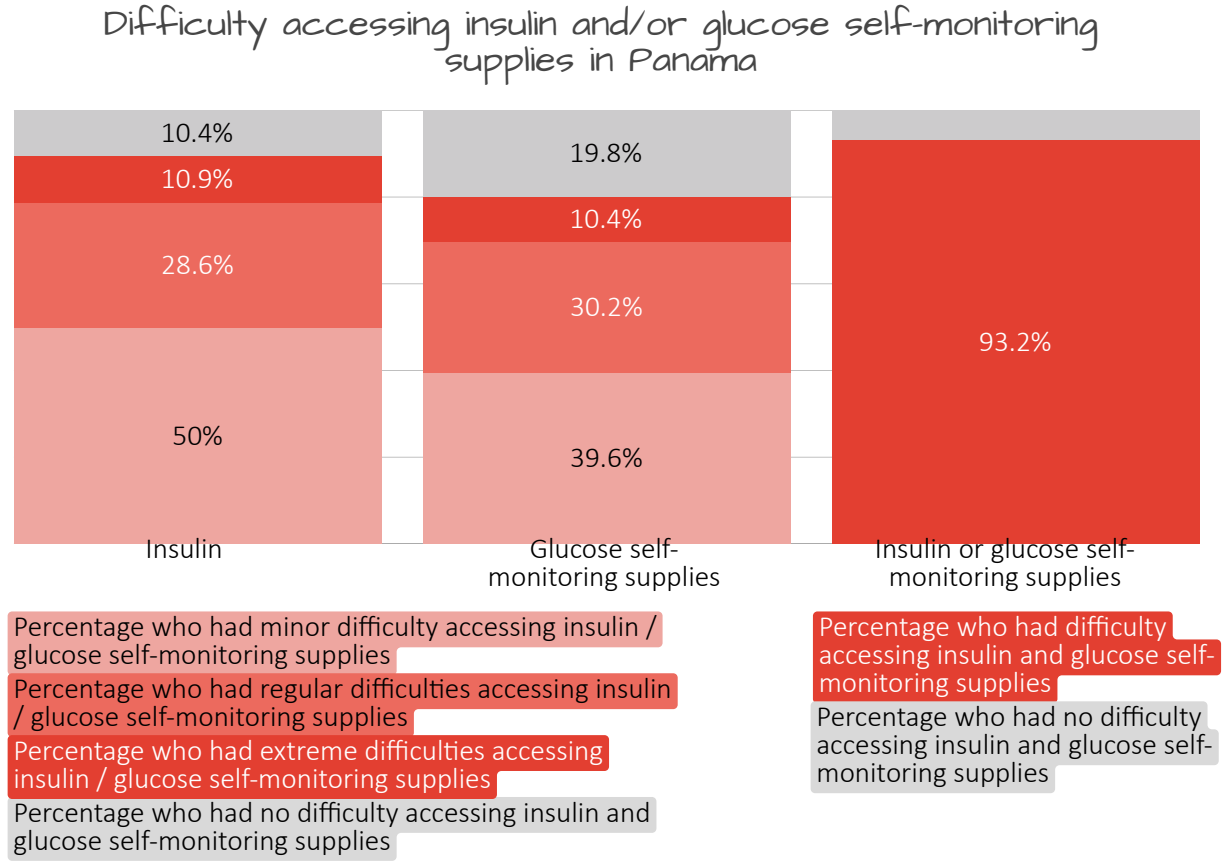
3.7x

Rationing of insulin and / or glucose self-monitoring supplies in Panama



Access to insulin and glucose self-monitoring supplies

Access to these critical supplies is also becoming more difficult. In 2024, an overwhelming 93.23% of survey respondents in Panama reported challenges in obtaining insulin and glucose self-monitoring supplies. This data shows that, despite the public healthcare system, there are still major barriers to accessing essential medications.



Conclusion

Despite having public healthcare coverage, people in Panama still face financial strain and inconsistent access to insulin. This inequality underscores the importance of not just local efforts to improve public healthcare systems but also global support. Equitable pricing, increased availability of biosimilars, and stronger regulations are necessary to ensure that people living with diabetes can access the care they need at a price they can afford. Policy change is not only possible but essential, and it must be informed by the lived experiences of those who rely on insulin to survive.

T1International

Out-of-Pocket Expenses and Rationing of Insulin and Diabetes Supplies: Findings from T1International's 2024 Survey

Appendix 2: United States of America Fact Sheet

Introduction

The United States is one of the wealthiest countries in the world, yet access to affordable insulin remains a persistent crisis. T1International's 2024 Out-of-Pocket Expenses and Rationing Survey found that high costs, inconsistent insurance coverage, and systemic patent abuse have left many people living in the United States rationing their insulin and forgoing essential diabetes care. This fact sheet highlights key findings from the survey respondents in the United States and explores the structural barriers—like lack of price regulation and fragmented healthcare—that continue to endanger lives. An estimated 1,476,859 people are living with type 1 diabetes in the United States, but an estimated 380,000 are "missing"- they would have been alive today if they hadn't died early due to complications. The United States received 199 qualified responses meaning that we could do independent analysis, including 11 or more responses in five states.

Insulin costs and its impacts

In the United States in 2024, survey respondents living with type 1 diabetes were spending on average $151.97 per month on insulin and $258.67 per month on glucose self-monitoring supplies for a total of $410.64 per month, down from $471.10 in 2022. On average, survey respondents spent 5.99% of their income on insulin and glucose self-monitoring supplies.

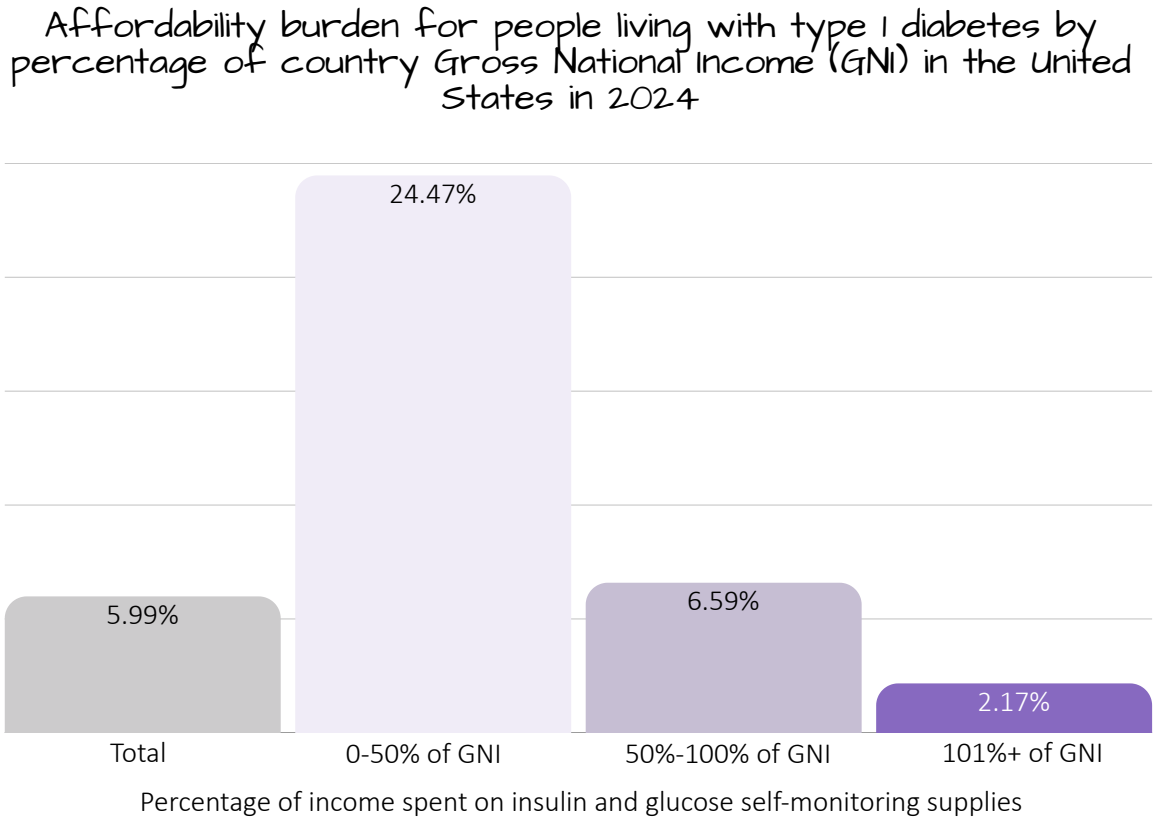
Note this is less than the estimate of diabetes-related expenditures of $874.78 per month estimated by the IDF Atlas, likely due to the fact that diabetes-related expenditures include all types of diabetes but also include other expenses including insurance costs, hospitalizations, etc. This is also different from the median spend of $50 on insulin and $100 on glucose self-monitoring supplies, likely due to the number of survey respondents spending $0 or spending $35 or less compared to the number of survey respondents with very high costs.

$411

spent each month by survey respondents on insulin and glucose self-monitoring supplies in the United States

These expenses are also less than 2022 data that showed that insulin is an extreme financial burden for over 14% of Americans who use it, consuming at least 40% of their available income.

Lower-income households are disproportionately affected, spending 22.76% of their income on insulin and glucose self-monitoring supplies compared to less than 2% spent in households at 1.5 or more times the country's gross national income (see Table 12).

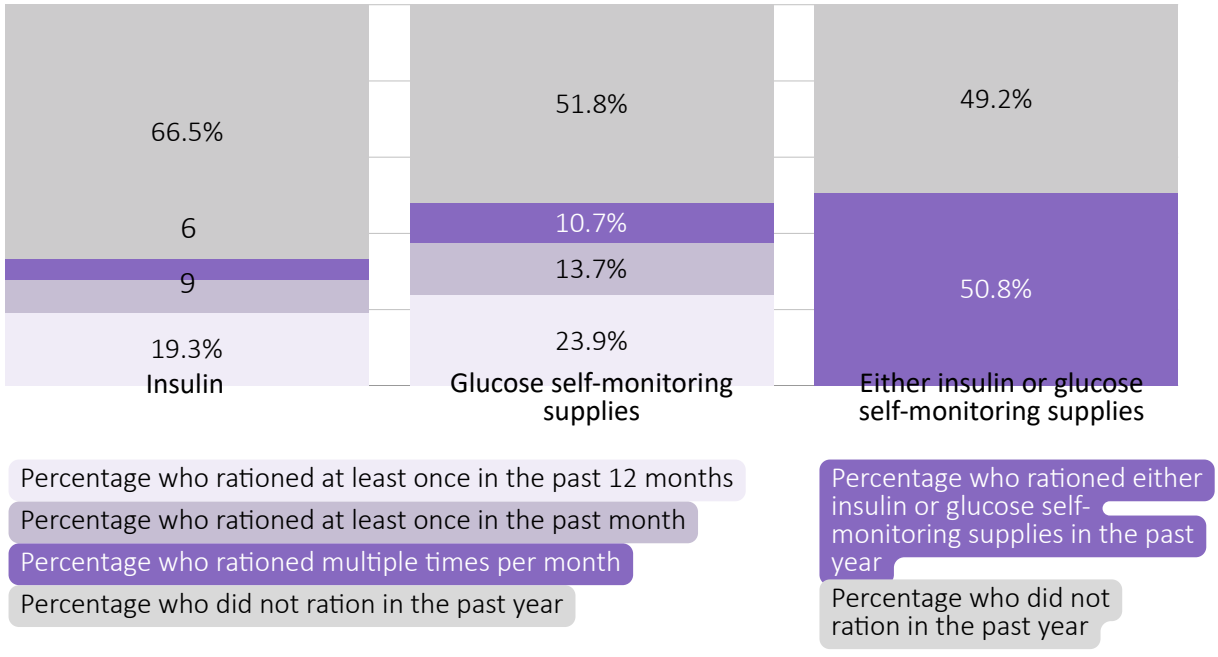


51%

of all survey respondents in the United States rationed insulin or glucose self-monitoring supplies

The consequences are dire—one in three survey respondents (33.50%) rationed insulin, and nearly half (48.22%) reported rationing glucose self-monitoring supplies in the past year.[27] In total, over half of all survey respondents (50.76%) were forced to ration either insulin or glucose supplies, putting their health and lives at serious risk. Other data shows that certain demographic groups face even higher rates of rationing, with Hispanic/Latino and Black individuals being more likely than white counterparts to resort to insulin rationing. Any rationing is unacceptable and underscores the urgent need for systemic change.

Rationing of insulin and / or glucose self-monitoring supplies in the United States

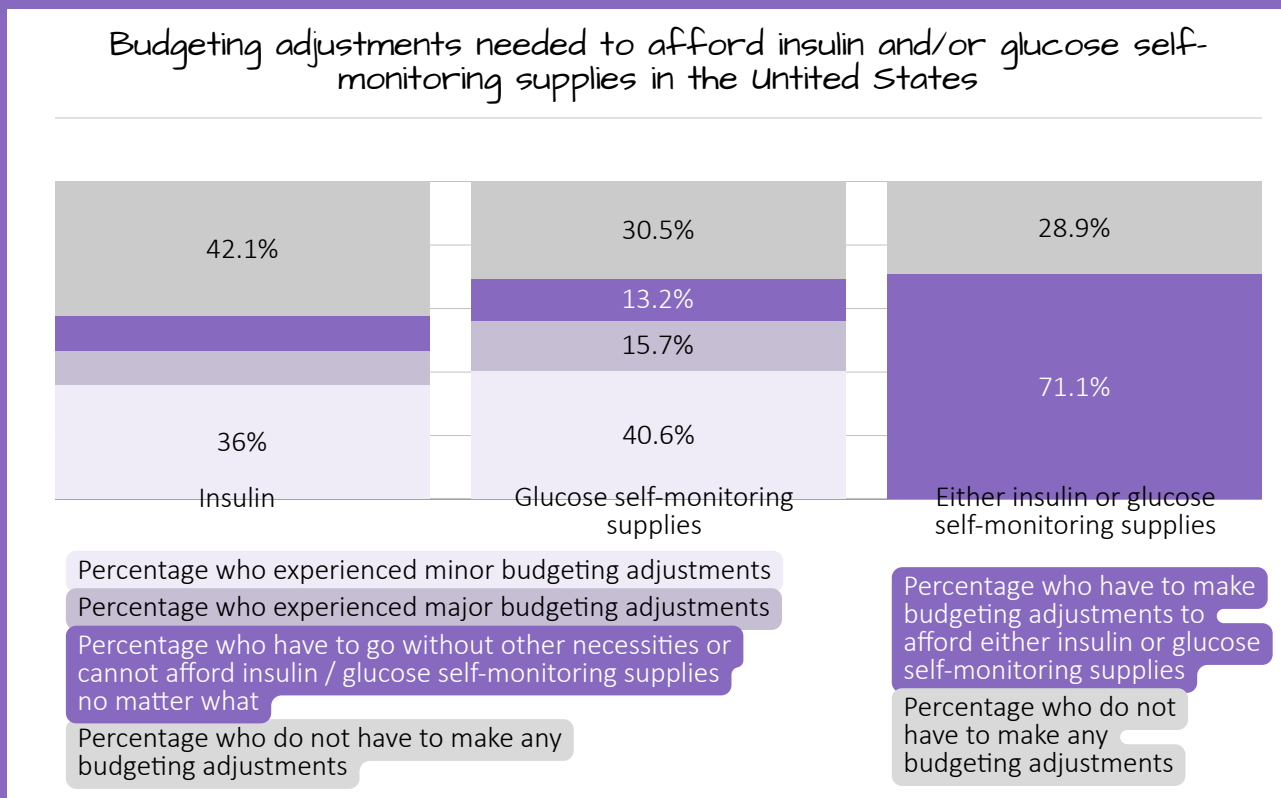


27. This number is much higher than the 20.4% reported rationing in the National Health Interview survey, likely due to the Out-of-Pocket Expenses and Rationing Survey being just for people with type 1 diabetes.

1 in 3

of all survey respondents in the United States rationed insulin last year

In addition, a total of 71.07% of people adjusting their budget to afford both insulin and glucose self-monitoring supplies.



No matter insulin and glucose self-monitoring supplies costs, access also remains a problem: 57.87% of people had difficulty accessing their insulin and 64.97% of people had difficulty accessing glucose self-monitoring supplies, for a total of 72.59% of people struggling to access their insulin or glucose self-monitoring supplies.

Despite promises by politicians and insulin manufacturers for $35 insulin, only 42.13% of people are spending $35 or less per month on their insulin prescriptions in the United States

58%

Difficulty accessing insulin and/or glucose self-monitoring supplies in the United States in 2024

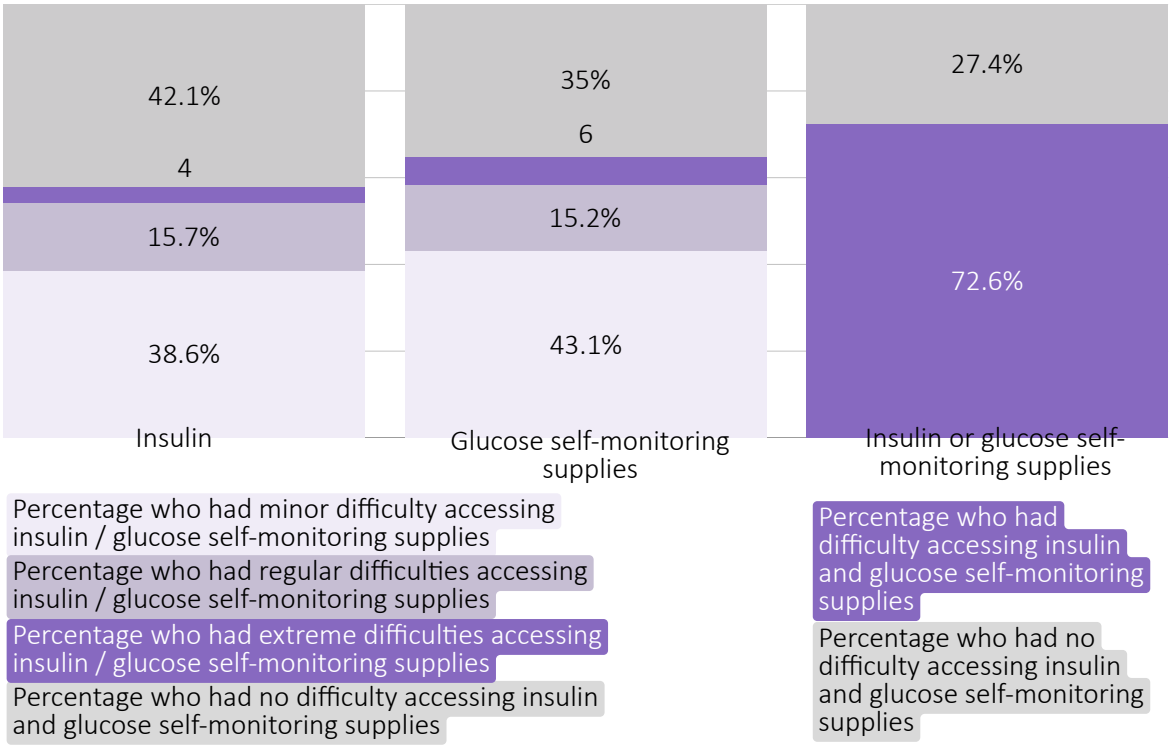


Photo: Demonstrators outside of Congress for the Global Day of Action for #insulin4all, March 2024.

Listen to patients

Not to Big Pharma

Survey respondents from the United States

When [analogue] insulin is not available, it is sometimes necessary to completely change my established protocols [and switch to human insulin]. It takes time to readjust. It is also extremely scary until a supply can be obtained.

[In] the past year, there were [occasions] when my insulin was not available. I eventually [had] to change my treatment protocol and use a different insulin with different activity profiles.

I have Medicare and even though they don't have a list of approved insulin, every time I've submitted my RX it gets rejected. But they can't tell me which one would be accepted. So my [Doctor's] office has to submit another kind of insulin and I hope it goes...

I am very thankful to have access to Costco pharmacy pricing on my diabetes supplies as well as a financial assistance program/discount card from FIASP and OmniPod. Without these programs I would never be able to afford my supplies monthly.

Since I have been on Medicare, all of my insulin and diabetes supplies have been 100% covered by insurance.

...Not being able to access the drug that keeps you alive feels like everyone in society wants you to die. Whether that's true or not, that's how it feels when you're going through that kind of thing.

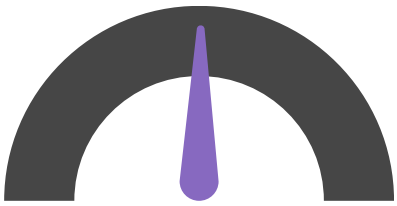
[If we had access to affordable and accessible insulin and glucose self-monitoring supplies,] we wouldn't have to choose between my diabetes care supplies and good-quality food. We would be much less stressed and wouldn't have to worry so much about whether the cost of taking care of my diabetes negatively impacts the rest of our lives.

Insulin accessibility has improved for me in the past couple of years, but the cost of CGM is crazy expensive.

Impacts of Medicare's $35 insulin copay cap

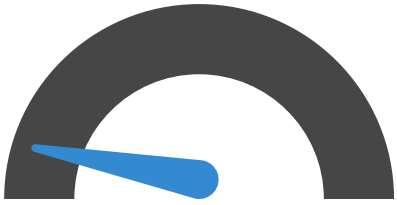
While we did not ask for the age of the persons living with type 1 diabetes, we could sort by ages for households with only one person living with type 1 diabetes. In doing so, we found that survey respondents who were 65 years old or older – those presumably on Medicare plans – paid on average $206.00 for insulin (see Table 13). This is about six times the legislated $35 insulin copay for Medicare beneficiaries. Interestingly, it is also more than the average $151.97 spent on insulin across all survey respondents in the United States, or about 4 times the manufacturers' promises).

Only 45% of presumed Medicare beneficiaries spent $35 or less on insulin per month. These are similar results to other data showing that about 150,000 Medicare beneficiaries, or about 40.60%, are not accessing $35 insulin as promised by statute. This could be because Medicare plans do not need to cover all insulin dosage forms and types, leaving some patients paying out-of-pocket.



Average cost of insulin for Medicare beneficiaries: $206.00

Average cost of insulin in the United States: $151.97



Promised price of insulin for Medicare beneficiaries by the U.S. government and promised cost of insulin by insulin manufacturers: $35.00

Copay Cap Analysis

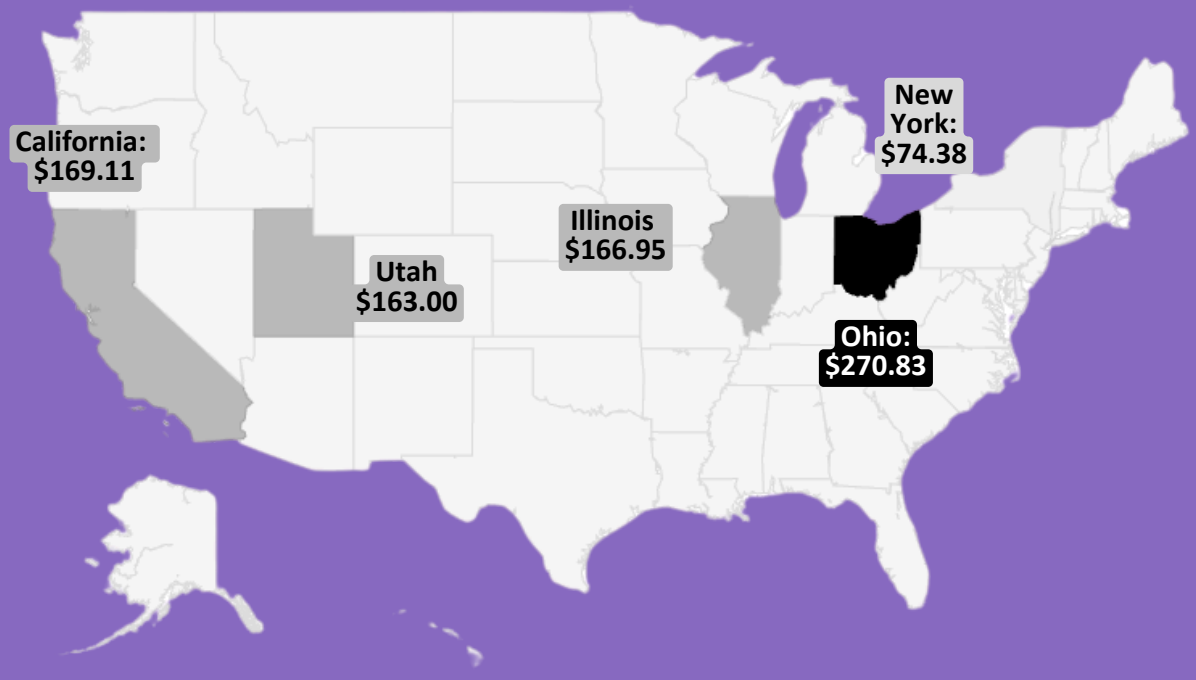
In certain states, we had eleven or more qualified responses, allowing us to look more closely at the data in each state (see Table 14). States where insulin copay cap policies were in effect had patients spending en par or slightly less than U.S. averages, but none were spending an average close to the statutory amount.

In Utah, where there is HB207, the Utah Insulin Savings Program, people should get insulin for $30 per prescription per month. There, survey respondents are paying on average over five times more, at an average cost $163.00 per person on insulin.[28] In addition, Utahans are reporting spending $220.00 on glucose self-monitoring supplies, totaling 17.57% of their income.

In Illinois, where state employees should only have to pay $100 per insulin prescription due to the passage of SB0667 in 2019,[29] survey respondents are paying on average about 66% more, averaging spending $166.95 per month on insulin copays. Also in Illinois, continuous glucose monitors must be covered by insurance for people with diabetes; survey respondents are spending on average $261.18 on glucose self-monitoring supplies. This totals to $428.14 per month on insulin and glucose self-monitoring supplies, amounting to 11.19% of each person's income.

$30 is how much people in Utah should be spending on insulin each month, yet they are paying on average $163

Insulin costs in certain US States



In New York, where law S7506 allows for $100 per insulin prescription per month, survey respondents are spending on average $74.38 on insulin. This law appears to be working.[30] However, survey respondents are spending more than $100 on their glucose self-monitoring supplies, coming in on average at $127.38 per month for a total of 2.37% of their income on insulin and glucose self-monitoring supplies.

While the laws in Utah, Illinois, and New York undoubtedly support many people living with diabetes to afford their insulin and glucose self-monitoring supplies, much more must be done to ensure full enforcement and to ensure that everyone is covered: state laws only apply to state regulated plans and those without insurance are left with no regulated recourse.

In California, the state is working on publicly producing insulins for $30 per month per prescription. The implementation of this law cannot come soon enough; Californians with type 1 diabetes who filled out the survey are paying more than five times that promise, shelling out $169.11 per month on insulin on average. Meanwhile, survey respondents are spending much more on glucose self-monitoring supplies, at $437.14, totaling over $600 per month spent, which is 18.96% of their reported income. Perhaps the state of California can invest in publicly manufacturing glucose self-monitoring supplies as well.

Moreover, data suggests that states that do not have any insulin cost retention measures in place are paying the highest cost for their insulin. In Ohio, there are no laws containing costs of insulin and survey respondents spent on average $270.83 on insulin, almost double the other states where we have this data. Overall, Ohioans are paying on average $179.17 on average for glucose self-monitoring supplies, totaling 12.51% of their income.

Conclusion

The data make one thing clear: affordability is not just a low-income country issue. In the U.S., policy failure, not a lack of resources, is to blame. T1International calls for a federal price cap, not just copay caps, that guarantees affordable insulin for all, including those without insurance. Emergency access laws like Alec's Law and Kevin's Law are crucial stopgaps, but the long-term solution must address the root causes of unaffordable insulin—monopoly power and a broken patent system.

28. This is significantly more than another study reporting insulin costs at $27 per patient per month under this policy, under the $30 cap.
29. HB 2189 passed in 2023 will lower copays to $35 per month but the policy will not go into effect until July 1, 2025.
30. In addition, starting in 2024 for state-regulated health insurance plans, people should be spending $0.

T1INTERNATIONAL

OUT-OF-POCKET EXPENSES AND RATIONING OF INSULIN AND DIABETES SUPPLIES: FINDINGS FROM T1INTERNATIONAL'S 2024 SURVEY

Appendix 3:

World Health Organization Fact Sheet

Introduction

The fifth World Health Organization's (WHO's) Global Diabetes Coverage Target goal is that 100% of people living with type 1 diabetes have access to affordable insulin and glucose self-monitoring supplies. T1International advocated that the World Health Organization define affordable as: insulin and glucose self-monitoring supplies make up 5% or less of a person's income in any given country.

In November 2024, the WHO came out with its metric of affordability for insulin and glucose self-monitoring supplies. They defined affordable as: when the sum of the national poverty line and out-of-pocket expenses of insulin and glucose self-monitoring supplies does not exceed the minimum wage of the lowest-paid government sector worker. This metric has been measured using three proxy indicators according to the global diabetes monitoring framework including (i) the inclusion of insulin, insulin delivery devices and blood glucose self-monitoring in the national health benefit package; (ii) affordability of insulin, insulin delivery devices and blood glucose self-monitoring; and/or (iii) availability of core medicines, which for this target would be insulin.

However, real-world data suggest that the survey data is largely accurate and most appropriately defines affordability for people with diabetes around the world, as evidenced by our survey responses and data from the 2025 IDF Atlas.

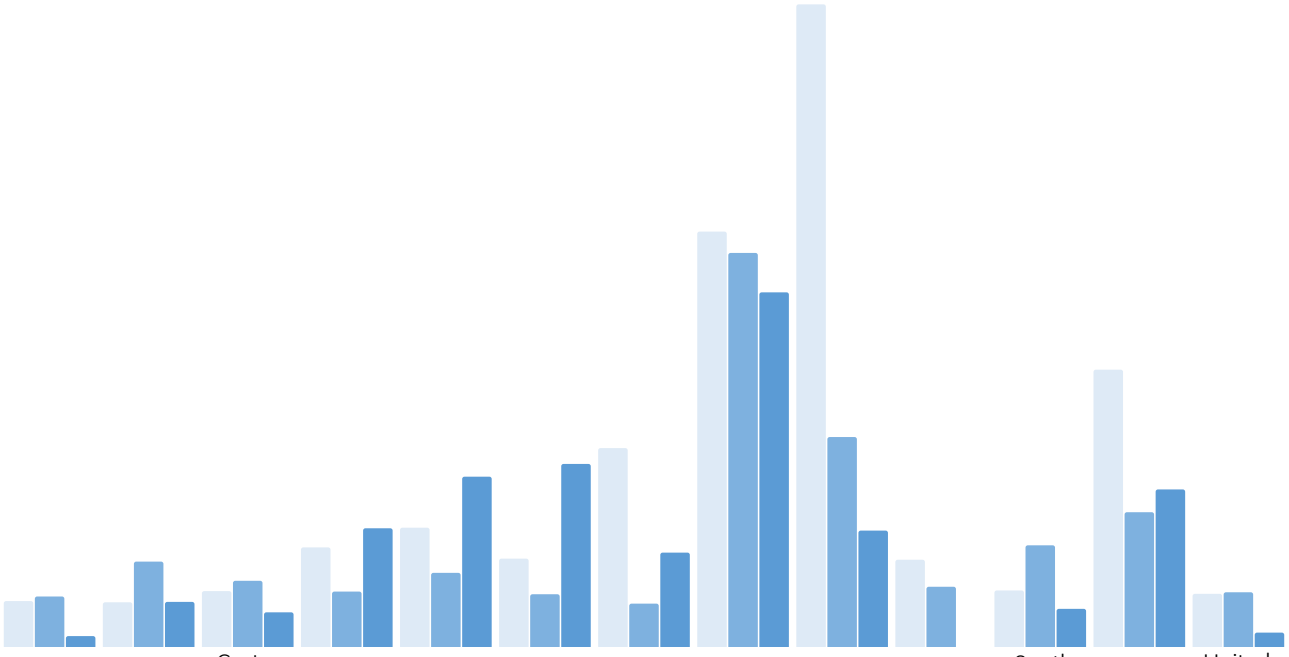
Methodology

Our survey data had 11 countries where we had 11 or more survey responses. We estimated the WHO metric of insulin and glucose self-monitoring supplies affordability (national poverty line and out-of-pocket expenses combined as less than the salary of the lowest-paid government sector worker, hereafter, "Affordability Index") for each country using the most recently available National Poverty Line and lowest paid government sector worker salary data. We then used data from T1International's 2024 Out-of-Pocket Expenses and Rationing Survey and the 2025 IDF Atlas (see Table 15). All conversions were made using most recently available World Bank conversion data and calculated to monthly units.

Discussion

Guatemala's Affordability Index (1.516 for our survey response data and 0.902 for IDF data) is quite close to Panama's (1.497 for our Survey data, 1.031 for IDF data), but in Guatemala, survey respondents are spending more than double as a percentage of their income on insulin and glucose self-monitoring supplies (78.87% in Guatemala compared to 36.06% in Panama). Other comparative data is more similar: in Panama, 93.75% of survey respondents had to make budgeting adjustments while in Guatemala, 100% of survey respondents had to make budgeting adjustments to afford their insulin and glucose self-monitoring supplies. Guatemala would be considered an affordable country using the IDF Atlas data.

Comparison of percentage of income spent on insulin and glucose self-monitoring supplies to World Health Organization's Affordability Index from survey data and IDF Diabetes Atlas data



	Canada	Colombia	Costa Rica	Egypt	Ghana	Guatemala	India	Nigeria	Pakistan	Panama	South Africa	Tanzania	United States
World Health Organization's Affordability Index using T1International Out-of-Pocket Expenses Survey Data	.784	.763	.956	1.714	2.050	1.516	3.42	7.158	11.078	1.497	.967	4.776	.909
World Health Organization's Affordability Index using IDF Diabetes Atlas Data	.863	1.465	1.134	0.948	1.271	.902	0.740	6.790	3.615	1.031	1.746	2.317	.936
Percentage of income spent on insulin and glucose self-monitoring supplies	4.4%	19.2%	14.8%	51.1%	73.3%	78.9%	40.6%	152.8%	50.0%	31.4%	16.2%	67.7%	6.0%

Photo: #insulin4all demonstrators outside of Eli Lilly in 2022.

In Tanzania, Ghana, and Guatemala survey respondents are spending about 70% of their income on insulin and glucose self-monitoring supplies (67.68% in Tanzania, 73.34% in Ghana, and 78.87% in Guatemala) according to our survey. However, their Affordability Indexes vary widely from 1.516 in Guatemala to 2.050 in Ghana to 4.776 in Tanzania. Using the IDF Atlas data, the Affordability Index offered a similar variety from affordable (0.902) in Guatemala, to 1.271 in Ghana, and 2.317 in Tanzania. Again, these three countries were spending about 70% of their income on insulin and glucose self-monitoring supplies.

Similarly, Pakistan and India both have survey respondents spending a similar percentage of their income on insulin and glucose self-monitoring supplies (40.20% in India and 49.95% in Pakistan) but have very different Affordability Indexes - 3.423 in India using our survey data and 0.740 if using IDF Atlas data, and 11.078 in Pakistan, or 3.614 if using IDF Atlas data.

According to our survey data, the Affordability Index, Colombia (0.763) should have more affordable insulin than Canada (0.784). (If using the IDF Atlas data, the range is slightly further with Canada at 0.863 and Colombia at 1.465.) Canada's data indicates that their insulin and glucose self-monitoring supplies would be affordable compared to T1International's metric of 5% or less of a person's income (4.42%) as well. But in Colombia, survey respondents are spending 19.16% of their self-reported income on insulin and glucose self-monitoring supplies.

According to the WHO Affordability Index, South Africa also has affordable insulin and glucose self-monitoring supplies (.967); this number rises to 1.746 if using the IDF Atlas data. Yet survey respondents are spending 16.18% of their income on insulin and glucose self-monitoring supplies and 100% of people who took the survey have to make budgeting adjustments to afford their necessary medications and supplies.

According to the WHO Affordability Index, the United States is almost an affordable country (.936 using survey data, 1.162 when using IDF Atlas data) when it comes to insulin. Additionally, survey respondents reported spending 5.99% of their income on insulin and glucose self-monitoring supplies. However, 50.76% have rationed insulin and glucose self-monitoring supplies in the past year. Additionally, 71.07% of survey respondents had to make budgeting adjustments to afford their insulin. These metrics do not indicate the affordability and accessibility of insulin and glucose self-monitoring supplies in an almost-affordable country.

While there is some alignment between more and less affordable insulin and glucose self-monitoring supplies between T1International's measures and the WHO's metrics, it is clear from T1International's survey data that insulin and glucose self-monitoring supplies are more unaffordable for more countries and larger portions of the population than WHO's metrics purport.

Limitations:

The WHO's Affordability metric has limitations that weaken its utility and credibility as a gold standard. The WHO does not provide data on countries' National Poverty Line, Lowest Paid Government Sector Worker, and more. In many countries, the lowest-paid government sector worker data is outdated, inconsistently applied, or not publicly reported at all. The lowest-paid government sector worker data also does not take into account places where this income may be remarkably different from average wages or other more commonly used wage schemes like minimum wage for private sector workers. Furthermore, the metric fails to reflect how household income is distributed when multiple family members rely on essential medicines, or how affordability is impacted by common barriers like informal market costs, supply shortages, or transportation expenses.

The WHO also does not define how out-of-pocket expense data are collected or validated. The recently published 2025 IDF Atlas attempts to estimate out-of-pocket expenses by extrapolating ratios of WHO Global Health expenditure data from 2022 on health expenditure in both US Dollars (USD) and International Dollars (ID). But these figures are modeled estimates, combining all types of diabetes, rather than grounded in real-world, self-reported costs for people specifically living with type 1 diabetes.

While modeled data like the IDF Atlas provides useful global estimates, the strong alignment between their projections and the findings of T1International's Out-of-Pocket Expenses and Rationing Survey strengthens the credibility and reliability of our grassroots survey methods. Despite differences in methodology—one using economic modeling from existing datasets, and the other relying on self-reported data from people with type 1 diabetes—both sources point to the same alarming trends: that people across income levels and regions are experiencing severe financial burdens to afford essential diabetes care. This convergence indicates that T1International's patient-centered, community-informed survey design captures real-world conditions with accuracy, reinforcing the importance of incorporating lived experience into global data systems. Our findings are not only consistent with established global frameworks, but they also provide critical nuance and detail that top-down models often miss.

Without a clear, participatory, and patient-centered data collection, affordability metrics risk becoming disconnected from the daily realities people face. Countries can be classified as having "affordable" insulin and glucose self-monitoring supplies while individuals there report spending 30%, 50% or even 100% of their income to stay alive. To genuinely advance health equity, the WHO must urgently revise these affordability frameworks in partnership with affected communities. This should include meaningful, real-world affordability thresholds – such as spending no more than 5% of household income on insulin and diabetes care – and the use of transparent, publicly accessible methodologies rooted in patient-reported lived experience data. Without this, essential medicine access metrics will continue to fail the very people they are meant to protect.