



IT'S NOT OVER

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

Agenda:

- Welcome and introductions
- History and methodology
- Results:
 - High Costs
 - Rationing
 - Access
- Limitations and future research
- Acknowledgements
- Q&A





Our Vision

A world where everyone with diabetes – no matter where they live – has everything they need to survive & achieve their dreams.

Our Mission

To support local communities by giving them the tools they need to stand up for their rights so that access to insulin and diabetes supplies becomes a reality for all.

We stand up for affordability and accessibility and are fighting for an end to the insulin price crisis. We do not accept funding from pharmaceutical companies or any organization that would compromise our ability to advocate for #insulin4all.

History

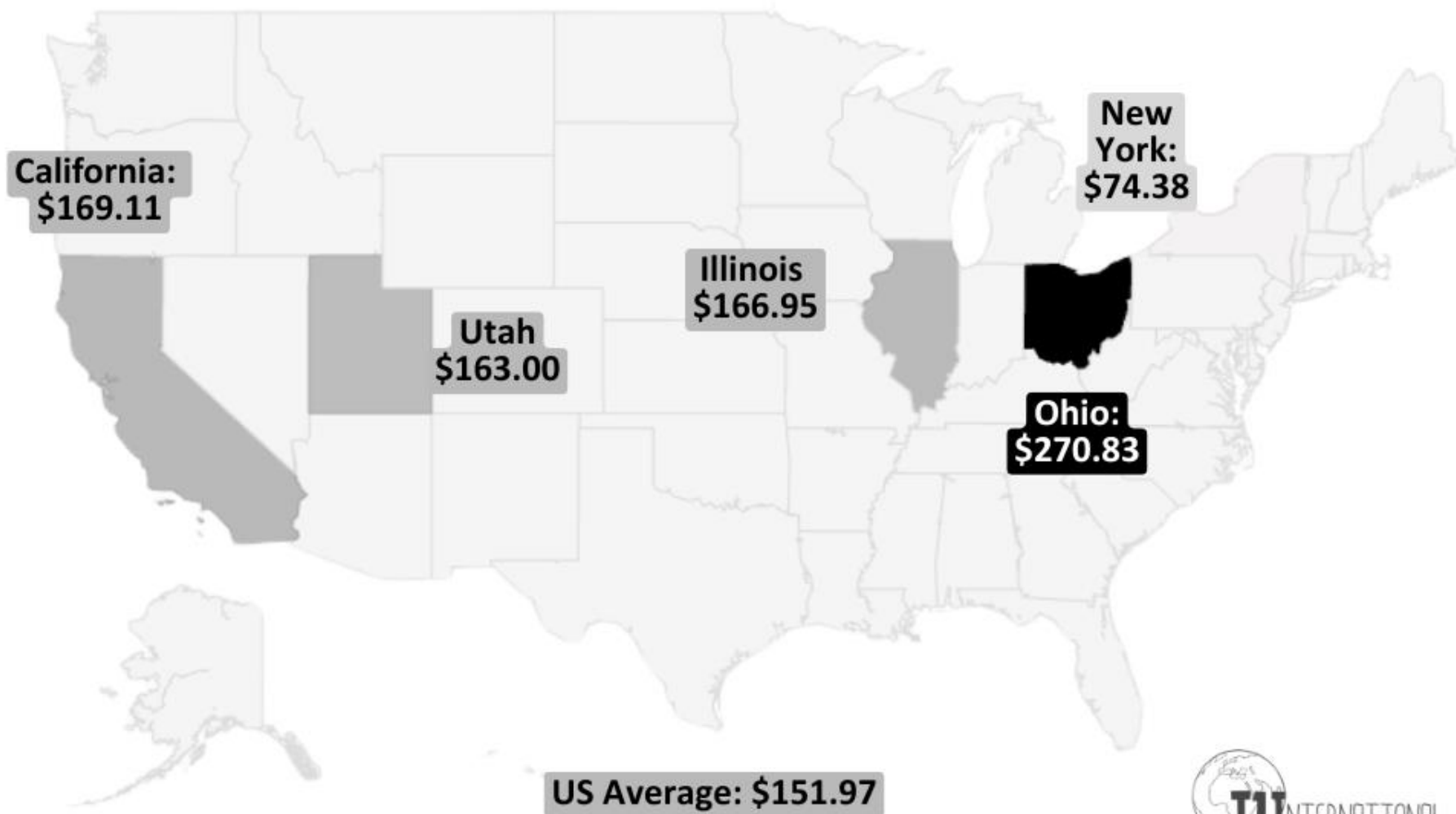
- Bi-annual reports since 2016
- 2020 and 2022 were peer-reviewed and published in scientific journals

Methods

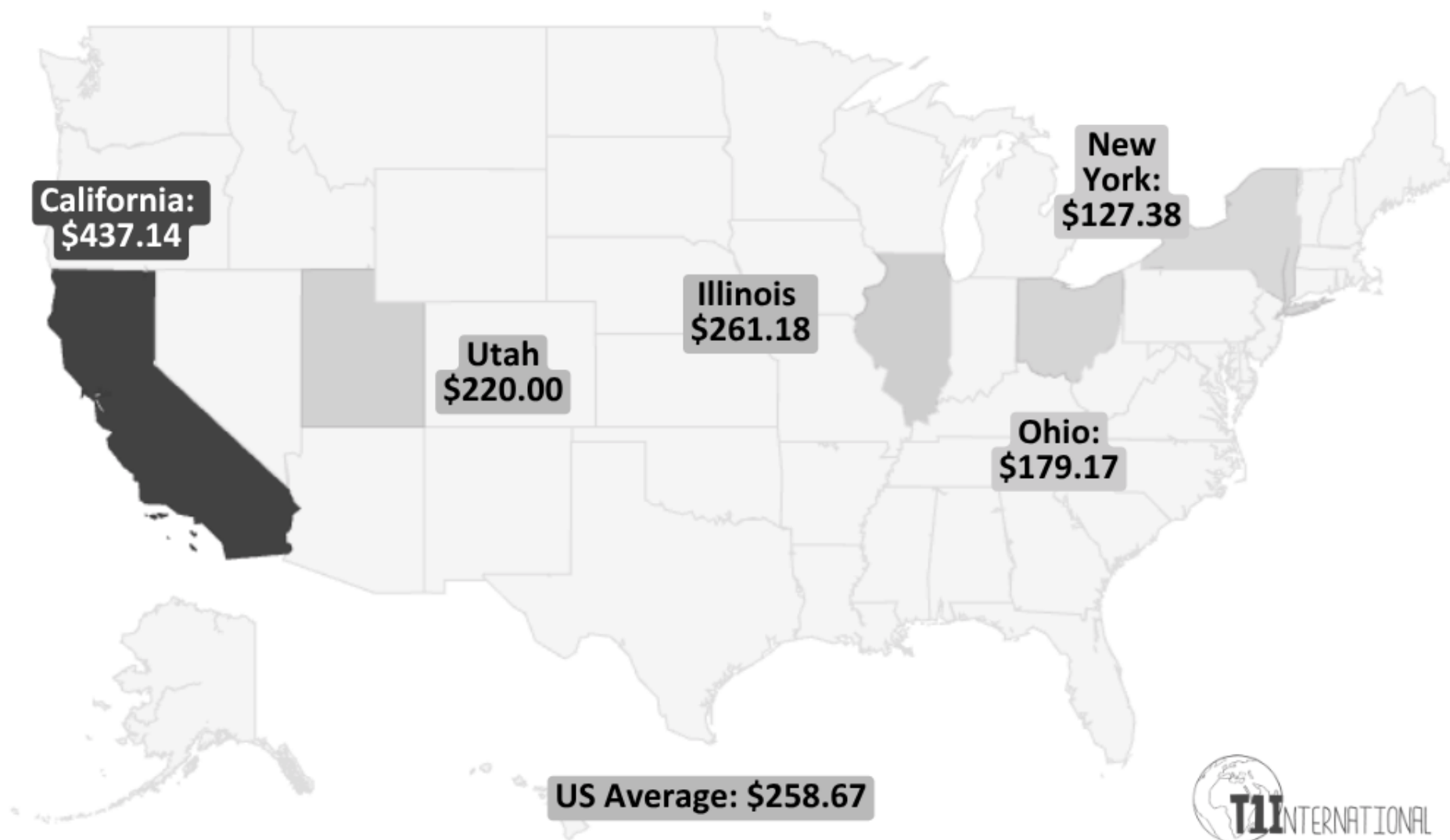
- Over 1,000 respondents
- Respondents from 55 countries
- Survey offered in 5 languages
- Just for people with type 1 diabetes



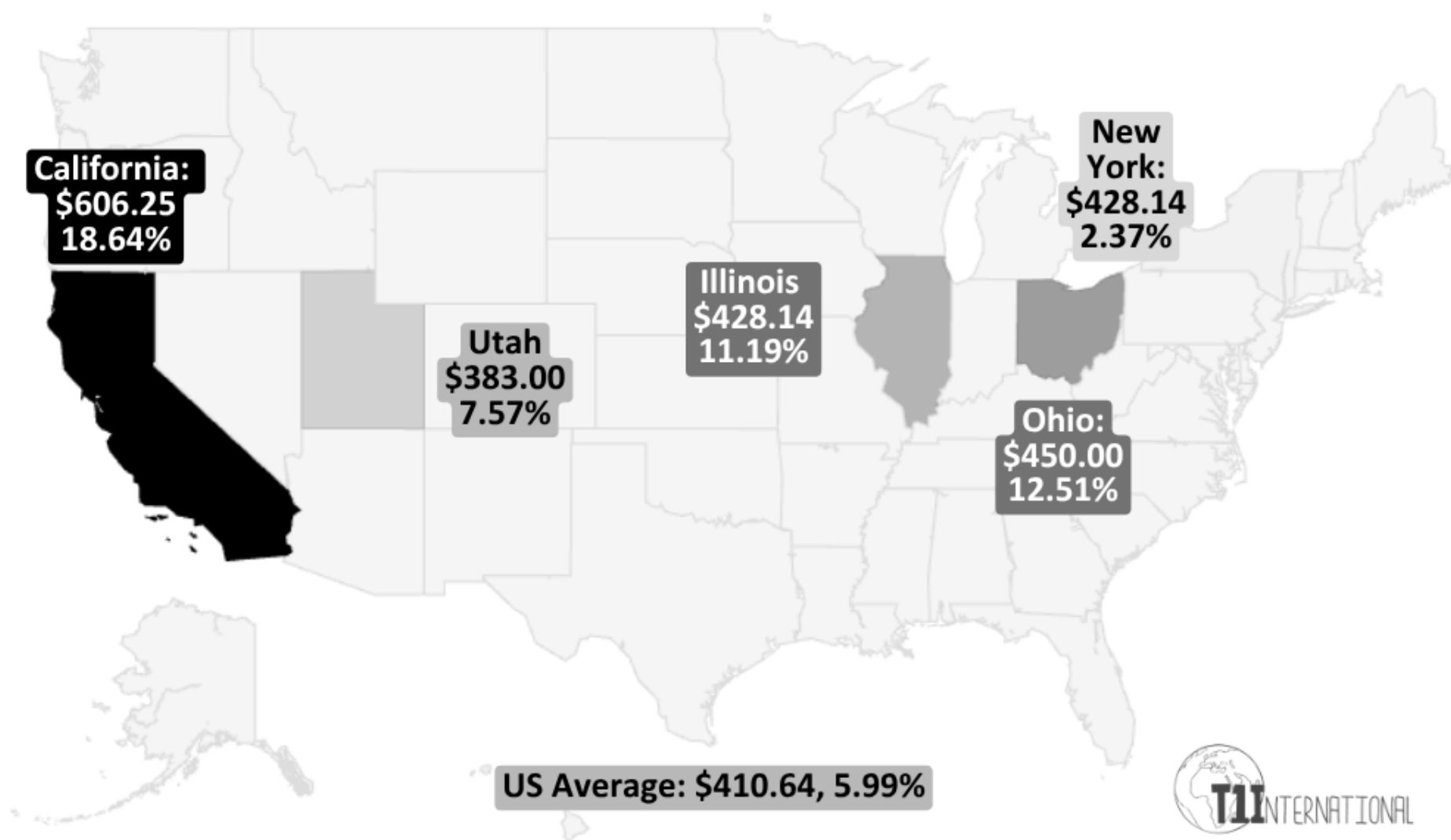
Average monthly out-of-pocket insulin expenses per person living with type 1 diabetes in certain US states



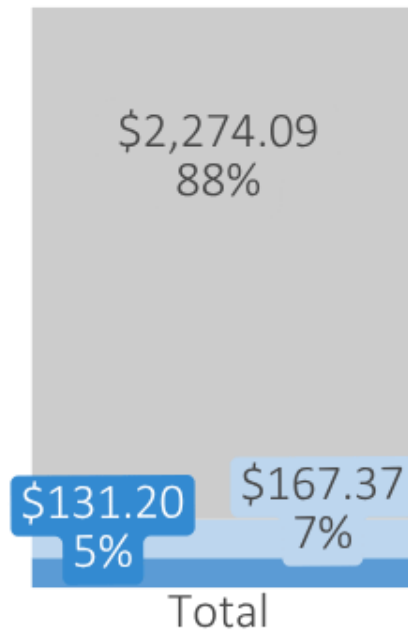
Average monthly out-of-pocket glucose self-monitoring expenses per person living with type 1 diabetes in certain US states



Average total monthly out-of-pocket insulin and glucose self-monitoring expenses and percentage of monthly income per person living with type 1 diabetes in certain US states



Costs

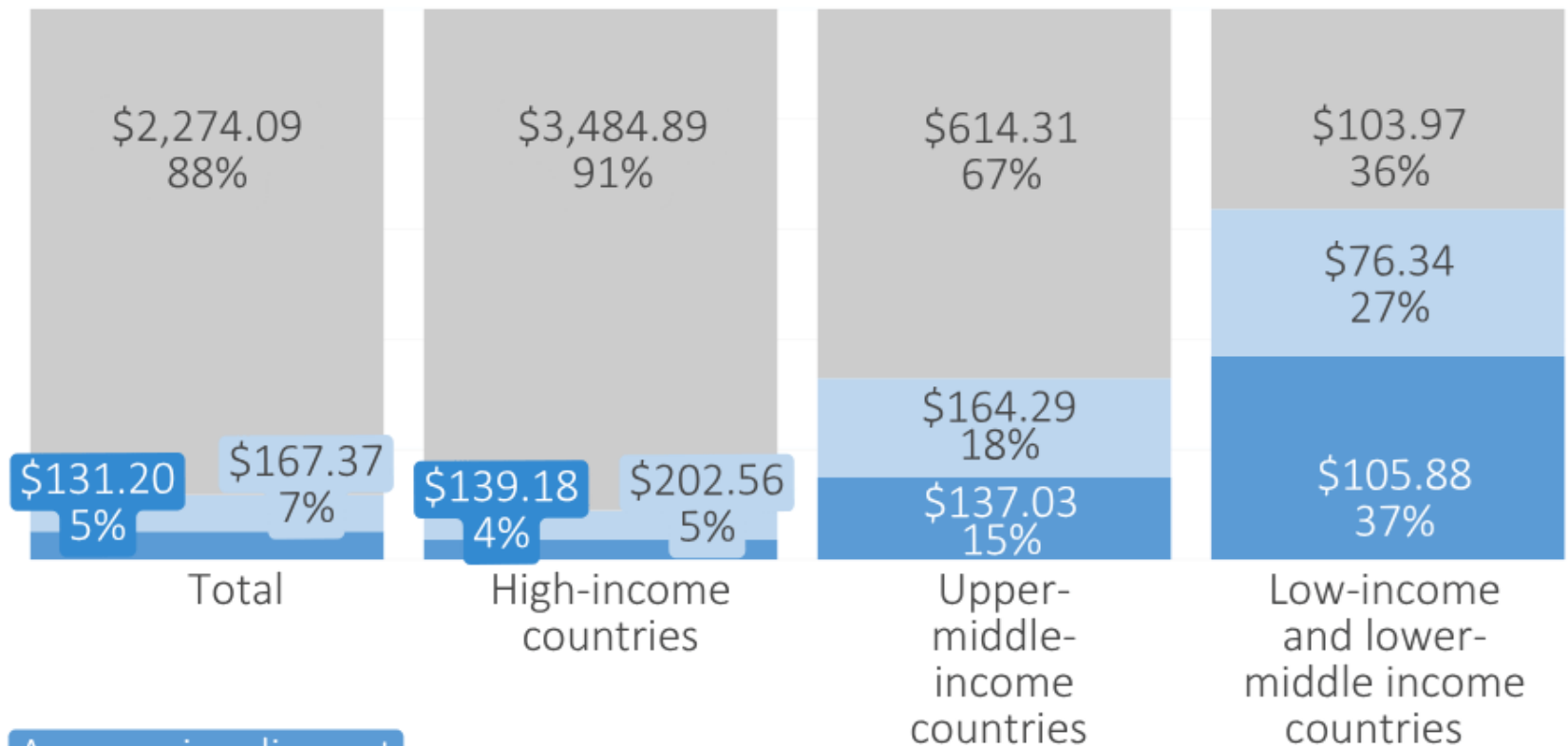


Average insulin cost

Average glucose self-monitoring cost

Average income not spent on insulin and glucose self-monitoring supplies

Costs

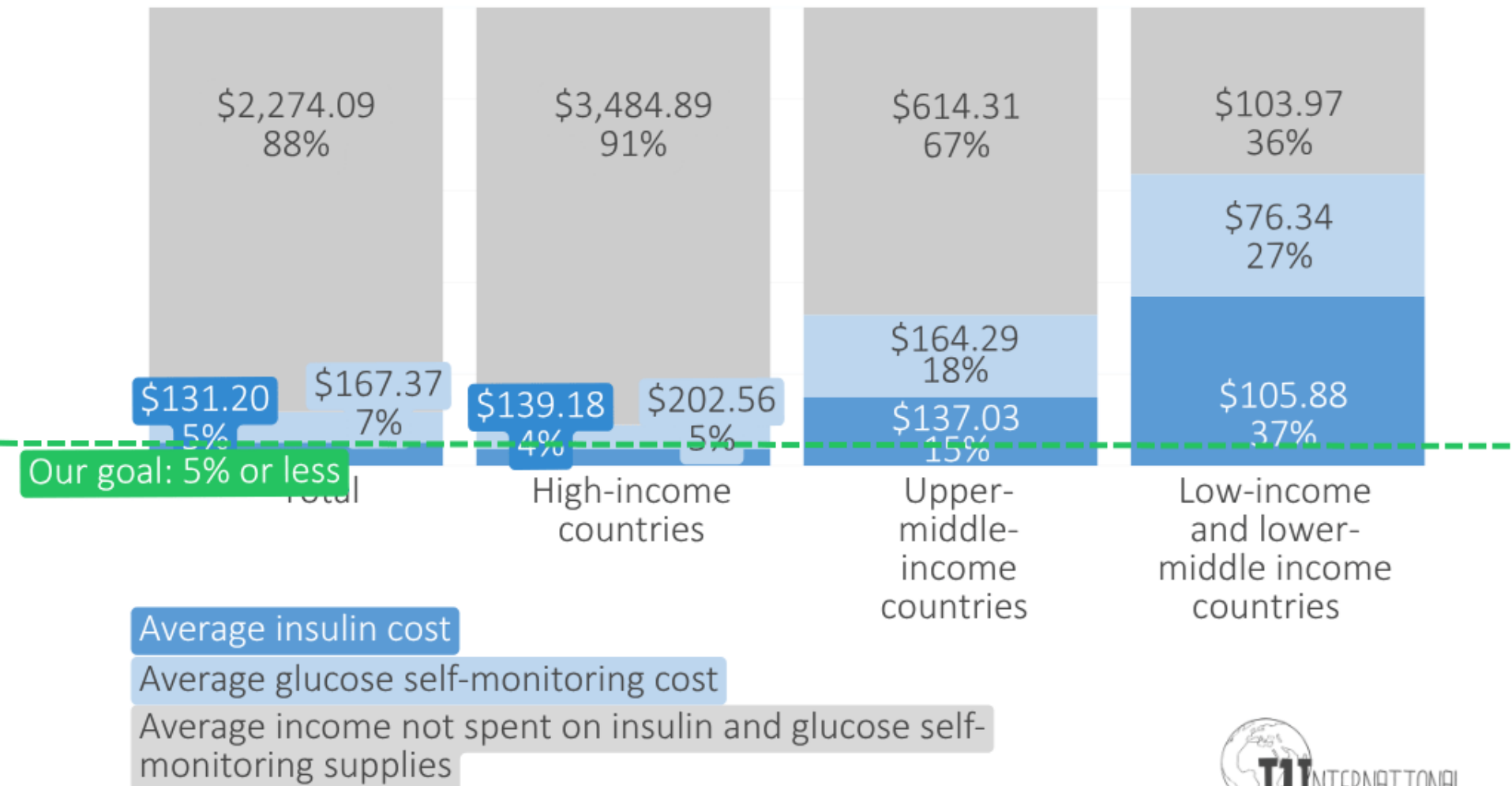


Average insulin cost

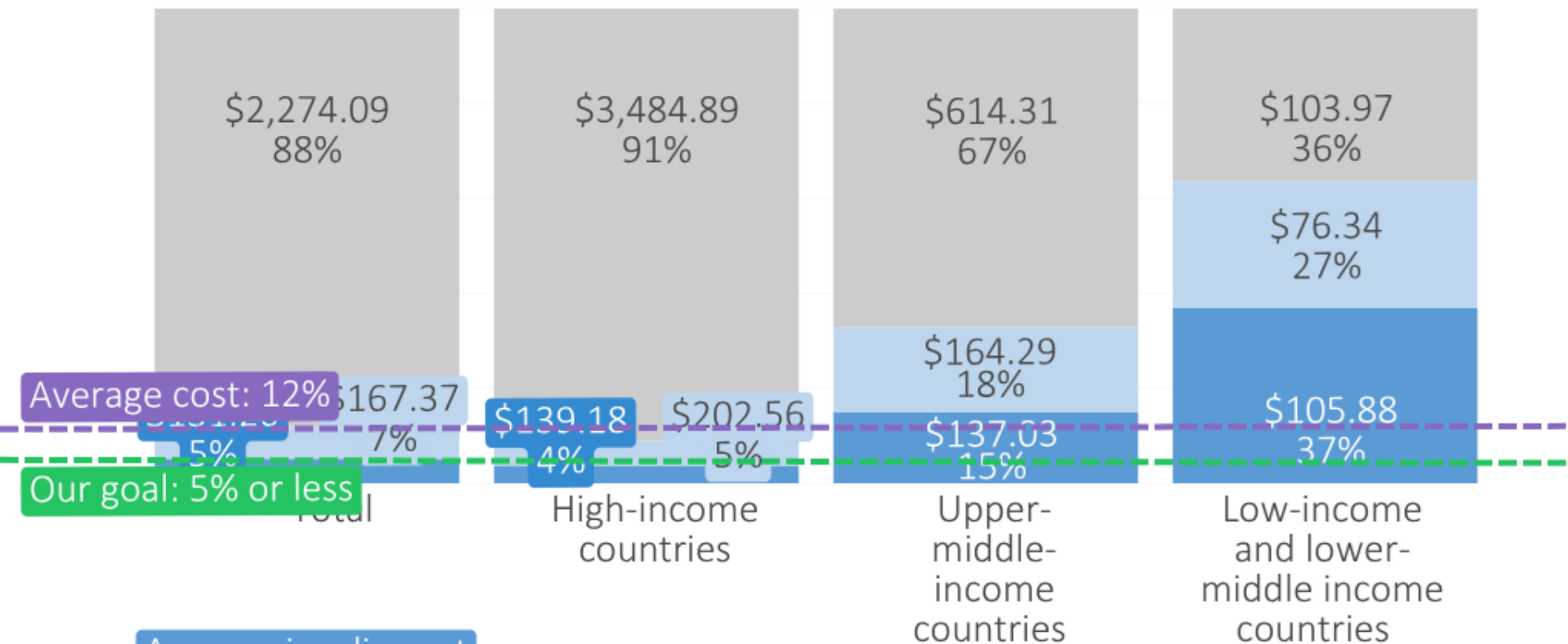
Average glucose self-monitoring cost

Average income not spent on insulin and glucose self-monitoring supplies

Costs



Costs

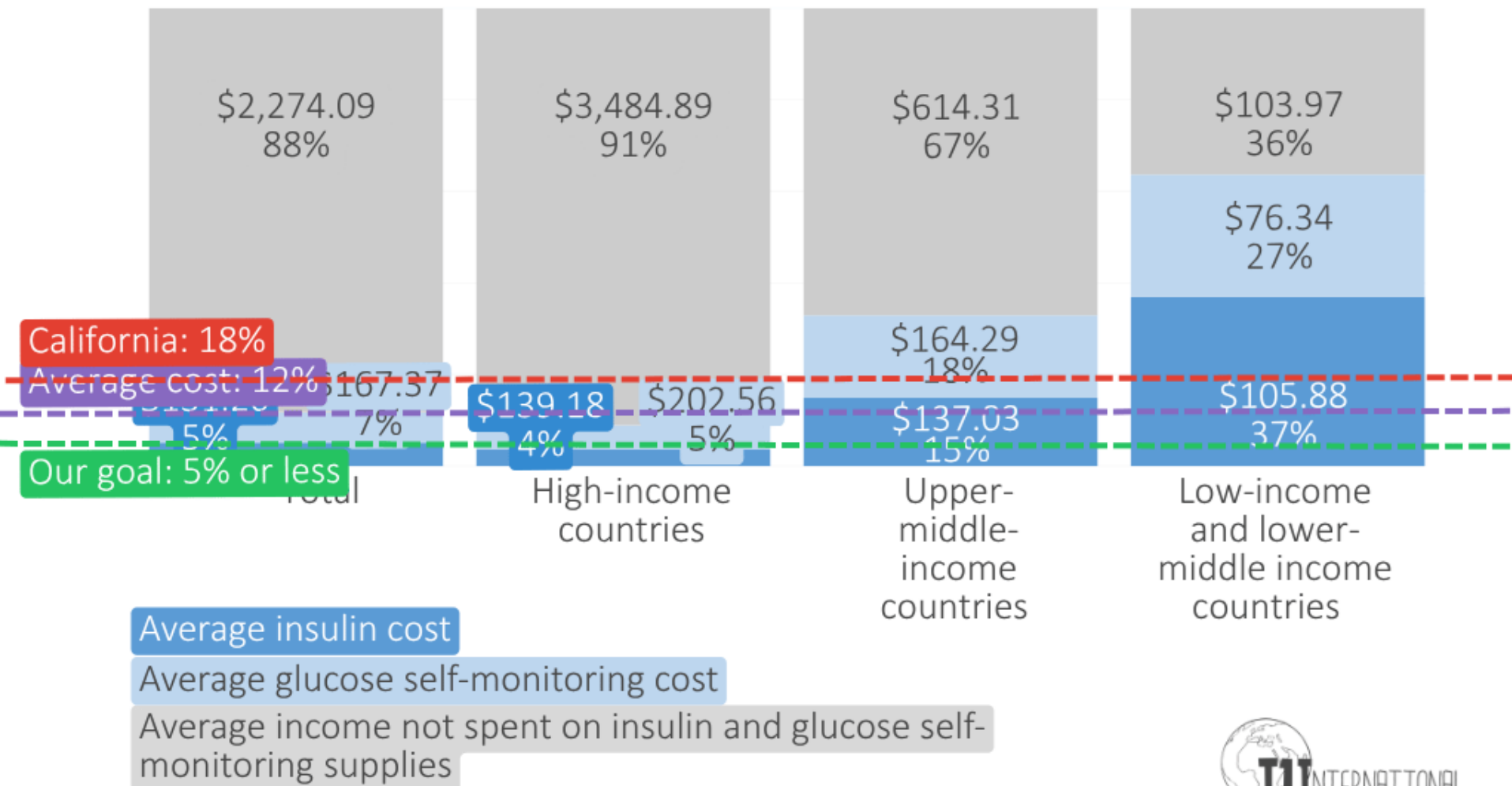


Average insulin cost

Average glucose self-monitoring cost

Average income not spent on insulin and glucose self-monitoring supplies

Costs



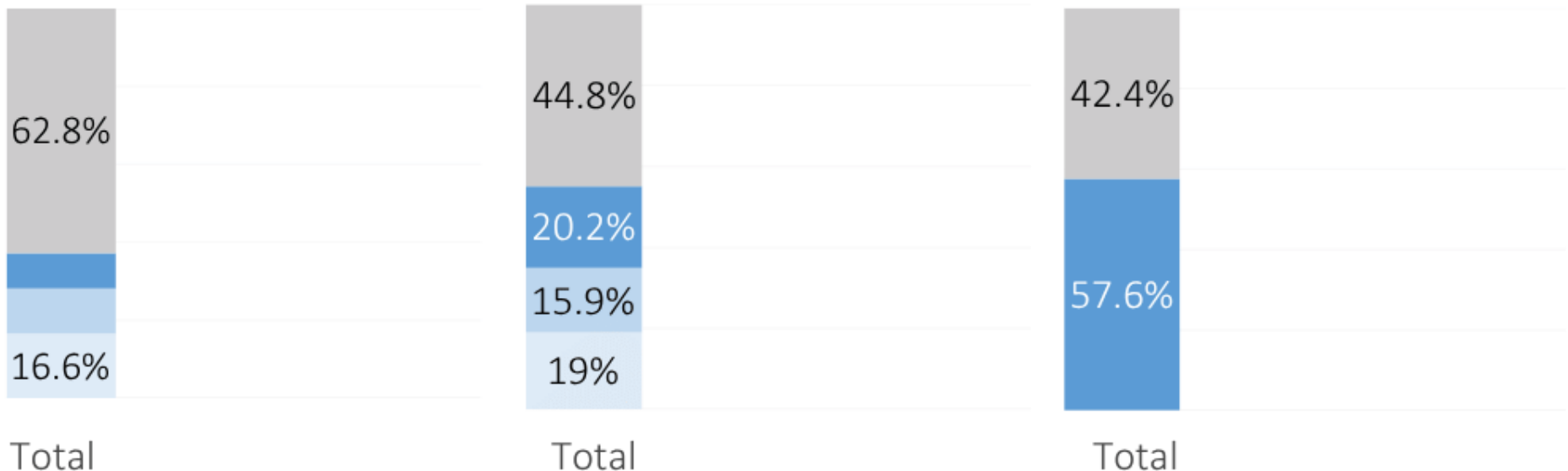
Rationing

How frequently were any of the following true: someone in your household skipped or delayed taking an insulin dose or delayed purchasing insulin in order to save money?

How frequently were any of the following true: someone in your household skipped or delayed testing their glucose, or delayed purchasing blood glucose testing or monitoring supplies (such as sensors for a continuous glucose monitor) in order to save money?

- At least once in the past 12 months
- At least once in the past month
- Multiple times per month
- Not in the past year

Rationing



Frequency of rationing
insulin

Frequency of rationing
glucose self-monitoring
supplies

Rationing either insulin or
glucose self-monitoring
supplies

At least once in the past 12 months

At least once in the past month

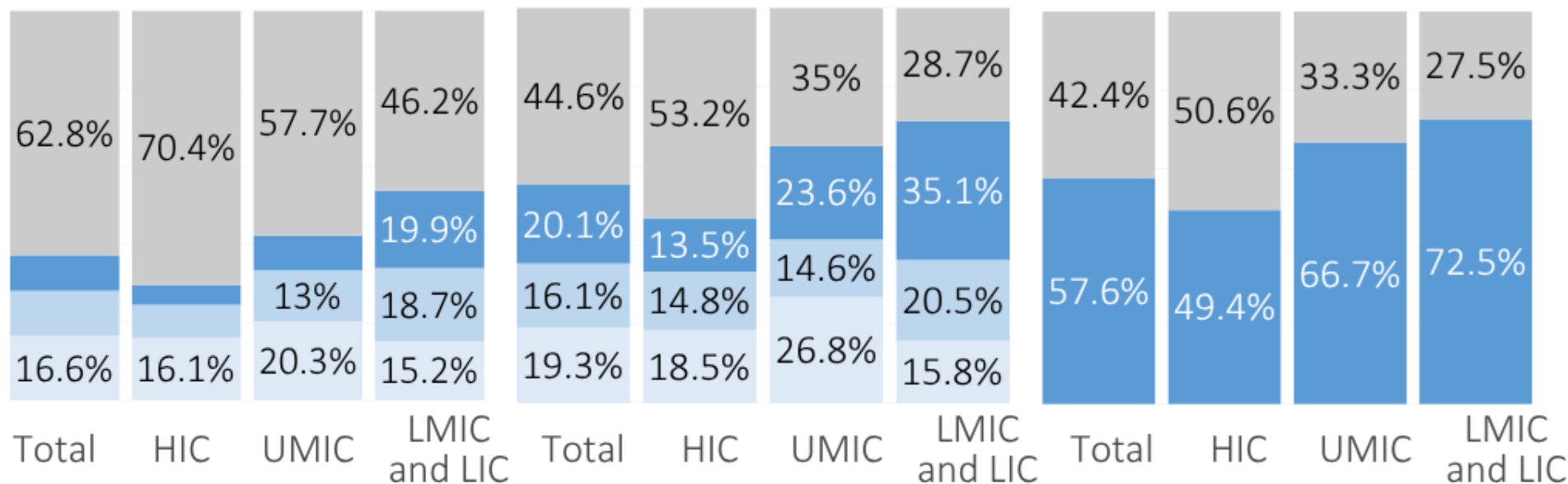
Multiple times per month

Did not ration

Rationed insulin or glucose
self-monitoring supplies at
some point in the past month

Did not ration

Rationing



Frequency of rationing insulin

Frequency of rationing glucose self-monitoring supplies

Rationing either insulin or glucose self-monitoring supplies

At least once in the past 12 months

At least once in the past month

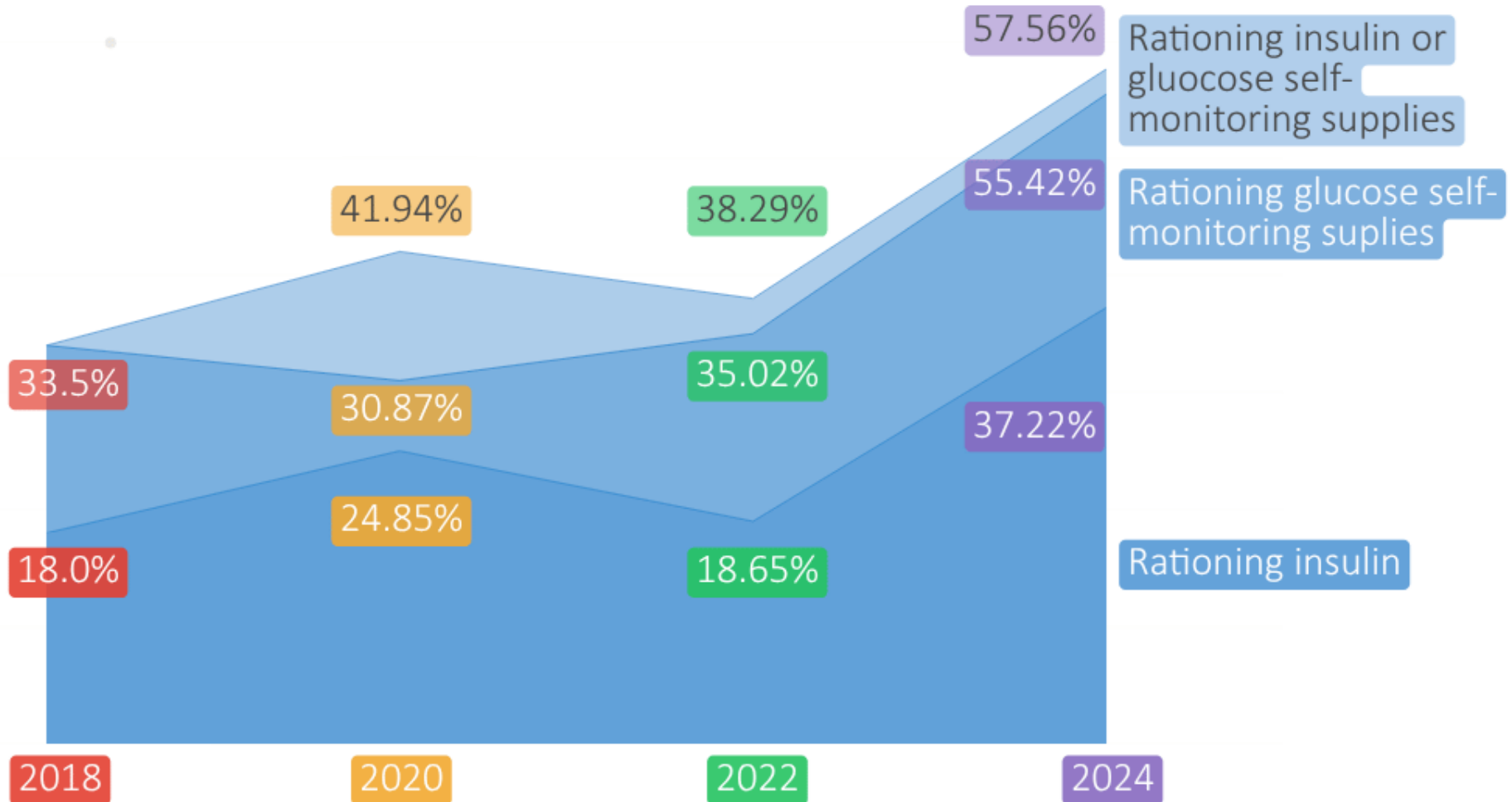
Multiple times per month

Did not ration

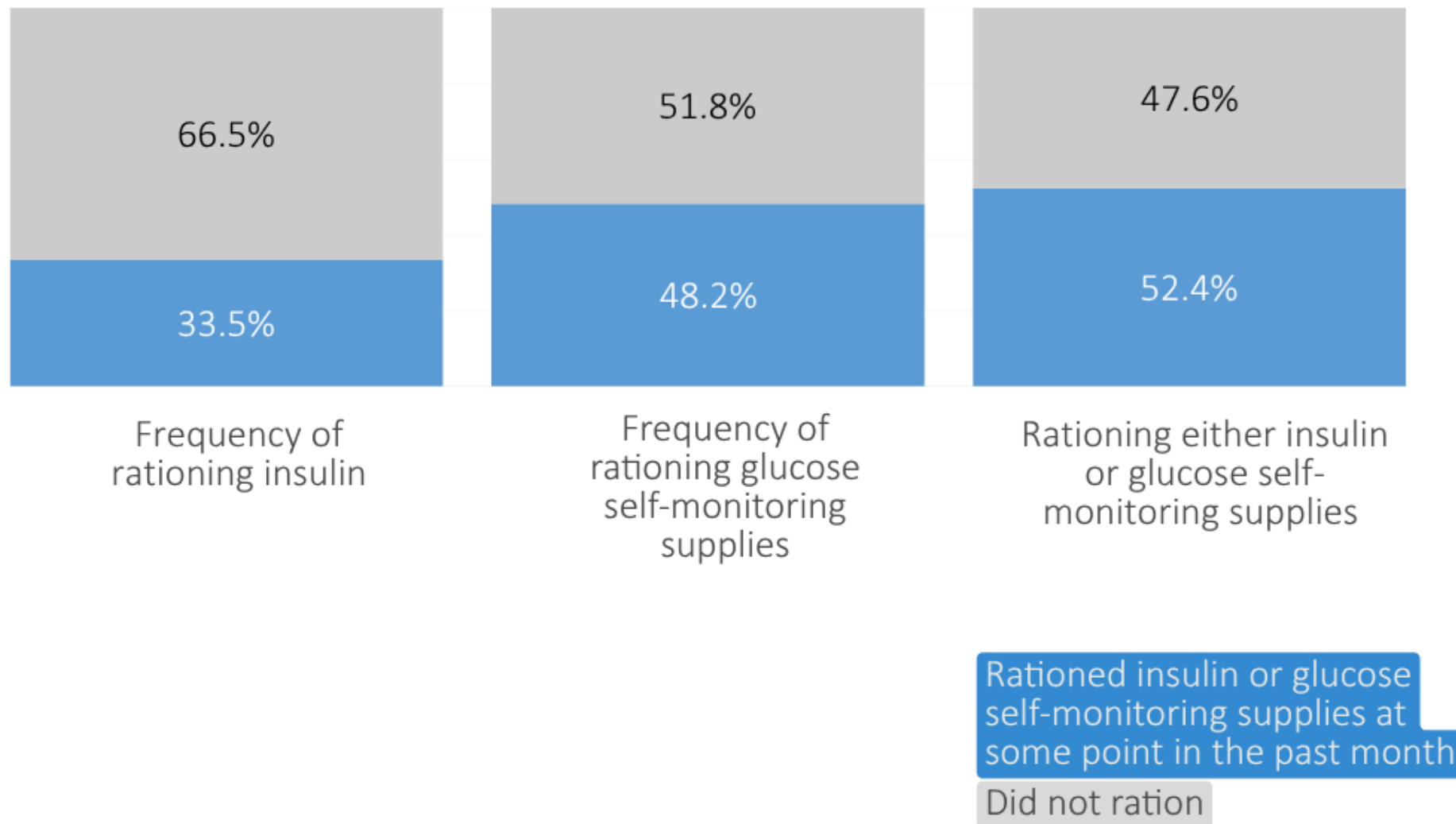
Rationed insulin or glucose self-monitoring supplies at some point in the past month

Did not ration

Rationing over time



Rationing in the US

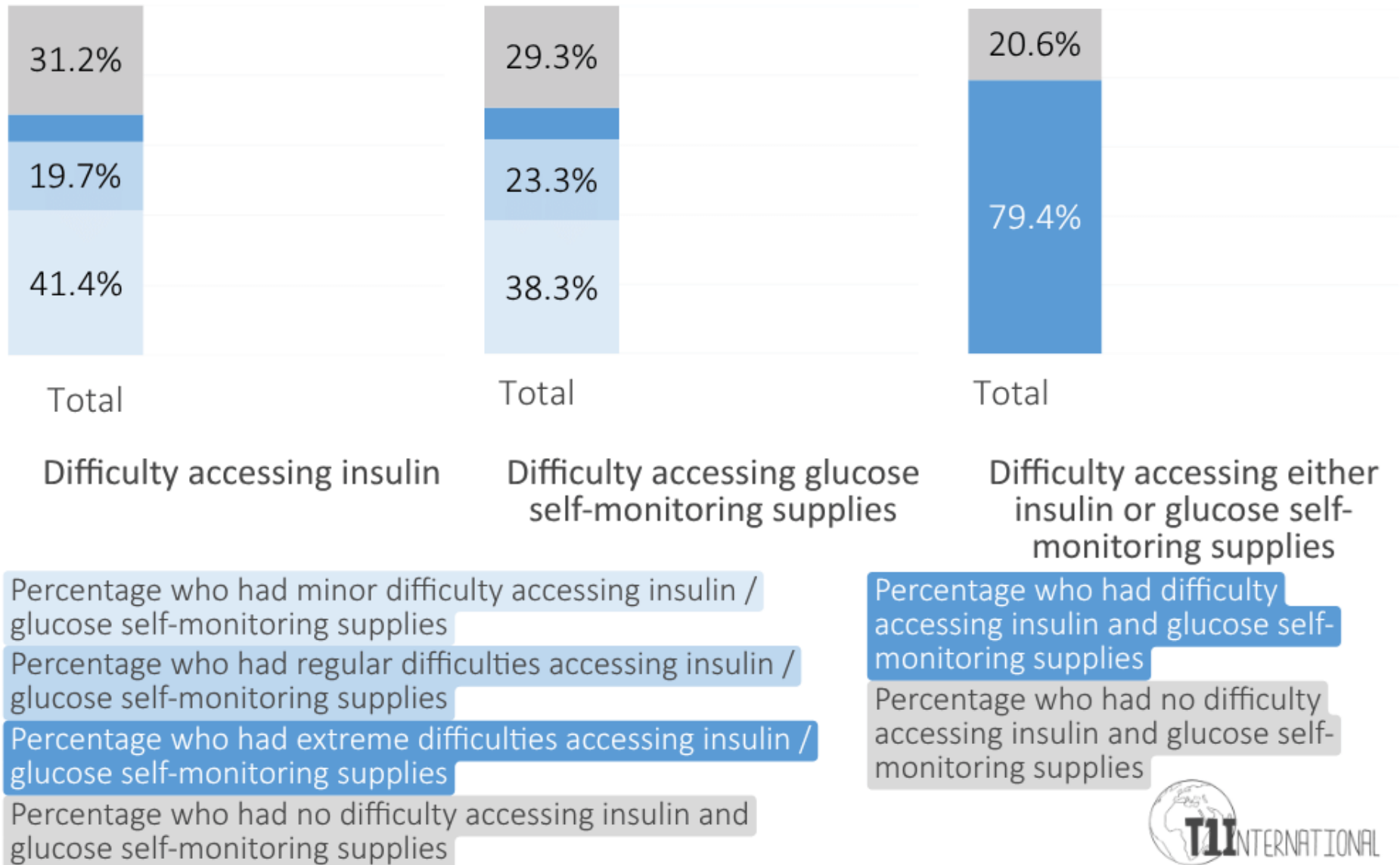


Access

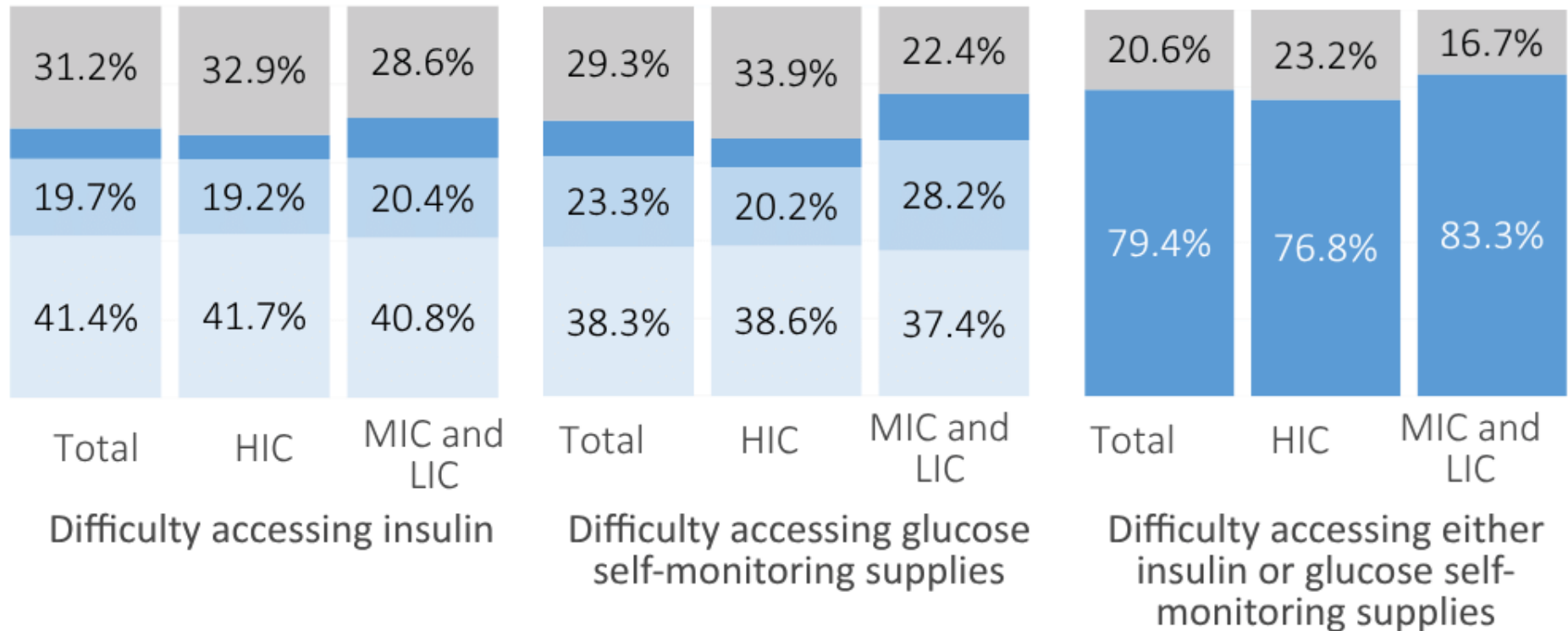
We have minor/regular/extreme/no difficulty accessing insulin / glucose self-monitoring supplies

- occasional/regular/frequent inventory concerns at local pharmacies,
- occasional/regular/frequent accessibility issues with your provider to prescribe glucose testing supplies if prescription is needed,
- occasional/regular/frequent required travel to far away pharmacies,
- etc.

Access



Access



Percentage who had minor difficulty accessing insulin / glucose self-monitoring supplies

Percentage who had regular difficulties accessing insulin / glucose self-monitoring supplies

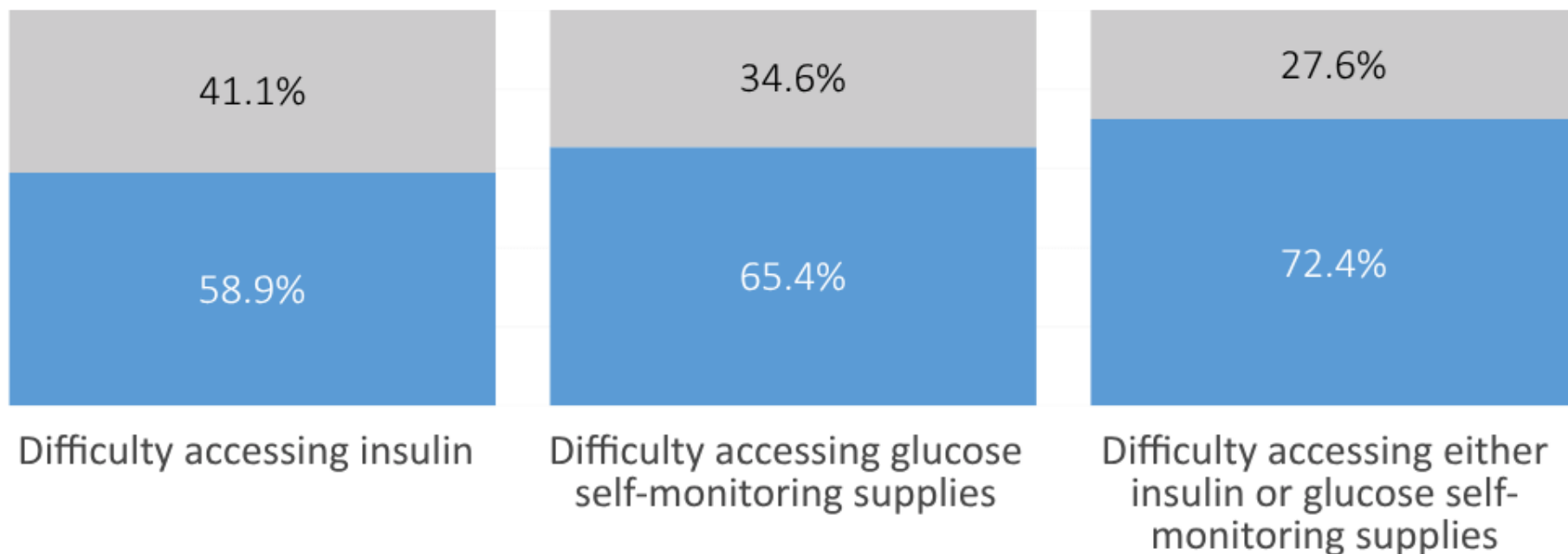
Percentage who had extreme difficulties accessing insulin / glucose self-monitoring supplies

Percentage who had no difficulty accessing insulin and glucose self-monitoring supplies

Percentage who had difficulty accessing insulin and glucose self-monitoring supplies

Percentage who had no difficulty accessing insulin and glucose self-monitoring supplies

Access in the US



Percentage who had difficulty accessing insulin and glucose self-monitoring supplies

Percentage who had no difficulty accessing insulin and glucose self-monitoring supplies

Access in the US

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.

...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.

Limitations

- Digital divide
- Language
- Self-selection
- Scope
- Existing data for comparisons



Future research

- All types of diabetes
- Type of data collection
- Breakdown by gender, age, etc.
- Break down by insulin and glucose monitoring type
- Expand survey translations
- Study long-term health outcomes of insulin rationing



Thank you!

Thank you to authors: Katarina Braune, Sara Helena Pereira e Silva Gaspar, Pilar Gomez, Campbell Mitchell, Elizabeth Pfiester, Yvonne Kamau, Maham Tahir, and Chris Toavs. Survey data support was by Josh Weinstein and with pro bono support from the Analysis Group. Additional review was done by Ravjot Samra, Katie Souris, and more. Translation was done with support from Ali Hisham, Hatem Mallek, Mohammed Seyam, Anne Durieux, Amina Taguirov, Nina Touche, Lucía Feito Allonca, Bruna Amaral, Sara Helena Pereira e Silva Gaspar, Grant Cosmas, Lucy Johnbosco, Mbolonzi Mbaluka, Heri Mijinga, and John Peter Mwolo. Survey outreach was done by: Jose Antonia Lopez at Aprendiendo a Vivir; Lucy Johnbosco at Diabetes Consciousness and Community (DiCoCo); Mridula Bhargava at Diabetes Fighters Trust; Pilar Gomez at DiabetesLATAM; Daniela Rojas at Diabetica Solutions; Dana Brown at Democracy Collaborative; Fabiola at DiabetCentro; Dr. Jackie Maalo, Dialeb; Sana Ajmal at Meethi Zindagi; Stephane Besançon and Nina Touche at Santé Diabète; Vivian Nabeta at Sonia Nabeta Foundation; and many more individuals and organizations around the globe, as well as by T1International's communications team including Elizabeth Pfiester, Lib Gatti, and Chris Toavs. This initiative was conceived by T1International's Founder, Elizabeth Pfiester. Former iterations of this report in previous years was 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, Yanbing Chen.



Thank you

t1international.com/access-survey | skasper@t1international.com