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Costs and underuse of insulin and diabetes supplies: Findings from the 2020 T1International cross-sectional web-based survey

Elizabeth Pfiester [a,1], *Katarina Braune* [a,b,c,1], *Axel Thieffry* [d], *Hanne Ballhausen* [b,c,e], *Katarzyna Anna Gajewska* [f,g], *Shane O'Donnell* [h,*]

[a] *T1International, Cheltenham, UK*
[b] *Charité - Universitätsmedizin Berlin, Department of Paediatric Endocrinology and Diabetes, Berlin, Germany*
[c] *Berlin Institute of Health, Berlin, Germany*
[d] *Center for Biosustainability, Technical University of Denmark, Copenhagen, Germany*
[e] *#dedoc° Diabetes Online Community, Dedoc Labs GmbH, Berlin, Germany*
[f] *School of Public Health, University College Cork, Cork, Ireland*
[g] *Diabetes Ireland, Dublin, Ireland*
[h] *School of Sociology, University College Dublin, Belfield, Ireland*

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ABSTRACT

Aims: To investigate self-reported out-of-pocket expenses (OoPE) associated with insulin and diabetes supplies for people living with type 1 diabetes (T1D) worldwide.
Methods: A web-based, cross-sectional survey was conducted from August to December 2020. The analysis included comparisons between responses from countries with no, partial, and full healthcare coverage.
Results: 1,066 participants from 64 countries took part in the study. ~25% of respondents reported having underused insulin at least once within the last year due to perceived cost. A significant correlation was observed between OoPEs and reported household income for respondents with partial healthcare coverage. 63.2% of participants reported disruption of insulin supplies and 25.3% reported an increase of prices related to the COVID-19 pandemic.
Conclusions: This study confirms previous reports of ~25% of people in the United States with T1D using less insulin and/or fewer supplies at least once in the last year due to cost, a trend associated with the extent of healthcare coverage. Similar trends were observed in some middle/low income countries. Moreover, patients reported an increase in insulin prices and disruption of supplies during the COVID-19 pandemic. This study highlights the importance of self-reported OoPEs and its association with underuse/rationing of insulin.

* Corresponding author: Shane O'Donnell, Research Scientist, OPEN Project Coordinator, School of Sociology, University College Dublin, Belfield, Dublin 4, Ireland.
E-mail address: shane.odonnell@ucd.ie (S. O'Donnell).
[1] These authors have contributed equally.
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1. Introduction

Despite the centennial of insulin's discovery by Frederick Banting, Charles Best, and colleagues at the University of Toronto in 1921 [1,2], half of the people living with diabetes worldwide cannot access or afford it [3]. Since the discoverers sold the patent for 1 USD each, and Banting famously said "Insulin does not belong to me, it belongs to the world" (https://insulin100.utoronto.ca/about), the cost of insulin has dramatically increased globally: For example, since the 1990s, the cost of analog insulin in the United States (US) has increased by well over 1000% [4]. High out-of-pocket expenses (OoPEs) and restricted access have been associated with insulin underuse, which in turn can lead to clinical outcomes associated with increased risks for long-term complications and premature death [5,6]. Insulin underuse is a leading cause of diabetes ketoacidosis (DKA) admissions in people with diabetes from minority populations [7]. Furthermore, differences in household income were found to be relevant for access to home refrigeration, usage of insulin pens, insulin pumps, glucagon and ketone strips, hemoglobin A1c (HbA1c) testing, and complications screening in children and adolescents with type 1 diabetes (T1D) [6,8]. However, while the cost of insulin may be as much as four times higher in the US compared to other OECD countries [9], access to insulin also varies worldwide, with many lower/middle-income countries (LMICs) lacking universal coverage of diabetes medications [10]. While a significant body of literature highlights the prevalence and impact of cost-related insulin underuse in the US [11–15], further research is needed at a global level with an emphasis on how this practice varies across countries with differing healthcare coverage types. Particularly, there is a pressing need in the context of the SARS-CoV-2 (COVID-19) pandemic, where disruptions of supply chains may have led to further precarity in access to insulin in some regions [16–18]. To our knowledge, this is the first study investigating self-reported out-of-pocket expenses and its effects on rationing of insulin and blood glucose testing in context with health coverage, country, and country income level.

Self-reported access to insulin and other diabetes supplies, as well as OoPE associated with the use of diabetes treatment, has been monitored by T1International in the last decade. T1International is a United Kingdom (UK) registered Charity (T1International.com) that advocates for people with type 1 diabetes around the world. It is a patient-led not-for-profit organization that receives no funding from pharmaceutical or industry donors. In both 2016 and 2018, T1International completed a web-based survey on access to insulin and diabetes supplies. The results are freely available on the T1International website (www.t1international.com/access-survey), but have not previously been published. The aim of this study is to present contemporary data concerning OoPEs, the extent of insulin and supply underuse, and the degree of financial coverage people with T1D are experiencing across the world. The study focuses primarily on the US rationing and healthcare coverage results as they compare to those of other countries.

2. Material & methods

2.1. Survey design

A web-based, cross-sectional, anonymous survey (**Supplementary Data 1**), titled "Type 1 Diabetes Access to Insulin and Supplies Survey", was conducted from August to December 2020 using the Research Electronic Data Capture (REDCap) platform [19]. The survey was co-developed by four people, three of whom are living with T1D, ensuring that questions were relevant and easy to understand for the participants. The questionnaire comprised items about healthcare coverage (e.g. health insurance, types of insulin and supplies, and associated costs). OoPEs were defined at the beginning of the survey and local currencies were converted to USD using the online XE Currency Converter tool (www.xe.com). Prior to launching the survey, T1International utilized a pilot group of N = 10 volunteers from North America, South America, Europe, Asia, and Africa. Based on their feedback on readability, usability, and clarity of the survey questions, alterations were made to improve the survey tool before sharing it with the wider T1D community.

2.2. Participants and procedures

The survey was open to people diagnosed with T1D aged 18 years and above, their partners, caregivers of children and adolescents with T1D, as well as healthcare professionals (HCP) responding on behalf of their patients. Informed consent to participate was required to proceed to the survey questions. Respondents were informed that no identifiable information would be collected and that no compensation or other financial reward for participating would be received. All work was carried out in an ethical manner and in accordance with the Declaration of Helsinki. The survey was linked from the T1International website and disseminated using online newsletters, emails, and social media platforms (including Facebook, Instagram, LinkedIn, and Twitter). It was also shared by local partner organizations where T1International advocates are active as well as global partners of T1International.

2.3. Data analysis and statistical tests

Quantitative analyses were conducted within the R statistical framework (www.r-project.org) and figures were produced using the ggplot2 package (https://ggplot2.tidyverse.org). The analysis included comparisons between countries with full, partial or no healthcare coverage. The underuse analysis of insulin and diabetes supplies frequencies were conducted on the basis of two groups with, on the one side, *Never*, and on the other side all other frequencies (*Once per year or more*, *Once per month or more*, *Once per week or more*, and *Every day*). The base R function *chisq.test()* was used and resulting *P* values were corrected with the Bonferroni method [20]. The *cramerV()* function from the rcompanion package (www.rcompanion.org) was then used with bias correction to measure the degree of association. All statistical significance

thresholds were set to 0.05. When indicated in the axis legend of the relevant figures, a pseudocount of 1 USD was added to all declared OoPEs in order to retain the null values (0 USD) during the log-transformation necessary to facilitate visualization. The original survey dataset and associated R scripts are publicly available on the Github repository: https://github.com/athieffry/T1International-OoPE-survey-2020.

3. Results

3.1. Represented countries and healthcare coverage landscape

Responses from a total of 1,080 participants were recorded over a total duration of 5 months. Fourteen participants did not indicate their consent and were subsequently removed. Of the 1,066 responses that were included in the analysis, 671 (62.9%) were female, 789 (74.2%) were adults living with T1D, 117 (10.9%) were caregivers, 12 (1%) were partners and 4 (0.4%) were HCPs providing care to people with T1D. Participants were based in 64 different countries (Fig. 1A). The majority of responses originated from the United States (US, N = 542, 50.8%), followed by Ghana (GH, N = 46, 4.3%), and Canada (CA, N = 35, 3.3%). To mitigate the rapidly decreasing sample size while still allowing insightful comparisons by considering diverse geographic locations and country income levels, most of the downstream analyses were focused on the five most represented countries. This subset consists of the US, GH, CA, Philippines (PH, N = 28, 2.6%), and the United Kingdom (UK, N = 26, 2.4%). Overall, three groups could be distinguished on the basis of healthcare coverage distribution in the top five most represented countries, with i) mostly *full* healthcare coverage (UK), ii) mostly *partial* coverage (US, GH, and CA), and iii) mostly no coverage (PH) (Fig. 1B).

3.2. Out-of-pocket expenses in the five most represented countries

To identify the main drivers of OoPEs, participants were asked to report their monthly expenditures in USD (see Methods) for the following categories: insulin (short- and long-acting, mixed, and other types), devices (insulin pumps and continuous glucose monitors), glucagon kits, and testing strips for blood glucose and ketone levels (Supplementary Data 1). A significant but weakly positive correlation was observed between OoPEs and reported household income (Table 1) for respondents with *partial* healthcare coverage (r_s: 0.27, P = 4.3e-6, N = 565). Devices were the leading category of OoPEs (276.8 USD; 95% CI [236.2, 317.3]) followed by insulin (155.3 USD; 95% CI [128.0, 182.5]), glucagon (61.1 USD; 95% CI [50.1, 72.1]), and test strips (45.1 USD; 95% CI [39.1, 51.1]) (Fig. 2A). Participants with *full* healthcare coverage had the lowest self-reported OoPEs with virtually all respondents reporting 0 USD (Fig. 2B, D). However, monthly expenses were similar overall between *none* and *partial* healthcare coverage (Fig. 2B). Countries could clearly be distinguished into three categories with regards to expenses: i) the UK showing low OoPE amounts, ii) Ghana, Philippines, and the US grouping towards the highest OoPE amounts, and iii) Canada occupying a relatively uniform OoPE distribution (Fig. 2C).

To minimise the risks of univariate analysis and gain a more granular understanding of OoPEs, we broke down

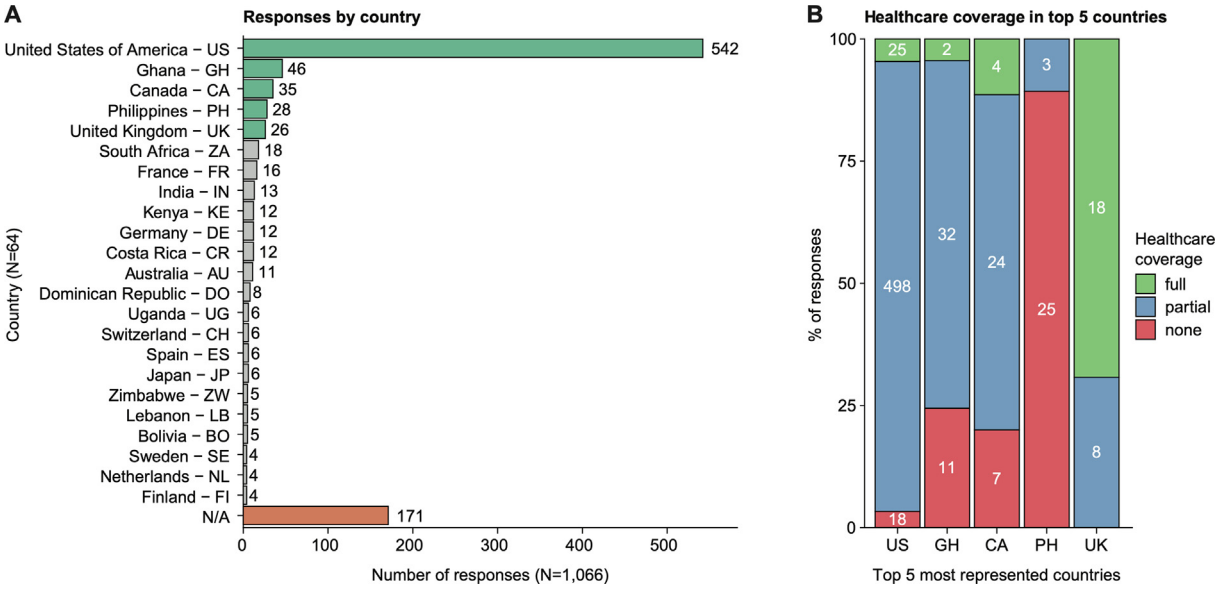

Fig. 1 – Response by country and healthcare coverage in top 5 countries. (A) **Ordering of countries (Y-axis) per number of responses (X-axis). Countries are indicated by full name followed by the alpha-2 code. Top 5 most represented countries are indicated in green, others in grey. N/A: not attributed. Only countries with more than 3 respondents are shown.** (B) **Ratio of reported healthcare coverage types (Y-axis, percent) in top 5 most represented countries (X-axis). Colors indicate the type of healthcare coverage, ranging from none (red) and partial (blue) to full coverage (green). White numbers denote the number of responses. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)**

Table 1 – Demographic characteristics of the study cohort.

Characteristic	Answers	Worldwide (N = 1,066)	Top 5 most represented countries (N = 677)
Gender	Female	671 (62.9%)	509 (75.2%)
	Male	233 (21.9%)	151 (22.3%)
	Transgender	2 (0.2%)	2 (0.3%)
	Other	7 (0.6%)	7 (1%)
	Prefer not to answer	8 (0.7%)	7 (1%)
	NA	145 (13.6%)	1 (0.1%)
Connection to T1 diabetes	Person with diabetes	789 (74.2%)	574 (84.7%)
	Caregiver	117 (10.9%)	92 (13.5%)
	Partner	12 (1%)	11 (1.6%)
	Healthcare professional of a person with diabetes	4 (0.4%)	0 (0%)
	NA	144 (13.5%)	0 (0%)
Monthly household income (USD)	< 1,000	115 (10.8%)	65 (9.6%)
	1,000–1,499	37 (3.5%)	31 (4.6%)
	1,500–2,999	149 (14%)	127 (18.8%)
	3,000–4,999	98 (9.2%)	85 (12.5%)
	greater than 5,000	36 (3.4%)	31 (4.6%)
	NA	631 (59.1%)	338 (49.9%)
Country income level	Low	11 (1%)	0 (0%)
	Middle	181 (17%)	74 (11%)
	High	703 (66%)	603 (89%)
	NA	171 (16%)	0 (0%)

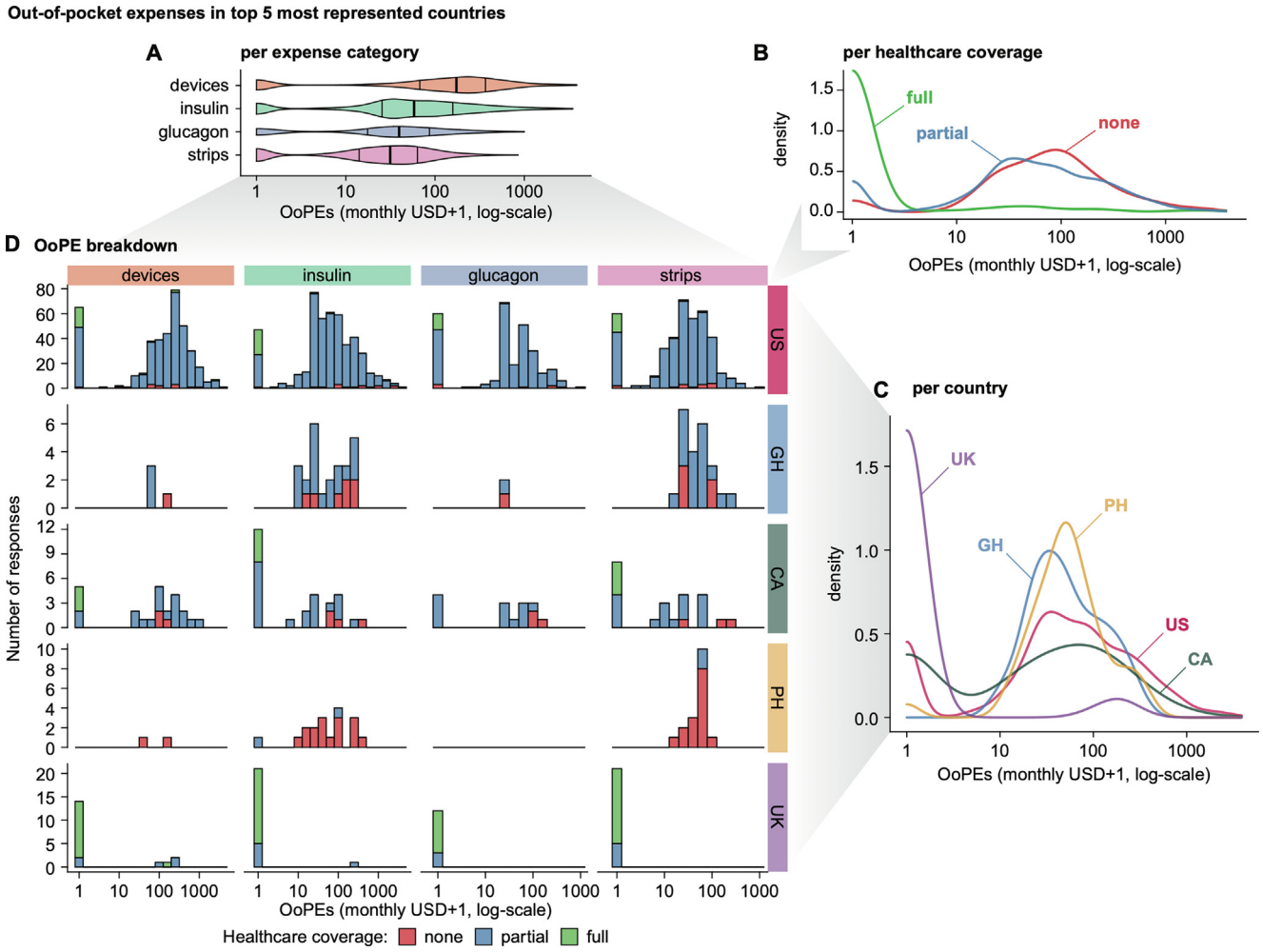

Fig. 2 – Overview of Out-of-Pocket Expenses in the top 5 most represented countries. (A) Violin plot of self-reported Out-of-Pocket Expenses (X-axis) indicated in USD (pseudocount: +1, log-scale), for testing strips, glucagon kit, devices and insulin (Y-axis). The strips category (pink) includes both blood glucose testing strips and ketone testing strips. The devices category (orange) comprises insulin pumps and continuous glucose monitors. The insulin category (green) encompasses short-acting, long-acting, mixed-types, and other types of insulins. Violin ticks indicate quantiles and areas are proportional to the number of responses. (B) Density distribution of Out-of-Pocket Expenses (X-axis, organized as in A) per healthcare coverage type (colors) in the top 5 most represented countries (rows). (C) Density distribution of Out-of-Pocket Expenses (X-axis, organized as in A) per country (colors). (D) Breakdown of Out-of-Pocket Expenses (organized as in A) per expense category (columns), country (rows), and healthcare coverage (bar colors). Y-axis indicates the number of respondents. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

expenses by all factors considered above (country, healthcare coverage, and category of expenditure) (Fig. 2**D**). This led to the confirmation that most participants with *full* healthcare coverage originated from the UK and reported virtually no OoPEs (Fig. 2**D**). While most respondents with *partial* healthcare coverage reported OoPEs in the vicinity of 100 USD per month, a considerable number also reported 0 USD in the US and Canada. We note that insulin and test strips were the two categories for which the highest number of reported OoPEs were incurred, independently of healthcare coverage and country of origin. The great majority of participants reporting to be without any healthcare coverage were based in the Philippines and Ghana.

3.3. *Impact of the COVID-19 pandemic*

Participants were asked whether their access to insulin and diabetes supplies was affected by the COVID-19 pandemic. All five aforementioned countries had at least half of the participants reporting an impact of the COVID-19 pandemic, a proportion even higher in Ghana and Philippines (Fig. 3**A**). Specifically, the most reported COVID-19 impact was a disruption of supply (63.2%, N = 203), and a considerable fraction of participants reporting disruption to their insulin supplies also reported an increase of insulin price (25.3%, N = 203), most frequently in Ghana. Insulin access issues as a consequence of COVID-19 were mostly observed in Ghana and the Philippines (Fig. 3**B**).

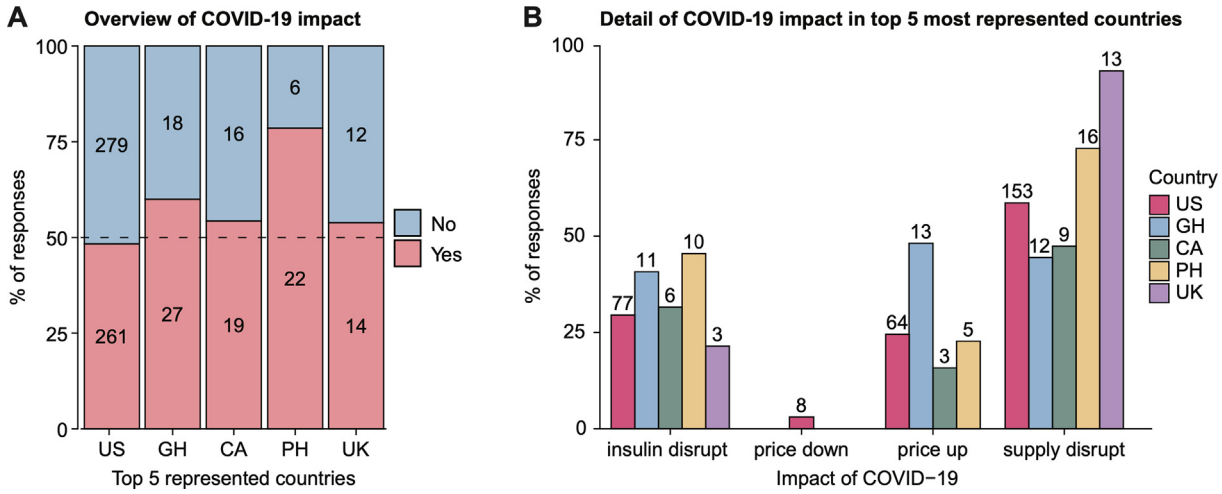

Fig. 3 – Impact of the COVID-19 pandemic in the top 5 most represented countries. (A) Overview of respondents (Y-axis, percent) in the top 5 most represented countries (X-axis) reporting an impact of the COVID-19 pandemic. (B) Detail of COVID-19 pandemic impact categories ('Yes' answer in A) in the top 5 most represented countries (bar colors). Y-axis shows the percentage of responses.

3.4. *Rationing of insulin and blood glucose testing*

To examine cost-related underuse of medication, we then analyzed the extent of rationing of insulin and blood glucose testing strips. All countries considered, rationing of blood glucose testing strips (41.3%, N = 721) was higher than rationing of insulin (25.9%, N = 779). A significant increase of underuse frequency was associated with lower healthcare coverage for both insulin intake (χ^2 [df = 2, N = 776] = 29.0, adjusted *P* = 4.8e-7) and blood glucose testing alike (χ^2 [df = 2, N = 716] = 54.9, adjusted *P* = 1.16e-12), with moderate effect sizes as indicated by Cramer's V coefficients of 0.19 and 0.27, respectively (Fig. 4**A**). A similar trend was observed in relation to country income-level (categorized as *low*, *middle*, or *high*) with the underuse frequency of blood glucose testing (χ^2 [df = 2, N = 704] = 62.87, adjusted *P* = 2.22e-14, Cramer's V: 0.29) and, though to a much lower extent, insulin intake (χ^2 [df = 2, N = 756] = 11.17, adjusted *P* = 0.037, Cramer's V: 0.11) (Fig. 4**B**).

In the five most represented countries (Fig. 4**C**), responses from the UK demonstrated no insulin underuse (0%, N = 24) and the lowest rationing of testing strips (13%, N = 23), closely followed by Canada with 11.5% (N = 26) and 25% (N = 24), respectively. In contrast, rationing in the US was well above 25% for both insulin intake (29.8%, N = 483) and blood glucose testing (39.8%, N = 447), a situation only met in the Philippines (29.4% and 70.6% respectively, both N = 17) and Ghana otherwise (51.6%, N = 31; and 90.9%, N = 33). Philippines and Ghana were the countries with the most reported insulin or blood glucose testing underuse, with Ghana being the sole country reporting a majority of respondents underusing both insulin and blood glucose testing.

4. Discussion

The main strengths of this study resides in its international breadth and its focus on costs associated with T1D management: To the best of our knowledge, this is the first study to cross-nationally compare OoPEs associated with diabetes medications and how costs impact self-management behaviours. Notably, the design of the survey was patient-led and the majority of people involved in the creation and analysis of the study are living with diabetes. The self-reported nature of the survey also brings insights into how these perceptions of incurred costs impacts on self management practices, both through the quantitative data and also through qualitative data gathered in an open text box (Supplementary Data 2). Generally, the greater the extent of coverage of diabetes-related expenses by the state or health insurance, the less likely insulin rationing and underuse was reported. This study highlights the importance of healthcare coverage and its direct effect on unhealthy and dangerous behaviors associated with insulin rationing.

This study reports unequal access to insulin and other diabetes-related supplies by people living with type 1 diabetes worldwide. 1,066 participants from 64 countries took part in the study, and one out of every four respondents reported having underused or rationed their insulin at least once within the last year due to high cost. The large differences between the US and other high-income countries, in terms of insulin and blood glucose testing rationing, as well as overall costs, were particularly striking. This may be partly explained by the fact that the majority (92.1%) of US respondents had access to partial coverage of their healthcare costs. Findings for the number of people with T1D in the US who had rationed insulin in the past year (29.8%) aligns with findings from previous studies on insulin underuse [12]. Indeed, the circumstances for US people living with T1D appeared to be on par with most lower-middle income countries in the extent to which cost related insulin underuse was reported by participants. In contrast, insulin underuse is virtually non-existent in the UK.

In terms of the global south, the majority of respondents from the Philippines and Ghana reported to be without any

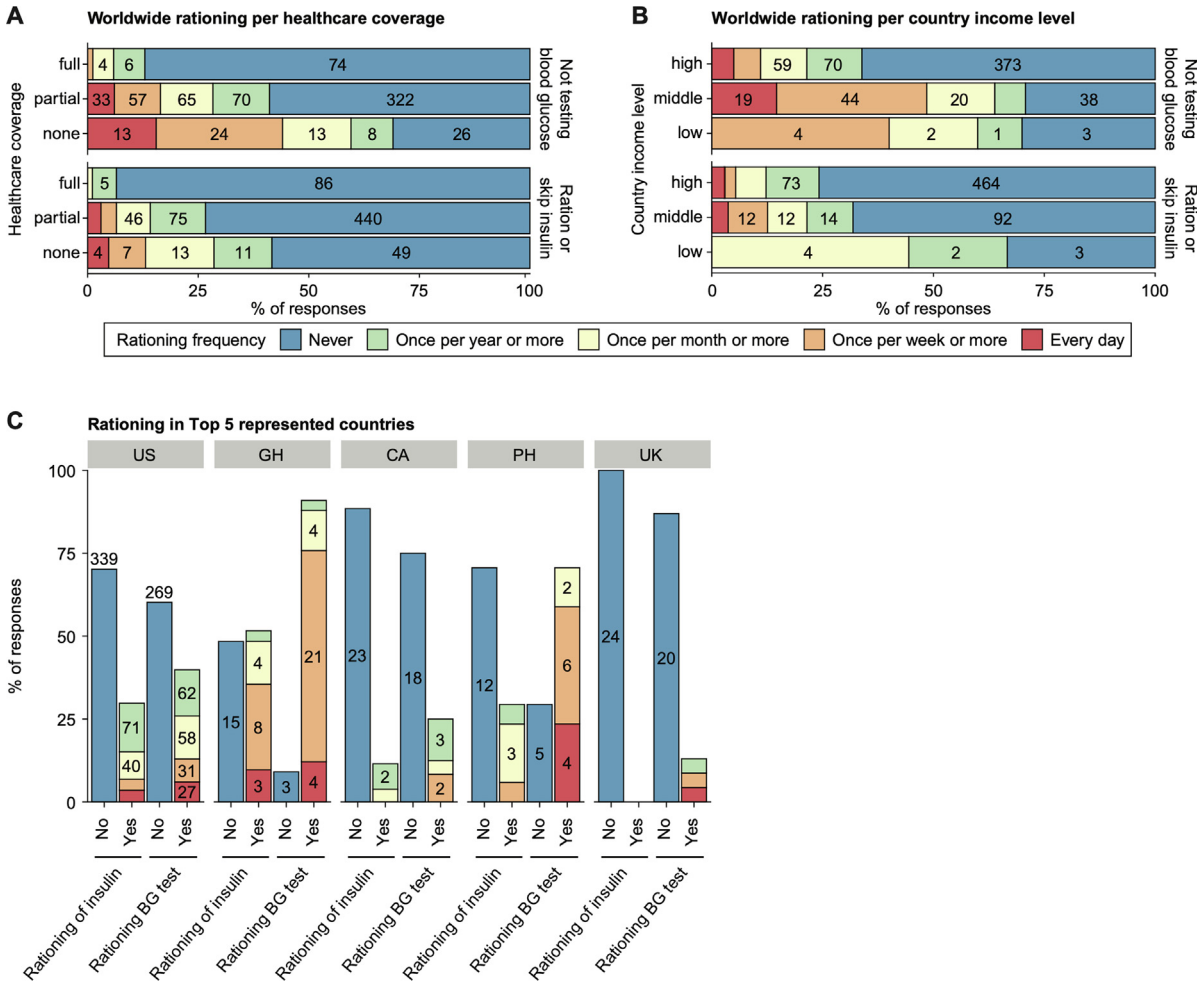

Fig. 4 – Underuse of insulin and blood glucose testing. (A) **Worldwide overview of rationing frequencies (bar colors) for i) not testing blood glucose levels (top), and ii) rationing/skipping insulin due to cost (bottom), divided by healthcare coverage types (Y-axis). X-axis indicates the percentage of responses.** (B) **Organized as in A but with Y-axis denoting country income level.** (C) **Detail of rationing frequencies (bar colors) in the top 5 most represented countries (columns). Y-axis indicates the percentages of responses. X-axis shows the categories of rationing as in A, but grouped into 'No' (Never) and 'Yes' (any positive frequency).**

healthcare coverage. From this observation naturally results a lower priority of glucagon kits, pumps, and Continuous Glucose Monitoring (CGM) devices for diabetes management, a priority that might be confounded with difficulty of access, as recently reported [21]. The impact of COVID-19 on access to insulin and supplies was also prevalent. Across the five most represented countries in this survey, approximately half of respondents noted the impact of the pandemic on their supply access, with most (63.2%) noting that access had become more difficult. This perceived insulin supply disruption and increased cost might be in part related to difficulty accessing medical personnel during the pandemic.

Unmistakable trends were observed in the relationship between underuse, healthcare coverage, and to some extent country income-level. In the UK, a high-income country, instances of insulin underuse were virtually nonexistent. This may be partly explained by the universal healthcare coverage model of the National Health Service (NHS) whereby medication costs incurred by patients are largely reimbursed by the state, thus for the most part eliminating the need for any (cost-related) underuse of insulin. By contrast, insulin underuse was common in most low-income countries and many middle-income countries alike, in addition to the unique situation of the United States which was an outlier among high income countries. The paradoxical situation of the US could be linked with the lack of Universal Health Coverage and that healthcare delivery is predominantly based on private insurance, or tied to employment. This generates an insulin underuse tendency among those who are unemployed (or employed without an adequate insurance package). Consequently, this contributes to socioeconomic inequalities in diabetes outcomes, as evidenced by the large number of people with diabetes who are uninsured in the US [22] and several deaths due to unaffordable insulin [23]. Among the US participants who reported having adequate health insurance in this study, many expressed feeling trapped within their current employment and unable to move on to a new role, fearing the loss of health insurance plan (see Supplementary Data 2). How the imperative to secure adequate health insurance affects career

and life trajectories of those living with diabetes in the US, and other countries with only partial health coverage, is worthy of future inquiries.

Importantly, we note that, even within the NHS, recent restrictions around access to test strips introduced as part of government cost-containment measures are giving rise to rationing among people living with diabetes [24]. The consequences in terms of ability to successfully manage diabetes is unknown. Furthermore, there is also evidence of growing inequalities in access to state-of-the-art technologies such as CGM and insulin pumps, even within countries with universal systems of healthcare provision, which may lead to the exacerbation of inequalities in diabetes outcomes in the future [25,26].

We note that this survey encountered several limitations, the most prominent of which was the low number of respondents outside the US. Also, marginalized individuals and communities are likely under-represented due to Internet access requirements to complete this survey. Similarly, respondents must have been engaged with online activities or organizations focusing on diabetes care and probably demonstrate a proactive attitude in diabetes self-management practices. The survey was only disseminated in English. We acknowledge the existence of reasons for insulin underuse other than access and costs, such as allergic reactions [27], insulin purging [28], hypoglycemia anxiety [29], and mental health-related aspects, which have not been captured in this study. Additionally, precise standards of care vary widely across nations and specificities are beyond the scope of this study. Future research should more deeply explore OoPEs for people with diabetes in low-income countries, rural areas, and communities without internet access or high literacy or English language rates. It should also address access to diabetes education, specialty care, HbA1c testing, screening for diabetes-related complications, and psychosocial support, in addition to access to medication and tools.

In conclusion, insulin and supply underuse are issues of global concern. These issues have only been exacerbated by the global COVID-19 pandemic. The cost of insulin and other necessities for people with T1D should be reduced to ensure standard of care, minimize disease burden, and meet health needs. This study highlights that while there are many factors that impact physical and mental health of people with T1D, reducing the cost of insulin and supplies would decrease instances of insulin and supply underuse, and therefore diabetes-related health complications and mortality. Finally, this study adds to limited international evidence on OoPEs of people living with T1D, and its effect on diabetes management practices. These findings will help to inform and remind healthcare providers, policymakers, politicians and health service planners of the importance of equal access to this life-saving medicine.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: EP is employed as Executive Director of T1International. KB received funding from the European Commission Horizon 2020 program, the DFG-funded Berlin Institute of Health (BIH) Digital Clinician Scientist program, the BIH Junior Clinician Scientist program, the BIH QUEST center, the German Diabetes Association (DDG) and Wellcome Trust; and fees for medical consulting and public speaking from Roche Diabetes Care, Dexcom, Medtronic Diabetes, Diabeloop, Sanofi Diabetes, BCG Digital Ventures and Novo Nordisk; all outside the submitted work. AT analyzed the data in quality of consultant for T1International. KG received fees for public speaking from Novo Nordisk and is an employee of Diabetes Ireland, an organization cooperating with companies producing insulin and supplies. All other authors declare no conflict of interest.

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Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.diabres.2021.108996.

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