

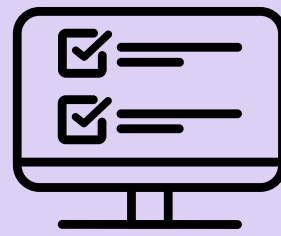
Diabetes Ireland

Charity Number: CHY 6906

LIVING WITH DIABETES IN IRELAND: FINDINGS FROM THE SURVEY ON EXPERIENCING, ACCESSING AND USING DIABETES HEALTH SERVICES BY PEOPLE WITH DIABETES

Why?

- Diabetes can be a relentless and burdensome chronic condition, affecting people of all ages and their families. It's estimated that approx. 300,000 people live with diabetes in Ireland.
- People have to **self-manage** diabetes daily (e.g. adapt to nutritional advice, take medicines, inject insulin, check glucose levels etc.) 7 days a week, 365 days a year, with no breaks or holidays.
- To self-manage their diabetes well, **regular access to healthcare professional support, multidisciplinary teams (MDT), diabetes education, annual reviews, treatment that suits their lifestyle and needs and keeps them safe from complications, are absolutely vital.**
- We often hear from people that they can't access their teams, and experience long waiting lists to access MDTs, treatments and diabetes technology - we just had no data and structured information.



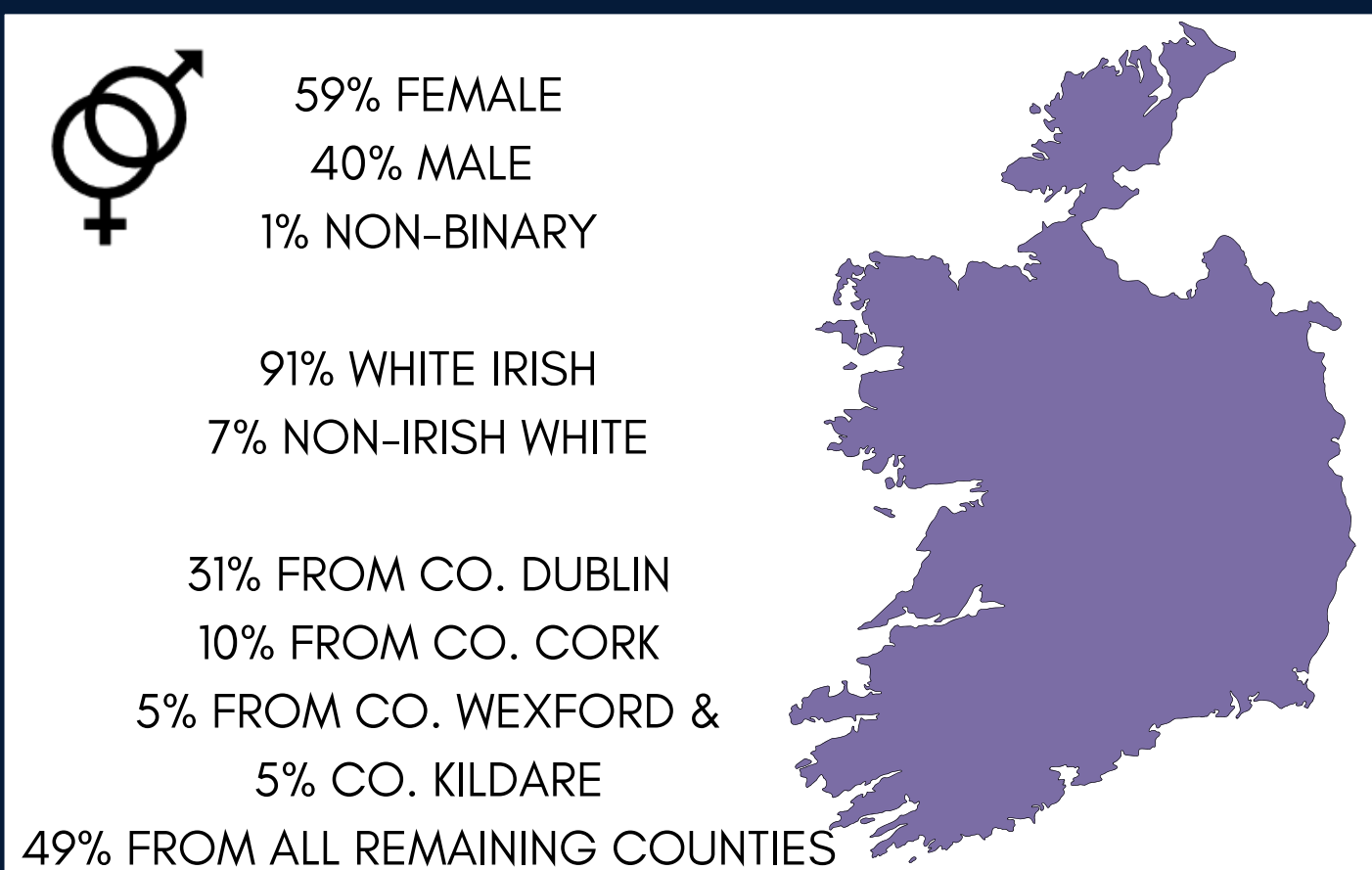
THE SURVEY TOOL

- Anonymous
- Online
- Based on the 'Patient experience of diabetes services' survey conducted in the UK in 2013
- Adapted to Ireland in 2022/23

How?

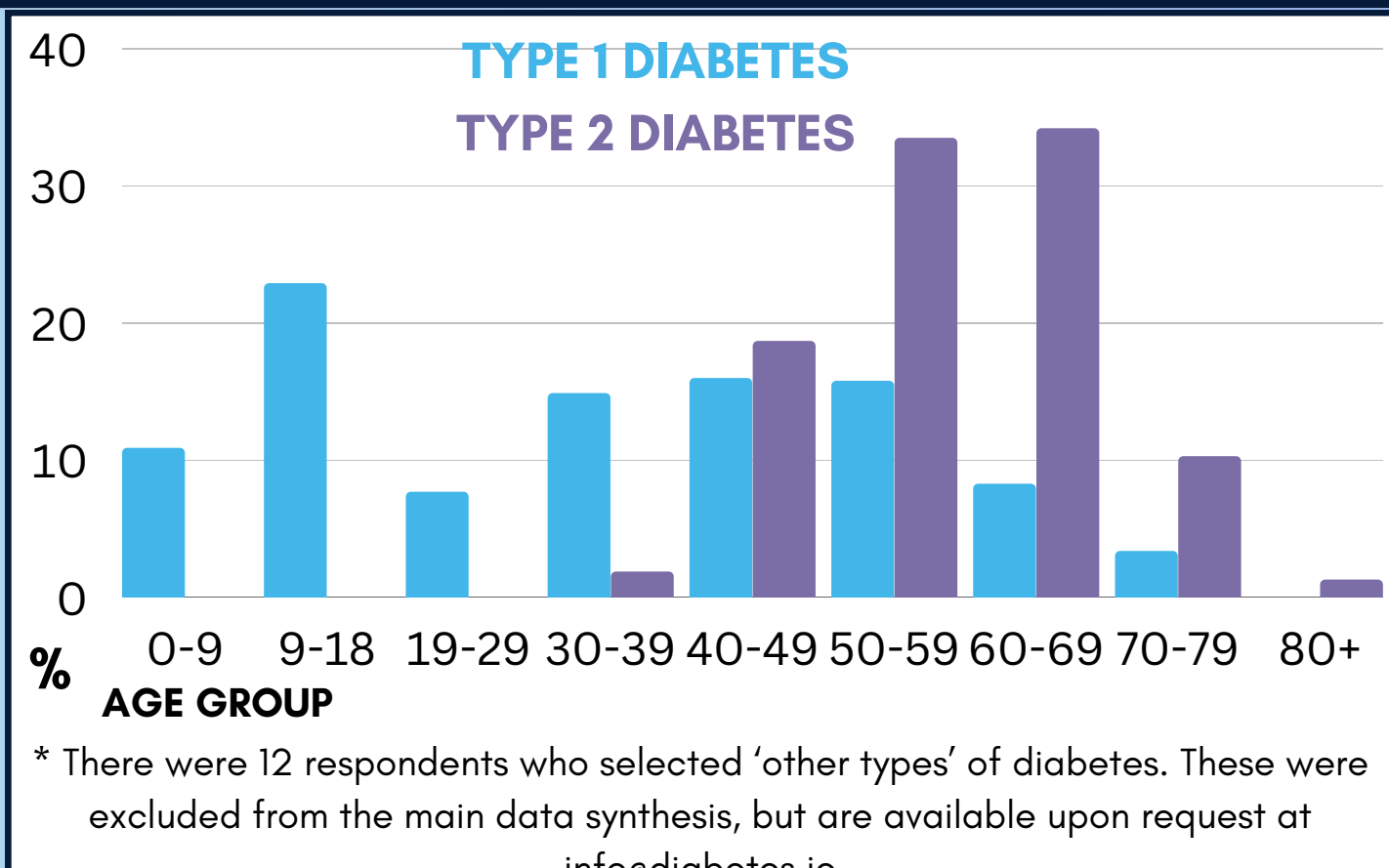
- Together with healthcare professionals, researchers, academics and people living with diabetes we conducted a survey to ask about:
 - Living with diabetes since diagnosis
 - Management of diabetes
 - Diabetes care received
 - Diabetes check-ups
 - Appointments in 2022.
- We asked all adults living with diabetes (any type) and parents of children with diabetes.
- People were recruited online via social media, member's newsletters and communication between 16/1/2023-5/2/2023.
- Research Ethics Committee at RCSI: University of Medicine and Health Sciences ethically approved this study.
- Data (including open-ended responses) were analysed. Descriptive statistics were used.

IN THE ABSENCE OF A DIABETES REGISTRY AND CLINICAL AUDITS, THIS STUDY IS THE FIRST OF ITS KIND IN IRELAND TO GATHER THE EXPERIENCES OF PEOPLE WITH DIABETES ON THEIR MEDICAL OUTCOMES, TREATMENTS, HEALTH SERVICES ACCESS, WAITING LISTS, LEVELS OF SATISFACTION WITH THEIR CARE, AND ISSUES THAT THEY FACE AND PERCEIVE ETC.



About Participants & Diabetes

DIAGNOSIS



Children with diabetes 120 parents/carers completed the survey. At the time of diagnosis, **76% of children experienced typical diabetes symptoms** (thirst, exhaustion, urination etc.). In 53% of cases a GP made an initial diagnosis. **Almost all children were hospitalised then**, with 24% treated in an Intensive Care Unit (ICU). **At admission, 40% had Diabetic Ketoacidosis (DKA).** At the time of the data collection, the average diagnosis duration for children was around 3.5 years.

Type 1 diabetes 230 adults with **type 1 diabetes** completed the survey. At the time of diagnosis, 82% experienced typical diabetes symptoms. In 52% of cases a GP made an initial diagnosis; **81% were hospitalised then**, with 16% treated in an ICU. **At admission, 41% had DKA.** At the time of the data collection, the average diagnosis duration for was 24 years (67y the longest).

Type 2 diabetes 155 adults with **type 2 diabetes** completed the survey. At the time of diagnosis, 34% had no symptoms at all; for 18% initial diagnosis was made via screening, or at another medical appointment; in **69% of cases a GP made the diagnosis**; **90% didn't have to be hospitalised, but 10% had to be.** On average, the average diagnosis duration was 8.5 years.

IMPORTANT!

MORE THAN **40% OF PEOPLE WITH TYPE 1 DIABETES IN IRELAND EXPERIENCED DKA AT THE TIME OF DIAGNOSIS. THIS RATE IS VERY HIGH WHEN COMPARED TO OTHER EUROPEAN COUNTRIES AND COULD BE AVOIDED WITH BETTER AWARENESS OF SYMPTOMS** (INCLUDING GPs AND HEALTHCARE PROFESSIONALS), IMMEDIATE BLOOD OR URINE TESTING, AND EARLY SCREENING.

'My child felt unwell, was lethargic and vomiting. He lost weight (...) and started waking during the night to go to the toilet; during the day was not excessively thirsty or urinating. All the symptoms ignored by GP'

'Was brought to GP a lot prior to diagnosis and GP did not recognise symptoms. Diagnosed in emergency dept after vision completely blurred over' (Adult)

Living with diabetes

COMPLICATIONS & COMORBIDITIES

Children with diabetes

SEVERE

Only **10% of children** experienced at least one episode of **severe hypoglycaemia**, **2% had DKA** other than at the time of diagnosis. **78% of children did not have to be hospitalised** since diagnosis.

LONG-TERM

Children **have no diabetes-specific complications, only comorbidities specific to diabetes or other non-specific conditions**: 8% coeliac disease, 4% mental health related, 2% hypothyroidism.

82% OF CHILDREN HAVE DIABETES ONLY

Type 1 diabetes

45% of adults experienced at least one episode of **severe hypoglycaemia**, **27% more than once**; **16% were hospitalised**. **19% had more than one DKA episode** and had to be hospitalised. **59% have not been hospitalised** since diagnosis.

39% have diabetes-related complications or comorbidities: 28% have retinopathy, 20% hypothyroidism, 18% hypertension, 11% mental-health related issues. 20% have other conditions, but are not sure if these are diabetes-related.

41% HAVE DIABETES ONLY

Type 2 diabetes

8% of adults with type 2 diabetes had at least one episode of **severe hypoglycaemia**, **3% reported DKA**. **94% never had to be hospitalised** due to diabetes.

34% have diabetes-related complications or comorbidities: 30% hypertension, 21% high cholesterol, 19% mental-health related issues, and 15% retinopathy. 21% have other conditions.

46% HAVE DIABETES ONLY

WE SPEND A LOT ON TREATING DIABETES-RELATED COMPLICATIONS AND HOSPITALISATIONS IN IRELAND. WITH THE DEVELOPMENTS IN DIABETES TREATMENTS, EDUCATION AND BETTER SUPPORT, THE COMPLICATION RATES SHOULD DECREASE AND RISK BE MINIMISED. INVESTMENT IN BETTER STANDARD OF DIABETES CARE IS NEEDED NOW.

Treatment

DIABETES TREATMENT AND SELF-MANAGEMENT

Glucose monitoring

Type 2 diabetes

The majority of adults with type 2 diabetes (**59%**) treated diabetes with **tablets and/or injections other than insulin**, 27% were on metformin only, 8% managed diabetes through lifestyle interventions only (nutrition, exercise), and **6% had to take insulin**. Of those taking insulin, 42% had to inject once, 21% two/three times a day, and 37% were on basal-bolus therapy.

Most of those with type 2 diabetes (54%) do not check glucose levels daily. **30% monitor glucose levels once or twice a day**, and **16% multiple times** a day. Of those who have to monitor their glucose levels, **92% do it via finger-pricking** only, and **8% use flash** glucose monitoring.

Type 1 diabetes

All adults with type 1 diabetes take insulin to manage diabetes. The vast majority (**58%**) were on basal-bolus therapy (multiple daily injections - **MDI**). **33% were on insulin pumps** (including 17% on Automated insulin delivery - AID systems). 7% were injecting insulin 2/3 times a day.

The vast majority of adults (**66%**) use continuous glucose monitoring (CGM) or CGM as part of an AID system (**12%**). **10% used flash** glucose monitoring and 12% were using blood glucose meters to finger prick only.

Children with diabetes

Almost all children use insulin (if not, that's due to a very recent diagnosis). The majority (**54%**) were on **insulin pumps (28%)** or **AID systems (26%)**. 42% were on MDI.

The **majority of children (71%)** use CGM or **CGM as part of AID system (17%)**. Only **7% used flash** glucose monitoring and 5% were using blood glucose meters and finger pricking only.

UPTAKE OF TECHNOLOGY BY RESPONDENTS WITH TYPE 1 DIABETES IS VERY HIGH AND IS PROBABLY HIGHER THAN NATIONAL ESTIMATES. THERE ARE ALSO NO DIFFERENCES IN THE UPTAKE BETWEEN DUBLIN AND THE REST OF THE COUNTRY. THIS MIGHT BE DUE TO THE NATURE OF DATA COLLECTION (ONLINE RECRUITMENT VIA DIABETES GROUPS), SELF-SELECTION AND PARTICIPANTS' INTEREST IN DIABETES. ALL CHILDREN, HOWEVER, COMMENCED INSULIN PUMPS IN PUBLIC CLINICS. **29% OF ADULTS COMMENCED THEM PRIVATELY. A THIRD OF ALL WHO WERE ON PUMPS, WERE ON WAITING LISTS FOR LONGER THAN A YEAR.**

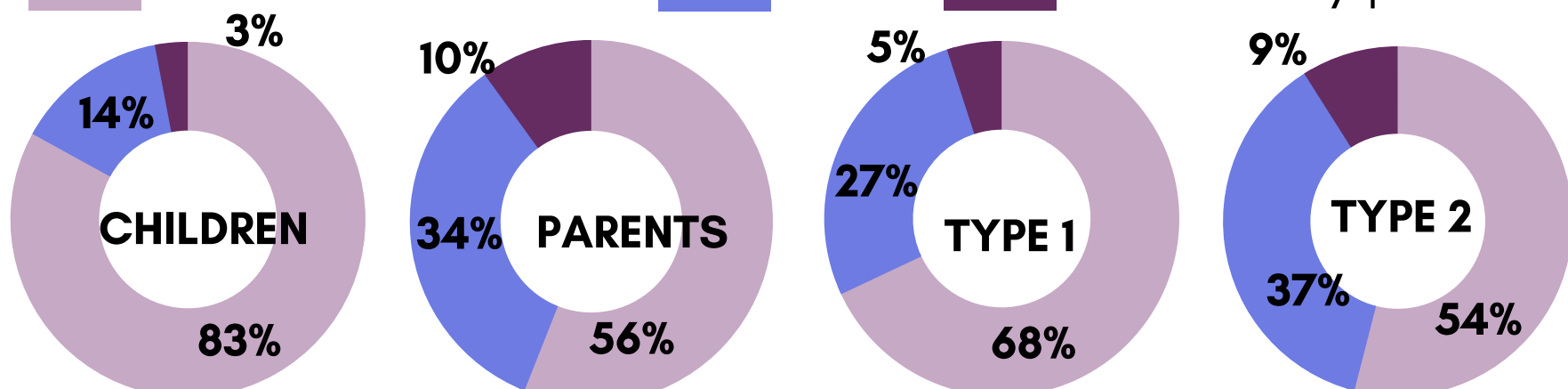
'12 years waiting for a pump. I have wanted a pump since diagnosed and was always actively discouraged from pursuing it. Long wait has made life very difficult.' (Adult)

'Starting on pump therapy has been life changing. (...) As a parent, I'm getting more sleep as there are very few hypo episodes compared to when using insulin injections' (Parent)

MY GENERAL WELL-BEING IS...

GENERAL HEALTH AND WELL-BEING

Excellent or Good Fair Poor or Very poor



People rate their own health and well-being as being good or excellent, but one-third of respondents assess it as fair, poor or very poor, mainly people with type 2 diabetes (46%) and parents/carers of children (44%).

44% of parents replied that their children's mental health is discussed as part of diabetes care, as well as their own mental health (16%). 17% of children and 7% of parents were given some advice, but would have preferred more. **22% of children and 49% of parents have not discussed their mental health but they would have liked to.**

15% of adults with type 1 and 21% of those with type 2 diabetes discuss their mental health as part of diabetes care. 6% of adults were given some advice, but would have preferred more. **46% of those with type 1, and 43% of those with type 2 have not discussed their mental health but they would have liked to.**



INFO@DIABETES.IE



WWW.DIABETES.IE

⊕ Access and Use of Diabetes Care

ACCESS

Children with diabetes

REIMBURSEMENT

91% of children are under the Long-Term Illness (LTI) Scheme, 48% of parents receive a carer's allowance, and 53% have a Medical or GP visit card.

MAIN PROVIDER

90% of children receive care in outpatient diabetes clinics. Only 4% are treated in private diabetes clinics.

DISTANCE

The majority of children (47%) travel for more than 25km to their main diabetes clinics, 15% for more than 50km.

Type 1 diabetes

93% of adults with type 1 diabetes are under the LTI Scheme, and 26% have a medical or GP visit card.

76% have their main diabetes care in outpatient diabetes clinics, 16% in private diabetes clinics. 3% receive GP care (privately).

Most adults (41%) travel for more than 25km to their diabetes clinics. 24% for more than 50km.

Type 2 diabetes

78% of adults with type 2 diabetes are under the LTI Scheme, 25% have a Medical Card and 14% GP visit card.

67% receive their main diabetes care in GP practices, but 38% pay for it privately (29% have medical/GP cards). 23% attend outpatient diabetes clinics and 8% private clinics.

The vast majority (67%) travel less than 10km or between 11-25km (16%). Less than 20% travel for more than 25km.

CARE RECEIVED IN 2022

Children with diabetes

Almost **all children (97%) had a face to face appointment in 2022**, 3% were only recently diagnosed. The **majority (68%) had three (37%) or more (31%) appointments**. For the first appointment with the current diabetes team 73% of children had to wait for less than 3 months. The **median waiting time between appointments was 4 months**.

Type 1 diabetes

88% of adults with type 1 diabetes had a face to face appointment in 2022, 9% had not, and 3% had a remote one. 41% had two appointments, 22% had three or more. **One-third had only one appointment**. For the first appointment with the current diabetes team 40% of adults had to wait for less than 3 months, and 16% for less than 6 months. **10% had to wait more than a year**. The **median waiting time between appointments was 8 months**.

Type 2 diabetes

Most adults with type 2 diabetes (**76%**) had a face to face appointment in 2022, but **20% had not**. Of those who had, **53% had two appointments, 22% had three or more. 20% had only one appointment**. For the first appointment with the current diabetes care provider, 43% had to wait for less than 3 months, and 12% for less than 6 months. **9% had to wait more than a year**. The median waiting time between appointments was 6 months.

ANNUAL REVIEW CHECKS IN 2022

PERCENTAGE OF PEOPLE WITH DIABETES WHO HAD THE FOLLOWING ANNUAL DIABETES CHECKS IN 2022:

	Weight/BMI	Blood pressure	HbA1c	Time in Range (TiR)*	Cholesterol	Creatinine	Micro-albumin	Foot exam**	Retina Screen (Eyes)***
Children with diabetes	85%	70%	94%	90%	52%	59%	59%	25%**	37%***
Type 1 diabetes	74%	91%	93%	76%	87%	80%	78%	64%	84%
Type 2 diabetes	68%	85%	92%	38%*	84%	74%	68%	58%	84%

* TIME IN RANGE IS USUALLY CHECKED ONLY IN PEOPLE USING CGM **/** SCREENING FOR COMPLICATIONS IS RECOMMENDED USUALLY AT 12 YEARS OF AGE / PUBERTY

IMPORTANT!

Clinical guideline recommendations state that children with diabetes should have appointments quarterly, and adults with diabetes every 6 months. The annual reviews including blood/urine tests and other checks should be done annually (with some exceptions). The findings of this survey suggest that **not everyone had all annual review checks in 2022**. Moreover, **9% of adults with type 1 diabetes had no appointment at all, 33% of those who had, received only one appointment in 2022**. Of those with type 2 diabetes, 20% had no appointment, and another 20% had one appointment. In these cases, **the clinical guideline recommendations for 42% of adults with type 1, and 40% with type 2 diabetes are not met**.

DIABETES EDUCATION

Children with diabetes The majority of children (87%) received diabetes education: 40% individual only, 21% in group setting, and 26% received both types of education. Almost all know why they have to receive their medication (insulin), are aware of different treatment options and 85% have a plan on how to manage diabetes, but 48% would have preferred to have it written.

Type 1 diabetes The majority of adults with type 1 diabetes (58%) were offered structured diabetes education (DAFNE or Berger). 48% attended. 24% have not although they would have liked to. Almost all know why they have to receive (insulin), and 90% are aware of different treatment options. 71% have a plan on how to manage diabetes, but 61% would have preferred to have it written.

Type 2 diabetes The majority of adults (59%) were offered structured diabetes education, 31% have not, but would have liked to. 51% attended structured education: mainly CODE (35%) and DESMOND (14%). Almost all know why they have to receive their treatment, but only 70% are aware of different treatment options. Only 50% have a plan on how to manage diabetes and 73% would have preferred to have it written.





Quality of diabetes care

Children with diabetes

The median haemoglobin A1c level (HbA1c) of those who decided to share this information (n=53) was 54 mmol/L (7.1%) and was at similar levels as in 2020 (pre-COVID pandemic).

Type 1 diabetes

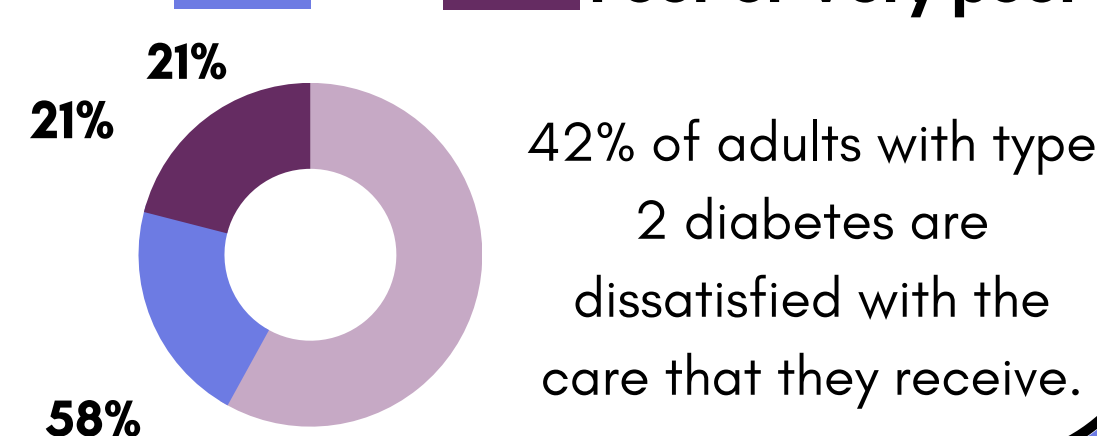
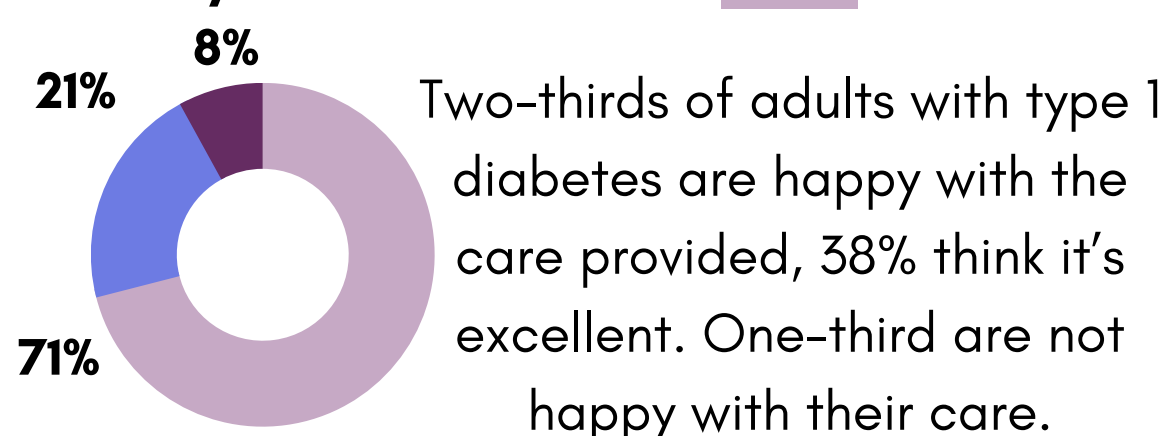
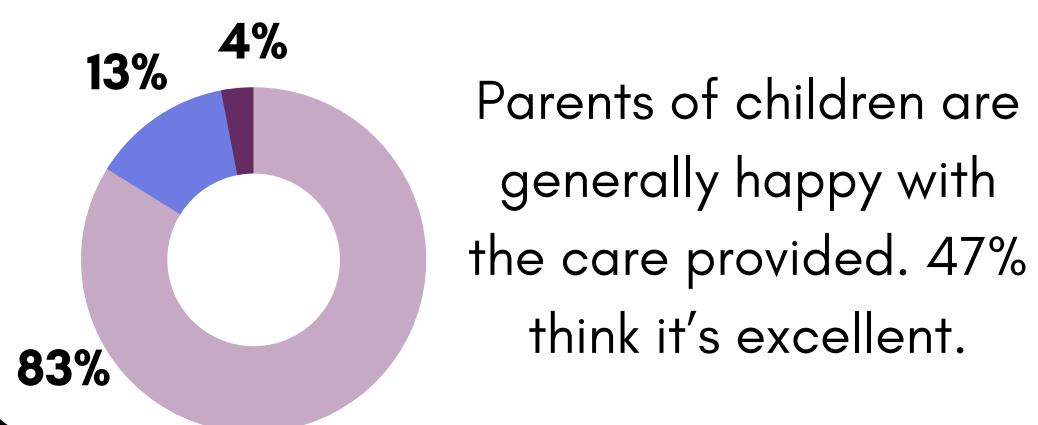
The median HbA1c level of those who decided to share this information (n=119) was 53 mmol/L (7%) and was at similar levels or lower than in 2020 (pre-COVID pandemic).

Type 2 diabetes

The median HbA1c level of those who decided to share this information (n=49) was 52 mmol/L (6.9%) and was at similar levels or higher than in 2020 (pre-COVID pandemic).

DIABETES CARE THAT IS PROVIDED TO ME / MY CHILD IS...

Excellent or Good Fair Poor or Very poor



OPINION ABOUT CARE

CONFIDENCE WITH DIABETES MANAGEMENT

Parents/carers of children (94%) replied that as a result of their diabetes appointments in 2022, they are **generally confident with managing diabetes**. 54% of them got more confident following recent diabetes appointment, for 40% it remained the same.

Adults with type 1 diabetes (96%) are **generally confident with managing diabetes** as a result of their diabetes appointments. 44% replied that they gained more confidence after the recent diabetes appointment, for 52% confidence remained the same.

Adults with type 2 diabetes (93%) are **generally confident with managing diabetes** as a result of diabetes appointments. 55% gained more confidence as a result of recent diabetes appointments in 2022, for 38% it remained the same.

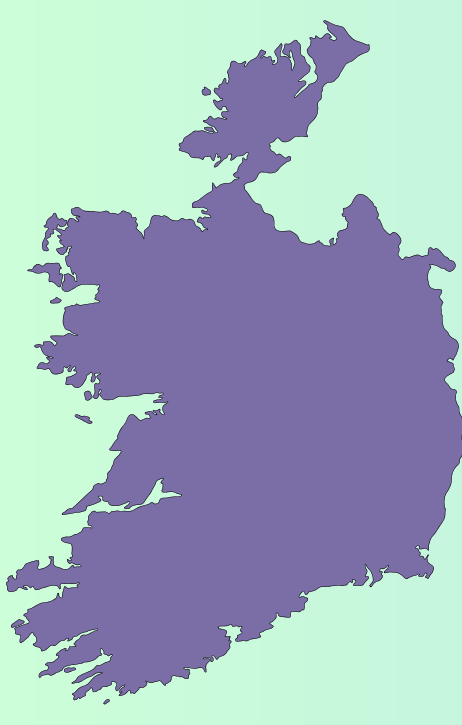
IMPORTANT!

13% of adults with diabetes had no diabetes appointment in 2022. For 28% of them the last appointment was in 2021, 23% in 2020 and 2019, 23% had their last appointment before 2018. 50% of them replied that they are confident in managing their diabetes. For 40% their confidence levels in managing diabetes in 2022 are a lot worse than before.

Regular and frequent diabetes appointments, as advised by clinical recommendations, are essential to provide people with diabetes with confidence and support regarding their diabetes management.

DUBLIN VS. REST OF THE COUNTRY

We often hear from people that diabetes care (and overall, health care) is centralised and that a post-code lottery in accessing services exists. We compared some of the responses from people based in Dublin (31% of all responses) to those living in other counties (69%). We found that, for example, adults with type 1 diabetes more often pay privately for their diabetes care if they live outside of Dublin (19% vs. 10%). They were also more often diagnosed with diabetes-related complications or comorbidities (41% v 35%), despite the same diabetes duration. The uptake of technology was, surprisingly, similar. Among people with type 2 diabetes, those from outside of Dublin were usually receiving their care in general practices (75% vs. 55%). People from Dublin more often were treated in outpatient diabetes hospital clinics (27% vs. 20%) or attended diabetes clinics privately (13% vs. 5%). Among people with type 2 diabetes, those living outside Dublin more often had increased occurrence of diabetes-related complications or comorbidities (48% vs. 20%), but it was mainly related to comorbidities like hypertension (40% vs. 18%) and mental health related issues (24% vs. 5%), not typical long-term diabetes-related complications.



CONCLUSIONS

In the absence of a diabetes registry and clinical audits, this survey explored the experiences of those living with diabetes and is **the first data source** about access and use of diabetes services, which **informs the key stakeholders and policy-makers about diabetes care and its gaps in Ireland**. The survey findings were presented to healthcare professionals and Oireachtas Members. Based on the survey findings, our Pre-Budget Submission 2024 has been launched with one main request: to develop a 10-year National Diabetes Strategy. Without strategic planning and long-term thinking, the increasing prevalence of diabetes and diabetes-related comorbidities and complications in an ageing population will hugely affect Government budgets due to unnecessary and avoidable hospitalisations and admissions. **We need to act now to reduce the disparities and offer the best standard of care to all people with diabetes, no matter where they live.**

Click [HERE](#) and [HERE](#) or scan for more information references



THE FULL REPORT WITH THE SURVEY FINDINGS IS AVAILABLE FOR RESEARCH PURPOSES UPON REQUEST. CONTACT INFO@DIABETES.IE
We would like to THANK ALL THE STUDY PARTICIPANTS who found time to complete the survey and share their experiences, the Diabetes Ireland Research Alliance (DIRA) and the RCSI: University of Medicine and Health Sciences for their support in the research process.