

KEYNOTE ADDRESS

CONNECTING RESEARCH TO PATIENT CARE



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EPIDIO DIABETES CONFERENCE

MAY 22, 2021 | WEBINAR

EMPOWERING PATIENTS
FOR
INDIVIDUALIZED CARE



NOTHING TO DISCLOSE



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OUTLINE OF PRESENTATION

- 1) T1D Exchange Clinic Registry: origin, background and current status
- 2) Updated Findings
 - i. Technology Use
 - ii. Glycemic Control
 - iii. Acute Complications
- 3) International Collaborations
- 4) Summary and Impact of the Registry and Network
- 5) Looking Forward



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T1D EXCHANGE CLINIC REGISTRY: ORIGIN

- Created through the Helmsley Charitable Trust
 - Mission to improve the speed of T1D research and development through the creation of new tools and strategic collaborations with all T1D stakeholders.
- David Panzirer – Trustee
- After in depth assessment of what was missing from T1D research, it was discovered that we really didn't understand how persons with T1D were managing diabetes and what the state of care was in the US
- The concept of building a clinic network of pediatric and adult endocrinology practices and establishing a large clinic-based registry to collect data on how persons with T1D were managing diabetes was formulated



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T1D EXCHANGE CLINIC REGISTRY: BACKGROUND

- 81 pediatric and adult endocrinology US clinics
 - 57 US sites initially were selected, later 24 more sites added
- Total registry enrollment 35, 147
 - Initial cohort: 2010 to 2012 - ~ 26,000
 - An additional ~10,000 enrolled from 2012 to 2015
- Data collected annually through clinic medical records and participant questionnaires



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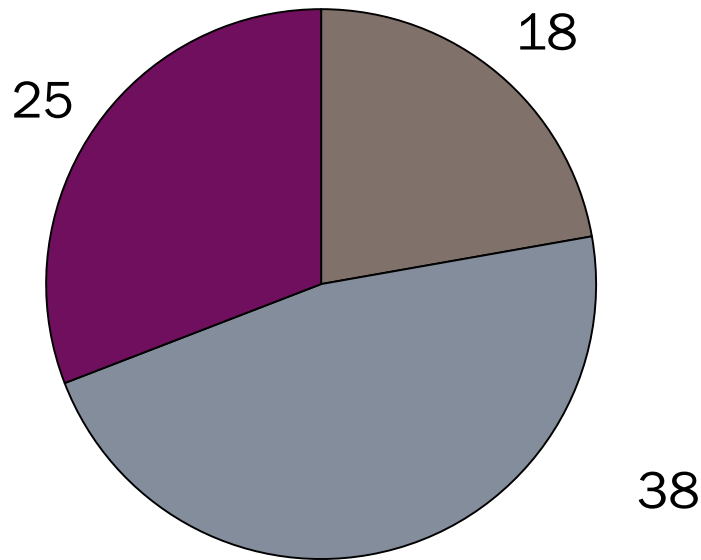
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CLINICAL CENTERS – 81 CLINICS

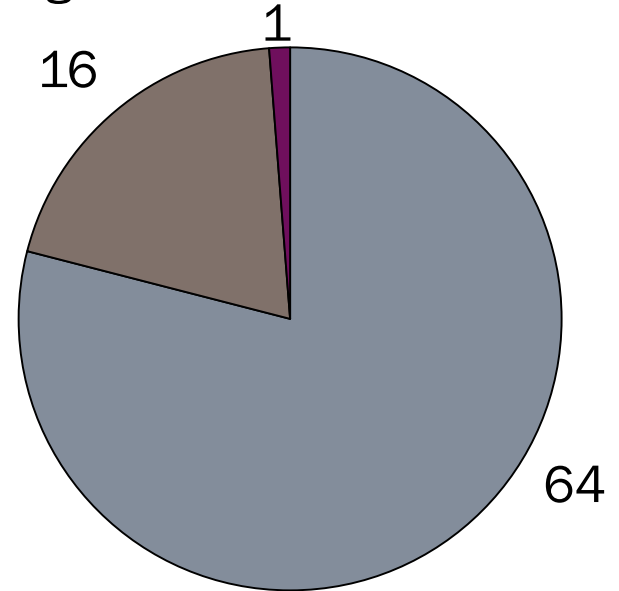
Types of Patients

■ Adult ■ Pediatric ■ Both



Setting

■ Institution ■ Community
■ Managed Care



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CLINICAL CENTERS



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T1D EXCHANGE CLINIC REGISTRY DATA COLLECTION

- Data collected at enrollment and then annually
- Informed consent obtained
- Two-thirds of data obtained directly from participant's completion of a questionnaire
- One-third from medical records/clinic database



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COMPONENTS OF PARTICIPANT QUESTIONNAIRE

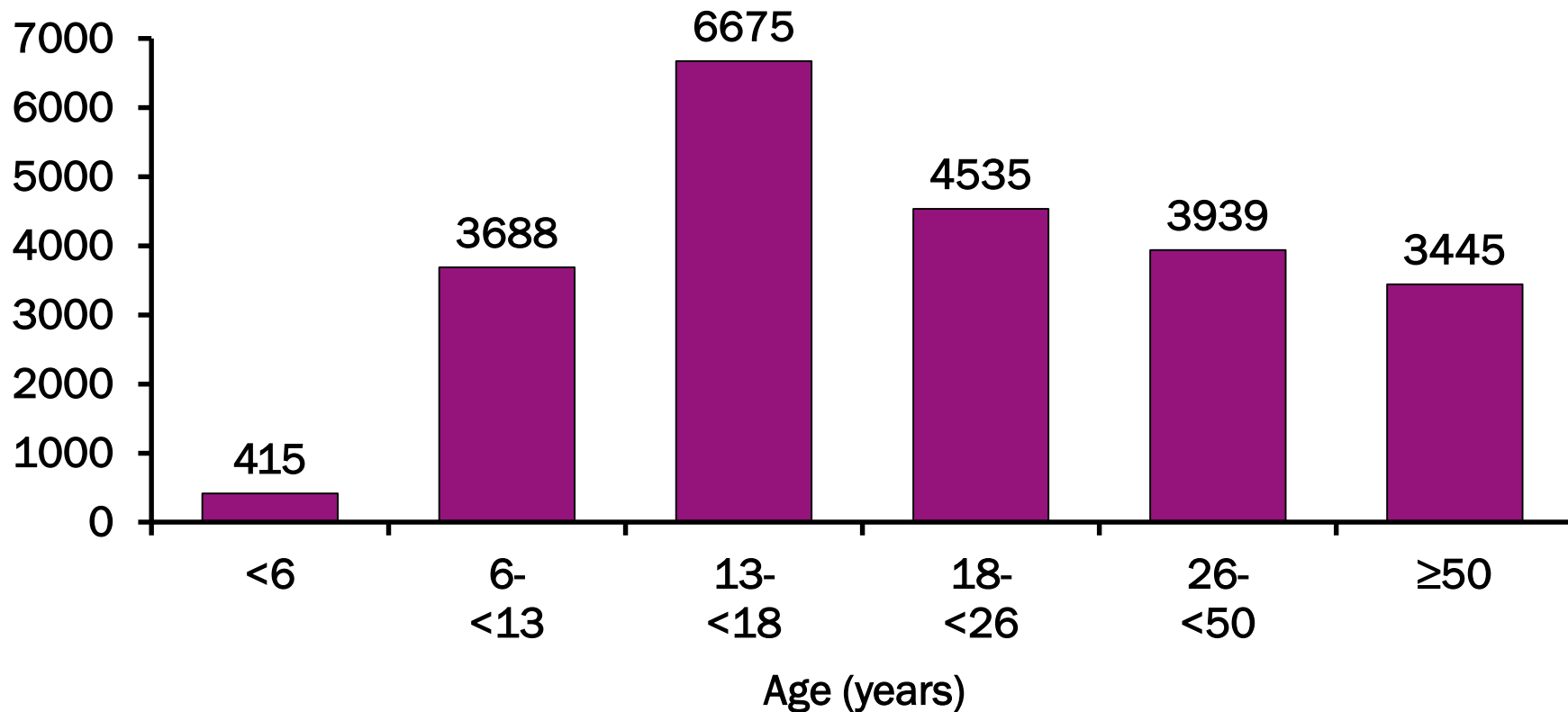
- Demographic and SES information
- Presentation and initial Tx of T1D
- Severe events (SH, DKA, hospitalizations)
- Insulin management
- Glucose monitoring
- General health and life style
- Family hx of T1D & other auto-immune diseases



COMPONENTS OF CLINIC DATA

- Diagnosis of T1D
 - Hx of DKA and SH
 - Insulin management
 - Glucose monitoring
 - Other medications
 - Other medical conditions/T1D complications
 - Physical exam
 - Lab values
- 

AGE DISTRIBUTION

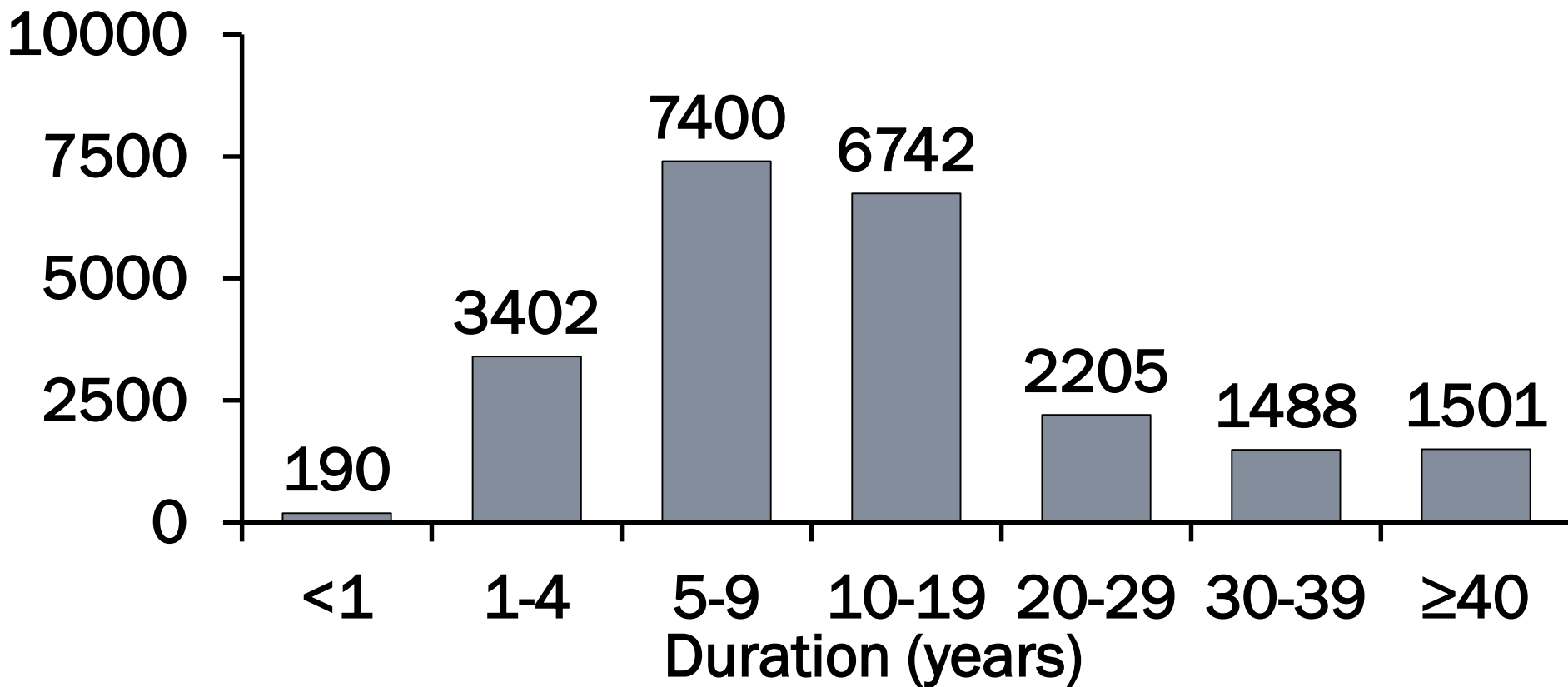


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DURATION OF T1D



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T1D EXCHANGE CLINIC REGISTRY: TOP FINDINGS – TECHNOLOGY USE

UPDATED DATA 1/1/16 – 3/31/18
N=22,929



Across all age groups over half of registry participants were using an insulin pump (~2/3rds).

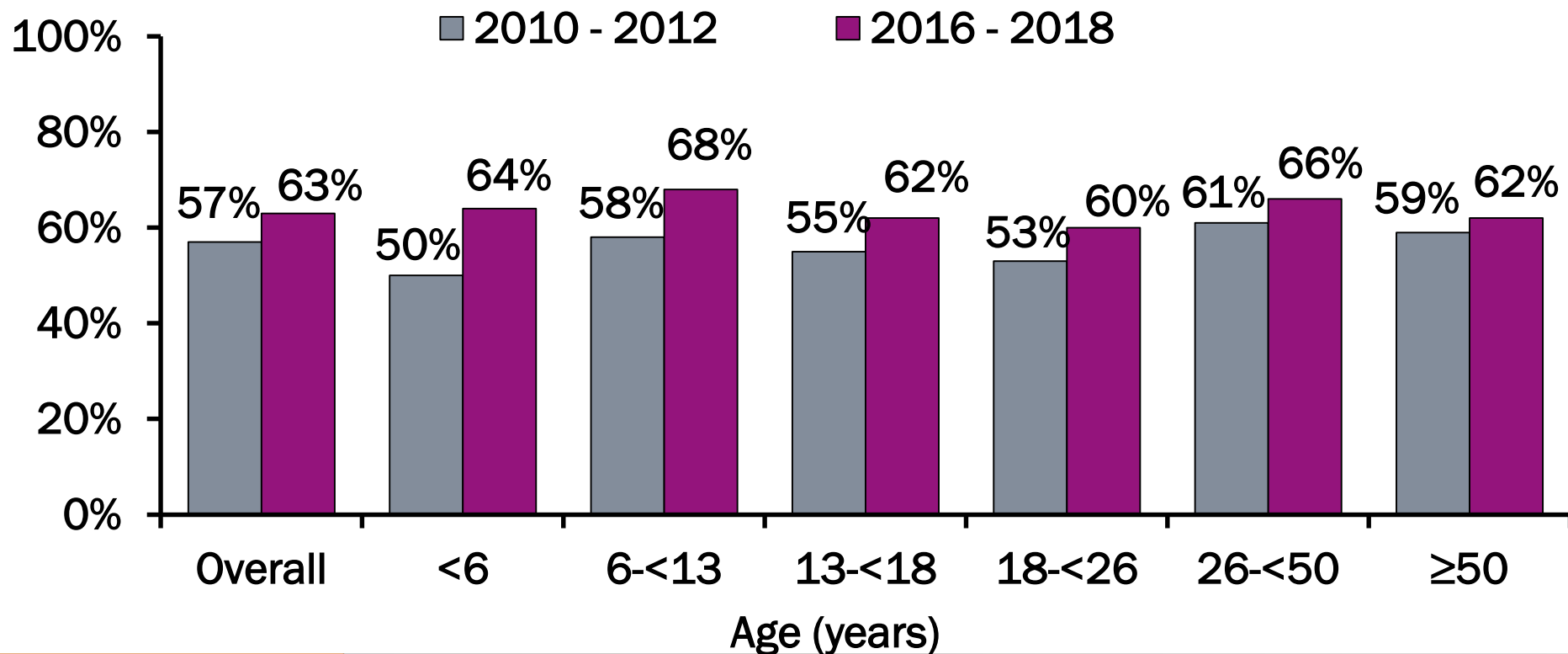


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INSULIN PUMP USE HAS INCREASED MAINLY IN YOUTH



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Continuous Glucose Monitoring use increased substantially, with the largest increase occurring in youth <6 years old.

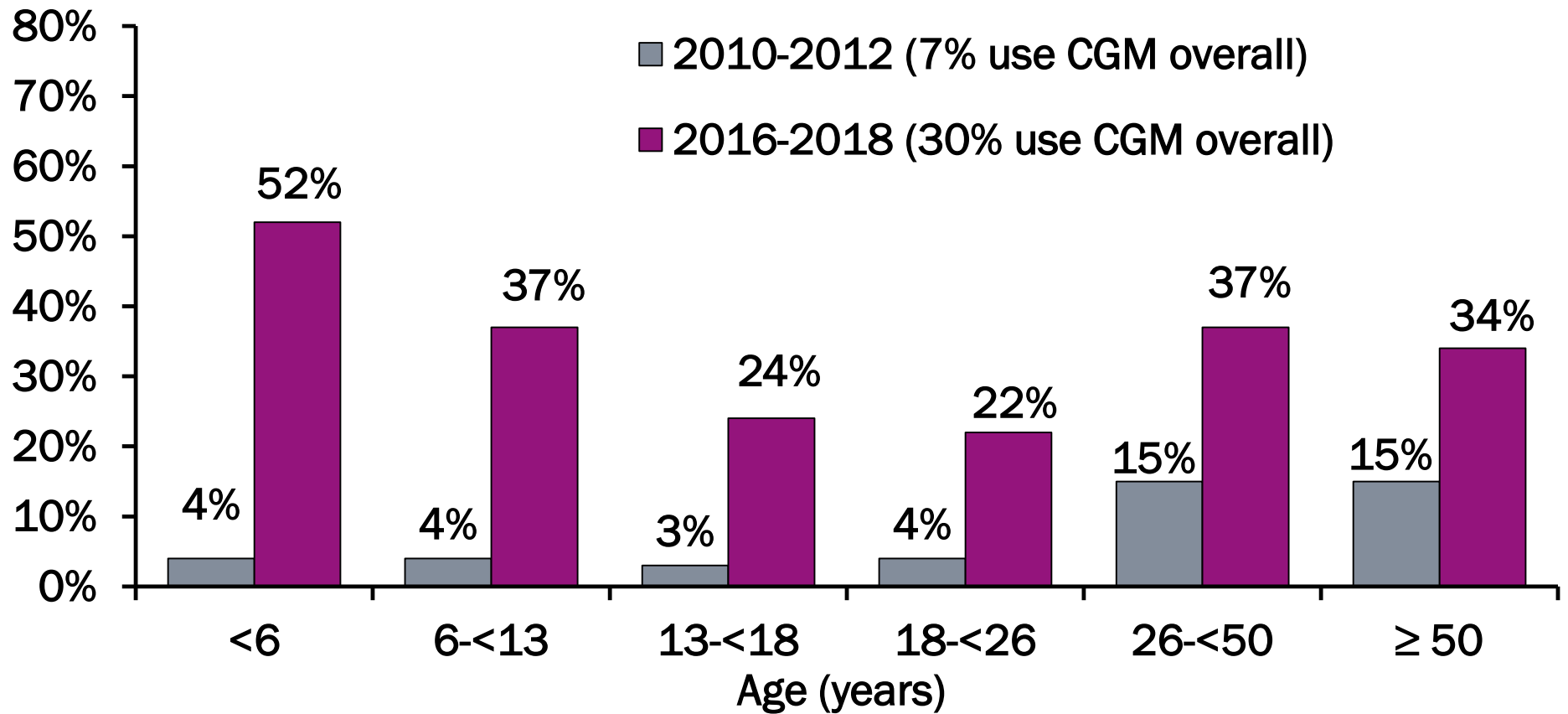


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CGM USE INCREASED SUBSTANTIALLY

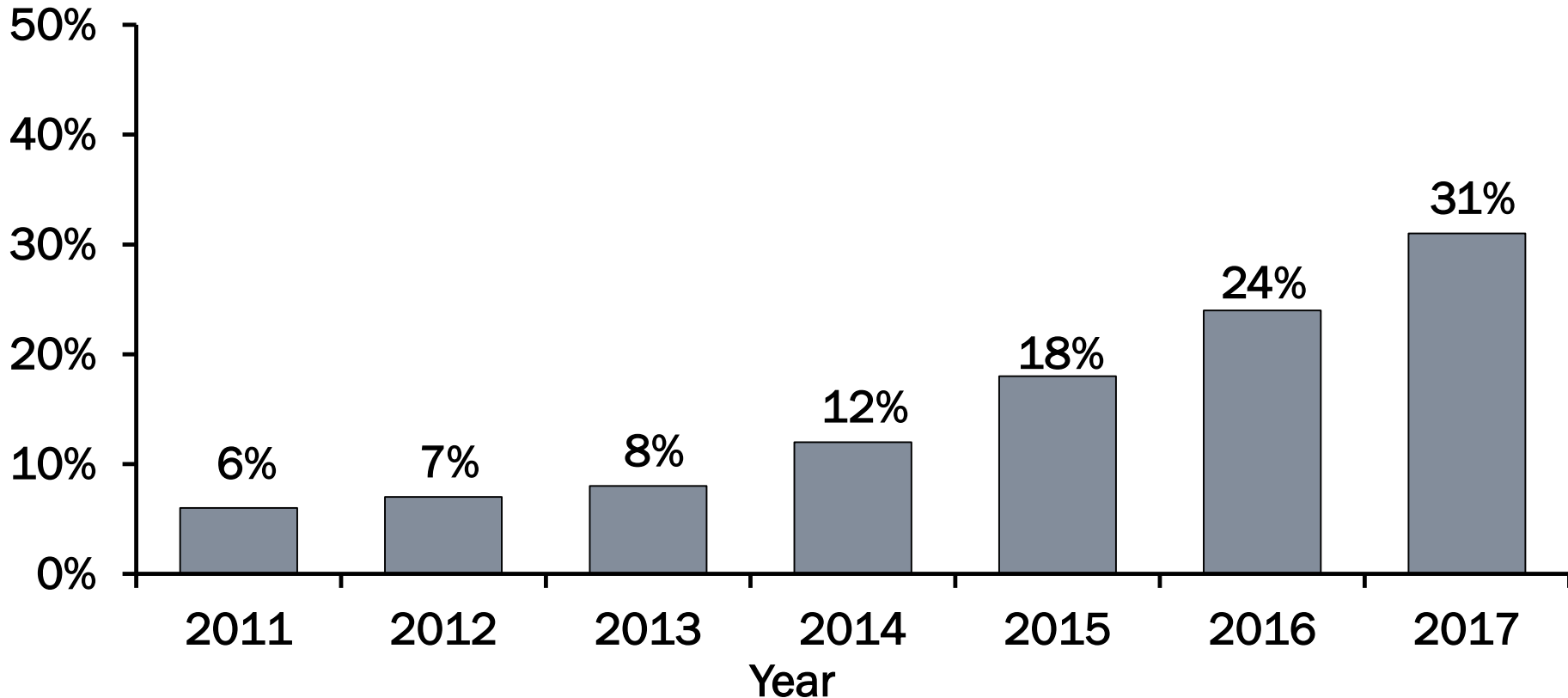


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CGM USE BY YEAR



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Use of CGM was more common among participants using an insulin pump but was also used by a substantial number of adults with T1D who use injections for insulin delivery.

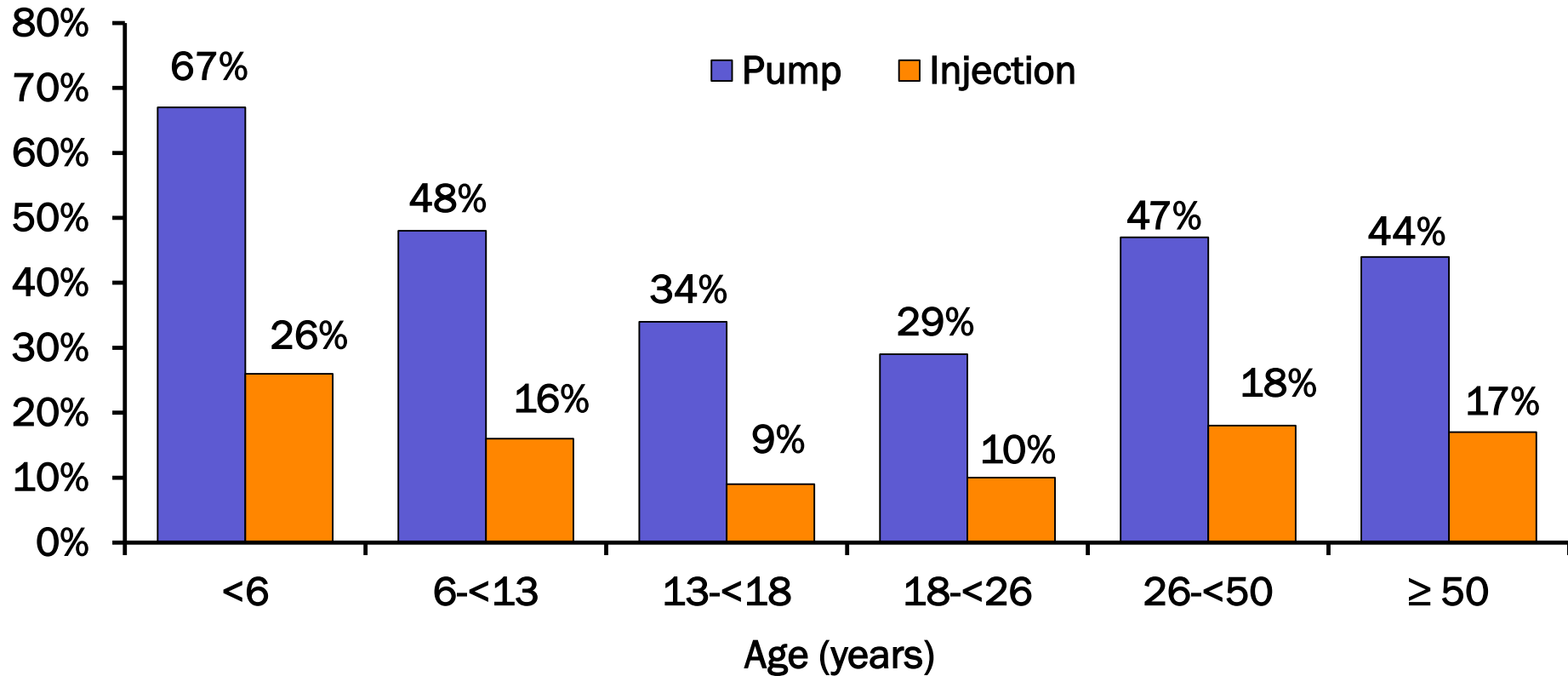


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CGM USE IN T1DX BY INSULIN DELIVERY METHOD



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T1D EXCHANGE CLINIC REGISTRY: GLYCEMIC CONTROL

DATA 1/1/16 - 3/31/18
N=22,929



Most adults and children with T1D
did not achieve HbA1c goals set by
American Diabetes Association (ADA).



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2018 ADA HBA1C TARGETS NOT MET BY MOST



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**Adolescents and young adults with
T1D have higher A1c levels than
younger or older individuals with T1D**

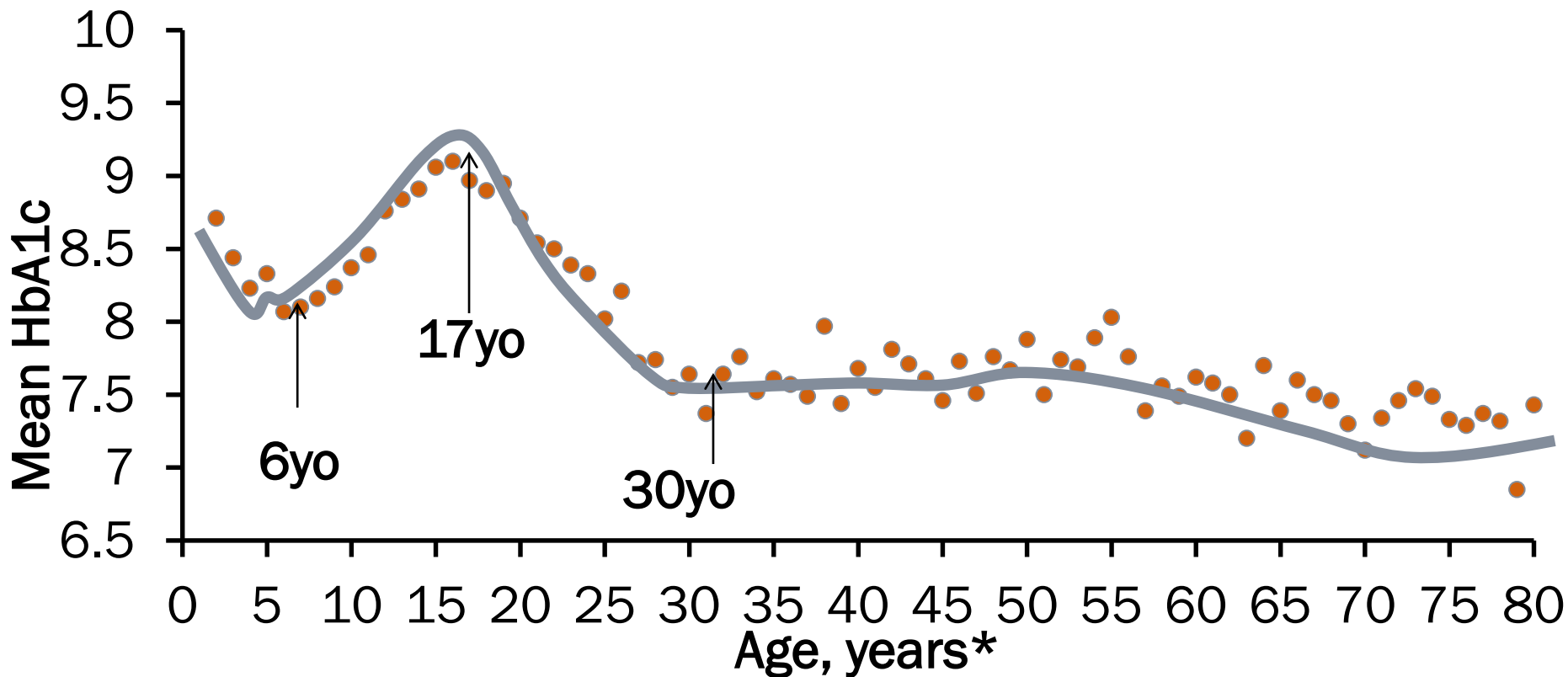


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AVERAGE A1C BY AGE



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Lower socio-economic status (income and education level) and non-Hispanic black race are associated with higher HbA1c across the age range.

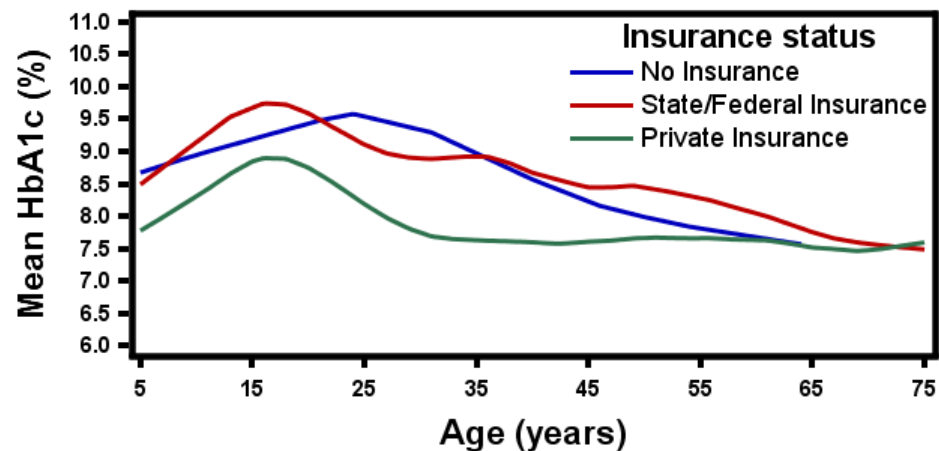
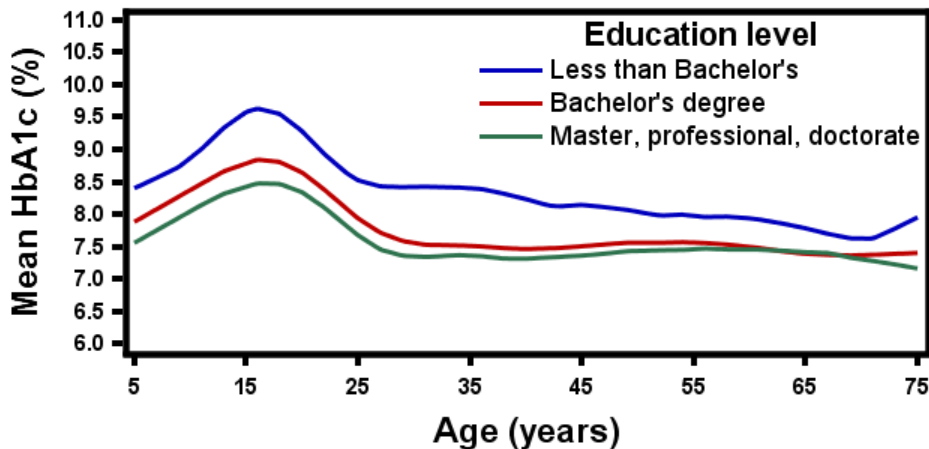
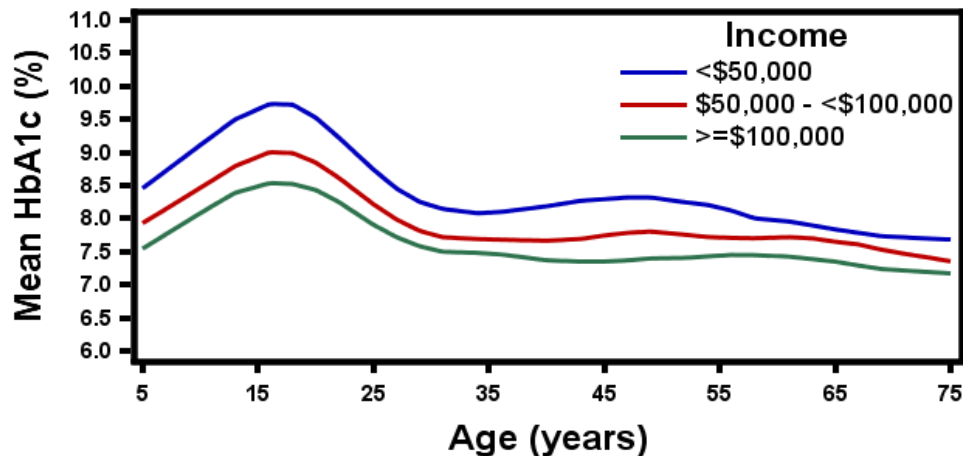


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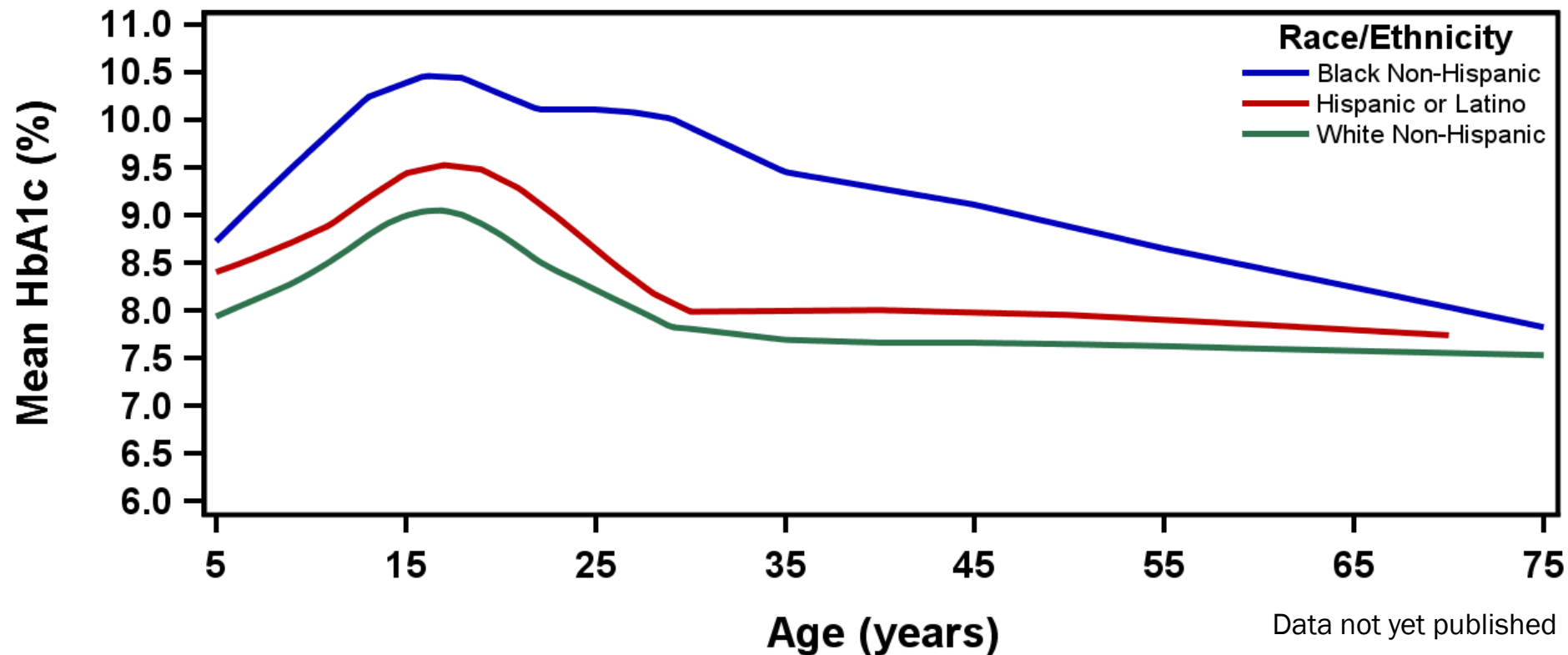
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AVERAGE A1C FROM EARLY CHILDHOOD TO ELDERLY BY SES



AVERAGE HbA1c BY AGE AND RACE/ETHNICITY



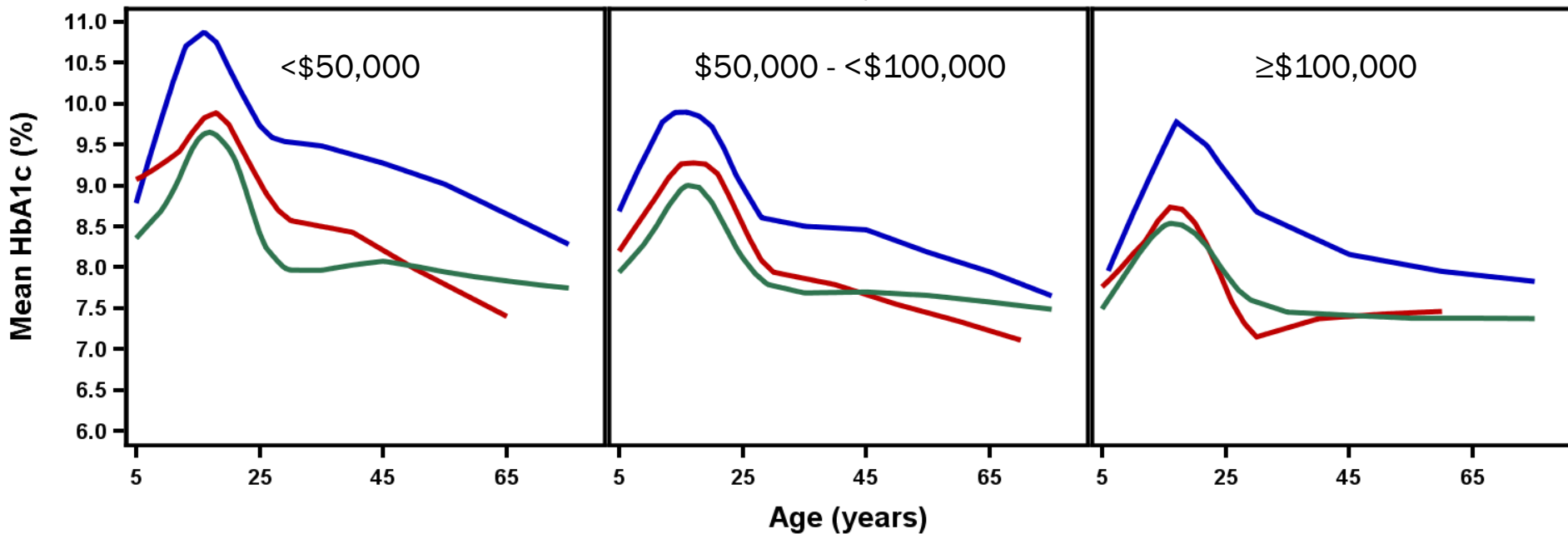
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HbA1c ACCORDING TO INCOME AND RACE/ETHNICITY

Race/Ethnicity
— Black Non-Hispanic
— Hispanic or Latino
— White Non-Hispanic



Data not yet published



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**CGM Users had a lower average HbA1c
regardless of insulin delivery method.**

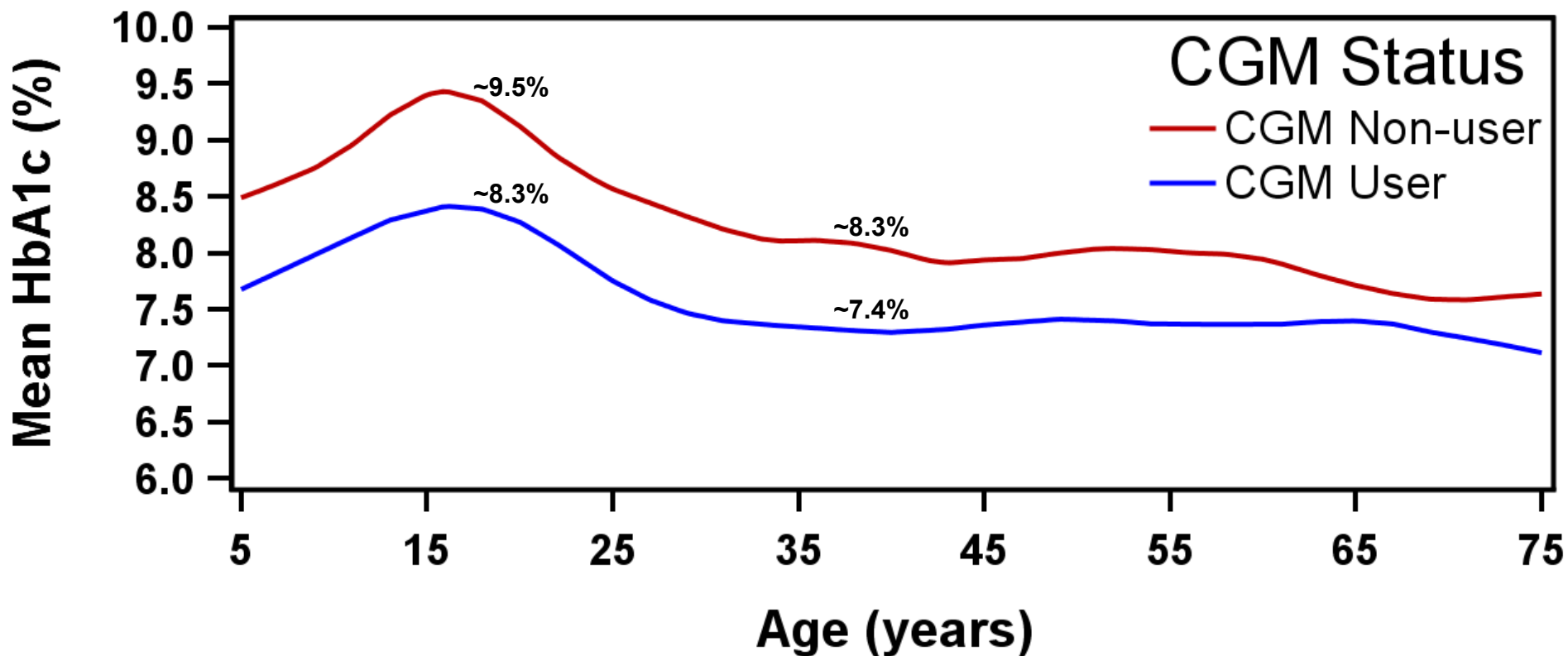


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AVERAGE A1C BY AGE AND CGM USE

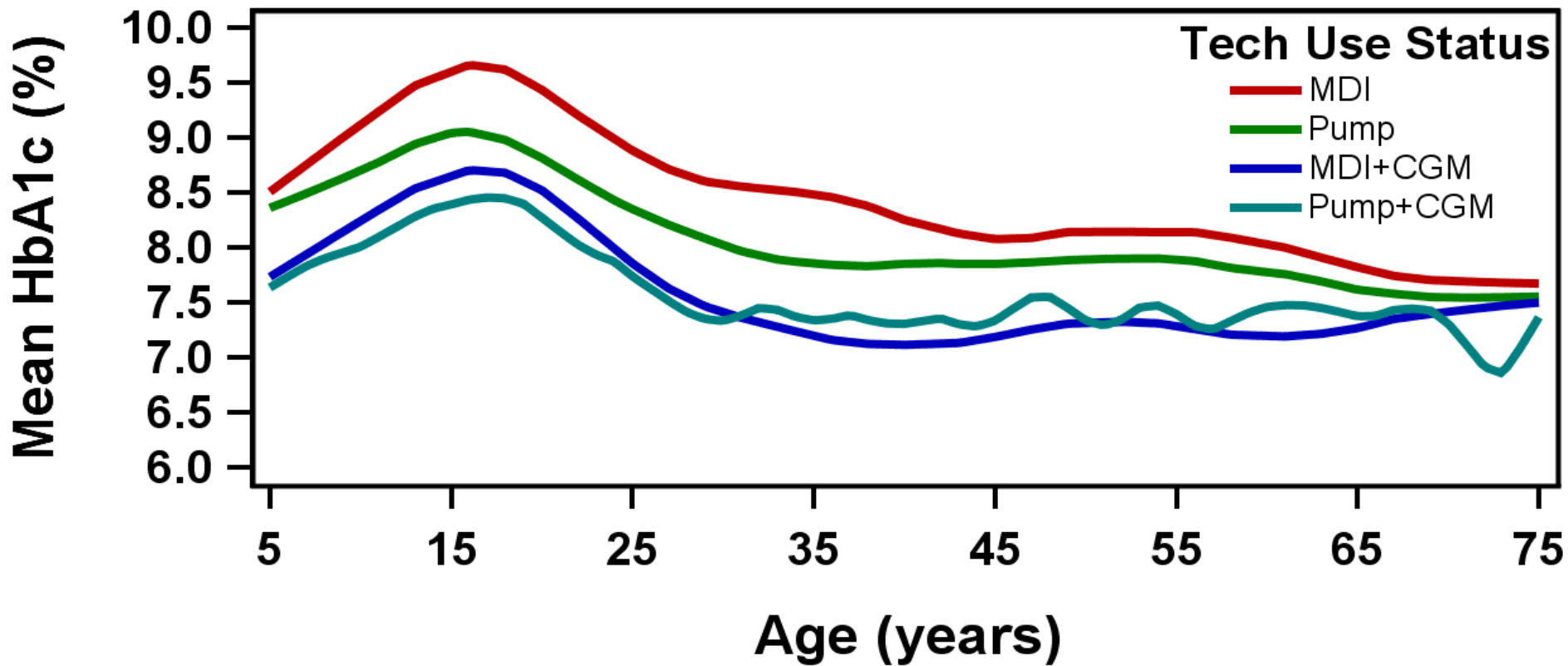


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A1C BY TECHNOLOGY USE



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**CGM Users had a lower average HbA1c
regardless of Income or Insurance Status**

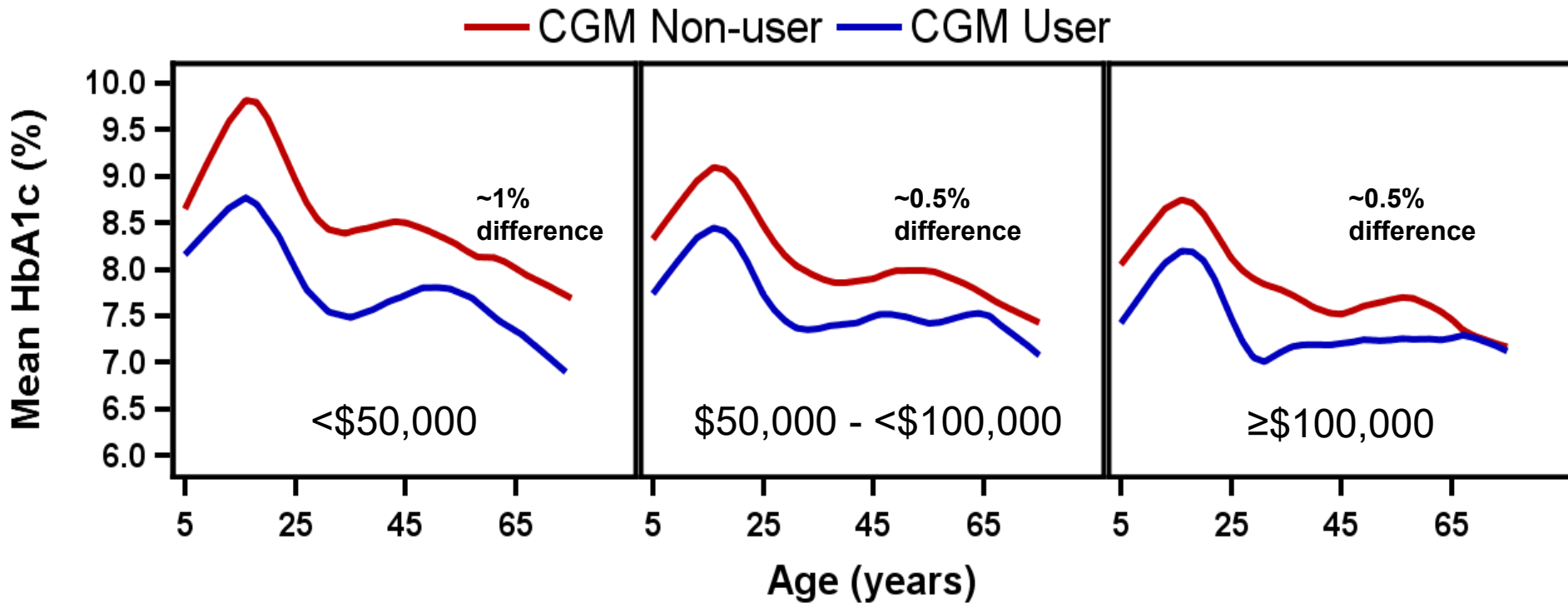


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AVERAGE A1C ACROSS AGES BY INCOME AND CGM

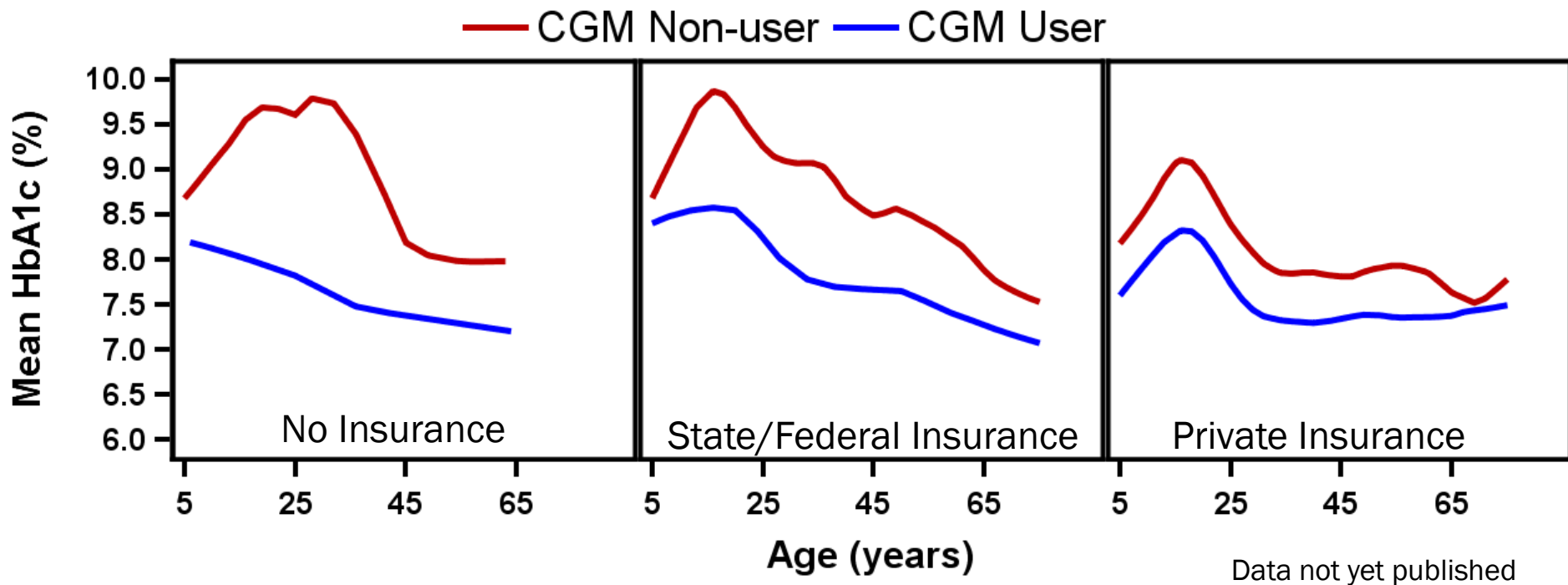


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AVERAGE A1C BY INSURANCE AND CGM



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**T1D EXCHANGE CLINIC
REGISTRY:
TOP FINDINGS – ACUTE
COMPLICATIONS**

**N = 11,109 completing the Year 5
questionnaire 2016-2018**

**Severe hypoglycemia resulting in seizure
or loss of consciousness occurred
more commonly in adults with
longstanding type one than has been
appreciated.**

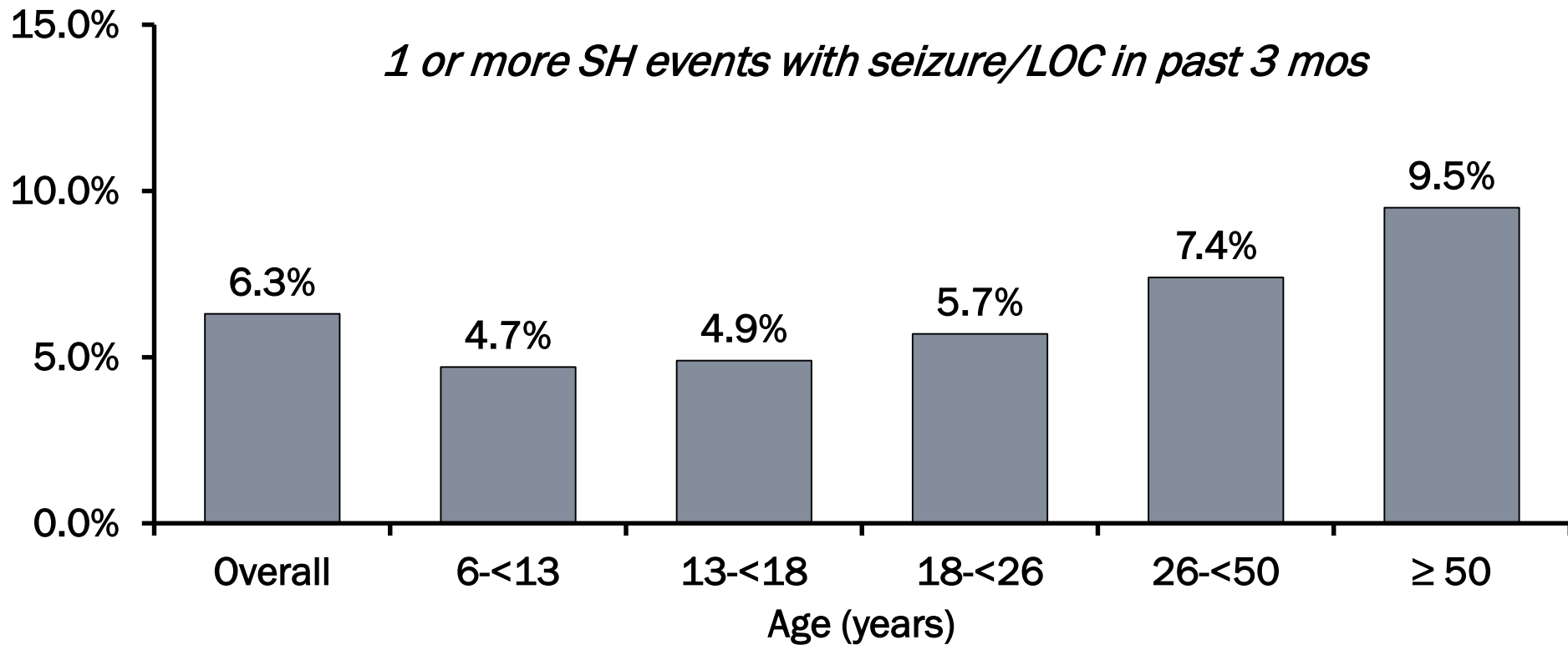


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SEVERE HYPOGLYCEMIA IN PAST 3MO BY AGE



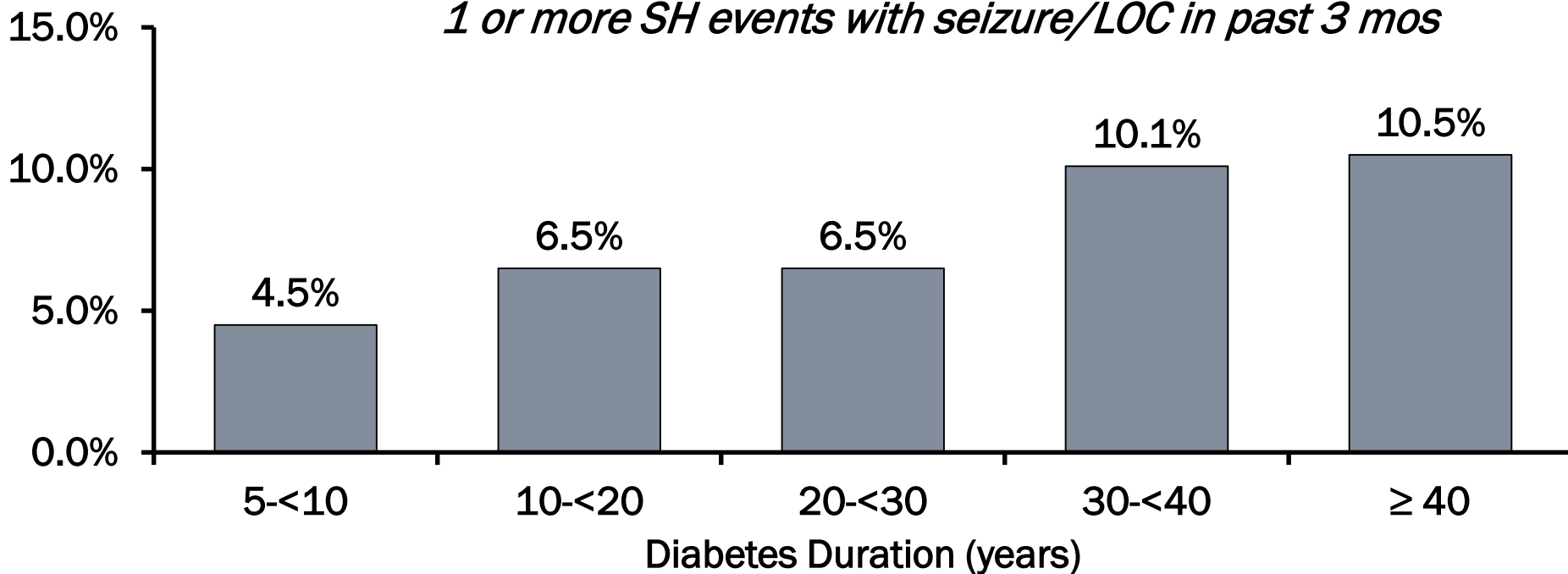
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SEVERE HYPOGLYCEMIA IN PAST 3MO BY T1D DURATION

1 or more SH events with seizure/LOC in past 3 mos



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In both children and adults the frequency of severe hypoglycemia was higher for both those with really low A1c AND really high A1c.

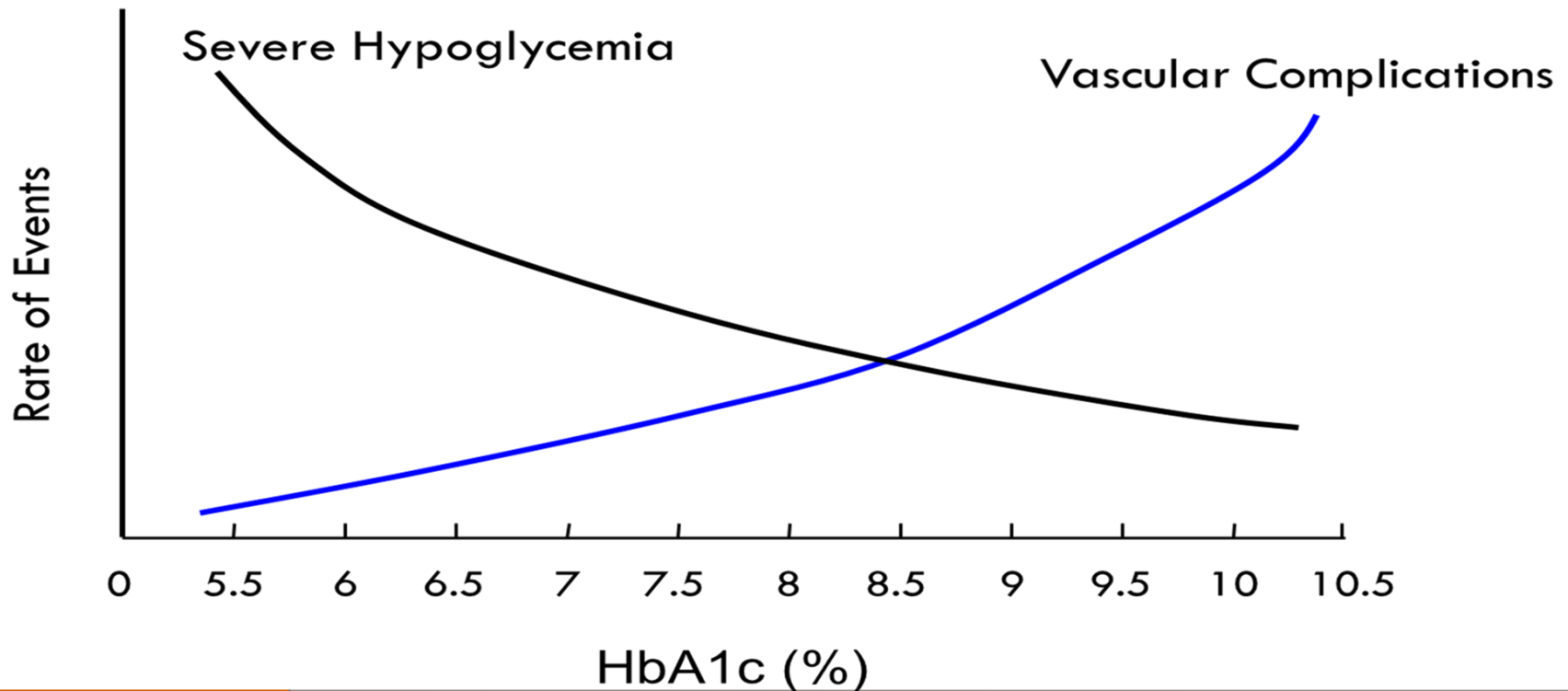


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1980s DCCT Findings: Lower HbA1C = Fewer Complications *BUT* More Hypo

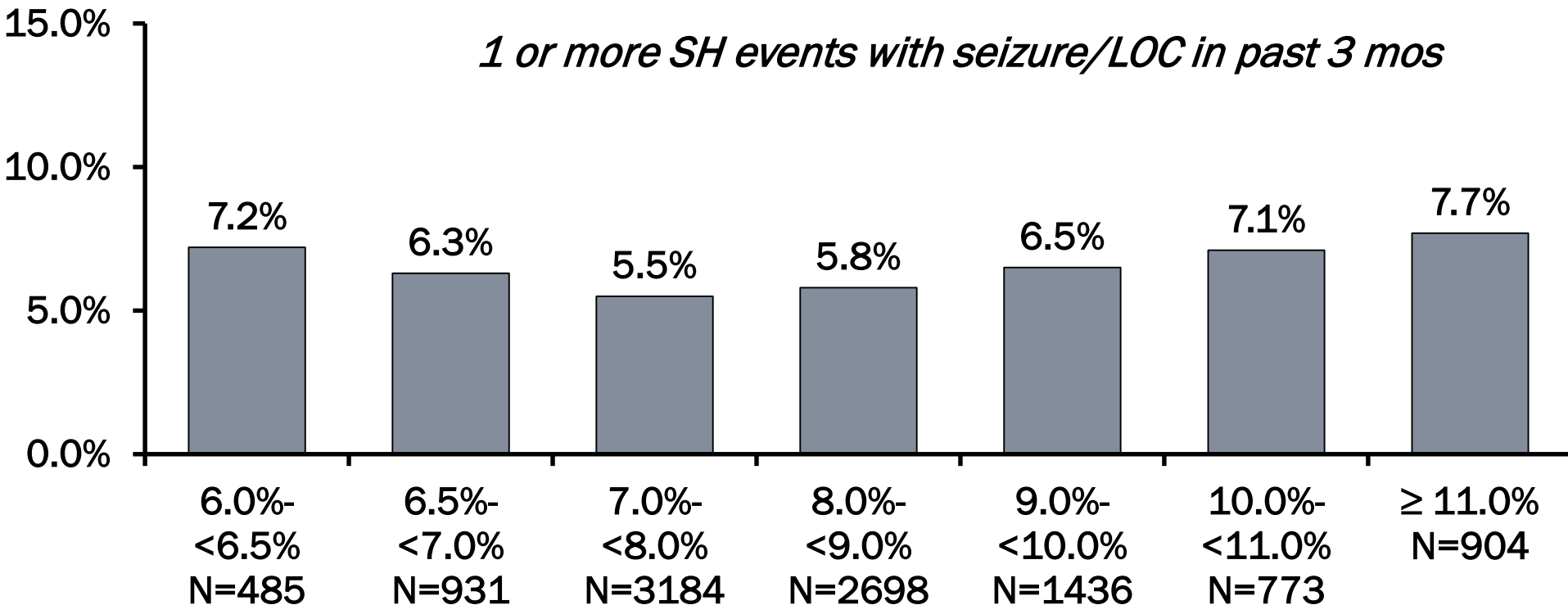


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SEVERE HYPOGLYCEMIA IN PAST 3MO BY HBA1C



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**The frequency of severe hypoglycemia
was less common among those using an
insulin pump or CGM**



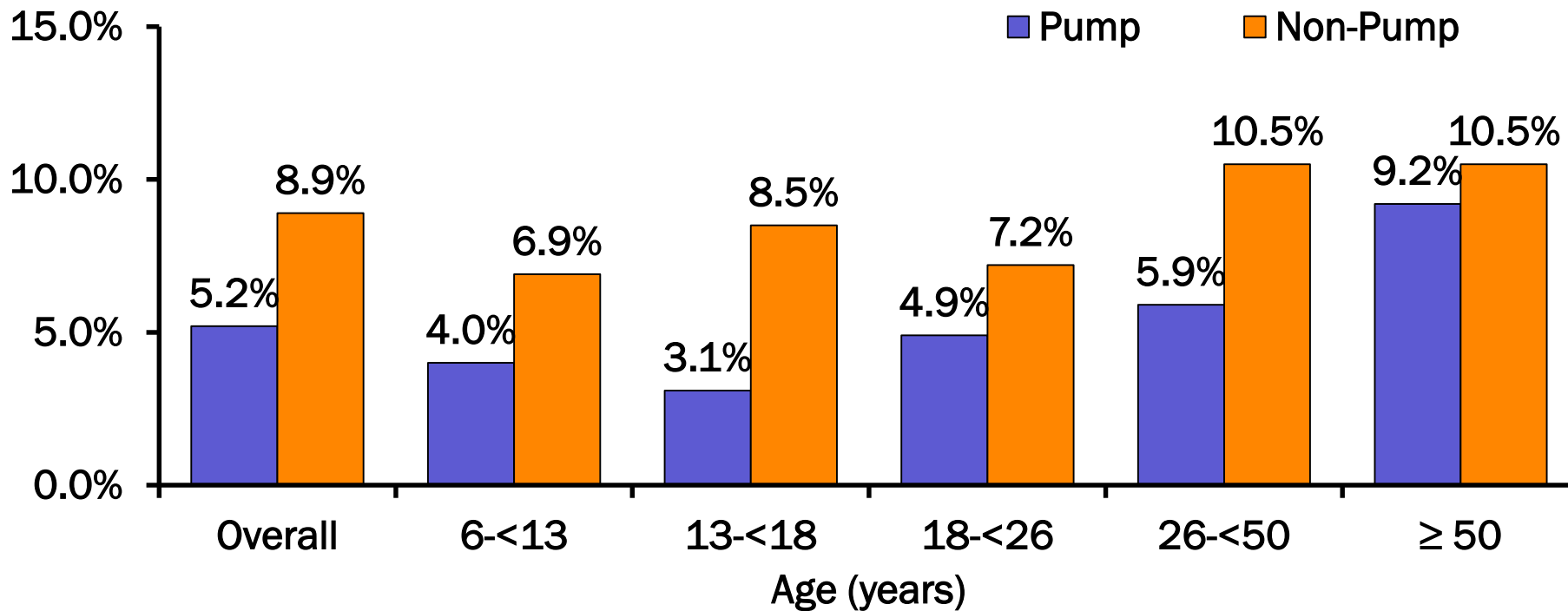
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SEVERE HYPOGLYCEMIA IN PAST 3MO BY PUMP USE

1 or more SH events with seizure/LOC in past 3 mos

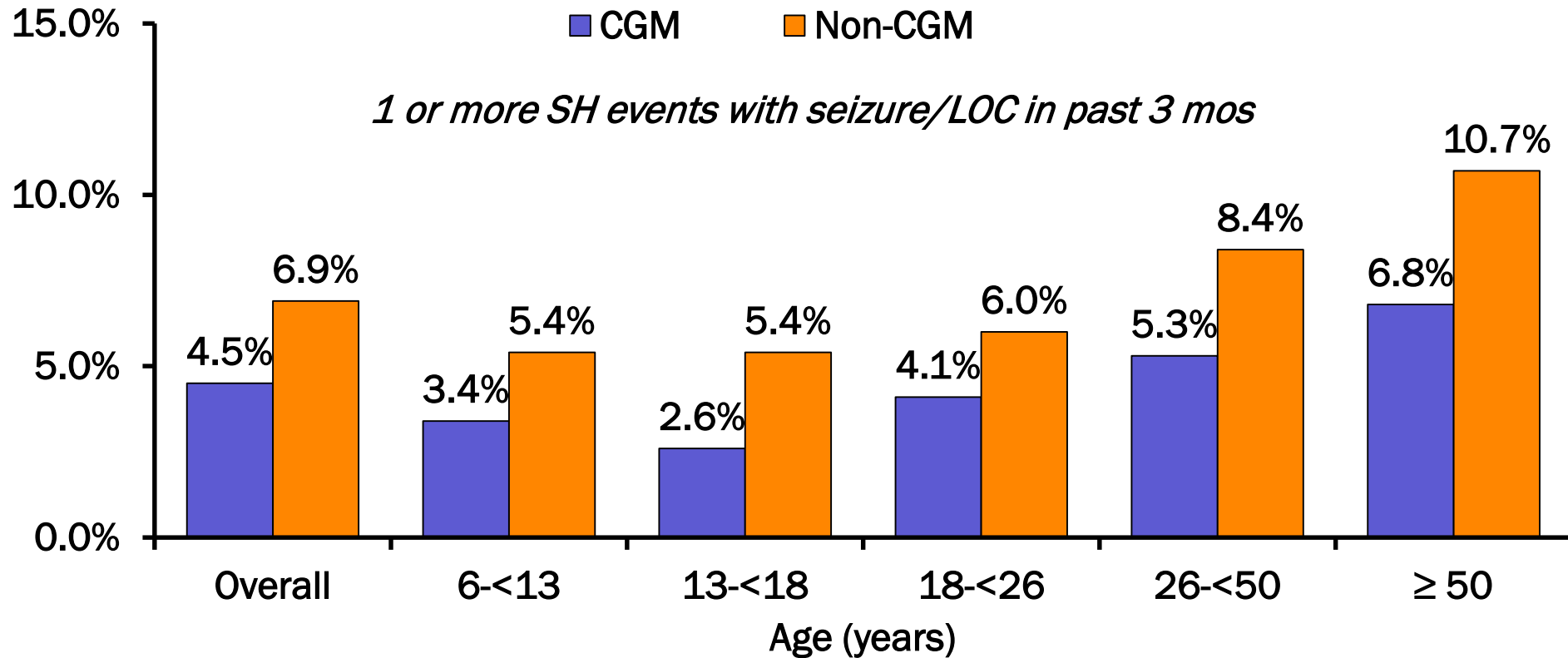


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SEVERE HYPOGLYCEMIA IN PAST 3MO BY CGM USE



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Diabetic ketoacidosis (DKA)* occurred more frequently in youth and young adults and among those with high HbA1c

*DKA defined as hospitalization overnight for very high blood sugar with ketones present in urine/blood

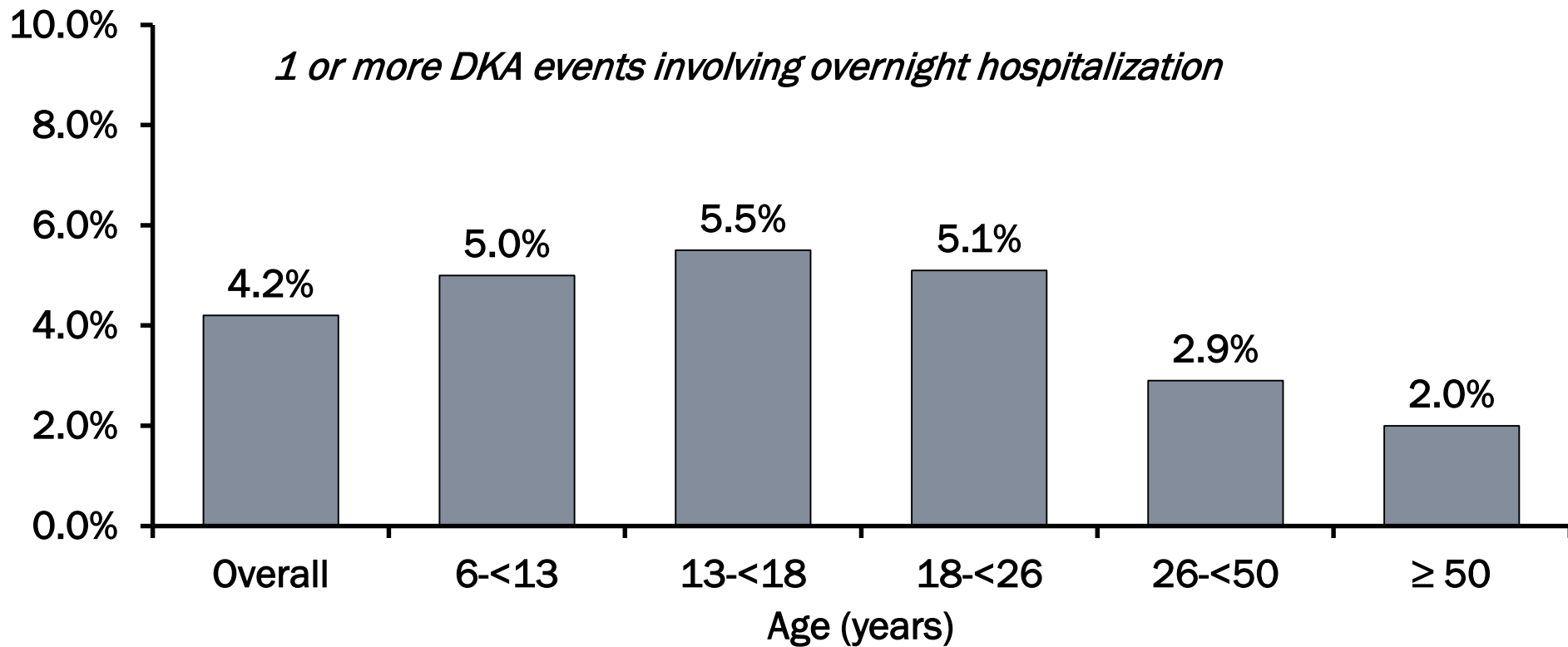


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≥1 DKA EVENTS IN PAST 3MO BY AGE



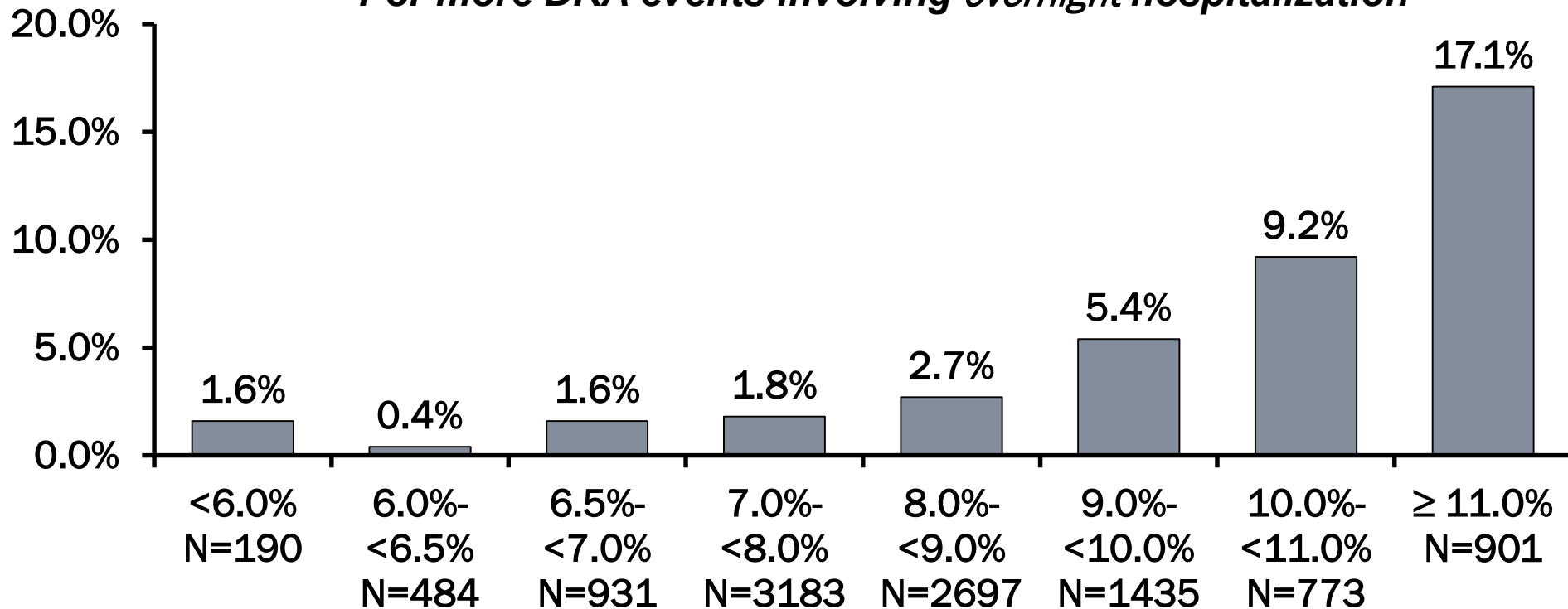
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≥1 DKA EVENTS IN PAST 3MO BY HBA1C

1 or more DKA events involving overnight hospitalization



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DKA occurred less frequently in insulin pump users than injection users among youth and young adults but at a similar rate in adults;

DKA occurs less frequently in CGM users than in non-users across all age groups

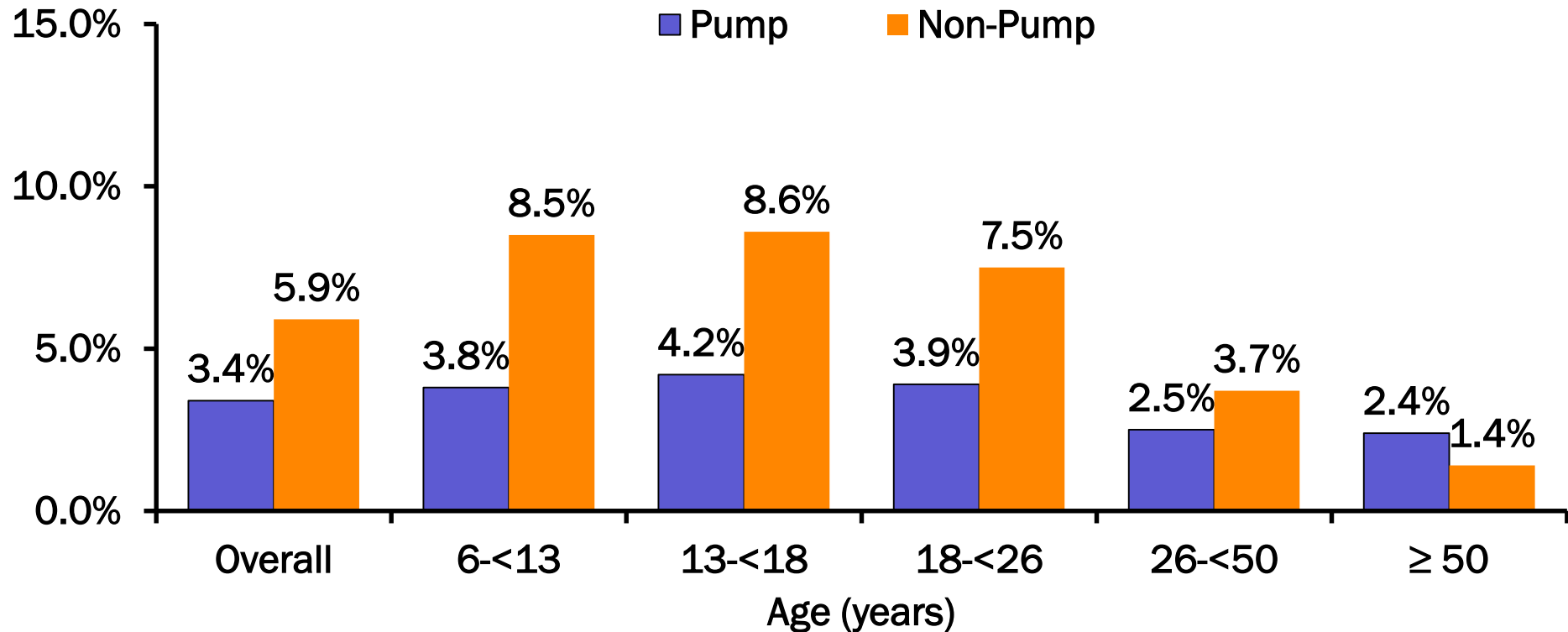


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≥1 DKA EVENTS BY PUMP USE

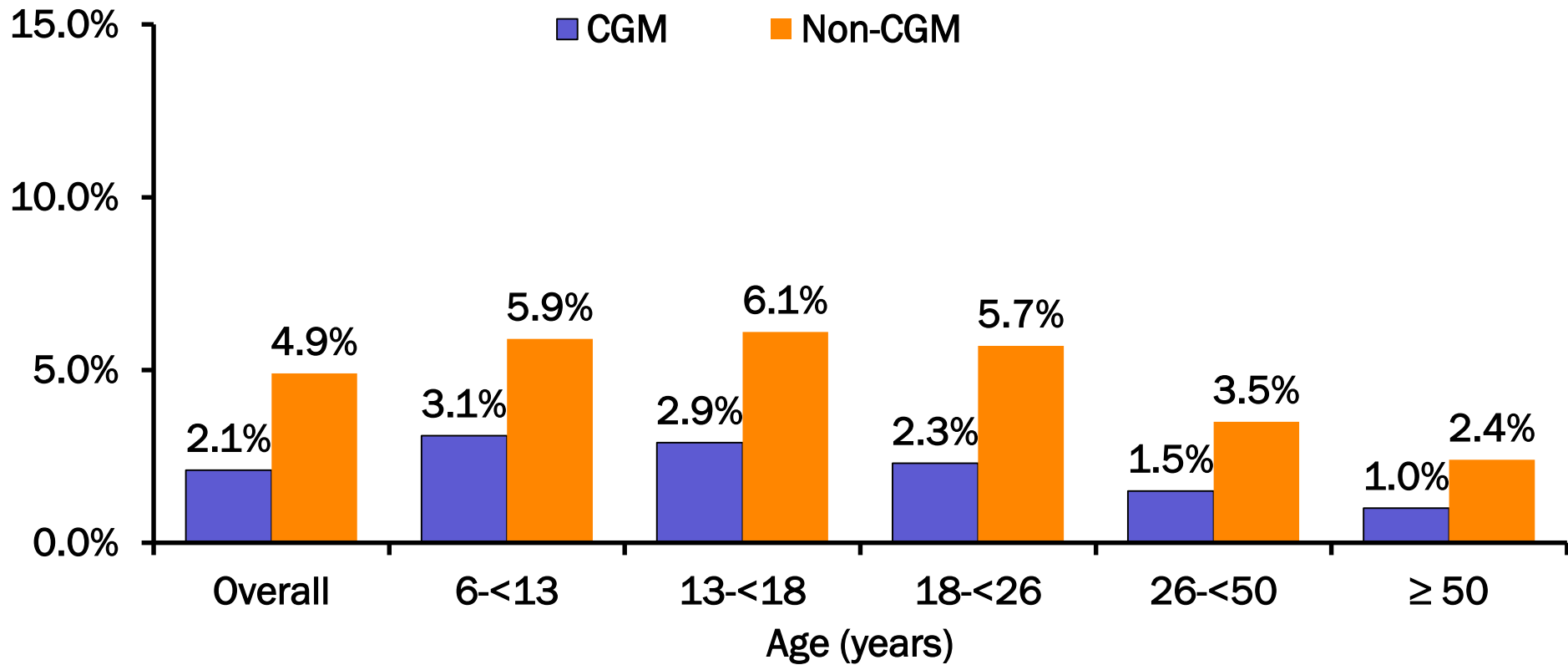


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≥1 DKA EVENTS IN PAST 3MO BY CGM USE



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INTERNATIONAL COLLABORATIONS

INTERESTING FINDINGS



A1c levels differ by country but the pattern of rise in A1c in adolescents is consistent

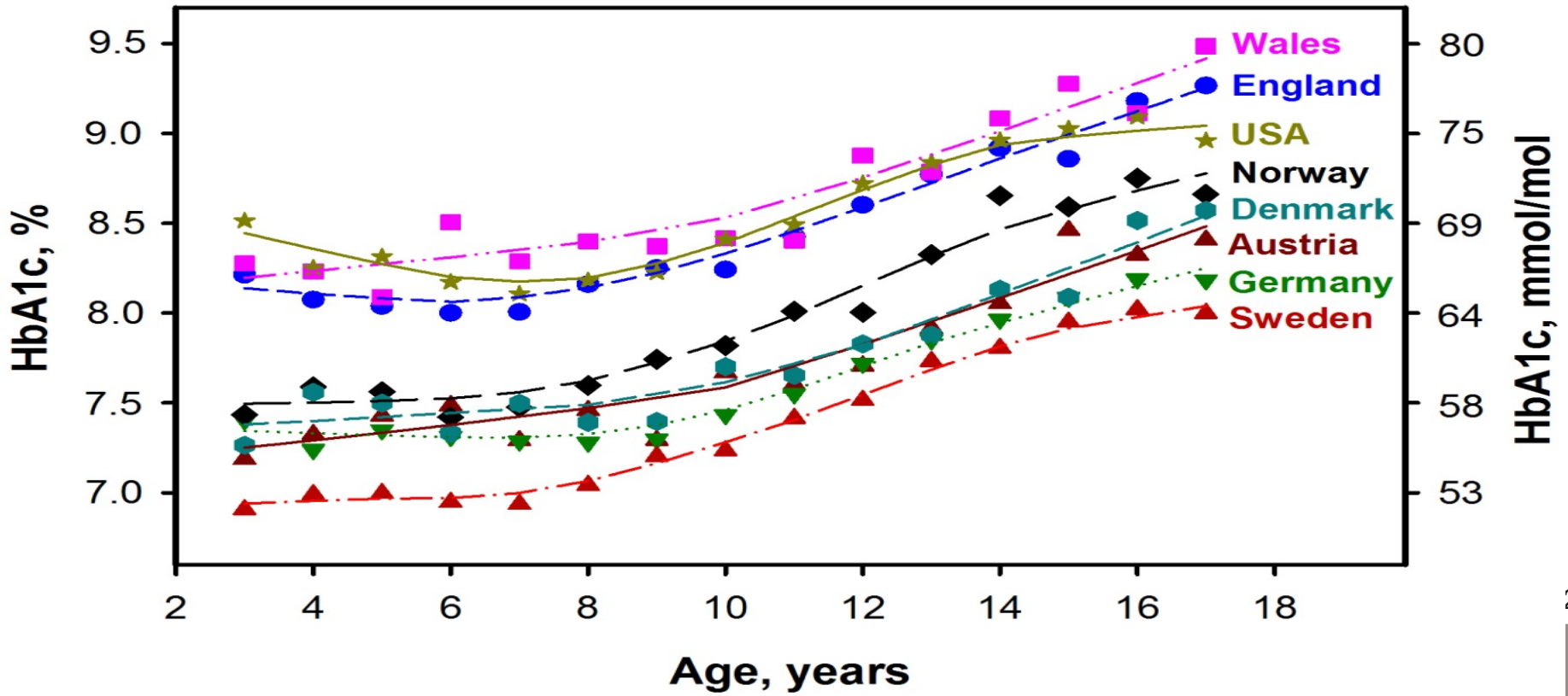


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A1C LEVELS DIFFER BY COUNTRY BUT THE PATTERN OF RISE IN A1C IN ADOLESCENTS IS CONSISTENT



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Individuals in the Germany and Austria
T1D Registry have a lower average
HbA1c across the age lifespan compared
with individuals in the US registry

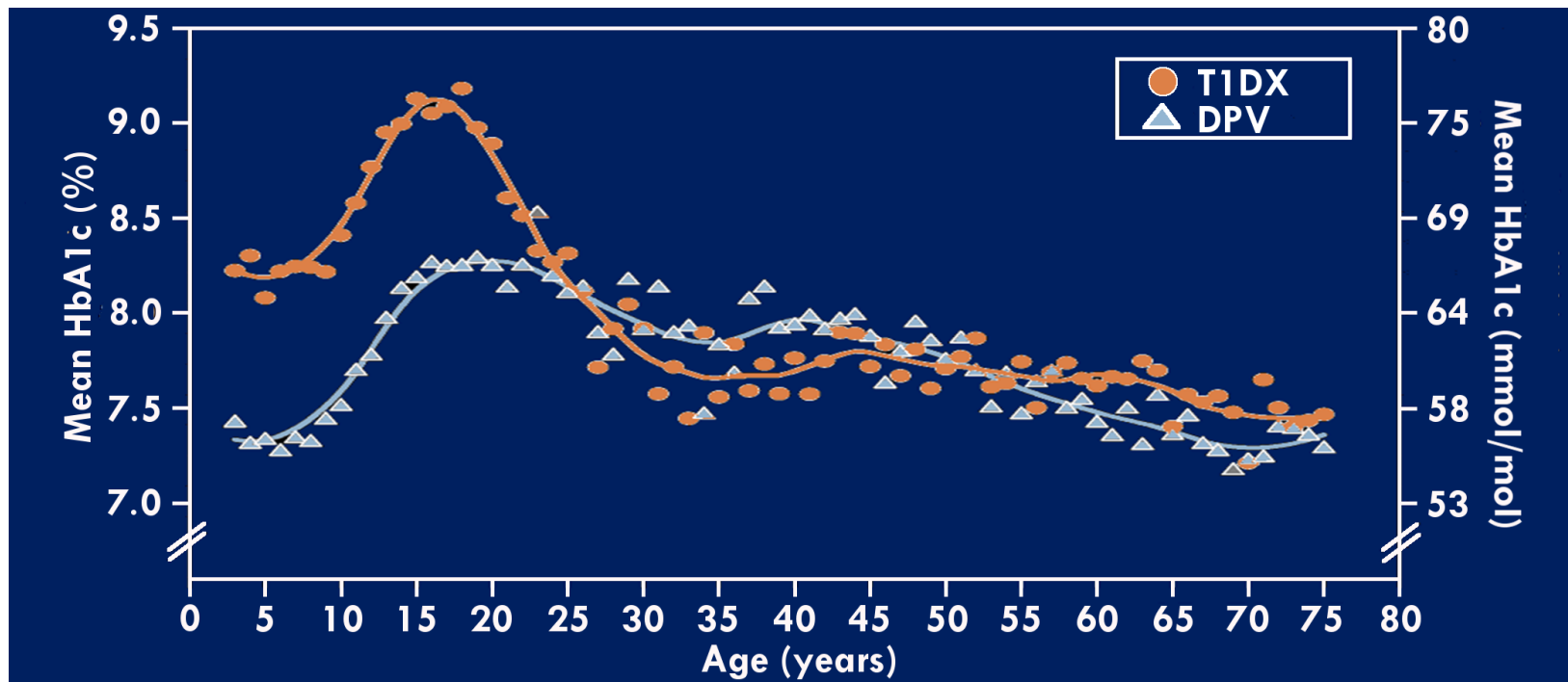


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T1DX (US) AND DPV (GERMANY AND AUSTRIA) HbA1c



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**SUMMARY AND IMPACT OF REGISTRY
AND CLINIC NETWORK**

IMPACT OF REGISTRY DATA

- The T1D Exchange clinic registry served to establish the state of T1D management and outcomes in the U.S. and illustrate how challenging living with diabetes really is!
- Data were used to support
 - Blood glucose meter strip coverage by insurers
 - Change in ADA guidelines for HbA1c goals for pediatric patients
 - FDA decision to expand Dexcom CGM labeling to include fingerstick replacement
 - CGM coverage by Medicare
- Collaborations with other registries around the world, which through the exchange of data has led to insights in comparing treatments and outcomes among different countries.



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CONNECTING THE FINDINGS WITH NEXT STEPS FOR IMPROVING CARE

- Technology use, particularly CGM use, increased drastically; However, penetrance of technology in the primary care setting is likely much lower and needs to be evaluated
- Despite increase in technology use very few youth and adults are meeting targets for glycemic control. New treatments and interventions targeted at improving education and management are needed to help people with diabetes achieve these goals.
- Although the curve of average HbA1c from early childhood to elderly shifts according to device use and SES factors, the shape of the curve remains reasonably constant with highest HbA1c levels in adolescents and young adults.
 - These findings emphasize the importance of targeting adolescence and early adulthood as the ages with the greatest need for improving diabetes management irrespective of device use and SES.
- There is an urgent need to address disparities in blood glucose control and technology use across socioeconomic status and race/ethnicity



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THE LEGACY OF THE T1D EXCHANGE CLINIC REGISTRY

Raising awareness of T1D and challenges in day to day management among health care providers, researchers, companies, insurers, regulators, the press and people with and without diabetes

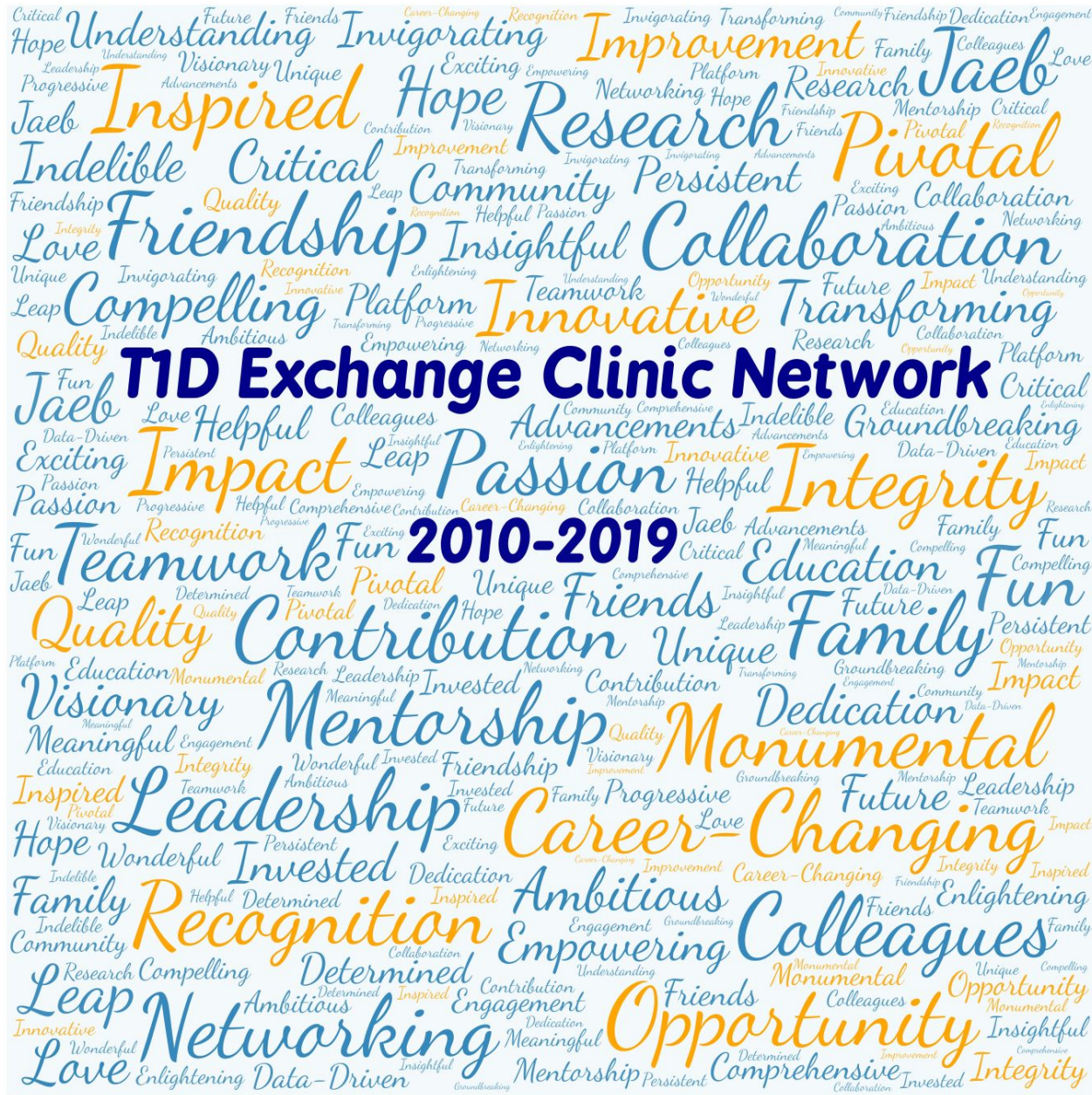


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THE LEGACY OF THE T1D EXCHANGE CLINIC NETWORK



LOOKING FORWARD

BRIEF SUMMARY OF QUALITY IMPROVEMENT COLLABORATIVE

- The T1D Exchange QI Collaborative (T1DX-QI) is a large cohort with 37 national clinics engaged in data sharing and quality improvement to improve outcomes funded by the Helmsley Charitable Trust. This effort stemmed from the T1D Exchange registry.
 - Participating clinics are sharing data and best practices to improve care delivery for people with type 1 diabetes.
- 32,000+ patients
- Some of the first initiatives of the QI collaboration are to
 - Increase screening for depression
 - Increase CGM use
 - Increase insulin pump use
 - Reduce % of patients at high risk for adverse outcomes
- GOAL – Improve care and lives of those living with diabetes.
- The effort is ongoing and hopes to expand the number of clinics and patients participating



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T1D EXCHANGE VIRTUAL REGISTRY

- Coordinated by T1D Exchange office in Boston, MA
- 12,000+ participants
- Annual surveys and targeted data collections
- Opportunities for participation in studies
- If you have T1D and are interested in joining the virtual registry you can register at the link below

<https://t1dregistry.org/landing>



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THANK YOU TO PARTICIPANTS!!

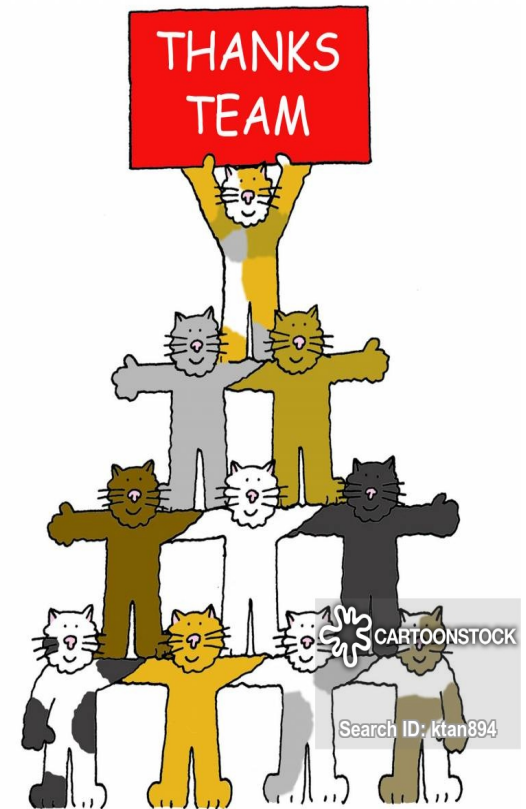
For providing data to accelerate research and improve outcomes

Thank you to Research Teams at each clinic

- This journey has been an incredible team effort!

Thank you to the Helmsley Trust

- For having the vision for the T1D Exchange and supporting this great effort



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