The Land that Time Forgot

How bridges to nowhere, abandoned tracks, and sinkholes stand between us and the diabetes care we deserve (and how to fix them)

Mark A Clements, MD PhD
Professor, Pediatrics
Pediatric Endocrinology
Children's Mercy Hospital

The Rick and Cathy Baier Family Endowed Chair in Pediatric Endocrinology

Medical Director, Pediatric Clinical Research Unit

Director, Endocrine/Diabetes Research

Disclosures

Chief Medical and Strategy Officer, Glooko

Research support, Abbott Diabetes Care

Research support, Dexcom

Research support from

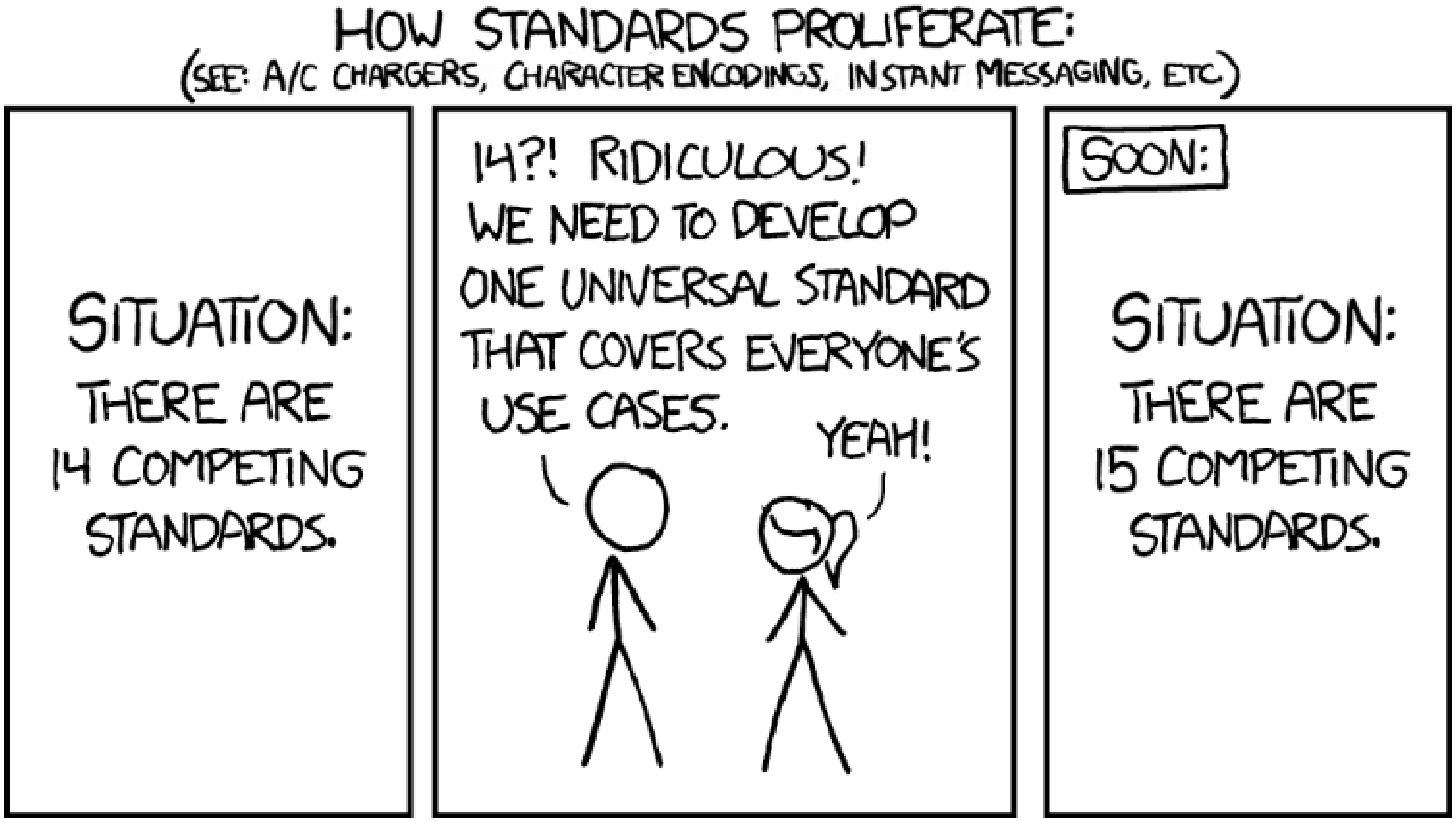
- NIDDK, NCATS, NICHD
- JDRF
- CIHR
- Helmsley Charitable Trust

Thanks

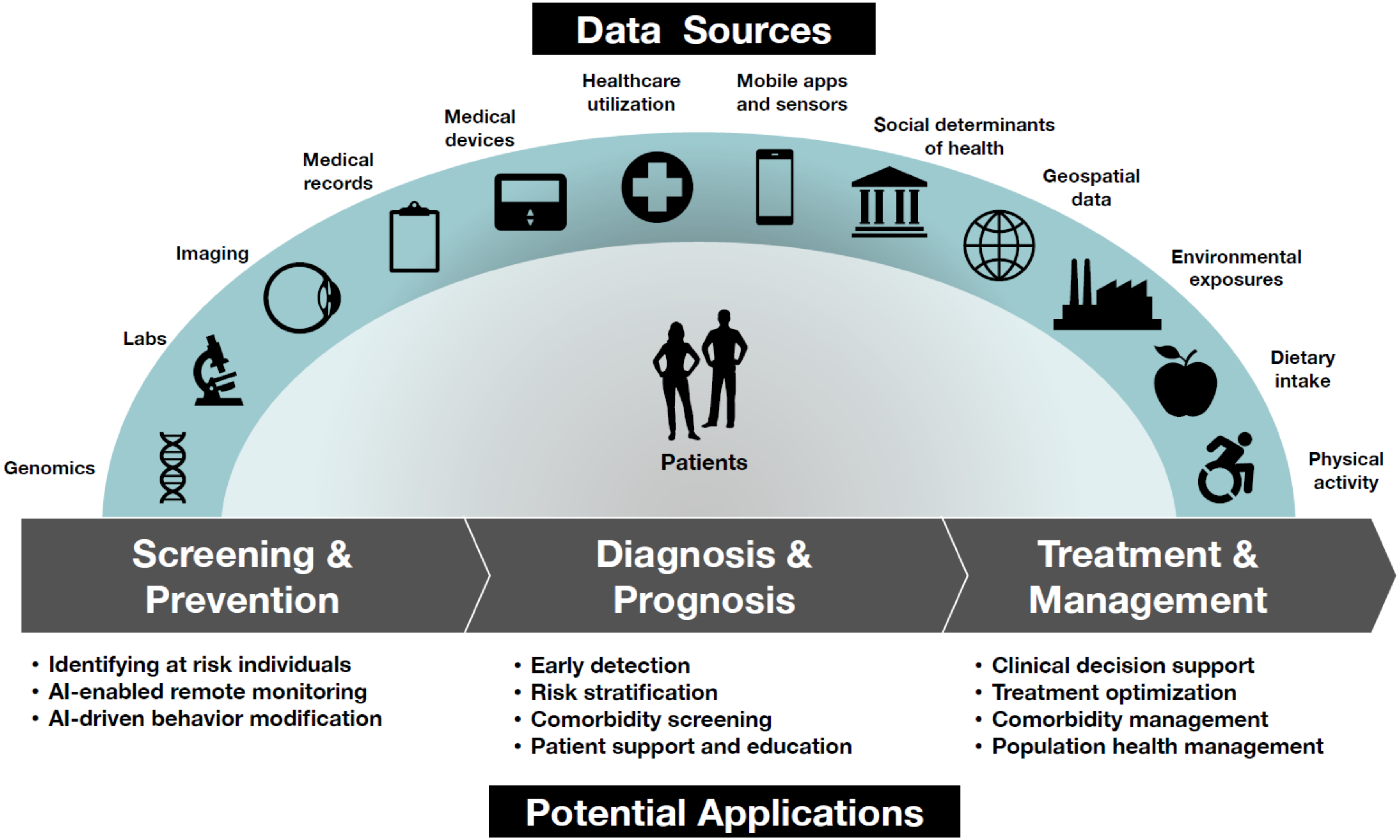
To Juan Espinoza, with whom I work closely, and whose images I borrowed for some of my slides

What are the bridges to nowhere, abandoned tracks, and sinkholes?

- *Bridges to nowhere*: Data silos with little to no interoperabilities
- *Abandoned tracks*: multiple competing data standards and specifications
- *Sinkholes*: data ownership claims impeding integration, interoperability and innovation


HOW STANDARDS PROLIFERATE:
(SEE: A/C CHARGERS, CHARACTER ENCODINGS, INSTANT MESSAGING, ETC.)
SITUATION:
THERE ARE 14 COMPETING STANDARDS.
14?! RIDICULOUS! WE NEED TO DEVELOP ONE UNIVERSAL STANDARD THAT COVERS EVERYONE'S USE CASES.
YEAH!
SOON:
SITUATION:
THERE ARE 15 COMPETING STANDARDS.

Data types and sources in diabetes and metabolic disease care are diverse

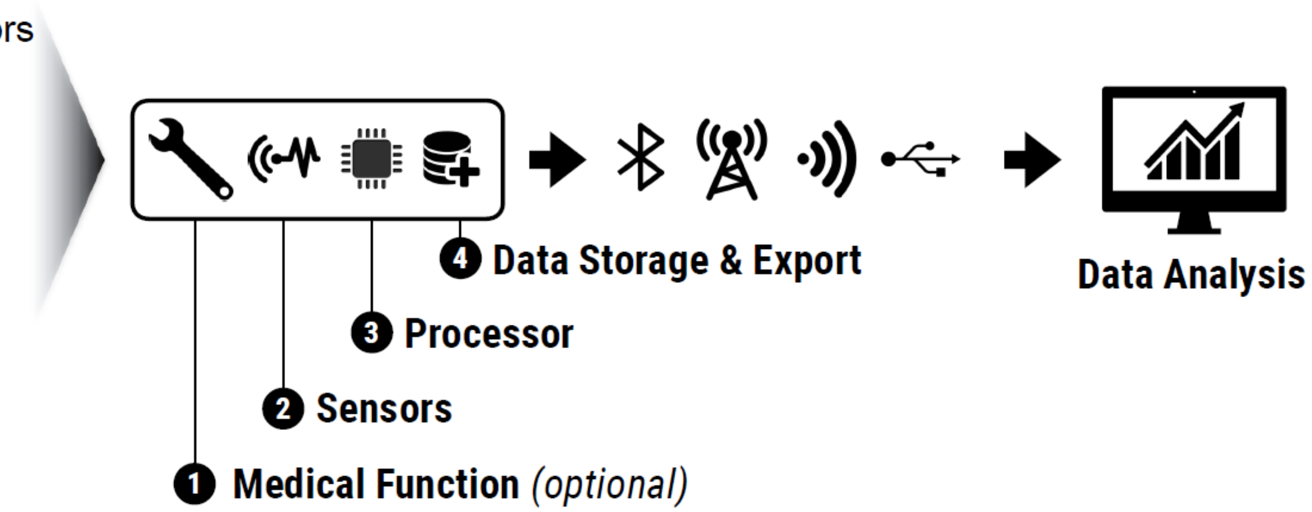


Adapted from
https://www.healthcatalyst.com/learn/insights/5-reasons-healthcare-data-is-difficult-to-measure

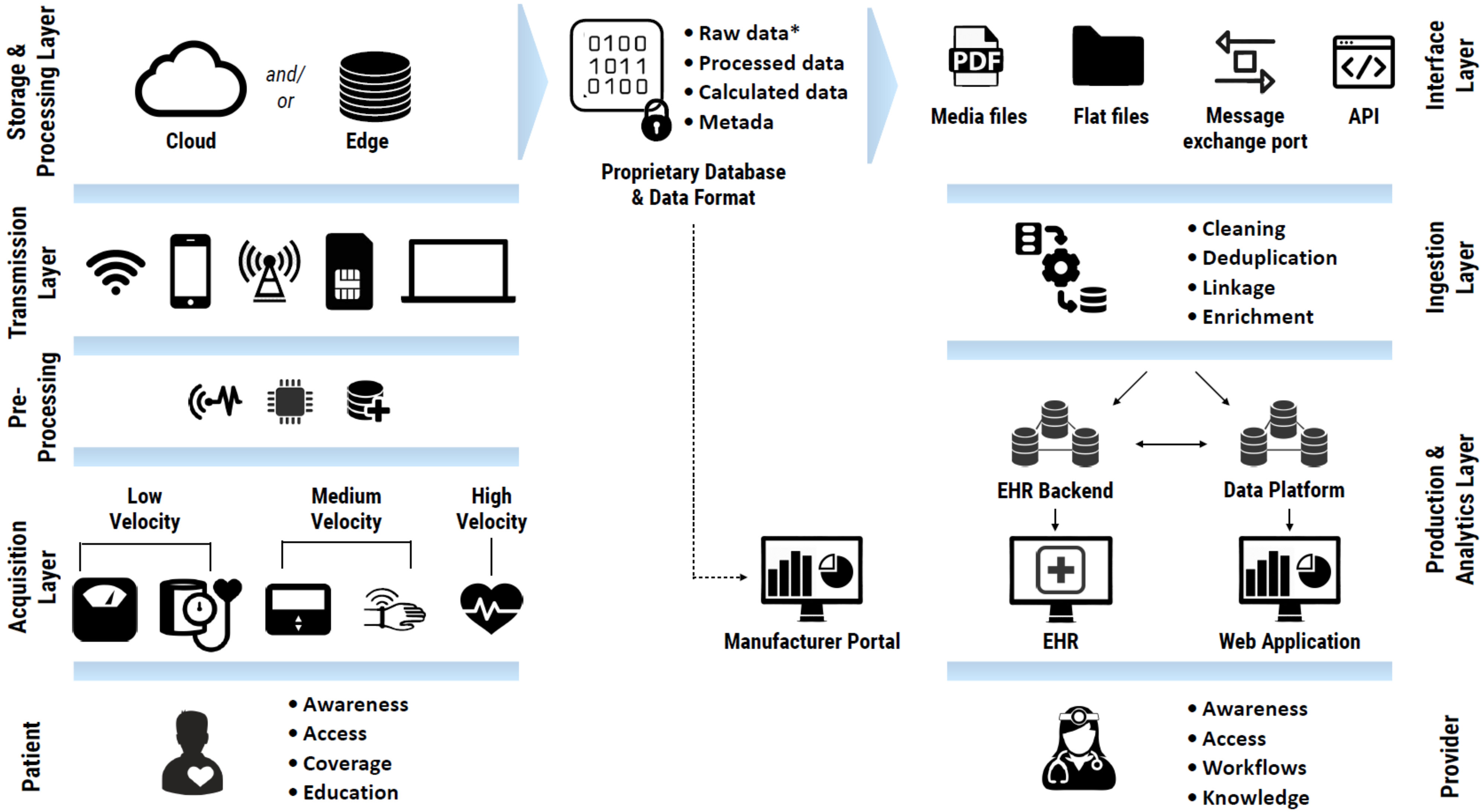
Why Healthcare Data are Difficult

Abstraction of Devices

- Electrophysiological sensors
- Photoplethysmographic sensors
- Biochemical sensors
- Acoustic sensors
- Mechanical sensors
- Amperometric sensors
- GPS
- Accelerometers
- Thermal sensors



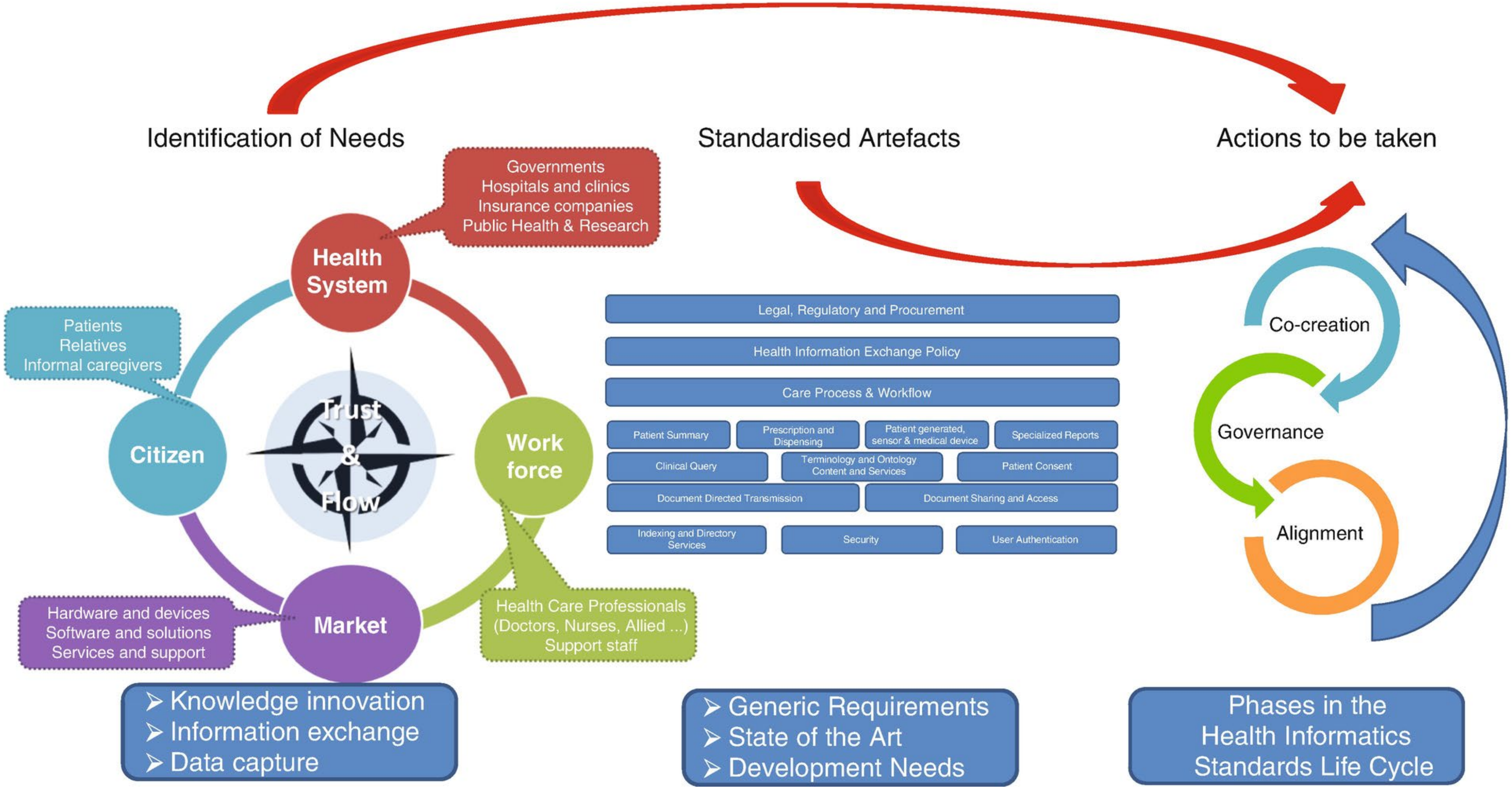
Bridges to nowhere



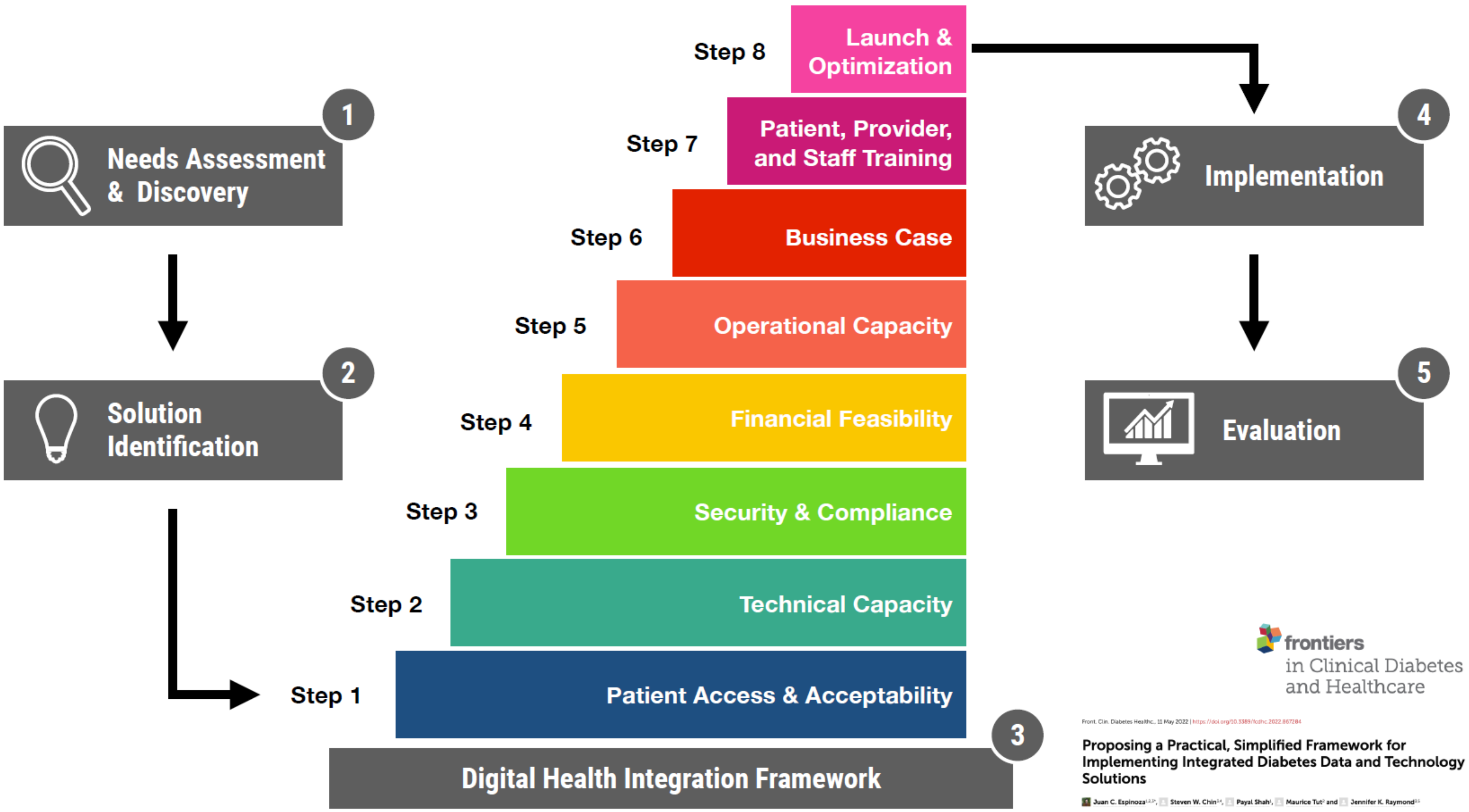
Gaps

Data ownership/rights
Risk Mitigation/contracting
Regulatory/Privacy obligations
Multiple competing data standards/specifications
    OMOP, PCORNET, T1D Exchange, CDISC
Multiple competing data access methods
Lack of technical expertise and resources at healthcare institutions

Designing Data Interoperability is Complex



Schultz S, Stegwee R, Chronaki C; Standards in Healthcare Data in Fundamentals of clinical data science, editors Kubben P, Dumontier M, Dekker A; pp19-36; first online 22 Dec 2018; accessed 28 May 2025



frontiers in Clinical Diabetes and Healthcare

Front. Clin. Diabetes Healthc., 11 May 2022 | https://doi.org/10.3389/fcdhc.2022.867284

Proposing a Practical, Simplified Framework for Implementing Integrated Diabetes Data and Technology Solutions

Juan C. Espinoza[1,2,3*], Steven W. Chin[3,4], Payal Shah[1], Maurice Tut[2] and Jennifer K. Raymond[3,5]

The pace of innovation in diabetes care is increasing yet…

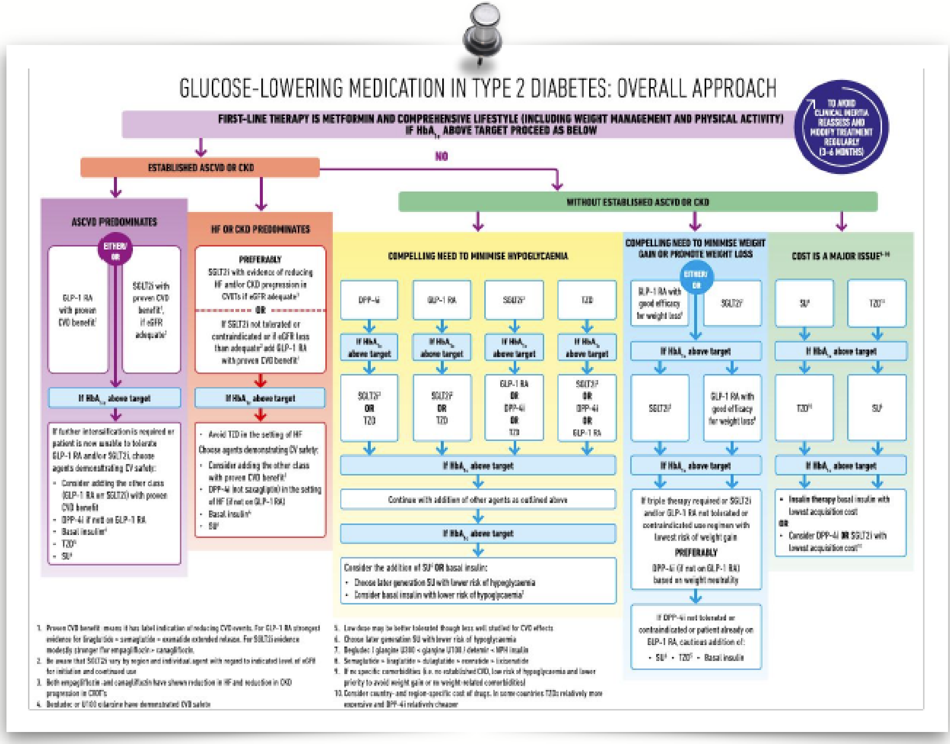
- It is still difficult to visualize the real costs that data silos and lack of standards create
  - In healthcare delivery
  - In innovation and research
- I would argue that the cost is quite significant and that we have an ethical obligation to design interoperable data ecosystems that support the creation of true learning health networks

What becomes possible with true data interoperability (after solving for data standards)?

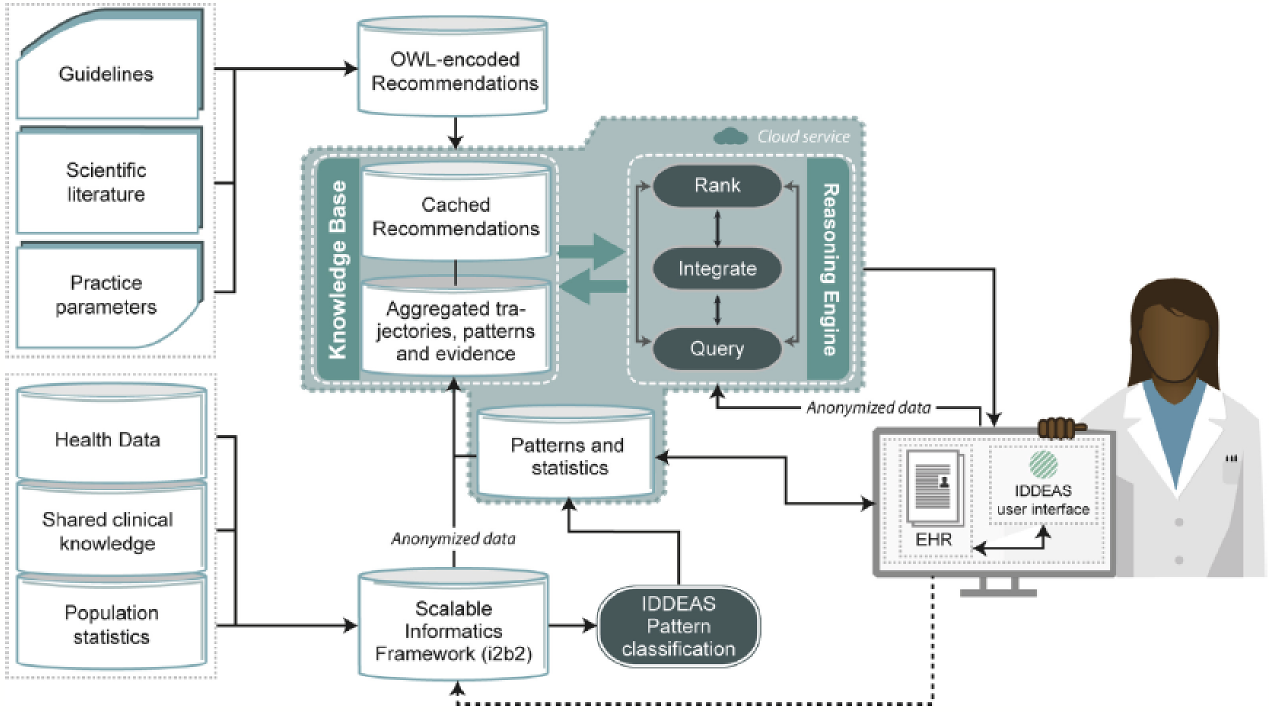
Clinicians

Clinical Decision Support Systems for Diabetes

CDS



CDSS



- Davies, M.J., D'Alessio, D.A., Fradkin, J. et al. Management of hyperglycaemia in type 2 diabetes, 2018. A consensus report by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). Diabetologia 61, 2461–2498 (2018). https://doi.org/10.1007/s00125-018-4729-5
- Clausen CE, Leventhal BL, Nytrø Ø, et al. Clinical Decision Support Systems: An Innovative Approach to Enhancing Child and Adolescent Mental Health Services. J Am Acad Child Adolesc Psychiatry. 2021;60(5):562-565. doi:10.1016/j.jaac.2020.09.018

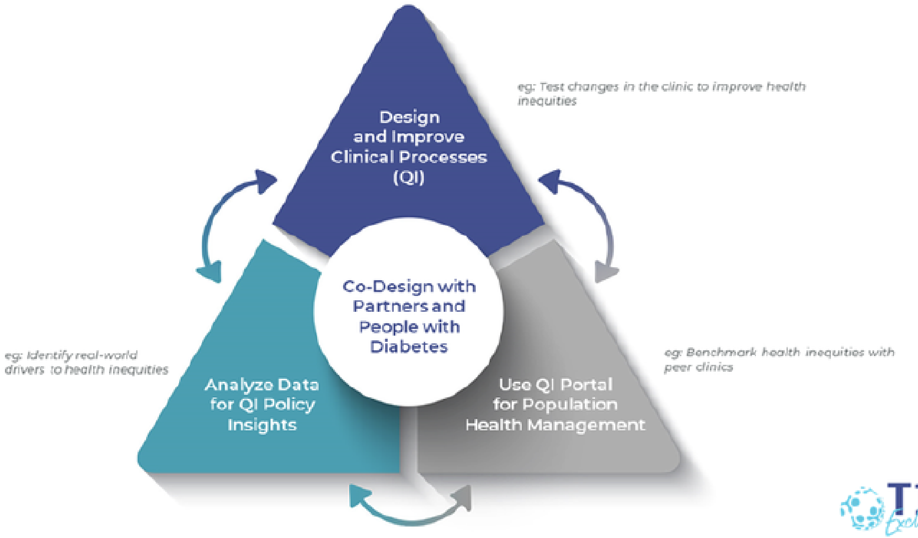
Population Health Management Dashboards

Ferstad J et al., Population-level management of type 1 diabetes via continuous glucose monitoring and algorithm-enabled patient prioritization: Precision health meets population health; Pediatric Diabetes 2021 Nov;22(7):982-991.

Learning Health Networks are powered by data

- Intended for use outside of typical 1:1 clinician-patient interactions
- Improve quality of care
- Identify and prioritize patients at higher risk
- Match patients to intervention pathways
- Help direct limited resources to the patient who need them the most

T1D QI Population Health Improvement Framework



- Schmittdiel JA, Gopalan A, Lin MW, Banerjee S, Chau CV, Adams AS. Population Health Management for Diabetes: Health Care System-Level Approaches for Improving Quality and Addressing Disparities. Curr Diab Rep. 2017;17(5):31. doi:10.1007/s11892-017-0858-3
- Prahalad P, Rioles N, Noor N, et al. T1D exchange quality improvement collaborative: Accelerating change through benchmarking and improvement science for people with type 1 diabetes. J Diabetes. 2022;14(1):83-87. doi:10.1111/1753-0407.13234

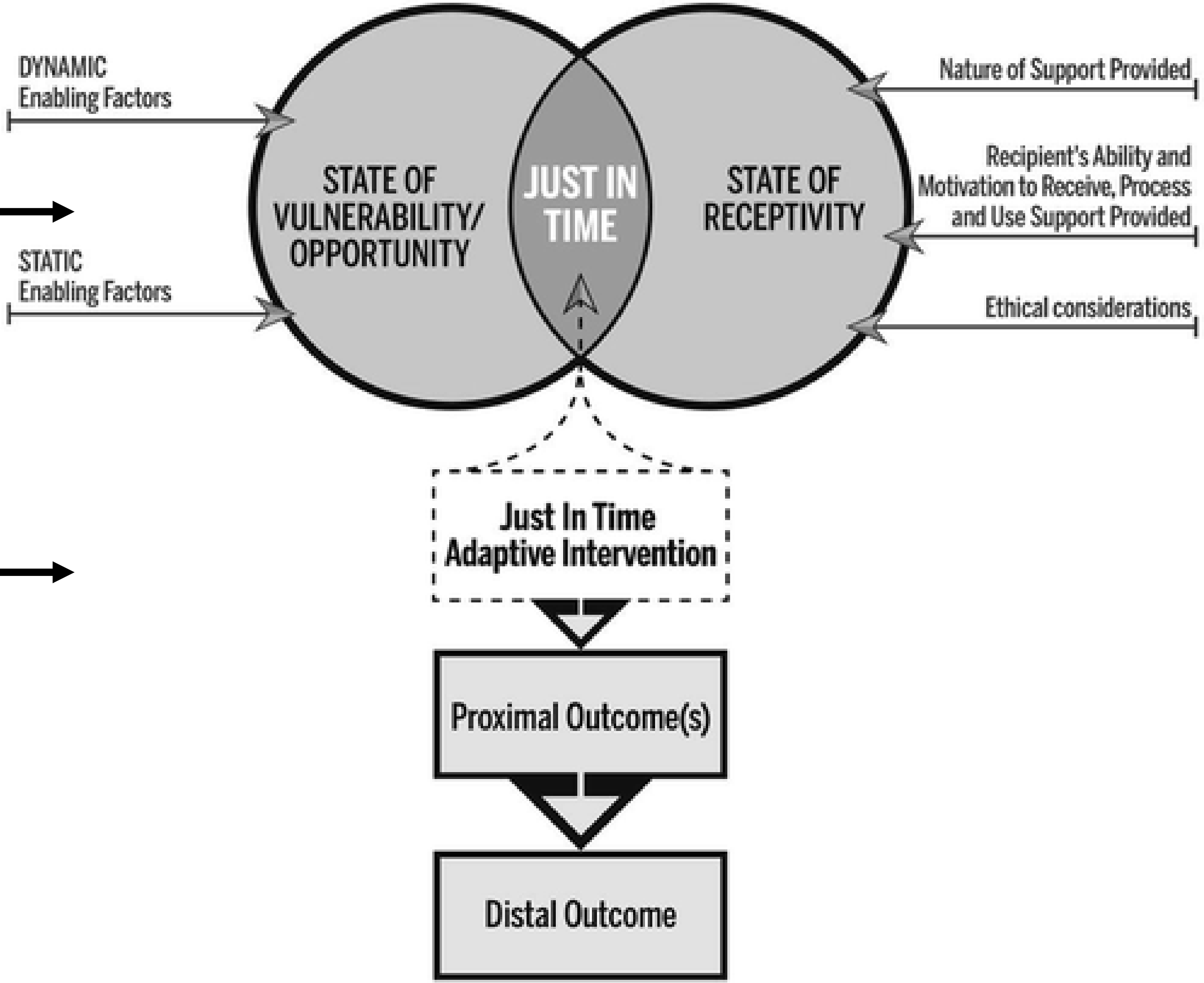
What becomes possible with true data interoperability (after solving for data standards)? *(continued)*

Persons with diabetes or metabolic disease

Just-in-time Adaptive Interventions: Identifying the right context for nudging

Reinforcement learning engine

Reinforcement learning engine



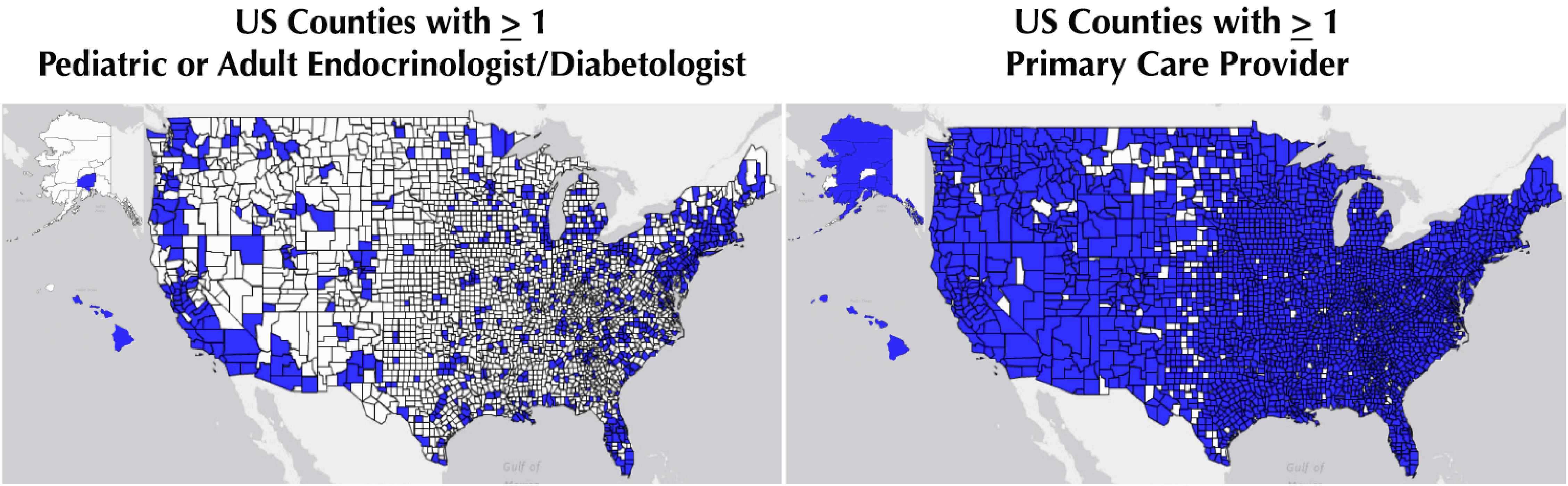
Time of day
Geolocation
Mood/distress
Glucose
Activity level
etc

Psychological theory
Strategy
(behavioral economic, CBT, relational agent, etc)
Form
(text, image, meme, GIF)
Tone of voice
(empathetic, authoritative, motivational)

Nahum-Shani I et al., Health Psychology 2015

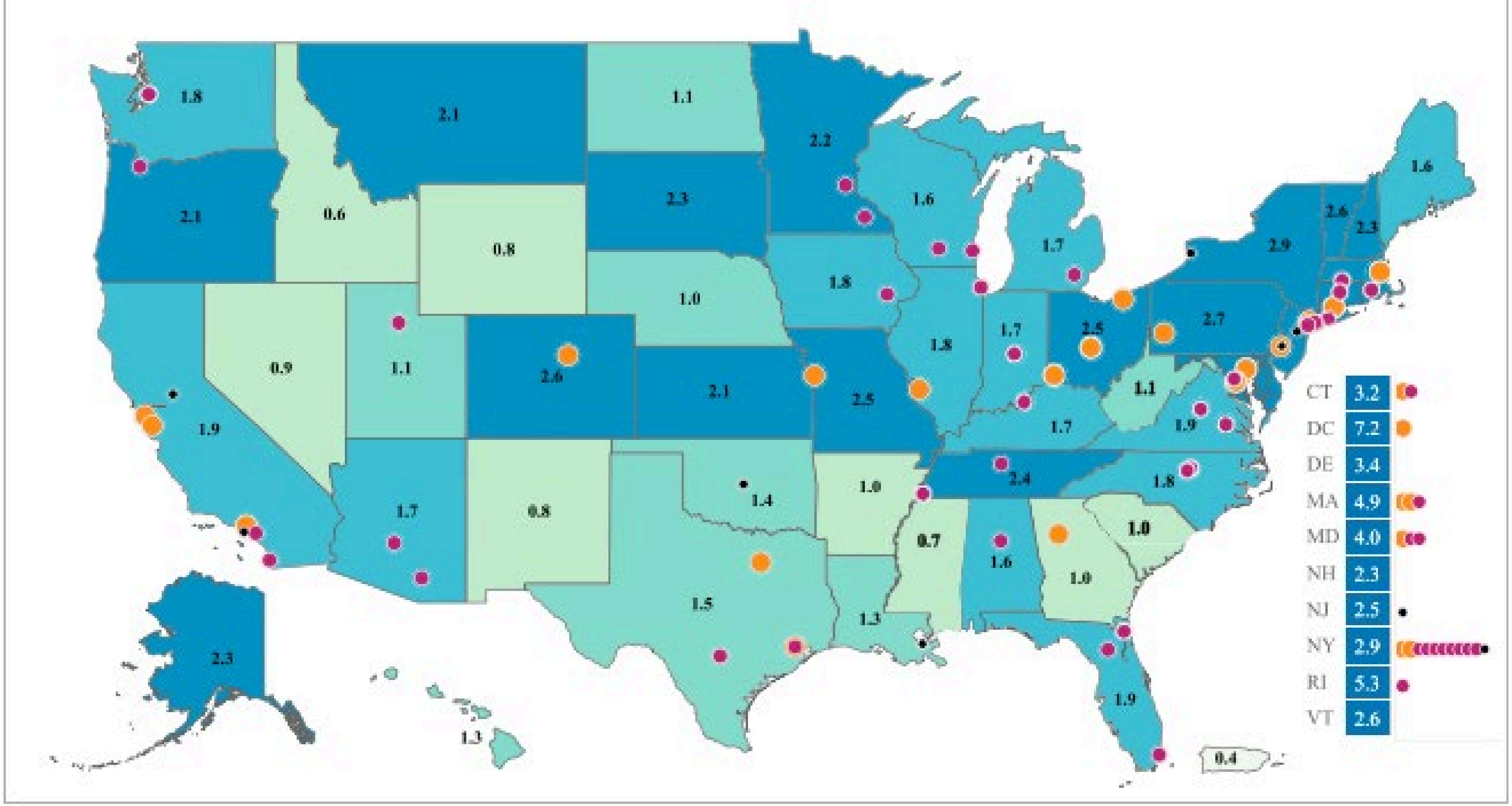
Why these innovations matter…

There are not enough specialists to manage endocrine/diabetes conditions!



Distributions of Endocrinologists/Diabetologists and Primary Care Providers Across the US

Oser SM, Oser TK. Diabetes Technologies: We Are All in This Together. Clinical Diabetes 2020;38(2):188-9.



Child Health Needs and the Pediatric Endocrinology Workforce: 2020–2040

Tandy Aye, MD,[a,b] Charlotte M. Boney, MD, MS,[c] Colin J. Orr, MD, MPH,[d,e] Mary B. Leonard, MD, MSCE,[b] Laurel K. Leslie, MD, MPH,[f] David B. Allen, MD[g]

Diabetes self-management is complex

Pillars of Self-Management

Glucose Monitoring

Insulin Dosing

Healthy Eating/Carb Count

Physical Activity

Healthy Coping

Problem solving

Reducing Risk

Intervention Strategies

Peer mentoring

Behavioral Economics

Mindfulness/Meditation

Relational agent

Cognitive Behavioral Therapy

Just-in-time Adaptive Intervention

And more…

RISING T1DE
ALLIANCE

We ultimately want to achieve a "smart" system:

Enhanced Data Collection

↓

Real-time data listening + Prediction

↓

Risk Stratification / Actionable Alerts

↓

Mobile App

Physical Activity Intervention

Group Telehealth

JITAI

Community Navigator

Behavioral Economic

CGM

Smart Insulin Pen

Hybrid Closed Loop

Online Peer Communities

Mentoring Program

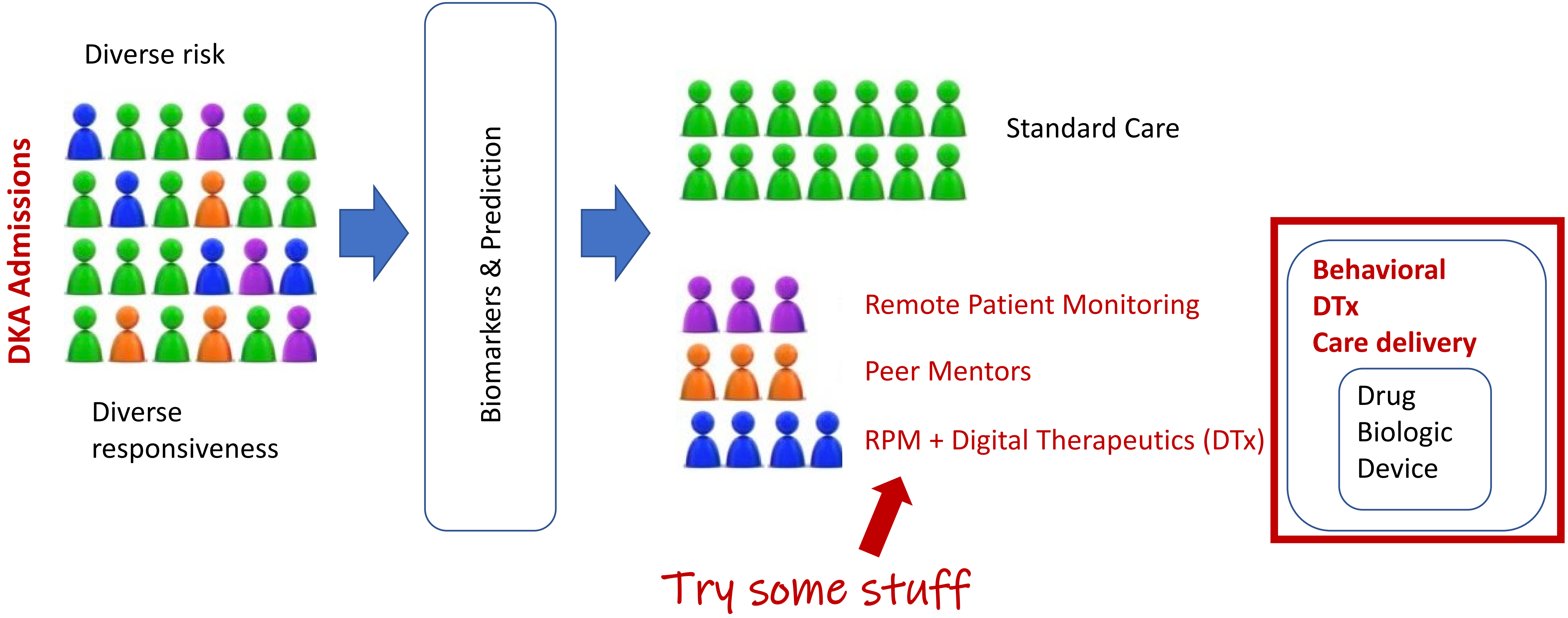
Remote Patient Monitoring

Insulin Pump

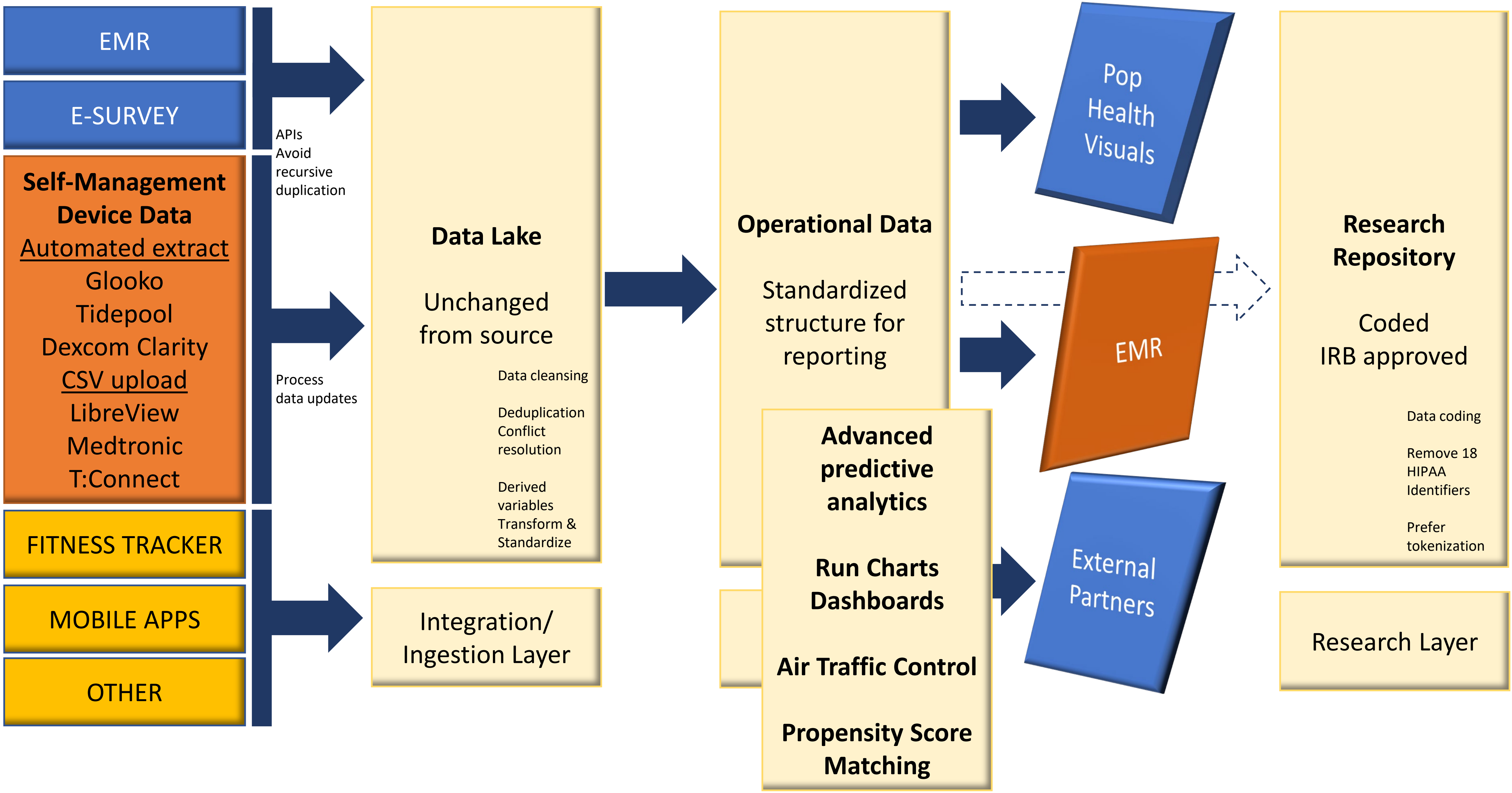
Coaching

Healthy Eating Intervention

Diabetes Care Transformation: Population Health Management



D-DATA DOCK STRUCTURE



Predicting hospitalization for DKA

DIABETES TECHNOLOGY & THERAPEUTICS
Volume 00, Number 00, 2025

DOI: 10.1089/dia.2024.0484

DTT

Open camera or QR reader and scan code to access this article and other resources online.

ORIGINAL ARTICLE

Predicting and Ranking Diabetic Ketoacidosis Risk among Youth with Type 1 Diabetes with a Clinic-to-Clinic Transferrable Machine Learning Model

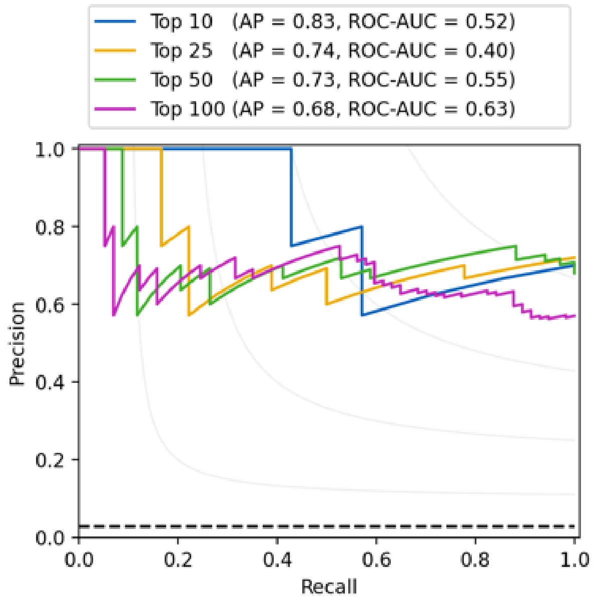
Craig Vandervelden, PhD,[1] Brent Lockee, BS,[1] Mitchell Barnes, BS,[1] Erin M. Tallon, PhD, RN,[1] David D. Williams, MPH,[1] Anna Kahkoska, MD, PhD,[2–4] Angelica Cristello Sarteau,[2] Susana R. Patton, PhD,[5] Rona Y. Sonabend, MD,[6] Jacob D. Kohlenberg, MD,[7] and Mark A. Clements, MD, PhD[1]

DKA risk prediction model performance

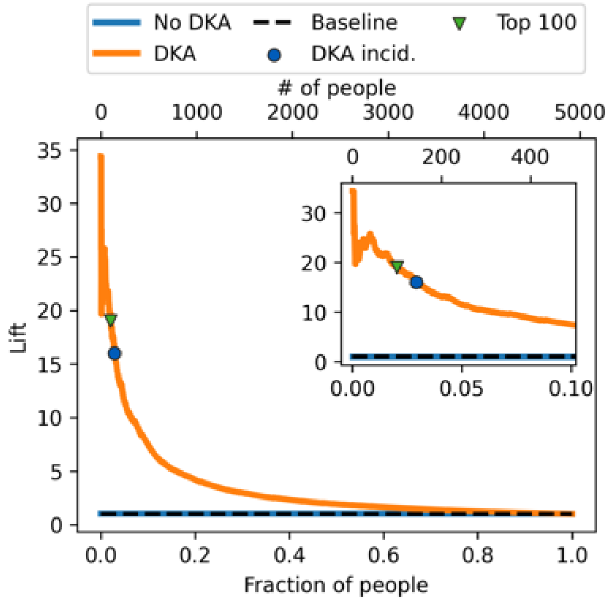
Results: model performance and feature importance

All results from the (out-of-sample) validation set

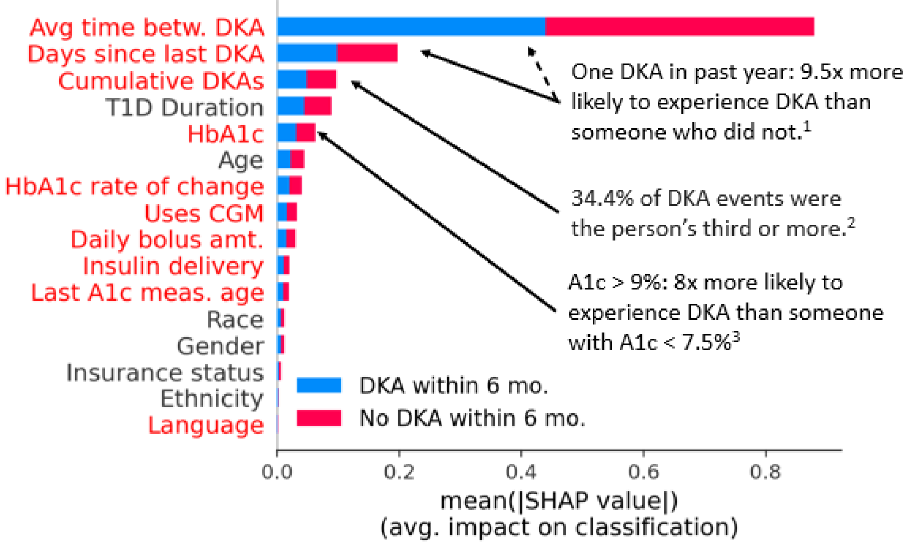
Top N risk precision-recall



Lift curve



SHAP values (feature importance) of top 100



Modifiable risk factor
Non-modifiable risk factor

The solution: build model with features derived from T1D Exchange data standard

Model development and feature engineering

Set building

Training
(60% | 19,569)

Testing
(20% | 2443)

Validation
(20% | 2450)

- Sets are partitioned by individual (model validated against new people)
- Stratified by DKA incidence

Feature engineering

Demographics/SDOH
- Sex
- Race
- Ethnicity
- Primary language
- Age
- Insurance status

Diabetes mgmt.
- CGM Usage
- Insulin delivery route
- Average bolus amount

Lab results
- HbA1c %
- Age of HbA1c value
- Rate of HbA1c change (with prior measurement)

Diabetes history
- T1DDuration
- Time since last DKA
- Avg. time between prior DKAs
- Cumulative # of DKAs

Model selection

DKA events are **imbalanced** (IR = 34, DKA incidence = 2.9%)

Ensemble (soft voting) of gradient-boosted tree methods:

$$p_{DKA} = w_{XGB}\, p(\text{dmlc XGBoost}) + w_{LGBM}\, p(\text{LightGBM})$$

Hyperparameter optimization

Model hyperparameters found using Bayesian hyperparameter optimization.

150 optimization iterations for each child model.

Maximize average precision (area under precision-recall curve) of the **test set**.

Weights for soft voting are scanned in increments of 0.01.

What is the T1D Exchange Quality Improvement Collaborative?

A network of 62 centers engaged in innovative care design, audit and feedback, and benchmarking

Centers share data from their electronic health records to a central data repository

The data specification is very detailed and includes clinical observations, patient reported outcomes, and clinician documented care factors

When clinics cannot share a particular data feature, they are generally working toward changing their clinical documentation to allow it

End result: Any forecasting models built using T1D Exchange data are immediately evaluable and potentially disseminable to the 62 T1D Exchange centers

New, scalable model to classify ΔA1c > 0.3%

Can assess accuracy as a classification problem: "Can the model accurately classify people whose A1c rises over 0.3% (clinically significant threshold)?"

Classification metrics:

- **Sensitivity:** true positive rate
- **Specificity:** true negative rate
- **Positive predictive value (PPV)**: chance that predictions with ΔA1c > 0.3% are true
- **Negative predictive value (NPV):** chance that ΔA1c < 0.3% are true

ΔA1c > 0.3%	Original model	New model
Sensitivity	21.3%	26.4%
Specificity	86.1%	89.8%
PPV	55.5%	54.7%
NPV	57.3%	72.3%

ΔA1c > 0.4%	Original model	New model
Sensitivity	11.7%	16.6%
Specificity	93.5%	95.3%
PPV	54.1%	55.3%
NPV	62.0%	76.5%

New scalable model for 14-day Time in Range

TIR Features Derived from CGM Data

- Biweekly average wear time
- Biweekly average TIR
- Biweekly coefficient of variation
- Biweekly skewness of blood glucose values
- Biweekly kurtosis of blood glucose values
- Biweekly crossing rate of 54 mg/dL
- Biweekly crossing rate of 350 mg/dL
- Biweekly rate of CGM slope sign change
- Biweekly waveform length
- Biweekly autocorrelation (lag 2)
- Biweekly autocorrelation (lag 3)
- Biweekly HGBI
- Biweekly LGBI
- Biweekly COGI
- Biweekly GRI Hypo Component
- Biweekly GRI Hyper Component
- Biweekly GRI

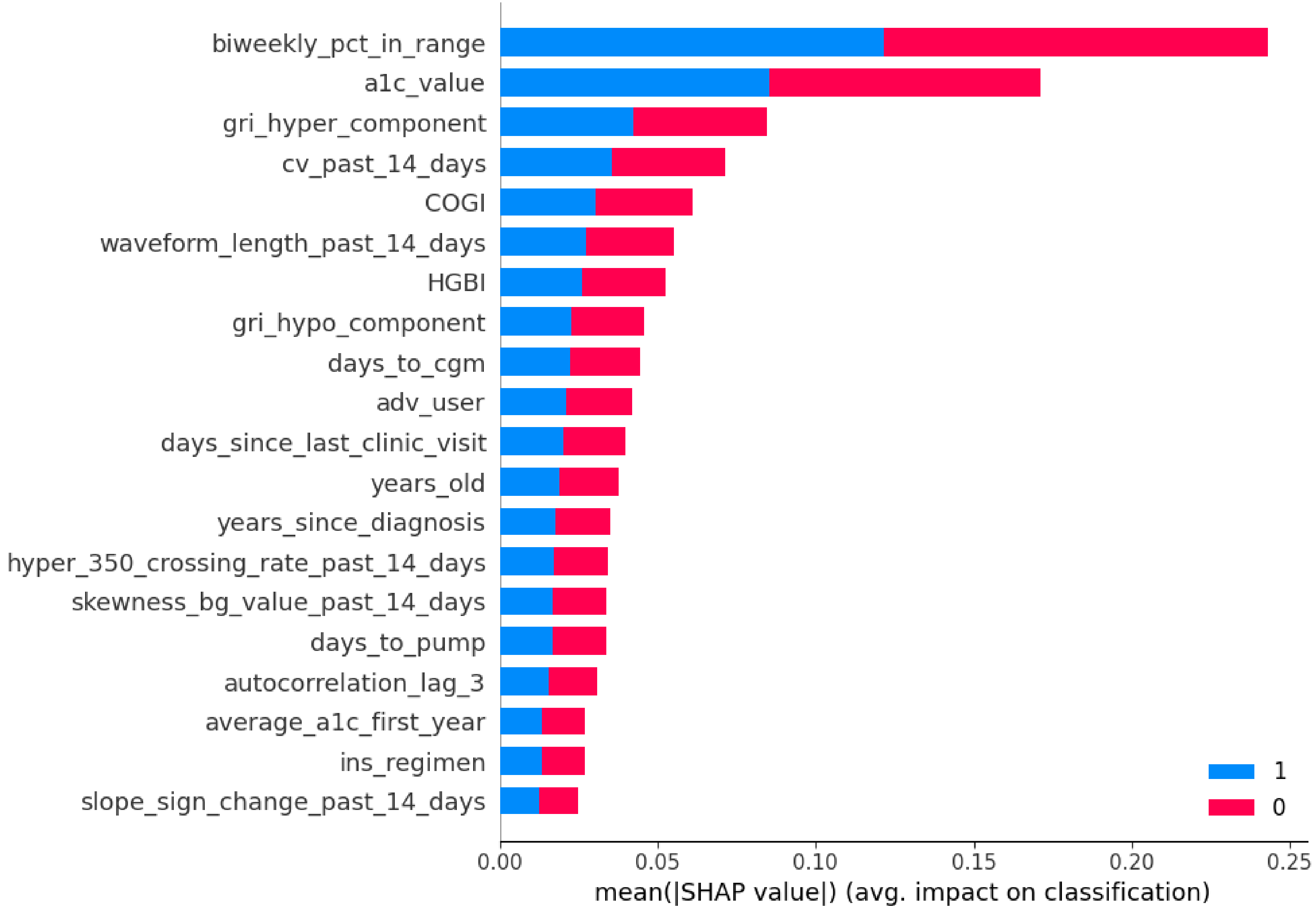
TIR Features from EHR Demographics

Age	Years since T1D diagnosis
Days since last clinic visit	Race
Ethnicity	Gender
Language	Primary insurance status

TIR Features from Clinical Observations

- Most recent Hba1c value
- Average HbA1c value in the first year following diagnosis
- Days from diagnosis to initiation of CGM
- Days from diagnosis to initiation of insulin pump
- DKA at onset or diagnosis (indicator)
- Current insulin delivery regimen
- Technology integration indicators (pump user, open loop user, predictive low glucose suspend user, hybrid closed loop user, advanced hybrid closed loop user)

Feature Weights



Innovations in care based on non-predicted biomarkers

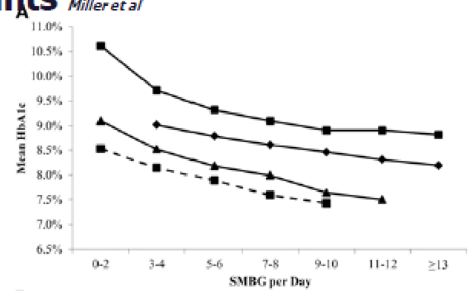
The Six Habits

1	Uses Continuous Glucose Monitor or checks blood glucose 4 times/day
2	Gives 3 or more insulin injections per day
3	Gives insulin before eating
4	Uses insulin pump
5	Reviewed blood glucose data for patterns at least once since the last clinic visit
6	Changed insulin doses at least once since the last clinic visit (by family or clinic)

The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-Term Complications in Insulin-Dependent Diabetes Mellitus

The Diabetes Control and Complications Trial Research Group*

Evidence of a Strong Association Between Frequency of Self-Monitoring of Blood Glucose and Hemoglobin A1c Levels in T1D Exchange Clinic Registry Participants *Miller et al*



Original Article

A contrast between children and adolescents with excellent and poor control: the T1D exchange clinic registry experience

- BG frequency per day ≥5
- Bolusing before meals
- Missing doses < 1 / week

A Minority of Patients with Type 1 Diabetes Routinely Downloads and Retrospectively Reviews Device Data ***Wong et al***

- Routine Reviewers of Data had lower A1c (7.8%) vs. those who did not (8.6%)

@joyclee

Feasibility of Electronic Health Record Assessment of 6 Pediatric Type 1 Diabetes Self-management Habits and Their Association With Glycemic Outcomes

Joyce M Lee [1] [2], Andrea Rusnak [2], Ashley Garrity [1] [2], Emily Hirschfeld [1], Inas H Thomas [2], Michelle Wichorek [3], Jung Eun Lee [4], Nicole A Rioles [5], Osagie Ebekozien [5], Sarah D Corathers [6]

1. Checks glucose at least 4 times a day

2. Gives at least 3 rapid-acting insulin boluses per day

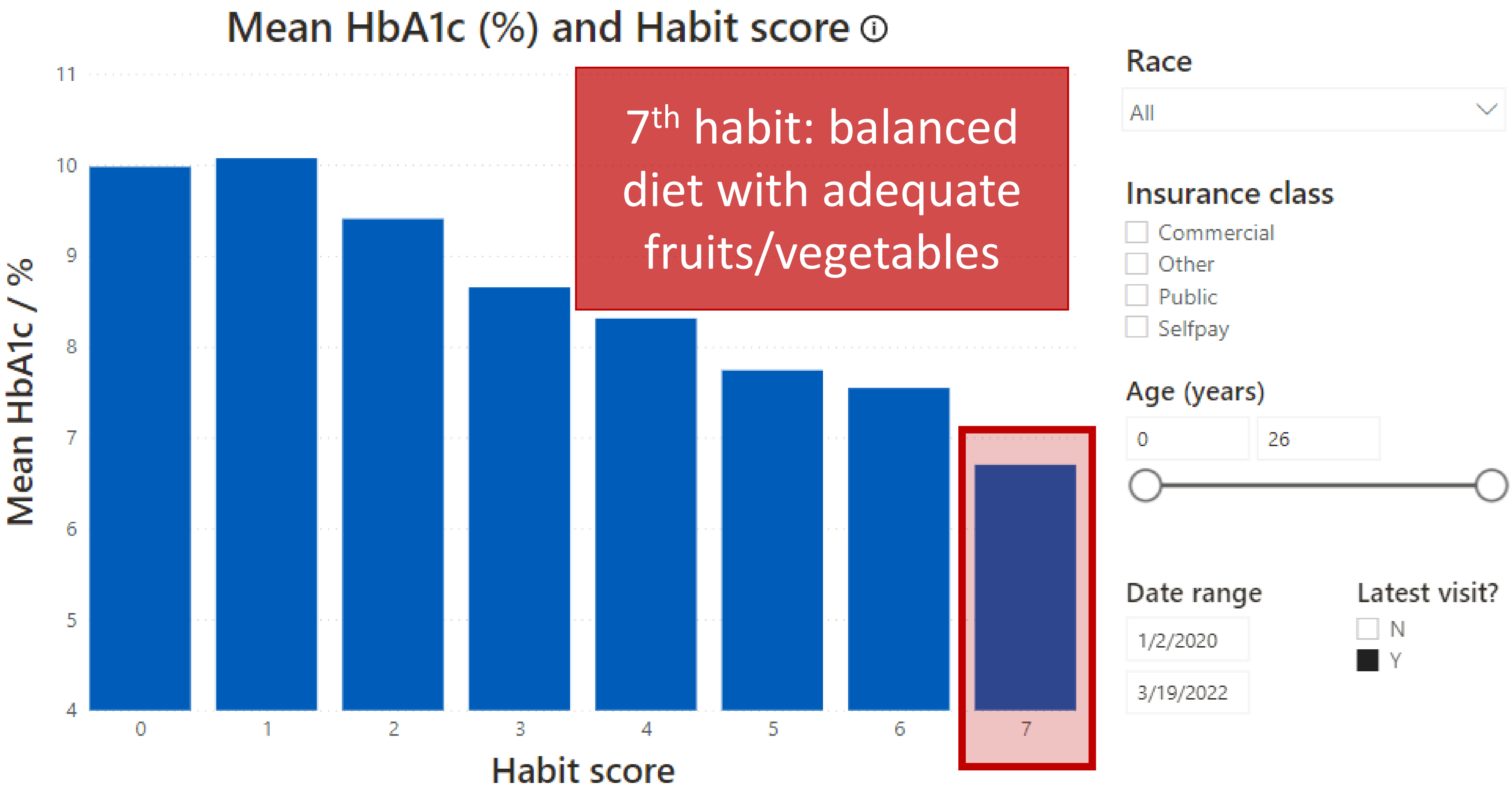
3. Uses insulin pump

4. Delivers boluses before meals

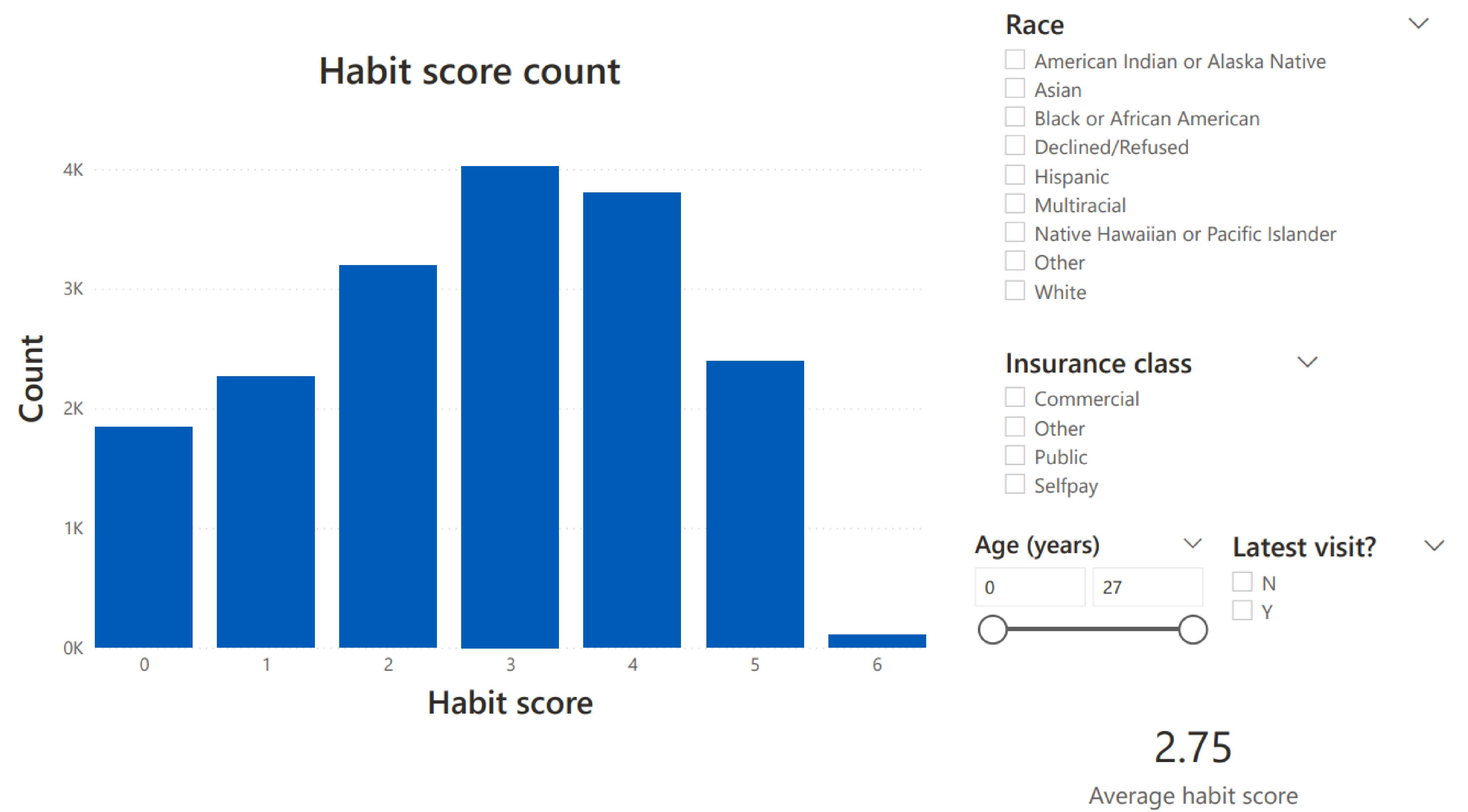
5. Reviewed glucose data since last clinic visit

6. Has changed insulin doses since last clinic visit

Lee et al. JAMA Diab & Endo 2021



Mean HbA1c (%) and Habit score
11
10
9
8
7
6
5
4
Mean HbA1c / %
0
1
2
3
4
5
6
7
Habit score
7th habit: balanced diet with adequate fruits/vegetables
Race
All
Insurance class
Commercial
Other
Public
Selfpay
Age (years)
0
26
Date range
1/2/2020
3/19/2022
Latest visit?
N
Y


Habit score count
Count
4K
3K
2K
1K
0K
0
1
2
3
4
5
6
Habit score
Race
American Indian or Alaska Native
Asian
Black or African American
Declined/Refused
Hispanic
Multiracial
Native Hawaiian or Pacific Islander
Other
White
Insurance class
Commercial
Other
Public
Selfpay
Age (years)
0
27
Latest visit?
N
Y
2.75
Average habit score

Population-level management of type 1 diabetes via continuous glucose monitoring and algorithm-enabled patient prioritization: Precision health meets population health

Johannes O. Ferstad[1] | Jacqueline J. Vallon[1] | Daniel Jun[1] | Angela Gu[2] | Anastasiya Vitko[2] | Dianelys P. Morales[1] | Jeannine Leverenz[3] | Ming Yeh Lee[3] | Brianna Leverenz[3] | Christos Vasilakis[4] | Esli Osmanlliu[3,5] | Priya Prahalad[3,6] | David M. Maahs[3,6,7] | Ramesh Johari[1,6] | David Scheinker[1,3,8]

Abstract

Objective: To develop and scale algorithm-enabled patient prioritization to improve population-level management of type 1 diabetes (T1D) in a pediatric clinic with fixed resources, using telemedicine and remote monitoring of patients via continuous glucose monitor (CGM) data review.

Research design and methods: We adapted consensus glucose targets for T1D patients using CGM to identify interpretable clinical criteria to prioritize patients for weekly provider review. The criteria were constructed to manage the number of patients reviewed weekly and identify patients who most needed provider contact. We developed an interactive dashboard to display CGM data relevant for the patients prioritized for review.

4T Intervention

Technology
Teamwork
Targets
Tight control

TIDE Dashboard

Patients

			% Time Worn	Avg G	% Time in Range	% Change in TIR	% Time Below 70	% Time Below 54
(1) Lows below 55 > 1%	[redacted]	DASH	85%	179	50%	-7.5	3.7%	1.6%
			84%	180	37%	-13.4	10.2%	1.4%
			86%	180	56%	25.5	5.0%	1.0%
(2) Lows below 70..			86%	137	76%	3.3	4.4%	0.2%
(3) Drop in TIR > 15%		Tandem	86%	192	42%	-23.5	1.0%	0.0%
			85%	168	56%	-20.4	0.3%	0.0%
(4) TIR < 65%			53%	279	21%	10.7	0.0%	0.0%
		DASH	86%	205	36%	-5.3	1.4%	0.4%
		DASH	79%	183	38%	-14.0	3.6%	0.7%
			85%	194	48%	2.6	3.3%	0.8%
		Tandem	81%	201	50%	-1.1	0.0%	0.0%
		Tandem	84%	188	54%	5.4	1.0%	0.4%
			85%	179	55%	11.4	1.5%	0.2%
		Tandem Order	85%	169	62%	-1.2	0.2%	0.0%
		DASH	84%	163	63%	0.9	2.1%	0.1%
		DASH	82%	157	64%	-8.3	1.7%	0.3%
		Pump Class	86%	175	65%	14.5	0.9%	0.0%
(5) Missing Data (e.g. wear time < 50%)			27%	190	18%	-31.4	0.0%	0.0%
		DASH Order				0.0		
						0.0		
						0.0		
(6) Meeting Targets		Tandem Order	86%	153	67%	-6.6	1.6%	0.0%
		EROS	82%	159	70%	10.5	3.0%	0.4%
			86%	168	71%	16.0	0.6%	0.0%
		Omnipod 5 Order	85%	146	74%	0.4	1.9%	0.5%
		Tandem	86%	139	75%	-3.3	3.2%	0.3%
			86%	150	75%	-10.7	0.3%	0.0%

Continuous Blood Glucose Risk Categories

CBG Risk Category	Patient Count
(1) Extreme Lows > 1%	122
(3) Large Drop in Time in Range	12
(4) Low Time in Range	90
(5) Insufficient Data	69
(6) Extreme Highs > 3%	11
(7) No Alerts	11
Total	**315**

Vendor

- [ ] carelink
- [ ] clarity
- [x] glooko
- [ ] tconnect

Most Recent Week CBG

1

Date of Week

1/1/2022 2/27/2022

Date	CBG Risk Category	CBG Days	Wear %	Time in Range	Ratio > 180	Ratio > 250	Ratio < 70	Ratio < 54	TIR Previous Week	Bolus Score	M
February 20, 2022	(1) Extreme Lows > 1%	7.00	98.66	0.76	0.20	0.03	0.04	0.04	0.84		0
February 20, 2022	(1) Extreme Lows > 1%	6.00	68.60	0.57	0.37	0.16	0.06	0.06	0.17		1
February 20, 2022	(6) Extreme Highs > 3%	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]		1
February 20, 2022	(4) Low Time in Range	7.00	97.82	0.19	0.81	0.56	0.00	0.00	0.03		1
February 20, 2022	(4) Low Time in Range	6.00	73.21	0.33	0.67	0.36	0.00	0.00	0.23		1
February 20, 2022	(1) Extreme Lows > 1%	7.00	98.41	0.70	0.26	0.01	0.04	0.04	0.57		1
Average		**5.75**	**74.87**	**0.52**	**0.45**	**0.22**	**0.02**	**0.02**	**0.53**	**0.59**	

Emerging Feature: Mealtime Insulin BOLUS Score

Rising Tide Alliance Approach

Clinical and Operational Map

RISING T1DE ALLIANCE

STEP 1

Data Source	Referral Reason
EHR & patient forms data (Traditional)	**Clinic-Based**
	Clinic Team Referral
	New Onset Diabetes
	Intake form • Positive screening • Self-enrollment
	Hospital-Based
	DKA Admission
	Case Manager Referral
D-Data Dock (Enabled)	**Timely Monitoring**
	EHR monitoring; two A1c values > 9
	Real-time, remote CGM monitoring
	Pop Health Dashboard of all Patients
	Predicted Risk
	90-day change in A1c
	180-day DKA risk

STEP 2

Referral methods vary by 'Reason for Referral'

Who provides follow-up:

- Rising T1DE team
- Certified Diabetes Care Education Specialist
- Hospital social work
- Community Based Organizations
- Digital Health Resources

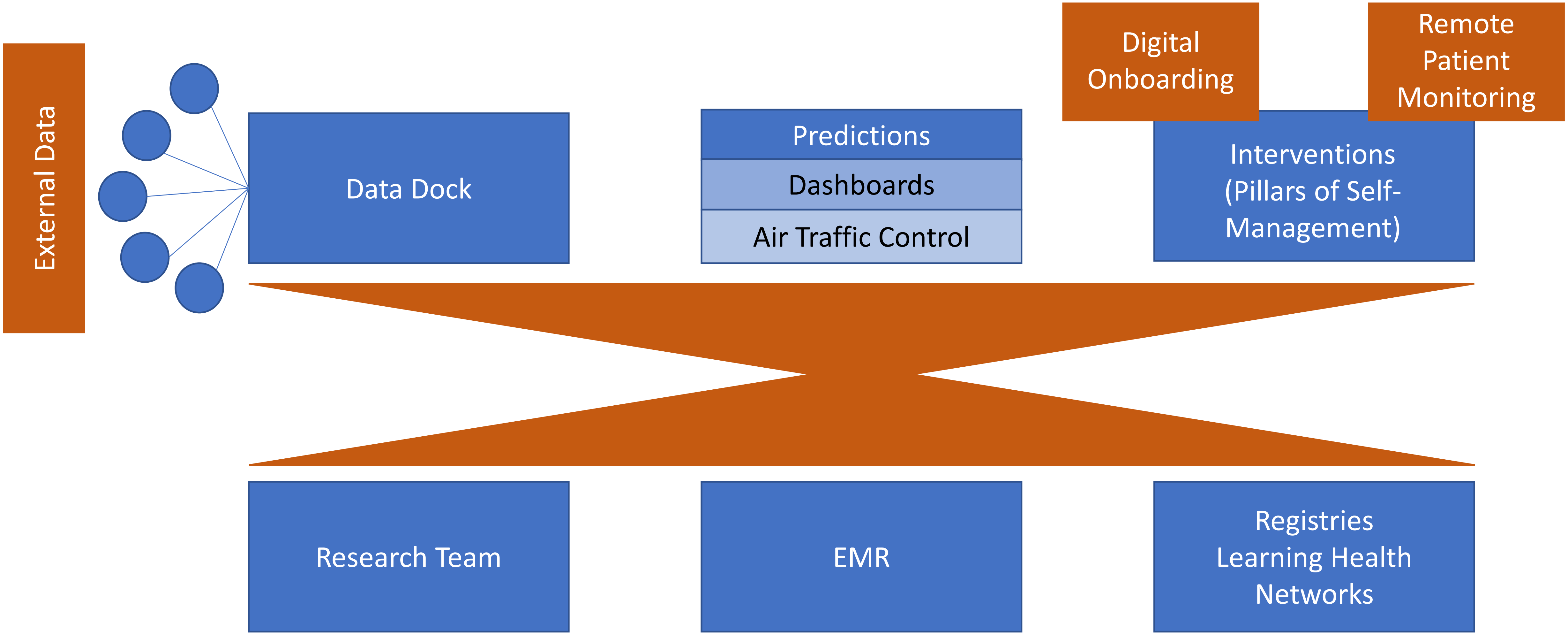
STEP 3

Area	Interventions
Core RPM	Diabetes educator biweekly visits in between quarterly standard of care visits
	Additional care referrals
mHealth	Happy Bob – gamified CMD management
	KIDDO – wrist wearable to promote physical activity
	MyCare – CMH app focused on education & management
	Nudge- uses software to promote physical activity in teens by goal setting, monitoring & daily feedback via text
	Sweetch- AI-enabled app uses just in time adaptive tech to promote health habits
Behavioral	Healthy Eating Habits- MyPlan
	Coin2Dose- financial incentives for bolus engagement
	Diabetes Discord Peer support promotes healthy coping
Improving Clinic Experience	Spotlight AQ-smart adaptive patient survey to guide clinic visit discussion
	QUEST-gathers data in focus groups, semi-structured interviews or surveys

STEP 4

Performance Tracking

A new kind of ecosystem for care within a diabetes clinic



Conclusion

Lack of data interoperability and standards is very costly

Designing for interoperability saves healthcare dollars
Designing for interoperability accelerates research
Designing for interoperability accelerates the pace of innovation

Team of talents

Role – Children's Mercy	Name
Executive Lead	Mark Clements
Project Coordinator	Emily DeWit
Diabetes Educators	Katie N, Rachel D, Laura J
Project Assistant 1, 2	Britaney S, Katelyn E
Project Assistant 2,3, 4	Jude E, An H, Claire P
Project Assistant 5, 6	Sarah A, Rebekah E, Priscilla
Project Assistant 7, 8	Megan E, Sophie M
Senior Data Scientist	Brent Lockee
Data Engineer/Pgrmr	Mitchell B, Harsh J
Data Scientist/Pgrmr	Erin T., Kelsey P
Data Scientist/Pgrmr	Craig V., Amey W.
Statistician	David Williams

Role – Childrens Mercy	Name
Executive Lead	Juan Espinoza
Program Manager	Grace Garcia
Program Coordinator	Shahida Qazi
Project Manager	Lawrence Lett
Data Scientist	Eric Williams
Implementation Specialist	Sadaf Javaid
Communications	Rachel Spencer

Role – Lurie Children'	Name
Advisory Committee Chair	Sanjeev Mehta, Joslin
Director, Intervention Dev.	Susana Patton, Nemours
QI Clinical Champion	Ryan McDonough, Children's Mercy

Role – Stakeholder Advisory	Name
Dave Walton, Sarah Corathers, Rona Sonabend	
Juan Espinoza, Helen DuPlessis, D. Williams, Purvi Sevak	
Nana Jones, Sanjoy Dutta, Gregory Howe, Sally Jercha	

RISING T1DE ALLIANCE

Thank you

- visit https://risingT1DEalliance.org
- email me at maclements@cmh.edu