T1D Exchange

Clinical Leadership Committee

April 26, 2024

Agenda

1. Welcome – Todd and Devin
2. Announcing new 2024-2026 Co-Chairs – Todd and Devin
3. Update from Working groups
    a) Hybrid Close Loop – Carol Levy
    b) Transition – Faisal Malik
    c) Diabetes Distress - Alissa Roberts
4. Monogenic Diabetes Project - Devin

Clinical Leadership Committee

Purpose: Provide expert consultation, deliberation, and advice on the overall quality improvement initiatives, including aims, drivers, interventions to improve processes and clinical outcomes in diabetes care. Advise on strategic direction of the collaborative and new partnership exploration.

Outgoing 2022-2024 Chairs

Todd Alonso, MD
Barbara Davis Center

Devin Steenkamp, MD
Boston Medical Center

Incoming 2024-2026 Chairs

Carla Demeterco-Berggren, MD, PhD
Rady Children's Hospital

Francesco Vendrame, MD, PhD
University of Miami

Data Science Committee

Purpose: Guide development and update of T1D/T2D data specification, and metrics to support improvement efforts in the collaborative.

Outgoing 2022-2024 Chairs

Joyce Lee, MD, MPH
C.S Mott Children's Hospital

Marina Basina, MD
Stanford Medicine

Incoming 2024-2026 Chairs

Ryan McDonough, DO,FAAP
Children's Mercy Kansas City

Nirali Shah, MD Icahn School of Medicine at Mt. Sinai

Data Governance Committee

Purpose: Expand research and QI focus through academic and industry support for projects and support collaborative viability by reviewing new EMR data-based industry/sponsored project proposals, monitoring ongoing sponsored projects, and brainstorming/proposing new industry partnerships with T1DX-QI/T2DX-QI.

Outgoing 2022-2024 Chairs

Daniel DeSalvo, MD
Baylor College of Medicine/Texas Children's Hospital

Carol Levy, MD
Icahn School of Medicine at Mt. Sinai

Incoming 2024-2026 Chairs

David Hansen, MD, MPH
Upstate University Medicine

Georgia Davis, MD
Grady Memorial Hospital

Publication Committee

Purpose: Reviewing publication proposals and drafts manuscripts. Monitoring publications progress and brainstorming/proposing new avenues to share insights from the collaborative.

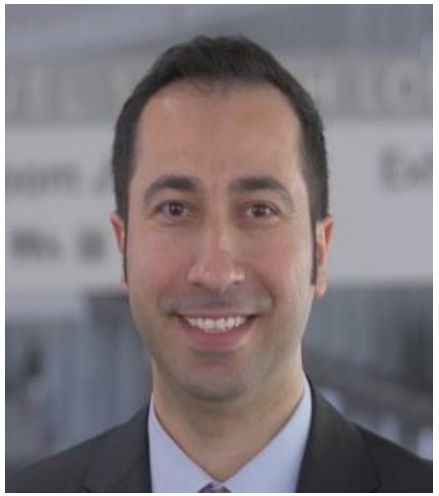
Outgoing 2022-2024 Chairs

Shideh Majidi, MD, MSCS
Children's National Hospital

Shivani Agarwal, MD, MPH
Montefiore Einstein

Incoming 2024-2026 Chairs

Stephanie Crossen, MD, MPH University of California Davis



Halis K. Akturk, MD
Barbara Davis Center

PWD Advisory Committee

Purpose: Provide patient perspective/insight into the care experiences of those with T1D, in an effort to prioritize and improve comprehensive and compassionate person-centered and family-centered healthcare and achieve the T1DX-QI goal of providing the highest quality of care to every person with diabetes.

Outgoing 2022-2024 Chairs

Jeff Hitchcock,
Children with
Diabetes

Amy Ohmer,
C.S Mott Children's
Hospital

Incoming 2024-2026 Chairs

Jeniece Ilkowitz, RN, MA, CDCES
Hassenfeld Children's
Hospital at NYU Langone

Emily Coppedge, NP
Weill Cornell Medicine

QI Champion Committee

Purpose: Foster interprofessional collaboration for QI analysts and coordinators. To facilitate discussions on QI methodologies, QI initiatives, and QI best practices to enhance clinic processes, workflows, and patient outcomes.

Incoming 2024-2026 Chairs

Blake Adams, BSN, RN
Le Bonheur Children's Hospital

Lydia Holly, BSN, RN
Children's National Hospital

HEAL (Health Equity Advancement Lab)

Purpose: The T1DX HEAL Program is a network of health equity clinical and research leaders aiming to provide thought leadership around the diabetes health equity initiatives. The HEAL Program will contribute to best practices regarding equitable diabetes care through multiple strategies

Incoming 2024-2026 Chairs

Ashley Butler, PhD
Baylor College of Medicine/Texas Children's Hospital

Selorm Dei-Tutu, MD, MPH
Baylor College of Medicine/Texas Children's Hospital

International Collaboration

Purpose: Provide expert consultation, deliberation, and advice on international collaborations to promote new partnerships and relationships with other diabetes collaborative and networks.

Incoming 2024-2026 Chair

David Maahs, MD, PhD
Lucile Packard Children's Hospital. Stanford University

T1D Exchange

Hybrid Closed Loop Working Group Updates

April 2024

Participating Centers

- **Pediatric Members**

Allison Smego – University of Utah
Amanda Perkins – Children's National
Amit Lahoti – Nationwide Children's
Carla Demeterco-Berggren – Rady Childrens
Christy Mendoza- Rady Childrens
Blake Adams – Le Bonheur Children's
Janine Sanchez – University of Miami
Jenise Wong – University of California San Francisco
Joyce Lee – University of Michigan
Liz Mann – University of Wisconsin
Malak Abdel-Hadi – Nationwide Childrens
Melissa Ladd – Nationwide Children's
Rebecca Campbell – Barbara Davis Center
Shideh Majidi – Children's National
Siham Accacha – NYU Langone Long Island
Todd Alonso – Barbara Davis Center
Emily Coppedge- Cornell
Den Desalvo- Texas Children's

- **Adult Members**

Georgia Davis – Grady Memorial
Carol Levy – ISMMS (Mount Sinai)
Ruth Weinstock – SUNY upstate

T1D Exchange

Working Group

Hybrid Closed Loop Work-Group

Leads: Emily Coppedge NP, CDCES (Weil Cornell Medical Center-*Pediatrics*) and Carol Levy MD, CDCES (ISSMS-*Adult*)

T1DX-QI Support Staff : Trevon Wright

Workgroup Aim

- Increase the utilization of Automated Insulin Delivery System use among people with T1D by 10% from baseline in 6 months.
  - Monthly calls (confounded by clinical availability)->half team on most calls on alternating days of week
  - Survey developed for clinicians at team member sites to gain further clarity regarding barriers to prescribing/patient adoption of AID systems
    1. Survey creation
    2. Survey completion

Survey Highlights

Barriers for prescribing HCLs (Select all that apply): 90

Q7 - Barriers for prescribing HCLs (Select all that apply): - Selected Choice	Percentage	Count
Systems (Insurance/Prior Authorizations)	69%	62
Patient Glycemic Control (Frequent DKA/A1c Level)	26%	23
Clinical Resources and Pump Policies	10%	9
Patient Factors (literacy level, education, length of diagnosis, inconsistent CGM use, inconsistent follow up)	83%	75
Provider confidence in recommending and managing technology	7%	6
Other	6%	5

Survey Highlights

Barriers for patients starting on HCLs (Select all that apply): 88

Q8 - Barriers for patients starting on HCLs (Select all that apply): - Selected Choice	Percentage	Count
Education: (Access to education/training)	31%	27
Systems (Insurance/supplies)	63%	55
Social Barriers (time off from work/school, time commitment for training)	56%	49
Personal Barriers (wearing devices, hesitancy of change, device compatibility)	91%	80
Other	2%	2

Next Steps

- Creation/sharing templates for provider use for prior authorization
- Best practices to be shared by sites: Approaches for those with device hesitancy/health literacy/limited follow up
- Attempt to find a day of week to maximize attendance

Questions/Feedback/Suggestions?

On behalf Emily and Carol: A huge thanks to Trevon and all team members

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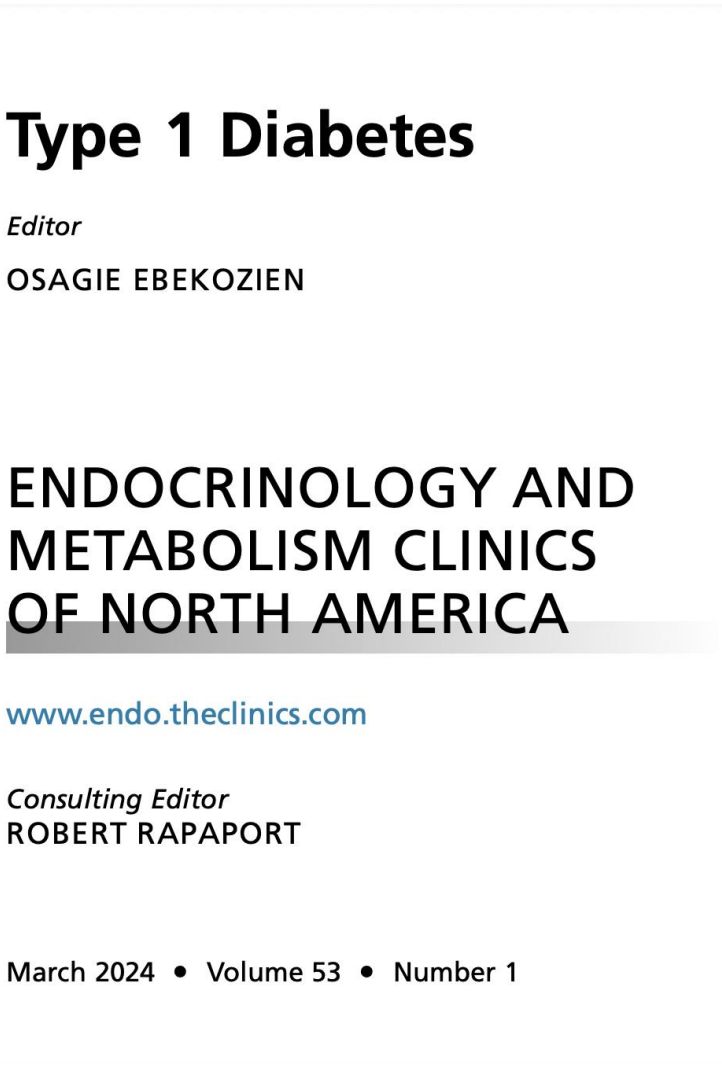
Health Care Transitions Working Group

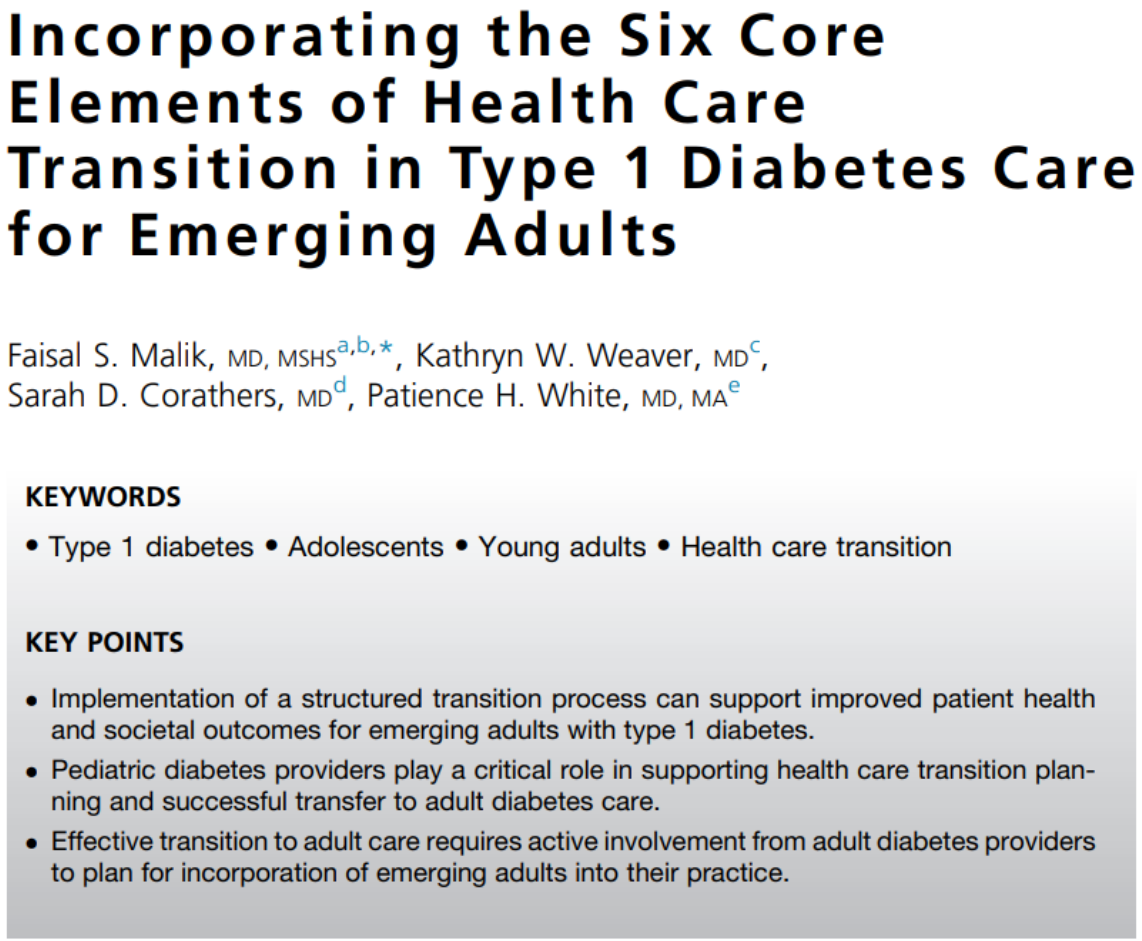
April 2024

Workgroup Objectives and Deliverables

- **Support workgroup members on how to leverage Got Transition's Six Core Elements of health care transition (HCT) to guide local HCT efforts**

Workgroup Objectives and Deliverables





Incorporating the Six Core Elements of Health Care Transition in Type 1 Diabetes Care for Emerging Adults

Faisal S. Malik, MD, MSHS[a,b,*], Kathryn W. Weaver, MD[c], Sarah D. Corathers, MD[d], Patience H. White, MD, MA[e]

KEYWORDS

• Type 1 diabetes • Adolescents • Young adults • Health care transition

KEY POINTS

- Implementation of a structured transition process can support improved patient health and societal outcomes for emerging adults with type 1 diabetes.
- Pediatric diabetes providers play a critical role in supporting health care transition planning and successful transfer to adult diabetes care.
- Effective transition to adult care requires active involvement from adult diabetes providers to plan for incorporation of emerging adults into their practice.

Workgroup Objectives and Deliverables

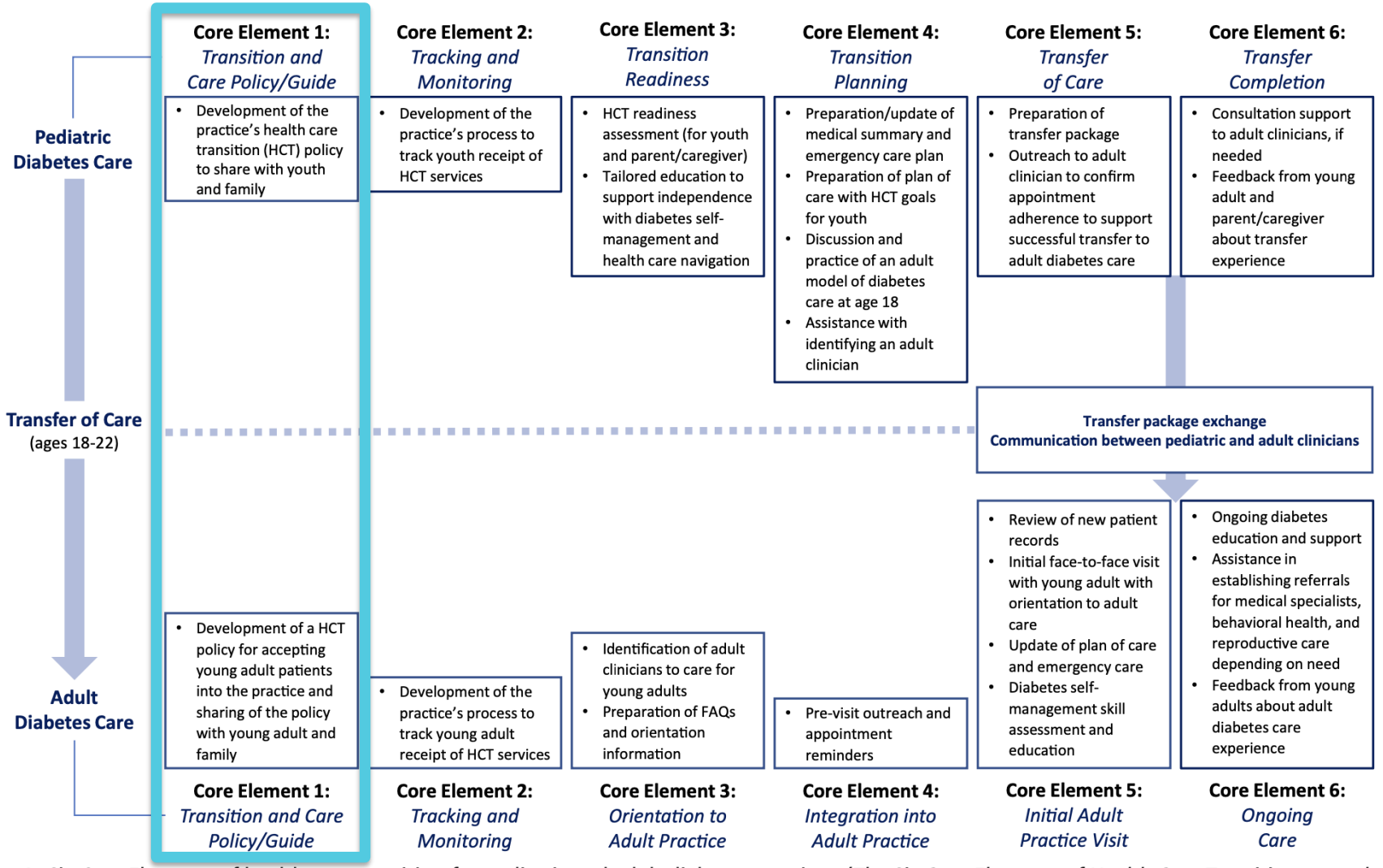


Fig. 1. Six Core Elements of health care transition for pediatric and adult diabetes practices. (*The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®. This version of the Six Core Elements has been modified and is used with permission.*)

Malik et al

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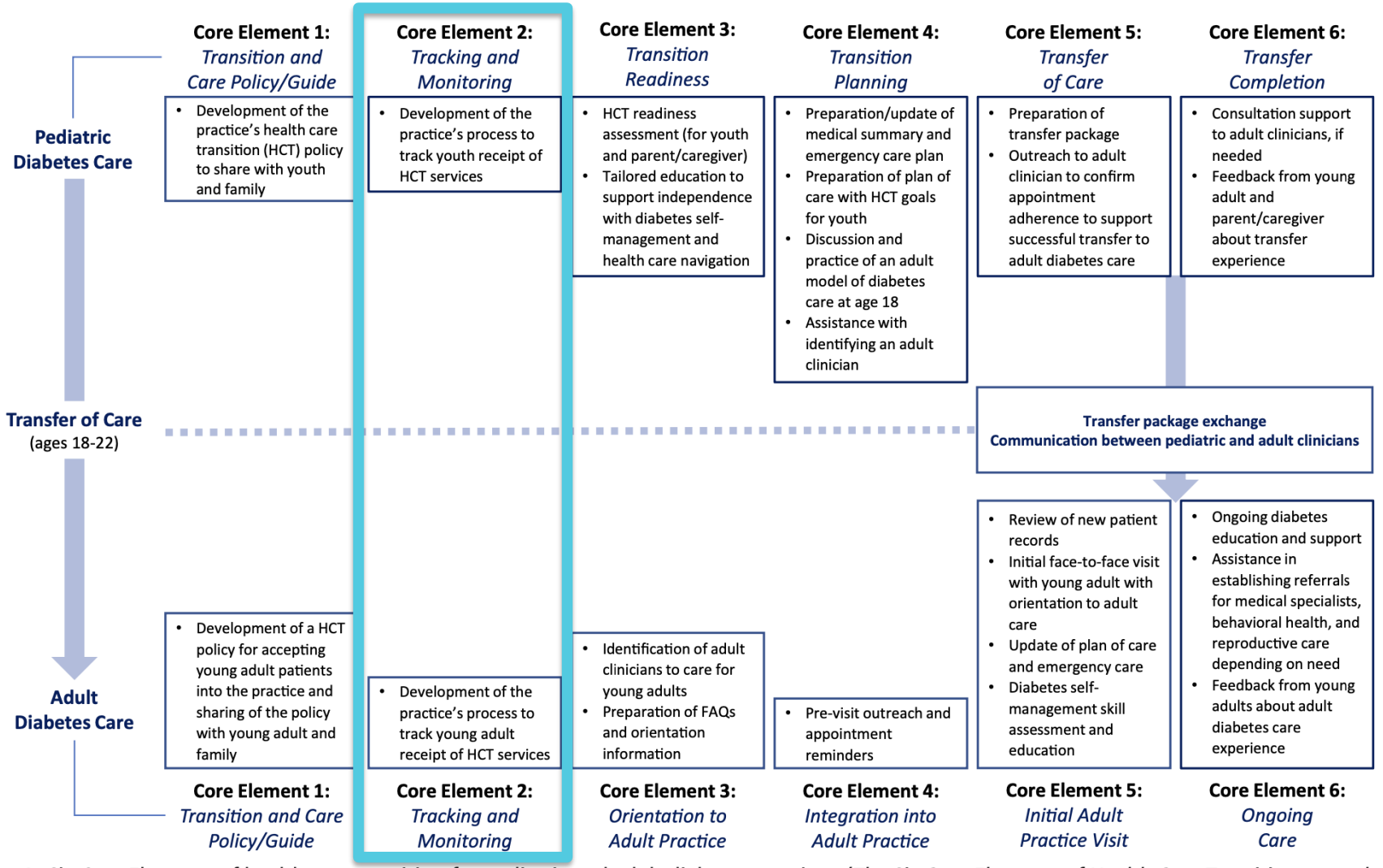
Workgroup Objectives and Deliverables



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Malik et al

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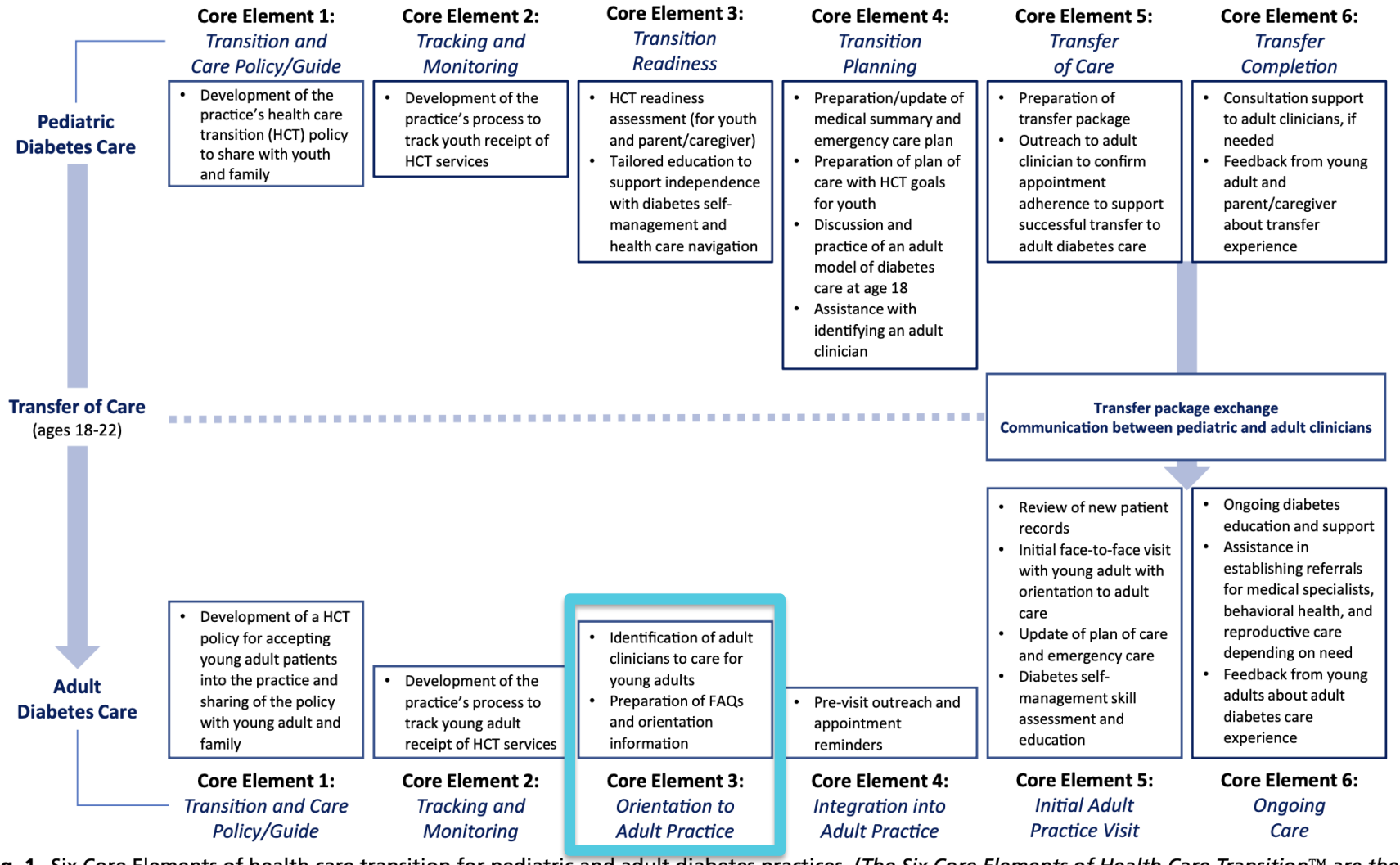

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Malik et al

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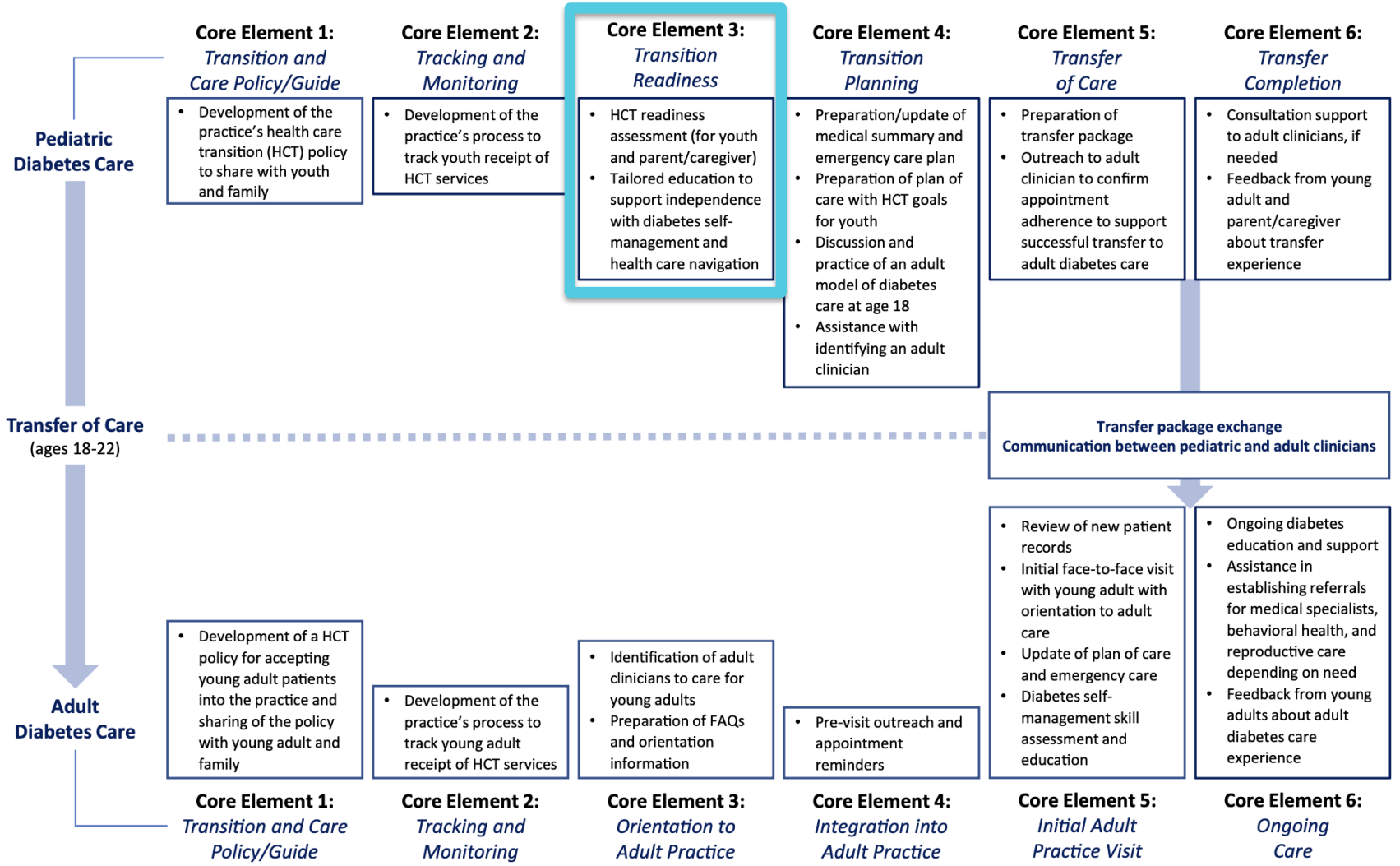

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Malik et al

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Workgroup Objectives and Deliverables

- Support workgroup members on how to leverage Got Transition's Six Core Elements of health care transition (HCT) to guide local HCT efforts

- **Increase adult center participation in HCT efforts within T1DX-QI**

Participating Centers

Pediatric Members (16 Pediatric Centers)

- Moniquie Maher – Barbara Davis Center
- Lauren Waterman – Barbara Davis Centers
- Mark Clements, – Childrens Mercy Kansas City
- Amy Ohmer – C.S Mott Children's Hospital
- Donna Eng – Helen DeVos
- Meredith Wilkes – Icahn Mt Sinai
- Risa Wolf – Johns Hopkins University
- Grace Nelson – Le Bonheur Childrens
- Charlotte Chen – Montefiore Einstein
- Sarah Rosenheck – Montefiore Einstein
- Anita Peoples – Nationwide Children's
- Beth Edwards – Nationwide Childrens Hospital
- Malak Abdel-Hadi – Nationwide Childrens Hospital
- Manmohan Kamboj – Nationwide Childrens Hospital
- Ming Chang Hong – Nationwide Childrens Hospital
- Sheila Denehy – NYU Langone Long Island
- Siham Accacha – NYU Langone Long Island
- Ines Guttmann Bauman, – Oregon Health and Sciences University
- Katie Craft, – University of California San Francisco
- Laura Jacobsen – University of Florida
- Inas Thomas – University of Michigan
- Jordan Ross – University of Tennessee
- Vana Raman – Utah Intermountain Health
- Allison Smego- Utah Intermountain Health

Co-Chairs

- Faisal Malik – Seattle Children's Hospital
- Sarah Corathers – Cincinnati Children's Hospital
- Shivani Agarwal – Montefiore Einstein

T1DX-QI Support Staff

- Holly Hardison

Adult Members (6 Adult Centers)

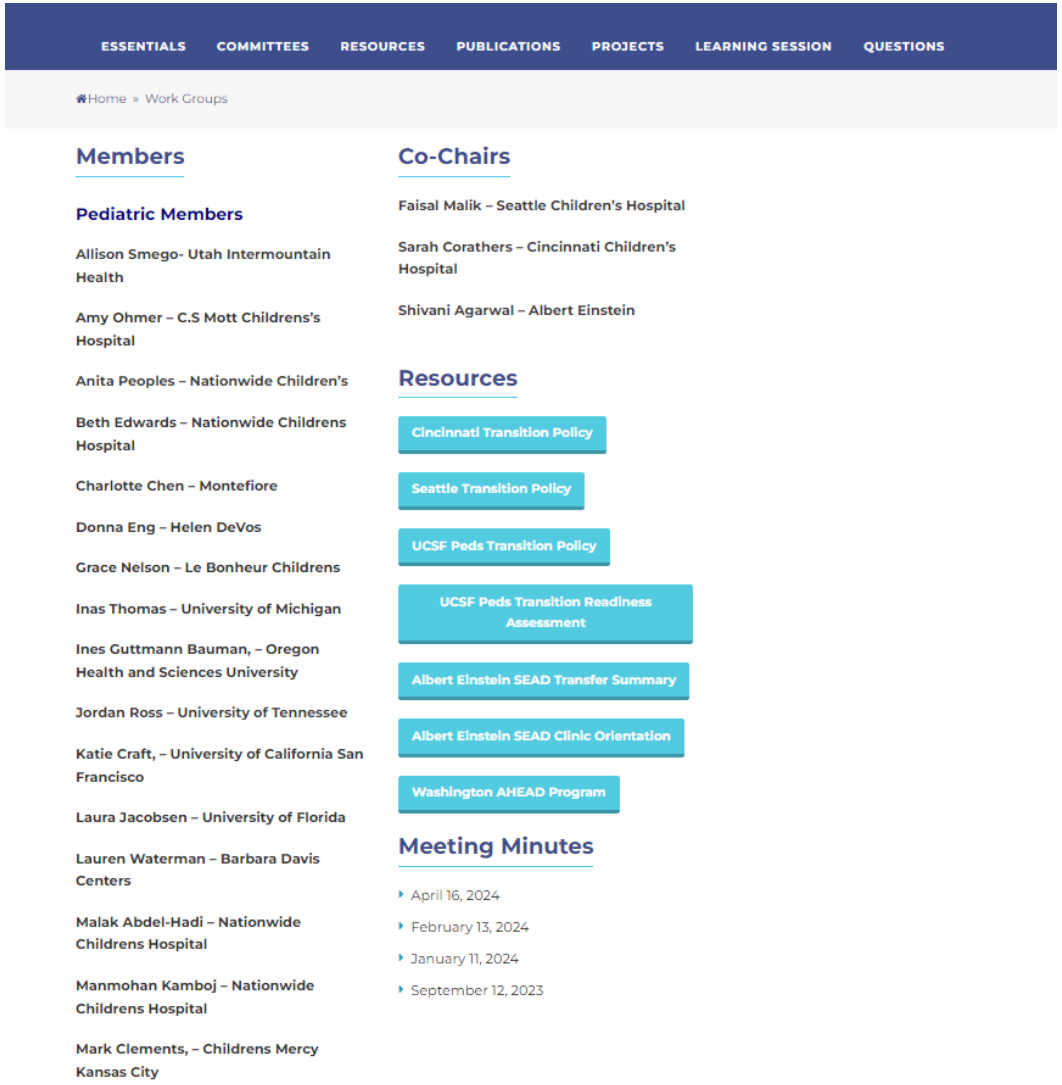
- Michael Greenberg- Montefiore Einstein
- Farahnaz Joarder- Oregon Health and Sciences University
- Ryan Tweet – Oregon Health and Sciences University
- Deborah Plante – University of California Davis
- Andrew Welch – University of Cincinnati
- Daniel Tilden – University of Kansas Medical Center
- Kate Weaver – University of Washington

T1D Exchange

Workgroup Objectives and Deliverables

- Support workgroup members on how to leverage Got Transition's Six Core Elements of health care transition (HCT) to guide local HCT efforts
- Increase adult center participation in HCT efforts within T1DX-QI
- **Share best practices and develop shared resources on HCT**

Workgroup Objectives and Deliverables



Workgroup Objectives and Deliverables

- Support workgroup members on how to leverage Got Transition's Six Core Elements of health care transition (HCT) to guide local HCT efforts
- Increase adult center participation in HCT efforts within T1DX-QI
- Share best practices and develop shared resources on HCT
- **Select QI metric for HCT for pediatric and adult centers**

Questions or Comments?

Diabetes Distress Screening

T1D Exchange Working group update

Participating Clinical Centers

Pediatric	Adult
Cincinnati Children's	Boston Medical Center
Hassenfeld Children's	Oregon Health and Science University
Indiana University	University of Michigan
Nationwide Children's	
Seattle Children's	
Texas Children's	
University of Alabama	
University of Michigan	
University of Wisconsin	

Group Aims

1. Determine best practices for screening for diabetes distress (recommended tool, population, process, response)

2. Track diabetes distress screening vis Smartsheets, then new data specs

3. Share screening processes and responses

4. Perform PDSA cycles to improve screening rates with participating clinics

Group Aims

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PAID-T- recommended annually for ages 12-18 yo

- **Not feeling motivated to keep up with my daily diabetes tasks.**
- **Feeling that my friends or family act like "diabetes police" (e.g. nag about eating properly, checking blood sugars, not trying hard enough).**
- **Feeling that my friends or family don't understand how difficult living with diabetes can be.**
- **Worrying that diabetes gets in the way of having fun and being with my friends.**

14 items, total score calculated
Validated ages 12-18 yo
Shapiro et. Al -> score >=44 indicated high DD

1 **Not a problem**

6 **A serious problem**

Journal of Pediatric Psychology, 2017, 1–11
doi: 10.1093/jpepsy/jsx146
Original Research Article

OXFORD

Psychometric Properties of the Problem Areas in Diabetes: Teen and Parent of Teen Versions

Jenna B. Shapiro,[1] MA, Anthony T. Vesco,[2] PhD, Lindsey E. G. Weil,[3] MA, Meredyth A. Evans,[2,3] PhD, Korey K. Hood,[4] PhD, and Jill Weissberg-Benchell,[2,3] PhD, CDE

Diabetes Distress Scale - recommended annually for ages 18+

Original Diabetes Distress Scale (17-item DDS) and newer Diabetes Distress Assessment System (DDAS)

Recommendation: T1DDAS and T2DDAS. Both scales have the same **core scale** of 8 items. Each also has a set of **source scales**: 7 for the T2DDAS and 10 for the T1DDAS

8 item core scale: **Intensity** of DD in both types of diabetes using a single measure.

Average score of 2 or higher indicates significant DD

	Not A Problem (1)	A Little Problem (2)	A Moderate Problem (3)	A Serious Problem (4)	A Very Serious Problem (5)
1. I feel burned out by all of the attention and effort that diabetes demands of me.					
2. It bothers me that diabetes seems to control my life.					
3. I am frustrated that even when I do what I am supposed to for my diabetes, it doesn't seem to make a difference.					
4. No matter how hard I try with my diabetes, it feels like it will never be good enough.					
5. I am so tired of having to worry about diabetes all the time.					
6. When it comes to my diabetes, I often feel like a failure.					
7. It depresses me when I realize that my diabetes will likely never go away.					
8. Living with diabetes is overwhelming for me.					

Group Aims

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2. Track diabetes distress screening vis Smartsheets, then new specs

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Diabetes Distress tracking

Smartsheets- clinics input every month

- Numerator: patients screened for DD
- Denominator: Patients eligible for DD screening

Updated Data Specifications: for each encounter

- Screened for DD yes/no
- Screening tool used
- Item number
- Total score

Group Aims

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Examples of PDSAs and work currently ongoing at centers

OHSU using handouts and MyChart screener. MAs are entering data. Software tells how many completed but not rates of success

Nationwide: Hired new psychologist. Screening DD twice a week. Submitting DD abstract to ISPAD

Adult centers: limited behavioral resources, implementation into clinic work-flow is challenging with high throughput at adult clinics

BMC: identifying people with SDOH and DD for tech focus, to support with more resources. Working on data mapping flow sheets

University of Michigan, Adults: Have embedded into Epic, have screened over 1,000 PWD, completing a dashboard this summer. Offering MOC 4 credits to clinicians who use the flowsheet, conduct screening, and refer to resources.

Seattle Children's: pairing depression and distress screening- same process. PAID-T is administered via MyChart in Epic- elevated responses flagged.

Next Steps

- There are Diabetes Distress measures in the Smartsheet. More centers will be documenting distress screening in Q2 2024 and beyond.
- Data Science Committee will add Diabetes Distress elements into the Data Spec in 2024.
- It's important to discuss the distress with PWD, even if time is limited. Clinicians in the group recognize the need to discuss distress with PWD because of the importance of the topic and the scarcity of behavior health trained clinicians available in practice. How can we develop soft skill development [training] among endocrinologists?
  - Train during Diabetes Distress meeting
  - Train at the learning session in November
  - Ryan Tweet, PhD and Katherine Semenkovich, PhD are willing to co-lead a training that could be appropriate for the adult-pediatric clinicians
- Resource ideas
  - Change package for Diabetes Distress with best practice tools for dissemination
  - Dot Phrase template for documentation in EMR

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