T1D Exchange (T1DX) Health Equity Advancement Lab (HEAL) Meeting Agenda

January 25, 2022, 1-2:30 pm EST, Zoom

Participants:

Ananta Addala, Ashley Butler, Carla Demeterco, Osagie Ebekozien, Holly Hardison, Kristopher Leeper, Shideh Majidi, Faisal Malik, Makaila Manukyan, Ann Mungmode, Margarita Ochoa-Maya, Ori Odugbesan, Gary Puckrein, Nicole Rioles, Janine Sanchez, Devin Steenkamp, David Walton

Agenda:

Time	Item	Facilitator
1:00-1:10 pm 10’	**Welcome** ● Welcome ● Centering	 Osagie Ebekozien Ann Mungmode
1:10-1:40 pm 30’	**National Minority Quality Forum advocacy example**	Dr. Gary Puckrein
1:40-2:10 pm 30’	**T1D Health Equity Advocacy** ● Brief sharing ● National advocacy efforts ● HEAL Advisory Committee opportunities	T1DX staff
2:10-2:30 pm 20’	**Updates and Close Out** ● Summary of next steps ● Next meeting 4/21, 1 PM EST	T1DX staff

Minutes:

Welcome

Introduction: When you hear advocacy what word do you think of?

- Voice, urgently needed, persistence, making a noise, representation, change, access, social determinants of health, applied best practices, justice, this meeting

National Minority Quality Forum advocacy example

Dr. Gary Puckrein shared a historical context for why racial-ethnic health inequities persist today

- Unfortunately, many hospitals and healthcare companies prioritize financial risk; this causes healthcare to lose site of the patient and is removed from the purpose of protecting patients
- History on segregation of patients and inequality regarding standard of care for patients
    - Consider African American history – Black men could not own property, have health insurance, etc.
    - In the 1940s, there were four doctors treating all Black patients in the state of MS
    - Segregated healthcare was enforced by law, immediately building inequities in
    - It was illegal for Black individuals to visit a public library
- While the outward manifestations of racism may have disappeared, but the legacy system has produced persistent inequities

National Minority Quality Forum (NMQF)

- NMQF has developed a comprehensive database with over 5 billion patient records on many illnesses, and using GIS can produce maps on the zip code-level
    - US Diabetes Index
- Key learnings
    - Geography matters – mapping at the zip code-level is valuable
    - Predictable forces shape markets – there is enough data that outcomes are highly predictable; despite the robustness of the data, it is often not used to change the outcome or the risk
    - Consumption patterns can be shaped
    - Resource management can be improved

Advocating for change

- Policymakers don't always use evidence-based science when forming policy
- In 2008, 48% of Black and 54% of Hispanic patients had no health insurance
- We need to flip the paradigm from financial risk to patient advocacy
    - E.g., reducing the burden of a heart attack would increase cost in the system
    - Need to counter frame of reference – e.g. opposition payers that call healthcare a scarce commodity that needs to be rationed

T1D Health Equity Advocacy

What is within T1DX HEAL scope? What change can we affect in the next year?

- How can we address a cost-balancing equation
    - What is cost advantage? Metrics that show advantages economically
- Are we going for paradigm shift (longer effort) or immediate impact?
- Policymakers may only see the next year
    - Budget needs to even out at end of the year; we can't implement cost-saving measures over ten years if it costs money upfront/investment
- Medicaid program is very deeply flawed for this reason
- We can take advantage of T1DX clout
- The data is already summarized; we should focus on something that is action-oriented
- Addressing provider/all staff (MDs, CDEs, etc.) bias – "every patient is a candidate" for devices
- Public is generally unaware of difference between type 1 and type 2 diabetes
    - Patients/public can benefit from differences between the two
    - Patients with T1D get misdiagnosed with T2D
- Behavioral health inequities exist too; how do we support patients throughout their T1D journey
    - Are their advocacy efforts aimed more around this?
    - Rady has nurse care navigators to support families in assuring they get supplies, troubleshooting, medications, etc.
    - BMC has a diabetes technology navigator and pharmacy technician
- Addressing prior authorizations
- T1DX can use publications to put pressure where due
    - It doesn't need to be robust RCTs, but like we're already doing, how to move the needle with the data we have
    - Can we publish how long it takes for DMEs to be covered?

- We know from our experience that QI science can improve the operational level within institutions, but policy puts a cap on how much improvement we can have

What examples of advocacy have we seen/been a part of that have been successful?

- In Florida, was able to demonstrate that covering supplies reduces DKA admissions
    - Have clear case studies and documentation; “this is what happens when patients xyz”
    - Positioning clinical vignettes and stories in as high a level as possible

Who else do we need in the room?

- Connect with patient reps and other groups to assure we’re headed in the right direction
- Payers – we need to understand their viewpoints and priorities and align on values
- We want to have a chorus of voices
- Including research funding agencies
- Advocacy and Policy/Procedure Efforts

Updates and Close Out

- We may have some homework between now and next meeting so by next meeting we have a clear decision on what we will work on
- Next meeting Monday April 4, 2022, 1 pm EST