T1D Exchange

Advisory Committee January Meeting

1-17-2024

Agenda

- Advisory Committee Co-Chair Nominations
- Ending Diabetes Discrimination
  - End Diabetes Stigma and Discrimination Campaign
  - Review of Dr. Jane Dickinson's Use of Language paper (Diabetes Care)
- Review Slides from Ideal Survey
  - Review Results
  - Brainstorm ideas how to communicate findings
- ADCES Conference Submission Brainstorm

Co-Chair Nominations

- New Co-Chair Term will begin June 1st
- Use this link to view the Advisory Committee Charter
- Use this link or scan the QR code to submit nomination
    - Please review the committee charter before nominating

Ending Diabetes Stigma

Use this link to sign!

Diabetes and Language

CONSENSUS REPORT | OCTOBER 17 2017

The Use of Language in Diabetes Care and Education FREE

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Table 1: Guiding Principles for Communication with and about People Living with Diabetes

Diabetes is a complex and challenging disease involving many factors and variable
Stigma that has historically been attached to a diagnosis of diabetes can contribute to stress and feelings of shame and judgment
Every member of the health care team can serve people with diabetes more effectively through a respectful, inclusive, and person-centered approach
Person-first, strengths-based, empowering language can improve communication and enhance the motivation, health, and well-being of people with diabetes

Table 3: Recommendations

Use language that
1. is neutral, nonjudgmental, and based on facts, actions, or physiology/biology
2. is free from stigma
3. is strengths based, respectful, inclusive, and imparts hope
4. fosters collaboration between patients and providers
5. is person centered

Table 2: Key Definitions

Word/Phrase	**Definition**
Strengths-based language	Opposite of a deficit approach; emphasizing what people know and what they can do. Focusing on strengths that can empower people to take more control over their own health and healing. Example: Lee takes her insulin 50% of the time because of cost concerns (instead of Lee is noncompliant/nonadherent).
Person-first language	Words that indicate awareness, a sense of dignity, and positive attitudes toward people with a disability/disease. Places emphasis on the person, rather than the disability/disease. Example: Lee has diabetes (instead of Lee is a diabetic).

Table 4: Suggestions for Replacing Language with Potentially Negative Connotations

Language with potentially negative connotations	Suggested replacement language	Rationale
Compliant/compliance, noncompliant/noncompliance, adherent/nonadherent, adherence/nonadherence	"He takes his medication about half the time." "She takes insulin whenever she can afford it." "He eats fruits and veggies a few times per week." Engagement Participation Involvement Medication taking	The words listed in the first column are inappropriate and dysfunctional concepts in diabetes care and education. Compliance and adherence imply doing what someone else wants, i.e., taking orders about personal care as if a child. In diabetes care and education, people make choices and perform self-care/self-management. Focus on people's strengths—what are they doing or doing well and how can we build on that? Focus on facts rather than judgments.
Controlled/uncontrolled, well controlled/poorly controlled	Manage "She is checking blood glucose levels a few times per week." "He is taking sulfonylureas, and they are not bringing his blood glucose levels down enough."	Control is virtually impossible to achieve in a disease where the body no longer does what it is supposed to do. Use words/phrases that focus on what the person is doing or doing well. Focus on intent and good faith efforts, rather than on "passing" or "failing." Focus on physiology/biology and use neutral words that don't judge, shame, or blame.
"Are you a diabetic?"	"Do you have diabetes?" Person living with diabetes Person with diabetes Person who has diabetes	Person-first language puts the person first. Avoid labeling someone as a disease. There is much more to a person than diabetes. When in doubt, call someone with diabetes by their name.
Imperatives Can/can't, should/shouldn't, do/don't, have to, need to, must/must not	Have you tried…" "What about…" "May I make a suggestion…" "May I tell you what has worked for other people…" "What is your plan for…" "Would you like to consider…"	Words and statements that are directives make people with diabetes feel as if they are being ordered around like children. They can inflict judgment, guilt, shame, and blame

Table 4: Suggestions for Replacing Language with Potentially Negative Connotations

Language with potentially negative connotations	Suggested replacement language	Rationale
Regimen, rules	Plan Choices	use words that empower people, rather than words that restrict or limit them
Fail, failed, failure "She failed metformin."	"Metformin was not adequate to reach her A1C goal."	people don't fail medications. If something is not working, we choose a new direction
"Words or phrases that threaten "You are going to end up blind or on dialysis."	"More and more people are living long and healthy lives with diabetes. Let's work together to make a plan that you can do in your daily life.	Many people who are not reaching metabolic goals understand they are at risk for complications. Scare tactics rarely are effective. Work together on specific, achievable, and realistic self-directed goals that can improve metabolic outcomes
Unmotivated, unwilling	John has not started taking insulin because he's concerned about weight gain. He sees insulin as a personal failure."	Few people are unmotivated to live a long and healthy life. The challenge in diabetes management is there are many perceived obstacles that can outweigh the understood benefits. As a result, many people conclude that changes are not worth the effort or are unachievable
Refused	Declined	Use words that build on people's strengths and respect the person's right to make their own decisions
Imperatives Can/can't, should/shouldn't, do/don't, have to, need to, must/must not	Have you tried…" "What about…" "May I make a suggestion…" "May I tell you what has worked for other people…" "What is your plan for…" "Would you like to consider…"	Words and statements that are directives make people with diabetes feel as if they are being ordered around like children. They can inflict judgment, guilt, shame, and blame

T1D Exchange

T1D Exchange

What is your idealized appointment?

11/30/23

Demographics

83 responses
- 54 PWD (65%)
- 22 Parent of person with T1D (27%)
- 7 Caregiver of Person with Diabetes (8%)

Where care is received?
- 29 Pediatric (35%)
- 51 Adult (61%)
- 4 Other (5%)
    - McNeely Diabetes Center, St. Paul, MN
    - CDE in Houghton, Johannseburg, South Africa
    - Transitioning in between peds to adult

How are topics documented?
- Intake form (MyChart etc) (24%)
- Fill out questions before rooming (10%)
- Nurse/MA ask while taking vitals (6%)
- Endo/NP/Diabetologist ask during visit (59%)
- Other (1%)
    - Have the details discussed confirmed in a letter to me that is cc'd to my GP, but ONLY if the initial letter is correct. This isn't always the case!!

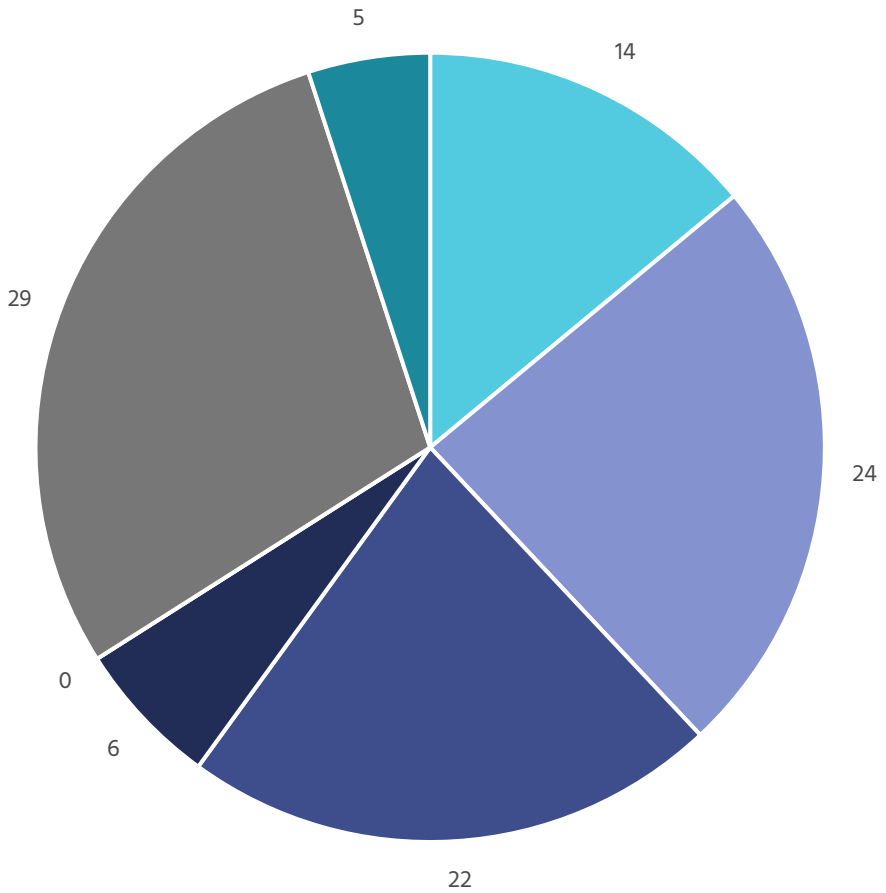
What Lab Option is Most Appealing?

Other comments:

All tests can be done by GP and forwarded on. I wouldn't need or want to go to the clinic beforehand. It's a complete waste of time and money for me (self-employed)!

All of the above are helpful at different times.

He has to be sedated to get blood drawn



Order of preference on which provider is seen?
1 highest – 6 lowest priority N=83

- **Visit 1:1 with Endo or Diabetologist**
  - 1 (51), 2 (23), 3 (5), 4 (1), 5 (3), 6 (0)
- **Visit 1:1 with Nurse Practitioner**
  - 1 (9), 2 (17), 3 (13), 4 (31), 5 (13), 6(0)
- **Visit 1:1 with Nurse/Educator**
  - 1 (4), 2 (6), 3 (25), 4 (21), 5 (27), 6(0)
- **Visit with Endo and Nurse Separately**
  - 1(5), 2(18), 3(22), 4(21), 5(15), 6(2),
- **Visit with Endo and Nurse/Educator at same time**
  - 1(12), 2(19), 3(17), 4(8), 5(23), 6(4)
- **Other**
  - 1(2), 2(0), 3(1), 4(1), 5(1), 6(77)

Order of Preference on topics to discuss
1 highest – 7 lowest priority N=83

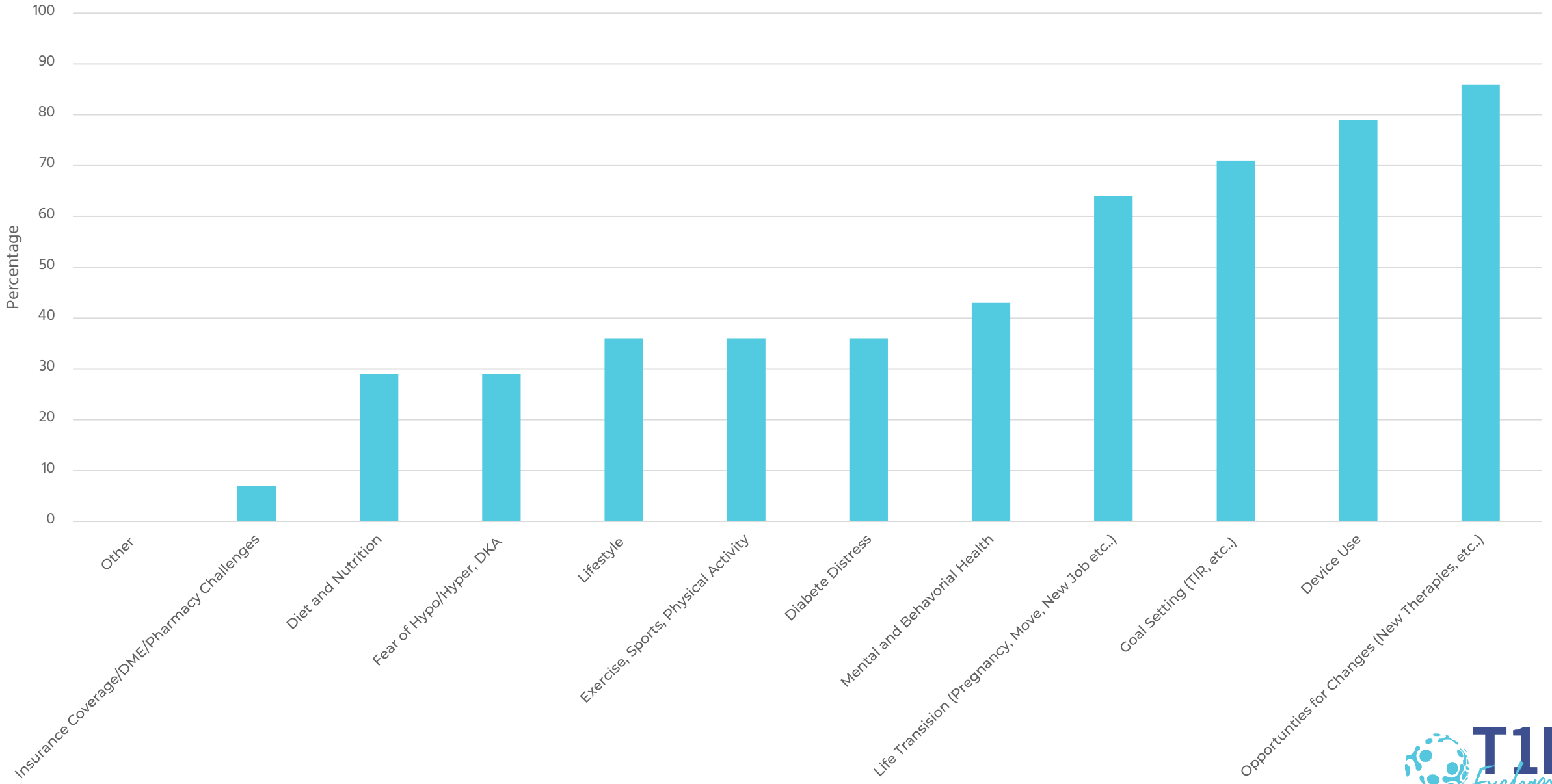
- **What has been going well with diabetes management**
  - 1 (19), 2 (16), 3 (15), 4(10), 5(12), 6(10), 7(1)
- **What has been challenging with diabetes management**
  - 1 (19), 2 (20), 3 (20), 4 (14), 5 (8), 6(1), 7(1)
- **What I need most help with**
  - 1 (25), 2 (23), 3 (18), 4 (5), 5 (7), 6(5), 7(0)
- **Any significant life changes since last visit (home, work, school)**
  - 1 (4), 2 (7), 3 (11), 4 (30), 5 (20), 6 (10), 7(1)
- **Any Significant changes to health since last visit**
  - 1 (13), 2 (10), 3 (14), 4 (15), 5 (26), 6 (5), 7(0)
- **What has been happening in my life lately**
  - 1 (1), 2 (5), 3 (4), 4 (8), 5 (10), 6 (52), 7(3)
- **Other**
  - 1 (2), 2 (2), 3 (1), 4 (1), 5-6 (0), 7(77)

T1D Exchange

How would you like to spend visit time?

- Giving me an outline of what we will discuss during visit and me arrange topics (18%)
- Giving me a list of topics suggestions (18%)
- Allow me to share my list (63%)
- Other (2%)
  - The visits are too long and not helpful. I would prefer them be shorter
  - Make eye and foot tests mandatory with each six month or yearly visit

What topics should be discussed during visit



Quotes

- I wish that providers would ask at each visit if we think the suggestions, they have made will work for us or if we agree with their assessment/orders.
- I would like to see my doctors look more at my lifestyle and personal needs. I think it is important for my doctors to understand where I am in life and how my diabetes management might look different than other patients who are older or younger.
- Ideally would love to have an authentic conversation and not have providers, nurse educators or RNs be rushed, have their backs facing a patient, or not listening/repeating. Additionally, it is important to spend time hearing patient self identified needs that may take a moment to uncover - and may not even be what is on the intake form - but it is critical in creating a care management plan that supports the individual person living with T1d.
- To be seen as a person and listened to.
- Visits being kept to and not being cancelled with no explanation given
- So many doctors waste time go over things the patient does need. Let the patient drive the conversation so they can highlight the help/challenges/concerns!

Quotes

- More than 20 minutes of time if needed. More overall care for my health. More proactive than reactive. No one mentions pancreatic enzymes missing nor wants to deal with it. Nor is the potential of gastoparesis discussed and when I bring it up told to discuss with my primary.
- Opportunity to speak with counselor - mental health specialist
- My current visits are with either my endocrinologist or NP. (I never see more than one professional at one appt.) Both are helpful and fit my personality. There is mutual respect and appreciation for what the other does, thinks and suggests. I manage my diabetes and my team respects that. I see no other educators or specialists because none is needed at this point. This disease is different for each person and therefore what my appts look like might not be right for others. The single most important consideration is for the patient to feel comfortable with the appt style.
- Being able to submit questions ahead of time, especially for diabetes education visits, possibly electronically
- My diabetes is well-controlled so my main concerns are usually insurance or prescription related. However, I like talking about how things have been going, not necessarily with the intent of changing anything, as well as hearing about any research studies my endo is involved in.
- Being roomed on time, getting out on time, free parking, labs/visit all at the same time to avoid myltiple trips. Also, RD & SW access at the visit. A patient navigator or CHW would also be helpful.

T1D Exchange

Quotes

- I was disappointed last time when I mentioned my stress with diabetes and asked for a referral to a mental health provider who understands T1 diabetes. My provider had 0 suggestions. She practices at an academic medical center. I think that's unacceptable. They should have a list like this on hand!

- I don't really want to spend time talking about my life or what I do with my free time every day. I want to be as efficient as possible. At every visit, I'm asked what sports I play, how school is going, what hobbies I have, etc. and I just see this as a water of time when the provider is often begging schedule already. I also do not enjoy taking time out of my day to go to these mandatory appointments every three months, so I'd prefer to check the minimum boxes and get in/out asap

- Discussion about new and upcoming therapies that I might be interested in

- I feel that we are very lucky (compared with stories I've heard about other people's endos), our daughter's peds endo is absolutely wonderful! Listens to anything we say, responds quickly to emails if we have questions/concerns, allows us to make whatever changes we feel are necessary (sometimes we run it by her, sometimes we don't...depends what we're adjusting).

- Advice, resources, new research findings as applicable for new technology.

- Better knowledge of the Endo with how different foods/ fats/proteins effect blood sugar

Quotes

- An Endo that doesn't tell me that my A1C is cause for concern when it is below 5.5 (in other words, in a non-diabetic range)

- Time to discuss new diabetes technology, review data (TIR, COE), review the legislative and political climate of diabetes, advocacy efforts and new research.

- Taking personal circumstances into account, such as physical disability and diabetes; more and better info about the latest technology

ADCES Brainstorm

Can we use data from survey above to submit abstract?

What story do we want to share?