



# Engaging People with Diabetes in a National Learning Network: Insights from the T1D Exchange

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## Background

- National learning health networks should design stakeholder engagement (SE)<sup>1</sup> opportunities and involve people with diabetes (PWD) in quality improvement (QI) interventions to improve healthcare delivery for people of all ages with diabetes.
- Using a Chronic Care Model of participatory design, T1D Exchange QI Collaborative<sup>2</sup> (T1DX-QI) convenes a PWD committee and supports shared decision making with their healthcare providers (HCP) across T1DX-QI's 55 medical centers.
- T1DX-QI convenes a Patient/Parent Advisory Committee, providing patient voices and insights to the learning health network to engage in meaningful, high-quality care co-led by PWD.

## Methods

- T1DX-QI surveyed centers, asking if they have involved PWD or their parents in care improvement activities. A subset of centers who answered positively were asked six additional (qualitative questions) about the frequency and types of SE they practiced and identified as best practices.
- Through the T1DX Online Community, four questions were asked to PWD to learn about their shared decision-making experiences with their HCP regarding priority-setting and goal setting. They could also share comments, which are included in the Results. 10/8/2022-10/12/2023.

## Results

- There were 1,127 responses to The Question Of The Day survey.
- Of the respondents, 22% reported their HCP asks about their diabetes goals and priorities before or during the visit and 10% reported their HCP asks about life goals and how they align with their diabetes goals and priorities. 34% reported their HCP brings up goals from previous discussions.

Fig. 1 PWD Feedback on Their Care Experiences

My Endo and I have a collaborative appointment each and ever time. We are working together through my T1D management.

I keep a list [...] of issues or questions that I want to discuss with my endo. I also keep track of my test results... Sometimes I don't have any specific issues. The basic goals are simply to keep things in check and avoid the lows. My endo is fantastic, and she lets me be human and "live a little" to enjoy life. I really can't ask for anything more.

When I first met my....endo, I specifically [said] that I expected her to consider me an equal partner in diabetes management decisions. She readily agreed and has kept her word. Before each appointment I make a list of subjects/concerns and send it to her via MyChart. I share the list with a nurse who asks me a variety of questions for the first half of the appointment. On the chart notes I'm given after each appointment, her management goals are listed, not mine.

I am not asked, but I am told what my goals should be. (No lows, but under a certain number, etc.) That is what I expect.

Our medical system is not conducive to asking or answering question about goals. The time allotted is filled with being weighed, having an A1C done, a foot check... and [...] pump questions. Life goals, without question, and diabetes goals beyond getting a better A1C, are way too time consuming to squeeze into whatever's left of an appointment. Medicare takes care of most of that time with checking off boxes. A lifetime disease deserves way more time for discussion than it's getting. The system's broken!

I have learned to stay silent.

- Data from T1DX-QI's 2022 Annual Survey affirmed that 17 of 54 centers (31%) have patients/parents involved in QI activities. Five are adult practices; 12 are pediatric practices.
- T1DX-QI surveyed centers, asking if they have involved PWD or their parents in care improvement activities. A subset of centers who answered positively were asked six additional (qualitative questions) about the frequency and types of SE they practiced and identified as best practices.
- In spring 2023, nine out of the 17 centers with patient/parent involvement were survey and answered qualitative questions about their experiences with SE. Of those nine centers, 44% offered PWD advisors a financial stipend or gift card for their time.

### Clinicians Share What They Have Learned From Their Patient/Parent Advisors

It's incredibly valuable to have ideas to bounce around with others and important that families feel heard. It also has helped guide us in our outreach for QI projects knowing what they like/don't like.

They provide a perspective that is not available to the team without them. They often act as advocates, raising the bar for expectations for clinical care and outcomes.

We love their ideas and had an extremely successful [meeting] for our patients where our FAC acted as a panel with predetermined questions to help new onset[...] parents deal emotionally with a diagnosis. They provide the most insightful information to the medical students that a lecture would not be able to. People want to share their experiences and help others and teach others. Its also extremely therapeutic to them, not just [for] those they are helping.

We think we have a good idea, but when we run it past our parents, they give us helpful feedback about why it may or may not work. They have identified "Failures" in our process that we didn't think of and have brainstormed ideas that were from those with lived experience.

Our group is not very diverse and have learned that there are voices in our community that we are missing. Finding ways to increase diversity or include families with a language other than English would be something I would be interested in learning from others about.

Fig. 2.

How Do QI Teams Engage w/PWD For Feedback?

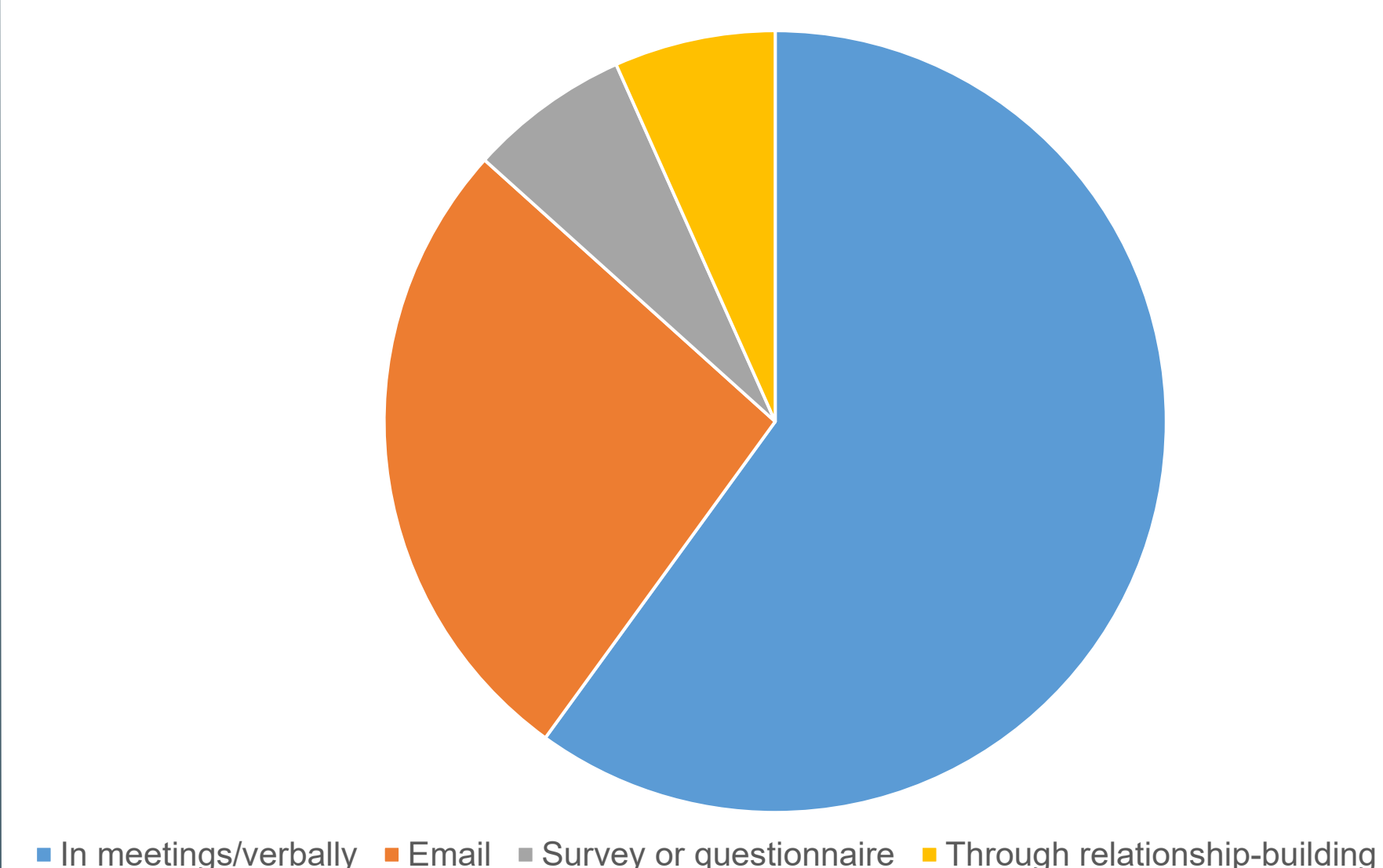


Fig. 3

Meeting Frequency/SE For PWD & Care Teams

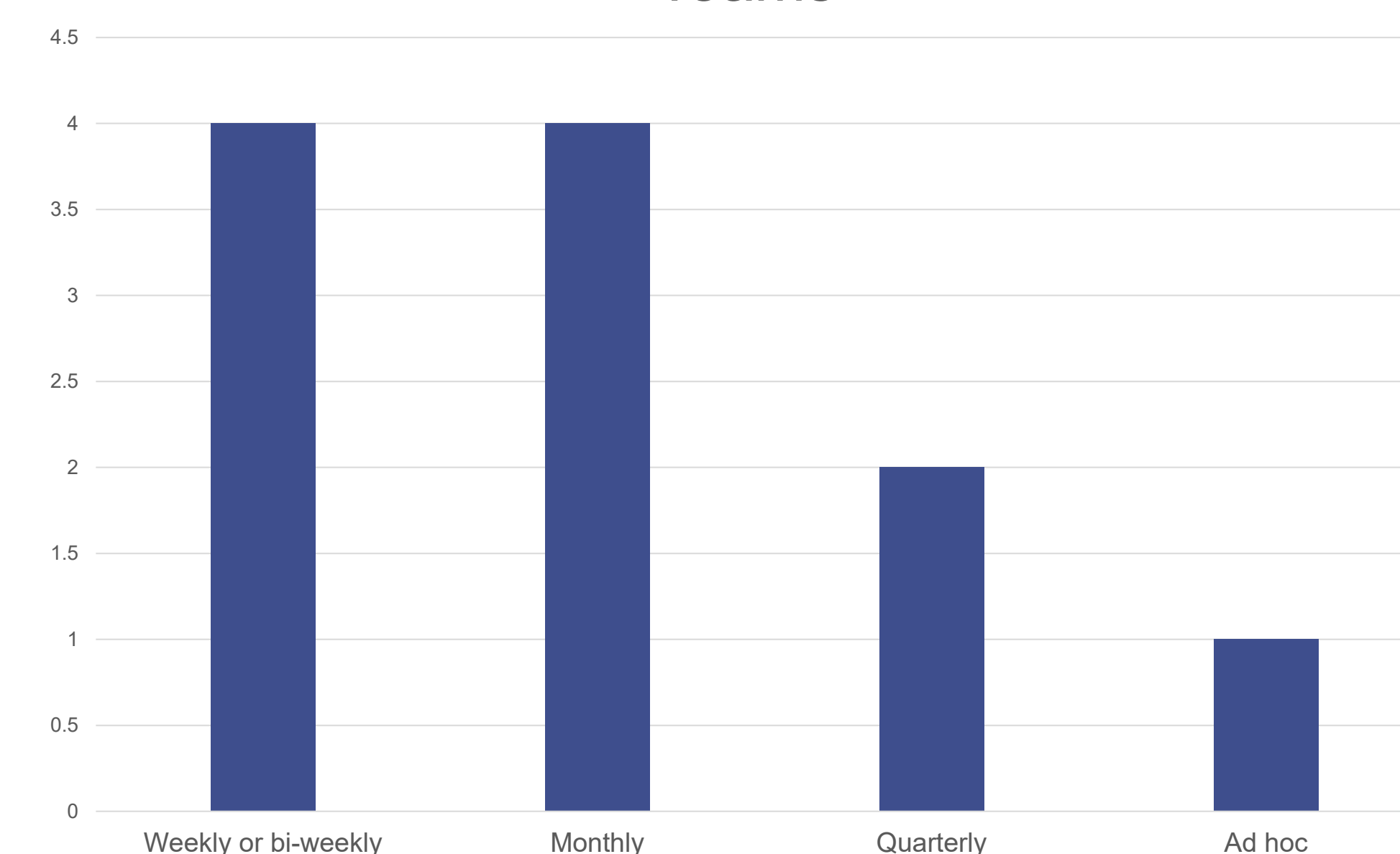


Fig. 4

Does Your Clinic Compensate PWD Advisors?

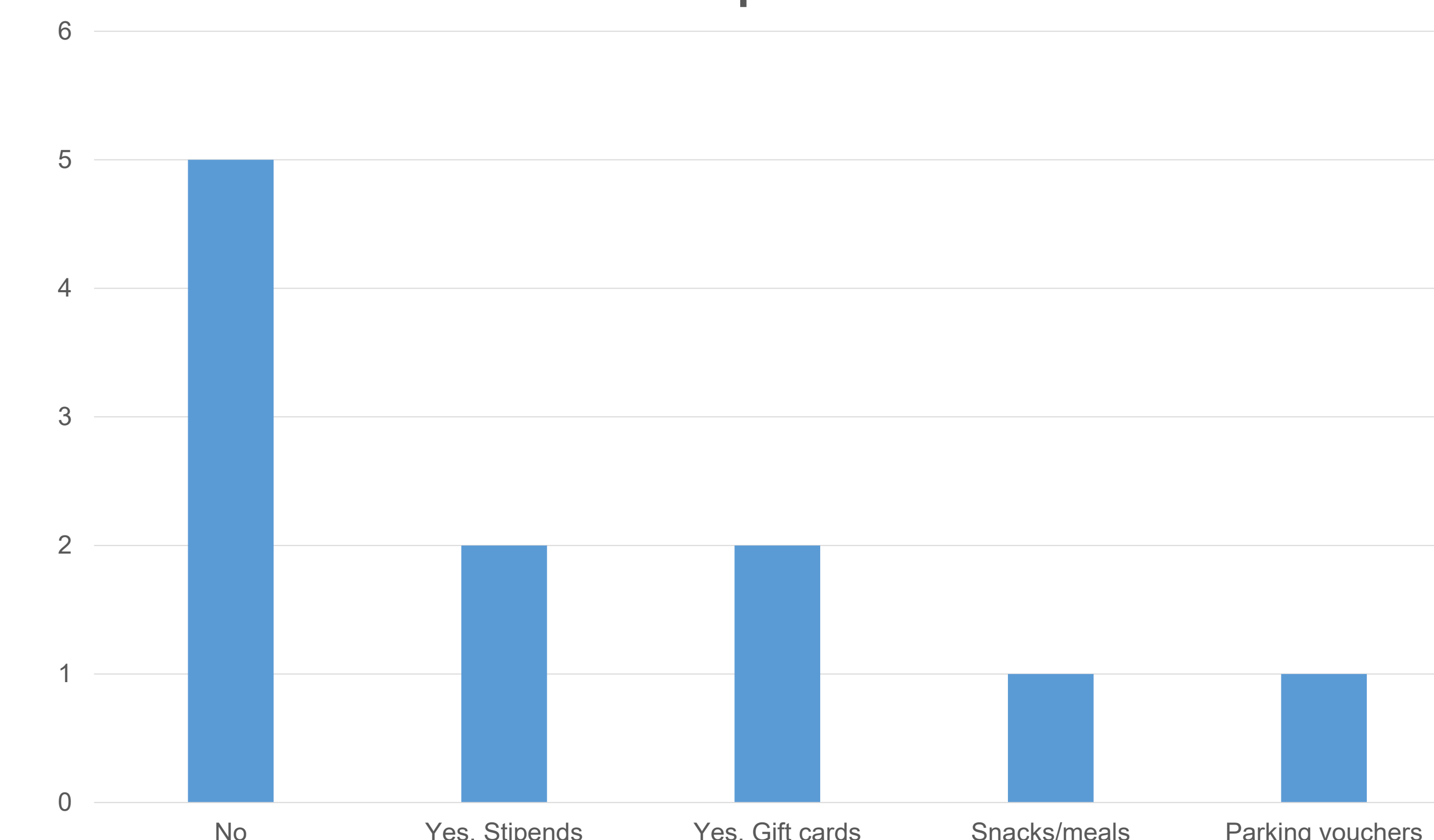


Fig. 5

## Conclusion

- The number of centers utilizing PWD in their QI initiatives has grown over the last five years but there are more opportunities to increase SE in practice, especially in the adult diabetes centers. Having SE helps to ensure that PWD priorities are identified.
- Incorporating SE in QI initiatives helps some centers make the care experience more relevant and effective.
- The higher degree of patient/parent engagement in pediatric versus adult practices (71,29) suggests that we need to rethink how we engage adults with diabetes in practice design to accommodate their needs and priorities.
- Through the T1DX Online Community, we learned that, nationally, most HCP do not ask PWD about their diabetes or life goals. There are opportunities in clinical practice flow to ask PWD about their goals so that HCP can provide more meaningful, person-centered care.

## Acknowledgements

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## References

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