

Background

- Involving people with diabetes (PWD) in research and Quality Improvement (QI) has led to improved processes in clinic and a deeper understanding of how care can be individualized for each patient¹.
- Understanding the importance of inclusion of PWD to elicit real world perspective, T1D Exchange Quality Improvement Collaborative (T1DX-QI), has expanded its Advisory Committee to engage more PWD in care improvement processes.
- Engaging PWD in clinical care can lead to improved processes, but there are challenges in how to effectively engage them.

Aim

The aim of this study is to investigate common practices from T1DX-QI centers in engaging PWD in QI efforts.

Methods

- In 2022, T1DX-QI surveyed 11 clinics with active PWD stakeholders to learn about their approaches.
- T1DX-QI asked additional survey questions to eight clinics that responded positively to the use of PWD stakeholders, asking how they include PWD in their QI work and how they collaborate, communicate, and elicit feedback.

Results

- Of the 8/11 (73%) that responded to additional engagement survey questions, all had at least one PWD advisor engaged with their team.
- Four (50%) had PWD advisory panels
- Four (50%) invited PWD to join QI process teams
- Eight clinics (100%) engage PWD in meetings

Citation

1. O'Hara, M.C., Cunningham, Á., Keighron, C. et al. Formation of a type 1 diabetes young adult patient and public involvement panel to develop a health behaviour change intervention: the D1 Now study. Res Involv Engagem 3, 21 (2017). <https://doi.org/10.1186/s40900-017-0068-9>

PWD Engagement Survey Results

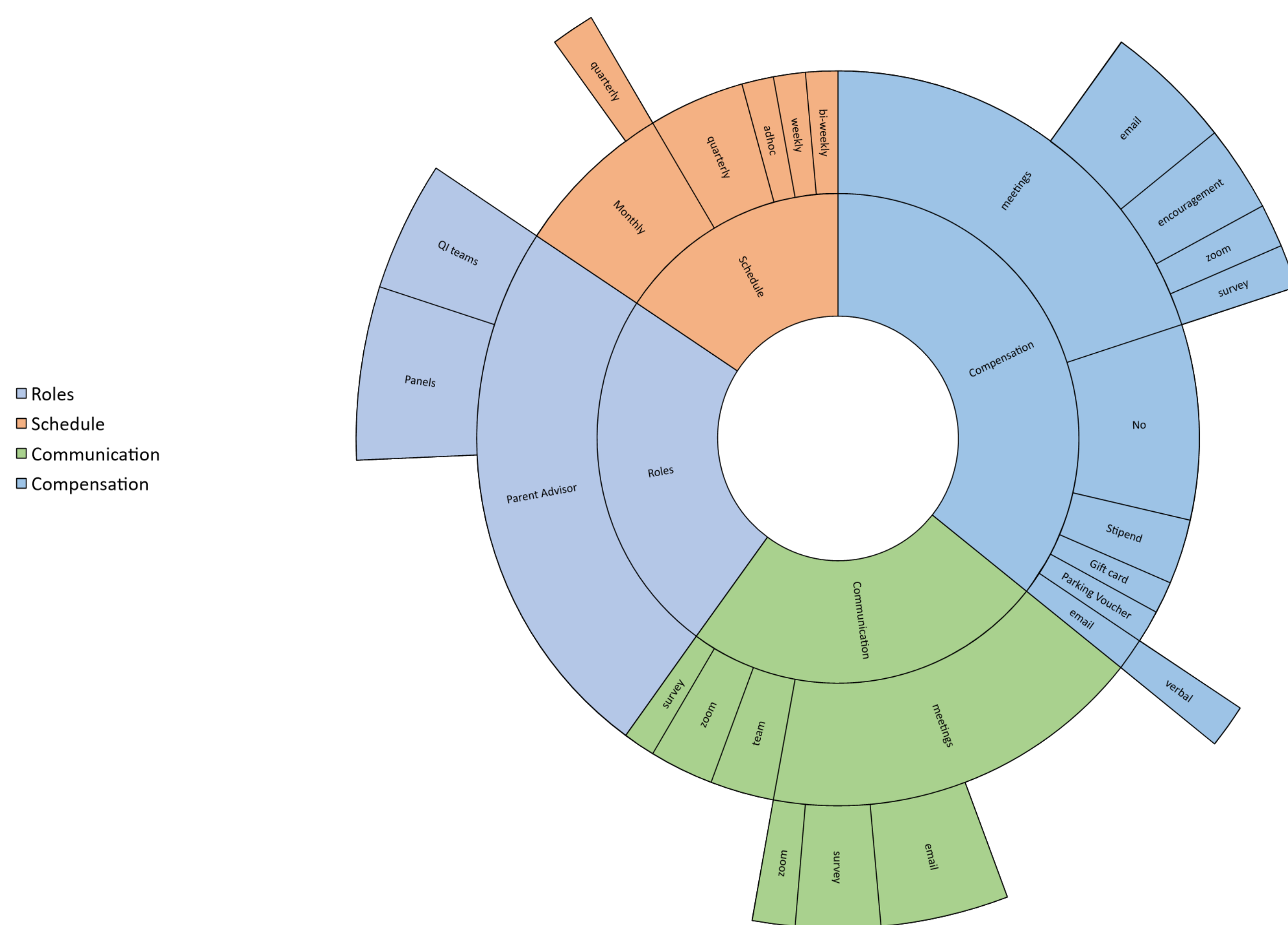


Figure 1 shows how the clinics engage PWD in their multidisciplinary teams.

- Stakeholders were a heterogenous range of PWD including adolescents, young adults, older adults, as well as parents
- Seven clinics (88%) used surveys and/or email to solicit feedback from PWD
- Two clinics (25%) reported that their PWD advisors were “part of the team”
- Four clinics (50%) offered compensation using stipends or gift cards
- Two clinics (25%) provided food and/or parking vouchers

Demographics	N=8		
Type of center [Peds vs Adult]	Pediatrics 8 (100%)		Adult 0 (0%)
Approximate # of PWD served [0-500, 501 - 1000, over 1001],	0-500 1 (12.5%)	501-1000 1 (12.5%)	>1000 6 (75%)
Percent of Minority [0 - 30%, 31% and above]	0-30% 5 (62.5%)		>31% 3 (37.5%)
Percent of PwTD on Public Insurance [0 - 35%, 31% and above]	0-30% 3 (37.5%)		>31% 5 (62.5%)

Discussion

- Two of the clinics with strong PWD advisor roles are also supported by hospital policies that require stipend payments for patient advisors. At these locations, the patient engagement numbers are considerably higher than at any of the other institutions.
- Clinics that compensate PWD for their time and contributions through some kind of financial stipend are best able to diversify the PWD group, so they are not limited to volunteers who are largely white, educated, and affluent. Limiting to this group of people with resources can skew perspectives and representation, which is problematic.
- Clinics with strong collaborative engagement made PWD/advisors a true part of the team, inviting them to internal meetings, including them in internal email messaging, and assigning them tasks related to the QI activities. Having this level of engagement requires having advisors with the time, capacity, and resources to contribute.

Conclusion

- There are more opportunities to increase PWD engagement in co-design and co-production in practice.
- Asking PWD how they would like to contribute to the team may result in more collaborative engagement.
- Clinics that make clear role definitions, set expectations, and support and empower advisors lead to successful engagement with PWD which also leads to improved outcomes, better policies, and stronger clinical programs.

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