Tell Me More: The Culture, Resources, and Metrics Needed to Sustain Patient-Reported Outcomes in Transplant and Cellular Therapy

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BACKGROUND

- Transplant and cellular therapy (TCT) is among the most resource-intensive care a health system delivers, with a significant treatment burden.
- Patient-reported outcomes (PRO) and agenda-setting questions support person-centered care but can be difficult to integrate into routine practice.
- Most studies examine early implementation and value, but little research addresses how to sustain an established PRO program.

Before the visit: PROMIS-29, NCI Distress Thermometer, and agenda-setting questions

In the EHR: co-designed patient level dashboard

In the visit: symptoms are tracked over time; patient concerns and priorities guide conversations and care

OBJECTIVE

To understand what providers and administrative leaders believe is required to sustain a PRO program and how its long-term value should be measured.

METHODS

- 25 semi-structured interviews
- June–October 2025
- Conducted a qualitative analysis to identify themes across both groups

12 TCT providers: 5 physicians, 4 RNs, 3 APPs

13 health system leaders: 4 cancer center, 3 quality & safety, 3 informatics and data, 3 system-level operations

Sustaining patient-reported outcomes requires a supportive culture where health systems resource them, leaders champion them, and value is measured.

Required Resources for PROs

"I do think there could be more support services roles to be able to follow up on the issues that are flagged." - Provider

"We need the technical capability, analytics, the EHR, data warehouse, personnel." - Administrative Leader

Organizational Culture

"Wouldn't it be great if every patient in the cancer center is involved in something like this." - Provider

"The system needs to incorporate [PROs] as part of system-wide learning, and [...] put patient-reported outcomes on the system quality scorecard." - Administrative Leader

Role of Leadership

"It's important for our leaders to encourage use for overall success of collecting this data and also helping implement specific routes to show how the data [...] can be used for other purposes." - Provider

"I think we have to function as advocates, facilitators, connectors. We have to create the opportunity and space for it to occur." - Administrative Leader

RESULTS

Metrics to Measure Value

Domain	Providers (n=12)	Leaders (n=13)	Example Metrics
Clinical & functional health	●	◔	Survival, readmissions, quality of life, avoidable complications, SDOH, symptom trajectories
Experience of care	◕	●	Patient experience, timeliness and access to care, clinician satisfaction, shared-decision making
Implementation	◕	◕	Completion rates, PRO-triggered referrals, implementation barriers, ability to respond to PRO concern, operational decision-making
Costs	◔	◕	Avoidable care escalation, financial trends, financial toxicity, ROI

Share of each group who raised this domain: ◔ ≤25%, ◑ 26–50%, ◕ 51–75%, ● >75%

Differing Perspectives

- **Providers** focused on clinic workflows and resources to respond to concerns, saw leaders mainly as advocates, and were less aware of build and analytics costs.
- **Administrative leaders** emphasized system-wide obstacles and resource strain; some worried PROs add burden, while providers said PROs save them time.

CONCLUSION

PROs can be sustained when supported by adequate resourcing, engaged leadership, and sharing of findings. Future analysis should measure the value of PROs using quantitative metrics.

ACKNOWLEDGMENTS

We thank the TCT patients and caregivers, clinicians, and healthcare administrators at Dartmouth Health and the Dartmouth Cancer Center, and the Epic4Research team for making this work possible.

Funding: Pfizer Inc, PROTEUS Consortium, and the Dartmouth Cancer Center.
IRB: Dartmouth Hitchcock STUDY02000891

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