Defining Patient-Centered Outcomes in CAR T–Cell Therapy: Is There a Need for a Patient-Informed CAR-T PROM?

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INTRODUCTION

CAR T–cell therapy offers transformative potential but presents unique burdens that generic PROMs may fail to capture. Centering patient perspectives ensures value-driven, equitable care and informs meaningful outcome measurement.

OBJECTIVES

To understand the treatment experience and quality of life among individuals undergoing CAR T–cell therapy by integrating survey and thematic data and to support the development and feasibility testing of a patient-informed CAR T–specific PROM.

METHOD

Three web-based surveys (30 to 40 minutes each) were completed by individuals who had received (Group 1) or were seriously considering (Group 2) CAR T–cell therapy.

- Survey 1 assessed the relevance of PROMIS-29 v2.0.
- Survey 2 explored PROMIS-29 content gaps and the relevance of altered or new questions and identified domains important to patients.
- Survey 3 evaluated the draft CAR T–specific PROM for clarity, feasibility, and perceived value.

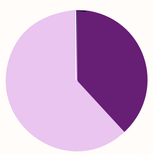
Data were analyzed using mixed methods, combining Likert scale responses and qualitative thematic analysis.

RESULTS

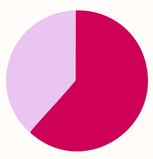
- In Survey 1 (**n=22**), participants found PROMIS-29 generally relevant and reported limitations in capturing social functioning and physical decline: **30.8%** of infused and **44.4%** of considering participants reported likely difficulty completing PROMs during the first post-treatment week.
- Survey 2 (**n=21**) identified content gaps including disease-related anxiety, immunosuppression-driven isolation, exercise, ability to complete ADLs, memory, sleep, and unmet expectations around treatment outcomes.
- Survey 3 (**n=19**) showed high feasibility of the draft CAR T–specific PROM: **89.5%** were able to complete the tool independently, and **63.2%** found it useful even without clinician input. Participants noted the value of integrating a CAR T–specific PROM into patient-provider communication and long-term care planning.

SURVEY 1

PROMIS-29: RELEVANT BUT INCOMPLETE



30.8%
Infused



44.4%
Considering

SURVEY 2

UNMET NEEDS IN EXISTING PROMs

SURVEY 3

HIGH FEASIBILITY & VALUE OF CAR T–SPECIFIC PROM

89.5%
Able to complete independently

63.2%
Found useful even without clinical input

CONCLUSIONS

Patient feedback was essential in creating a relevant and practical CAR T–specific PROM. These results highlight the importance of patient-centered collaboration in developing tools that enhance care quality, facilitate shared decision-making, and better align clinical innovation with patient experiences.

REFERENCES

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Abbreviations: ADL, activities of daily living; CAR, chimeric antigen receptor; PROM, patient-reported outcome measure; PROMIS-29, 29-question Patient-Reported Outcomes Measurement Information System.

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