

# Outcomes Scorecard

In the Starzl Network, we want to focus on **patient-centered outcomes**. These are outcomes that are **important to a patient’s survival, function, or feelings**

- As identified or affirmed by patients themselves OR
- Judged to be in the patient’s best interest by providers and caregivers.

The following questions will help your team develop **patient-centered outcomes for your project** that align with what PARTNER stakeholders (parents/caregivers, young adults with transplants, and transplant providers) told us was important to them.

- **Treatment or intervention:** What will you do in this project to improve life or health for young people with liver transplants?
- **Study period/length:** We know that priorities and challenges can be very different at different stages of the transplant journey: At what point after liver transplant will your treatment or intervention start? How long will it last for?
- **Outcomes:** How will this treatment or intervention improve the life or health of children with liver transplants?

In PARTNER, we learned from patient partners and other providers about key things that they want to see children with liver transplants **ACHIEVE** (benefits of a treatment or change in care) and **AVOID** (burdens of life with a transplant or of transplant-related care).

Please review these lists in the PARTNER Roadmap (see Ch. 3C) and tell us - in this project, what specifically do you think the treatment/intervention will help children with transplants:

ACHIEVE? (please use 1 row for each item – list from most to least important for this project)	How will you evaluate this during the project?	What information about this will you collect from providers or medical records?	What information about this will you collect directly from patients or parents/caregivers?

The PeLTQL is a survey developed by and for pediatric liver transplant recipients, to assess quality of life after liver transplant. The PeLTQL is an important patient-reported outcome that we have used in the Starzl Network. Please review the PeLTQL questions ([link here](#)).

- Do you think that the treatment/intervention in this project will impact quality of life for young people living with liver transplants?
- If so, will you use the PeLTQL to assess quality of life in your project?
- If you prefer not to use PeLTQL, please tell us why. (This is OK – but will help us understand limitations of the PeLTQL)
- What other patient-reported outcome measures do you plan to use in this project?
  - For this section, please consider:
    - Attributes of high-quality patient-reported outcome measures:  
<https://mmshub.cms.gov/sites/default/files/Patient-Reported-Outcome-Measures.pdf>
    - (Other recommended patient-reported outcomes measures – in progress, eliciting feedback from Starzl Network stakeholders)