

**Core
Outcome
Set**



Delphi Survey

Round 2 FAQs



WHY ARE WE DOING ROUND 2?

Round 2 is your chance to see how others rated each outcome and reconsider your rating. A Delphi survey is a consensus survey. This means the end goal is to come to a decision together.

WHY AM I SEEING AN OVERVIEW OF RESPONSES FROM OTHER PARTICIPANTS?

A Delphi survey is a consensus survey. This means that we work as a group to come to an agreement throughout the process.

WHY ARE THERE SO MANY OUTCOMES?

The outcomes come from multiple sources, including scientific literature, caregiver focus groups, and ACD's patient registry. Our team originally gathered over 1,000 outcomes and condensed those to the list of 85 you saw in round 1. Through the Delphi process, we will reduce this to the final 8-10 outcomes.

WHY ARE SOME OF THE OUTCOMES SO SIMILAR?

The outcomes we gathered came from many sources. Sometimes different terms are used for similar outcomes. This is why we need your help to find the most accurate terms for the most important outcomes for GAMT and CTD.

ALL OF THESE OUTCOMES ARE IMPORTANT! WHAT SHOULD I DO?

a. This is the tricky part! Since our goal is to reduce this list to 8-10 outcomes for a final COS, we will need to be slightly more selective in which outcomes we rate as "most important".

WHAT HAPPENS AFTER ROUND 2?

We will do a third and final round of the Delphi survey, approximately 1 month later. In round 3, you will be asked to rank your most important outcomes. After round 3, there will be a final consensus workshop with a small group of patients, caregivers, and CCDS experts to finalize the COS.

HOW DO I PARTICIPATE?

If you completed the previous round, you will receive an email with a personalized email link. If you did not participate in round 1 or did not receive a personalized email link, you can participate by clicking this [link](#).

I DID NOT COMPLETE ROUND 1. CAN I STILL PARTICIPATE IN ROUND 2?

Yes, you can participate in round 2 even if you did not complete round 1.

WHY DID WE REMOVE OUTCOMES IN ROUND 2?

Only outcomes that were rated “Important” or “Most Important” by at least 70% of participants in round 1 were included in round 2. This is intentional and part of the consensus process.

WHAT HAPPENED TO MY COMMENTS FROM ROUND 1?

Round 1 comments will be shared and discussed in the consensus meeting, helping us arrive at the best final Core Outcome Set.

