Core Outcome Set

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What is a Delphi Survey?

✓ A survey that is designed to gather opinions from multiple people and eventually reach agreement (“consensus”).

✓ Delphi surveys are confidential to make sure that everyone has an equal say.

✓ Delphi surveys have multiple rounds (usually between 2 and 3 rounds). This means that participants get more than one chance to give their opinion.

✓ The figure below outlines the steps involved in a Delphi survey. All of the information included in the figure is repeated in the text that follows.

The Delphi Process Summary:

Round 1 Survey

A list of outcomes is produced by the research team and sent to each participant to rate the importance of each one.

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Round 2 Survey

Participants are presented with their ratings from round 1, along with a summary of how others rated each outcome. Participants are asked to rate the remaining outcomes.

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Further Survey Rounds

The process of seeing the results and re-rating the outcomes can be repeated in a further round.

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Consensus Meeting

The research team uses the results of the Delphi surveys and further discussions with patients, caregivers, and professionals to produce the final core outcome set.

What Happens in Round 1 of the Delphi Survey?

- The research team has developed a list of possible outcomes that we want to ask you about. We created this list after looking at many research papers, analyzing data from our CreatineInfo Patient Registry, and conducting focus groups with parents/caregivers of CTD and GAMT deficiency patients.
- In round 1, we will ask you to rate the importance of each outcome on a scale from 1 to 9.
- When you complete the survey, your ratings will be sent back to the research team along with the ratings from all other participants. We will then summarize the responses for each participant group (patients, parents/caregivers, and health care professionals) in a graph. These graphs will be included in round 2 of the Delphi Survey.

What Happens in Round 2 (and Possibly Round 3) of the Delphi Survey?

- We will ask you to complete the survey again. You will be given a reminder of how you rated each outcome last time. You will also see the summary graph showing how each group rated the outcomes. No one can see another individual participant's ratings, you can only see the overall results for each group as a whole.
- Looking at your previous ratings and the summary graphs, we will ask you if you would like to stick with your original rating or change it. You are not under any pressure to change your rating if you don't want to. It is perfectly fine for you to stick to your own rating even if you rated the outcome differently than the majority of the group.
- The research team will review the results from round 2 and decide if a 3rd round is needed. In that case, the steps above would be repeated in round 3.

What Happens After the Delphi Survey?

- After the last round, a diverse group of stakeholders will meet in person to discuss the Delphi survey results and reach a consensus on the final list of outcomes for the COS.
- At the end of this process, the research team will produce a report on the outcomes that patients, parents/caregivers, and health care professionals agreed were the most important outcomes. These are called the 'core outcomes' for CTD and GAMT deficiency patients.
- The stakeholder group will determine if two separate COS are needed for CTD and GAMT deficiency, informed by Delphi results.

[This information is adapted from the Core Outcome Measures in Effectiveness Trials initiative, https://www.comet-initiative.org]