Consortium for Patient-Centered Research on PFIC

Principles for Steering Committee Collaboration

Purpose

This document provides guidelines for Steering Committee (SC) members to be used while developing the consortium's governance charter and patient-centered CER research agenda. It was drafted based on input from the SC orientation sessions held on March 26, 2026 and April 29, 2026, and finalized based on group agreement.

1. Shared Values

The following values are meant as a guide to how SC members collaborate. Each value is paired with a concrete description of what it means in practice.

Value	What This Means in Practice
Shared Ownership	All SC members are co-owners of the committee's processes and outputs. No single member or group holds greater claim to the work.
Shared Language	The group communicates in plain language. When technical or clinical terms are necessary, they should be defined so that all members can fully participate. Members are encouraged to ask for clarification at any time.
All Knowledge Counts	Experience living with PFIC, nursing and clinical expertise, and research knowledge carry equal weight in SC discussions and decisions.
Transparent Reasoning	When the SC makes a decision, the reasoning behind it is stated in terms all members can understand.
Accessible Participation	Meeting schedules, materials, and formats should take into account the practical realities of all members — such as parents managing childcare or members in different time zones.
Active Inclusion	The group notices and corrects patterns where some voices dominate or others go unheard.
Mutual Accountability	Every member is answerable to the group for their contributions and commitments, regardless of professional status.
Commitment	Members commit to consistent, active participation in SC meetings and activities.
Mission Focus	Our shared commitment to advancing patient-centered CER on PFIC and improving outcomes for patients and families grounds all SC decisions.
Ambition	We approach research with openness and creativity and avoid assuming that past limitations are permanent. At the same time, we weigh creative exploration against feasibility so that all perspectives inform our priorities.

2. Communication Norms

2.1 Meeting Facilitation

- Zoom Chat may be used for minor comments and quick answers.
- For major comments please use the Zoom hand-raise feature to signal you want to speak. SC Co-Chairs will call on members in order.
- SC Co-Chairs will use the rabbit Zoom emoji reaction to signal when a speaker should conclude their comment.
- SC Co-Chairs will seek to actively invite input from members who have not yet spoken.

2.2 Respectful Exchange

- Acknowledge all contributions respectfully—including those you disagree with.
- Practice charitable interpretation: assume good intent behind questions or comments that land differently than intended.
- Be mindful of gaps in shared understanding between and within member groups.
- Avoid jargon or explain it immediately. When a term is unfamiliar to some members, pause and define it.
- Avoid talking over one another. Interruptions degrade Zoom's closed captioning for members who rely on it.
- Practice active listening: minimize distractions and use non-verbal cues such as Zoom emoji reactions, nodding or smiling to show you are following.

2.3 Continuity for Absent Members

- Meetings will be video recorded. Summaries, chat logs, and recordings will be shared with members who cannot attend.
- Brief post-meeting surveys will provide the opportunity to express ideas or concerns that did not get airtime, so they can be addressed in a future session.

3. Decision-Making

3.1 Process

The SC will follow this sequence when a decision is needed:

- **Seek consensus first.** The default is to discuss until the group reaches agreement.
- **Move to a formal vote** when consensus cannot be reached within the time available.
- **Resolve stalemates.** If a vote does not produce a clear outcome, the issue is tabled for a maximum of one meeting cycle to allow further input. If unresolved after a second vote, Co-Project Leads make a final determination during the project period. If a deadline does not permit a full meeting cycle, Co-Project Leads will step in sooner, with input gathered asynchronously where time allows. Post-project, a designated PN

ombudsperson (Board and/or SMAB representative, to be specified in the governance charter) assumes this role.

3.2 Voting Rules

- Use ranked or rated voting when possible to capture the range of preferences. In the event of a tie, SC Co-Chairs will facilitate additional discussion; if the tie persists, Co-Project Leads will cast the deciding vote.
- When a yes/no vote is necessary: a three-fifths majority (8 of 14 members) is required for a motion to pass. Abstentions are excluded from the vote count but are still recorded. In addition, at least two members from each of the two majority stakeholder groups (patient/parent and clinician/researcher) must have voted for the result to be valid. This dual-majority group quorum prevents any single group from being outvoted when underrepresented in a given meeting.
- Any minority stakeholder group within the SC (e.g., nursing professionals) is afforded a formal minority position right: any minority stakeholder member may submit a concern before a vote is called, which the SC must substantively discuss, with SC Co-Chairs confirming the concern has been addressed before the vote proceeds.
- Zoom polls will be used regularly to gather input and for formal votes.

4. Addressing Challenges

The table below identifies challenges the SC anticipates and the agreed-upon responses for each. The final two rows describe the general escalation path for concerns not covered by a specific response.

Challenge	Agreed Response
Heated exchanges or interruptions	SC Co-Chairs will use de-escalation language. Avoiding interruptions is a shared group norm.
Member input being undervalued	Acknowledge this risk openly and proactively—not only when it arises. The PEET engagement surveys conducted after each SC meeting will include a specific check on whether members felt their input carried equal weight. Co-Project Leads will follow up on any concerns.
Gaps in shared understanding across (and within) member groups	Practice charitable interpretation. Be aware of each person's starting point. Use plain language and define terms. Recognize that differences also exist among patient/parent members—in PFIC subtype, age, disease stage, and advocacy experience—and keep the bigger picture in view: progress for one type can benefit all.
Tension between research ambition and feasibility	Designate a neutral third-party broker for unresolved conflicts in this area. Suggested candidates include a PFIC Network Board member and/or SMAB ombudsperson.
Existing relationships among SC members	SC Co-Chairs will invite members to voluntarily disclose any existing patient–provider or professional relationships with other SC members, modeling by disclosing their own connections first. Members are

	expected to disclose new relevant relationships as they arise. SC discussions are treated as confidential and not shared outside the committee without agreement; specifics of a formal confidentiality agreement will be established in the governance charter.
General Escalation	
A member feeling consistently unheard	Any member may raise this concern directly with the SC Co-Chairs or Co-Project Leads. Post-meeting surveys are anonymous and can surface this. Co-Project Leads will follow up individually.
A process that is not working	Any member can flag process concerns. Co-Project Leads will bring these to the Project Team for review. SC meeting structure will be revised based on post-meeting survey feedback throughout the project.