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International Children's Advisory Network

# Putting Youth at the Center: Best Practices for Pediatric Engagement and Patient-Centric Design

Every Child.Everywhere #iCANMakeADifference

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# What is iCAN?

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- A 501(c)3 nonprofit dedicated to empowering every child, everywhere by working to improve pediatric health, medicine, research, and innovation by putting kids at the forefront

- 46 member organizations working at the local and international level to empower youth voices globally

- A dedicated platform for children and families to give input and feedback into study designs, treatment plans, and educational materials of our industry partners

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# The iCAN Summit

- The iCAN Summit gives the scientific community a rare opportunity to engage directly with children and families, gaining insight from their lived experiences with diagnoses, treatments, and medical devices—or simply from their perspective as kids.
- At the 2025 Summit, more than 150 attendees—including 75 children—from 11 countries across four continents took part.
- Examples of Summit engagements include reviewing research protocols, providing feedback on assent forms, and contributing to the creation of patient-facing websites and materials.

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# Initiative: iCAN x Novartis (From Patient Insight to Patient Impact: A Co-Design Journey )


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# From Patient Insight to Patient Impact: A Co-Design Journey

- Novartis's 2025 iCAN Summit session, "Pediatric Clinical Trials: Let's Build Tools Together," showcased the power of patient-centric co-creation. Aiming to design a trial website for kids, Novartis asked, "How can we use children's insights to improve pediatric patient recruitment?" Following the iCAN Feedback Loop, the session put young patients at the center, turning their creativity into meaningful outcomes.

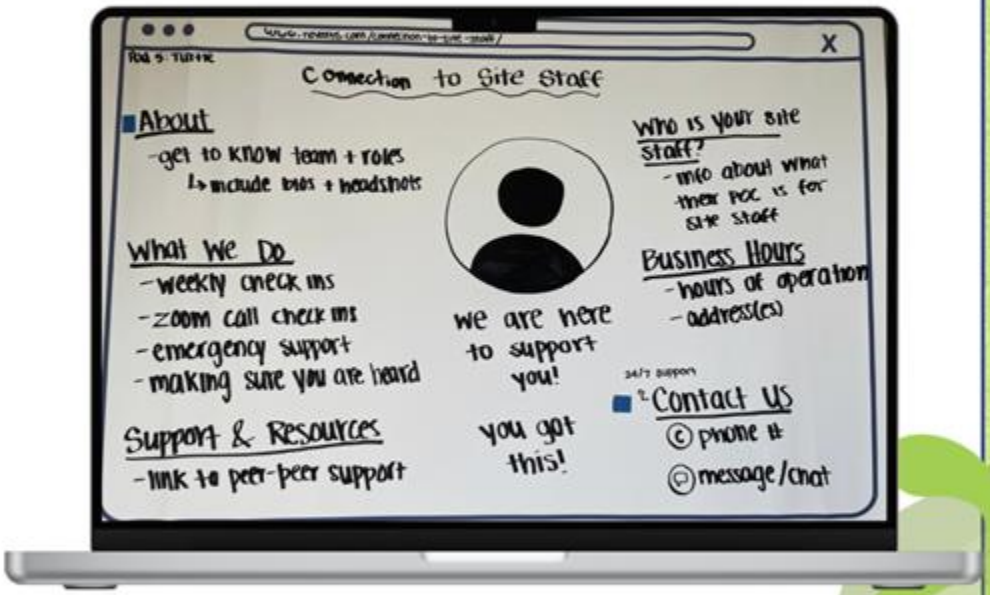
- During the Summit, Novartis invited our young participants to share what they would want featured on a clinical trial recruitment website.

# Example: "Connection to Site Staff"



**Feedback Highlight:**

- A deeper review of this page reveals a strong focus on personal connection. Unlike a traditional "About" page, the kids' version emphasizes:
- Warm, friendly messaging that highlights genuine human-to-human relationships
- Prominent visuals featuring site staff up front and center
- Clear, reassuring mentions of 24/7 support and a commitment to "making sure you are heard"



# Example: "Trial Updates"

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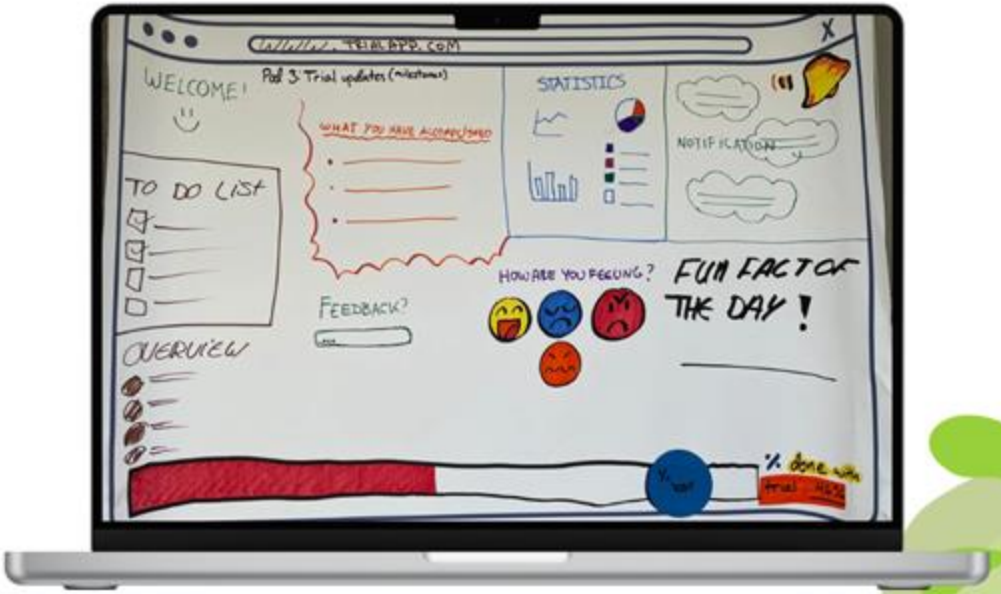
**Feedback Highlight:**

- iCAN youth members broke down getting updates from a trial in a navigable way, focusing on the most important features.
  - Positive language like "what you have accomplished" instead of "what you have left to do"
  - Visuals to help kids understand trial timeline
  - Interactive elements like "Fun Fact of the Day" to keep the user consistently checking the page.



# Measuring Impacts

- To date, all the feedback from the completed surveys and summit session has been shared with Novartis' program team members. They are actively using the summary data from the iCAN surveys to shape the setup of their trials. The website engagement data collected at the 2025 Summit will play a crucial role in developing a trial website, which is scheduled for release around 2029.

- Additionally, the team is incorporating the insights from the surveys into their Clinical Development Plans, outlining the overall program strategy and deliverables. There are three assets that will benefit from this input, directly impacting the planned pediatric trials launching over the next three years.

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# Initiative: iCAN x Eli Lilly (Digital by Design: Powered by Pediatric Voices)

**Diana L. Fisher**

Associate Director, Patient Engagement: Access and Retention – CoDesign, Eli Lilly

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# Patients as Partners: Designing With, Not For

*How the CoDesign Team and Early Legal & Ethics Alignment Enable Meaningful Patient Engagement*

- At Lilly we leverage CoDesign to design clinical studies in collaboration with patients, caregivers, and HCPs.
- We gather feedback from participants and apply it to improve how studies are designed and experienced by the sites and patients.
- Partnership is strongest when the patient voice is included early enough to shape trial decisions.

*2025 iCAN Partnership: Digital by Design – Powered by Pediatric Voices*

- Session: "Digital by Design: Powered by Pediatric Voices" (iCAN Summit, July 15, 2025).
- Purpose: understand youth/caregiver perceptions of digital tools and improve the digital clinical trial experience.
- Format: 40 min, 7–8 patient/caregiver pods, each pod focused on 1 topic; 6–9 questions per topic (mix of closed + open-ended).
- Topics: General study preferences; Digital experience; Customization/Motivation/Rewards; Open-ended reflections.

# What We Heard: Actionable Pediatric Digital Trial Insights

- **Burden drives feasibility:** willingness depends on study intensity and fit with busy schedules/visit burden.
- **Apps are acceptable (often preferred):** app check-ins can be frequent; reminders via **app notifications** preferred over phone calls.
- **Trust = transparency:** youth want clarity on security and how data is used; meeting the people behind the tools helps.
- **Privacy controls matter:** older youth want privacy/consent options around parent visibility.
- **Make it engaging:** colorful, interactive, game-like elements; customization + streaks/rewards support motivation.

# Additional Guardrails: Trust + Safe Participation

*Guardrails that protect trust and enable honest input*

- Clarity about what the session **is / is not**
- **Share insights according to individual level of comfort; insights collected are deidentified and aggregated**
- Activity design supports inclusion: iCAN breakout pods with **note-takers + leader** and clear roles/timekeeping.

# Summary

1) Patients as partners works when the patient voice shows up before decisions are locked.

2) Compliance isn't a hurdle—it's how we protect trust, especially with youth.

3) Standardized reviews so we can move fast without compromising integrity.

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# Initiative: iCAN x Pfizer (Data Heros)

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# Impact Framework – Taking Youth Voices back to the right clinical development teammates

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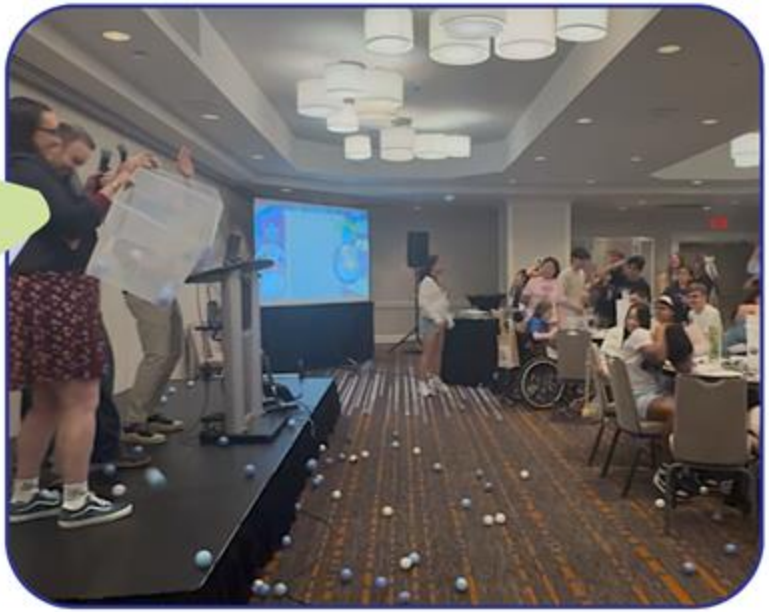
- **iCAN Summit** July 2025
- **Feedback to vendor partners** September 2025
- **Central metrics tracking across all studies** January 2026
- **Piloting with clinical trial teams** March 2026



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# Youth Group: Key Challenges – Direct Feedback

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### Emotional & Mental Load

"I'm overwhelmed by everything."
"My social battery is low."
"I got bullied and don't want to be on my devices."
"I feel like I'm not a normal kid when I do it."

### Physical or Medical Barriers

"I get migraines a lot."
"I was too tired from my period."
"Fatigue from treatment makes it hard to focus."
"I felt too nauseous to use my phone."

### Low Engagement / Boredom / UX Problems

"It's too boring to do every day."
"The questions never change."
"I'd rather play games or watch videos."
"It doesn't feel like it matters."

### Cognitive Barriers / Understanding

"I don't understand the questions."
"It's hard to know what it's asking."
"The medical words are confusing."
"I wish someone explained how to do it better."

### Technology Access + Functionality Issues

"My phone died."
"I had no Wi-Fi all weekend."
"The app glitched and wouldn't open."
"I forgot to charge my phone."

### Forgetting, Avoidance, Procrastination

"I forgot again today."
"I procrastinate and then it's too late."
"One missed day turns into a week off."
"I have no incentive."

### Psychological & Social Safety

"I'm embarrassed my friends might see."
"I don't want to be reminded of my illness."
"It makes me feel different from other youth."
"I'm scared someone will read my answers."

# Task Owner Mapping

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## eCOA Vendors

- Test Lexicon with youth
- Gamify where possible
- Involve study teams and youth to customize

## Clinical Study Teams

- Incorporate youth voices into eCOA platform customization
- Test messages with youth
- Advocate for participants to receive information on how their data are used – plain language summaries

## Sponsor Organization

- **Partner early**
- **Build review timelines**
- **Have feedback loops to inform other study teams**

Ensure we are debriefing the right partner who can take action on participant feedback.

# Incorporating Youth Voices is a work in progress

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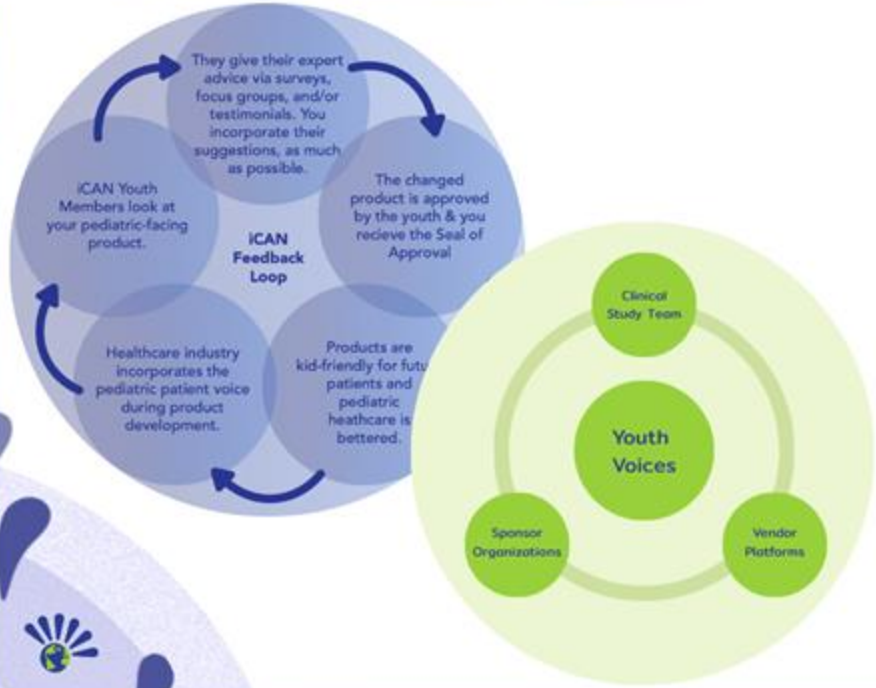
*Use continuous process improvement internally to drive more youth voices in protocols*




*Role based & Time bound*

- Avoid the Data Dump
  - Separate feedback into action by task in your company
- Have fun
  - Create meaningful interaction
- Show alignment
  - Share information with vendors or cross functionally to drive change.

*Feedback loops*

- Create time bound structures to know how feedback is being used
  - What else can we learn?
  - What has changed?
  - What can we bring to new development teams working in this demographic?

## Final Thoughts

- This is their journey — and in pediatric healthcare, giving children a seat at the table is just the beginning. We must empower them to shape the conversation, set the agenda, and help build the table itself. By centering young patients' lived experiences and including their voices at every step, we create care and treatments that truly reflect their needs, perspectives, and potential.

## Contact iCAN

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