



Pediatric Patients Expert Group

March 21th, 2025

Online Meeting

<https://invents-he.eu/>



INVENTS has received funding from the European Union's Horizon Europe Research and Innovation program under grant agreement 101136365.



Funded by the Swiss State Secretariat for Education, Research and Innovation (SERI).



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Ground Rules for a Teen Focus Group

Speaking Rules

- **Respect and Active Listening** – Everyone should listen without interrupting and respect each other's opinions, even if they disagree.
- **Fair Speaking Time** – Everyone gets a chance to talk. If you've spoken a lot, let others have a turn.
- **Speak Freely, No Judgment** – This is a safe space. You can share your thoughts without fear of being judged.
- **Keep It Short and Clear** – Try to be brief so everyone has time to express themselves.
- **It's a Discussion, Not a Debate** – We're here to share experiences, not to convince others.





Ground Rules for a Teen Focus Group

Confidentiality Rules

- **What's Said Here, Stays Here** – What we talk about in this group should not be shared outside.
- **Anonymity is Key** – If any thoughts from this session are shared later (in a report, for example), they will remain anonymous.
- **Recording for Content Analysis Only** – The session will be recorded, but only for content analysis. The recordings will be deleted once the project is over.
- **Session Summaries for Accuracy** – At the end of each session, we will provide you with a summary of the key points discussed to ensure we understood you correctly.
- **Respect Personal Information** – Don't share personal details about others outside this group.





Feedback on the February 21st PEG

Summary – Patient Experience Meeting

- **Participants' Motivations:** Personal experiences with rare diseases driving commitment to improving healthcare.
- **Medical Care Experiences:** Challenges in diagnosis, feeling unheard by healthcare professionals, treatment disappointments.
- **Disease Management & Research:** Emotional impact of medical interactions, reliance on self-research for treatment insights.
- **Non-Pharmacological Approaches:** Exploration of alternative therapies (physiotherapy, Pilates), tracking treatment effectiveness.





Today's Discussion

Clinical Trial Feedback: The process of clinical trials and how patient feedback on new treatments can be systematically captured and integrated into decision-making.

- Have you ever participated in a clinical trial? If so, tell us about it.
- Would you take or not an experimental treatment? Tell us about it.
- During the meeting, we talked to you about in-silico clinical trials. Did you understand well? Would you be willing to take a treatment designed solely based on mathematical models?





Today's Discussion

Regarding patient associations, we need to know

- How (by what means i.e. concretely) can experience feedback be collected?
- What are your connections with patient associations?
- Do you think patient associations are able to make your voice heard?
- What could be the levers to encourage people like you to participate in experience feedback, for example, on a treatment?





Thank you for your participation

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