

## Patients Expert Group (PEG) Meeting Report 30 May 2025

### Minutes

#### Purpose of the Session

- Demonstrate how **your opinions influence the development, approval and real-world use of medicines.**
- Present and test-run a **draft Patient-Preference Questionnaire** that grew out of previous face-to-face and online workshops.

#### Presentation: Benefit–Risk & Patient Preferences

- **Benefit–Risk Assessment** explained with a balance metaphor: regulators only license a treatment when benefits clearly outweigh risks.
- **Why preferences matter:** even when two drugs look similar on paper, what adolescents are willing to trade off (e.g. fast relief + itchiness vs. slower relief + no rash) can change regulatory decisions.
- Live poll showed divergent views: some would accept quicker relief plus mild itching; others preferred slower onset with no side-effects.

#### Walk-through of the Draft Questionnaire

Sections previewed on-screen:

1. **My treatment & how I'm doing now** – current regimen, adherence, perceived effectiveness, openness to switching.
  2. **Hospitalisation & impact** – recent admissions and day-to-day effect of the condition.
  3. **Decision-making** – who usually decides (self, parents/carers, clinicians, shared).
  4. **Ranking exercises** covering:
    - Relationship with healthcare professionals
    - Experience of living with the condition
    - Treatment features (efficacy, side-effects, convenience, access to other care)
    - Diagnosis & care pathway
    - Daily life & independence
    - Participation & empowerment
- **Anonymity:** no answers can be traced back; multiple submissions technically possible.
  - Link (and QR code) shared in the chat; completion time ≈ 5 minutes.

### Group Feedback & Live Ranking

- Most rated “**trustful relationship with healthcare professionals**” as top priority, closely followed by “experience of living with the condition”.
- For participation & empowerment, the order typically was:
  - 1 Being listened to when decisions are made
  - 2 Being able to give my opinion on treatments
  - 3 Easy ways to contact the care team
  - 4 Being informed about research/clinical trials
- Suggestion: separate “parents/carers” from “other adults” in decision-making items.
- No additional missing topics were identified during the call; participants invited to flag any via the questionnaire.

### How Regulators Use Preference Data

- **Discrete-Choice Experiments (DCEs)** illustrated: respondents pick between hypothetical treatment profiles; modelling quantifies the “maximum acceptable risk” for a given benefit.
- Real-world example: a new alopecia areata therapy was licensed because preference data showed patients were willing to accept infection risk to regain scalp/eyebrow/eyelash hair. Without those data regulators would likely have refused approval.

### Next Steps & Action Items

#	Responsibility	Action	Timeline
1	<b>All PEG members</b>	Complete the online questionnaire (link provided).	As soon as possible
2	<b>All members</b>	Encourage peers who missed the call to complete it.	Before next meeting
3	<b>Facilitators</b>	Collate questionnaire responses and adjust wording/topics where needed.	By next meeting

### Closing

- Thanks for the lively input and patience during the long presentation.
- Reminder: WhatsApp group remains open for any questions between sessions.