Neuroendocrine Life Alliance (NLA) 2026 Patient Summit Impact Report

1. Executive Summary

The Neuroendocrine Life Alliance (NLA) 2026 Patient Summit delivered a **high-impact, patient-centred educational and support event**, demonstrating exceptional levels of satisfaction, engagement and perceived value among both participants and speakers.

- **97% of attendees rated the event as Excellent or Good**
- **97% found the event informative or very informative**
- **100% would attend similar events in future**

Qualitative feedback highlights three core areas of impact:

- **Improved patient knowledge and understanding of treatment pathways**
- **Increased hope and confidence about future care**
- **Reduced isolation through meaningful peer connection**

The event also received **strong endorsement from expert speakers**, reinforcing its credibility, professional delivery, and sector value.

2. Reach and Engagement

- **38 participants completed evaluation feedback**
- **Face-to-face delivery strongly preferred** (76%)
- **73% would be willing to pay for future events**

Speaker engagement further demonstrates impact:

- One session series attracted **~60 participants across multiple back-to-back sessions**
- High levels of **participant interaction and post-session discussion** were reported

3. Participant Experience

Overall Satisfaction

Attendees reported overwhelmingly positive experiences:

- “All sessions brilliant… very positive and hopeful.”
- “Not possible to single out any one part… it was all most valuable.”

Informational Value

Participants consistently highlighted the quality and relevance of information:

- “Getting very clear information from experienced specialist clinicians.”
- “Receiving up-to-date information.”
- “Latest available advances in treatment.”

This demonstrates **successful delivery of expert-led, evidence-based education**.

4. Impact on Patients and Families
4.1 Increased Knowledge and Confidence
Attendees reported gaining actionable insight into their condition and care:

- "Learning… what I might face in the future."
- "Gleaning information to help my children and myself with current treatments."

4.2 Hope and Emotional Reassurance
A recurring theme was renewed optimism:

- "Hearing about upcoming treatments… hope for my grandchildren."
- "The pace of change… made me feel hopeful."

This highlights the event's role in **supporting emotional wellbeing alongside clinical knowledge**.

4.3 Connection and Peer Support
The Summit significantly reduced isolation:

- "Meeting people who are in a similar situation."
- "Feeling there is a support network… that understands."
- "Sharing experiences."

Participants particularly valued **face-to-face connection within a rare disease community**.

5. Quality of Programme and Speakers
Session Delivery

Morning and afternoon sessions were consistently rated highly, with multiple sessions receiving **majority "Excellent" ratings**
Participants emphasised:

- Expert-led sessions
- Access to leading clinicians and researchers
- Updates on trials, treatments and research developments

Participant Priorities
Analysis of open responses shows attendees most valued:

- Specialist clinical expertise

- Research and treatment updates
- Opportunities for networking
- Disease-specific learning

6. Speaker Feedback (Professional Endorsement)

Feedback from invited speakers strongly reinforces the event's success, organisation and impact:

- "A HUGE congratulations on organising such a fantastic event… everyone seemed to be getting so much out of it."
- "I really enjoyed my sessions and got some great feedback… around 60 people in all. So really great turnout."
- "Quite a lot of people asking questions afterwards… strong interest in future sessions."

Additional speaker reflections included:

- "Thank you for a really well organised event. I really enjoyed the morning."
- "It was a lovely day and well organised."
- "You did a super job organising… participants were amazing and asked lots of questions."
- "It has been a pleasure to attend."

This demonstrates:

- **Strong professional credibility**
- **High engagement during sessions**
- **Demand for continued collaboration and future programming**

7. Areas for Improvement

Constructive feedback has provided clear direction for future development:

Accessibility and Delivery

- Improve microphone use and audibility
- Ensure audience questions are repeated

Programme Design

- Provide clearer session descriptions in advance
- Increase opportunities for Q&A and small-group discussion

Networking Enhancements

- Introduce methods to identify shared conditions (e.g. badges)

Practical Considerations

- Broaden catering options to suit dietary needs
- Allow additional breaks between sessions

8. Conclusion

The NLA 2026 Patient Summit has demonstrated **significant impact across education, emotional wellbeing, and community building**.

Key achievements include:

- Delivering **trusted, specialist-led information**
- Creating **meaningful peer connections**
- Enhancing **hope and confidence among patients and families**
- Establishing a **highly valued, scalable model for future events**

Both **participant and speaker feedback confirm the event as a high-quality, impactful and strategically important initiative** within the neuroendocrine community.

9. Key Impact Statement

The NLA 2026 Patient Summit achieved outstanding participant satisfaction and demonstrated measurable impact on patient knowledge, confidence and wellbeing. Attendees valued expert-led education, opportunities for peer connection, and access to the latest research developments. Speaker feedback further confirmed the event's quality, engagement and professional credibility, with strong demand for future delivery