

Lessons Learned from QSPainRelief Patient and Layman Events & Recommendations for Future Events

What Went Well

1. Hybrid and Virtual Formats Expanded Access

- Online access enabled broad participation from patients and organisations across Europe, especially during COVID-19.

2. Patient-Friendly Presentations

- Presentations were crafted in layman language, including visuals, and reviewed for accessibility by patient representatives from Pain Alliance Europe ([PAE](#)) who also supported the project with dissemination and as a valuable member of the scientific and ethical advisory board ([SEAB](#)).

3. Interactive Elements

- Live Q&A sessions, question collection during registration, and chat functions fostered interaction.

4. Strategic Partnerships with Patient Organisations

- Events were embedded in major assemblies (e.g. PAE's General Assembly, GA, or the General Assemblies of QSPainRelief). During the 1st and 5th QSPainRelief GA Meeting, the respective presidents of PAE, first Joop van Griensven and later on Deirdre Ryan, gave the keynote lectures, ensuring a wide reach and high attendance.

5. Multichannel Promotion

- Event visibility was enhanced via the [project website](#), social media, flyers, newsletters, and direct contact with past study participants. For the 2nd (hybrid) event, printed advertisements (event poster + info brochure about the event) were distributed at local pharmacies.

6. Demonstrations of Scientific Tools

- Live demos (e.g. CHDR's PainCart®) helped patients connect with complex scientific procedures.

7. Follow-up Content Creation

- Talks and related Masterclasses were shared as barrier-free webinars with subtitles, enabling broader post-event dissemination about the project (see [project video](#) and [E-Learning](#) about the project).

What Could Be Improved

1. Enhanced Patient Involvement

- Involve patient groups even more in the process of planning the layman events, shaping not only the agenda, promotion, and content, but also the feedback-collection (e.g. via questionnaires) and the post-event outreach activities.

2. Enhance Patient Visibility During Events

- Patient representatives should be more visibly positioned on stage (especially for online audiences) to symbolise patient-centricity.

3. Boost Promotion to Elderly & Non-Digital Audiences

- Use even more traditional media, like newspapers, radio, and community networking to better reach demographic target groups at 60+ years of age.

4. Time Event Seasonally & Logistically

- Avoid harsh winter dates; offer hybrid/recorded alternatives to accommodate the often reduced mobility of pain patients, the unpredictable nature of their disease (each day is different), and other pain-related issues (comfortable seats, wheelchair access, etc.)

5. Further Link Research to the Daily Life of Patients

- Explain clearly how the science (e.g., QSP models) translates into new treatments or benefits for individual patients (for example by graphically outlining an “improved treatment path” of an exemplary patient)

6. Utilise Existing Large Conferences or Patient Gatherings

- Host future sessions as side-events of larger, established conferences or patient-centred congresses to maximise the reach and impact.

Best Practices for Organising Patient & Layman Events

1. Start with Patient Co-Design

- Collaborate with patient representatives in defining purpose, format, agenda, and language of the event.

2. Ensure Local Language and Lay-Friendly Content

- Use locally understandable language (not only English), plain and easy language (not too scientific), infographics, and real-life examples.

3. Hybrid or Multi-Access Options

- Offer live, but also recorded, hybrid (face-to-face and online), written, and graphical formats to accommodate all accessibility needs.

4. Interactive Format is Key

- Use polls, Q&A, live chat, and patient-centred podium discussions; collect questions beforehand to tailor the session.

5. Multi-Channel, Inclusive Promotion

- Mix digital (social media, email) and traditional (posters, flyers, newspaper ads, radio ads, direct community outreach) communication to reach older target audiences.

6. Professional Presentation Support

- Include support teams for the graphical design, translation(s), and technical support on site to ensure a smooth and appealing experience.

7. Post-Event Engagement

- Collect feedback (e.g. via questionnaires and personal conversations) and share presentations and materials, answer remaining questions, and provide recordings with subtitles for sustained impact.



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