



Hope for families with life-limiting epilepsy

Dravet Syndrome UK's Patient and Public Involvement and Engagement Guide

Dravet Syndrome UK (DSUK) recognises the valuable role of Patient and Public Involvement and Engagement (PPIE) in research and is committed to supporting research that serves the needs of our community. This guide outlines good PPIE practice when working with people living with Dravet Syndrome, and how DSUK can support and streamline this process.

What is PPIE?

PPIE means involving patients, families, carers, and the public in research design, delivery, and evaluation.

'Research carried out with or by members of the public rather than to, about or for them'
- National Institute for Health and Care Research

Research that involves families from the outset is likely to be:

- More relevant: addresses questions that matter to patients and families, not just researchers
- More likely to be adopted: if families have shaped it, they trust it and actively support it
- More ethical: families are treated as experts, not subjects

PPIE vs Participation

PPIE: People with lived experience work with researchers to improve study design before research begins, and sometimes whilst it is ongoing. This might include meeting with researchers to share their experience, reviewing study documents to make sure they're clear and appropriate, or giving feedback on research priorities and what families need most.

Research Participation: People with lived experience take part in studies or trials themselves, including surveys, interviews, and other research activities.

How to Make PPIE Meaningful

Effective PPIE should be a genuine partnership where researchers learn from people with lived experience and actively incorporate their feedback. DSUK believes PPIE should never be a 'tick-box' exercise but rather a meaningful collaboration that improves the quality and relevance of your work. This is particularly important in the rare disease landscape, where researchers don't truly understand the reality of the condition; families living with Dravet Syndrome have vital insights that can strengthen study accessibility and impact.

PPIE discussions should focus on specific questions about your study and build on background research you've already completed. Families living with Dravet Syndrome often have significant care responsibilities, so their time is valuable; before planning PPIE activities, review the resources on DSUK's website for basic information about Dravet Syndrome.

Whilst families are experts in Dravet Syndrome, jargon should be avoided or explained in plain language. For examples, please see our [Research Terms A-Z page](#).

Dravet Syndrome UK's Lived Experience Board

Dravet Syndrome UK has established a board of families living with Dravet Syndrome who are interested in contributing to research. This is primarily a dedicated group of PPIE advisors, though members may also choose to participate in studies as research participants.

If you're seeking to recruit participants for your study or trial (as opposed to PPIE input), DSUK has a separate process for advertising research opportunities to our community.

What Board Members Do

Members work with researchers to improve study design before research begins, and sometimes whilst it is ongoing. Board members may be asked to participate in various activities dependent on your project needs. Member activities might include:

- Reviewing study protocols and patient information sheets
- Attending workshops to co-design research protocols
- Advising on trial feasibility and burden
- Helping prioritise research questions
- Providing feedback on recruitment materials and participant communications

The Process

1. Contact research@dravet.org.uk with a completed enquiry form. We will assess this based on community benefit and board capacity.
2. If your request is approved, DSUK will share your project details with board members in our monthly opportunity email. The email will include information about your project, what's involved, time commitment, and reimbursement details. Board members then decide which opportunities interest them.
3. DSUK will collate the details of interested board members and provide you with contact details for a representative group.
4. You can contact board members directly about the project. For individual activities (such as reviewing documents), you coordinate directly with board members. For group activities (such as workshops), DSUK will join the session to ensure a safe, structured, and accessible environment, whilst you provide the content expertise and manage the session agenda.
5. Send a short summary to DSUK about the activity and its impact.

Communication

DSUK (research@dravet.org.uk) must be copied in all email communications with board members. This helps us monitor board member workload, track the impact of our board, and provide support if needed. Once your PPIE activity is completed, please do not contact board members independently for updates or further input. Instead, contact DSUK to discuss any additional needs. This protocol prevents board members from being over-burdened and ensures DSUK can appropriately match ongoing requests with board capacity.

Reimbursement and Recognition

DSUK believes that lived experience input should be fairly valued. We understand that reimbursement isn't always possible and support requests that do not include reimbursement. However, we strongly advocate for PPIE contributions to be recognised and compensated wherever feasible. Current NIHR INVOLVE guidance recommends payment rates of £20-30 per hour for PPIE involvement, plus reimbursement for travel expenses, caring costs to enable participation, and other reasonable expenses.

Following the activity, we ask that you send DSUK a short summary of the key themes and suggestions you heard from board members, what you changed in your project as a result, and any suggestions you did not implement, and why. This feedback ensures accountability and helps families see the value of their involvement; DSUK shares these summaries with board members who contributed.

We ask that you acknowledge DSUK's Lived Experience Board in your grant reports and publications.

DSUK consultation vs PPIE

DSUK staff members and trustees have years of experience consulting on research studies and clinical trials. We also have people with lived experience on our team, giving us unique perspectives. At the early stages of your project, DSUK can provide strategic advice on working with the Dravet Syndrome community, review patient-facing materials, and share priorities. This helps you shape your approach and understand the landscape before detailed design work begins.

When you have specific design questions and materials ready for review, PPIE activities bring insights from diverse backgrounds and experiences. This ensures your study works for different ages, geographies, and family situations. This is formal public involvement that you can document in your research applications and publications.

If you are unsure on whether to request consultation from DSUK or our Lived Experience Board, please contact us and we will be happy to direct you on which would be most appropriate.

Ethical and Compliance considerations

DSUK's Lived Experience Board works with all organisation types. Confidentiality agreements can be arranged where needed. Pharmaceutical companies should ensure their PPIE activities comply with the Association of the British Pharmaceutical Industry Code of Practice, particularly Clause 27.

PPIE advisory work does not require Health Research Authority or NHS Research Ethics Committee ethical approval because board members are acting as advisors to improve research, not as research subjects.

Questions?

For enquiries about PPIE opportunities, to discuss whether DSUK organisational input or board PPIE would be most appropriate, or if you have questions about any aspect of this guide, contact research@dravet.org.uk.