

Patient and Public Involvement End of Year Highlights Report 2025

211 Registered Scottish Medicines Consortium (SMC)
Patient Group Partners (PGPs)

125 Patient Groups actively engaged with

61 Individual submissions to SMC

9 Joint submissions to SMC

43 Presentations at 12 SMC Committee meetings

45 Patient representatives supported to
participate at 27 Patient and Clinician Engagement
(PACE) meetings

52 Patient representatives supported to participate at
12 SMC Committee meetings

4 Abbreviated assessments with PGP participation

55 Decision Explained documents published

12 Media Releases prepared for 73 medicines

PGP Feedback n=17

100% were satisfied with the opportunity to contribute to medicine discussions at the SMC Committee meeting.

100% reported that the support from the SMC Public Involvement team was good or excellent.

100% who received feedback on strengthening their submission found the advice useful.

"Scotland continues to set an example in placing patients at the heart of healthcare decision-making"
(on working with SMC)
Cystinosis Foundation UK

Abbreviated Submissions

- Involvement of PGPs in the abbreviated submission process was reviewed to identify opportunities for improvement.
- Findings confirmed PGPs value the opportunity to contribute.
- A new form is being developed to capture key questions.
- This enhancement will strengthen reporting and improve the overall experience of participating PGPs.

SMC Connect

- Soft launch of new portal.
- Received 16 submissions from PGPs through the portal.

"The new system is much more efficient than the previous form. I also like that we can update information, save it while we work on it, and share access with others"

Haemophilia Scotland

PACE

100% PGPs said they had sufficient opportunity to bring the patient and carer experience to discussions at the PACE meeting.

Public Partners

- ✓ 2 new Public Partners recruited.
- ✓ Introduced an enhanced induction and ongoing learning programme.



Feedback

Working with SMC Public Involvement Team

- “We felt supported by the SMC team.”
- “We had regular and very helpful communication with the SMC team who explained the process and what they needed from us.”
- “Very good and clear correspondence.”
- “I was provided with detailed information about the process and how I would be involved.”
- “We appreciated the prompt to include more patient quotes in our submission to help strengthen it.”
- “Whenever I work with the SMC Public Involvement Team, I have found them supportive and informative. They seem a very good team to me and as a patient you feel your time is valued.”

Participation at SMC Committee Meeting

- “I'd like to acknowledge that the Chair conducted the meeting fairly and effectively.”
- “Very well run and we were given an adequate amount of time to share our views.”
- “We felt our opinions were invited and welcomed.”
- “The SMC meeting was respectful, and I felt patient voice was genuinely heard.”
- “The session was fine except that we were the fifth technology to be discussed that day, so there was a lot of hanging around.”
- “It’s a highly technical discussion referencing scenarios and models that we are blind to and using a lot of jargon. This makes it hard for us to come back on specific points, even though we feel that we can contribute to aid discussions.”

Participation at Patient and Clinician Engagement (PACE) Meeting

- “We found the experience to be a very positive one and the SMC team was very good at making sure we had everything we needed to bring the patient and carer voice to this process.”
- “The PACE meeting was a very respectful and positive experience. I felt our group was really heard and well represented in the report.”
- “There was plenty of support in the lead up to the PACE meeting and the meeting itself provided a calm, friendly/relaxed atmosphere in which patients/patient representatives (& clinicians) could share their stories/views.”
- “It was a good discussion. There was documentation to review in advance, and we didn't have much lead in time. We were able to get our points made.”