

A summary of the report

Speaking up for patients

Patient organisation involvement in Health Technology Assessment (HTA) with a focus on Patient and Clinical Engagement (PACE) at the Scottish Medicines Consortium (SMC)

Cancer52 is passionate about ensuring the patient voice is heard in all spheres of healthcare, from policy to practice.

Ensuring the patient voice is heard is particularly important for rare and less common cancers where there may be gaps in the evidence base reflecting small patient numbers. Cancer52 believes that patients can contribute to a fuller understanding of the impact of new medicines and this should be taken seriously as part of Health Technology Assessments (HTA).

Evidence from academics tells us that there is no gold standard for patient and patient group involvement in Health Technology Assessment. But what does patient organisation involvement feel like for those taking part, and what can we learn from the new Patient and Clinical Engagement (PACE) process at the Scottish Medicines Consortium (SMC)?

A new process, introduced in 2014, PACE allows patient groups and clinicians to talk in a separate meeting with SMC staff, without economists and companies present, about the benefits of new end of life and orphan medicines that might not look, at first, to be cost effective for the NHS in Scotland. Pharmaceutical companies request PACE. The All Wales Medicines Strategy Group (AWMSG) has a similar approach, known as a Clinician and Patient Interest Group (CAPIG) process.

Nine members of Cancer52 who have taken part in PACE talked about their experience. They told us that PACE “feels like a breath of fresh air”. It’s an open approach, fully supported by the staff at the SMC, and helps patient organisations to raise relevant issues. It does take time to prepare and participate. Despite the impact of PACE being unclear, all of those who shared their experience said they’d take part in PACE again. They say their experience at PACE feels very different to their experience at appraisal committees at NICE, where there can be a perception that economics dominates and patient perspectives are left to last.

While there is no gold standard for patient and patient group involvement in HTA, Cancer52 believes that all parties – including patient organisations - need to share experience, learn from each other, evaluate the effectiveness of their approaches to patient involvement and jointly develop best practices. We recommend that:

1. AWMSG and SMC publish their evaluations of CAPIG and PACE in a timely fashion so that others can learn from their experience.
2. A conference is organised to bring together HTA agencies and patient organisations to reflect on their experience of patient organisation involvement and to learn lessons from across the UK.
3. NICE re-order their agenda for Appraisal Committee meetings to start with the patient perspective, with the lead lay member presenting an overview followed by an opportunity for attending patient groups to correct any factual mistakes.

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