

Comments on CSO strategy

In relation to 'Partnership with Scottish Patients and the Public' section:

It is encouraging to see partnership with Scottish patients and the public as a key area for action. Lay involvement in policy and strategy committees is good, through the Public Engagement Group, although there is a need to broaden membership of this group, particularly if they are being expected to take on more responsibilities.

Although the strategy mentions 'encouraging' the research community to do more to engage the public, there is no mention of resources. Adequate resources and expertise to support PPI will be essential if anything is to change. CSO does not currently invest sufficiently in this – PPI needs a dedicated post to facilitate activity. The benefits of this can be seen at NIHR, which has a National Director for Public Participation and Engagement in Research.

For grant applications to CSO, a more substantial lay summary is needed and applicants should be given feedback on the patient involvement aspects of their application. If PPI really matters, CSO should turn down applications and reject reports if they don't have adequate/properly funded PPI.

There is a great need for leadership to encourage healthcare researchers to engage with PPI. CSO needs to work with the Research Governance community to ensure PPI is promoted at the research design stage. NIHR in England provides bursary funding (£350 per project) through the Research Design Services to support patient involvement at the design stage; could CSO replicate this modest investment across health boards/research networks?

Regarding a trial register, accessible patient information would be useful to people seeking enrolment in trials. Expectations need to be managed, so as well as linking with SHARE, people could be advised of opportunities for patient involvement as well as participation in studies.