

Patient and public involvement at NICE: a strategic review

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Cancer 52 all members meeting – 24 January 2017

Background – three triggers

1. Long standing programme – want to ensure we're in line with evidence based practice on involvement
2. Recommendation 8 in the NICE Triennial Review :
“NICE should continue to work with patient groups to make its approach to supporting patients more transparent and identifying where it can provide more support to those participating in the work of NICE.”
3. Concerns expressed by some Board members about our capacity to deliver a ‘gold standard’ public involvement service in the future.

Background – what's happened to date?

- Literature review – focused on public involvement in clinical guideline & standard development – now published!
- Stakeholder survey and meeting – prioritisation exercise
- Oversight group – 3 meetings
- Senior Leadership Team review
- Senior Management Team review
- Public Board meeting review
 - Papers here –
https://www.nice.org.uk/event/stleonardsonsea_july_2016
 - Minutes available here w/c 19/9 –
https://www.nice.org.uk/event/nottingham_septpublicboard_2016
- Approved for consultation by SMT on 22/11

Limitations

- Focus on patient and public involvement in NICE's guidance and standards programmes only
- Excludes all other PPI activity - managed either by PIP or other teams (see later) - to be considered as 'phase 2'
- Large sections of NICE about to go through organisational change/reducing financial situation – need to take these changes into account
- Pragmatic approach – need to future-proof activities

Overall ambitions

- Standardising how we engage with and involve lay people across our guidance and standards programmes.
- Involving people earlier and keeping them involved throughout the development process.
- Being clearer on how we find information about people's experiences of care and how we take account of that experience in our guidance.
- Recruiting a broad pool of people with knowledge and experience of specific conditions or services. This group can be drawn on as needed to join decision-making bodies.

Overall ambitions

- Introducing a formal feedback process. This will enable people who help develop our guidance and standards to be aware of the impact of their contribution.
- Making better use of social media to:
 - communicate with people about our guidance and standards
 - make it easier for people to communicate with us.
- Reinforcing the message among our staff that involving lay people is everyone's responsibility.

Other areas we support, not included in the review

- Accreditation
- Appeals
- Bursary scheme for the NICE conference
- Citizens Council
- Commissioning support documents
- Endorsement
- Fellow and Scholars
- Guidance development project
- Indicators
- Insight community
- MIBs
- Meetings in public
- Office for Market Access
- PASLU
- PIN
- Scientific advice
- Shared Decision Making Collaborative
- Student champions

Next steps

- Consultation now live - <https://www.nice.org.uk/about/nice-communities/public-involvement/consultation>
- Available until 28th February 2017
- Encouraging submissions via SNAP survey
- Analyse responses – March 2017
- Implementation plan to May 2017 Board meeting
- Implementation – May 2017 onwards, possibly aligned with updates to manuals

