

Patient involvement in Technology Appraisal:

Summary report

1. Introduction

A Health Select Committee report published in January 2013 included a recommendation that stated 'It is important for the credibility of NICE and for the decisions that it makes that the patient voice is effectively and openly represented in all its work'. This led to the Market and Audience Intelligence (M&AI) team leading a project to explore the experiences of patients in the Technology Appraisals (TA) process.

Aims and objectives

The overarching aim of the research was to explore and understand patient experts' and organisations' perceptions of engagement in the TA process, and specifically identify any barriers to engagement.

The key objectives were to:

- (i) Understand patient experiences of the TA process by consulting patient experts and patient organisations.
- (ii) Identify potential barriers to engagement with the TA process by consulting patient organisations that are involved and not involved with the NICE TA process.
- (iii) Explore the factors that influence perceptions of engagement with the TA process, such as level of experience working with NICE.
- (iv) Take a holistic approach to understand the experience of patients and patient organisations and their impact, by obtaining the views of TA committee Chairs and appropriate NICE staff.
- (v) Produce a list of recommendations based on the findings that PIP and TA will use to create actionable recommendations for their programmes.

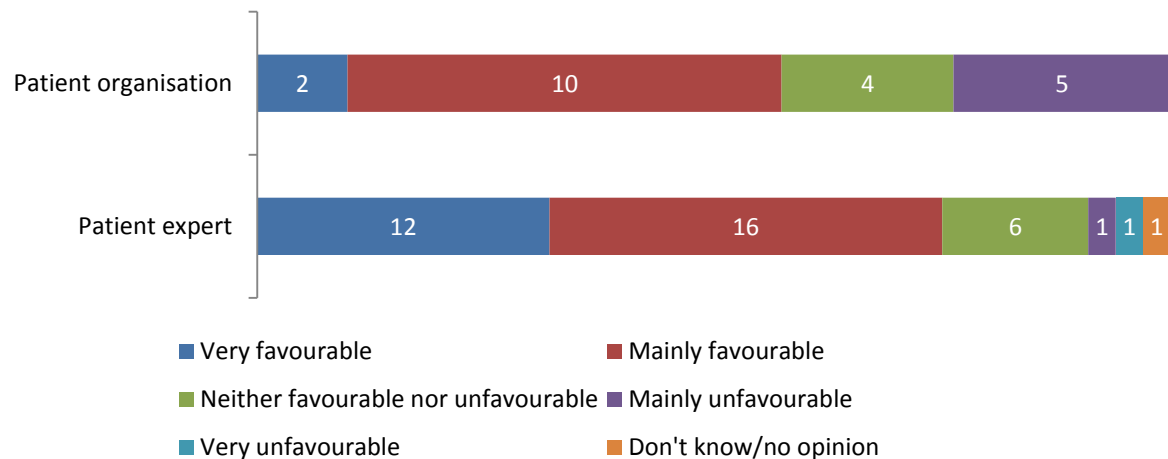
A mix of interviews, focus groups and surveys was used to gather feedback from patient experts and organisations engaged with the TA process, patient organisations who have not been engaged in the TA process and internal stakeholders.

Due to the limited number of responses to the survey with engaged patient experts and organisations, the results throughout are reported as numbers rather than percentages.

2. Perspectives of the experts and organisations

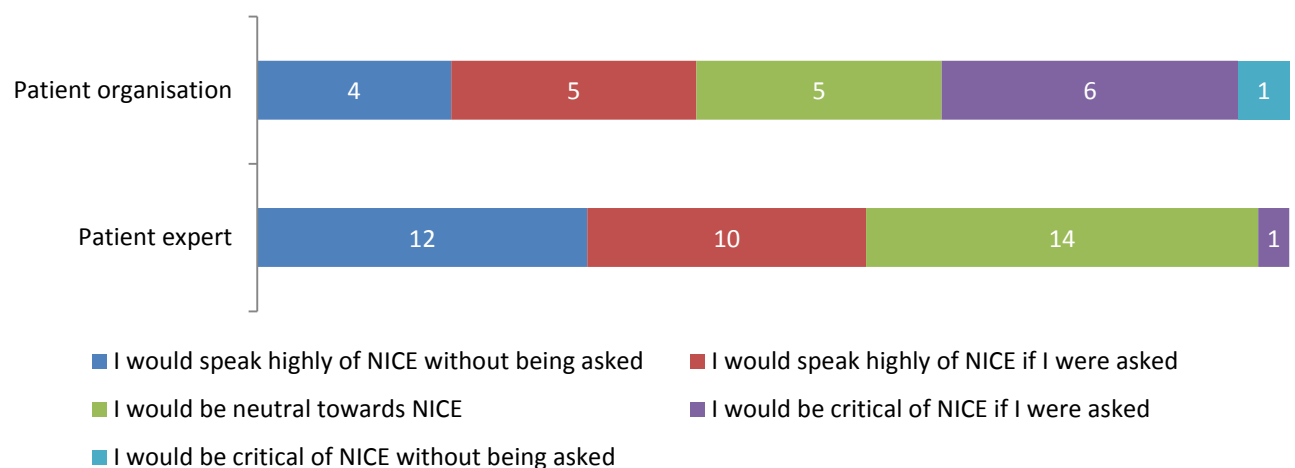
Engaged patient experts and organisations tended to hold a favourable opinion of NICE, with an indication that patient experts tended to be slightly more positive than patient organisations (28 out of 37 patient experts and 12 out of 21 patient organisations rated their perception as mainly or very favourable).

Figure 1: Opinions of NICE



Brand advocacy, how a person would describe an organisation to third parties, provides an indication of an organisation's reputation. 22 in 37 experts and 9 out of 21 patient organisations indicated that they would speak highly of NICE. However, 7 out of 21 patient organisations would be critical of NICE (6 if prompted and 1 if not).

Figure 2: Advocacy of NICE



Those not engaged in the TA process believe that NICE is performing an important role and its work is widely regarded as evidence-based and of a high quality. 16 out of the 20 organisations said they would speak highly of NICE (12 if prompted and 4 if not). Engaging

with patients, professionals and industries is thought to be vital for setting a standard for excellence. Participants therefore strongly support NICE's engagement with patient organisations.

"Obviously it's all very well to say, this medication, for example, is the best medication, but actually people who have to take that medication say, 'Well no actually it's absolutely horrible for taking, you get all these side effects.' You know, that's an important perspective that has to be taken into account. I would say that patients or service-user organisations are absolutely key stakeholders." Mental Health charity

3. Understanding of the process

Patient organisations had a good understanding of the TA process

Engaged patient organisations did feel they had a good understanding of the TA process, which was also reflected in the views of Chairs, Associate Directors, and Project Managers. Unlike patient experts, patient organisations have a role throughout the process. This role is to elicit views from the wider population and consider the context of the national policy.

Patient organisations not engaged in the TA had limited understanding of the process but were unanimous on the importance of incorporating the patient voice into TA decisions.

Patient experts tended to report that they fully understood what was expected of them

Most (27 out of 36) patient experts reported fully understanding what was expected of them in their role. However, they were not explicitly asked to explain what they thought their role entailed so it is not clear whether their understanding matches that of internal stakeholders.

Chairs, Associate Directors and Project Managers felt that generally patient experts had a good understanding of the overall process and their role, but some said that this was not necessarily the same for everyone.

Internal stakeholders felt that patient experts who had been involved in the process for multiple topics tended to have a better understanding of what was expected. However, patient experts who have taken part in the development of other NICE guidelines, such as Clinical Guidelines or Public Health guidance, can sometimes get confused about the different processes and their role. This suggests a need for further clarity about the role so there is a consistent understanding and application across all committees.

Internal stakeholders also discussed that patient experts from a patient organisation can sometimes assume the role of advocate: *"they are laypeople mostly and they feel they are*

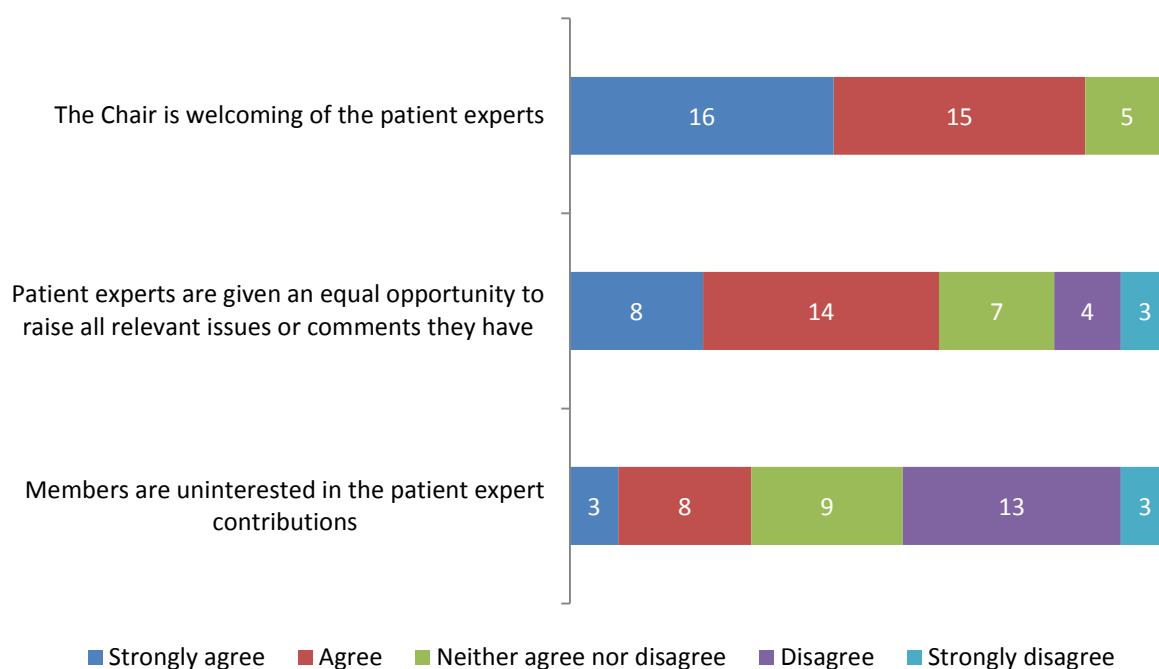
advocates”. However, advocacy is not a role that NICE looks to the patient experts to deliver; an expert is expected to provide more detailed information to help the committee make its decision. Again this points to the need for clarity about the role so that patient experts are clear about what is expected of them and ensures that there is consistency in the approach.

4. Experience of the process

A warm welcome received, although some concerns from experts about the value of their contributions

Patient experts stated that the Chair was welcoming of them on the day of the committee (31 out of 36 agreed). 22 out of 36 experts felt that they were given an equal opportunity to raise all the relevant issues and comments they had, although 7 disagreed with the statement. 11 out of 36 also felt that members were uninterested in the contribution of patient experts.

Figure 3: Experience of patient experts on day of committee



5. Perceptions of the TA process

Positivity about the overall process

Overall experience of the TA process appeared to be positive, with almost three quarter of respondents (38 out of 58)¹ rating it as good or excellent. One patient expert commented: *“I fully enjoyed/appreciated getting involved and being able to offer my knowledge and experience as someone living with [condition]. I would be very happy to offer my services in the future”*.

Some scepticism over the extent to which patient opinion is genuinely taken into account

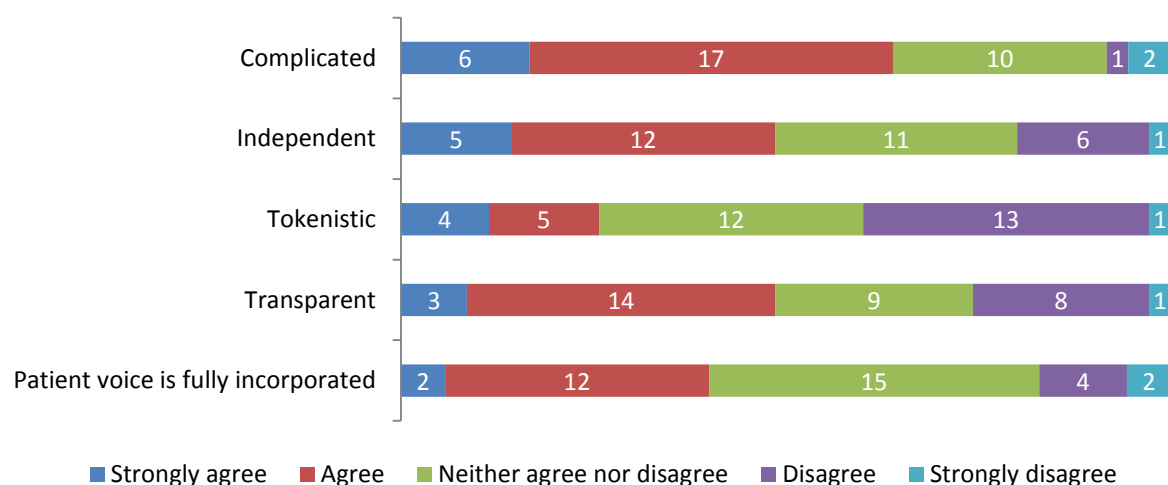
Despite this overall positivity about the process, there was some scepticism about the extent to which patient opinion is genuinely taken into account.

“Mostly I have felt included in the process. But, unsure how much the patient opinion is taken into account in the process.” Patient expert

On the whole, patient experts felt the committees’ decisions are based on the best available evidence but there are mixed opinions from the patient organisations.

“I do think they are actually trying, but I don’t know whether, at the end of the day their job is more on the financial side than it is on the patients’ side.” Cancer charity

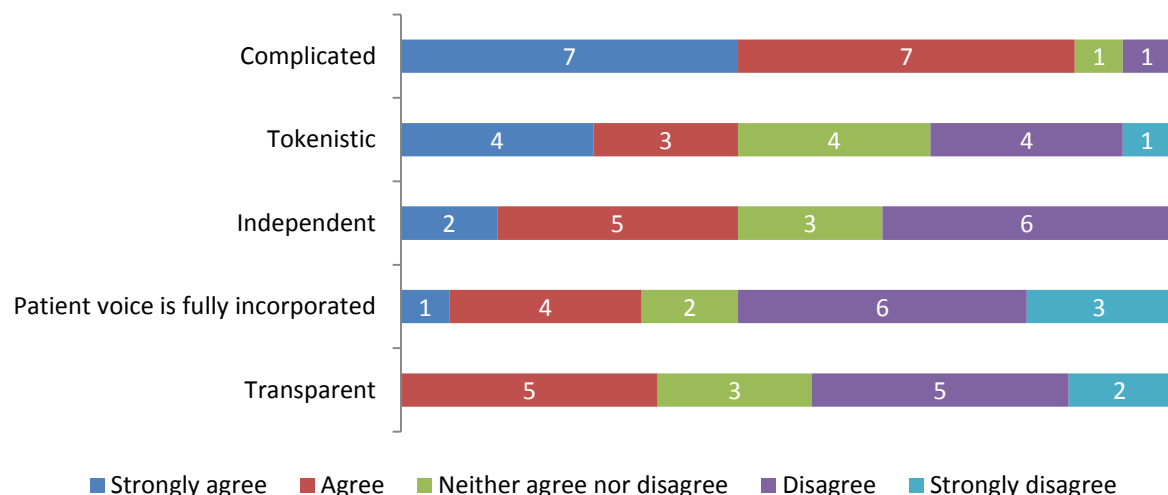
Figure 4: Perceptions of TA process - patient experts²



¹ Patient expert and patient organisation survey responses combined

Among other engaged patient organisations, while many are convinced that the patient voice is already incorporated into the TA process, there was a small number who expressed cynicism over the inclusion of the patient voice, suggesting that there may be an element of tokenism involved. Some of this appears to originate from the belief that NICE's main priorities are clinical and cost effectiveness, making the user experience secondary.

Figure 5: Perceptions of TA process - patient organisations²



Organisations not engaged in the process are unsure about the impact that patient organisations' involvement actually has on the final outcome.

A feeling for some that cost comes before clinical effectiveness and patient outcomes

13 out of 16 patient organisations and 19 out of 35 patient experts felt that the TA committee focuses on cost before clinical effectiveness and patient outcomes. From NICE's perspective, they would like patient organisations to provide more comment on cost effectiveness, but this is something that rarely happens.

"Our concerns are for the patient, NICE's concerns are for the cost. The committee has far too many 'experts' who know nothing about the disease needing the new drug." Patient organisation

² Note that numbers are used in the chart and not percentages

Committee meetings can be a daunting experience

Attending the committee meeting is generally considered a daunting experience for patient (12 out of 16 patient organisations, 20 out of 36 patient experts agreed). For some this may constitute a barrier for future engagement in the process.

A need for greater transparency around decision-making

There was some disagreement about the transparency of the process (9 out of 35 patient experts and 7 out of 15 patient organisations disagreed or were unsure that the process was transparent). Some of the issues regarding transparency relate to the decision-making process.

“I have a generally favourable impression of NICE but there are occasions when the organisation hides behind a dark curtain on some decisions. That brings unfavourable comments from all quarters.” Patient organisation

“Possibly more information on who the parties are who will make the final decision, also a simplified description of how they will make that decision.” Patient expert

Support from PIP was well received

Generally the survey respondents were positive about their experience of working with PIP. One respondent commented *“They are really helpful. An invaluable source of assistance.”* and another said *“Extremely professional staff, highly recommend working with Heidi and Lizzie.”*

The majority of patient experts felt they had the right level of support from PIP on the day of the committee. However, several people commented that they would like more support before the committee meeting (4 respondents) or once the draft guidance was released for consultation (6 respondents). This largely links to the point about the large amount of technical information which some respondents struggled to read and digest.

6. Internal perceptions of the process

Importance of relationship management

As well as the hands-on support they provide to patient experts, PIP felt they have a role of ongoing relationship management with patient organisations. This can be particularly important when an organisation does not consider the TA decision to be favourable.

Importance of consistency in approach to how patient evidence is heard and incorporated into the process

Chairs feel their role is to welcome the experts personally, include them in discussions and allow them time to share their views at the end of the meeting. One Chair talked about how they all had different styles of engaging experts but were all effective. This was seen as a challenge for NICE as it is important that the style of the Chair does not impact on the outcome of the TA:

“I think we all end up being quite effective but we really do have different styles and that’s a challenge for NICE because they don’t want completely divergent decisions.” Committee Chair

PIP also talked about how the different styles of the Chairs leads to variability in how patient evidence is incorporated across TA topics:

“The Chair and the attitude of the Chair towards the patient evidence and patient experts is paramount in how involved those experts are in committee and how many questions they get asked and things. And this is an area we’re hoping to strengthen in the coming months and we had a meeting about it just yesterday to ensure that there is consistency of buy in from the Chairs.” PIP

7. Facilitators to engagement

This section covers the facilitators to engagement in the TA process identified, in the most part, by the internal participants. The external participants were not explicitly asked about this but several points were identified through open ended comments.

Primarily NICE is considered a world leader at patient engagement

The process enables patients and advocates to become involved throughout the TA process, treats patients and professional groups equally, and allows patients to appeal the committee’s final decision.

Support and guidance provided by PIP as a dedicated resource for patients

Patient experts and patient organisations commented on the invaluable support they received from PIP and the TA administrative staff.

“With the patient experts, PIP would normally be quite involved with them. Whether we develop a sort of personal relationship with the organisations depends just I guess on how things go. I mean maybe if an organisation has questions that they want addressed, you know, and they’re not sure about some point of process then we’ll very happily speak to them.” Project Manager

A positive and beneficial experience for participants

The committee meetings are an opportunity to meet with clinical experts in the field and this enables patient experts and organisations to broaden their networks.

Patient experts also felt that their involvement in the TA process was an interesting and valuable experience.

“Being a Patient Expert gave me confidence and a better understanding of how the process worked and enabled to think how my input could make a difference to hundreds of people not just myself.” Patient Expert

8. Communications

The need for clear and relevant communications

Email is the primary means of contact with NICE for many organisations. Many participants indicated that they receive a large volume of emails from NICE, which was valued as a source of important information but few find time to read each email in detail, particularly if it is not immediately clear whether the information will be relevant:

“If I look in my inbox, there are at least eight different consultations or opportunities to engage with NICE, and NICE could only be one drop in the ocean of the various number of things that we would hope to do or expect to do by the people we represent.” Public Health charity

Other patient organisations not engaged in TA discussed using NICE’s website to access key products. Many find it difficult to find the information they are looking for and describe it as not user-friendly. There are also concerns that it would be inaccessible for members of the general public.

9. Improvements and recommendations

Figure 6 summarises suggestions from the patient experts and patient organisations (engaged and not engaged with TA) on how the TA process could be improved.

Figure 6: Suggested improvements to the TA process

Improvement	Suggested by
Patient friendly communication including simplifying forms and the language used in paperwork and by the committee	All
Clarification on the process explaining how patient evidence influences the final decision	All
Involving patients throughout the process	Patient Organisations
Providing support to complete relevant forms	Patient Organisations
Hold all meetings in public to improve transparency	Patient Organisations
Changing the makeup of the committee for example by making it smaller and involving more patients	Patient Experts
Publicise 'lower resource' options for participation (e.g. only being involved in one or two stages of the Appraisal)	Not engaged patient organisations
Minimise the amount of travel required by patient organisation representatives and consider the use of dial-in and Skype-in facilities	Not engaged patient organisations
Clarify the eligibility criteria and the use of declaration of interests	Not engaged patient organisations
Consider facilitating relationships between patient organisations and relevant clinical experts to enable them to submit evidence	Not engaged patient organisations
Investigate the notion of the 'translation step' from patient language into professional language so that the patient evidence is presented in a way that will stand up to scrutiny of the professional committee	Not engaged patient organisations

Recommendations

This section summarises the key recommendations that would help to address the identified barriers:

- **More targeted NICE wide communication:** Currently patient organisations receive multiple emails from different channels, due to time pressures they often cannot read these in detail and therefore miss relevant information. Need to raise awareness of appropriate opportunities for patient organisations to get involved.
- **Explanation and clarification of the role:** Clarify the TA process and the role of the patient expert and patient organisation as well as what is expected of them. This could build on the support material already produced by PIP (e.g. hints and tips)

- ***Reaffirmation of role and expectations of patient experts and organisations:***
Chairs and committee members to be more directive about what evidence is not useful in the committee meeting.
- ***Improve transparency and feedback to aid in reaffirming role and expectations of patient experts and organisations:*** Create a feedback loop to patient experts and patient organisations at the end of the process. This could involve providing more detailed feedback separately about which elements of their evidence was useful and how it was used by the committee.
- ***Improve transparency in decision-making process:*** Explain in lay terms how NICE uses the principles of cost effectiveness in its decision making, perhaps using visuals to make the information more accessible.