National Institute for Health and Care Excellence

Technology Appraisal Patient Expert Survey 2012 Report

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Public Involvement Programme

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Table of Contents

Recommendations

- The action plan is published separately.

Appendix

- The questionnaire

Introduction

The aim of this survey was to find out from patient experts about their experience in NICE technology appraisals. It was designed both as a stand-alone evaluation and also as a follow-on from an earlier survey with patient experts in 2006-2007 so that we could additionally look at the trends and progress between the two surveys. This document presents the results and recommendations from the second survey only. It is intended that a separate document will compare the two surveys.

The recommendations from this survey will inform improvements to how we support patient experts and inform the design of an exit questionnaire for patient experts, to continually monitor improvements and issues.

Executive summary

We based the questions on the 2006-2007 survey, editing it to make it easier to complete online via Survey Monkey. The methodology was largely determined by the 2006-2007 survey; we used a questionnaire based on the original one from 2006-2007 and used an equivalent time period and sample size. We sent the questionnaire to 62 patient experts who had attended committee meetings over a retrospective 18 month period in 2010-2011.

We had a high response rate of 78%, with 73% completing the whole questionnaire.

Two thirds of our patient expert sample had attended more than one technology appraisal and thus felt more confident when contributing. Those with personal experience of a condition, who do not work for a patient or carer organisation, tended to correspond with the percentage of people who came to only one technology appraisal meeting.

Patient experts' experiences vary widely from patient to patient, from topic to topic, and according to how much prior experience they had had at committee.

They felt well supported by PIP in their preparation for committee, however they felt that they would like more help understanding their role at committee.

The majority found the information sent out to patient experts before the meeting easy to understand and informative, however some said that the forms were less clear and helpful. A major area they wanted more help with was completing their personal statement.

A recurrent theme in the survey was that the role of the Committee Chair was key to the patient experts' level of participation. However, there was a lack of clarity about the role of the lead lay member.

Many found the committee meetings daunting although most of them said they felt welcomed. They thought the meetings to be very large, formal and with a lot technical language, and that the emphasis on the clinical and cost effectiveness overshadowed patient issues. Only 40% understood the slide presentations and could follow and participate in the discussions. Fewer than half thought that the patient issues were represented in the slides and nearly a quarter felt that they could not raise all the issues that they thought were relevant to the committee meeting.

Being able to raise relevant issues at committee is of paramount importance to patient experts. A combination of factors would seem to contribute to patient experts not feeling that they can do this: they were not sufficiently sure of or confident in their role; they felt intimiated at the meetings; and some had difficulty following the slide presentations and discussions.

Three quarters of the patient experts said that their overall experience of the committee meeting was excellent or good, however there were comments that the patients' presence was 'tokenistic' and that the patient experience has little to do with the committee's overall determination.

Most received copies of the draft guidance and knew that they could comment on it. A high number understood some or most of the guidance, and over two thirds felt that it addressed the key patient issues and that their contribution made a difference.

Over a third of patient experts predicted the committee decision wrongly, primarily because they though the committee would say 'no' when most decisions were positive.

The most negative results of the survey were unrelated to the appraisal development and arose instead from expenses, in particular the electronic expenses system.

A third of patient experts found the electronic expenses system hard to use. A quarter of patient experts never use it, with some of them having found it so hard to use that they were put off ever trying again. A number of those who used or tried to use the system needed help from Finance, PIP or the committee administrators.

Only half the patient experts were aware that they can use a paper claim form if they have problems with the electronic expenses system. Patient experts also find the expenses policy difficult to understand. Only the minority found the online system very good.

The conclusions are presented as themes which grouped under headings:

- What is going going well
- What could be improved

The recommendations are presented in the action plan.

Method

Methodology

We used a survey based on the original questionnaire for the 2008 study which had been emailed to participants as a Word document, with one or two exceptions who needed other formats. This survey was predominantly online, via Survey Monkey, but also had the option of phone calls or paper copies depending on a participant's preferences and needs.

Population size and timeframe

For both surveys we took a retrospective 18 month sample of patient experts to give us a comparable sample in both in time period and number of experts. For this second survey the time period was from July 2010 to December 2011 and included 62 patient experts. This timeframe spanned a change in project managers in PIP and a comparison between the support given by each was not intended, but we were aware that it had the potential to affect results.

Survey design

In order to compare the findings, we used the original survey as a basis and updated it so that it would be appropriate as an online questionnaire. We also included two new sections, one on patient expert expenses and the second was the final section on patient expert priorities. We included the section on expenses because this kept being reported to us by patient experts as a problem and we wanted to explore the issue in a more quantifiable way. We added the patient expert priority question to cross-refer it to the first part of the questionnaire, so that we could focus on our resources on the higher priority issues that needed improvement.

Survey delivery

We sent the questionnaire out to 62 people who had attended any technology appraisal committee meeting during an 18 month period between July 2010 and December 2011. We chose an 18 month retrospective period to match the period of the phase 1 survey conducted in from May 2006 to October 2007 which was also an 18 month retrospective period and had a similar number of recipients (n61).

All the responses were via Survey Monkey, except for the two patient experts with visual impairments who had the survey read out to them over the phone by an independent interviewer, who entered the responses into Survey Monkey on their behalf.

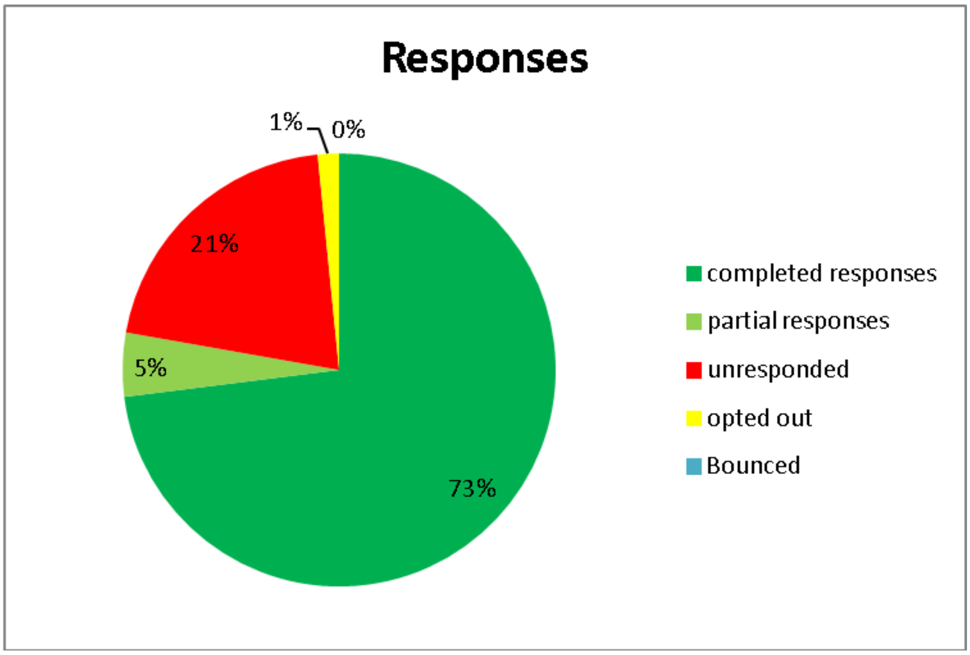
The patient experts were divided into two groups, the first with the previous project manager (Lizzie Amis) in post whilst they were experts and the second when the next project manager (Heidi Livingstone) had taken up the post. Both groups received identical emails via Survey Monkey inviting them to participate, but from the different individuals that had supported them as patient experts. Those who didn't respond were sent reminders via Survey

Monkey, again from the original project managers and then a remaining 6 received an individual email directly from the relevant project manager. This was in keeping with the original 2006-2007 survey.

Findings

Response rate

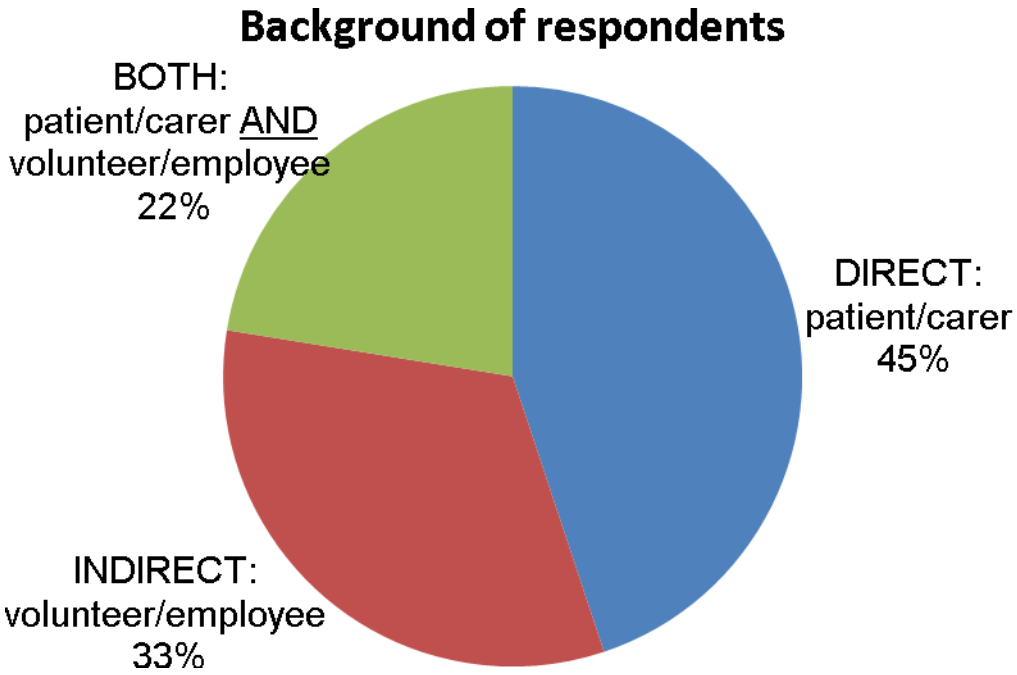
We had a 78% response rate, with 73% of respondents completing the whole survey.



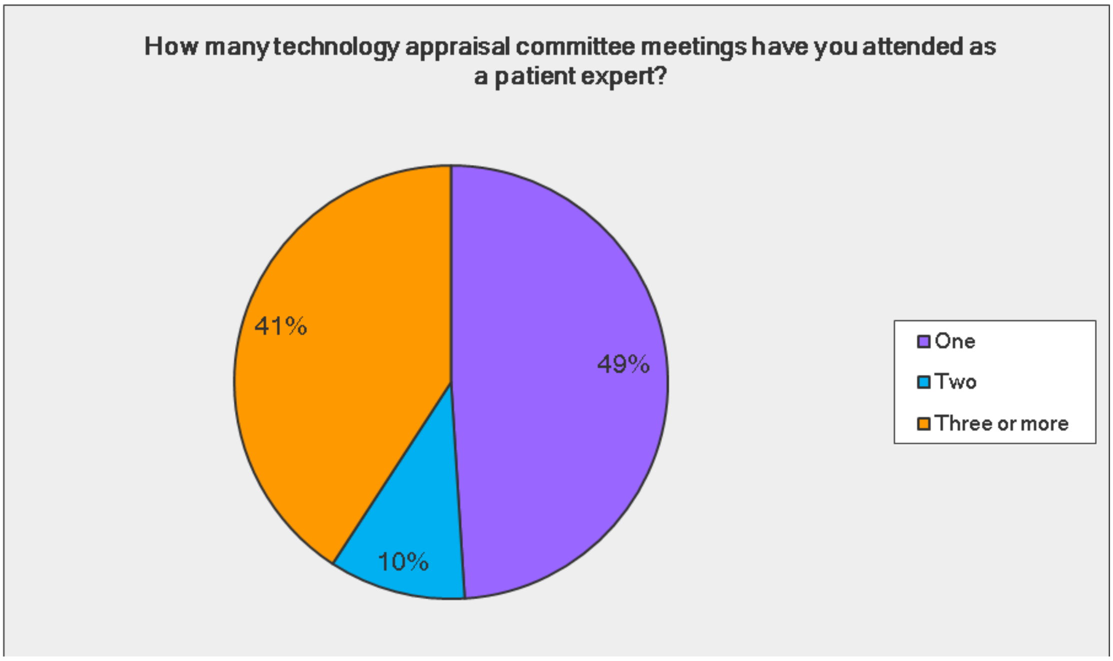
Information about the respondents

About two thirds (67%) of respondents were patients or carers with direct (personal) experience of the condition for which the technology was being appraised. Of this group, two thirds (45% of all respondents) were patients or carers who did not work for a patient or carer organisation, and one third (22% of all respondents) had personal experience and also worked for a patient carer organisation.

The remaining third (33%) were either volunteers or employees of patient and carer organisations.



From the results of this survey, patient experts fall within two main groups; those who come to one committee meeting (41%) and those who come three or more meetings (49%). Only10% had been to two meetings. Without a follow up survey of the 10% it is not possible to say whether that 10% will come back for further meetings and join the larger group of repeat attendees.



We did not ask how many respondents had personal experience of the particular technology being appraised.

Summary

Patient experts have a tendency to come to more than one technology appraisal topic, particularly those who work at, or volunteer for, a patient organisation.

There seems to be a correlation between people who have direct personal experience of a condition and who came to one TA committee meeting. Without follow up, it is not possible to say whether this is because they also have direct experience of the particular technology being appraised and would, thus, be slightly less likely to come back to appraisals which were on the same condition, but a different technology.

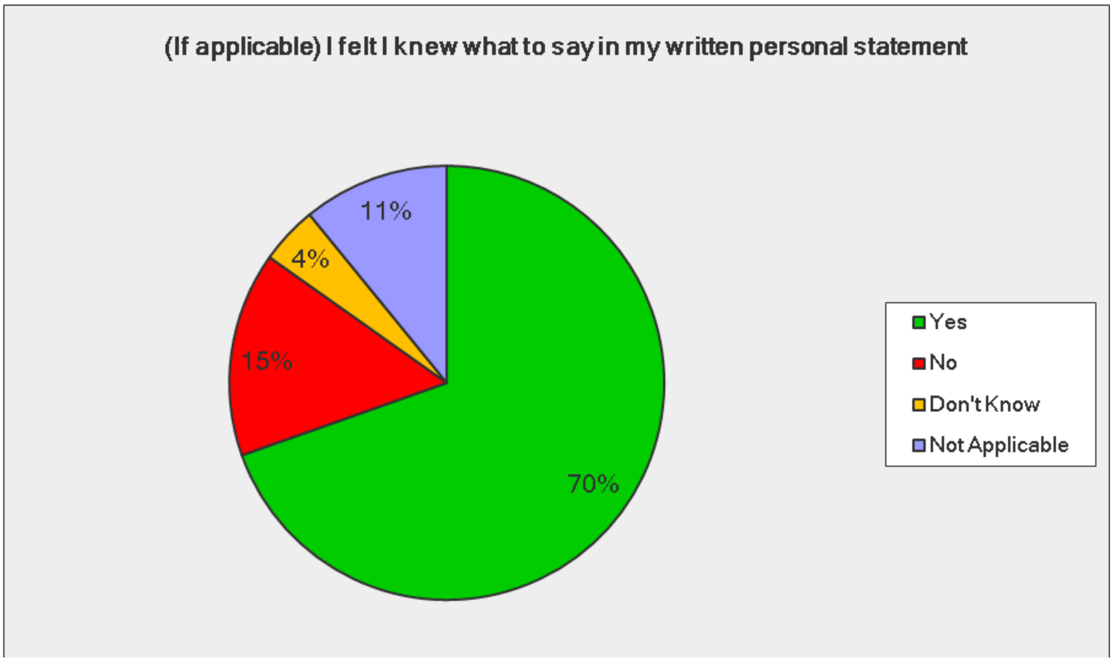
Written information before the meeting

Nearly 90% of people found the letter inviting them to be a patient expert both easy to understand and informative, and this figure dropped only slightly for the 'hint and tips on being a patient expert document'. People found the latter easy to understand, but slightly less informative. The comments received about the hints and tips said that some people did not remember receiving it, sometimes due to the amount of paperwork received from NICE.

> *"Some of the questions on the response form seeking comments on the technology being appraised are daunting. I think for anyone interested in becoming part of a NICE review, basic training / induction, should be available - perhaps an on-line course to keep costs to a minimum, explaining (i) what NICE is seeking to understand from you (ii) what insight is helpful to the NICE committee (iii) what to expect at the meeting - which is very daunting!"*
>
> *"too many papers sent at the same time timescales were not made clear"*

The forms were slightly less easy to understand (80%) and informative (78%) whilst people wanted most help with understanding what was needed from the patient expert personal statement.

> *"Prior to participating as a patient expert, I had been dealing with many NICE forms and procedures - I had therefore got very used to the NICE terminology. However, from experience with our first patient expert, I know that these forms were quite difficult to understand for him - and I had to guide him through the process."*
>
> *"I'm not sure I received guidance on the personal statement. I took an example from [a patient organisation] as my guide."*
>
> *"The personal statement's objectives are not clear. I had to learn by experience that the purpose was to elicit my emotional as well my physical response to my illness"*



Even somebody who answered that the personal statement was not difficult to fill in then added the comment:

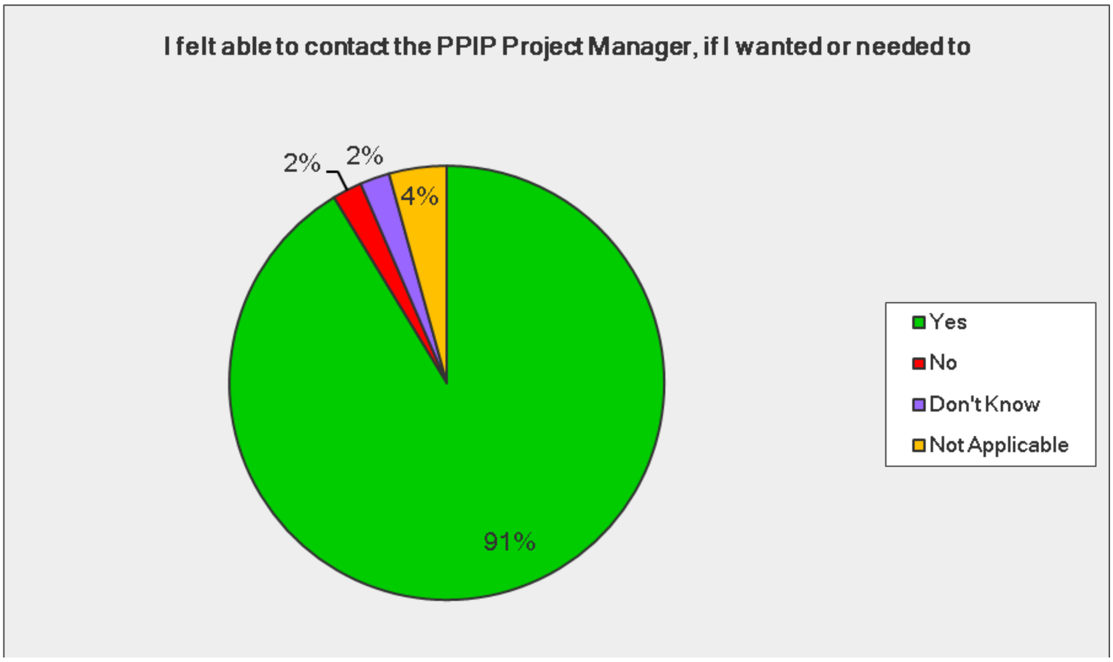
> *“Although "Yes" has been answered, I feel there is still room for improvement/clarification, particularly in the case of the personal statements.”*

Summary

The majority of people found the information sent out to them before the meeting easy to understand and informative. However the forms were less clear and helpful; there were too many and they found the different timescales confusing. 15% of those asked wanted more help with completing the personal statements.

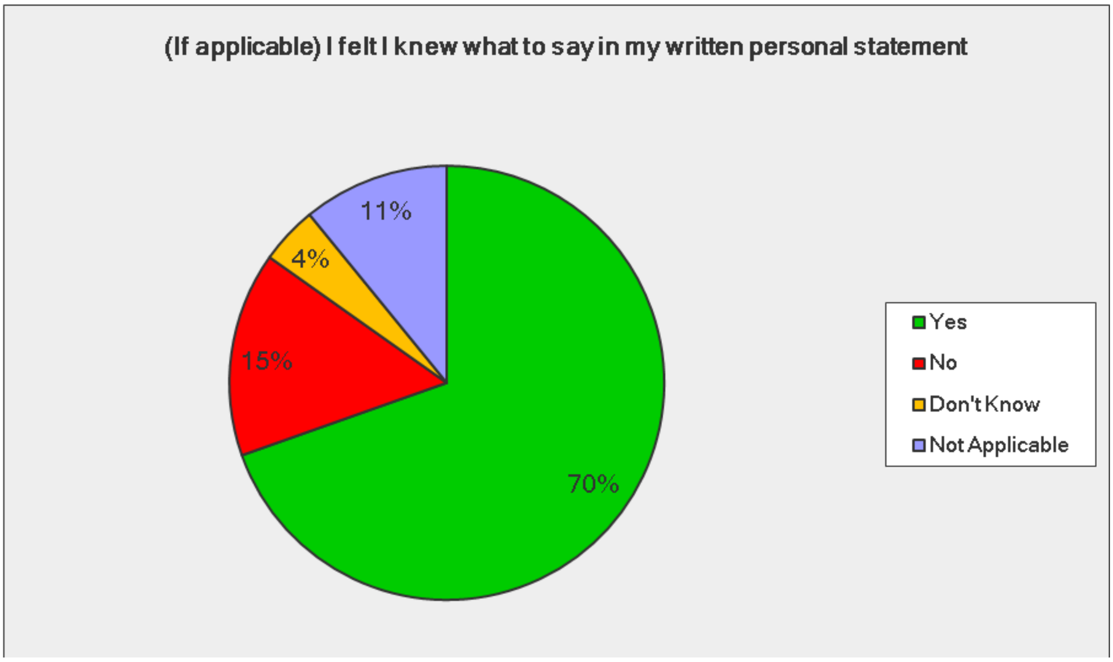
Information and support before the day - provided by the Patient and Public Involvement Programme

Around 90% of patient experts said that they were contacted by the PPIP project manager in enough time to help them prepare for the meeting and that they could contact her if they wanted to (91%) whilst 26% felt they didn't need to contact her. Only 4% (n2) found it difficult to contact her.



Slightly less positive was that despite the contact, just 83% felt they had been given an explanation of their role at committee, and as earlier, 15% of people felt that they did not know what to put in their personal statements.

> *"I only felt that I knew what to say in my written statement because I work for an organisation that is NICE savvy and has in house research expertise."*
>
> *"Took my guidance on personal statement from [a patient organisation] rather than PPIP manager"*



Several people commented that they received help on their personal statements from their nominating organisations rather than the PPIP project manager.

> *"Most of my dealing we're[sic] through [nominating patient organisation] and it was them who contacted me and I knew that I could contact them at any time."*

Summary

The patient experts felt well supported by PPIP in their preparation for committee and that the project manager was approachable, however they felt that they would like more help understanding their role at committee and in particular with completing their personal statement. Help with the personal statement often comes from the nominating organisation; PPIP encourages this as the nominating organisations have the specific knowledge around the particular condition and technology.

Support on the day

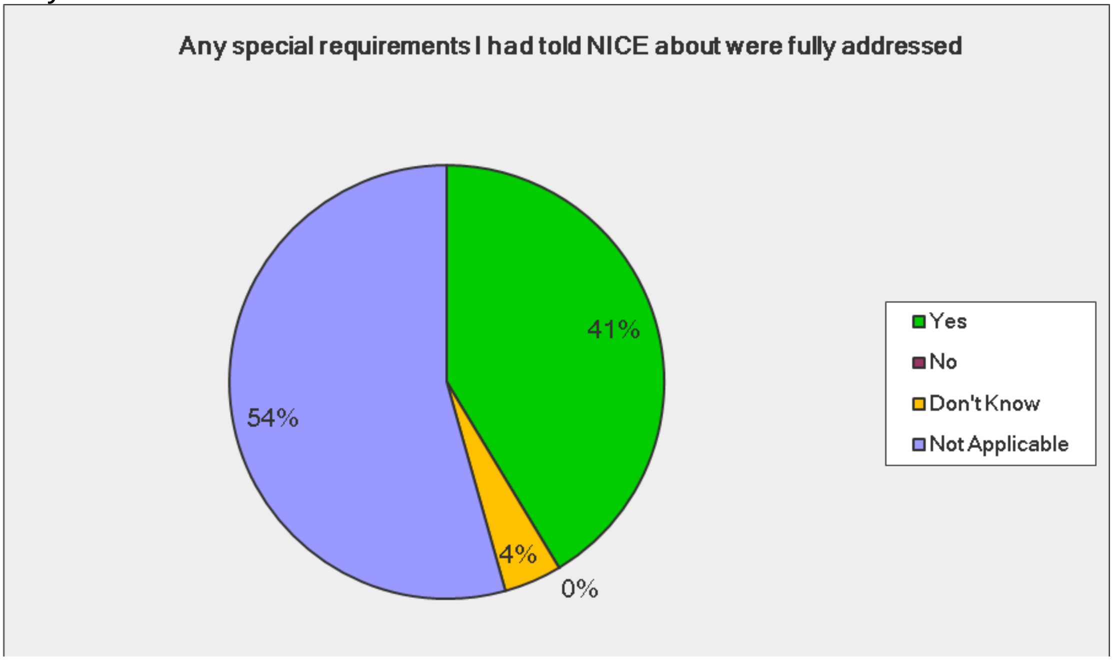
Everybody was greeted by a member of NICE staff on the day. All except 13% of patient experts were introduced to the chair, with over half of them meeting before the meeting. Some of the 13% could well be due to the fact that some patient experts had been to previous meetings.

> *"The Chair of the committee came up to me afterwards but I wasn't formally introduced."*
>
> *"I know the Chairs and familiar with the process"*
>
> *"Not sure if I met the chair, was introduced to so many people and it is difficult because of my eyesight. I was a little shocked by how large the meeting was!"*

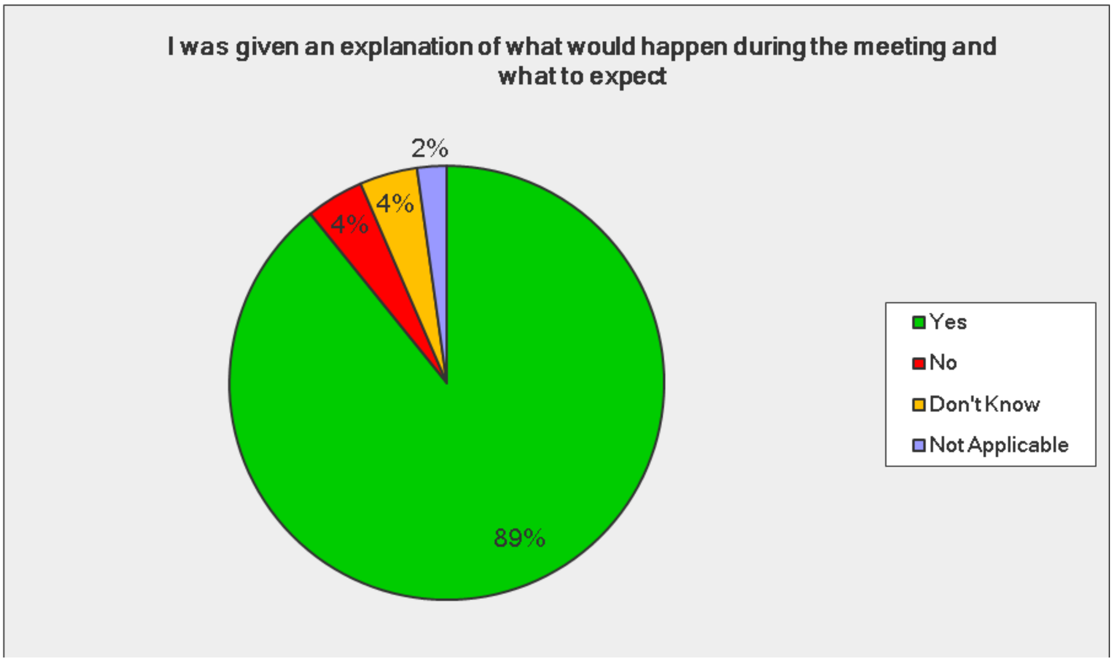
One attendee who has been a patient expert on several occasions found the PPIP support over attentive until she commented on it:

> *"It would be helpful to check with patient representatives whether they want to be met by the PPI team before the meeting. Certainly after having attended a couple of the meetings and being involved closely with NICE work I did not feel I needed to be met and felt it was slightly patronising (why would a patient representative need to be met but not a clinician giving evidence to the Committee for the first time...). Having said that, the PPI team responded very well when I raised this with them and did not insist on sending someone to meet me on future occasions."*

Over half the patient experts did not have any special requirements for the day, those that did said that they had been met, although two people said that they did not know.



Nearly 90% of patient experts said that they were given an explanation of what would happen at the committee.



However, more work needs to be done on explaining patient expert roles sufficiently and reiterating them before the meeting as well as explaining the role of patient experts at second or third meetings for the same topic.

> *"The whole process is quite daunting and I can imagine many patient experts being overwhelmed by the experience. It is worth repeating some instructions on the day."*
>
> *"Very brief explanation given as an over view and not enough to really be that helpful or accurate."*
>
> *"I was given an explanation for my attendance at the first meeting, but not the second or third. it also was not clear why the patient who attended the first meeting, was not needed for the second or third."*

Summary

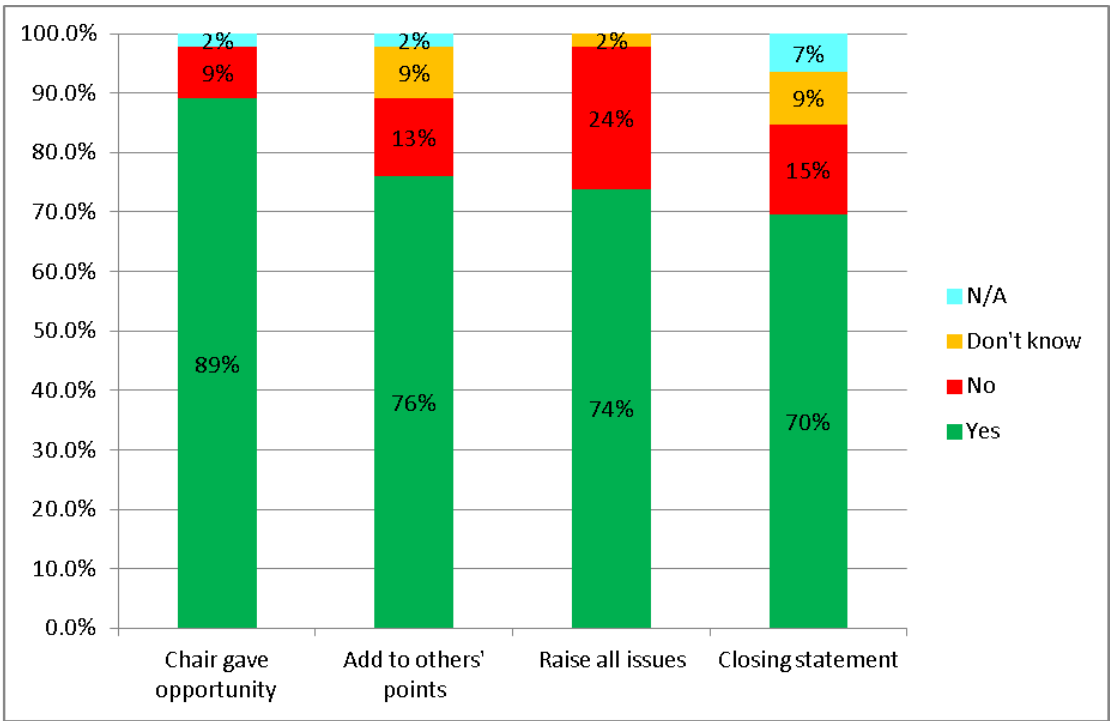
Everybody was greeted by a member of NICE staff on the day, most were introduced to the chair either formally or informally at some stage before or during the meeting, and nobody who identified themselves as having special requirements did not have them met.

The role of the patient expert is explained in the 'hints and tips' document sent to all patient experts attending a committee meeting for the first time, or those who have not been a patient expert for some time. The information is also repeated briefly over the telephone the week before the meeting. However, patient experts are saying that they need more information and that they would like to go through some of the key points again before the meeting, as the experience can be daunting.

The role of the patient expert at the second and third meeting is less clear. The PPIP team has started sending out brief information about the role of the patient expert in this meeting, but their attendance is less frequent and, possibly as a result, the information about their role more difficult to find.

Experiences during the committee meeting – the patient expert contribution

Nearly 90% of patient experts who responded said that the committee chair gave them opportunity to contribute to the discussion. They were less likely to feel confident to add to points which were raised by other people (76%) or to raise all the issues that they felt were relevant to the meeting (74%). 70% had the chance to make a closing statement.



Although statistically the feedback about the chairs involving the patient experts is good, some of the comments left show that the patient experts' opinions can vary from meeting to meeting and can be mixed.

> *"At one meeting (of three attended) the chair was not very interested in my contributions or that of the expert in that field. This was not the case at other meetings where I had a very good interrogation by the committee."*
>
> *"I was critically addressed by the chairman after I raised a critical note on the subject"*

It seems that as patient experts gain in experience, understanding and confidence in committee meetings increases their feeling that they can participate.

> *"My ability to participate fully in the discussions improved as I gained more experience of attending Appraisal Committee meetings. Many of the comments I made were not in response to a direct request from the Chair. I think that Chairs should be more aware of the need to involve patient representatives, and particularly patients who are present to*

> *talk about their experiences and may not have the confidence to contribute without being asked by the chair.”*

Some patient experts said how daunting the process can be.

> *“I was kindly given the opportunity to raise points but at times felt I had to grab them and interject, if I hadn't I don't think they would have been heard. I think the process could be daunting for patient witnesses who are perhaps shy in coming forward or for those with conditions that inhibit expression. I did not realise that the committee would consist of so many people who had no idea about [the condition] and its ramifications either for those with it or society in general.”*

> *“Was not happy with what people said at the meeting [...] The meeting was very structured and we could only speak when spoken to, the meeting is very daunting and it is hard to contribute when everyone else around the table is a professor/consultant. Only asked 1 or 2 questions during the discussion no closing comments.”*

Overall the patient experts seemed to feel less able to contribute if the chair did not involve them directly and feel less comfortable with contributing to the committee discussions unless they are asked to specifically.

> *“Although I was able to answer questions, I didn't feel that I was able to follow on with points made by others unless specifically asked to comment.”*

> *“The tenor of the meetings has always been very formal. I have never felt able to interject. If this is to be welcomed then it should be explicitly stated. As it was I have always felt that I am there to be interviewed and my perspective/experience elicited, not offered.”*

> *“Only at the end a lot was very technical and couldn’t understand some of it. The doctors know best and didn't feel like I could contribute. Thought that the manufacturer was selling their product in a strong way. Didn't feel like I had many issues to discuss.”*

> *“This is probably more about me than the process or the committee - I felt that whatever I might have to say might be viewed as irrelevant or not appropriate so I decided against.”*

Some patient experts overall experiences were quite negative.

> *“I had a very poor, disappointing and dissheartening [sic] experience at the 2ndACD - I expressed my concerns in a letter. In fairness to NICE, the letter was akcnowledged [sic] and I felt that my concerns had been addressed, but I remain concerned about the attitude adopted by committee members towards patient group representatives and their perceptions around the validity of the contribution we have to make.”*

> *“The meeting proceeded at a significant pace and a very complex and long presentation was given by the health economists team. Time precluded a discussion about the real impact of a negative appraisal on patients, and I still not convinced the appraisal committee understands the condition fully enough.”*

> *“The answers refer to the second appraisal I attended only. There was a marked difference in the patient expert involvement between the 2 appraisals (second was much improved). The debates were academic and not open to patients . I felt I was in the wrong meeting and patronised at the closing comments by my contribution which was listened to in silence . It is an intimidating experience”*

However, opinions vary between patient experts:

> *“The opinion of the patient expert is not always requested and not always taken into consideration.”*

And

> *“I was always made to feel very welcome and valued”*

Summary

Patient experts’ experiences vary widely from patient to patient, from topic to topic and depending on how much experience the patient experts have of the technology appraisal committee meetings. A number of patient experts find the committee meetings very large, formal and daunting and that patient issues are overshadowed by technical language and the emphasis on the clinical and cost effectiveness.

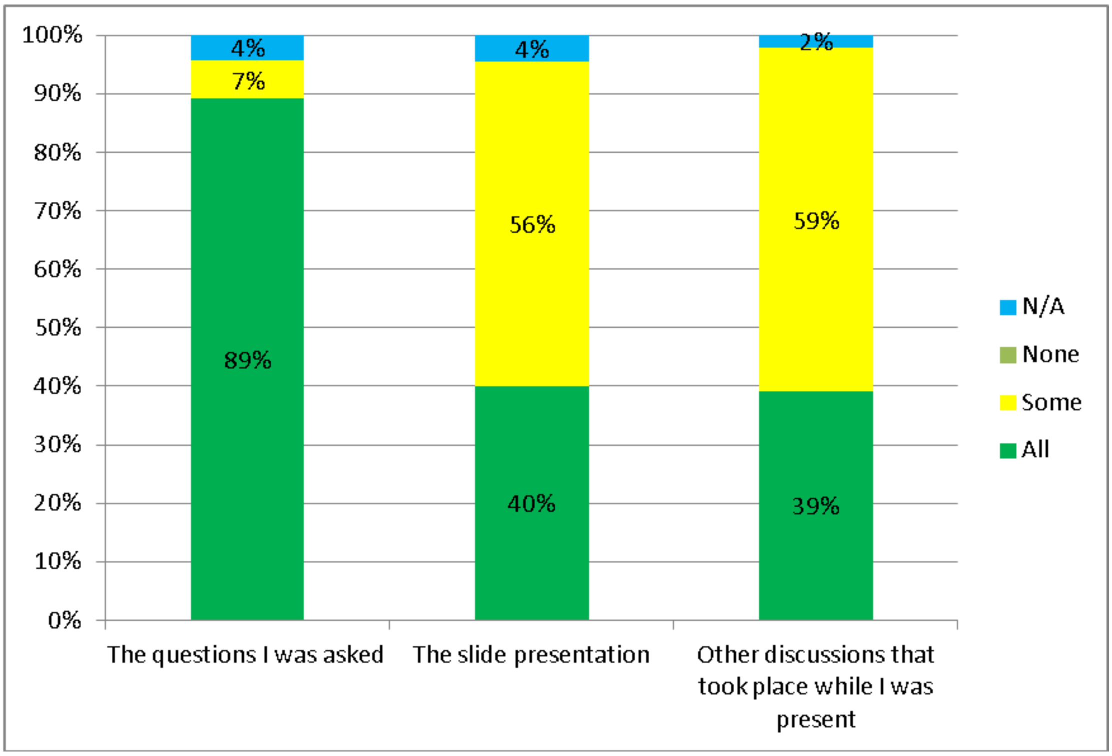
Most feel that their participation comes through the chair including them in the discussion (nearly 90%) rather than being able to participate directly in the discussion. This indicates that much of the patient contribution depends on the chair’s skill and diligence in including them. Nearly a quarter felt that they could not raise all the issues that they thought were relevant to the committee meeting.

The ability to make a closing statement can be the opportunity for those who do not feel that they have had the opportunity to raise key issues during the discussions to include their points, so it is interesting that the figures for these two aspects are broadly similar.

Experiences during the committee meeting - overall experience

Nearly 90% of the patient experts who responded said that they understood all the questions that they were asked, whilst the remainder said that they understood some of the questions or that the question was not applicable to them. Nobody said that they did not understand the questions they were asked.

However, patient experts found it much harder to understand the slide presentation and the other discussions that took place whilst they were present.

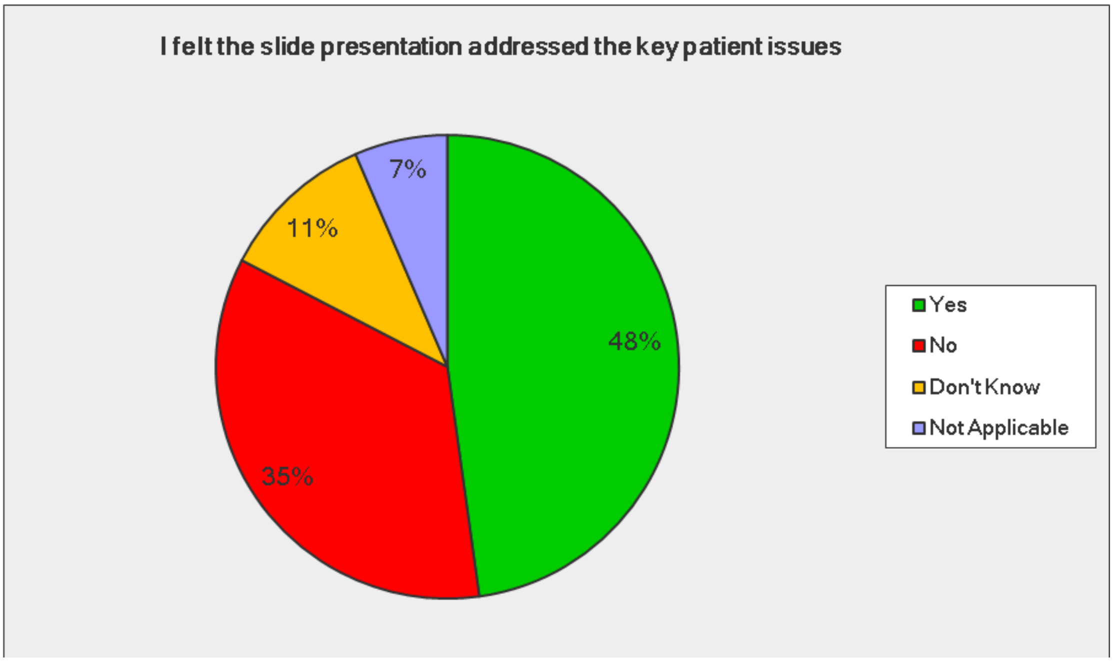


> *"Quite technical information with a lot of knowledge presumed - acceptable given the technical nature of the project."*

A couple of patient experts had suggestions for how the slide presentations could be improved.

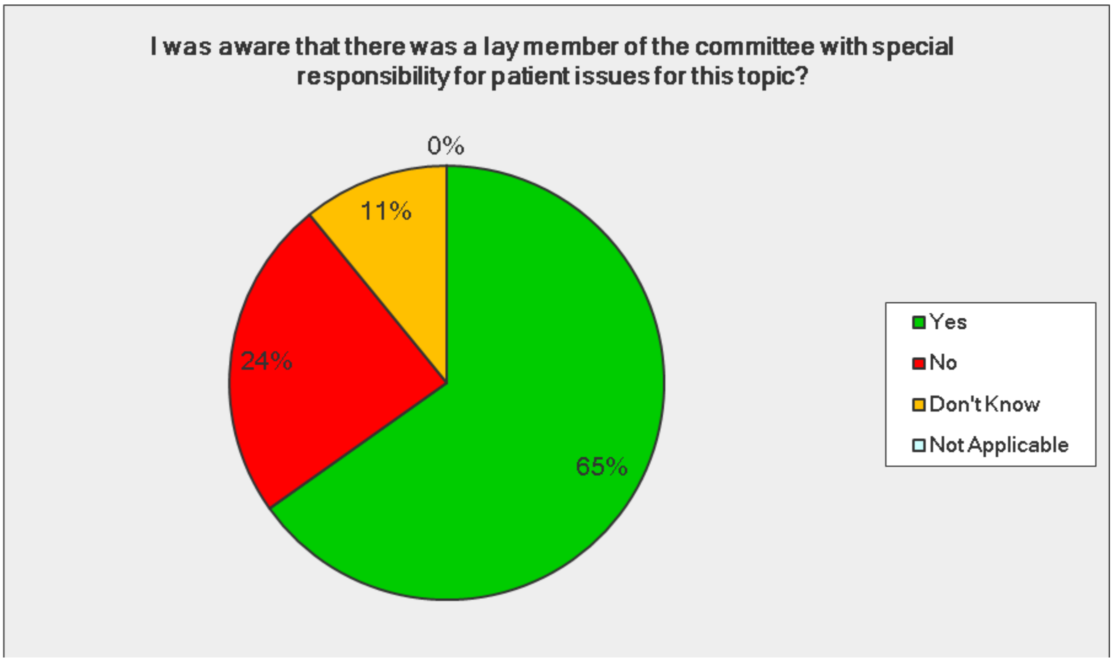
> *"Slide presentations are very lengthy and at times just read by the presenter. Should adapt complex statistical data to more visual graphics - pie charts and bar charts for alternative ways of formatting and illustrating information, wherever possible."*
>
> *"I did not understand all of the slides, I think a crib sheet of the terms and brief summary of the acronyms used by the ERG would be useful to decipher their information!"*

Not only did the patient experts find the slide presentation more difficult to understand, but also only just under half the patient experts (48%) thought that the slides addressed the key patient issues, with over a third (33%) saying that they thought they were not addressed.



> *"The slide presentation did not properly address patient needs and the reasons why one of the technologies appraised was more beneficial to some patients than others. This had to be explained by the clinical experts."*
>
> *"There was patient experience as far as goes side effects etc. however the patient experience is far more than this. My overriding feeling with NICE TAs is that it is hard science driven, and the wider patient issues have little consideration/value to the determination."*
>
> *"The cost effectiveness Committee 'lead team' member addressed issues that could not be described as 'key patient issues' but were rather (broadly) NHS resources issues. There are generally a large number of slides in his presentation. He is very capable but it is very difficult to follow given the time constraints. I doubt if anyone but the health economists can follow the detail. [My patient organisation] have some constructive suggestions as to how this problem might be addressed at a more general level."*

Only 65% of patient experts were aware that there is a lay member of the committee responsible for that particular appraisal topic.



The comments about the lay members and the lay lead role vary and show that there could be an improvement in awareness of and understanding of the lay members of the committee and the lay lead role.

> *“I introduced myself to the lay member by chance but still don't understand the role.”*
>
> *“I am aware that all appraisal committees have lay members but was unaware of the member(s) in question on this committee. They did not make themselves known to me in that capacity, neither was it apparent who they were by anything any member said during the course of the meeting/s.”*

About a quarter of patient experts do not know that there are lay lead members and do not understand the role.

> *“I had no idea a lay member was on the committee to look after patients' needs and that person never spoke. I do not know the his or her level of understanding of this condition or the heterogeneity of patients.”*

Where the lay lead role is recognised and the lay member engages with the patient expert, this seems to be postive.

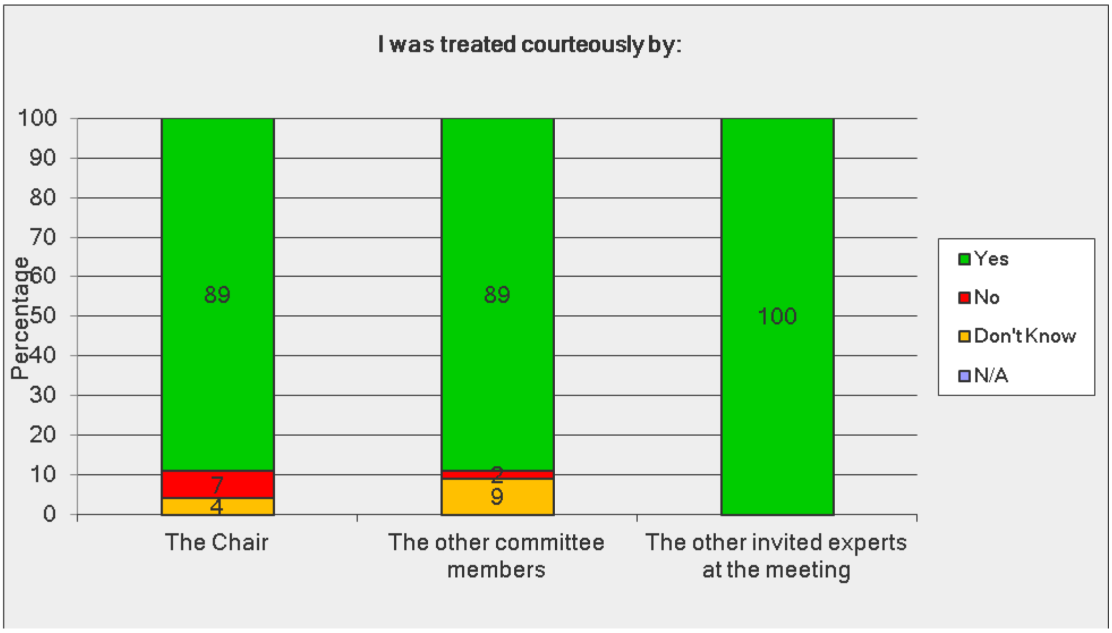
> *“The lay members of the committee (or one of the committees) were lovely, friendly and supportive. The others did not acknowledge the patient representatives.”*

Overall all the patient experts were treated courteously; all were treated courteously by the other patient experts and nearly 90% by the other committee members and the chairs.

> *"Everyone was very nice and helpful was very surprised by how well run and detailed the meeting was."*

Despite the courtesy shown, some were still daunted by the meeting.

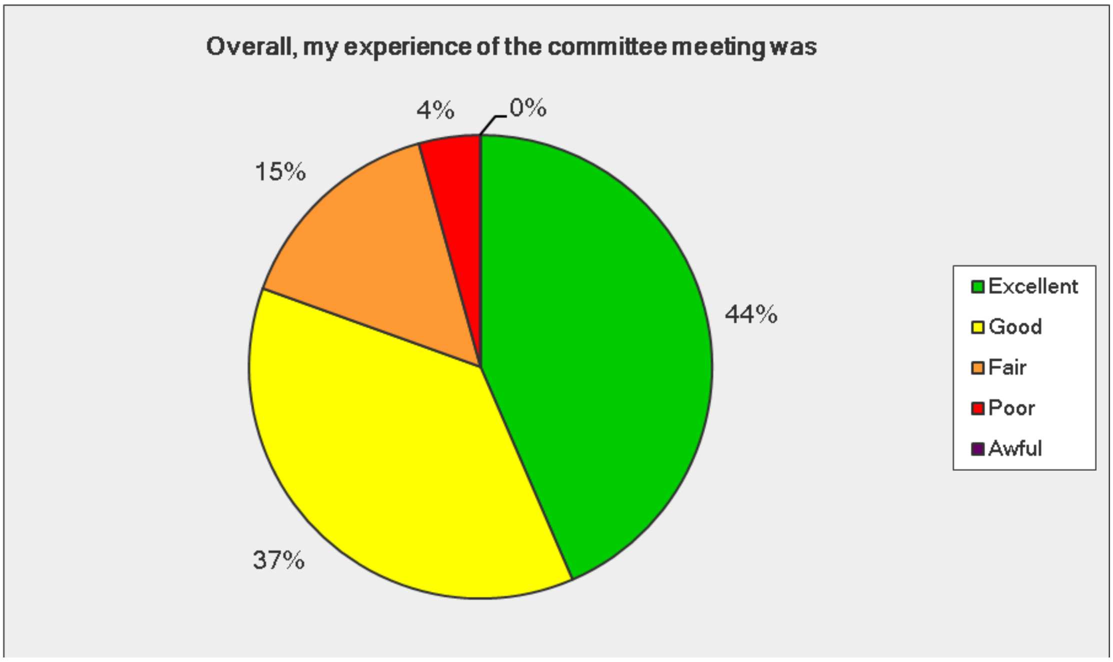
> *"Treated courteously but the meeting was very structured and this made it feel a bit formal. No one was rude but I felt that everyone else was an 'enemy."*



Some of the comments supplied expand on explain the three people's experience with their chairs.

> *"The chairman was not so nice to me after raising a point of criticism."*
>
> *"I have experienced tough Chairmen in business meetings but I found [name given] menacing. The attempts to set us at ease were laboured."*
>
> *"My letter to NICE goes into more detail. I also felt there was considerable confusion over the need for an additional meeting, and how this would impact on time scales. I also felt that some committee members had a less than positive attitude to the appraisal due to [aspect of previous topic in this condition]. Whilst I was treated with disrespect by the chair, I felt the other expert (clinician) was treated abominably and much of her expertise (which she was voluntarily offering up to the committee) was dismissed. This was done in a way that fundamentally questioned her approach to medical ethics."*

Despite the various issues with the finding the committee meetings daunting, and finding the slide presentation and the general discussions not particularly easy to follow, identify with or participate in, just over three quarters of the patient experts said that their experience of the committee meeting was excellent or good (37%, n17) and whilst two people said it was poor (4%), nobody said that it was awful.



A common thread, born out by the the fact that the slide presentations and general discussions are more difficult to follow and participate in is the technical knowledge and language required for the meeting overall.

> *"There was a great deal of technical back history material for a lay person to absorb before trying to make a valid contribution at this stage."*

The comments reflect that each topic and committee meeting can be different and regardless of the amount of preparation and information the meetings can still feel 'tense' and challenging for patient experts. It also seems that those already familiar with technology appraisals, which around half are, are likely to understand more and be less daunted.

> *"As I participated in three appraisal committee meetings in the given timeframe, and each of them were different, it is difficult to give an overall rating. Generally, I feel that the time spent on different aspects of the appraisal makes it difficult for patient representatives to have a 'good' experience of the meeting, in the sense that the majority of the meeting is (quite understandably) spent on efficacy and cost-effectiveness issues. I was able to follow most, but not all of the discussion, particularly the often detailed discussion of aspects of the health economic modelling. It is also difficult to have a good experience of a committee meeting when the atmosphere at the meeting is tense, the approach to the manufacturer is adversarial and it becomes clear that the Committee is not likely to recommend a treatment that I as representative of a patient organisations believe patients should have*

> *access to. This will have an impact on the assessment of my experience of the committee meeting even if I am treated in the most courteous way by everybody and have been received (and taken on board) all the necessary information prior to the meeting."*
>
> *"An inexperienced patient expert would find the whole process difficult. The lay members are often overruled and not taken seriously enough. The conversation is mostly spent on economic issues which very few people manage to follow correctly."*

Another criticism which is reflected is that some patient experts feel that their presence can sometimes seem tokenistic.

> *"Some meetings have been better than others. At some I would say 'fair' rather than good, due to feeling at times tokenistic."*

That the chair is key to the amount of patient participation is again brought out in this patient comment on their overall experience of the meeting.

> *"I also thought that patient input varied depending on the Chair. Each time I left a meeting I was more puzzled than when I had arrived as to what it was the Committee were really seeking!"*

One patient expert commented on the presence of a PCT (commissioning) expert:

> *"What was apparent was the vociferous opposition of a PCT representative on the committee to any recommendation that would have an impact on PCT budgets. I strongly object to their presence on committees given every PCT in England funds the NHS Solutions for Public Health initiative Commissioning Support Advisory Services including the PCT the Committee member represents. In our view he is conflicted."*

Summary

Just over three quarters of the patient experts said that their overall experience of the committee meeting was excellent or good. At least 90% of said that they were treated courteously by the committee and that they could answer all or some of the questions that they were asked. Despite this, there is considerable room for improvement; only about 40% said that they understood the slide presentations and could follow and participate in the discussions. Just under half thoughtt that the patient issues were represented in the slides.

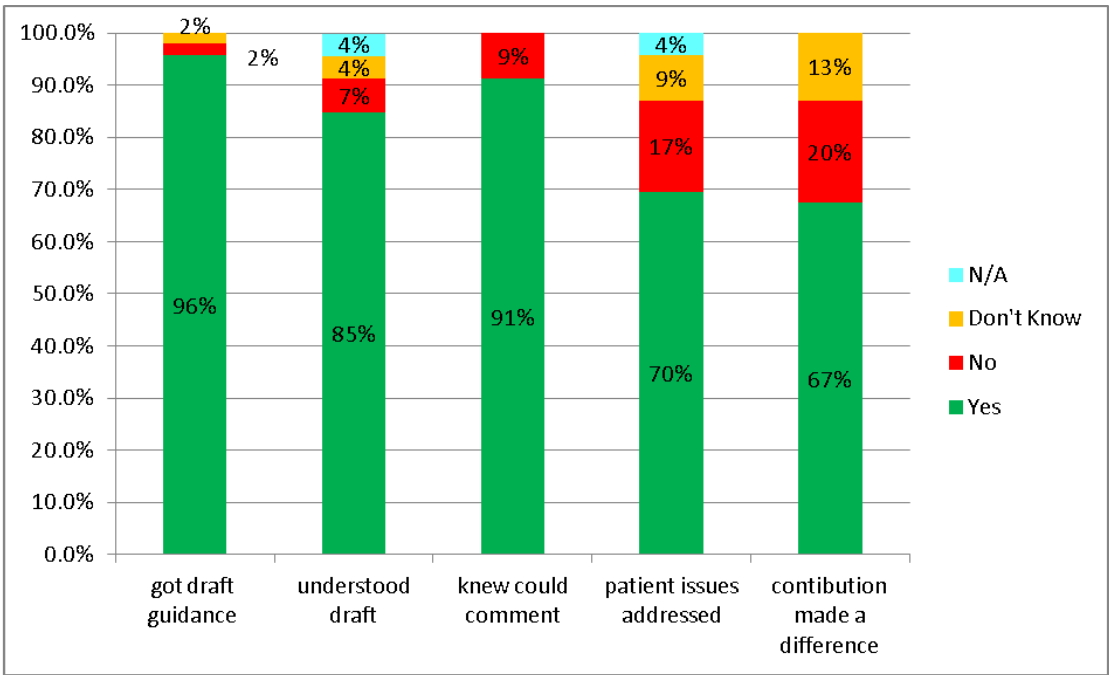
There were comments about the patients presence being 'tokenistic' and that the patient experience has little to do with the committee's overall determination. There was recognition that the patients input is now included in the ACD.

Again there was general feedback about how daunting the meetings are and the amount of technical language. Those who have attended committee meetings before and are familiar with technology appraisals are less likely to be daunted by the meeting.

It is again apparent how important the role of the chair is although three respondents had quite strong negative reactions to the chairing in their meeting. There were also comments about the manufacturers present and PCT representatives, although the comments might coincide whether they are in agreement with the patient view or not. Although 65% knew that there was a lead lay member responsible for their topic, there was a lack of clarity about what their role is.

After the meeting

Over 90% of patient experts recieved the draft guidance and knew that they could comment on it, and 85% felt they understood the guidance . Some of the patient experts who added comments explained that they understood either ‘some’ or ‘most’ of the draft guidance and not necessarily all.



70% felt of patient experts felt that patient issues were addressed in the draft guidance and comments that they added gave more insight into the variations in opinions.

> *“None of the guidance documents in my view demonstrate a detailed understanding of the variance of the condition and patients, and why the different technologies are necessary for different patients. This is not an easy condition to understand fully - it needs more time than I think the Committee has in reality to understand it.”*

> *“Key patient issues were not addressed in that the drug is not being rolled out as an alternative to [comparator] (to which it has shown to be more effective) which can impinge heavily on daily life and the ability to engage productively in work. Rather it has been made available as an option should treatment with [same comparator] prove ineffective. Which is better than nothing.”*

Other patient experts thought that although some of the key issues were addressed some still were not and point out what they see as the flaws regarding NICE’s methodology for including patient issues.

> *“Obviously some key patient issues were addressed but not all. I fail to understand how NICE can be a partner in an initiative like the Technology Strategy Board (TSB) 'Stratified Medicine Innovation Platform' which accepts that randomised clinical trial (RCT) evidence is not exhaustive, although not without value, whilst simultaneously elevating RCT evidence via inclusion/exclusion criteria, to be the sole clinical evidence on which economic models are built. The key patient issue is that clinically speaking not all patients, even though they have the same diagnosis, are the same. The modelling effectively shuts out evidence that might offer redress to that relied upon.”*

At slightly under 70%, the majority of patient experts felt that their contribution had made a difference. There are a number of views why patient experts were sceptical about how much difference they made, for example somebody again raised the issue of patients’ evidence agains the ‘objectivity’ for RCTs

> *“In this context my contribution makes no difference because it lacks 'objectivity' against the RCT evidence and patients, and all those except health economists, are effectively shut out of discussion of the cost effectiveness evidence.”*

Another felt that because they were asked limited questions, they could not have helped the committee very much.

> *“I felt that the limited questions I was asked could not have helped the committee at all.”*

Another view was that the written patient organisation submission was more likely to make a difference to the committee’s final decision than their oral input.

> *“I felt that our contribution as an organisation made a difference, however I do not believe that my oral contributions made any difference to the committees final decision. More importantly, it's impossible to determine from the FAD (which was over 50 pages long) what 'swung' the committee from a no decision to a yes decision. I felt that [name given] made a fantastic contribution to the meeting, but this was because of her strength of character and background in working*

> *with the media, that she was able to articulate her thoughts and opinions in such an intimidating and hostile environment."*

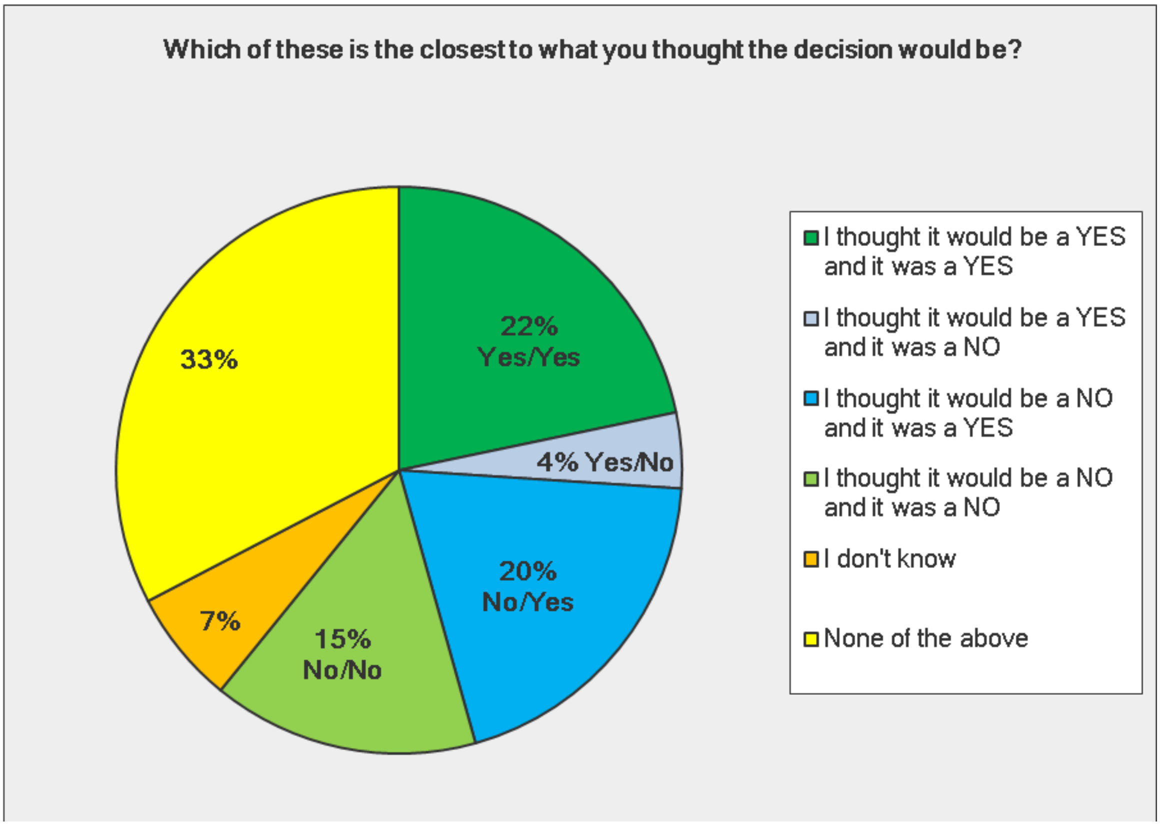
And again, there was the recurring theme that the patient role was seen as tokenistic.

> *"Having spent 10 years taking part in NICE appraisals, I believe NICE seeks the views patients and patient experts because it has to and because it has to be seen to, and that, while it is charming, respectful and polite to us, NICE does not give our views the weight that they deserve in making their decisions."*

However, there was a more pragmatic view:

> *"Attending three meeting it was inevitable that not all would meet our expectations."*

Patient experts were asked what they thought the decision would be in the guidance that was produced after their meeting. Over a third had the outcome they expect whilst around a quarter did not. The main reason for the difference is that more patient experts were expecting negative decisions than positive and this proved to be wrong (annually around 80% of technology appraisal guidance recommends use of the technologies). Around a third of the patient experts thought that the outcome would be negative – and more than half of those were wrong – whilst those who thought the outcome would be positive (around a quarter) where mainly right.



> *"I have attended six full meetings and two scope meetings. In the full meetings I felt it was (i) going to be 'no' and it was 'no' (ii) felt it was going to be a 'no' or very limited and it was a full 'yes' In the last one, I thought it was going to be 'yes' and it was... this was based on experience not the summary at the meeting!!"*

Although some patient experts unfortunately have attended appraisals where the outcome has always been a 'no'.

> *"As far as I recall it was a 'no' and I had expected a 'no' for two of the appraisals and a 'no' when I had expected a 'yes' for one of them."*

> *"In my experience, NICE's default position is to say no to cancer treatments, hence the creation of the cancer drugs fund to counteract this. I expect it's decisions to be negative and they usually are, as they were last year."*

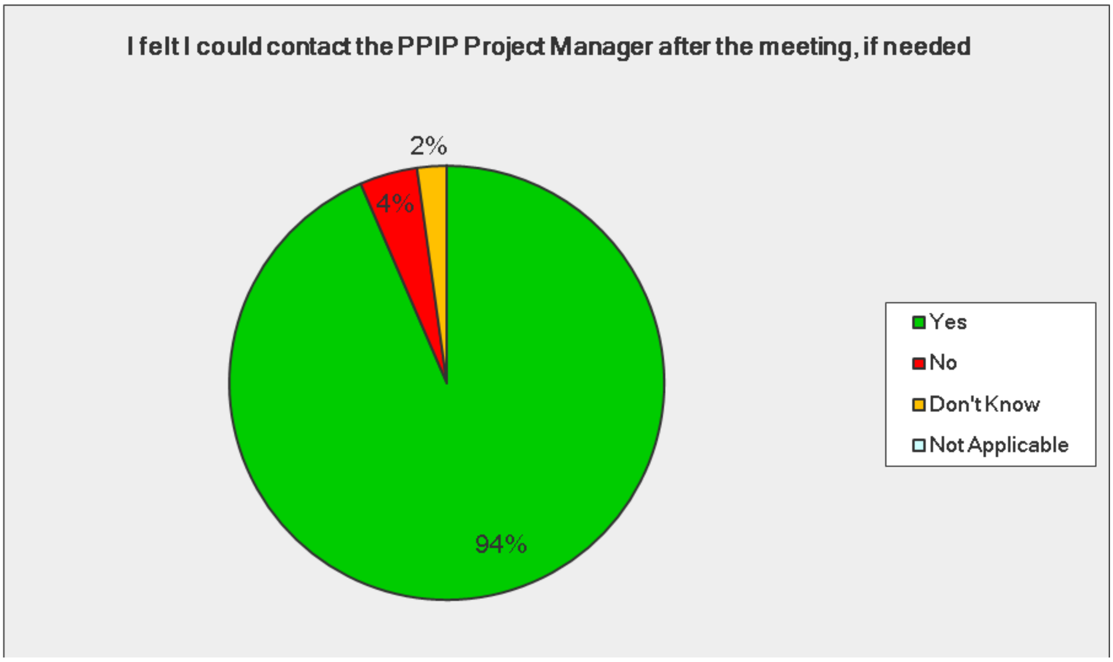
Although many patient experts seem to struggle with predicting the outcome, there are some who do not and some who get it right much of the time.

> *"Two technologies were being appraised. It seemed pretty clear to me that it was going to be yes for one and no for the other."*

> *"n/n, y/y. n/n. once I thought no and the appraisal passed the drug."*

Most (94%) patient experts felt that they could contact the PPIP project manager after the meeting if they needed to, although some prefered to contact their nominating organisation whilst others did not feel they needed the support and one person knew that they could in theory, however unfortunately:

> *"I tried and did not get any reply"*

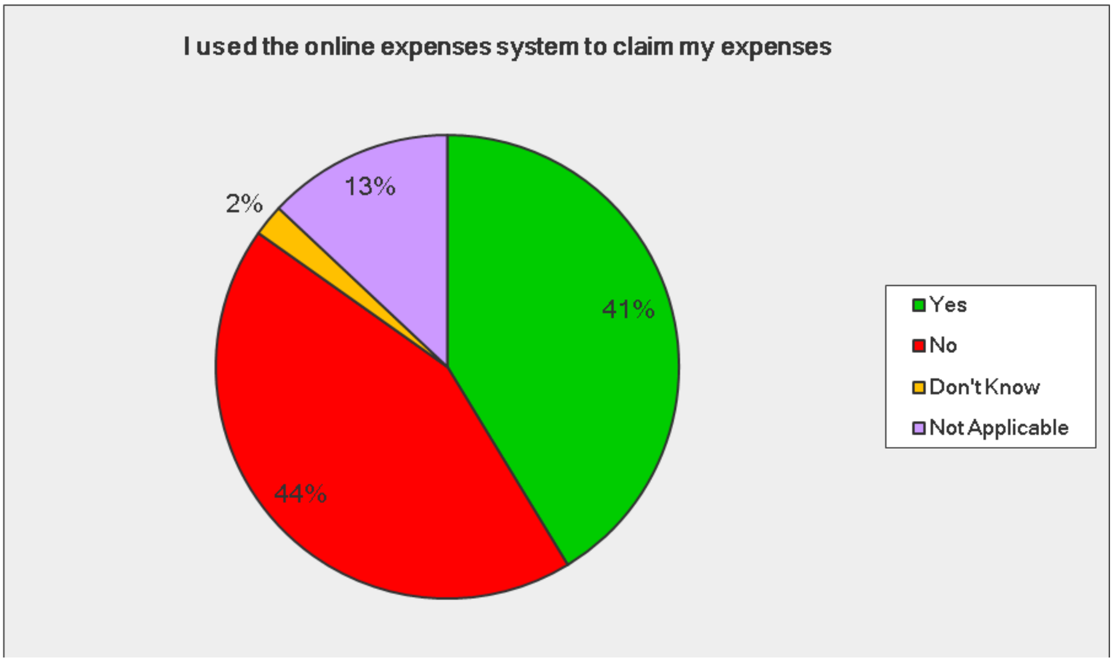


Summary

Nearly all the patient experts received the draft guidance and most of those knew that they could comment on it. Whilst a high number understood some or most of the guidance over two thirds felt that it addressed the key patient issues and that their contribution made a difference. Patient experts were asked whether the committee decision was the one that they expected; over a third predicted the outcome correctly whilst a quarter did not. This was mainly because around a third expected the committee to say ‘no’ to a technology and in fact most of those decisions were positive.

Expenses

Only slightly more patient experts (44%, n20) did not use the online expenses system than did (41%, n19).

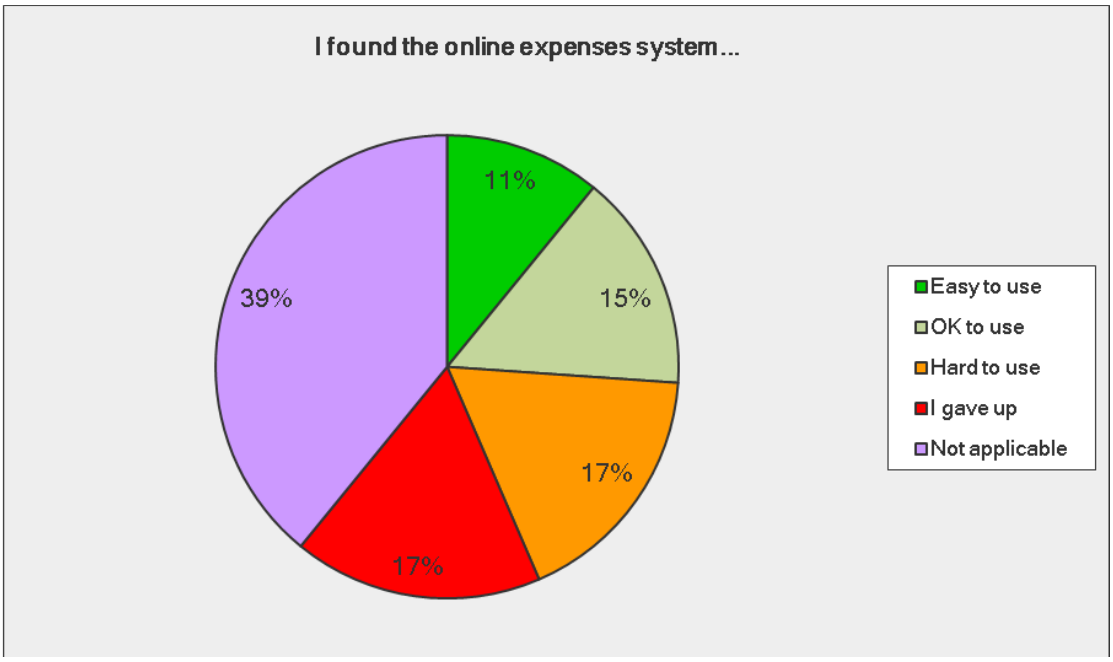


The patient experts gave the following reasons of why they did not use the expenses system:

> *"I actually don't remember if I claimed my expenses or not, I I think I funded this myself - I wasn't sure what I was able to recover."*
>
> *"The online claim form was impossible to use and everything was done through one of the NICE employees. It took a while to be paid."*
>
> *"I did not use the online expense system to claim because I am not sure it was available but I have used it since for a attendance at [another NICE] meeting."*
>
> *"I did not claim expenses"*
>
> *"I have a season ticket for the train and a bus pass so did not need to claim."*
>
> *"My computer did not react to the online- expense system"*
>
> *"The expenses procedure is now pretty time consuming and it was actually cheaper for me - and the charity in terms of my time - for me to claim my expenses from them."*

More people (34%) found the expenses system hard to use or gave up whilst only around a quarter (26%) of all those asked found it easy or OK to use.

39% (n18) did not think that the question was applicable.

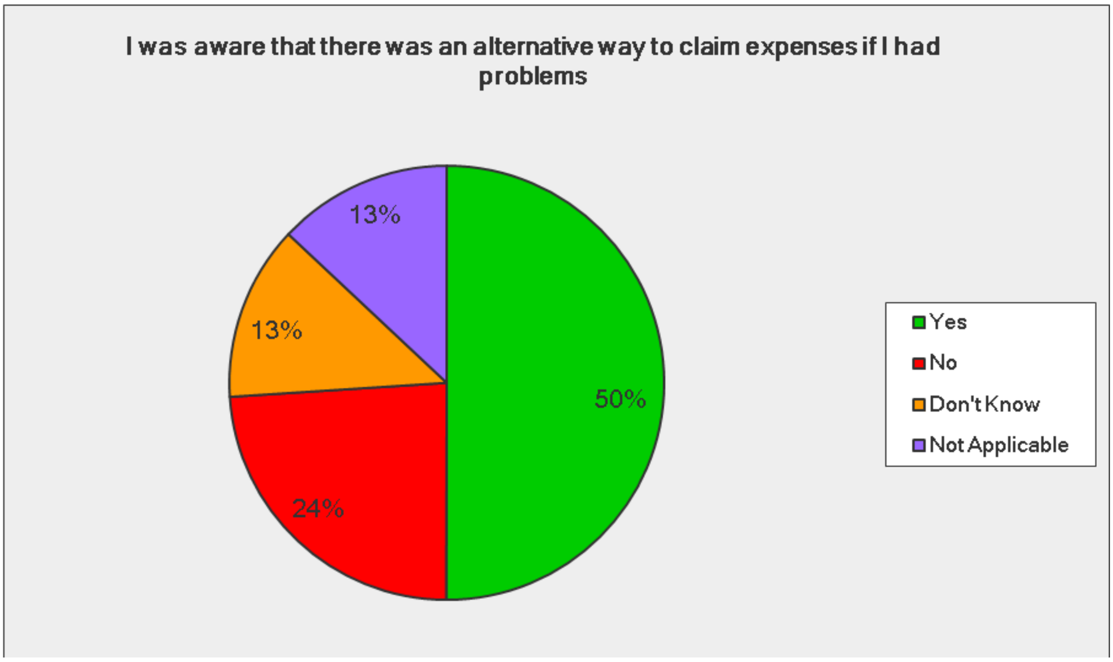


Those who added comments explained their answers thus:

> *"My daughter did the expenses for me so I am not sure. Expenses were mislaid and had to phone up and chase, but [PPIP Project Manager] dealt with it very quickly and after this it was fine."*
>
> *"If you needed to update details for eg change of car then process seemed very long winded and it took ages for the change to be authorised. The expenses claim page does seem to be designed with corporate staff in mind rather than those in the PPIP who may not use as regular"*
>
> *"I found the online process difficult to follow. The "Helpline" number sorted out my problems"*
>
> *"This was the worst part; it seemed needlessly complex for the relatively small amounts of money involved, necessitating several consultations by phone before clearance."*
>
> *"The expenses system was far too complicated, and as far as I could see meant for employees. As a patient expert I only would be likely to make a one off claim for my expenses. It could surely be made simpler for invited patients/experts."*
>
> *"I found the system very confusing and ended up contacting the administrator to find out about different ways to claim expenses"*

> *"NICE helped me out to apply."*
>
> *"I was amazed when the expenses system automatically calculated my travel distance from home to the railway station . Very NICE . Very Big Brother"*
>
> *"My son who works for I.B.M. helped with the online form and thought the process was fairly dreadful."*

Half the patient experts knew that there was an alternative to the online system, whilst around a quarter did not. The rest either were not sure or said that the question was not applicable.



> *"Phoned your office and was advised to put all receipts in the post and they were dealt with promptly and efficiently - thank you"*
>
> *"Was only advised that paper option was still available recently. Expenses forms should be able to be submitted on the day of attendance and handed to appropriate NICE administrator. Burden on representative post event is an added burden to the process"*
>
> *"The charity claims and I am not sure how they did this."*
>
> *"I have never claimed expenses for NICE work."*

When asked what improvements could be made across the whole patient expert experience one of the issues that came up was expenses, with the following comments.

> *“I think it would have been better to be able to make the claim for expenses on the day of the meeting and be paid either there and then, or within a few days.”*
>
> *“The expenses claim system could be a lot simpler!”*
>
> *“But in all honesty I did not know, which expenses to claim, hence I was "freebie" for NICE.”*
>
> *“More help with expenses”*

Summary

Of all the feedback in the patient expert survey, the area with the most negative results and room for improvement was patient expert experiences with the NICE expenses system. Some patient experts are put off claiming expenses at all.

Around 40% of patient experts use the online system and slightly more (1 person more) do not. Around a third of patient experts found it hard to use or gave up, whist about a quarter did use it. Half of patient experts are aware that there is an alternative system if they encounter problems. A number of those who used or tried to use the system needed help from Finance, PPIP or the committee administrators. The minority found the online system very good.

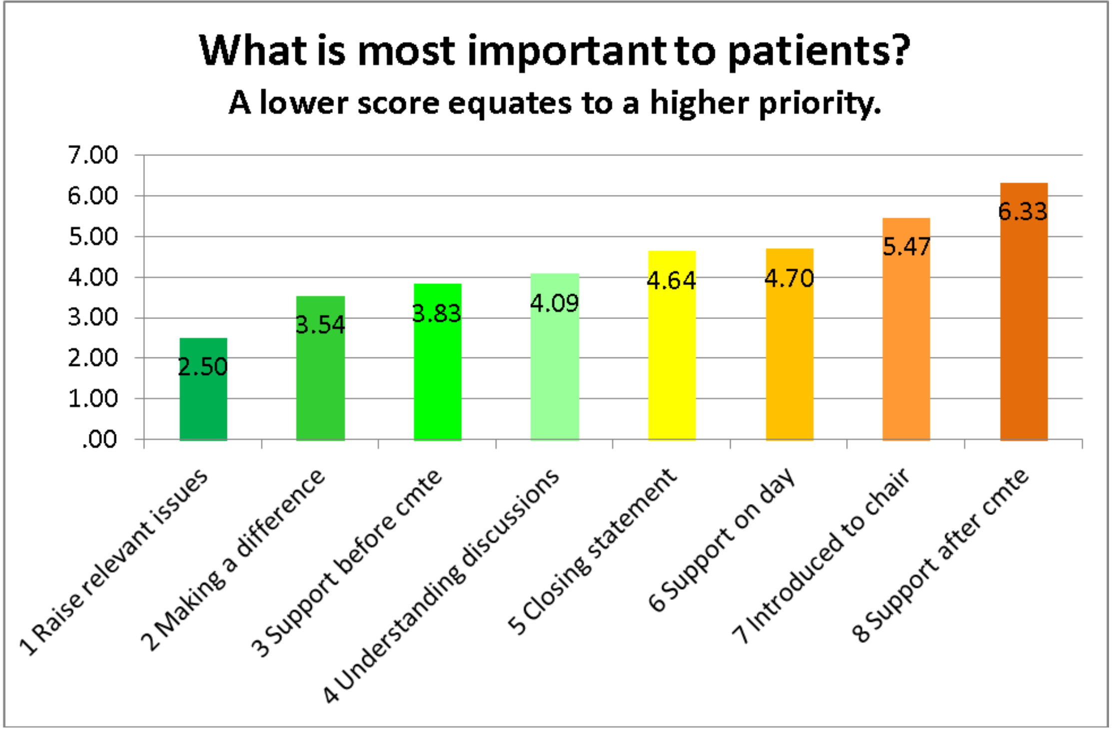
From the comments, the patient experts also find the expenses policy difficult to understand.

What is most important to patient experts?

The most important issues for patients are:

1. Being able to raise relevant issues at the committee meeting
2. Feeling that their contribution made a difference
3. Contact and support before the committee meeting
4. Understanding the committee discussions
5. Being offered the opportunity for a closing statement
6. Support on the day
7. Being introduced to the Chair
8. Contact and support after the meeting

The table below shows the order of importance.to patient experts



Additional areas that are important to patient experts.

- an understanding of how my oral and written contributions will inform (not influence) a final decision
- NICE support to understand cost effectiveness issues
- Understanding of technology jargon
- Complexity of expenses issues
- Time to read the papers: there was insufficient time to read these before the first meeting
- Feeling that my contribution was valued even if it did not lead to a positive outcome.
- Possibility to add an after-thought to the discussion after the meeting perhaps by email.
- Preparation of a patient statement
- Opportunities to talk to other patient reps

Further information from patient experts on how the patient expert involvement could be improved.

About the survey itself

- This questionnaire is a really good idea but has forgotten a lot of information and would have preferred it if it was done as an exit style questionnaire straight after the meeting.
- The survey was too long - If the survey was genuinely about finding out what patients/patient group reps got out of being involved in a TA experience, what was good about it, where things could be improved, it would be helpful to consider involving them in designing the survey. - Many of these questions are irrelevant and or could be better phrased. There are too many questions about contact and availability of PPIP If you want to evaluate patient experience, patient groups and patients should be asked to complete an evaluation within a week of an FAD so that it's fresh in their mind. NICE should be clearer on time scales NICE should consider working with PIN [Patients Involved in NICE] to look at how this survey could be improved I would welcome the opportunity for PPIP to feedback the results of the survey to a PIN meeting
- To be asked asap after the meeting (not a year or more later when I can't remember)

Committee paperwork

- Providing the written papers with sufficient time to read them: it is hard work reading the material and cannot be done by an 'amateur' in one or 2 sittings
- PowerPoint presentations should be tailored to meet clinical and lay audience, wherever possible. Slide handouts can be difficult to read as too much info on one slide. Colour copies may assist for ease of reading and note taking. May help to send [PowerPoint presentation] to lay patient experts/organisations before the date, to help with familiarity and prep for questions or further understanding.

Communication about changes in committee dates and suspensions

- Communication about changes in dates / suspension of meetings could be better. I have had a couple of occasions where I have not been aware that they have been changed or revised until very close to the date and have had to cancel travel plans at short notice.

Timekeeping at the committee

- The meeting ran over and felt that it was a bit rushed at the end, not just for me, but for all the people there. and I missed my train.

Patient expert role

- more explanation of what they expected from me, felt a bit in the dark. thought that someone who struggles with big meetings might have struggled.
- Clarity in advance as to what the committee would most value in our responses. I sometimes feel that I could send a pre recorded

statement! I could add, I believe much greater value to the considerations if I a)felt able to enter into any discussions after the interview (Maybe an informal coffee discussion to give more verbose answers to anyone who was interested in a specific point) Or maybe that the patient experience is more scientifically gathered. For example, NICE wants to know if the side effect X was worth it for you - The patient organisation would happily gather specific data for NICE, or refer members to a survey. At the moment its far too bland, predictable and frankly useless. A tick box exercise.

- better prepared members please. I love ad hoc, but not at all times
- The process needs to be made more human and accessible with the p.e. being able to debate and not be ignored
- Change the way NICE views the opinions and views of patients and patient experts - i.e. give them the weight that they deserve and stop treating them as necessary evils from people "who would say that wouldn't they" in their efforts to improve people's lives and quality and length of lives.

Which part of the committee the patient expert remains for

- Whether or not patient experts benefit from attending the whole meeting will depend to a large extent on the knowledge of the patient expert. It would make sense to give them an option to only attend the parts of the meeting that discuss the patient experience, and perhaps the part discussing clinical effectiveness. Some patients may wish to follow the health economic discussions but they are unlikely to be in the majority. By sitting through these lengthy technical discussions they will inevitably gain the impression that the patient experience side is only a minor aspect of the decision-making and that can be frustrating. It may of course just be a reflection of the reality...

Technical jargon

- I feel the Patient Expert process works very well. The only improvement would be to have a better understanding of the technology jargon. While as a patient you understand the technology and the difference it makes, it would help to have insight into jargon used, particularly by pharmaceuticals
- Have non NICE terminology for truly inexperienced patient experts.
- Some Jargon(including medical abbreviations) busting
- I found the experience very technical and challenging, but it was all handled well. I think it would have been very difficult to engage someone who was not professionally trained in the field in the discussion and if that were planned in the future the process would need a review.

Meeting being intimidating

- The committee had been in session for 30 minutes before I and the other 3 "experts" were asked to join - rather intimidating to enter a room of 50+ professionals - the Chair then asked us to introduce ourselves and started with me - I had no idea that I needed to turn on the microphone and it would have been more thoughtful for one of the

other "experts" to go first as they had all attended these meetings before and knew what to expect - I felt it was a deliberate attempt to intimidate me and would definitely put off a timid person
- The (understandably necessary) reliance on statistical arguments and counter-arguments can be very intimidating!

Being introduced to the chair

- I think it would be useful for patient experts to be introduced to the chair before the meeting and given the chance to offer a closing statement as a closing statement, so that any points that arise during discussion can be dealt with effectively given that it's not always possible to comment at the time.

Expenses

- I think it would have been better to be able to make the claim for expenses on the day of the meeting and be paid either there and then, or within a few days.
- The expenses claim system could be a lot simpler!
- But in all honesty I did not know, which expenses to claim, hence I was "freebie" for NICE.
- More help with expenses

Other

- Give patient experts the opportunity to use built-up experience in further sessions?
- From observing other patient experts, some don't understand what they are allowed to ask for with the drug and why.

Positive feedback

- Had a really good day and enjoyed it.
- I thought the help I received before & during the day was very good, would not think it could be improved
- Personally, I thought the whole experience was fine, since I was a last minute add on.
- I think that the system works very well in terms of the support and information provided by NICE personnel
- Thank you for the opportunity to contribute to one of these committees.
- This team was excellent. Use them all the time!
- Nothing stood out as in need of any major improvement.
- I thought it left little scope for improvement - well done.

Additional information patient experts want to tell us about being a patient expert.

Patient expert role and participation

- NICE need to decide what the role of the patient and patient group rep is for during an appraisal - without this being made clear, patients and patient groups will continue to have negative experiences of the appraisal process. More practical support is needed - if PPIP reps sit in during appraisals, a list of 'types' of questions you may be asked would be a good start. Also, I would welcome the opportunity to work with the appraisal directorate at NICE to look at how we could improve the patient submission template. I think the TA workshop (and accompanying PIN guide) will help, but to do this effectively, NICE will need to determine what is 'best practice' in terms of evidence they prefer/value from patients and or patient groups.
- I felt that (in the last TA) my contribution was ignored because it didn't say what the committee wanted it to. The only reference to patient experience referred to in the provisional determination was that of the non patient organisation rep. If NICE are going to ask more than one patient/rep, then equal value and reporting should be given to both submissions.

Timing of committee meetings

- The only problem was waiting due to the previous meeting running late. Everyone was helpful and tried to make it as 'painless' as possible

Patient expert statements

- My only concern is about the statement a patient is asked to write prior to the meeting. Many of the technologies have only been used in trials so any view given can only be based on research and general experience of being a patient not on direct experience.

Jargon

- The one thing that I feel Patient Experts would benefit from is further understanding of the jargon used

Committee members

- Some of the committee members don't appear to be really listening to the discussions - which is very disconcerting when a patient discusses their life.

Committee treatment of manufacturer

- The NICE committee were really horrible to the drug company reps . They were rude , questioned their ethics and morality and asserted they were fiddling the data . This is shocking behaviour.

Health economics and understanding the committee's role

- I found it frustrating that part of the discussion seemed to be just about the numbers game; we await the outcome, so hope that the decision is based on a full consideration of all the material.

- It can be difficult to follow some of the economic evidence presented. Suggest NICE could run a series of induction to Appraisal technology workshops throughout the year to induct new patient experts into the process- half day would be adequate and could be run by project managers?
- However, [the PPIP] cannot influence what happens at the meetings which can leave patients baffled and disillusioned, especially when the outcome of the meeting is a negative recommendation. Having said that, the way the patient expert contributions are now reflected in the ACDs make it much easier to see where they have had an impact and especially for patient organisations that has helped justify the effort and resources put into involvement in the process.

General

- I was told that there would be an email circular going around requesting add on thoughts for the appraisal, but nothing came out it. And I had something I wanted to add as a response to a doctor's question, but effectively now did not have a chance. Obviously they did not require the email circular for the final decision, but this one point keeps nagging me, though.

Positive feedback

- At the end was very impressed with how well the meeting was run and how well prepared people were. Now has a much better impression of who NICE is. Is a good way to understand what NICE is and what it does.
- My experience as a Patient Expert has been a very positive one. I have felt involved at each stage and feel welcomed at the appraisal meetings.
- I was glad to have been given the opportunity to participate.
- I enjoyed the day spent at the meeting and it gave me a better understanding of what NICE do and how they work. I did not expect to understand all of the issues raised, but I found it interesting to hear the various comments and statements from experts.
- I was pleased that my points were listened to and recorded as said in the final report
- I believe it was a very professional and really well handled process.
- Overall a very interesting experience - any concerns or worries were dealt with by all the people at NICE who I spoke with both before, during and after the meeting. Grateful for the opportunity to make a difference - and a wonderful result - thank you all.
- I feel the process (at least as far as Patient Expert experience is concerned) had improved considerably between my first (2009) and second (2010-11) appraisal meetings.
- However good advance information and support, experience counts, so I felt more prepared and better able to make a contribution on the 2nd occasion.
- The process can be daunting and the support received pre and post appraisal has been very helpful especially when being a NICE novice.
- Knew I had a lot of experience to offer the NICE appraisal process. I felt my contribution was valued and carefully considered. I would have no

reservations about being involved again or recommending the role to other patients. All the staff and members of the appraisal were approachable, knowledgeable and appreciative. The support both prior to and after the meeting from [PPIP Project Manager], in particular, has made it a very rewarding experience.

- I think this is a really good system and very important. I know the patients I represent value having a voice at the table
- Generally, the PPI team do an excellent job at supporting patient experts both individual patients and representatives of patient organisations. They show great flexibility and a determination to make the process work for patients.
- I enjoyed this, and do value the role and importance of the committee - increasingly with experience of more committee meetings. It is very difficult to strike the balance as each appraisal is different. I do feel NICE is always seeking to improve and take on board comments.
- I felt listened to and able to contribute in a small way to the decision making process. Thank you
- Overall experience was/ is very positive. Please accept apologies for being critical. I don' t like soft support from either side.
- Greatly appreciate the help from the NICE staff, and their consideration.
- It was very interesting and I`m glad I had the opportunity to take part.

Conclusions

The conclusions are presented as themes which grouped under headings:

- What is going going well
- What could be improved

What is going well

Overall feedback about the patient expert process

Overall the feedback about being a patient expert is positive although there are a number of areas for improvement. Several of the patient experts commented on how much they enjoyed the day, appreciated the opportunity to get involved or that the team working on it were excellent. The patient experts highlighted the areas that are of most importance to them and the the only area which is highlighted as particularly poor is the online expenses system.

Survey response rate

The response rate to the survey was excellent with some patient experts saying that they would prefer to feed back straight after participating. Patient experts seem keen to feedback and improve the process. The findings of this report will be used to draft an exit questionnaire for all patient experts who attend committee meetings.

PPIP support

PPIP support is deemed to be very good and welcomed by most patient experts. They find the help and support before the meeting as well as on the day of the meeting particularly helpful and are largely aware that the support is ongoing should they need it. One repeat patient expert person found the ‘soft’ support more than personally required but she acknowledged that this was changed when she let PPIP know she did not need extra support. Another patient expert pointed out that however good the support was from PPIP, or indeed the courtesy shown by the committee, what really mattered was how much the difference the patient expert role made in the committee meeting and to the guidance.

Support before the meeting

This is one of the top three most important issues to patient experts and the feedback that NICE does this well. Improvements can be made in the paperwork and clarifying the patient expert role and helping with personal statements.

Role of the chair

The role of the chair is important; patient experts feel that how much they are included in the meeting depends on how much the chair involves them. Although not one of the most important aspects of the meeting, patient experts felt that if they were introduced to the chair they were more comfortable and able to participate.

The chair’s key role could be capitalized on if the chair could explain or reinforce the role of the experts, and how they can participate, when he or she opens the meeting.

A minoritiy of patient experts, however, had highly negative experiences with their chairs.The role of the chair is something that should be included in any exit questionnaire so that it can be monitored.

Understanding the questions put to patient experts during the committee

Most of the patient experts understood most of the questions put to them at the committee meeting.   This may be because the chair seems to play a large role in including and putting questions to the patient experts. If this is the case then that role could be built on further. Additionally, the terminology used and questions asked would be relevant to the patients.

Understanding the guidance

85% of patient experts said that they understood all or some of the guidance. Perhaps it should be noted here that the version of the guidance they receive is not written for a patient and public audience.

What could be improved?

Clarity about the patient expert role and purpose

Patient experts often receive support from their nominating organisation as well as considerable support from the PPIP team and have the role of the patient expert explained to them in writing in the ‘hints and tips’ document and over the phone. Despite this, they still do not feel clear enough about their role.

They do not quite understand how they fit in given the clinical and technical nature of the discussions and the length and weight given to these aspects during the meeting. New patient experts, in particular, are unsure about how to contribute and the meeting; what they can say that is of most use or most persuasive to the committee. They do not see clearly whether or how their contribution has informed the final outcome. One patient expert did say, however, that it was an improvement to see the patient issues reflected in the ACD now.

Patient experts are being increasingly invited back to second and third committee meetings, their role here less clear to them than during the initial meeting.

Patient expert statement/submission

In addition to not understanding their role sufficiently, patient experts would like more help into what to include in their statements and how this gets weighed up against the manufacturer’s submissions, the modelling and the health economics.

They would like more guidance on the purpose of the personal statement; what they should be including and what is of most help to the committee. Those organisations who work frequently with NICE are able to give more support to the patient experts about their statements than those newer to NICE who need more support from PPIP. PPIP can help with the types of questions they may want to answer and the types of things they may want to include but have no specialist knowledge of the topic.

It seems that most of the patient experts do not fully understand the lay lead role (and thus presumably the lead team) they do not realise how their information feeds into the slides at the committee meeting.

Paperwork before the committee

A number of new patient experts find the number of forms, the names of the forms, which ones they have to complete, by when and why, confusing. There is a clear acknowledgement by experienced patient experts that new patient experts would or do find the forms confusing and that they received too many.

Role of the lay lead

Although two thirds of patients said that they were aware that there was a lay lead, there was some lack of clarity of the role and how it related to the patient experts. Where the lay lead and the patients interacted during the committee, this was seen as very positive. There is scope to have more clarity about the lay lead role, to increase its profile and role with the patient experts - either during the committee or welcoming them before it starts. Not only could the lay lead make the patient experts feel less intimidated at the meeting, they could also help reinforce what the patient expert role is and ask some key patient focussed questions during the committee.

Understanding the slide sets

Around 40% of patient experts do not understand the slide sets, they also feel that the slides do not adequately reflect patient issues. This may be for a several reasons: because the clinical lead member writes for a clinical audience; and the lay lead member writes only a few slides. We know from lay leads that the patient issues are sometimes hard to find, either due to the calibre of the statements and submissions or the fact that these come in late. (The potential lack of sufficient information in the statements may also be due to the patient experts not knowing what is expected from their statements). Additionally the terminology, or ‘jargon’ as the patient experts often refer to it, used in the slidesets is difficult for patient experts to follow.

Understanding the committee discussions

This is one of the top four most important issues to patient experts and thus a key area for improvement. The committee discussions were difficult to follow for the same reasons as the slide sets including the language and terminology.

Being able to raise relevant issues at the committee meeting

Being able to raise relevant issues at committee is of paramount importance to patient experts. A combination of factors would seem to contribute to patient experts not feeling that they can do this: they were not sufficiently sure of or confident in their role; they felt intimidated at the meetings; and some had difficulty following the slide presentations and discussions.

Closing statements

Although the opportunity of having a closing statement is not one of the patient experts' top four priorities, it does seem to be a safety net whereby they can add things that they do not feel that they have had an opportunity to say elsewhere in the meeting. Given we know from this survey they do not always feel able to raise all the relevant issues elsewhere in the meeting, this safety net could be important.

Feeling that their contribution made a difference

This is one of the top two issues of important to patient experts and thus another key area for improvement. Although the majority of the patient experts felt their contribution made a difference, there were issues of: a feeling of tokenism; the organisational statement being more relevant than the patient expert presence; feeling that not all patient issues were addressed; feeling that patient issues and evidence are not viewed equally with the RCT evidence and the health economics.

Perhaps if the patient experts were more secure in their role and the patient issues more obviously addressed in the guidance, this would change their perception. Another suggestion from a patient expert was that they should be able to opt in or out of the health economics presentation and part of the discussion, as this is difficult to follow and can give the impression that the patient evidence is not valued.

Understanding technical terms/jargon

This is a thread that runs throughout the TA process, from the terminology in the paperwork through to understanding the slides and following the committee discussion. Using 'jargon' can be interpreted as deliberatelysetting out to exclude people. However, NICE does produce a glossary and it does produce patient versions of the guidance so we do have the capacity to make the process and guidance more accessible to patients and the public, maybe this could spread more to the correspondence and the committee.

Experiences at the committee meeting

Experiences vary from from appraisal to appraisal but overall the majority of patient experts have good experiences at the committee meeting. However, many said that they found it daunting, intimidating or tense, some even found it adversarial. Much of this might be improved by increasing the role of the chair and lay members in helping to understand the role and purpose of patient expert and including them in the meeting.

Where there are mutliple meetings in a day, the start times can be delayed giving patient experts the feeling that the end of their meeting is rushed and that they miss their trains home.

Decision outcomes

The more experienced patient experts seem to be able to understand the committees decision making more and thus be able to predict the decision making better. Only a third of patient experts predicted the committee outcome correctly, mainly because they thought the outcome would be negative whereas most of them received a positive recommendation.

This survey itself

Patient experts thought that the survey questionnaire was too long and would have been better as an exit questionnaire, they also recommended that patient experts should have been involved in its development. We did not state in the introduction of the survey that the questionnaire had been piloted with a patient expert although we did state that it was based the phase 1 questionnaire so that a comparison could be made.

Expenses

This is an issue that patient experts feel particularly strongly about, purely because it takes a disproportionate amount of effort for something not related to the guidance process itself. This is the main area of improvement from the survey.

Many people found the online expenses system is hard to use, a number of people gave up or do not use it at all and instead claim from their nominating organisations. There were a few patient experts who found it very clever and were impressed. Only half knew that there was an alternative way of claiming expenses.

The expenses policy is also difficult for patient experts to follow so they are left uncertain what to claim and so sometimes do not and so combined with the electronic system, this stopped a number of them claiming.

NICE PATIENT EXPERT QUESTIONNAIRE

What did you think about being a NICE Patient Expert?

This survey is about your experiences of being a Patient Expert in NICE's Technology Appraisals process.

We are asking all Patient Experts from last year to tell us about their experiences so we can see:

- how the process is working;

- if we offer the right support; and

- if there is anything we can do to improve our process.

Data Protection. The personal data submitted on this form will be used by the National Institute for Health and Clinical Excellence for work on patient and carer participation in NICE technology appraisals and will be held on the Institute's databases for future reference and in accordance with the Data Protection Act 1998.

Please complete the questionnaire by 16 April 2012

About you

1. Did you attend as (tick all that apply):

☐ A patient?

☐ The relative or carer of a patient?

☐ A paid employee of a patient/carer organisation?

☐ A volunteer from a patient/carer organisation?

☐ Other? (please specify)

2. How many technology appraisal committee meetings have you attended as a patient expert?

○ One

○ Two

○ Three or more

About your experiences of being a NICE Patient Expert

The next set of questions is about your experiences of being a Patient Expert as part of the NICE Technology Appraisals process.

For each question, please tick one box (please note: N/A = not applicable).

3. The letter I received from NICE inviting me to be a Patient Expert was:

	Yes	No	Don’t know	N/A
Easy to understand	○	○	○	○
Informative	○	○	○	○

4. The ‘hints and tips’ information sheet, explaining how to prepare for the committee meeting and what would happen, sent by the Patient and Public Involvement Programme (PPIP) Project Manager was:

	Yes	No	Don’t know	N/A
Easy to understand	○	○	○	○
Informative	○	○	○	○

5. The forms I was asked to complete were:

	Yes	No	Don’t know	N/A
Easy to understand	○	○	○	○
Informative	○	○	○	○

6. Instructions about how to complete the written personal statement prior to the meeting (if you were asked to provide one) were:

	Yes	No	Don’t know	N/A
Easy to understand	○	○	○	○
Informative	○	○	○	○

7. Please use this space to explain any ‘No’ answers to questions 3 to 6

Information and support before the day - provided by the Patient and Public...

8. The PPIP Project Manager contacted me at a point that allowed me sufficient time for preparation.

- ○ Yes
- ○ No
- ○ Don't Know
- ○ Not Applicable

9. I felt able to contact the PPIP Project Manager, if I wanted or needed to

○ Yes
○ No
○ Don't Know
○ Not Applicable

10. If you did contact the PPIP Project Manager, was it easy to do so?

○ Yes
○ No
○ Don't Know
○ Not Applicable

11. I was given an explanation of what my role at the committee would be

○ Yes
○ No
○ Don't Know
○ Not Applicable

12. (If applicable) I felt I knew what to say in my written personal statement

○ Yes
○ No
○ Don't Know
○ Not Applicable

13. Overall, I felt well supported in my preparations for the day

○ Yes
○ No
○ Don't Know
○ Not Applicable

14. Please use this space to explain any ‘No’ answers to questions 8 to 13

Support on the day

15. On the day of the meeting I was met and welcomed by a NICE staff member

○ Yes
○ No
○ Don't Know
○ Not Applicable

16. Any special requirements I had told NICE about were fully addressed

○ Yes
○ No
○ Don't Know
○ Not Applicable

17. On the day of the meeting, I was introduced to the Chair of the committee:

○ Before it
○ During it
○ After it
○ Never

18. I was given an explanation of what would happen during the meeting and what to expect

○ Yes
○ No
○ Don't Know
○ Not Applicable

19. Please use this space to explain any ‘No’/’Never’ answers to questions 15 to 18

Experiences during the committee meeting - your contribution

20. The Chair gave me the opportunity to contribute to the discussion

○ Yes
○ No
○ Don't Know
○ Not Applicable

21. I felt I could add points to issues raised by others at the meeting

- ○ Yes
- ○ No
- ○ Don't Know
- ○ Not Applicable

22. I felt I had the opportunity to raise all the issues I wanted that were relevant to the committee discussions

- ○ Yes
- ○ No
- ○ Don't Know
- ○ Not Applicable

23. I was given the opportunity to make closing comments at the end

- ○ Yes
- ○ No
- ○ Don't Know
- ○ Not Applicable

24. Please use this space to explain any 'No' answers to questions 20 to 23

Experiences during the committee meeting - overall experience

25. I understood:

	All	Some	None	N/A
The questions I was asked	○	○	○	○
The slide presentation	○	○	○	○
Other discussions that took place while I was present	○	○	○	○

26. I felt the slide presentation addressed the key patient issues

- ○ Yes
- ○ No
- ○ Don't Know
- ○ Not Applicable

27. I was aware that there was a lay member of the committee with special responsibility for patient issues for this topic?

○ Yes
○ No
○ Don't Know
○ Not Applicable

28. I was treated courteously by:

	Yes	No	Don't Know	N/A
The Chair	○	○	○	○
The other committee members	○	○	○	○
The other invited experts at the meeting	○	○	○	○

29. Overall, my experience of the committee meeting was

○ Excellent
○ Good
○ Fair
○ Poor
○ Awful

30. Please use this space to explain any ‘No’/’None’/’Fair’/’Poor’/’Awful’ answers to questions 25 to 29

After the meeting

31. NICE sent me the draft guidance produced by the committee

○ Yes
○ No
○ Don't Know
○ Not Applicable

32. I understood the draft guidance

○ Yes

○ No

○ Don't Know

○ Not Applicable

33. I was aware that I could make comments on the draft guidance to NICE

○ Yes

○ No

○ Don't Know

○ Not Applicable

34. I felt key patient issues were addressed in the draft guidance

○ Yes

○ No

○ Don't Know

○ Not Applicable

35. I felt that my contribution made a difference

○ Yes

○ No

○ Don't Know

○ Not Applicable

36. Which of these is the closest to what you thought the decision would be?

○ I thought it would be a YES and it was a YES

○ I thought it would be a YES and it was a NO

○ I thought it would be a NO and it was a YES

○ I thought it would be a NO and it was a NO

○ I don't know

○ None of the above

Please specify if you answered 'None':

☐

37. I felt I could contact the PPIP Project Manager after the meeting, if needed

○ Yes
○ No
○ Don't Know
○ Not Applicable

38. Please use this space to explain any ‘No’/’None’ answers to questions 31 to 37

Claiming your expenses

39. I used the online expenses system to claim my expenses

○ Yes
○ No
○ Don't Know
○ Not Applicable

40. I found the online expenses system...

○ Easy to use
○ OK to use
○ Hard to use
○ I gave up
○ Not applicable

41. I was aware that there was an alternative way to claim expenses if I had problems

○ Yes
○ No
○ Don't Know
○ Not Applicable

42. Please use this space to explain your answers to questions 39 to 41, if you would like to

What is most important to you?

43. Please rank the following statements using a scale of 1 to 10.

Rank 1 is the most important and rank 10 is the least important.

Please rank at least the top 8 statements.

If we have missed any key issues, please include them in your ranking using the 'Other 1' and 'Other 2' fields below, and then specify what these are using Q44.

Contact and support before the committee meeting	
Support on the day	
Being introduced to the Chair	
Having the opportunity to raise the issues I felt relevant	
Understanding the committee discussions	
Being offered the opportunity for a closing statement	
Feeling that my contribution made a difference	
Contact and support after the meeting	
Other 1 (please specify using Q44 below)	
Other 2 (please specify using Q44 below)	

44. If you have used the 'Other' fields above in your answer to question 43 please specify these

Other 1

Other 2

Anything else?

45. Please add any further information about how we could improve the Patient Expert process here

46. Is there anything else that you want to tell us about your experiences of being a Patient Expert?

.... all done!

Thank you for completing this questionnaire.

Once we have heard from everyone, we will analyse the responses and then write our report. We will let everyone who completed the survey know our findings.

If you have any questions in the meantime please contact Heidi Livingstone on 020 7045 2183.

Thank you again – and please remember to submit your response using the button below!