

National Institute for Health and Care Excellence

Public Involvement Programme Annual Report 2017/18

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Executive Summary

1. This report describes NICE’s public involvement activities, and the work of the Public Involvement Programme (PIP), during 2017-18.
2. During 2017/18 we have engaged, involved and supported people and communities across the breath of NICE work programmes. In doing so, we have helped to ensure that NICE’s guidance, standards and advice are relevant and meet the needs of people using health and social care services. Additionally, we have strengthened NICE’s reputation for public involvement regionally, nationally and internationally by showcasing NICE’s work in this field.
3. 2017/18 has been a busy, challenging and fulfilling year for the Public Involvement Programme. In particular, we finalised the recommendations from our strategic review of public involvement. Our report is constructed around the priorities for improvement that the Board approved and demonstrates the real progress we have made over the year. In addition this report covers the PIP's routine key performance indicators
4. The area against which we have made the greatest progress is in the routine and successful use of our social media profile to both bring people to us and to share messages with our audiences, with a ten-fold increase in Twitter mentions, and an 8-fold increase in followers.
5. We continue to lead on NICE’s shared decision-making agenda, working closely with national and international partners to move towards a system that considers patient autonomy and choice, supported by high quality evidence, as the norm.

Patient and public involvement at NICE

1. NICE seeks to improve the health and wellbeing of the population through our evidence-based guidance and quality standards. NICE believes that lay people and the voluntary and community sector organisations that represent their interests should have opportunities to contribute to developing NICE guidance, advice and standards. Therefore, as part of our core values, we work with patients and members of the public so that our guidance and standards:

* take direct account of the perspectives of people who use health and social care services
* support people to make informed choices about the services, interventions, care and treatments available to them.

1. This involvement means that our guidance and other products have a focus and relevance for the people most directly affected by our recommendations – the people who use health and social care services, their carers, families and the public. NICE is committed to continuing and developing its patient and public involvement work, a commitment underpinned by our policy[[1]](#footnote-1).

Public Involvement Programme

1. PIP works across all of NICE’s programmes to ensure that lay people (and the organisations that support them) have opportunities to participate meaningfully in our activities, and that people are supported to do so. At any one time we support between 200 and 250 individual lay committee members and experts.
2. During the business year we recruited 65 new lay members to our committees through open advertising, and identified a further 15 specialist Quality Standards Advisory Committee members (80 in total). In addition we identified several more people to offer their expertise to the committees – 82 patient experts for technology appraisal, highly specialised technologies and medical technologies committees and 23 patient experts for NICE’s Scientific Advice programme (105 in total).

Table 1 – recruited lay members

Table 2 – identified experts and specialists

1. We hosted the 4th Shared Decision-Making Collaborative meeting and developed the shared decision-making aspects of the NICE website[[2]](#footnote-2). We held 35 meetings with voluntary and community sector organisations to share information with them about NICE’s work and to help them become more involved in topics of interest to them.
2. We also delivered 31 international, national, regional and local speaking engagements speaking engagements. Whilst some of these events took place in our London and Manchester offices we also presented at regional Healthwatch meetings in the West Midlands, North West and London. Traveling even further afield we have shared our expertise in patient and public involvement internationally at meetings and conferences in the Czech Republic, Italy, France and South Africa.

Training and masterclasses

1. During 2017-18 we ran 3 training days for newly-recruited lay guideline committee members, 2 for our lay core committee members, 2 masterclasses for patient and voluntary sector organisations, and contributed to 2 induction sessions for guideline committee chairs.
2. Feedback from our training days has been positive with our guideline committee training scoring an average of 4.9 out of 5 for the day as a whole. As in previous years the part of the day where former lay members shared their experiences was highly valued. Attendees also gained reassurance and mutual support from meeting and speaking with other new lay members:

“I found the discussion very helpful, in particular to hear from experienced lay members”

“I found it really helpful to meet with other lay members to understand my role better and to build confidence”

“It all starts to make sense now! Really helpful to meet other lay members and understand where we all fit in”

Lay committee members

Feedback from lay members and experts

1. As part of our commitment to reviewing and improving how we involve people in our work we have continued to send an exit survey to people who have finished work on our committees. In 2017-18 we sent surveys to 99 people and received 46 responses – a 46% response rate. This is an improvement from last year’s response rate of 26% and may be in part due to sending reminders and discussing the exit survey with people before they leave their committee.
2. This year we have seen an increase in people rating their experience of being on a NICE committee as ‘good’ or ‘excellent’ from 88% in 2016-17 to 91% in 2017-18. Several lay members noted their trepidation at starting on a NICE committee and whether their voices would be heard but then said that once they had settled into the committee they felt able to contribute and that their views were valued. As with previous years the role of the Chair was felt to be crucial to ensuring that lay members were fully included in discussions.
3. Some challenges encountered by lay members included quantitative evidence being preferred over qualitative data, complex clinical discussions and use of clinical language, and delays with expenses and papers. However the majority of lay members reflected positively on the impact for them personally of working on a NICE committee:

“Working with NICE has completely changed my working and volunteering life[...]It has enabled me to access paid employment and given me a career path which I would never have dreamed of had I not been involved with NICE”

Lay committee member

1. In 2017-18 we have worked with colleagues to take forward actions resulting from previous years’ exit surveys. These actions have included:

* regularly sharing raw data from the exit surveys and meeting with NICE teams to discuss any issues
* producing guidance for recruiting teams to consider when shortlisting and selecting lay members
* developing advice for chairs on best practice for lay involvement
* revising lay member information packs and checklists for phone calls with lay member to ensure that issues important to them are covered.

1. In response to comments from lay members, in 2018-19 we will be launching a simplified version of the exit survey to reduce the amount of time needed to complete the survey and to aim to increase the number of responses to our exit surveys.

Implementing the strategic review of public involvement

1. The Board approved a number of areas for improvement as a consequence of the strategic review of public involvement. Progress against these areas is noted below.

Reducing unwarranted variation

1. One of the key recommendations from the public involvement strategic review was to consider ways of reducing unwarranted variation between programmes at NICE to enable those outside of the organisation to better navigate through our work. We have embarked on some projects aimed at addressing some of this variability.

Voluntary and community sector evidence submissions for diagnostics and interventional procedures

1. We have initiated a project asking voluntary and community sector (VCS) organisations to submit evidence during the development of diagnostics and interventional procedures (IP) guidance. The submissions enable VCS organisations to tell us about any patient data, perspectives, and issues that might help inform the published evidence and committee discussions. Previously only individual patients were invited to contribute to the evidence gathering aspects of these processes. This project aligns diagnostics and IP with other CHTE programmes that already consider this type of evidence.

Table 3 Evidence submissions - experiences so far

| Interventional procedures | Diagnostics |
| --- | --- |
|  |  |
| * The first IP evidence submissions were presented to the Interventional Procedures Advisory Committee (IPAC) in February 2018. The committee’s feedback was that the evidence submissions were useful to help fully understand the condition and its impact on someone’s quality of life, and that it would be useful to have more specific information from VCS organisations about the individual procedure in question rather than generic information about the condition and its treatment. * We have fed this back to the submitting organisations to help improve the quality of future evidence submissions. | * PIP collaborated with overseas colleagues to develop an international template to supporting patient organisations in submitting evidence to inform diagnostics guidance. This template is accompanied by a guide to completing the template. * We used the template first for ‘Lead-I electrocardiogram devices for detecting atrial fibrillation in primary care[[3]](#footnote-3)’. The guidance is still in the early stages of development * The committee will be asked to evaluate the impact of the evidence submission(s) from patient organisations on the guidance. This evaluation will then be fed back to the submitting organisation(s), to help them to understand where they have made a difference, and to encourage them to continue to provide quality patient evidence. |

Harmonisation of business language across NICE

1. PIP is working with the Content Strategy Steering Group, the Digital Services team, the Digital publishing team and the records manager to improve consistency and reduce unwarranted variation in terminology. This includes working with the project to streamline the processing of consultation comments, to identify technical changes that will improve consistency of language. For example a recent consultation within the technology appraisals programme used the broad term 'stakeholders' in its communication, rather that the appraisals-specific term 'consultee'.
2. This work also includes a ‘product audit’ to effectively categorise and streamline NICE products. To date this audit has identified a number of inconsistencies in how concepts and documents are named. We will be working collaboratively on how to remove these inconsistencies for the benefit of our users and for our staff.

Enhancing recruitment and involvement

1. Our strategic review of public involvement also recommended that we broaden how we identify people to work with us, and to consider the mechanisms for involvement beyond committee membership.

Black, Asian and minority ethnic community focus group work

1. NICE’s equality objectives commit us to increase the proportion of applications for advisory committee positions from people from black, Asian and minority ethnic (BAME) groups. As part of the NICE Equality and Diversity Group’s (NEDG) we have focused on the recruitment of lay members, with the aim of increasing engagement with people who describe themselves as from black, Asian and minority ethnic groups, and the organisations that represent them.

PIP Expert Panel

1. One of the outcomes from our strategic review of public involvement was to set up an Expert Panel of patients and the public. The aim of the Panel is to provide:

* an expanding pool of patient and public expertise with knowledge and experience of NICE's work to contribute to NICE committees
* an efficient mechanism to identify people to work with us, enabling access to specialist input as experts, reviewers and as members, without going through an open recruitment process on each occasion
* peer support to newer patient and public contributors, alongside support provided by NICE staff.

1. We will use the panel to identify topic expert committee members (currently also known as 'specialist members') and patient experts, wherever possible. If there is no-one suitable, we will run the standard recruitment and/or nomination processes. Open recruitment will continue for core committee members, and for guideline committee members for brand new subject areas or substantive updates.
2. So far we have asked alumni members of committees and former expert patients, who have taken part in our work the last 2 years if they would be interested in joining the panel. To date nearly 100 alumni have expressed an interest in membership of the panel and we will expand on this membership to recruit new panel members in the early part of 2018/19. The panel will be refreshed on a regular basis.

Table 4 - Black, Asian and minority ethnic community focus group work

| What did we do and what did we learn? | What action did we take? | What will we do next? |
| --- | --- | --- |
|  |  |  |
| We designed an engagement project to identify barriers to BAME involvement as lay members at NICE, working with representative organisations.  Organisations told us that in order to fully engage with BAME communities we would need to work at a local or regional level to meet people in their local communities rather than relying on national organisations. They also told us that our recruitment materials were too detailed, technical, and difficult to understand. | We also engaged directly with the public as well as speaking to organisations. The aim was to look at the recruitment documents and identify what information was needed and how it should be presented. We worked with the Greater Manchester BME network to facilitate a focus group at their January 2018 quarterly meeting. Over 80 people attended and participated in the event, sharing their views around what could be improved.  The key messages were:   * use simple English and less technical language * have information available in different languages * ask for less information on the application form - have a one page overview of the key information, with other information in a FAQ document * present information in more engaging formats (e.g. videos, infographics) * have more options for involvement other than travel to London for meetings, as this this is a barrier to most people. * run focus groups and other engagement activities to increase inclusion. | Two more focus groups are planned in 2018; one in Birmingham and another in London. The findings of these focus groups will be reported to the NEDG, with key recommendations for NICE to consider. |

Involvement opportunities in the guidelines surveillance programme

1. The surveillance team within the Centre for Guidelines uses a range of methods to assess whether a guideline needs updating. These include information gathering through evidence reviews, questionnaires and information on guideline implementation. The PIP has been working with the Centre for Guidelines team to engage key voluntary and community sector (VCS) organisations at an early stage in the surveillance process.
2. The opportunity to comment was extended to VCS organisations on a pilot basis, with the aim of obtaining information about the experiences of people using relevant health and care services, giving us direct insight into patient views about the guideline. Such information can help the surveillance team understand the guideline’s current context from a user perspective. It can also help the team shape their searches for evidence.
3. The pilot covered 5 topic areas - oral health, physical activity, critical illness rehabilitation, domestic violence and alcohol. In response to a low response rate and feedback from VCS organisations as members of PIN (Patients Involved in NICE), the timeline for responses was extended to 3 and then 4 weeks. Unfortunately this did not increase the rate or quality of responses. Following the pilot, PIP has been working with the surveillance team to explore alternative and potentially more effective approaches to engagement with VCS organisations.
4. In 2018/19 the PIP’s expert panel will be another potential source of feedback on guidelines. We will invite panel members with experience relevant to the topic, to contribute their expertise at an early stage of surveillance.

Involving people early and throughout development of guidance

1. Evidence from the strategic review recommended that we needed to consider means of involving lay people as early as possible in the guideline development process, to ensure a person-centre approach. We are working with colleagues in the guidance development teams to pilot novel methods of early and ongoing involvement.

Guideline scoping – supporting adult carers

1. For the guideline on the [provision of support for adult carers](https://www.nice.org.uk/guidance/indevelopment/gid-ng10046)[[4]](#footnote-4) we supported a lay person to be part of the group that developed the guideline’s scope. It is not routine to include lay people in a guideline’s scoping stages. To support this we developed new written materials to help them understand their role on the group, the scoping process, and how they could have the greatest impact. Following this successful pilot a guide was co-produced by PIP and the lay member for future lay members involved in the scoping process. The guide forms part of the newly updated suite of lay member guides, which provide additional support and information to lay members.

“Involving lay members ensures that actual user experience is considered as part of the scoping exercise. Positive and negative experiences, impact of current practice on the service user and their family, and knowledge of local and regional differences in current practice, all contribute to ensuring that the Guideline Committee will focus on where the best improvements and most appropriate outcomes can be achieved. At all times I felt my contributions were valued, considered, and helped shape the final scope."

Lay member

ME/CFS – early engagement workshop

1. For the update of the guideline on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), NICE involved people with lived experience of the condition, along with other stakeholders, before beginning work on scoping for the topic. Over 45 people, representing 37 different organisations supporting people with ME/CFS, attended a workshop in January 2018. This early engagement is a first for NICE guideline development and reflects the need to address the continuing debate about the best approach to treating people with ME/CFS. It also mirrors a commitment from our review of patient and public involvement to involve people early (and throughout development).

“We wanted to get the views and insights of as many people as possible who are affected, either directly or indirectly, by ME/CFS to make sure we understand the issues that are important to them. The clear message from the workshop was the need to ensure the new guideline properly addresses and resolves the continuing debate about the best approach to treating people with this condition. It also confirmed our intention to ensure robust representation of people with ME/CFS, or their carers, on the independent committee that will develop the guideline. Therefore we will recruit a guideline committee which will include 4 people with the condition or their carers, rather than the usual 2. Additionally, we will include a lay member on the recruitment panel for the chair of the guideline committee.”

Professor Mark Baker, director of the NICE centre for guidelines

Information, intelligence and evidence on people’s experiences of care

1. A critical recommendation from the public involvement strategic review was the need to be more explicit about how we look for, integrate and report on the use of evidence relating to people’s experience of care. We have run a number of projects looking at how we might broaden this key aspect of NICE’s work.

Patient experts for medical technologies – Peristeen[[5]](#footnote-5)

1. Two patient experts were invited to give their personal experiences of Peristeen to the Medical Technologies Advisory Committee (MTAC). Peristeen is an irrigation system for people who experience problems with their bowels, for example, some people with spinal injury.
2. Patient experts do not normally directly participate in MTAC meetings however as Peristeen is a technology used directly by the patient, it was important for the committee to be able to ask questions of people with personal experience. The patients who attended the meeting said that Peristeen had been life changing in managing their bowel conditions.
3. The patients were able to:

* talk about what it is like using the technology and how it fits into their daily routine
* explain how frequently they need to use the technology, which was a key factor in the economic model
* explain their support and training needs: how it can take a while to become used to Peristeen, and that it might not be suitable for everyone
* give real world context to the patient-reported outcome measures. A small improvement meant the difference in being able to leave the house and not. One patient expert said that it had enabled them to go camping with their children, which had not previously been possible.
* describe how they had both considered colostomy before trying Peristeen.

1. The guidance states that Peristeen can improve people’s quality of life and promote dignity and independence. It also notes that it may take several weeks before a person is comfortable using it, which was a key point the patient experts made. The experts expressed gratitude at being able to help others by sharing their experiences with NICE.

“It is a form of therapy for me to talk about this”.

Patient expert

Commentary from patients for interventional procedures – 2 case studies

1. “Patient commentary” is the term used at NICE to describe questionnaire-based evidence from people who have experience of the procedures considered by our interventional procedures (IP) programme. Information from patients with direct experience is summarised and presented to the committee alongside other forms of evidence.
2. From February 2016 to February 2017 the PIP assessed the impact of patient commentary in developing IP guidance. Committee members’ views on each commentary were captured using a standardised pro forma. 20 individual procedures were assessed during this time period for which the PIP sought patient commentary for 17 of these procedures. We received patient commentary for 7. In 2017-18 we analysed and considered the results of the information. We anonymised, analysed, and correlated responses against the section of the published guidance which contains comments from the committee.
3. Our analysis told us that commentary from patients routinely had an impact on the committee’s decision-making. Key findings identified that the commentary is equally useful for guidance updates as for new guidance and that the interpretation and assessment of ‘impact’ varied across committee members but the majority agreed it reinforced the other evidence. Measuring the impact of commentary from patients seems to have raised its profile with committee members. The published guidance includes more reference to patient issues during the pilot than in preceding years. To date no discernible patterns of impact have been identified, nor have any criteria for when patient commentary may not be required. These patterns may emerge as the quantity of data increases

Table 5 Interventional procedures case studies

| Low back pain – joint fusion surgery | Dupuytren’s disease – radiation therapy |
| --- | --- |
|  |  |
| We received 15 questionnaires from patients who had had joint fusion surgery for low back pain. The committee noted the published evidence demonstrated the procedure to be safe and to work well. Information from patients identified that people commonly had to use crutches for a number of weeks following surgery. A comment was added to the guidance to reflect this. | We received 34 questionnaires from patients who had had radiation therapy for Dupuytren’s disease. The committee noted that the patient feedback demonstrated a lack of understanding from the patients of the purpose of the procedure. A committee comment was included in the guidance suggesting clinicians provide patients with clear, written information about the procedure and its purpose. |

Improving feedback to people and organisations

1. A significant recommendation from the public involvement systematic review, and one where we could make the most improvement from our current practice, was formally feeding back to lay contributors on the impact of their participation.

Feedback to lay participants – highly specialised technologies and interventional procedures

1. As part of our routine processes, we seek evidence from patient organisations in a systematic and rigorous way. This evidence is known as ‘organisational submissions’. Providing feedback to organisations taking part in health technology assessments is internationally recommended by the [HTAi Patient and Citizens Involvement Group’s values and standards](https://www.htai.org/interest-groups/patient-and-citizen-involvement/pcig-home/values-and-standards/)[[6]](#footnote-6). It has also been requested by patient organisations informally and substantiated by the data in the PIP strategic review. As a consequence we have started to capture the impact of evidence from patient organisations on committee decision making for two NICE guidance programmes – interventional procedures and highly specialised technologies.
2. We involved committee members and guidance producing staff in designing the data capture forms. These were piloted and re-evaluated together with the committees and staff and are now in routine practice, capturing in real time the committee’s views on the impact of the organisational submissions. The information is then fed back to the organisations who submitted evidence. To ensure that they remain fit for purpose the impact forms and feedback letters will be reviewed regularly. We are extending this pilot to diagnostics and medical technologies guidance.
3. The data generated from this exercise, including any recurring themes, will be used to enhance the quality of the submissions by:

* feeding back to the submitting organisations, highlighting the aspects of their submission that the committee members found most helpful, and indicating how things might be expressed more usefully in future evidence submissions
* informing future guides, templates and PIP support to patient groups.

Performance feedback guide for chairs and lay members – technology appraisals

1. For many years lay committee members have been asking for feedback on their contributions to committee work. In the past feedback has been ad hoc and inconsistent, without guidance to either party. Formal feedback is recommended on an annual basis, but this should be voluntary and supportive. It is an opportunity to provide feedback and comment on a committee member’s contribution for their personal development and for the efficient and smooth running of the committee.
2. Committee chairs and senior managers have asked for support in providing constructive feedback. As one of the outcomes of the strategic review of public involvement, the PIP has produced a feedback guide and template for lay members, committee chairs, and NICE senior managers to use together. The guide aims to promote feedback that can increase the individual lay member’s performance, their value to the committee and their personal development goals. The feedback has the potential to enable chairs and senior managers to better understand and integrate the lay members they work with. Included in the guide are suggested areas for discussion, to give all participants the opportunity to ask questions and provide feedback throughout any discussion.

Taking action on feedback from lay members

1. Lay members provide valuable feedback about their experience of work on a NICE committee, both during their involvement and more formally as part of the Public Involvement Programme’s exit survey which helps us to understand what works well and what needs to change or be improved. We discuss and agree actions resulting from the exit survey with the guidance development teams. In response to lay members’ feedback guidance teams have committed to:

* ensuring staff routinely check with candidates about any special requirements related to illness or disability, at interview and on appointment
* establishing preference for meeting papers (electronic/paper, home/meeting) ahead of the first committee meeting
* reminding technical staff not to use jargon
* offering lay members an agenda slot or the opportunity to do a short presentation
* considering if there is more staff can do to plan in advance for including qualitative evidence and expert testimony where appropriate.

Expanding our use of social media

1. From August 2017, we increased our presence on Twitter using our team account @NICEGetInvolved. This has helped us to reach more members of the public and different communities, and work and communicate more effectively with our stakeholders. Table 6 below compares our Twitter activities in April 2017 to that in March 2018. We currently have 1876 followers on Twitter and work collaboratively with the Communications team running the primary NICE Twitter account to ensure we are mutually supportive.

Table 6 Social media profile

| Activity | April 2017 | March 2018 |
| --- | --- | --- |
|  |  |  |
| Tweets - posts from our user name | 8 | 77 |
| Tweet impressions - our posts delivered to other people's feeds | 5264 | 130,000 |
| Profile visits - people viewing our profile | 343 | 2,128 |
| Mentions - people mentioning our user name in their tweets | 5 | 57 |
| New followers - people choosing to follow all of our posts | 8 | 79 |

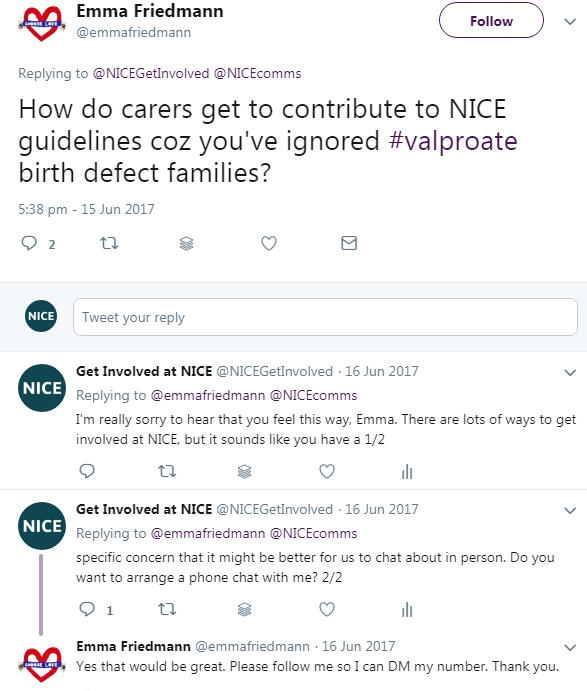
1. Table 7 outlines some case studies demonstrating the impact of social media on the PIP in the past year.

Table 7 social media case studies

| Case study 1 - improving how we recruit people from diverse backgrounds | Case study 2 - celebrating the achievements of our lay members |
| --- | --- |
|  |  |
| We went out to open recruitment to find two lay specialist committee members to join the committee developing a [quality standard on Black, Asian and other minority ethnic groups: promoting health and preventing premature mortality](https://www.nice.org.uk/guidance/indevelopment/gid-qs10039)[[7]](#footnote-7).  We knew that we would normally struggle with this type of recruitment, but through actively targeting different communities on Twitter, we were able to attract 19 applications for the two roles available.  This is particularly important when, on average, we receive 9 applications for each specialist committee member role. | We have used Twitter to work more closely with our lay members – both present and past. This is a great way to celebrate their achievements whilst working with NICE.  Sharing this kind of content also helps us to demonstrate that members of the public do help to shape NICE guidance, and make a big difference to the work that we do. |

Using Twitter to tackle concerns people have with NICE

1. Using Twitter has allowed us to have conversations with people we would not normally be in touch with. This includes being able to address any concerns people have about NICE.
2. Social media has proved to be a great way to reach more people that we normally would, and particularly helps us to address preconceptions people may have about working with NICE as a lay member.
3. For example, we have been able to explain that people can take part in developing NICE guidelines even if they are not on one of our committees.



Social ‘media for evidence generation – IP commentary case study

1. To ensure we have information from patients with direct experience of procedures assessed by our interventional procedures programme, we proactively seek their experience through a formal questionnaire process. Collectively we refer to the information from this work as ‘patient questionnaires’.
2. To help increase the response rate of patient questionnaires in the IP programme, the PIP now produce the questionnaires online and publicise them via social media channels, such as Twitter. The link is also emailed to relevant patient organisations to encourage them to share via their social media and communication channels, such as newsletters. Questionnaires are still also being sent in hard copy to clinicians performing the procedure to be forwarded on to their patients for feedback.

Making involvement everyone’s business

SDM lunch and learn sessions and technical forum

1. Shared decision making is growing in profile across NICE. To help NICE staff learn more about SDM the PIP and the Medicines and Technology Programme ran lunch and learn sessions in both the London and Manchester office. Both sessions were well attended and we were delighted to see people there who hadn’t had any previous involvement in NICE’s SDM work.
2. PIP also worked with the Science Policy and Research team to secure Professor Richard Thomson as a speaker at a NICE Technical Forum meeting. Richard posed whether guidelines and shared decision-making were potentially incompatible bedfellows. We are pleased to say that the answer was a definitive ‘no’!

Guideline committee chairs’ training

1. Chairs of NICE committees have a vital role to play in making sure that the committee functions effectively and in an inclusive manner, with members accorded equal status and all voices heard. Over the years, positive feedback from lay members about their experience on a NICE committee has consistently been correlated with good chairing.

‘The Chair always made me feel my contribution was important.’

‘I was treated with respect and as an equal member of the group. My views were given equal consideration to others.’

1. All new guideline committee chairs, are invited to an induction training day organised by NICE’s Centre for Guidelines with input from the Public Involvement Programme and other teams. During the training days, we aim to ensure that chairs understood the value of patient and public involvement in NICE’s work and their role in making it work in practice. Together with an experienced chair, we discuss effective chairing, provide insights on the perspective of lay members and advise on supporting them effectively. Overall feedback for both training days run in 2017/18 was very positive.

Developing a resource for working with people with dementia

"People living with, and affected by dementia, become experts by experience in their own right. They bring their own unique contribution which can only add to the expert knowledge of the professionals round the table. It is refreshing to see that NICE has acknowledged this, and fully involves people living with, and affected by dementia.”

Chris Roberts, lay member on the NICE Guideline Committee: Dementia - assessment, management and support for people living with dementia and their carers[[8]](#footnote-8)

1. NICE produces guidance and advice that influences the treatment and care people living with dementia receive. Involving people living with dementia, in guidance development, is vital in ensuring the recommendations are relevant and beneficial to those using services. To support the teams at NICE, the PIP has developed a tailored resource to support staff who are, or may be in the future, working with people living with dementia. The resource provides staff with the knowledge and practical skills to ensure people living with dementia are successfully involved in the development and use of NICE guidance.
2. People living with dementia have created a wealth of information and advice for organisations on how to include people with living with dementia. [The Dementia Engagement and Empowerment Project (DEEP)](http://dementiavoices.org.uk/)[[9]](#footnote-9) online resources were used to develop the resource, with contributions from the lay members sitting on the dementia guideline committee and NICE staff.

Student champions – spreading PPI knowledge and thinking

1. NICE offers a learning programme to students who are interested in understanding more about NICE and championing use of our guidance. The students come from a range of healthcare fields including medical, nursing, pharmacy, dentistry, midwifery and allied healthcare, and may be joined in future by social care students. In 2017/18 the PIP team contributed to this programme for the twice-yearly Learning about NICE days, organised by NICE’s education team and attended by 100 students in total.
2. The day included a mix of presentations and exercises, plus a panel of senior NICE staff and Board members answering students’ questions. The PIP contributed to the planning of the programme and participated on the day to reinforce the importance of the patient perspective and person-centred care, and share knowledge on patient and public involvement in NICE guidance. The overall feedback for both events was very positive.

Other projects

International work

1. We have spread the message about NICE and its approach to patient and public involvement through a wide range of international conferences and meetings including:

* 6 presentations and workshops at the 2017 HTAi conference
* 2 sessions at the Guidelines Evidence Summit
* 2 sessions at international meetings of the European Society of Cardiology
* a presentation on patient and public involvement in HTA for policy makers in the Czech Republic
* a presentation at the International Shared Decision Making conference.

1. We have also presented to several international deputations at NICE, including visitors from Qatar and the Swedish Health Ministry.

Shared Decision Making Collaborative

1. The fourth Shared Decision Making Collaborative was held on 22nd June 2017, with a focus on the challenges to putting shared decision-making into practice, future policy developments, and a review of progress made over the year by organisations identified in our joint action plan for shared decision making. NICE’s contribution to the action plan included:

* enhancing and building on our existing collection of decision support tools
* securing a referral to develop a clinical guideline on best practice in shared decision-making
* proposing an approach for quality-assuring decision support tools
* advocating for funding for shared decision-making research
* considering how to record shared decision-making in clinical encounters.

1. Our Shared Decision Making Collaborative community continues to grow, and now numbers well over 100 people who are engaged and enthusiastic about this agenda and embedding it in routine practice.

Engaging with Healthwatch England and the local Healthwatch network

1. Over the past 12 months PIP have completed an engagement project with the Healthwatch network. With 152 independent local Healthwatch organisations in England, PIP developed a strategy to engage with as many organisations as possible. Through support from Healthwatch England PIP ran focus groups at regional Healthwatch network meetings to inform the network about NICE’s work, and to discuss how they can use NICE guidance to support their work.
2. The key points that emerged were the various techniques local Healthwatch employ in using NICE outputs to improve local services. These include:

* helping them measure what ‘good’ practice looks like
* providing a framework to create questionnaires and research projects
* providing information and support when speaking with the public
* support their service delivery recommendations to providers and commissioners.

1. These examples can be used by other voluntary and community sector organisations. We will publish good practice examples as part of the PIP communication strategy. These will be used to inform and encourage other organisations to replicate and use NICE resources in their own work.
2. NICE sponsored an award at the national Healthwatch England conference, celebrating the use of NICE guidance to make local service improvements. The winner of the award has since submitted a shared learning example ([‘improving quality of care in residential care and nursing homes’](https://www.nice.org.uk/sharedlearning/improving-quality-of-care-in-residential-care-and-nursing-homes)[[10]](#footnote-10)), demonstrating the impact of NICE guidance on the Isle of Wight. PIP also supported the field team at the conference, disseminating the messages about how NICE guidance can support the Healthwatch network.
3. To continue a close partnership working PIP facilitates quarterly meetings with the NICE field team, adoption and impact team and Healthwatch England.

Lay member expenses

1. PIP has taken on the processing of lay member expenses to ensure a centralised and person-centred approach to reimbursing our lay members’ out-of-pocket costs. Expenses are now routinely paid within 2 weeks of submission and informal feedback from the lay members has been positive, with one describing the service as ‘BRILLIANT!’ We will continue this process through into 2018/19, working collaboratively with our colleagues in the finance team.

Lay member learning event

1. On 1 November 2017 the PIP hosted a successful event with 21 core lay members of standing committees to celebrate their contribution to NICE guidance, explore challenges and share learning, and discuss new developments in NICE’s work. The programme was developed in collaboration with the lay members and included a mix of learning and sharing experiences, with presentations, exercises, and discussion.
2. Participants gave very positive feedback about the event, with comments indicating it had been a really useful and valuable day. Lay members valued the opportunity to network, share experiences and ideas, and learn about new developments at NICE. The opportunity to focus on the minutiae of guidance development was also popular in the parallel sessions on health economics and use of patient/public evidence. In our panel Q & A, participants liked hearing from senior NICE staff and a non-executive director as they responded to questions posed by lay members.

“NICE panel was a good pointer to current NICE thinking and allowed lay members to input ideas”

Lay member

1. In celebrating the public voice in NICE’s work and the role of lay members, participants appreciated hearing about the impact on guidance of patient evidence and involvement, with a range of examples cited. This was accompanied by a summary of action to improve patient and public involvement in NICE’s work, following our strategic review on this topic. Reflecting on this event, Angela Coulter, NICE non-executive director, commented:

“NICE is extremely fortunate to be able to draw on the knowledge and wisdom of a strong group of committed lay members through its Public Involvement Programme. The depth of their knowledge and unique perspectives were very much in evidence in the discussions at this successful event. I believe NICE is way ahead of the game when it comes to integrating professional and lay perspectives, thanks to the strong lead provided by this programme and its staff.”

Our plans for the coming year

1. Alongside our core work with the lay committee members and experts, we will build on the work of 2017/18 we will, during 2018/19, continue to implement the recommendations from the strategic review of public involvement including:

* introduction of new members of the Expert Panel, including piloting early and ongoing involvement
* pilot novel methods in relation to user-focused evidence
* pilot public involvement training for NICE staff
* expand the PIP's social media strategy and enhance our web presence
* work across NICE to remove unwarranted variations across programmes.

1. We will deliver the fifth Shared Decision Making Collaborative meeting to enhance networking amongst a community of practice, and to explore advances in SDM thinking, and continue to work on other SDM-related work across NICE in collaboration with our sister team, the Medicines and Technologies Programme.
2. We will work collaboratively with our colleagues in the regions, particularly the Medicines and Prescribing Associates and the Field Team, to enhance the messages about the role of lay people and communities in supporting implementation of guidance, to enhance quality of care

Conclusion

1. PIP looks forward to the ongoing challenges presented to NICE and the team in 2018/19. NICE and the external environment in which it operates continues to change and NICE’s public involvement approaches are changing too. We hope that the coming years provide opportunities to enhance our person-centred approaches and support the people and communities who are our core constituents.

National Institute for Health and Care Excellence, June 2018

1. <https://www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy> [↑](#footnote-ref-1)
2. <https://www.nice.org.uk/sdm> [↑](#footnote-ref-2)
3. <https://www.nice.org.uk/guidance/indevelopment/gid-dg10018> [↑](#footnote-ref-3)
4. <https://www.nice.org.uk/guidance/indevelopment/gid-ng10046> [↑](#footnote-ref-4)
5. <https://www.nice.org.uk/guidance/mtg36> [↑](#footnote-ref-5)
6. <https://www.htai.org/interest-groups/patient-and-citizen-involvement/pcig-home/values-and-standards> [↑](#footnote-ref-6)
7. <https://www.nice.org.uk/guidance/QS167> [↑](#footnote-ref-7)
8. <https://www.nice.org.uk/guidance/cg42> [↑](#footnote-ref-8)
9. <http://dementiavoices.org.uk/> [↑](#footnote-ref-9)
10. <https://www.nice.org.uk/sharedlearning/improving-quality-of-care-in-residential-care-and-nursing-homes> [↑](#footnote-ref-10)