

## **Public Involvement Programme Annual Report – 2014**



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# Public Involvement Programme Annual Report – 2014

*"NICE has developed a highly successful model for involving the public in its work. They have demonstrated that, not only is public involvement achievable in such a complex area of health decision-making, but that it is essential to improving the quality and legitimacy of those decisions. I greatly admire the way in which the Public Involvement Programme (PIP) team supports public contributors to ensure their voice is heard."*

*Simon Denegri,*

*National Director for Public Participation and Engagement in Research*

## Executive Summary

1. This report describes the work of NICE's Public Involvement Programme (PIP), and our contribution to supporting the development and implementation of NICE guidance, advice and quality standards during 2014.
2. It should be noted that the information in this report only covers the work of the Public Involvement Programme and not public involvement activities run by other NICE teams such as the holding of Committee meetings in public<sup>1</sup>, and the work of the Citizens Council<sup>2</sup>.

### ***Expanding and changing workload***

3. The team has worked hard to build knowledge and relationships in new fields of work, developing relationships with new stakeholder communities. We are in regular communication with the local Healthwatch networks, and have been encouraging the wider voluntary and community sector in supporting NICE guidance for their constituencies.
4. We continue to facilitate the identification and recruitment of, and support for, NICE's committee lay members, consistently attracting a wide range of applicants. We provide advice and support to the internal teams and collaborating centres, and continue to build on our national and international profile.

### ***Increasing profile of public involvement, and experiences of care***

5. NICE's public involvement work sits in a wider context of an increasing profile for patient and public involvement and engagement across the health, public health and social care fields. There is also an increasing research agenda in this area, with interest growing in initiatives such as user-defined outcome measures (as opposed to outcomes simply reported by users), the development of projects

<sup>1</sup> [www.nice.org.uk/get-involved/meetings-in-public](http://www.nice.org.uk/get-involved/meetings-in-public)

<sup>2</sup> [www.nice.org.uk/get-involved/citizens-council](http://www.nice.org.uk/get-involved/citizens-council)

such as the [COMET initiative](#)<sup>3</sup> user-focused core outcome sets, and the development and support for users as researchers<sup>4</sup>.

6. National Quality Board's [Improving Experiences of Care](#)<sup>5</sup> builds on the work that NICE has done to make recommendations and set standards to improve experiences of care that patients, service users and carers should expect, and sets out a shared understanding and ambition for good quality experiences of care.

### ***Planning for the future***

7. We are working with external experts and organisations to explore NICE's role in relation to public-facing initiatives such as shared decision-making and value-based healthcare, and the implications of these initiatives for how NICE approaches public involvement and its outputs.
8. We have commissioned a literature review of best practice in public involvement, to ensure that we test our model against evidence-based good practice, and to identify areas for improvement. This is to ensure that we are keeping abreast of new developments in the field.

### ***Conclusion***

9. In a time of uncertainty, and within a constantly changing organisation, the PIP provides NICE with an effective resource that is both technical and operational in its activities, with a high level of credibility both within and outside of the organisation. We ensure that one of the vital elements of NICE's decision-making – our lay members – is supported to contribute meaningfully to the development of our guidance, advice and standards.

## **Introduction**

10. NICE is committed to involving patients, carers, people who use health and care services and the public in the development of its guidance and other products. The aim of lay involvement in NICE's work is to ensure all our guidance products are informed by this unique perspective. As a result of this contribution, NICE guidance and standards have a greater focus and relevance for the people most directly affected by NICE recommendations.
11. NICE's approach to public involvement is based on the principle that the contributions of lay people, and organisations representing their interests, are integral to developing NICE guidance, advice and quality standards, and supporting their implementation.

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<sup>3</sup> [www.comet-initiative.org](http://www.comet-initiative.org)

<sup>4</sup> [www.invo.org.uk](http://www.invo.org.uk)

<sup>5</sup> [www.england.nhs.uk/ourwork/part-rel/nqb/#pub](http://www.england.nhs.uk/ourwork/part-rel/nqb/#pub)

*"The whole experience was enlightening; it gave me a real sense of the lengths NICE go to in order to produce the very best possible evidence based guidance"*

*Lay member*

12. Lay contributors to NICE's work have equal status to health and social care practitioners and other professional contributors. This applies at an individual level for members or expert contributors to NICE Committees, and for stakeholder organisations, including those run by or for users of services.
13. On NICE Committees, lay members' perspectives have equal value to those of professional and practitioner members when considering the evidence. The views of all members of a NICE Committee are given equal weight during discussions about the interpretation of the evidence, and lay members bring a unique perspective. The objective consideration of the evidence, combined with the diverse perspectives of the Committee members, ensures that no one 'voice' is able to dominate when drawing up the recommendations.
14. Involving lay people is integral to NICE's approach to developing guidance, quality standards and other products. NICE's methods and processes for involving lay people are based on the best available evidence, and on extensive practical experience. NICE has adopted a flexible model of involvement that allows us to develop different approaches for new areas of NICE work. This flexibility allows for the most effective lay input.

*"I felt that Committee members really listened to me and my views were reflected in the final publication".*

*Lay member*

15. This is the first Annual Report from NICE's Public Involvement Programme (PIP), a centralised team at NICE that develops and supports the organisation's public involvement activities. It is accompanied by a new guide that details the PIP's overall approach to supporting lay involvement in guidance development.

## The Public Involvement Programme

*"Public involvement is critical for any organisation, but particularly one like NICE whose work and decisions have such an impact on people using health and social care services, their carers and families as well as society as a whole. Supporting people to make a meaningful contribution to the work of NICE has been a significant achievement of the Public Involvement Programme and team over the years - an achievement which I hope will be sustained and strengthened in the future."*

*Andrea Sutcliffe,  
Chief Inspector of Adult Social Care*

16. The Public Involvement Programme (PIP) works across all of NICE's programmes to ensure that there are opportunities for lay people (and the organisations that support them) to participate meaningfully in NICE's activities, and that those opportunities are appropriately supported. At any one time the PIP provides support to between 250 and 300 individual lay committee members.

17. The PIP's work is supported and guided by NICE's Board-level [policy and principles](#)<sup>6</sup>.

18. Specific PIP areas of work covered in this annual report include:

- Support for new programmes
- Recruitment and identification of lay committee members and expert witnesses
- Training
- Raising awareness among NICE staff and other professionals
- Contribution to NICE process and methods reviews
- Implementation support and local outreach
- International work
- NICE annual conference
- Speaking engagements
- Patients Involved in NICE (PIN)
- Working with the voluntary and community sector
- Support for NICE's equality programme

<sup>6</sup> [www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy](http://www.nice.org.uk/about/nice-communities/public-involvement/patient-and-public-involvement-policy)

- New products
- Research and evaluation
- Other notable achievements

*"Being a lay member has increased my self-esteem and confidence. I retired early due to medical problems and lost self-esteem. Being a member of a guideline development group gave me back my confidence and enabled me to use skills acquired when working. I joined a NICE Committee after this which keeps my brain cells active. The overall regained confidence and skills have allowed me to contribute to health-related research and guidance outside NICE".*

*Lay member*

## **Team establishment**

19. The Public Involvement Programme (PIP) has an equal split of team members between NICE's London and Manchester offices, as detailed in the organogram in appendix 1. Last year saw significant changes to our staff, but at the time of writing, the PIP has its full quota of 12 staff members.
20. At the end of 2013, the PIP reorganised the team responsibilities and introduced a new post of Project Manager. The Project Manager is responsible for managing the PIP's administrative support team, and our business management, communications and events planning. In addition the Project Manager and their team have a key role in developing and supporting the new monitoring and management systems we have put in place to maximise efficiency.
21. We have merged a vacant part-time Public Involvement Adviser post with a vacant full-time Coordinator post to add a further full-time Public Involvement Adviser post to our establishment, and to ensure the most efficient use of existing resources.
22. We were particularly sad to say goodbye to one of the PIP's longest standing team members, Barbara Meredith, who retired in September 2014 after 11 years with the team. The team wishes her well in her retirement and thanks her for her outstanding contribution.
23. There have been various other changes to team staffing during 2014. All other staff movements can be found in appendix 2.

## Support for new programmes of work

*“Patients can make a real contribution.”*

*Lay member*

24. During 2014 the Public Involvement Programme (PIP) has supported the involvement of patients, carers and people using health and social care services in the first 4 safe staffing topics. This has included recruitment and support for standing lay committee members as well as specialist committee members for each topic. The PIP has also provided input into the development of the first 2 Information for the Public (IFP) documents to support the guidance on safe staffing.
25. The PIP began exploring direct patient input into NICE's Scientific Advice programme in 2014. Together, the 2 teams have developed a proposed process for identifying, selecting and supporting individual patient experts to contribute to appropriate Scientific Advice projects. The process is being piloted for 2 topics (November 2014 and January 2015) and will inform further development of the proposals.

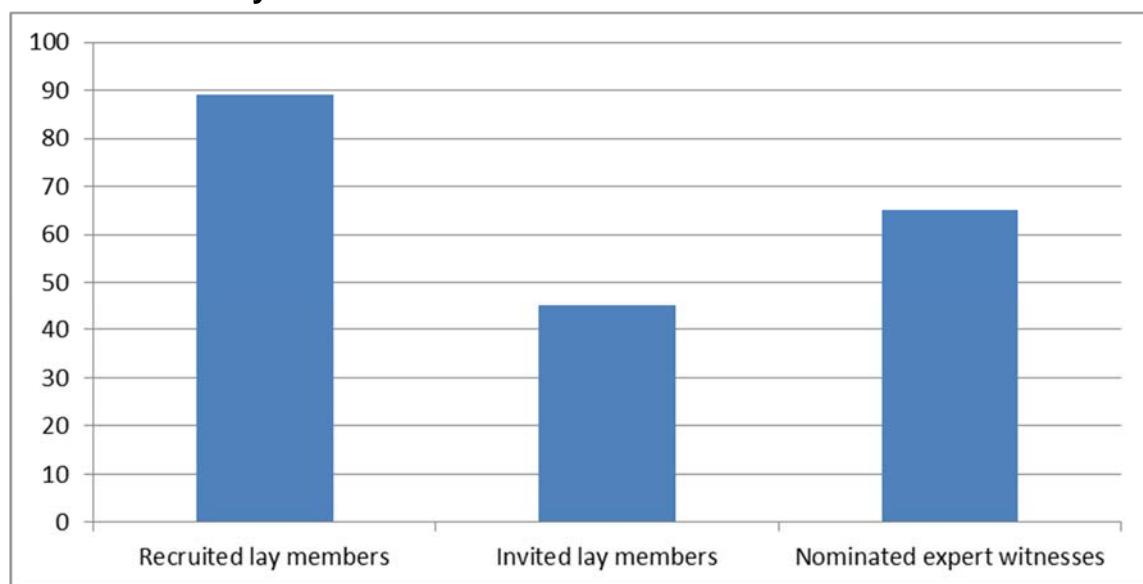
## Recruitment and identification of lay Committee members and expert witnesses

26. Lay members and expert witnesses are recruited or identified in 3 different ways, all of which are administered and supported by the PIP:
  - Open advertising and recruitment.
  - Targeted identification through expressions of interest.
  - Nomination: self-nomination, nomination by Committee members or via voluntary and community sector organisations.
27. During 2014, the Public Involvement Programme (PIP) helped to recruit 89 new lay members to our Committees and working groups, from 475 applications. In addition we identified 45 lay expert Committee members (known as specialist members or topic expert members) to sit on a variety of Committees. We also helped to identify 65 expert witnesses to give testimony to our Committees.

*“As a patient representative I felt supported, prepared and informed”*

*Lay member*

**Figure 1: number of lay members and expert witnesses recruited or identified between January and December 2014**



## Training

*'The training session was great. It was a pleasure to meet so many interesting and committed individuals whose personal, professional and life experiences had so much to offer in terms of the development of guidelines that meet the needs of patients, relatives and carers, and the clinicians that need to apply their knowledge, skills and judgement in their application'.*

*GDG training attendee*

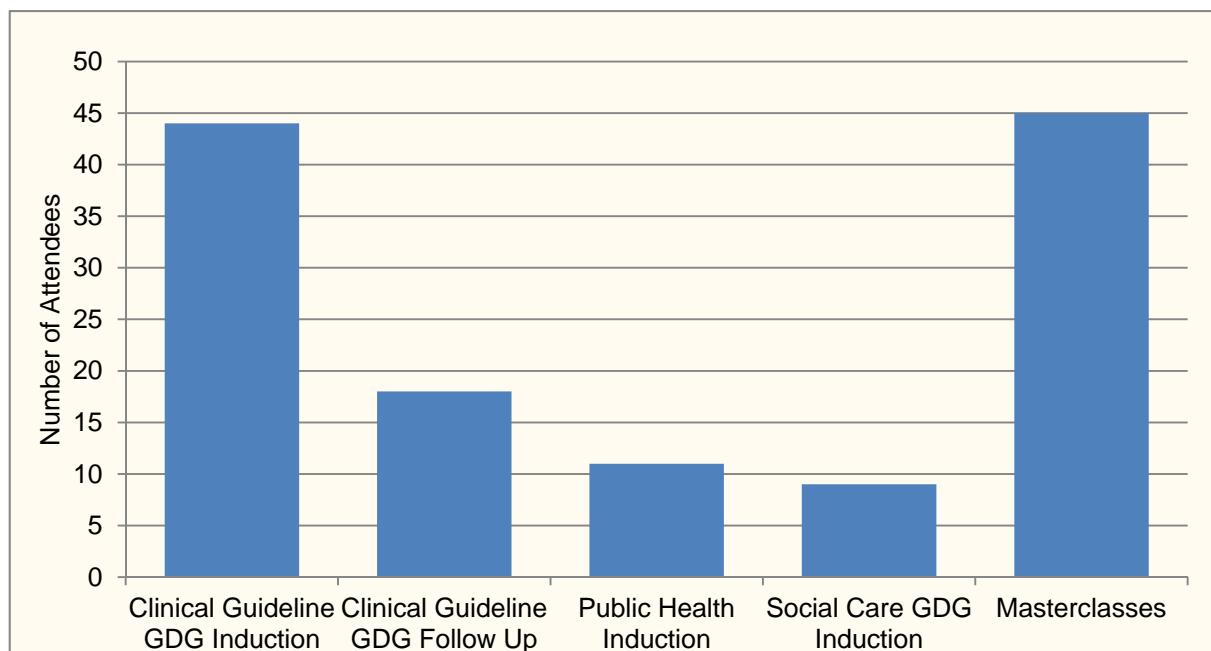
28. The Public Involvement Programme (PIP) delivers various training days across the year to key audiences. We run inductions and follow up workshops for lay members involved in developing guidelines. We also offer a series of masterclasses, aimed at voluntary and community sector organisations, who are interested in learning more about NICE to help them better understand how the organisation works, and the role they can play.
29. During 2014, we ran 9 lay member training sessions, attended by 82 people. These sessions were a mixture of 4 induction sessions and 2 follow-up workshops for lay members of guideline development groups (GDGs), 2 sessions for new Public Health Advisory Committee lay members, and a dedicated session for social care GDG lay members.
30. We ran 4 masterclasses for voluntary and community support organisations attended by 45 people.

31. All those attending training and masterclasses are asked to complete evaluation forms. This allows the PIP to regularly review these sessions to ensure they are high quality and suitable for the task, and to make any improvements as needed. On average, all PIP training sessions and masterclasses in 2014 were rated as 'good'.

32. Overwhelmingly, lay members report that they value the opportunity the training days give to meet other lay members who are on different stages of their NICE journey, to share experiences and get peer support. They also appreciate the time and space to learn more about NICE procedures such as research methodologies and health and social care economics, as this information helps them to understand the remit of NICE, and how all the different areas of work link together to support guidance development. It also gives lay members a greater understanding of their role and how it fits into the wider processes of guidance development.

33. Masterclass attendees reported that they had gained a much better understanding of NICE as a result of attending. Many stated that the masterclasses highlighted the breadth of evidence that NICE takes into account, and importantly, how their organisations can work with and support NICE. There was praise for the presentations and materials that could be taken away to share with colleagues and cascade the learning. Attendees were asked for suggestions for future workshops that will enable the PIP to continue to develop masterclasses that meet the needs of our stakeholders.

**Figure 2: number of people who attended PIP training sessions in 2014**



34. Below are sample responses from evaluation forms when asked what went particularly well at the training session or masterclass:

*“Being among very experienced NICE members. The exercises were very well planned.”*

*“Very well run – relaxed and informative.”*

*“Helpful day, well balanced.”*

*“Very high quality and extremely informative presentations.”*

*“There was lots of information which will help with the GDG.”*

*“Hearing other members’ experiences, finding out more about my role”.*

*“Well organised, good information prior.”*

*“I really appreciated the quality and helpfulness of the day. I feel enthusiastic and ready to start with my GDG.”*

*“Role of voluntary sector in supporting implementation – gave me ideas of things we can do.”*

35. Below are sample responses from evaluation forms when asked for suggestions for improvement:

*“Not enough time for discussion.”*

*“Some sessions are too long.”*

*“Perhaps more room for discussion of people’s experiences on the GDG.”*

*“More information on jargon.”*

*“NICE does not operate in a vacuum. The day could easily take account of the political context, across the UK, and the policy environment in which the organisation works.”*

*“Some of the case studies were too basic and simply described the activities of many modern charities (lobbying, passing on information, engaging with development groups). I would have liked more about how organisations had taken a guideline or quality standard and changed services for the better, ending the postcode lottery for good!”*

*“More people from the voluntary sector talking about what they have done to influence commissioning/get QS etc. take-up.”*

## **Raising awareness among NICE staff and other professionals**

36. The Public Involvement Programme (PIP) raises awareness among staff, Committee members and other professionals on the value of patient and public involvement and how to make it work in practice. In 2014, in addition to the day-to-day advice we offer to NICE teams and collaborating centres, we have also:

- Worked with NICE Committee chairs including contributing to 4 training days for new chairs of guideline development groups.
- Provided input to the Centre for Health Technology Evaluation’s new Good Practice in Chairing guide and revised Guide for Committee Members and similar work to support implementation of the unified Guidelines manual.
- Given presentations in numerous induction meetings for new NICE Committees and guideline development groups.
- Contributed to a meeting of NICE fellows and scholars, a learning day for student champions and a session for NHS management trainees.
- Provided inductions for new NICE and collaborating centre staff members.

## **Contribution to process and methods reviews**

37. [Developing NICE guidelines - the manual](#)<sup>7</sup> (published in October 2014) - The Public Involvement Programme (PIP) has been an active contributor in the development and implementation of the unified guidelines manual. This has included writing text for the manual including a new appendix of advice on involving children, young people and adults in the development of guidelines. We also helped produce the summary version of the manual for stakeholders. The PIP continues to be represented on various oversight and working groups to support the implementation of the manual.

38. Various members of the PIP have sat as members of steering and working groups for updates of other methods and process guides in 2014. This has included the Interventional Procedures Programme Manual, the [guide to the processes of technology appraisal](#)<sup>8</sup>, the proposed [Value Based Assessment of Health Technologies](#)<sup>9</sup> addendum to the [guide to the methods of technology appraisal 2013](#)<sup>10</sup>, and the joint process and methods guides update for the

<sup>7</sup> [www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview](http://www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview)

<sup>8</sup> [www.nice.org.uk/article/pmg19/chapter/foreword](http://www.nice.org.uk/article/pmg19/chapter/foreword)

<sup>9</sup> [www.nice.org.uk/Media/Default/About/what-we-do/NICE-guidance/NICE-technology-appraisals/VBA-TA-Methods-Guide-for-Consultation.pdf](http://www.nice.org.uk/Media/Default/About/what-we-do/NICE-guidance/NICE-technology-appraisals/VBA-TA-Methods-Guide-for-Consultation.pdf)

<sup>10</sup> [www.nice.org.uk/article/pmg9/chapter/foreword](http://www.nice.org.uk/article/pmg9/chapter/foreword)

Medical Technologies Evaluation Programme. PIP has also commented on other guides, as appropriate.

## **Implementation support and local outreach**

39. Encouraging and advising voluntary and community sector organisations to support the use of NICE guidance and standards is a central dimension of the PIP. During 2014 we continued our ongoing work to include patient and voluntary sector organisations' contact details in our Information for the Public publications, to provide readers with additional sources of support.

40. In 2014 we introduced routine activities to support individuals and voluntary and community sector organisations to be proactive in supporting the use of NICE guidance and standards. These activities include the following.

- Producing factsheets outlining the ways that voluntary and community sector organisations can help to put NICE guidelines into practice, which are distributed to key organisations for each guideline produced.
- Reviewing the content of workshops for lay members of guideline development groups has brought new content focusing on what individuals and voluntary and community sector organisations can do to support the use of NICE guidelines.

41. The Public Involvement Programme (PIP) continues to produce a monthly bulletin for the local Healthwatch networks and patient and public involvement leads working locally. We also work closely with the NICE Implementation Programme and Healthwatch England to provide advice to local Healthwatch organisations on supporting the use of NICE guidance and standards. We are planning work in collaboration with our Implementation Consultant colleagues that expands on this local outreach.

## ***Examples of support for implementation***

42. Three voluntary and community sector organisations have published their examples of practice in line with NICE guidance on the [Local Practice Collection](#)<sup>11</sup> in 2014.

- Against Violence and Abuse shared its experiences of providing domestic violence and abuse services in line with [NICE's public health guideline on domestic violence](#)<sup>12</sup>.

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<sup>11</sup> [www.nice.org.uk/about/what-we-do/our-programmes/local-practice-collection](http://www.nice.org.uk/about/what-we-do/our-programmes/local-practice-collection)

<sup>12</sup> [www.nice.org.uk/guidance/PH50](http://www.nice.org.uk/guidance/PH50)

- Action for Children shared its experiences of providing a service that matches care-experienced independent visitors with young people in the care system, in line with [NICE quality standard for looked-after children and young people](#)<sup>13</sup>.
- The Ministry of Parenting (a Community Interest Company) shared its experience of its Incredible Years (IY) group programmes with an IY home-coaching programme and information workshops. The programme is delivered by experienced practitioners in line with [NICE's clinical guideline on conduct disorders in children and young people](#)<sup>14</sup>.

43. Voluntary and community sector organisations have formal agreements with NICE to support the use of NICE quality standards. The PIP work with the team developing quality standards, to provide encouragement and advice to voluntary and community sector organisations.

## International work

*"The NICE Public Involvement Programme has worked in partnership with patients to develop and evolve processes that put patients' perspectives at the heart of its deliberations. Their willingness to share that experience with other agencies internationally has meant that HTAs around the world are becoming more patient centred".*

*Dr Karen Facey,  
Founding Chief Executive of the Health Technology Board for Scotland*

44. **Health Technology Assessment International (HTAi)**. The Public Involvement Programme is a member of the [HTAi Patient/Citizen Involvement Interest Sub-Group](#)<sup>15</sup> (PCISG) of the HTAi Board. We sit as a member of the PCISG steering group, as well as co-chair of the PCISG working group on Patient Involvement and Education. Furthermore we are a member of the Research Steering Committee convened by the PCISG to guide development of 2 research projects in 2014 – development of internationally agreed resources for patient involvement in Health Technology Assessment (including templates for patient group input into HTAs, and values and standards for patient involvement in HTAs). The PIP also actively participated in the 4-day face-to-face meeting of the PCISG in Scotland, in October 2014. This meeting included a visit to the Scottish Medicines Consortium (SMC), to observe a committee meeting, meet their Public Partners (lay committee members), and discuss public involvement activities and work with their public involvement staff.

<sup>13</sup> [www.nice.org.uk/guidance/QS31](http://www.nice.org.uk/guidance/QS31)

<sup>14</sup> [www.nice.org.uk/guidance/cg158](http://www.nice.org.uk/guidance/cg158)

<sup>15</sup> [www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html](http://www.htai.org/interest-sub-groups/patient-and-citizen-involvement.html)

**45. Guidelines International Network (GIN).** The PIP has contributed to the work of GIN as a steering committee member of the GIN Public working group. One of GIN Public's main areas of work has been the promotion and ongoing development of the [GIN Public Toolkit](#)<sup>16</sup> that includes good practice examples from NICE's work on involving patients and the public in guideline development.

**46. European Patient Academy on Therapeutic Innovation (EUPATI).** The PIP sits on the Project Advisory Board for [EUPATI](#)<sup>17</sup>, which is a patient-centred team of 30 organisations, led by the European Patients' Forum, with partners from patient organisations, universities, not-for-profit organisations and experts in patient and public engagement, along with many European pharmaceutical companies. EUPATI provides scientifically reliable, objective, comprehensive information to patients on the research and development process of medicines. EUPATI provides educational resources (online and face-to-face) to increase patients' capacity to be effective advocates and advisors in clinical trials, with regulatory authorities and on ethics committees. The PIP has presented at the National Platform Launches for EUPATI in the UK and in Ireland.

## NICE Annual Conference

47. The Public Involvement Programme (PIP) has worked closely with the Communications team and the NICE conference organisers to support patient and public involvement opportunities at the NICE conference. As in previous years, in 2014 we ran a bursary scheme to support the attendance of voluntary and community sector organisations, by offering delegate passes to the conference, the cost of which was met by NICE. PIP received 66 applications for a conference bursary and 26 delegates from voluntary and community sector organisations were able to benefit from the scheme. Our evaluation report highlights the value that delegates placed on being able to attend:

*“I would like to reiterate my thanks for running this scheme. It was a fantastic opportunity to be able to attend the conference - without the bursary place there is no way we would have been able to afford the travel and conference costs.”*

48. The PIP also contributed to the development of the 'patient centred care' stream at the conference, which focussed on patient experience, shared decision making and empowering people to manage their own care. Across the whole conference programme contributions were heard from patients, carers, people who use health and care services and leading figures in patient and public involvement nationally. This focus on patients, carers and people who use health and care

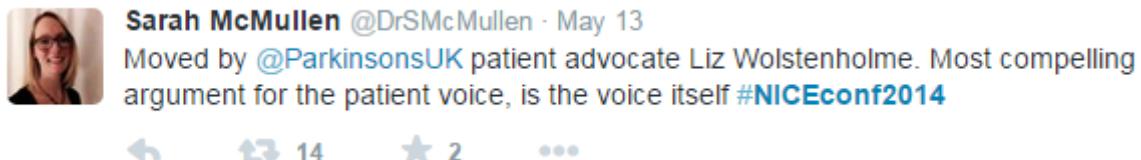
<sup>16</sup> [www.g-i-n.net/working-groups/gin-public/toolkit](http://www.g-i-n.net/working-groups/gin-public/toolkit)

<sup>17</sup> [www.patientsacademy.eu/index.php/en/](http://www.patientsacademy.eu/index.php/en/)

services was well received both from bursary scheme recipients and on social media (see figure 7):

*“The following session on 'Positive Person-Centred Care' was lively and gave great information. The speakers were entertaining as well as educative and this was my favourite session of the day.”*

**Figure 7: example of feedback from the NICE conference on social media (copyright Twitter)**



**Sarah McMullen** @DrSMcMullen · May 13  
Moved by @ParkinsonsUK patient advocate Liz Wolstenholme. Most compelling argument for the patient voice, is the voice itself #NICEnconf2014

## Speaking engagements

49. During 2014, the Public Involvement Programme (PIP) gave 15 speaking engagements at a local, regional, national and international level. These included the Canadian Agency for Drugs and Technologies in Health (CADTH) Symposium in Ottawa in April, the NICE Conference in May, regional Healthwatch events, and a Patient Information Forum (PiF) members' event in October.

## Patients Involved in NICE (PIN)

50. The Public Involvement Programme (PIP) works collaboratively with [Patients Involved in NICE \(PIN\)](#)<sup>18</sup>. PIN describes itself as: “a coalition of over 80 patient organisations and is committed to enabling patient groups to engage productively with NICE. Independent from NICE and the pharmaceutical industry, they use their combined knowledge, experience and direct contact with patients from a wide range of conditions, to ensure NICE puts patients, carers, and patient groups at the centre of all of its work. They act as a critical friend and a respected and equal partner in developing and shaping aspects of NICE's work. They provide a forum for enabling patient groups to engage with NICE.”

51. During 2014 the Chair of PIN, Drew Lindon, stepped down, as did the Vice Chair, Andy Pike. We wish Drew and Andy every success in the future. We are currently working with PIN's Executive Group in lieu of a formal Chair. The Executive Group currently comprises:

- Farhana Ali, Rare Diseases UK

<sup>18</sup> [www.nice.org.uk/about/nice-communities/public-involvement/pin](http://www.nice.org.uk/about/nice-communities/public-involvement/pin)

- Nick Bason, Bowel Cancer UK
- Heather Bird, Diabetes UK
- Lorna Lord, Ear Foundation
- Lee Marriott-Dowding, James Wale Fund for Kidney Cancer

52. PIN met 4 times during 2014 in February, May, August and November. Topics and speakers from the year are shown in table 2.

**Table 2: topics and speakers from the Patients Involved in NICE (PIN) meetings in 2014**

Topic	Speaker(s)
NICE Implementation Collaborative (NIC)	Sally Chisholm, Programme Director, Health Technologies Adoption Programme
National Digital Health Strategy	Dr Sian Rees, Oxford University
Highly Specialised Technologies and NICE	Josie Godfrey, Associate Director, Highly Specialised Technologies  Farhana Ali, Executive Officer, Rare Disease UK
Quality Standards	Rachel Neary-Jones, Programme Manager, Quality Standards
Stakeholder engagement in Clinical Guidelines	Andrew Boaden, Senior Policy and Campaigns Officer, MS Society
NICE Pathways	Judith Richardson, Associate Director, Pathways

## **Working with the patient, and voluntary and community sector**

53. As part of our routine business we identified a wide range of patient and voluntary and community sector groups to register as stakeholders and consultees, and supported them in their interactions with NICE. We also conducted outreach visits with 26 patient and voluntary sector groups. These groups are listed in appendix 3.

54. We also held a meeting of children's and young people's charities in May 2014 to explore how NICE could best engage with this stakeholder group. The organisations who attended included Action for Sick Children, Association for Young People's Health, Barnardo's, Carers Trust, Coram Voice, National Children's Bureau, National Autistic Society, National Deaf Children's Society, National Youth Agency, Rethink, and Young Minds.

## Support for NICE's equality programme

55. The Public Involvement Programme contributed to the NICE annual equality report for 2013/14 by providing a detailed report of equality monitoring data from lay applicants to NICE advisory bodies. This analysis has informed the content of the 2014–5 Equality Forum which will be held in March 2015. We have also contributed to a review of the corporate equalities monitoring form with the aim of improving data collection.

56. We are continuing to support the implementation of research recommendations arising from NICE's equality objective 1, which is “to evaluate the most appropriate forms of advisory body participation by people with disabilities to ensure NICE meets its responsibilities under equality legislation”. This has included providing advice to guidance development teams on supporting disabled members of advisory bodies, and advising on plans for staff training.

57. In 2014 the PIP consulted our external network of children's charities about the involvement of children and young people in NICE's work, focusing on guideline development and our communication with young people. We obtained feedback on the draft version of the guidelines manual that sets out a systematic approach for including the views of children and young people in the development of guidelines. We have also begun work to develop the public involvement pages on our website, which will include consideration of specific audiences such as young people, and showcasing examples of how children and young people (and other groups) have been involved in NICE work to date.

## New products

58. The Public Involvement Programme (PIP) has supported the development of 3 patient decision aids<sup>19 20 21</sup> during 2014, providing advice and assistance to colleagues in the Medicines and Prescribing Centre and overseas collaborators.

59. A new guide has been produced to explain how NICE supports patients, carers, people who use health and care services and members of the public to participate in its work. It describes the core activities of the PIP. The guide provides an overview of the key principles that the PIP works to, along with more operational approaches to certain tasks. The guide is intended for organisations and individuals interested in public involvement at NICE, and may also be of use and interest to the NICE teams that the PIP supports through its work.

<sup>19</sup> [www.nice.org.uk/guidance/cg181/resources](http://www.nice.org.uk/guidance/cg181/resources)

<sup>20</sup> [www.nice.org.uk/guidance/cg180/resources](http://www.nice.org.uk/guidance/cg180/resources)

<sup>21</sup> [www.nice.org.uk/guidance/cg184/resources](http://www.nice.org.uk/guidance/cg184/resources)

## Research and evaluation

60. The Public Involvement Programme (PIP) is a member of [INVOLVE](#)'s Advisory Group<sup>22</sup>, which shares knowledge and experience of public involvement in research, and informs policy and practice in this area. The PIP participated in the INVOLVE 2014 Conference, including chairing two sessions.
61. The PIP is a member of NICE's Internal Research Advisory Group, to ensure public involvement is appropriately considered within NICE's methodology research agenda and associated projects. We have also been involved in specific research projects this year.

### ***Evaluation of additional lay input to social care guidance***

62. When the NICE Collaborating Centre for Social Care (NCCSC) started its work, the Social Care Institute for Excellence (SCIE) and NICE agreed to include 2 new arrangements for co-production with people who use services and carers, in addition to NICE's standard practices for involvement of experts by experience in guideline development.
63. These were:
  - a user/carers member on recruitment panels for GDG chairs
  - a user/carers member on scoping groups at the start of work on a guideline.
64. SCIE agreed to carry out a review of these arrangements to assess their reported impact on the work of GDGs, and any need for improvements in the process. The Co-production Team carried out the review with support from the PIP at NICE during the summer of 2014. The review comprised a short survey, sent to everyone involved in the recruitment of the chair and the scoping group for the GDGs. This included 12 people who took part in the chair recruitment and 49 people who were members of the scoping group across the following topics:
  - Home care.
  - Older people with long-term conditions.
  - Transitions from hospital to home.
  - Transitions from children's services to adult services.
65. The results of the survey indicated that the user/carers member on the GDG recruitment panel had a positive experience and provided a welcomed and useful addition to the process. There was a more mixed picture in relation to the scoping

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<sup>22</sup> [www.invo.org.uk](http://www.invo.org.uk)

groups. The results of the survey indicated that some people cannot see the benefit of user and carer involvement of this type.

66. This suggests there is a need to review the role of the user/carer member on the scoping group to make their role explicit. One person noted the technical nature of the group made involvement difficult. Having a clearer role, and ensuring everyone on the group understands this, would help to address this. A full copy of the report is available on request.

### ***Review of patient participation in the technology appraisals process***

67. In January 2013 the [Health Select Committee Eighth Report](#)<sup>23</sup> stated that 'it is important for the credibility of NICE and for the decisions that it makes that the patient voice is effectively and openly represented in all its work'. In response to this, NICE's Market and Audience Intelligence team was jointly sponsored by the Technology Appraisals team and the PIP to explore and understand patient experts' and organisations' perceptions of engagement in the technology appraisal (TA) process, and specifically identify any barriers to engagement.

68. The findings are that all groups feel that it is important that NICE incorporates patient evidence in all its work, particularly the TA process. While there is some room for improvement including transparency in decision making, those who have taken part in the NICE TA process are generally positive about NICE, PIP support and their overall experience. For organisations not engaged in the TA process the main barriers are a lack of resources, the organisation's own area of expertise, the language and tone of NICE communications and documentation, as well as NICE's perceived preoccupation with cost-effectiveness.

69. Suggested improvements include simplifying the TA paperwork and evidence submissions, developing alternative methods of participation and improving communication. TA and PIP are working together on developing an action plan.

## **Feedback from Exit Surveys**

*"My involvement with the NICE GDG provided experience, skills and knowledge which will remain with me throughout my working life. I was treated with respect and supported throughout the entire process, I felt my view was valued and the chair safeguarded the fact that I was a lay person effectively"*

*Lay member*

<sup>23</sup> [www.publications.parliament.uk/pa/cm201213/cmselect/cmhealth/782/78202.htm](http://www.publications.parliament.uk/pa/cm201213/cmselect/cmhealth/782/78202.htm)

70. The Public Involvement Programme (PIP) uses an online exit survey to enable lay people who have worked with NICE to provide feedback on their experiences. The survey is tailored to lay members depending on the type of committee member they have been. Results of the survey provide the PIP with opportunities to learn lessons and change or adjust things that are not working. Feedback from lay members is used to develop and improve the support the PIP provides, and to improve lay members' wider experience of working with NICE, with suggested new initiatives and areas for improvement implemented as appropriate.
71. Survey results are collected and analysed on a quarterly basis, and the findings are discussed at the PIP team meetings to identify recommendations for improvement. A copy of the first exit survey quarterly report (final quarter of 2013) is available on request. The PIP works with internal teams across NICE, along with relevant external stakeholders, to make improvements. The exit survey itself is reviewed every 6 months to ensure it remains accessible and fit for purpose.
72. For the reporting period January–December 2014, 30 exit surveys were returned; some of the results are presented in figures 3–6. Please note that these figures represent the actual numbers of returned surveys. It is to be acknowledged that the data on the return rate is imperfect, with a best estimate of about 26%.

### ***What's working well?***

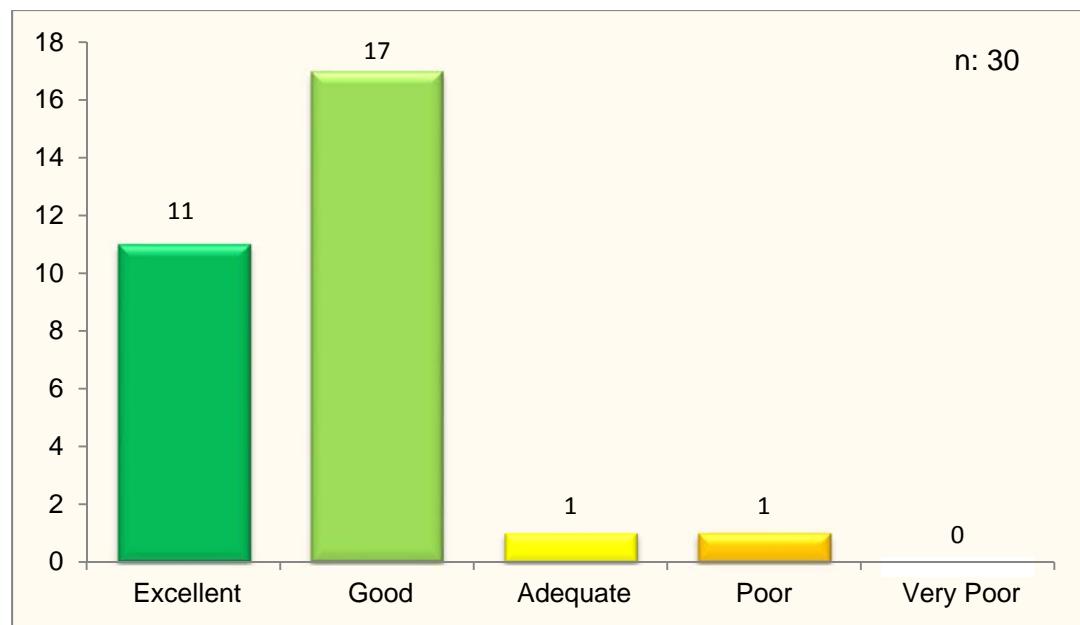
73. Overall, responses were very positive with a high number of respondents stating that they have enjoyed being on committees and that they felt supported, included, involved and valued. However, this was not the experience of everyone, as one lay member stated that they felt that their 'contributions were less valued than those of professionals', while another felt that there was 'a bit of a condescending attitude by some of the academics'.
74. Many lay members felt that the experience of being on committees and working with NICE has improved their knowledge, confidence and self-esteem, and in several cases has led to voluntary or paid work. There was praise for the competency of the chairs, for the organisation of meetings and the clarity of information, which was provided in a timely fashion. Overall, lay members felt proud to be able to contribute to NICE's 'high quality work'.

### ***What needs improvement?***

75. There was dissatisfaction with the expenses system, with one lay member finding 'the online registration for payment dreadful'. The physical challenge of carrying large amounts of printed information to and from meetings was mentioned and that could cause particular difficulties for lay members with disabilities. Another potential barrier to contribution was the process and fast flow of the meetings. There were real challenges for some lay members around accessibility of venues and travel/accommodation. One lay member stated a need for 'more

accessible/localised meeting venues such as Cardiff, Bristol, Cheltenham, Birmingham'.

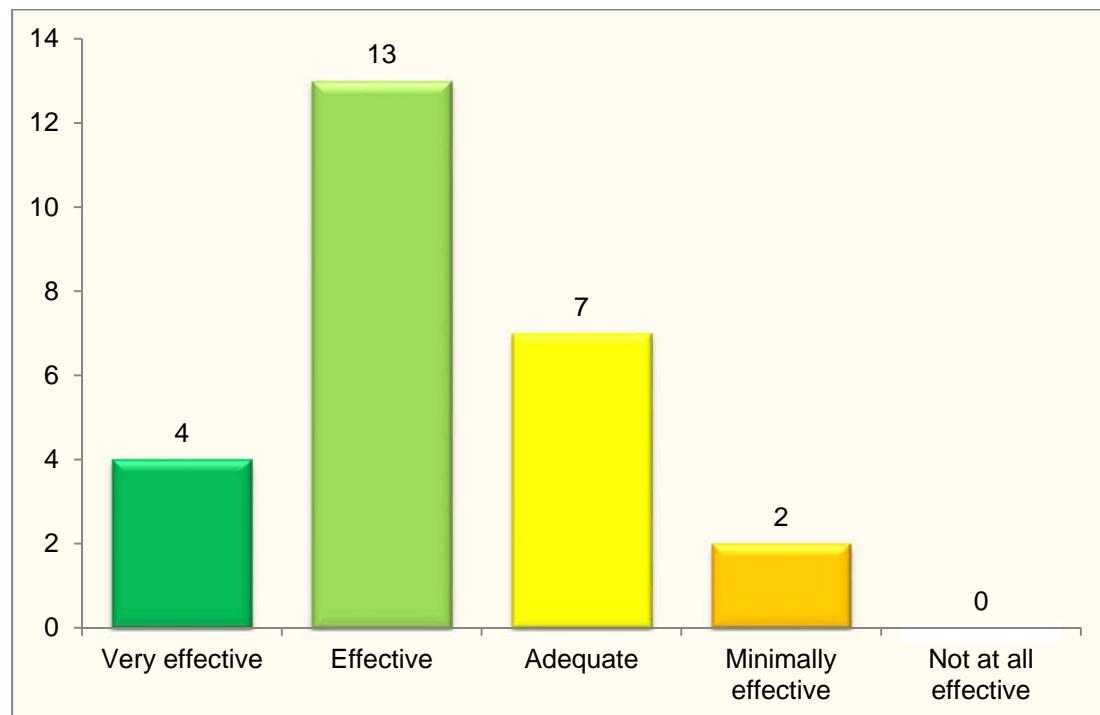
**Figure 3: overall experience of being a lay member on a NICE group or committee January–December 2014**



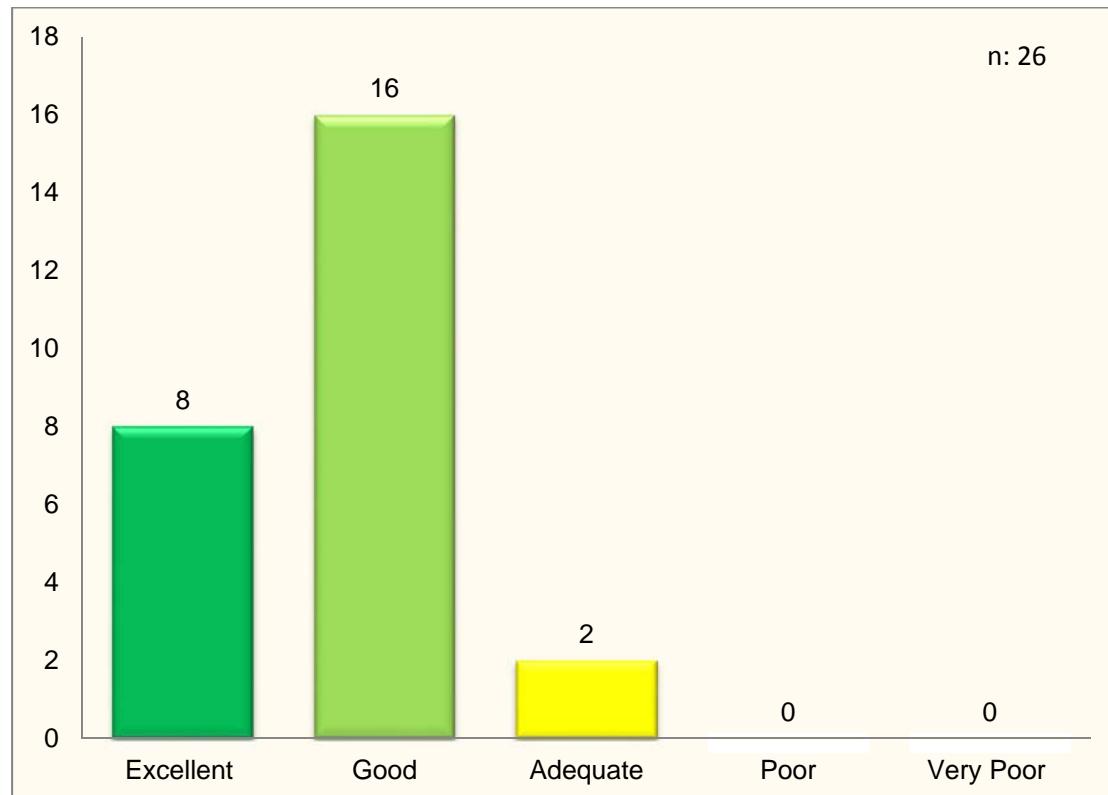
**Figure 4: ease of contribution to the work of the group or committee January–December 2014**



**Figure 5: effectiveness of contribution to the work of the group or committee January–December 2014**



**Figure 6: support from NICE's public involvement programme January–December 2014**



*"I am grateful for the opportunity to participate in the guidance development process to help make the NICE guidance and hopefully the NHS in turn better and more responsive"*

*Lay member*

## **Other notable achievements**

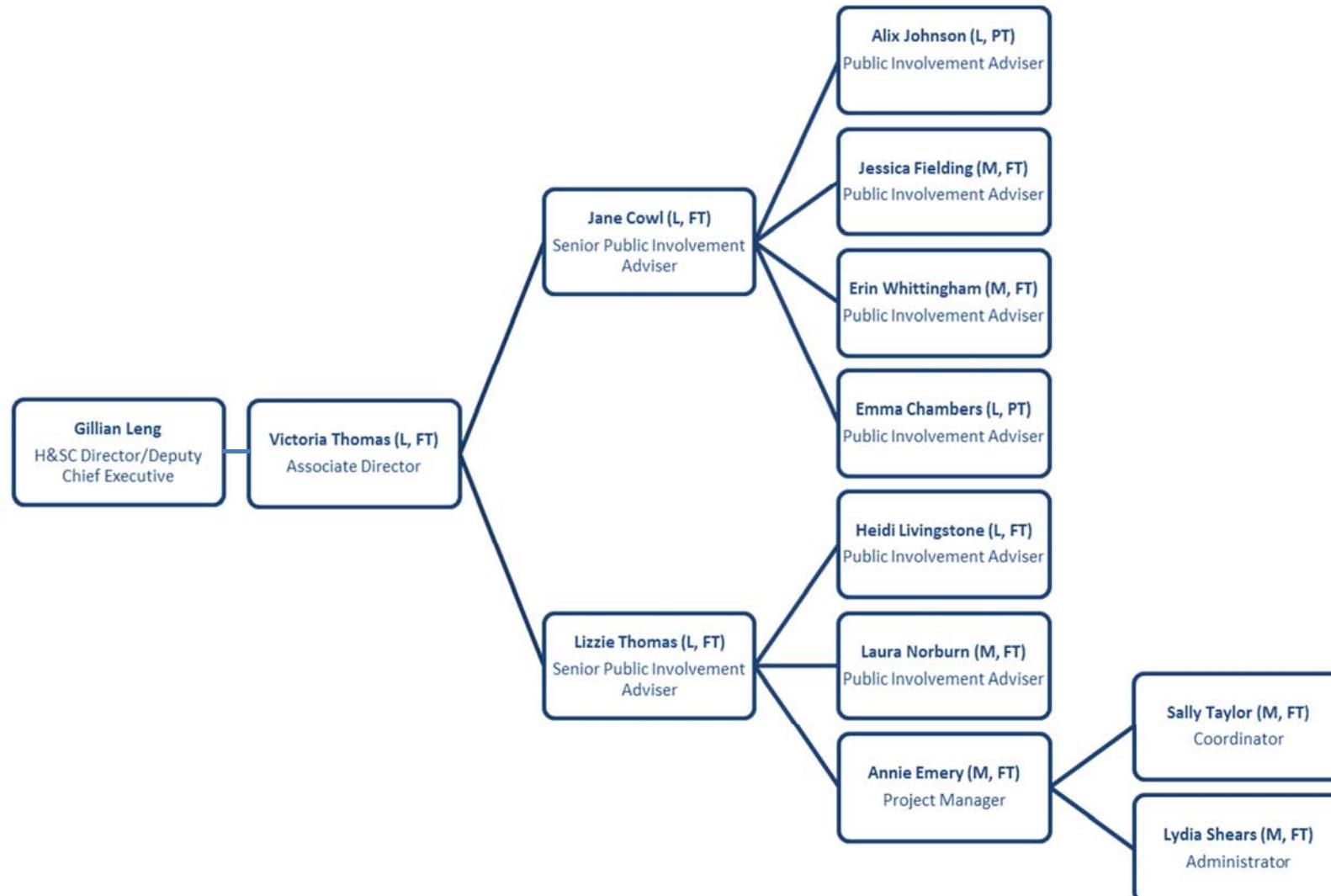
76. We have been working to improve the patient group attendance at Technology Appraisals scoping workshops and this year we have identified and supported the highest number of patient group attendance in any year to date. There were 61 patient group attendees who participated in 26 technology appraisal scoping workshops. The workshops were grouped into 6 batches across the year and we had an unprecedented record of 22 patient attendees in 1 batch.
77. Patient and public involvement has been embedded in the work of the Diagnostics Assessment Programme since its inception, but the challenging nature of diagnostic assessment means that meaningful involvement can be difficult to achieve. Over the past year we have seen an increase in interest in this work with 20 applications received for specialist committee membership for one particular topic and 14 people representing the experience of patients, carers and people who use health and care services attending the scoping workshop. To ensure a range of views were represented on the committee the DAP team opted to appoint 3 patient/carers specialist committee member for the topic rather than the usual 1 person.
78. The past year has also seen presentations from the patient/carers specialist committee member embedded into the lead team presentations given at Diagnostics Advisory Committee meetings. Having the patient/carers specialist committee member present their views and experiences as part of the presentation of the evidence has helped to ensure that patient and carer issues are fully considered, and the contributions of the patient/carers specialist committee members have been well received by the committee.
79. Of 46 Interventional Procedures topics in 2014, 35 topics were suitable for patient commentary. We gained practicing centres' agreement to send out questionnaires for 33 of them. Patients for 24 topics returned questionnaires. The return rate across these topics varied between 5% and 100%. Overall of the 860 questionnaires sent we had 197 back.

*Patient and public involvement (PPI) has become a core activity nationally and internationally. PPI in the work of NICE is world-leading in its scope, reach and influence. The Public Involvement Programme within NICE has evolved over the last decade to embed PPI into the core activities within NICE, demonstrating leadership at an international level. The patient reps within NICE have made important and significant contributions to the work of NICE, helping to ensure its outputs are relevant, appropriate, effective and acceptable from a public perspective. Many countries now look to the team for exemplars of practice. I congratulate the team on the progress they have made and look forward to future developments.*

*Dr Sophie Staniszewska,  
Lead for the PPI and Patient Experiences Programme,  
RCN Research Institute, University of Warwick*

## Appendix 1 – Public Involvement Programme Staffing Structure – February 2015

(L = London; M = Manchester; FT = Full-time; PT = Part-time)



## Appendix 2

### ***Public Involvement Programme: new starters, returning staff members, and those who left during 2014***

#### **New starters**

- Annie Emery, Project Manager (March 2014)
- Sally Taylor, Coordinator (September 2014)
- Lydia Shears, Administrator (October 2014)
- Jessica Fielding, Public Involvement Adviser (November 2014)

#### **Returning team members**

- Emma Chambers, Public Involvement Adviser, came back from maternity leave in April 2014.

#### **Leavers**

- Jessica Sims – successfully completed her fixed-term contract covering Emma Chambers' maternity cover
- Alex Curwen – joined the Medicines and Prescribing Centre
- Emma Stonier – joined the Costing team
- Jenna Dilkes – joined the Highly Specialised Technologies team.

## **Appendix 3 – Meetings with and visits to patient and voluntary sector groups 2014**

Action for Children

Age Action Alliance

Association for Research in the Voluntary and Community Sector (ARVAC)

Association for Young People's Health (AYPH)

Barnardo's

Beth Johnson Foundation

Breakthrough Breast Cancer

Cancer52

Children England

Community Catalysts

Crohn's and Colitis UK

Dementia Action Alliance

Diabetes UK

Disability Rights UK

Gauchers Association

Keyring (Working for Justice Group)

Lymphoma Association

Maslaha

MQ: Transforming Mental Health

MS Society

Muscular Dystrophy Campaign

National Pensioners Convention

National Voices

Regional Voices

Royal National Institute of Blind People (RNIB)

SCIE Co-production Network