NICE   
National Institute for Health and Care Excellence

# Picture of the heads and shoulders of a diverse group of people. The picture is in the shape of a speech bubble.

Public Involvement at NICE

Annual report 2019/2020

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Introduction

1. From our inception working with patients and the public, and the organisations who support them, has been core to NICE’s work. It is embedded in [our principles](https://www.nice.org.uk/about/who-we-are/our-principles) and our [patient and public involvement policy](https://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/public-involvement-programme/patient-public-involvement-policy). This report describes the work of the Public Involvement Programme (PIP), and broader public involvement activities across NICE, in the financial year 2019 to 2020.
2. We have supported the involvement of patients, people who use services, their families, carers and the public in the development of guidance and standards. We have recruited, trained and supported people to enable them to take part meaningfully in our work. We have also worked with our voluntary and community sector stakeholders to build relationships and improve how we involve those stakeholders in our work.
3. We have continued to support and promote public involvement at a national and international level through our work with the Health Technology Assessment International (HTAi) Patient and Citizen’s Involvement Group (PCIG), the International Network of Agencies for Health Technology Assessment (INAHTA) Patient Engagement Learning Group and through the Guidelines International Network (G-I-N) Public Working Group.
4. We have supported the growing shared decision-making agenda, holding the 6th meeting of our Shared Decision-Making Collaborative and contributing to ongoing developments in the field.
5. Finally, although extending beyond this reporting period, we have included information on public involvement work in response to the COVID-19 pandemic and our plans for the future in the extraordinary times in which we find ourselves.

Acknowledgements

1. We would like to acknowledge the huge contribution that patients, people who use services, their families, carers and the public have made to our work across the breadth of our activities, and to thank them for their dedication and commitment. We would also like to acknowledge our patient, voluntary and community sector stakeholders who have continued to participate in our work, help us to improve our processes for public involvement, and to act as a critical friend to NICE.

Facts and figures

Recruiting and identifying people to take part in our work

1. PIP supports the recruitment of patients, people who use services, their families, carers and members of the public across all NICE work programmes; in most cases we describe the people we recruit as ‘lay members’ (although some variation in that terminology occurs across the organisation). Our policy states that committees should have a least two lay members as part of their membership. In 2019/20 we received 494 applications for 79 committee vacancies and in the end recruited 63 people to join a variety of committees.
2. The disparity between the number of vacancies and the number of people recruited was a result of several factors, including:

* challenges in recruiting in topic areas where there is low voluntary and community sector activity – for example infectious skin conditions and ‘flu
* recruiting for topics affecting very young children and babies
* the diabetes suite of topics, where a range of different experiences was required, resulting in 9 potential vacancies. Ultimately either not all elements of experience could be recruited to or one applicant was able to speak to more than one type of experience.

Figure 1 – recruited lay members and applicants

[Download the data set for this chart](https://www.nice.org.uk/Media/Default/Get-involved/Meetings-In-Public/Public-board-meetings/Data-sets/sep20-board-paper-data-sets.xlsx)

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invited members and patient experts supported this year

1. As well as recruiting lay members we have supported 13 lay people to join our quality standards advisory committees as invited specialist committee members, 16 lay people to contribute to NICE Scientific Advice meetings, and 57 lay people to share their knowledge and experience with committees as a patient expert.

Involving individual people

1. Once recruited to a committee, lay members receive induction and training as well as ongoing support from a named member of the Public Involvement Programme. They also receive support from the team who are running their committee.
2. We are keen that our support meets the needs of the people who we are working with. In some instances we need to adapt the way we work to ensure that people’s needs can be met.

**Case study: supporting lay members with ME/CFS**

The Guideline Committee (GC) for ME/CFS (Myalgic Encephalomyelitis (or encephalopathy)/chronic fatigue syndrome) includes 5 lay members, 4 of whom are living with diagnosed ME/CFS. Due to the impact of the condition and the demands of GC meetings, the PIP team and the guideline developer have made significant adjustments to our regular process to safeguard the health and wellbeing of our lay members. This includes special seating arrangements (recliners) during training and GC meetings; additional overnight accommodation before and after meetings as needed, to allow for additional rest; longer lunch breaks than other GC meetings to allow for rest; lap desks to use for papers while using recliners and overnight accommodation at the same venue as GC meetings to minimise travel.

Lay members were consulted on what might help them and these adjustments were led by suggestions from them. This has also had a significant resource impact which was accounted for. Feedback from lay members has been extremely positive and they feel that the expected payback on their health has been much mitigated due to these adjustments.

1. In 2019/20 we created a guide for NICE staff which outlines the role and value of lay members and gives tips and suggestions from lay members themselves about how to support them during their work with us (shown in Figure 2). Please note that the guide was developed before the introduction of virtual committee working as a consequence of COVID-19. This will be amended to reflect new ways of working once these have bedded in.

Figure 2: How we support lay members – a guide for NICE staff

Figure 2 shows an image of a guide to supporting lay members. It says:
How to support lay members before and after meetings.
Section 1: Get in touch before the meeting - communicate with lay members before the meeting in the way they prefer. Inform people of any changes to meetings or delays in sending documents.

Section 2: send documents in advance - allow enough time for lay members to read documents (at least 1 week)

Section 3: Think about location and timing. Be mindful of location and ask about people's other commitments. Travelling may be difficult so offer video conferencing as an option. Think about timing, for example around holidays or religious festivals.

Section 4: check accessibility. Ask lay members if they have any specific accessibility needs. Check before the meeting that the venue us fully accessible. Provide documents in accessible formats. Assign a fire buddy to anyone who may need assistance evacuating the building. Ensure everyone in the room can hear what is being said; use microphones and encourage people to speak up.

Section 5: Think about seating arrangements. Plan seating to encourage contributions from lay members. Ask if they have any seating preferences. Ensure that the Chair can see all committee members.

Section 6: Get in touch after the meeting. Communicate with lay members after the meeting about their experiences. Ask for feedback to improve future experiences. If changes are made to the final recommendations without committee input, explain the reasons why to the committee.


Exit surveys

1. When a lay member finishes their work with us we ask them to complete an exit survey to hear about their experiences, and to hear any suggestions they might have for improvements. The data we receive is shared with internal teams and our external guideline developers, and an annual exit survey report is produced.
2. In 2019/20 we sent out 76 exit surveys and received 42 responses - an overall response rate of 55%. This is an increase from the response rate of 47% for the previous year. Ninety percent of respondents rated their experience of working with us as ‘good’ or ‘excellent’ this is down from ninety-five percent in the previous year, however the result still represents a positive picture of people’s experiences.

Figure 3 – overall experience of working on a NICE committee

[Download the data set for this chart](https://www.nice.org.uk/Media/Default/Get-involved/Meetings-In-Public/Public-board-meetings/Data-sets/sep20-board-paper-data-sets.xlsx)

1. Participants reflected on both the positive and negative aspects of their work with NICE and our guideline developer centres. Committee working and the role of the chair were highlighted as particularly positive elements of lay members’ experiences. The following factors were also identified as being influential in their experience of working on a committee:

* being listened to and having their views considered, respected and valued (n=12)
* being an equal committee member (n=6)
* a ‘friendly committee – made to feel welcome’ (n=5).

1. In response to the question 'What went well during your time on the committee?', 18 respondents (43%) across a range of programmes specifically complimented their committee chair, mentioning a key aspect of creating a constructive, open, calm and friendly environment.

*‘The chair of the committee made it really accessible, and so as a lay person I didn't feel lost or left out. The environment…was open and calm.’* – NICE lay member

1. Where chairing was felt to have been poor [n=3], respondents indicated that this prevented lay members from contributing effectively, demonstrating how crucial the role of the chair is to effective involvement. Other challenges that lay members faced related to meeting arrangements and administration – just over half (16 out of 29) of lay members who mentioned meeting arrangements and administration noted that they had had a problem. This included papers being sent late or tight deadlines being given [n=4], IT issues in meetings [n=3] and poor communication with developer teams [n=2].
2. Ninety percent of respondents were able to give at least one example of the impact they thought they had made on their committee. Eighteen respondents (43%) commented that their greatest achievement was ‘simply being there and representing the patient/carer view’. Nineteen other people (43%) were able to elaborate on how their involvement impacted on the guidance. The following themes demonstrate where lay members thought they had had an impact on the guidance:

* influencing rationales and recommendations (n=9)
* creating decision aids (n=2)
* identifying gaps in committee expertise and recruiting new members (n=1)
* challenging professionals’ views of the patient (n=4)
* highlighting patient views from consultation comments (n=1)
* influencing health economic factors (n=1)
* publishing the guideline (n=1).

Support and learning

Training days

1. As part of our support for new people joining guideline committees, we ran 3 face-to-face training days to equip them with the knowledge and skills to get the most out of their time on the committee. The training was focused around making an impact and covers:

* developing guidelines – what evidence NICE uses and how we look for and assess that evidence
* preparing for meetings - what to expect and how committees use evidence

making an impact – sharing knowledge, experience and ideas with former lay members.

1. Speakers from both within NICE and our developer centres contributed to each training session. Former lay members took part to share their experiences and knowledge of working with us. In total 32 people received training this year.
2. We asked attendees to provide feedback following each training day. Participants were asked to score (1-10) for each aspect of the workshop, where 10 = very good; 1 = very poor. Twenty-one participants completed a feedback form and an overview of this feedback is provided in table 1.

Table 1 – Summary of training day feedback scores

| Session | Range | Mean score |
| --- | --- | --- |
| I know what support and training is available to me | 6 to 10 | 9.0 |
| I understand my role as a lay member | 7 to 10 | 9.2 |
| I understand the guideline development process | 5 to 10 | 8.9 |
| I understand the different types of evidence that my committee will be looking at | 6 to 10 | 9.1 |
| I understand how evidence is prepared for my committee | 6 to 10 | 9.1 |
| I understand how committees develop recommendations | 6 to 10 | 9.0 |
| I know how to prepare for meetings | 7 to 10 | 9.4 |
| I feel confident that I can have a positive impact in meetings | 6 to 10 | 9.2 |

Online training modules

1. We have continued developing a suite of online training modules for lay members, which will enable them to access training resources at a time which is convenient for them. We developed training content in the Electronic Staff Record (ESR) platform, using the functions available for staff training. Lay members then tested the training modules using ESR as the platform to access them. We received valuable feedback from our users. Challenges with different web browsers and incompatibility with Apple products meant that ESR did not ultimately meet our requirements.
2. Following the user testing we have continued to explore how and where we can make training modules available to lay members. We have continued to develop modules using PowerPoint and voice-overs. In 2020/21 we will trial NICE Share as a potential platform to enable access to training modules. This will give us less sophisticated content as it will be in PowerPoint format but should enable the modules to be made available and easily accessible to our users.

Building relationships with voluntary and community sector organisations

1. Voluntary and community sector (VCS) organisations are a key stakeholder group for NICE. They make an invaluable contribution to our work throughout guidance development, and in supporting and promoting the uptake of our guidance. Developing and strengthening our relationships with VCS organisations is a key component of PIP’s work and one of the means by which we can achieve meaningful patient and public involvement.

Speaking engagements and meetings with voluntary and community sector organisations

1. In 2019/20 PIP took part in 9 national and international events as a speaker or panel member to share our learning and experiences of involving patients and the public in guidance development. We also held 12 meetings with voluntary and community sector organisations or umbrella groups. These meetings discussed NICE work in a specific topic area, gave an induction to the organisation for those who are new to working with us, and provided opportunities to address any issues raised.

Training and support for voluntary and community sector organisations

1. During the year we held two masterclasses for voluntary and community sector organisations. These were free to attend and were held in our London office.
2. Eighteen participants attended our ‘Intro to NICE’ masterclass and took part in interactive sessions exploring the range of guidance NICE produces as well as the opportunities to get involved in our work. The masterclass also included insight from two organisations who have worked extensively with NICE and who shared their experiences around involvement and the implementation of NICE guidance.

*‘Overall really helpful and I would definitely recommend to anyone thinking of engaging with NICE process.’* – masterclass participant

1. Our second masterclass specifically explored the highly specialised technologies (HST) programme. Fifteen participants from a range of rare disease organisations attended and took part in a range of activities to both build their knowledge about HST evaluations and discuss effective participation in the programme.
2. For both masterclasses we received detailed, thoughtful, and generally positive feedback from participants which is invaluable for planning future sessions. We are grateful to NICE staff, lay members, and the staff from voluntary and community sector organisations who contributed to the agenda for our masterclasses, and to all participants for their engagement and interest.
3. A further masterclass was planned for March 2020 with an agenda specifically covering implementation and the role of voluntary and community sector organisation in supporting and promoting the uptake of our guidance. Due to the COVID-19 pandemic this masterclass was postponed and will be rescheduled to take place virtually.

Patient involvement in health technology assessments: taking a coproduction approach

1. Starting in late 2018 and concluding in late 2019 we engaged voluntary and community sector organisations in a piece of work to look at ways of improving patient involvement in health technology assessments across NICE. This was part of a broader programme of transformation work undertaken by the Centre for Health Technology Evaluation.
2. The work took a co-production approach, overseen by a working group which included 6 people from voluntary and community sector organisations, working alongside NICE staff. Wider engagement and consultation took place with voluntary and community sector organisations including an independently-facilitated stakeholder workshop attended by 22 organisations. We conducted a targeted consultation, via a survey, which yielded responses from 52 organisations. Throughout the project external engagement, such as speaking engagements and meetings with organisations, took place to encourage participation in the work.
3. Areas for development within our processes, as identified by our voluntary and community sector stakeholders, included:

providing information about uncertainties that patient evidence might help address

exploring the role of real-world evidence in patient involvement

providing training and support to patient organisations

creating inclusive committee cultures

including additional steps during HTAs to incorporate patient evidence.

1. A final report, containing 18 detailed recommendations has been submitted to the Centre for Health Technology Evaluation and these will be considered for inclusion in updated process and methods guides which will be subject to public consultation during 2020. We will also consider how these recommendations might apply in relation to the Centre for Guidelines and across other NICE programmes.

Beyond guidance development

1. Voluntary and community sector organisations have engaged with NICE beyond our usual guidance development processes. They have contributed perspectives and insight to [NICE Impact reports](https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-uptake-of-nice-guidance/impact-of-guidance) and helped to develop a number of NICE [patient decision aids](https://www.evidence.nhs.uk/search?om=%5b%7b%22ety%22:%5b%22Patient%20Decision%20Aids%22%5d%7d,%7b%22srn%22:%5b%22National%20Institute%20for%20Health%20and%20Care%20Excellence%20-%20NICE%22%5d%7d%5d).

Working internationally

1. In 2019/20 PIP has maintained and built on its profile as a world leader in patient and public involvement.

Guidelines International Network (G-I-N)

1. The [G-I-N Public working group](http://www.g-i-n.net/working-groups/gin-public) (currently chaired by a PIP staff member) promotes good practice on involving patients and the public in developing and implementing guidelines across international guideline developers. Led by NICE and including chapters written by members of the PIP team, the G-I-N public working group is updating the [G-I-N Public Toolkit](http://www.g-i-n.net/working-groups/gin-public/toolkit) and aims to publish an updated toolkit in 2020/21.

Health Technology Assessment International (HTAi)

1. PIP have continued our involvement in the [Health Technology Assessment International’s Patient and Citizens’ Involvement Group](https://htai.org/interest-groups/pcig/) (HTAi PCIG), including as a member of the steering group for the PCIG. This year we have worked on a number of projects with our colleagues, including:

* Co-leading work to develop a summary of information for patients (SIP) for patients and organisations taking part in an HTA. The SIP provides information about the medicine or device, written in plain language, to enable patients to provide targeted input into HTAs. The key deliverables from the work will be a template SIP for use by industry, plus guides for patients, industry and HTA agencies and an introductory slide deck.
* Presenting two vignettes, an oral presentation and taking part in a panel session and workshop at the HTAi 2019 conference in Cologne.

PARADIGM

1. We took part in the HTAi PARADIGM workshop on Early Dialogues (similar to NICE Scientific Advice) in October 2019. The workshop explored tools to support the rationale for patient involvement, to review methods and frameworks and to develop tools for recruiting, interviewing and supporting patient experts in Early Dialogues. Several agencies took part from France, Germany, UK, Italy, Hungary, Spain, Norway and Sweden. NICE was invited to provide expertise and insight to support the development of standardised tools and resources.

There were several outcomes, including agreement on:

* documents to support the rationale for patient involvement in Early Dialogues for all stakeholder groups (e.g., values statements, fact-sheets, including the goals of patient involvement, and case studies to highlight the value of involvement)
* a process framework for in Early Dialogues: interviews and the meetings (despite variation between agencies)
* the types of resources needed to support the process, including guidance for stakeholders (e.g., what companies and patients can expect) and templates (e.g., invitation emails, conflict of interest forms and contracts)
* tools to support the interview and meeting processes, including logistical preparation checklists for meetings and guidance on interview techniques or support for the interviewer.

International Network of Agencies for Health Technology Assessment

1. PIP joined the International Network of Agencies for Health Technology Assessment (INAHTA) Patient Engagement Learning Group in 2019. The group’s purpose is to share knowledge and experience about patient engagement amongst member HTA agencies. We presented NICE’s approach to patient engagement and involvement in HTA via a webinar, focussing on our work evaluating the impact of patient input into the highly specialised technologies and interventional procedures programmes.

EVOLVE

1. PIP has taken part in the EVOLVE (giving patients a mEaningful VOice in the design and deLiVery of care) study as a steering group member, contributing to the research protocol and advising the project team. The aim of the EVOLVE study is to evaluate patient and public involvement (PPI) in clinical practice guidelines and to design and test an involvement model for PPI in urological cancer guidelines. The University of Aberdeen is the sponsor for the study with endorsement from European Association of Urology (EAU) Guidelines Office. The study is funded by Scottish urological cancer charity UCAN.

Supporting shared decision-making

NICE Shared Decision-Making Collaborative

1. In June 2019 PIP convened the 6th meeting of the NICE Shared Decision-Making Collaborative. Forty-eight people attended the event representing academia, voluntary and community sector organisations, professional organisations, regulators, Arm’s Length Bodies and commercial organisations, all of whom have a commitment to and interest in shared decision-making. The agenda facilitated updates on shared decision-making from a range of speakers, capturing national and international developments and addressing issues around health literacy and risk communication.
2. A ‘World Café’ approach was taken for the afternoon session where participants moved through a number of different groups, discussing key areas for action around shared decision making. New actions for the Collaborative were identified and refined at a follow-up meeting of core Collaborative members in November 2019. Launch and promotion of the new areas for action was planned for March 2020 but has been postponed to a more appropriate time given the COVID-19 pandemic and consultation on the upcoming shared decision-making guideline.

Communications

Social media

1. We have increased our presence on social media using the PIP team’s [@NICEGetinvolved](https://twitter.com/NICEGetInvolved) account. This has helped us to reach more members of the public and different communities, work and communicate more effectively with our stakeholders, and to take part in campaigns with our voluntary and community sector stakeholders.
2. In 2019/20 we achieved:

715 tweets

951,200 impressions

8 thousand profile views

18% more followers.

1. In October 2019 [@NICEGetinvolved](https://twitter.com/NICEGetInvolved) ran a twitter campaign for World Mental Health day. The campaign was delivered in partnership with our lay members and key stakeholders, promoting relevant NICE guidance, user experience, and examples of how services are being improved. 516 users directly engaged with the campaign, with messages generating 57,151 impressions.

Public involvement in a pandemic – meeting the challenge of COVID-19

1. The emergence of the COVID-19 pandemic in the spring of 2020 has had a profound effect on the way we work, and on the challenges faced by those we seek to involve. Although largely beyond the parameters for this annual report (2019/20 financial year) it would be remiss not to provide an update on the impact of COVID-19 on our work, and the contributions of voluntary and community sector organisations to NICE’s response to the pandemic.

COVID-19 rapid guidelines

1. Early on in the pandemic NICE was commissioned to develop and publish rapid guidance on a range of issues related to COVID-19. This necessitated a highly accelerated development process, in some cases reduced to one week. A targeted consultation exercise with stakeholders formed part of the process with a consultation period in some cases of only 5 hours, with 2 or 3 days’ notice.
2. PIP worked to identify voluntary and community sector organisations to take part in the targeted consultations and engaged with those organisations to explain the constraints we were working under and to encourage their participation where possible. As a consequence of our work building relationships with those stakeholders, as detailed earlier in this report, the response from voluntary and community sector organisations was overwhelmingly positive and they stepped up to the challenge magnificently, providing insightful comments across the COVID-19 rapid guideline topics.
3. We are aware however that the COVID-19 pandemic has had a profound effect on the voluntary and community sector with significant numbers of staff being furloughed and with huge uncertainty over funding for those organisations. PIP has maintained a dialogue with key voluntary and community sector umbrella groups to understand the impact on organisations and work with them to support their continued involvement where we can.

Involvement in a virtual world

1. The lockdown implemented in response to the threat from COVID-19 has moved patient and public involvement into the virtual world. NICE committee meetings are now held via videoconference which presents new challenges and opportunities for the meaningful involvement of lay members and patient experts in committee meetings.
2. Led by a cross-NICE team, training and support has been provided to committee members to enable them to take part in meetings successfully in the new virtual environment, and to train other members of staff to run virtual meetings. PIP has supported lay members in this change and regularly gathers informal feedback about people’s experiences of working in this way to ensure their contributions continue to be meaningful.
3. Use of virtual meeting software has allowed PIP to engage with patient experts attending committee meetings in a different way. An adviser from PIP has attended each technology appraisals committee meeting to provide support to patient experts joining those meetings. We have implemented a group waiting room for patient experts where PIP can provide information and answer any questions people might have before they move to the main committee group. The chat function in virtual meeting software means that participants have been able to ask PIP questions privately, or ask for clarification during a meeting – something that wouldn’t be possible face-to-face in a large meeting room.

Conclusion and future plans

1. As ever the Public Involvement Programme’s future plans will be guided by NICE’s overall strategic development. However there are several strands of work for which we have ambitions over the coming months. These include:

Policy and service review

1. We will initiate a formal policy review to ensure that we are adhering to best practice in relation to public involvement. As part of this we are planning to develop a conceptual framework for involvement so that our intentions and practice are transparent and explicit. This will lead into a review of our services and what we can offer to the internal and external landscape.

Strategic relationships with patient, voluntary and community stakeholders

1. We will develop and plan our future strategic relationship with patient, community and voluntary sector organisations, particularly building on the experience and learning during the pandemic which has significantly adversely affected our stakeholder community. Working with external stakeholders and internal colleagues from the Audience Insight team we will consider how stakeholder engagement might be reconceptualised in a way that works well for our stakeholders, enables them to contribute to our work efficiently and effectively, and is useful for us. Our relationship with patient, community and voluntary sector organisations is fundamental to our work and we need to make sure that it is fit for the future and takes into account the challenges that our stakeholders face, especially in the ongoing context of COVID-19.

Deliberative public engagement

1. We will work with our colleagues in the Science Policy and Research team to revive NICE’s activities in relation to deliberative engagement with members of the public, enabling us to gain the UK citizen’s perspective on issues of ethical concern and debate.

Equality and Diversity

1. We will work to support NICE’s ongoing commitment to supporting equality and increasing the diversity of our lay members and of the organisations with whom we work. We will also work with our colleagues in the guidance producing centres on any future developments of the equality impact assessments associated with all guidance.

International work

1. We will work with our colleagues in the Communications directorate to help plan and deliver NICE’s hosting of the 2021 HTAi conference, to be held in Manchester. One of the key plenary sessions is ‘patients at the heart of innovation’ which is an opportunity to showcase the different methods and processes by which patient organisations and individual patients are involved in supporting access to new medicines and other technologies.
2. We will continue to support international initiatives such as the European Patients Academy for Therapeutic Innovation (EUPATI) of which we are part of the founding and ongoing faculty. This gives patient advocates across Europe the opportunity for intensive and practical study in the field of medicines development from the laboratory, to licensing and health technology assessment.
3. Our role as Chair of the G-I-N public working group continues, and we will play a key role in developing and publishing the revised G-I-N public toolkit for developing guidelines in a patient-centred way. We will also work with INAHTA to publish a Patient Engagement Position Statement.
4. We will collaborate with our colleagues within NICE International to ensure that patient and public involvement is high on the agenda for international engagement

‘People like us’

1. The collaboration with our colleagues in the other Arm’s Length Bodies (through the People and Communities Forum) will be maintained, to ensure we are sharing good practice and working jointly and collaboratively wherever possible on matters of engagement with patients and the public.
2. We will also offer advice to other organisations within the health and social care field who wish to develop their patient and public involvement strategies, in order to build capacity and promote good practice.

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