Patient and Public Voice (PPV) Partners and Chairs Survey November 2016 – Report

Patient and Public Voice (PPV) Partners and Chairs Survey November 2016 – Report

Version number: 0.1

First published: November 2017

Prepared by: Public Participation team, NHS England

Classification: OFFICIAL

Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- had due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and

- had regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email england.contactus@nhs.net stating that this document is owned by the Public Participation team in the Directorate of Nursing.

Contents

1 Executive summary

During November and early December 2016, NHS England surveyed Patient and Public Voice (PPV) Partners and chairs of committees, working groups and forums with PPV Partner members about their views and experiences. This report summarises the responses to the two surveys and actions taken or proposed in response.

A total of 88 completed surveys were received from PPV Partners and seven from committee chairs.

The key themes identified from responses from PPV Partners were that:

- Most respondents feel that their input is valued and that they are respected contributors to NHS England's work, however, some are unsure about the impact of their role and there are concerns that involvement may be a 'tick box' exercise. These concerns are made worse by a lack of feedback about the impact of public participation / PPV Partner contributions.
- Some PPV Partners feel somewhat disconnected from wider NHS England activities / public participation opportunities and / or other PPV Partners.
- For some PPV Partners, there could be improvements in the consistency and timeliness of reimbursing PPV Partners' expenses, and some also have concerns about short preparation times before meetings.
- Some PPV Partners are concerned about the lack of diversity amongst NHS England PPV Partners, and especially that there should be greater representation of young people in roles.
- Many PPV Partners referred to public participation activity with organisations other than NHS England, especially through Clinical Commissioning Groups (CCGs) and GP Practice Patient Participation Groups (PPGs).

The feedback received as part of completed surveys has directly informed improvements in the induction process for PPV Partners as well as training and support available, guidance and training for NHS England staff about effective public participation (including supporting PPV Partners), and available resources to support reimbursement of PPV Partners' expenses and consistent, transparent approaches to PPV Partner recruitment.

Further detail about responses and actions is outlined in the report below.

2 Purpose

The purpose of surveying NHS England Patient and Public Voice (PPV) Partners was to find out about their experiences of involvement with NHS England, including induction, information, training and expenses reimbursement, how valued they felt public participation was and areas for improvement.

The survey for chairs of NHS England committees with PPV Partner representatives aimed to better understand their views about the role of PPV Partners and about the impact of their involvement.

It is intended that the surveys will be repeated on an annual basis to enable monitoring of trends and continual improvement in response to feedback.

3 Methodology

The survey for PPV Partners was sent to NHS England's 'Patient and Public Voice Partners' (also commonly known as 'lay representatives' or 'Patient and Public Involvement members') who were identified as being members of NHS England's committees, task forces or regular / formal working groups / forums as at summer / autumn 2016. Dissemination was via the Public Participation team directly, through regional colleagues and through other colleagues supporting key committees / programmes of work known to involve a significant number of Patient and Public Voice (PPV) Partners, for example Specialised Commissioning.

The survey for chairs of committees with PPV Partner members was sent to chairs of an NHS England group, board or committee that had one or more Patient and Public Voice (PPV) Partner members.

The surveys were distributed during November 2016 for response by early December 2016.

Both surveys were available for completion online through NHS England's 'Citizen Space' consultation hub, with paper copies and electronic Word document versions also available to improve accessibility.

The surveys (when completed online) were anonymous and completion of all questions was optional and / or there was a 'prefer not to say' option.

The key findings from the surveys are summarised in sections four and five, with 'free text' responses received as part of completed surveys presented as appendices.

4 Summary of feedback from Patient and Public Voice (PPV) Partners

Key themes

Key themes from responses were that:

- PPV Partners are involved in a wide range of NHS England programmes of work including Personal Health Budgets / Integrated Personal Commissioning, Academic Health Science Networks, service reviews, the New Care Models programme, and are members of committees including the Rare Diseases Advisory Group (RDAG), Patient and Public Voice Assurance Group (PPVAG) and a variety of Clinical Reference Groups.

- PPV Partners are clearly committed to making a positive contribution to the NHS, and many take their PPV Partner roles very seriously.

- Most respondents feel that their input is valued and that they are respected contributors to NHS England's work, however, some are unsure about the impact of their role and there are concerns that involvement may be 'tokenistic' or a 'tick box' exercise.

- These concerns are exacerbated by a lack of feedback about the impact of public participation / PPV Partner contributions, which needs to be addressed.

- Some PPV Partners feel somewhat disconnected from wider NHS England activities / public participation opportunities and / or other PPV Partners. Suggestions include supporting PPV Partners to meet and network.

- For some PPV Partners, there could be improvements in the consistency and timeliness of reimbursing PPV Partners' expenses, and some also have concerns about short preparation times before meetings

- Some PPV Partners feel that the process for getting involved should be simplified and / or that there is a need for greater clarity about roles and expectations.

- Some PPV Partners are concerned about the lack of diversity amongst NHS England PPV Partners, and especially that there should be greater representation of young people in roles.

- Some respondents call for greater integration of public participation activities and insight locally and nationally, with many supporting an enhanced role or greater engagement with Patient Participation Groups (PPGs).

- Another key theme is the suggestion for 'outreach' and other targeted engagement activity to seek the views of individuals and groups 'where they are', especially those underrepresented as PPV Partners.

Many respondents referred to public participation activity with organisations other than NHS England, especially through Clinical Commissioning Groups (CCGs) and GP Practice Patient Participation Groups (PPGs).

Summary

A total of 88 completed surveys were received during the review period – 86 completed online and two Word document surveys. Headline findings are as follows (to note that not all respondents answered all questions and for 'free text' questions responses have been categorised into themes):

- Respondents were part of a wide range of different committees and groups, with many part of other NHS groups beyond NHS England. Many respondents are part of multiple committees and groups for different NHS organisations, including NHS England committees, GP Practice Patient Participation Groups (PPGs), local Healthwatch and a range of local assurance and oversight roles.

- With regards to what extent NHS England values patient and public involvement, 73 respondents (83%) felt that it was valued ‘to some or a great extent’ whereas 12 respondents (13.6%) felt that it was valued ‘hardly’ or ‘not at all’. Key themes from ‘free text’ responses to this question were that it is valued some or very little depending on the group (31 respondents), that it is highly valued (12 respondents), that patient and public is not valued / a ‘tick box’ exercise (5 respondents), that NHS England is good at sending out surveys but poor at responding to feedback (5 respondents) and that there are delays in feedback / no feedback (3 respondents). Many respondents made comments about whether they felt that the wider NHS / their local NHS organisations valued patient and public involvement instead of or in addition to NHS England.

- With regards to what extent the group they were a part of valued patient and public involvement, 47 respondents (54%) felt that it was valued ‘to a great extent’ and 35 respondents (40.2%) ‘to some extent’. Key themes from ‘free text’ responses to this question were that it is highly valued (28 respondents), sometimes valued (10 respondents) and not really valued (9 respondents).

- Most respondents (43 / 50.6%) rated the induction process for NHS England Patient and Public Voice Partners as ‘very good’ or ‘good’, 16 respondents (18.8%) rated it as ‘acceptable’, and 11 respondents (12.9%) rated it as ‘poor’ or ‘very poor’.

- Most respondents (42 / 47.7%) also rated the induction and information for new Patient and Public Voice Partners as ‘very good’ or ‘good’, 22 respondents (25%) rated it as ‘acceptable’ and 11 respondents (12.5%) rated them as ‘poor’ or ‘very poor’.

- With regards to training for Patient and Public Voice Partners to develop, 40 respondents (45.5%) rated this as ‘very good’ or ‘good’, 17 rated it ‘acceptable’, (19.3%) and 17 respondents (19.3%) rated it as ‘poor’ or ‘very poor’.

- With regards to claiming expenses, 51 respondents (58.6%) rated this as ‘very good’ or ‘good’, 23 (26.4%) respondents rated it as ‘acceptable’, and 8 respondents (9.2%) rated it as ‘poor’ or ‘very poor’.

- Free text comments regarding induction, information for new Patient and Public Voice Partners, training and claiming expenses focused on support (or lack of) from colleagues (12 respondents), administration / preparation (for example paperwork) for meetings (11 respondents), training (10 respondents), induction (7 respondents), access to meeting venues / teleconferencing / videoconferencing facilities (5 respondents) and claiming expenses (4 respondents).

- Free text responses to the question ‘how do you stay in touch with the views of patients and the public in order to reflect their views on this group?’ can be categorised as being a member of (other) patient groups and programmes / support group meetings / charities / patient forums (34 respondents), being involved in the local area / listening to other people / attending local events / local news (33 respondents), national networks / peer networks / stakeholders (17 respondents), involved in a (local) hospital / GP surgery / Clinical Commissioning Group / council (16 respondents) and social media (8 respondents).

- With regards to their contribution as a Patient and Public Voice Partner having an impact on the work area, the majority of respondents (47 / 54%) responded ‘to some extent’, 15 respondents (17.2%) ‘to a great extent’, 11 respondents (12.6%) ‘hardly at all’, 5 respondents (5.7%) ‘not at all’, 9 respondents (10.3%) did not know.

- In terms of examples of how their views had been listened to, taken into account and acted on, and the difference this has made, key themes from free text comments were around being listened to (65 respondents), views being taken into account and actioned (53 respondents), making a positive difference (20 respondents), and not being listened to or not participating (3 respondents).

- With regards to other ways used to involve patients and the public in the group's areas of work, the most popular methods were user groups / patient groups / workshops / engagement events / networks / forums (35 respondents), none or do not know (15 respondents), publicity / media / social media (9 respondents), consultations (7 respondents), reporting / feedback (4 respondents) and surveys (4 respondents).

- Respondents’ ‘free text’ suggestions for other ways which could be used to involve patients and the public in the group’s area of work included improved and additional roadshows / health events / focus groups / meetings / networks (18 respondents), better transparency / communication / listening (17 respondents), prioritising / increasing the involvement of young people (16 respondents), raising awareness through social media / websites / advertising / virtual groups (5 respondents), financial recognition / rewards / increased funding (3 respondents).

- When asked for ‘any other comments’, respondents commonly referred to feeling valued / welcomed / involved (or not) (9 respondents), simplifying the process for becoming involved (3 respondents), a lack of engagement or tokenistic engagement (3 respondents). Many other respondents made a variety of ‘uncategorised’ comments.

5 Summary of feedback from committee chairs

A total of seven completed surveys were received from NHS England committee chairs, all completed online. This low response rate is of concern and perhaps suggests a lack of engagement by committee chairs in supporting Patient and Public Voice Partners. It will be interesting to see if the number of responses increases for future surveys, especially as there has been significant internal communication about public participation topics and resources during 2017.

Headline findings were that:

- Respondents chaired a range of different committees, with the majority (6 respondents) working in the South region.

- The majority of respondents (6) felt that patient and public involvement is valued by NHS England ‘to some or greater extent’, with just 1 respondent stating ‘hardly at all’.

- Respondents made positive comments about working with Patient and Public Voice Partners; however, there was a lack of clear examples of how their views had made a difference.

- The most common additional patient and public involvement activity undertaken involved working with local Healthwatch organisations, with 3 respondents referring to this.

6 Next steps – the impact of feedback

In response to feedback received as part of the surveys, as well as other relevant insight, the Public Participation team at NHS England have undertaken a range of actions. We have:

- Improved the induction process for new Patient and Public Voice (PPV) Partners including offering an induction webinar for all new PPV Partners and their NHS England ‘Lead Contact’.

- Developed and published NHS England’s PPV Partners Policy, categorising the different ways in which people can get involved in our work, and setting out expectations around the full ‘life cycle’ of a PPV Partner’s involvement from recruitment through to end of tenure. This Policy is supported by a range of resources for NHS England colleagues to use, for example template application forms and packs.

- Significantly increased training and development opportunities available to PPV Partners, including a range of online training modules covering topics such as equality, diversity and human rights, information governance and health inequalities.

- Provided face-to-face training and webinars for NHS England colleagues on a range of public participation topics including ‘10 steps to even better engagement’ and PPV Partner expenses.

- Started to develop an e-learning package for NHS England colleagues on ‘Developing Relations with Partners’. Due to be completed by December 2017, the package will include how to manage the four key stages of the PPV Partner ‘lifecycle’ (recruitment, induction, ongoing development and ending tenure).

- Revised the PPV Partner Expenses and Involvement Payments Policy to add clarity, and revised / created internal resources to support colleagues in effectively and consistently following the Policy. In addition, a webinar is available to colleagues specifically focusing on expenses for PPV Partners.

- Developed and re-launched the Involvement Hub, which now includes a much wider range of public participation resources as well as links to involvement opportunities and training.

- Promoted subscription to ‘InTouch’ NHS England’s online bulletin for patients and the public, and raised awareness of the Involvement Hub.

The 2017 survey for PPV Partners will include the same questions asked in 2016, plus additional questions asking about subscription to InTouch, the number of NHS England committees the PPV Partner is part of and diversity monitoring information. Supporting information will be amended to clarify that feedback is being sought about involvement with NHS England specifically, with a separate additional question asking for any comments about other NHS involvement, for example with Clinical Commissioning Groups (CCGs).

7 Contacts and alternative formats

If you wish to request a copy of the report, or if you have a query about its contents, please email england.nhs.participation@nhs.net or write to Public Participation team, NHS England, 7E56, Quarry House, Quarry Hill, Leeds, LS2 7UE.

Patients, carers and members of the public can also contact the NHS England Customer Contact Centre by telephone on 0300 311 22 33.

To receive regular updates about engagement activities and opportunities to get involved in the work of NHS England, sign up to receive our newsletter ‘InTouch’.

Appendix 1 – Note on free text responses

Appendices two and three contain ‘free text’ responses. In the interest of transparency, the ‘free text’ responses are published verbatim and do not therefore represent the view of NHS England.

Responses appear in “speech or quotation marks” to indicate that they are a quote from a survey participant and not a statement from NHS England.

Responses are unedited except:

- where information identifies, or is likely to identify, an individual or organisation (other than NHS England);
- references to brand, company, trade or product names;
- details of websites / blogs;
- text copied from other documents in full;
- language or opinion which may cause offence;
- comments which are irrelevant to patient and public participation in health and care.

Wherever text has been removed for one or more of these reasons, this is indicated by way of square brackets […]

Obvious spelling and grammatical errors have also been corrected for ease of reading. In all cases ‘NHSE’ has been written out in full (as ‘NHS England’). Where words have been inserted to aid understanding this is indicated by way of square brackets [around the inserted word].

Effort has been made to indicate quotes which relate to a single response, however, it should be noted that individual responses may be split where their attribution is unclear.

In the interests of document length, in longer responses, text which has been separated by spaces is listed as part of a paragraph, with appropriate punctuation.

Appendix 2 – Responses from PPV Partners

Question 1. Name of Group / Committee / Board you are a member of?

Respondents are / were part of a wide range of groups, committees, boards and programmes of work including *:

> *Note that responses have been split and titles formalised in the interests of clarity and to prevent identification of individuals.

- Academic Health Science Networks (AHSN).
- Clinical Commissioning Group (CCG) assurance.
- Community Education Provider Network (CEPN) Steering Group.
- Citizens' Senate.
- Clinical Commissioning Group (CCG) patient representation roles on committees, 'patient cabinets', patient reference groups, user panels, patient engagement forums and boards.
- Clinical Priorities Advisory Group (CPAG).
- Clinical Reference Groups (CRGs).
- Clinical Senates.
- NHS England Co-production Model Steering Group.
- Five Year Forward View People and Communities Board.
- Hospital Trust / Foundation Trust 'patient partners' and 'patient council' members, as well as involvement in decision-making bodies and specific programmes of work.
- Individual Funding Request (IFR) Panel.
- Involvement in revalidation and review of professionals and performance.
- NHS England Learning Disability and Autism Network.
- Local Healthwatch.
- National Female Genital Mutilation (FGM) Steering Group.
- New Models of Care programme including national and local interview panels, patient representatives and the Patient and Public Voice (PPV) Group.
- NHS Citizen.
- NHS England 'patient representatives' / Patient and Public Voice (PPV) Partners / representatives.
- NHS England Complaints Advisory Group.
- NHS Youth Forum.
- Patient and Public Participation Oversight Group (PPP-OG).
- Patient Participation Group members and chairs.
- Performance Advisory Group (PAG).
- Performers Lists Decision Panel (PLDP).
- Personal Health Budget and Integrated Personal Commissioning National Peer Network.
- Primary Care Oversight Group.
- National Programmes of Care (NPoC) Boards.
- Quality Surveillance Groups.
- Rare Diseases Advisory Group (RDAG).

- Regional Network for Perinatal and Infant Mental Health.
- Specialised Commissioning Oversight Group (SCOG).
- Specialised Commissioning Patient and Public Voice Assurance Group (PPV AG).
- Specialised Commissioning Collaborative Commissioning Programme Oversight Group (CCOG).
- Standard Setting for Accessible Information Advisory Group.
- Strategic Clinical Networks (SCNs) including sub-groups / working groups.
- Transforming Care Partnership Boards.

Respondents were also involved in recruitment of NHS staff, scoring of bids, the development / review of Gender Identity Services, a number of local and national voluntary and community sector organisations and groups, and Sustainability and Transformation Partnership (STP) activities. A number of respondents referred to themselves as Patient Leaders. Respondents were also involved with other national health and care organisations including Health Education England and the National Institute for Health Research (NIHR).

Question 2. Please select the category most relevant to your role with NHS England, or 'national' as appropriate? If you work with NHS England both nationally and regionally you can select two options.

Response	**Total**	**Percentage of responses**
National	47	42.7%
South	27	24.5%
Midlands and East	16	14.5%
North	11	10.0%
London	9	8.2%
Total	**110**	**100.0%**

Question 3. NHS England Directorate, if known?

Response	**Total**	**Percentage of responses**
Commissioning Strategy	14	32.6%
Transformation and Corporate Operations	9	20.9%
Medical	8	18.6%
Nursing	7	16.3%
Operations and Information	5	11.6%
Finance	0	0.0%
Total	**43**	**100.0%**

Not Answered	45

Question 4. Broadly speaking, to what extent do you feel that patient and public involvement is valued by NHS England?

Response	Total	Percentage of responses
To a great extent	19	21.6%
To some extent	54	61.4%
Hardly at all	12	13.6%
Not at all	0	0.0%
Don’t know	3	3.4%
Total	**88**	**100.0%**

- “Sadly not convinced. Went to the […] event and gave some valued feedback so I was told. Heard nothing since.”

- “I rather sense that NHS England are, to a degree, paying lip service to the process of using PPV [Patient and Public Voice] as an instrument to support the change agenda. I feel that views expressed by individuals on the PPV side of things, if not liked by NHS, are largely ignored, which, in my opinion, rather makes a bit of a mockery to the process.”

- “I was on a Specialised Commissioning Clinical Reference Group and these were slashed from 72 to 42 and patient representatives slashed from 200 to 120 and some of them from charities. We were all patients not paid charity workers. NHS Citizen spoiled by now being run by […] paid staff and no patient input or citizen summit with board. Now you have to fill in a massive application form to get on committees. I fill in every application and get told I am not experienced enough. I thought this was patients you wanted not university graduates and company directors. If you come from a deprived neighbourhood you do not qualify as a patient or public representative.”

- “I am not aware of any feedback on our work to assess our contribution or tell us! This applies to question 8 below too.”

- “To great extent for New Models of Care. Hardly at all at present for NHS Citizen.”

- “Patient involvement with the New Care Models team has been exemplary. This has been at a national, regional (i.e. […]) and local level (i.e. […]). See further comments in next section. Patient involvement with the STP [Sustainability and Transformation Partnerships] process has been abysmal. Planning has been ongoing for the best part of this calendar year and I am unaware of any patient input or consultation. I am left with the impression that ‘when the chips are down’, patient input is ignored.”

- “Patient involvement still needs to be addressed and fully accepted by NHS England as a partnership role aimed at helping to transform and deliver future care and support in both acute and primary care roles.”

- “You are great at sending out surveys [and] holding events but are you actually listening to patients? And if you are listening then why not act on the patients' views.”

- “I have been highly valued by some projects that I have worked to the extent that my contribution is of equal importance to NHS England staff and contractors. In other roles things change about patient involvement and you are not told that your role has disappeared.”

- “I feel they try and listen but do not often act upon what they are told.”

- “Recognition of the value of PPE [Patient and Public Engagement] is variable, but improving in last 2 years. For some NHS organisations, patient involvement is just tokenistic - I would be happy to give you examples.”

- “Lots of words and documents, action not so good. Normally overtaken by rapidity of scheme implementation excuses.”
- “Delays in processing payments and expenses; delays in feedback on roles.”

- “I personally feel it is improving regards to engagement but a lot more needs to be done and many panels across the board should have at least one PPV [Patient and Public Voice Partner] especially when it comes to new ideas, assessments and yearly feedback.”

- “Not sure whether it is a government exercise in ticking boxes, but I hope not.”

- “I work as an Associate Manager for Mental Health services for […]. I am also a Governor for […]. The trusts for which I work are deeply committed to patient and public involvement. However whether this is the same as NHS England, who knows? The staff and patients I meet with are deeply concerned about the impact the ongoing cuts are having to the morale of staff, the quality of care being offered and the general well-being of patients, especially in mental health. Whether NHS England are bothered is difficult to answer.”

- “So far I have not been involved in any NHS England activities, in spite of volunteering. The London-centric activities are unlikely to attract members such as myself, where travel to and from London is difficult, particularly with regular rail strikes and limited rail service.”

- “Those who manage the volunteers value the contribution and Clinical Senates do. However various aspects of NHS have experienced different quality of volunteer contribution. More ‘professional’ volunteer contribution is beginning to alter the perception of PPIs [Patient and Public Involvement members].”

- “I have never been made to feel unwelcome at the table and my views on behalf of families and people with a learning disability have been valued.”

- “The sessions I go to are not really relevant. I have pointed this out and nothing changes. I did try to go to a conference and had to pay for it myself rather than having the ability to claim it back like everyone else. I do not get any travel expenses, and have to take time off work to attend meetings."

- "Many committed staff members but too often lack of continuity of staff."

- "I think PP [patient and public] involvement is valued by NHS England because of the involvement they have in interviewing perspective candidates - from my experience I have been able to contribute to the interviews in terms of asking questions and also giving feedback to the panel from the point of view of a candidate."

- "My contributions feel valued and I can see that NHS England does listen as it can be seen in the documentation produced. I am treated as a fully participating member of the team."

- "As I have no contact with NHS England it is difficult to give a judgement."

- "I think the PHB [Personal Health Budget] and IPC [Integrated Personal Commissioning] programme is excellent at working co-productively, but I think it is the exception. My experience of the Transforming Care Programme at a local level is very different. It is top heavy with professionals and they seem very reluctant to work together with disabled people and their carers."

- "As some of our comments are heard and action taken, but some are just not heard as it would cost too much to implement the change needed to benefit all communities."

- "Most of the time patients are not involved in early stages of planning, such as in research and commissioning, but are there more as a tick box exercise. I have found this again and again, where a so called consultation is actually just advising of a predetermined change. A problem could be that commissioners and clinicians can speak a different language."

- "I feel NHS England does value PPV [Patient and Public Voice] but that they are really unsure as to how to enable [the] NHS itself to really listen and understand the PPV particularly at a very early stage of developing practice and policies. [The] NHS appears to continue to be over-protective of retaining their staff and rather blinkered as to how PPV can really be at the heart of NHS healthcare within a genuinely integrated health and social care system. E.g. […]"

- "I feel that my opinions and views are valued by the National […] in reaching its decisions."

- "Sometimes feel that some consultants on some boards resent public having a say."

- "When attending meetings I am always listened too, my comments and suggestions are taken on board. I feel valued and part of a team."

- “I think there are many processes within the NHS that try to address and improve patient and public involvement but I am not sure whether the really important messages actually are picked up and reach the real decision makers in the organisation to make a difference. I think there are times when the organisation is going through a process because they have to rather than [because they] feel they will benefit from it if done properly.”

- “IPC [Integrated Personal Commissioning] extremely strongly - best programme doing co-production. Other areas do not get true co-production.”

- “1. Very strong commitment evident in Five Year Forward View. But...feels like PPV [Patient and Public Voice] operates at the margins. PPE [Patient and Public Engagement] guidance to STP teams was not even distributed in May 2016 (it was all ready to go). It went out in September - but has been largely ignored. 2. NHS England new policies on mental health, dementia, cancer, etc. were coproduced. But...at the NHS England AGM [Annual General Meeting] in London, there were no PPV [Patient and Public Voice] representatives on the two panels which were assembled alongside Simon Stevens to present these policies. 3. I have a […] meeting tomorrow morning. But...I have had to chase the papers and have received them this afternoon, less than 24 hours before the meeting. How can I prepare properly?”

- “We, patients, are listened to but rarely heard…This seemingly being done to create the perception of PPI [Patient and Public Involvement]. Such a missed opportunity as the service status quo is reinforced and supported so little changes and little is innovated!!!”

- “I find that NHS (England) values their patient interlocutors: and do appreciate the input - although sometimes it is alarming how eye opening a patient perspective seems to be to both NHS clinicians and administrators.”

- “I say this as the position is still relatively new. I find that as time goes on and I have more involvement, my influence and input will become more significant.”

- “Progress has been made across the organisation to understand and appreciate the benefits of patient and public voice but work still needs to be undertaken to successfully embed it across the whole organisation.”

- “I am not at all sure after almost a year in this role that it is not just a ‘tick box’ exercise. However it is a new role and there are changes afoot so I may be premature in that judgement.”

- “It is very important that both health professionals and the wider public feel that disciplinary issues are considered and decided by a well informed and cogent group of individuals with no personal conflict of interest.”

- “We are always welcomed and engage well with all parties. We are there to ask the difficult question and so must retain a professional distance. Not always easy.”

- “The NHS England staff are really keen and extremely helpful in support of Patient Leaders. However, I feel that our presence fulfils a need to ‘involve patients’ but the involvement is peripheral to the actual task.”

- “Valued with the […] group but was also involved on the People's Panel for the EXPO 2015 but disappointed on the lack of engagement on EXPO 2016.”

- “NHS England recognises its legal duties in respect of communication, consultation and engagement of the public. That said, culturally as an organisation and network, this is rarely practised with a view that the public voice can genuinely contribute to the development of high quality transformation plans. It is more commonly a tick box exercise and is left to local NHS commissioners and providers to at times practice consultation and engagement in a meaningful way.”

- “I work with two different sets of people. For one group, I feel greatly valued. For the other, there is a great range of attitudes among the NHS professionals.”

- “It has been a very inclusive and welcoming process being involved in the […] and also great for networking and meeting others working in the field. However, I feel at times, that even though PPI [Patient and Public Involvement] representatives are always present and invited to events, that they do not really have much decision making power in reality. I would love to see some PPI representatives as co-leaders of networks and would be interested in this myself.”

- “Lip service can be paid to the inequalities that exist. A culture of secrecy and confusion exists.”

- “Slowly but surely, the value of patients’ opinions are being raised and acknowledged, both locally and nationally.”

- “I think it is valued but it is not consistent. There are challenges as NHS Citizen has been established and there is also NHS Choices but there is also local engagement and communication by the NHS and […]. There is still potential for patient and public experience of services to fall through a gap.”

- “Having worked in PPI [Patient and Public Involvement] for 13 years, I have seen the patient voice diminish, indeed some CCGs [Clinical Commissioning Groups] actively dislike patient representation. I have been impressed and enjoy working with NHS England because they finally accept that services need to be designed and redesigned by patients, who are the users. They respect those of us who are passionate about the NHS and work very hard for it. I would like to say that ‘to a great extent’ will be correct soon. Too many HCPs [Healthcare Professionals] do not yet appreciate our input.”

- “P&P [Patient and Public] involvement can sometimes feel like a process that is followed rather than an automatic, integral and valuable aspect of the way NHS England conducts its business.”

- "I am convinced by the work I have been involved with to date that NHS England is committed to PPV [Patient and Public Voice], with the only exception being the Sustainability and Transformation Plans which disappointingly were kept from public scrutiny until the last moment."

- " […] Patient and public involvement is not a major feature. There is a role in CCG [Clinical Commissioning Group] review meetings for the lay representative to make comment or ask a question. This does not always happen because of the pressure to cover all the performance topics."

- "It all depends on the department that you are working with."

- "[…]"

- "There is considerable work being done by NHS England around PPV [Patient and Public Voice] involvement, I have some caution as to whether it will be sufficiently joined up."

- "We are a very active group and have been not only been allowed but encouraged to be involved and input at the highest level. Our lived experience is very valued by the whole team."

- "I am answering this based on my broader experience of NHS England since its inception rather than on my experience with the […] network. As a broad generalisation, I feel that PPI [Patient and Public Involvement] is like the decoration on the cake. It has no material contribution to the whole but it does make the final presentation look better. In our area, despite my multiple involvements as a volunteer in the health sector I have never met any senior manager in NHS England. I am unaware of the name or activities of anybody involved in PPE [Patient and Public Engagement] in the […] area. No effort whatsoever has been made to bring people together or to help build peer support networks for volunteers like myself. Try as I might I cannot, hand on heart, claim to represent the views of all patients in my area though I may have far more contacts than most. To crown it all, the development of STPs [Sustainability and Transformation Partnerships] in complete secrecy has alienated all volunteers involved in NHS England and NHS related activities. Having said all that I cannot speak highly enough of the leadership and support that I receive in the […] network. […] is an inspirational leader and […] goes out of her way to ensure that I am properly involved in what is a very technical subject. Even the surgeons themselves are supportive of my role."

- "It depends on the organisation, some are excellent at involvement and others are aware of the need to involve, but are not too sure of how and with whom."

- "Experience varies. On groups closer to direct services (e.g. the CRG [Clinical Reference Group], […] review, […] and […] the PPV [Patient and Public Voice] input appears to have a greater impact. On groups concerned with FYFV [Five Year Forward View] policy and management (e.g. the […] and [...]) it is much harder to penetrate the jargon and make an impact."

- “I am always involved in these meetings.”

- “Although NHS England boasts about valuing PPI [Patient and Public Involvement] in promotional materials, in practice PPI opinions and perspectives are often ignored.”

- “Local NHS organisational teams do recognise this input but at the local Trust level less so.”

- “There are a large number of people that feel that patient and public involvement is a crucial part in getting the best service for them. Some people do however feel as the patient or public do not know how things work they cannot possibly feedback on how things should be improved. There are also those that feel that certain people such as children and young people are not interested and / or too busy to be able to make a valuable contribution.”

- “There seems to be a lot of research done on how to involve patients and the public but it seems to still be very led by the patient or public themselves rather than these people being encouraged to get involved.”

Question 5. To what extent do you feel that patient and public involvement is valued by the group you are a member of?

Response	**Total**	**Percentage of responses**
To a great extent	47	54.0%
To some extent	35	40.2%
Hardly at all	1	1.1%
Not at all	1	1.1%
Don’t know	3	3.4%
Total	**87**	**100.0%**

Not Answered	1	

- “See comments above. Personally, I have invested a huge amount of my own time in the process and have then been reprimanded because I did not tow the NHS line. NHS England have completely misunderstood that volunteers are precisely that, volunteers. I am more than slightly offended by the arrogance displayed.”

- “I am not a PPV [Patient and Public Voice] Partner I am on Interview Panels as a PPV Volunteer.”

- “I do not know the name of the group but it concerned senior appointments to Vanguard sites.”

- “As above.”

- “I cannot fault the national New Care Models team. They have gone out of their way to involve patients wherever possible and as a patient representative I feel as if I have been treated as an equal throughout. I can happily say the same for my input at a local level here in […].”
- “[…]”
- “In all the groups, of which I am a member, the patients' view is listened too and taken into account.”
- “As 4.”
- “Service users are at the core of our business. We are guests in their lives. We value what they have to offer and say and act upon it.”
- “I will only get involved with groups if I can provide meaningful engagement with tangible outcomes for patients and public. If I feel groups want my involvement just to tick a box, I will forego the opportunity.”
- “Engagement workstream thought of as an implementation and ideas centre of excellence. However far from universal acceptance by all other workstreams.”
- “Sometimes I feel that my suggestions / corrections / queries / proofreading are not appreciated.”
- “We have been asked not to share information outside the 4 walls so to speak, however sometimes getting a fuller picture in a number of specific groups problems can be solved, sometimes outside of the box or from the voluntary sector.”
- “Again unsure whether it is an NHS directive and they are following the party line.”
- “We would not have volunteered for this role if we did not value patient and public involvement.”
- “Patient Council was established as part of the move towards Foundation Trust status. As this has now been abandoned, the Council does not seem relevant and the Board take little notice of any of the members’ activities.”
- “Some organisations see PPVs [Patient and Public Voices] as a necessary evil because the process dictates that there should be PPI [Patient and Public Involvement] involvement. The quality of the involvement will reinforce or change their opinion.”
- “I think there is also respect for the real information the PPV [Patient and Public Voice] can give to the discussion.”
- “[…] and […] are totally committed to gathering PPV [Patient and Public Voice] and incorporating their views in the final outcomes.”

- “Within the […] group we are definitely valued but within […], NHS England values our input but I think it has taken a while longer for the demonstrator sites to understand our value.”

- “My groups always consult me when ‘patient’ issues arise.”

- “Some of our comments are taken on board but to implement them would be costly, so we feel we are heard but no action to move it on.”

- “The […] members deeply value their support given by us. They are the patients and we speak their language. The problem is attempting to get support upwards, as we are patient led and patient funded and very close to the ground with hearing patient situations in the current climate. But although knocking on the other ‘doors’ I am involved with - there has been no or very little inclusion.”

- “See above.”

- “As above.”

- “Current work on […] for Specialised Commissioning is very valued.”

- “I am always listened to and treated with equal respect.”

- “As a lay member of committees and an advisory group I feel my input is listened to and respected.”

- “Excelling in co-production and achieving ground breaking work.”

- “1. I sit on the […]. Has an excellent programme to implement. But…we are two PPV representatives amongst a group of managers trying their best to manage a shrinking programme. We are meant to seek assurance on progress – it is not really there - meant to measure impact - but the initiatives are stalled. 2. The […] roles are different and much better - I am an equal member of the group; nothing is agreed without the PPV representative (me) saying OK. Lot of respect and involvement. 3. The […] review team are engaging with patients, but in a very cagey way. We appear to be frightened of being open and honest, trying very hard to avoid public consultation. It is a sensitive area, but the defensive line we are taking is bound to make patients suspicious of what we really intend. I am a full member of the team, but have to work hard to influence decisions.”

- “By being there we are perceived to have been consulted and engaged but generally are overruled and or conveniently ignored, that is not heard!!!”

- “In the short time I have been doing this, I have received several notifications from the CCG [Clinical Commissioning Group] expressing their thanks for my input and support.”

- “Largely because this is a group focusing wholly on patient and public voice.”

- "I think that locally (this region) do value patient leader input but to what extent it influences actions I am not sure."

- "The team is very receptive to external independent advice to underpin their work."

- "If the zenith of meaningful public and patient involvement is coproduction, then Sustainability and Transformation Planning (2016 version) is at the opposite end of the spectrum. There has been a wish and will to at the very least communicate and inform as the STP [Sustainability and Transformation Partnership] has been developed locally, but NHS England directives have clumsily and misguidedly prevented this from happening. I believe this to be a reflection of NHS England's perspective on public and patient involvement, and for that matter, the involvement of staff / clinicians."

- "No consistency among the NHS professionals."

- "I think the […] Perinatal Network definitely values the PPI [Patient and Public Involvement] involvement in this network and we do always feel part of the team. I think perhaps we can sometimes be viewed too much as 'service users' when in reality most of the PPI representatives may have experienced some of the concerns being addressed by the network, such as perinatal mental illness, but are now recovered and may now be running organisations themselves, such as charities. In reality we are all patients, as we all use services, whether we work for the NHS or not. This sometimes is not fully recognised and there can be a slight feeling of 'service users' versus 'professionals'."

- "The bodies I belong to are mostly patient based, therefore patient involvement is vital for these bodies to continue operating with any effect."

- "I think our contribution to the […] is being valued increasingly, as the relationships have matured and we are now established as an organisation."

- "For the other groups / boards, some do some do not - they just 'tick the box' for our existence."

- "Unsure if lay member on these panels is able to offer the public and patient perspective and view in the way a totally unconnected member of the public / current patient might contribute."

- "The pathway to PPV [Patient and Public Voice] is a long and slow path containing a number of people within NHS organisations who are dedicated to encouraging and promoting PPI [Patient and Public Involvement]. Unfortunately, some of the organisations to which these dedicated people belong are not so dedicated to the PPV cause. In fact they sometimes pay lip service to the notion of PPV by appointing the representatives and then."

- "When attending meetings I do feel that my points of view are taken on board."

- “Not applicable in the strictest sense to […]. Not always utilised or the role clearly understood applied consistently in CCG [Clinical Commissioning Group] performance reviews.”

- “The national […] Steering Group is focusing in the planning and implementation of services that would be appropriate for the needs of clients they are caring for, [in] this instance […]. Meeting to discuss about existing models of good practice, reflecting on these, trying to find where the gaps are and how to overcome these could only be the best way of contributing to enhance the healthcare of affected clients. This is a great model of care that should be existing to make sure that continuous learning is sought in order to inform and improve practice for clients.”

- “I sit on two groups, one where PPV [Patient and Public Voice] input is new […] and the other where it is more established […], there does seem to be a noticeable difference between the two where I feel it is harder work to contribute to […].”

- “As a group we have been really fortunate to be involved with some amazing pieces of work and events. We as a group know first-hand just how much these pieces of work will better shape opportunities for people in our society with the most complex needs. Our whole group knows just how much our involvement has helped to shape the direction the pieces of work have travelled.”

- “As stated above good leadership, good support sense of team. Only issue to me are the limitations imposed on relevant patient contact through confidentiality and other access constraints.”

- “Again, the involvement is different in various groups and the extent to which I feel involved varies along with the personnel involved.”

- “I guess my answer above answers this question.”

- “Quite a few of my comments have been followed up.”

- “It is greatly valued by the […], because that is not chaired by NHS England. PPI [Patient and Public Involvement] is not valued on […] as any concerns raised about co-production of policies are ignored.”

- “Good evidence of the value placed on PPI [Patient and Public Involvement].”

- “The Youth Forum prides itself on involving young people from all walks of life to ensure that what they do is done not because one or two people think it is great but because patients and the public see it as something worth addressing. This was demonstrated a recent consultation to make our campaign suitable for children and young people by consulting over 200 children and young people across England.”

- “NHS England Youth Forum is all about including young people in healthcare. Our opinions are valued and we can see the difference we make.”

Question 6. How would you rate your experience of being a PPV Partner in the following categories?

Induction process

Response	**Total**	**Percentage of responses**
Very good	18	21.2%
Good	25	29.4%
Acceptable	16	18.8%
Poor	9	10.6%
Very poor	2	2.4%
Don't know	15	17.6%
Total	**85**	**100.0%**

Not Answered	3

Induction and information for new PPV (Patient and Public Voice) Partners

Response	**Total**	**Percentage of responses**
Very good	17	19.3%
Good	25	28.4%
Acceptable	22	25.0%
Poor	10	11.4%
Very poor	1	1.1%
Don't know	13	14.8%
Total	**88**	100.0%

Not Answered	0

Training for Patient and Public Voice (PPV) Partners to develop

Response	**Total**	**Percentage of responses**
Very good	13	14.8%
Good	27	30.7%
Acceptable	17	19.3%
Poor	13	14.8%
Very poor	4	4.5%
Don't know	14	15.9%
Total	**88**	**100.0%**

Not Answered	0

Claiming expenses

Response	Total	Percentage of responses
Very good	20	23.0%
Good	31	35.6%
Acceptable	23	26.4%
Poor	5	5.7%
Very poor	3	3.4%
Don't know	5	5.7%
Total	**87**	**100.0%**

Not Answered	1

- “Excellent administration in place.”

- “The above relates to my experience of interviews for […] - I have not been offered any training since then and the induction left much to be desired.”

- “The above apply to New Models of Care.”

- “Involvement throughout has been well planned and very ably supported. There have been hiccups with claiming expenses – it has been too slow on occasions – but to be fair I think this is largely outside the […] team's responsibility.”

- “NHS England should engage with patients in setting up and developing programmes and this has been shown by patients asking lots of questions and showing they have knowledge about some subjects that are being raised.”

- “It depends who you are working with.”

- “Needs to be more than just a tick box that it feels like.”

- “My experience is variable for above questions, in particular claiming travel expenses. I have waited for 4 months to get expenses paid, with me chasing every week. Clearly the department concerned was under pressure with lack of staff continuity and process issues, leading to a backlog of claims. Whilst I can accept a month or two delay under exceptional circumstances, there is no excuse for keeping volunteers out of pocket. This evidences a lack of leadership with little regard for patients who are involved. We are volunteers giving our time free because we are passionate about improving services and want to put something back in the system. Sadly, I have declined further involvement with the organisation concerned. Contact me for details if you require it.”

- “I have been surprised by the great similarity of NHS volunteering in some cases to a full scale job application process. It is interesting NHS England performance volunteering feedback is identical to formal employment performance assessment.”

- “Expenses claims have generally been good. One exception where I was accused of owing a large amount due to overpayment - eventually it was realised this was someone else! […] expenses have often been slow. Problem is that where I live in […], the High Speed train is the best way to get to London venues near St Pancras. NHS England will not pay for this service in advance so I am out of pocket for long periods. […] interviews are always scheduled for 8.30am for 9am. There is 2 hour journey from home (via slow train and tube: best for Skipton House). This makes it difficult for those of us who care for others. All interviews have had candidates drop out and have finished early. Given that candidates are also travelling distances it would make sense for a 10/10.30am start.”

- “You do not have a ‘not applicable’ button.”

- “Basically I have not been inducted or trained in being a voice by NHS England. However I have been trained by […] in being a Service Champion and I have transferred that training to being a voice.”

- “Do not knows are because I was catapulted in as an independent [representative] based on local staff knowing my prior history and background in the field within the various regional and national forums. Paperwork notoriously has been a bone of contention and yet […] are exceptionally good in ensuring that we have everything we need to be part of the process.”

- “I feel that the induction process of becoming a PPV [Patient and Public Voice] member could be improved. I cannot remember being invited or given a formal induction period. Especially as a young PPV representative it would be great to have had a specialised induction period and tailored support to ensure that the input I could provide is maximised. Would also be great if the information sent out to PPV in advance of participation in various roles could be easy read and in a format which could be understood by those of any age group and with any range of background knowledge of the role or project being asked to support on. I acknowledge this is not always feasible given time restraints but if it is feasible then it would be much appreciated.”

- “One meeting my deaf colleague had to leave as no BSL [British Sign Language interpreter] was booked. Sometimes interpreters for people with English [as a] second language [are] not booked. For me it always works as I communicate my needs ahead of the meeting, but some people cannot.”

- “Minimal experience of the above as a PPV [Patient and Public Voice] partner!”

- “There is often minimal notice which makes it really challenging to enable the level of involvement that I would like.”

- “NHS team very supportive.”

- “Initial training / induction was sketchy and there appeared to be confusion about my expected role.”

- “From working with two groups I feel that asking patients to read 50 or more pages of medical information within 2 days is asking a bit much.”

- “Some meeting venues are very difficult to access even though they state they are disabled friendly. This is different to being wheelchair accessible - the […] is awful and I think twice before attending meetings there. Sometimes meeting rooms can be very full so chatting to different people is challenging as difficult to navigate when in a wheelchair. It is always lovely to be given lunch but a lot of the time roll and sandwich fillings are unrecognisable.”

- “The NHS England team provide me with good support.”

- “Seamless and supportive process.”

- “1. I had the training for the […] roles - no choice, it is a statutory requirement. It was good. 2. But no training for or in any of the other roles. 3. Access to meetings via teleconferences / videoconferences is awful. The kit either does not work at all or very poorly. Being physically present is the only way that works effectively. 4. Induction, where it has happened, is very good. But it has happened in less than half the roles.”

- “Coproduction is seemingly just a throwaway phrase.”

- “I have been very impressed by the organisation and quality of material produced for meetings - to the extent that I have used it as exemplars for other organisations with which I am involved!”

- “The support from NHS England has been very good. Communication is good and in […] - our main point of contact - we have an exceptional ‘leader’. She always responds promptly and respects our role and input.”

- “Unfortunately my initial experiences with the PPV [Patient and Public Voice] process were poor. I am disabled […] and initially some staff at NHS England […] were unable to accommodate this fact. Accessibility and support was poor initially. […]. Induction was initially very poorly organised. I almost had to arrange it myself. There was an expectation that I could travel up and down to London on demand for separate meetings, when all induction could have been carried out in one visit, saving expenses and wasted travel time. I did not ever receive a formal acceptance letter for the role, and neither did I get an induction pack, until I made a fuss. I attended the first meeting before I had any induction. Part of the problem seemed to be that separate departments looked after recruitment, travel, expenses and organisation of the meetings, and they did not seem to communicate very well. There was an issue of taxi travel that took months to sort out due to bureaucratic internal procedures, rather [than] good common sense. The waste of NHS staff time involved in sorting some of these issues belies the fact that NHS is short of money.”

- “The training we were given when we took up this role was very rushed and somewhat raw, which being a new role I can understand. Preparation for meetings is entirely delivered by the NHS team and whilst we get to review it at a pre-meeting to our CCG [Clinical Commissioning Groups] assurance meetings, we have very little prior input. Feedback is an area that seriously needs some work done on it. Support is acceptable given the scale of the workloads that NHS staff have on their plates."

- "Information is often very close to a meeting. Back up papers of interest or signposting to useful information would help."
- "Would like to see more focus on equality and diversity of PPV [Patient and Public Voice] and participation."
- "Some staff offer excellent support but others are poor. Again, no consistency - it depends on the individual personalities. Which suggests a lack of sign up to the corporate view?"
- "The NHS team are always very approachable and friendly but there could be more of an ongoing process of training and involvement for PPI representatives."
- "Training for PPV [Patient and Public Voice] members is improving right across the board, enabling members to increase their knowledge and level of involvement. There appears [to be] little induction, preparation or pre-joining training for new members. There could be increased awareness of where PPV and PPG [Patient Participation Group] services are in operation, as well as improvement in recruitment."
- "Difficult to answer but there was little support when we joined the […]. It may be different now for new members."
- "It is erratic, depending on the seniority of staff members, and their experience working with hard working patient representatives."
- "The role of lay member attending […] is prescribed and distinct. It requires the individual to undertake training and receive 'accreditation' from the Medical Directorate running the panels in order to participate. The responses above are made in this context."
- "PPV [Patient and Public Voice] is a constantly is in a constant state of flux, so as much sharing of templates and processes is ever necessary."
- "These questions apply to regular activities. […] are ad hoc and some can be a 2 hour drive away."
- "It depends on who you are working for."
- "I am part of some pilot training to be held at the end of November so will be better placed to answer that afterwards. I have no involvement in planning of meetings and in terms of accessibility I find sitting in cramped rooms around a video camera where one can only see around half of the members at the other end of the video link as poor. […] Both administrative support staff have recently changed and I find their knowledge and support ability dips until they are up to

speed on requirements. I do feel that expenses should be paid by bank transfer in this day and age."

- "My personal experience has been exceptional. I have been valued, understood but most importantly been allowed to grow and develop my knowledge, skills and confidence to be able to input at a much higher level and in a more strategic way when needed. I have made amazingly strong relationships with many members of the team. I have been involved in the concept and planning process of events straight through to the delivery."

- "This is highly variable. I have never ever had any induction training for any NHS related role that I have been involved in other than 1 hour when I became a Foundation Trust hospital governor. Certainly in relation to […], any expertise that I have has been accumulated through involvement in the process of implementation over the past 5 years."

- "This varies according to the board or committee in question. Some of the induction has been exemplary and some non-existent, claims for expenses are always available, however, most of the monies come from NHS England and yet there is little consistency with the claims forms used! Also some organisations send me cheques from NHS England whist others pay straight into my bank account."

- "1. Had to press hard for induction on some groups. 2. Cannot recall any real training as such. 3. Some individuals try really hard to involve PPV [Patient and Public Voice] members, others much less so."

- "Should have a comment box which says not applicable."

- "PPV's [Patient and Public Voice members] are not allowed to influence the agenda."

- "Although there is the […] programme based in […] it is very generic and does not address the needs of those who want to become involved in revalidation (which is why I have developed a specific training package for such groups)."

Question 7. How do you stay in touch with the views of patients and the public in order to reflect their views on this group?

- "I am a member of many other groups."

- "By being very involved in what goes on in my local area."

- "I am a service user Governor of a Foundation Trust and I run my own Local Patient Group."

- "I do not know! There does not seem to be any formal means of keeping in touch with each other though I do see a few faces I know at other meetings I attend. As far as I am aware the interviews have finished so there may not be such a group anyway. On a broader front, I go to other meetings where I meet service users (e.g. […]) and keep in touch with Carers' Groups. I also attended NHS EXPO after hearing about it indirectly and belatedly; I was surprised not to be notified directly after my previous work with NHS England."

- "Regular updates from New Models of Care. NHS Citizen are reinventing itself for the better I hope."
- "Through my local patient groups mainly. I am involved at practice level and chair my local area group […]. The representatives there are excellent and never hesitate to let me know their views! I also keep in close contact with my CCG [Clinical Commissioning Group] communications team who are excellent."
- "I run several [social media] pages for patients to give feedback and comments on. I also attend both hospitals and GP surgeries to look and listen to, staff, patients and families. The information I gather helps me to give an honest and open approach to how the delivery of service is being achieved or given."
- "By listening to people, by taking part in as many events as I can and by being a member of the following groups… […] CCG [Clinical Commissioning Group] Patients Cabinet, member. […] Cancer Board, Member. […] Cancer Board, Member. […] Cancer Vanguard, Member. Healthwatch, […], Director. […] Patient, Public, Trust Involvement Task Force, Lead. General Practitioner sector group, Member."
- "Through PPG [Patient Participation Group] and other meetings."
- "N/A".
- "I do not know anything about the other people in this group. I know our own group holds regular meetings and events and have open comments on [social media] for people to contact us."
- "I am involved with a number of local and national patient groups and keep myself updated through patient surveys and opinion via social media. As a Community Champion for my CCG [Clinical Commissioning Group], I solicit opinion, comments and ideas from the community, including PPGs [Patient Participation Groups] and support groups. Additionally, […]. Our members are associated with other voluntary organisations, charities and Government agencies. We have a well-developed network to obtain feedback about service changes and proposals for change. I am also a patient living with a long term condition and have current patient experience of services."
- "I gather views from various patients at my GP surgery by conducting periodic interview surveys with patients as they wait for consultations. I also spend time canvassing the views of patients at my local A&E as part of my role representing the ED [Emergency Department] on the Patient Partner Council."
- "Area and surgery patient group views. Analysis of survey results. General local locality health awareness via local authority and current affairs."

- “Via PPG [Patient Participation Group], LPG [Locality Patient Group], communications and engagement group, talking to neighbours etc.”

- “I am a member of different groups within the community and listen to concerns and also compliments raised. As I cannot discuss my role as a PPV [Patient and Public Voice], I can put their opinions across indirectly.”

- “Attend as many meetings as possible. Have a role as a trustee for the […] and use that as a means of cascading information and acquiring it. Leaflet when I can, speak to friends and colleagues. […] CCG [Clinical Commissioning Group] staff provide good information contacts and send relevant paperwork for reading.”

- “I am a retired social care manager. Carer for a child […]. I am a trainer for […] - offering training to family carers / staff all over England and Wales. Am involved with several carers’ organisations.”

- “N/A.”

- “Through a continuous series of engagement events, surveys and a helpline.”

- “Via the NHS England staff but there is not, to my knowledge, any mechanism for keeping in touch with other voices. I keep in touch with other patients via a self-help group for Diabetics, presentations at various events such as sight awareness, surgeries with education days, library presentations, Healthwatch volunteering, involvement with […] and secretary to a local PPG [Patient Participation Group] for a General Practice.”

- “Various regional and national networks in LD [learning disability] - training sessions and the Expert Reference Group (either attending or through papers).”

- “Receive emails.”

- “Wide network of local and national contacts both lay and professional.”

- “I am a member of various young patient groups nationally and this allows me to take on board and digest the views of patients and then using my advocacy skills to reflect views on the work I am asked to be involved in.”

- “By going to all my local meetings and listening to people’s comments etc.”

- “I have my personal experience and also I work with people in receipt of a PHB [Personal Health Budget] and so I am able to pick up on trends, ideas and areas of concern.”

- “Talking to other patient / doctors. I am a supporter of […] and […].”

- “Through meetings, emails, telephone calls.”

- “I am well networked into the disability world at a local level - LD [Learning Disability] Partnership Board, chair the special interest group on […].”

- “Attending meetings frequently and getting newsletter developed by this group would work. Sharing good practice in [In Touch].”

- “Extensive feedback as Chair of […] and as a Neighbourhood Champion of a large housing association. No pathway to reflect their views.”

- “I work […] in a local community […]. I engage in conversations with as many people as possible regarding healthcare both their own and their thoughts of what else they would like to be able to access. I am a PPV [Patient and Public Voice member] with my local hospitals and medical surgery. I am an active member of several organisations including the […] and have previously had roles such as […].”

- “I am a PPE [Patient and Public Engagement] lay member of […] CCG [Clinical Commissioning Group] which allows me to regularly have contact with the general public and representatives of third sector organisations. I also chair a monthly public and patient group.”

- “Role is to assist in holding CCG [Clinical Commissioning Group] to account, not representing patient groups.”

- “Active on [social media] and attending support group meetings.”

- “Through semi regular meetings and [social media].”

- “I use my own personal experiences and those of my friends and relatives plus the input from the other panel / committee members to better understand the issues from a patient / public perspective. In my lay role I am objectively taking into account my perceived views of patients and public in addressing practitioner related issues.”

- “I am part of local groups and have many networks nationally such as […].”

- “1. I attend local groups (e.g. […] Support Group, […] CCG [Clinical Commissioning Group] public meetings, […] clinical research network PPE [Patient and Public Engagement] events, email contact with other PPV [Patient and Public Voice] representatives I know, visits to primary care centres, involvement in […] development sessions, attending NHS England events). I have other roles with […] - and this gets me into ‘patient discussions’. 2. I go to AGMs [Annual General Meetings] – NHS England, Local FT [Foundation Trust], local CCG [Clinical Commissioning Group] - as do many other patients. We go to find out what is going on and how good they are, or not. 3. I have 4 long term conditions, which take me to clinics and hospitals regularly - I talk with patients and clinicians. 4. I am a trustee on three charities. All are service providers. I meet parents, children, families, old people every week and pick up their experiences of us, the NHS, their GP, etc.”

- “I work collectively with a wide range of patients and national stakeholders to seek opinion and a mandate and as a patient with a range of life long conditions, I am ideally placed to not just show, demonstrate but deliver any necessary points.”

- “I am a member of a patient focussed umbrella group, and ask the other members for views on specific topics. In addition, our ongoing work informs my contributions to the work of the group - e.g. on access to treatment; the importance of ethical considerations; and the need to balance ‘need’ with cost.”

- “Various means: Healthwatch. Various voluntary roles within the NHS - ensures constant contact with patients.”

- “Membership of […]. I am a campaigner for a large disability charity that brings me into contact with patients. Keeping up with voluntary sector publications on the issues we cover.”

- “Contact with organisations and individuals who are members and maintaining proactive contact with a range of stakeholders outside meetings.”

- “I am connected with a number of relevant networks and organisations.”

- “I read as much NHS information and news for the area that I am involved in. Checking the CCG [Clinical Commissioning Group] website and attending general meetings. I also do local voluntary work via Healthwatch, my practice’s PPG [Patient Participation Group] and CCG PPI [Patient and Public Involvement] meetings to get a feel for local patient issues.”

- “N/A.”

- “I chair the patient participation group (PPG) at my local surgery.”

- “I work with Healthwatch and my local PPG [Patient Participation Group] group, In a broader arena I am a member of the […] and a large but ageing church. People know what I do and often talk to me.”

- “No, I do not see this role as representative, rather as a subject expert.”

- “Belonging to various patient involvement groups.”

- “Member of Peer Network and contact with demonstrator site.”
- “NHS Citizen, NHS England bulletin and other newsletters such as the […].”

- “The blanket ban to date on seeking the views of patients and the public has prevented this from happening.”

- “We are not there to reflect public views. We are there to provide an independent perspective.”

- “I run a grass roots charity for […] , therefore I have access to many parents who can give their feedback and I can then relate their views back to the group. I am also a member of national […] working voluntary sector and public groups across the UK, which include diverse groups of parents and families affected by these issues, from who I can gain insight and ideas. Some of these are also on social media and involve thousands of parents. Trustee of the […], patient etc.”

- “Word of mouth, personal experience, and observation of situations and locations.”

- “Constant dialogue.”

- “Media. Online patient forums. Being a Chair of a PPG [Patient Participation Group].”

- “We actively seek feedback and also have a monthly hot topic to stimulate feedback in a particular area. We participate in a huge number of meetings across the county as well as host some of our own. We have stands at hospitals to gather feedback. We also work closely with our county wide representative patient group, as well as with individual PPGs [Patient Participation Groups].”

- “I talk to patients wherever I go, and I ask questions of them and of their experiences, and especially in other meetings with other patients. Running a cancer support group which I did, informed me of the many different kinds of patients, and how many in this country do not want to talk about their illnesses.”

- “NHS is a regular topic in the community, within friendship groups, with neighbours and family and constantly reported in the news and media. Whilst the latter medium is not always reliable it does make for useful prompt to ‘test’ and check out views with others. Various contacts who regularly use services often give feedback.”

- “Via Healthwatch meetings and PPG [Patient Participation Group] surgery meetings, working with the local community and acute trusts.”

- “Generally speak to people to ascertain views.”

- “I don't. It is not applicable to the meetings at which I act as a lay representative.”

- “Participation in patient and community forums and reading communications from these organisations.”

- “We do not.”

- “Evaluation and consultation with patients and the public is part of the work I am involved with. Therefore, we do collect data that help us develop reports, to always keep on track with their needs.”

- “Locally I am part of Healthwatch and as such sit on a number of Boards and Programme Groups, I also sit on PPG [Patient Participation Group] networks where I have an opportunity to network and hear issues. I also subscribe to different outlets so I can sense check what I am hearing.”

- “As a group we are all active within our local areas as well as on a national level. A lot of us support our local CCG's [Clinical Commissioning Groups] to shape the way PHB [Personal Health Budgets] are delivered in our areas plus we try to support other families to navigate this crazy complicated world of having complex health needs and the services which are currently on offer. We all actively live and breathe Personal Health Budgets on a daily basis as we either hold them ourselves or for a loved one. For a lot of us our knowledge is current and ever ongoing.”

- “I have no access to patients that have experienced […] surgery in our area. We are working on a system of PROMs [Patient Reported Outcome Measures] for the hub and spoke aspect of […] surgery but all the patient contact has been dealt with by NHS personnel. As it happens I have had some experience through friends but that is limited and unrepresentative. This whole area could be so much better organised and effective if someone with a bit of vision and some authority was prepared to consider some revolutionary ideas about patient feedback.”

- “I attend local Patient and Public Participation Groups and local Trust meetings of patients and carers. I also belong to local Healthwatch who help me to stay in touch with local needs and patient groups.”

- “Member of Healthwatch […].”

- “Experience, listen.”

- “1. Through various networks I am involved in, my local PPG [Patient Participation Group], a couple of charities I work with and conferences I attend. 2. But most of the stuff we get at meetings is confidential - so how can you properly consult others? 3. We have raised the possibility of setting up specific reference groups - but it hasn't happened yet.”

- “By talking to people on my many outings to the doctors and hospital.”

- “[Social media] support groups; involvement in patient groups; [social media]; colleagues.”

- “I do not regard myself as a patient representative so do not collect views.”

- “We do this through a variety of methods such as consultations, feedback forms or surveys.”

- “As a group of young people with mixed experiences, we share our views together and also speak to our peers about what they think to try and gain a broader understanding of the views of young people both patients and the public.”

Question 8. To what extent do you feel that your contribution as a PPV Partner has had an impact on the work area?

Response	**Total**	**Percentage of responses**
To a great extent	15	17.2%
To some extent	47	54.0%
Hardly at all	11	12.6%
Not at all	5	5.7%
Don’t know	9	10.3%
Total	**87**	**100.0%**

Not Answered	1

Question 9. Please provide any examples you have of how your views have been listened to, taken into account and acted on, and the difference this has made.

- “See comments above.”
- “The managers on the interview panels listen to what I say.”
- “See above.”
- “NHS Citizen: online, Citizen Jury and Assembly. New Models of Care, views to be considered in January 2017.”
- “I think I was able to make good contributions to the recruitment processes I have been involved with. Similarly I am confident my views were heard and acted on during the various budget setting meetings I have been invited to. At a local level I am a member of the MCP [Multispecialty Community Provider] board and treated as an equal.”
- “I have given many examples of my findings to various programmes and whilst they are listened to I cannot say that my views are fully taken into account – they seem to be part of a collective approach from many public representatives who attend meetings. NHS England does not publicise a patient’s individual efforts to offer challenge or change to the delivery of services.”
- “It has broadened my knowledge base and given me a greater insight into the workings of the NHS.”
- “Depends who I am working with as a Patient Leader one group treated me as an equal, another group I felt paid lip service to all PPVs [Patient and Public Voice members] and did not tell them what was happening.”

- “Never given any feedback so do not know other than all suggestions are never taken into account and no reasons why or explanation why it is not being used.”

- “1) I have used statistics from the National Audit of […] to build a Business Case to successfully obtain additional funding for […] uptake. 2) I have influenced the […] [Academic Health Science Network], to develop a series of webinars to share and promote best practice and innovation about our […] programme. 3) The […] CCG [Clinical Commissioning Group] have listened to my views and ideas, to implement a PPE [Patient and Public Engagement] model to keep our community updated of impending service changes detailed in the 'Success Regime' and to obtain feedback and insight. 3) I have successfully campaigned for the use of apps for patients to better manage their medicines and conditions. Self-management / Patient Activation and education are consistent with the aspirations of the 5YFV [5 Year Forward View].”

- “I am a board member of the Organisational Development Steering group at my local hospital trust, and play a very active role in moulding the direction it takes. I have participated in selection panels for NHS England, thus making sure that new staff at senior levels are cognisant of the importance of patients’ voices.”

- “I am responsible for […] feedback form comment analysis. Patient representative views are valued by the steering group.”

- “Definition of quoracy at board level. Apologies for delays in payments. Invitation to represent patient views following positive feedback after first national role. Invitation to other events from head of communications and engagement locally and encouragement to apply for other courses and roles.”

- “Communication is a major issue especially those who have verbal difficulties, not just through another language, but those which are disabled, [people with] learning disabilities, mental health problems and also with patients who have carers who speak on their behalf not always present due to home / work / commitments - getting the right treatment /solution is a must. It was a question the panel had not thought of and was introduced in the question to the interviewers, all struggled to answer what steps could be taken and was a debate with the managers after on how they could improve treatment. Using the community and voluntary sector a lot more than they are in service delivery.”

- “One issue for us was the management of wheelchairs at the local hospital. They were never put back in the right area by patients, so were not available for others to use. We wrote to the Trust about our concerns and they have responded by providing a supermarket trolley style solution, so you have to put a £1 in. This is being rolled out across the 3 hospitals in our area.”

- “Previous membership of […] - direct involvement in shaping policy and facilitating parent focus groups. For […] participated in 2 large workshops on […] then wrote a report on findings. Helped organise a conference for […] members. My involvement in CRG […] is new but my lived experience plus professional knowledge will be useful. I also bring an extensive knowledge of Equalities […]) and have an in depth involvement with BME [Black and Minority Ethnic] groups.”

- “As part of a recruitment process. Proposed initiative publicity.”
- “There was […] allocated to explore setting up […] which was my idea as it would link up […] networks.”
- “None.”
- “Able to pass on experiences of previous projects e.g. Summary Care Record. […] Trust Governorship, Voluntary Sector health related groups, personal experience of communication between patients, public and healthcare professionals.”
- “My views have been taken into account in the interviews I have participated in because I get to feedback to the panel with my opinions as well as asking prospective candidates questions.”
- “I have only been to the one event so far which was interviewing for important posts in the […]. I felt I was listened to before and after the interviews.”
- “Patient Survey Results. Discharge of patients or not! […].”
- “I have been part of forming the guidance for Personal Health Budgets and worked on the format for rolling out of Personal Health Budgets. Also the guidance for […] and many other aspects in […].”
- “In trying to define a personal [health] budget NHS England worked very hard to ensure that everyone had an equal say and changed wording and concepts in line with views. The […] group has attendance by NHS England at all their meetings - it feels like a partnership - taking into account our views.”
- “[…] We talked about thinking family, and the effects of any new condition on the whole family unit. Around lived experience of certain groups [is] different, due to individuals’ access needs, having disabled people as role models in pictures of service users, so people recognise we matter too.”
- “[…] complimented me on my input during interviewing […] for the New Care Models. Otherwise mainly networking at various events with NHS staff and others which helps me to gain more insight from different viewpoints. Continuing to promote the work of NHS England through social media and face to face with others in different contexts.”
- “My views are always sought and listened to by other […] panel members and I feel I am influential in the panel decision making. Bringing a non-clinical perspective has been enthusiastically received.”
- “Contributed by writing a patient version of a […] guideline.”
- “Sharing my personal story always has an impact as it shows how my life has changed. At policy meetings wording has been changed to make it more user

friendly / direct instruction given. Requests made by my local peer network have led to very specific pieces of work being carried out to the gain of the CCG [Clinical Commissioning Group] and personal support. All of this gives me confidence to know that changes and policies are being put in place and practice to improve life not just for the authorities but to make significant changes to the way I live my life."

- "I have been proactive in suggesting improvements to process from time to time that have been incorporated in lessons learnt […] and subsequently progressed."

- "Created key features of […]. Strategic work planning with […]. Shaping policy with […]. Influencing national sites on importance of co-production if they are to embed […]."

- "1. […] services review. Strong personal involvement in PPE [Patient and Public Engagement] work. Helped to interpret and respond to patient feedback. The review is ongoing, so impact remains to be seen - but I am hopeful. 2. I am one of four core voting members on the […]. I chair the […]. I influence every case we discuss and strongly influence about 10%. It is here that I feel I make the biggest difference. 3. I say a lot in the […] and the […] - but I do not get the feeling we (the PPV members) are making enough difference. This may be because the groups as a whole are not making enough difference."

- "Our views are listened to, but as stated are often not heard and as such are not taken into account and so the difference made has not been as positive as it could be! The patient voice should be positively discriminated for in order to allow for patients to be in a better position to hold NHS England and service providers to account to deliver the necessary service innovation, which are required to ensure high quality service sustainability, that will improve patient outcomes and make a better use of finite resources."

- "Rather than specifics, I honestly believe that patients' viewpoints are taken into consideration, more so than before, on a general level. Members of the CCG [Clinical Commissioning Group] fully accept the role of the patient leader and their views. The main reason for this is that the two patient leaders that sit on our CCG do work hard in the background and make it our business to keep abreast of developments."

- "Feedback on my own and others' experience of the attendance at […] clinic. Experiences of before we had a national clinic compared to afterwards."

- "Challenge around consultation timescales. Promoting transparent decision making. Advocating proactive communications and engagement in key aspects of work. Involvement in developing prioritisation, generic policies. Service specifications and CRG [Clinical Reference Group] Review. Support, training and remuneration for CRG members. Participation Framework for Specialised Commissioning."

- "The CCG [Clinical Commissioning Group] assurance process has been cemented in and generally runs to the NHS agenda, with little flexibility. There is a new process based around Assessment and Improvement being introduced and I am hopeful that will provide a more inclusive relationship. It is fair to say that there has been a change in the way that the CCGs have been doing their presentation with a little more emphasis on showing how their actions impact on patients; this acknowledges the presence of the PL's [Patient Leaders]. It does however tend to suggest that the patient outcome was not previously a priority for either the NHS element or the CCG!"

- "Chair's casting vote."

- "I am a retired […] with a legal background, and my views on probity and process are actively sought and listened to, as a result no decisions we have made have been successfully challenged."

- "We attend the CCG [Clinical Commissioning Group] assurance meetings. Our questions are always fully answered but it would be difficult to measure any changes. Sometimes just being around the same table changes and challenges behaviour."

- "New to role and have had no feedback yet."

- "We have written the key features of […] so people can recognise what these should look like. The local peer network are starting to work with […] lead / local government to hopefully co produce pieces of work relevant to the […] process. This has been relatively slow to get going but realise this is a complex subject and perseverance will eventually win!"

- "NHS EXPO 2015 Co-Production Modelling Group."

- "The blanket ban to date on seeking the views of patients and the public has prevented this from happening."

- "Attitudes are becoming much more patient focused and less data driven. I do not need to say 'and what does that actually mean for patients?' anywhere near as often as when I first started. By making a positive contribution, I am welcomed and listened to far more than 2 years ago. I have helped to shift the focus from cost to quality."

- "I was involved in helping to devise questions for a survey which was circulated to […] and also gave input into where and how this could be circulated. I have also been asked to chair one of the […] Strategic Clinical Network conferences which I did alongside one of the NHS Clinical Directors. I have also been involved on the shortlisting panel for the NHS England […]."

- "[…] research, leadership good practice, Shared Decision Making."

- "My GP practice has changed several operational procedures as a result of matters arising from PPG [Patient Participation Group] meetings, making the experience of visiting the doctor's surgery more client friendly. We are slowly but surely seeing matters originating from the Patients Advisory Board [PABs] being adopted as national policies, although until there are more PAB's in other areas within NHS England (London), there can be limited progression in patient led national policies."

- "Planning meeting agendas so PPVs [Patient and Public Voice members] have enough time to contribute. Amending presentation styles and language."
- "I am actively included in each meeting, my views considered and reflected in the final decisions."
- "With NHS England we have achieved additional units of dental activity locally in two towns. With the local NHS we have continued the pressure to address problems with local ophthalmology services and changes are currently being implemented. We commented on the draft Primary Care Needs Assessment and these have been taken up and the survey is about to go live."
- "I really wish I knew. Lack of feedback is enormous, and should be addressed."
- "Objectivity of view regarding clinician behaviour, attitude and approach that requires clinician to undertake greater reflection and discussion with clinical mentor with subsequent feedback to panel on 'learning'."
- "Organising a regular meeting with the local Trust CEO [Chief Executive Officer] for all who want to meet them. Changes to meeting agendas to reflect the needs of patient and public opinion. Being involved in committees that are of interest to me and where my knowledge and expertise are utilised. Being involved in senior appointments and being able to discuss my reasons for choices that have resulted in an appointment."
- "Not really involved in giving views as such. My role depends on evaluating evidence and ensuring the Panel come to correct conclusion and everyone is involved."
- "Still waiting to actively participate."
- "See […]."
- "Contributed [to] various consultation exercises in relation to my field of work. Wrote academic papers that have been used to develop further research based on my recommendations. Piloted projects which have gained national recognition. […]."
- "I am not sure I can properly track this and I have set up a session to feedback this with […] where this will be one of the issues I wish to raise."
- "As a group we developed the […] which have been published. They are so important to make sure […] keeps its value and integrity. I recently went to a meeting with my local CCG [Clinical Commissioning Group] where a member of the […] team brought up the [documents] and how important they are. It is really rewarding for us to now see our work finally influencing at a local level as well as

a national level. The same [documents] have now been updated and adapted to work for the whole […] programme. There are so many pieces of work which we have been involved in but the fact that a role was created for someone with lived experience of […] within the national team really does go to show just how much our experience is valued."

- "At every opportunity I have been advancing the case for better organisation of […] and some improvements have occurred though I do not think that has arisen as a result of my efforts. Right now I am asking for a review of […] screening as I suspect it is not as effective as it should be. In relation to PROMs [Patient Reported Outcome Measures] I have been listened to but I do not feel any sense of ownership."

- "In research, the group have asked for lay member views and have incorporated them into their practice e.g. broadening the scope of who they ask to be involved. In other groups, the frequency and timing of meetings and changing location to accommodate a broader group. At the AHSN [Academic Health Science Network] in […], they regularly ask for patient and public opinion and act on their feedback, in such things as communication styles and methods, changing projects to encompass patient values and views, inviting patients and public to present and facilitate meetings. I co-chair the […] committee at the AHSN and […], alongside the director. This is helpful in that it is a learning process for me and her."

- "1. I chair the […] and in every case we deal with, my voice counts. 2. Similarly, at the […], I input to every case. I think I make a difference. 3. I helped to design the PP [Public Participation] engagement programme on the […] review - and then participated in it. Feedback from patients was good. 4. Not sure I can refer to such positive examples on the other groups. The CRG [Clinical Reference Group] is new and the signs are good. Very helpful and encouraging chair. 5. I make contributions to the […] and the […], and I think they are valued, but I cannot really see tangible impacts for these contributions. Others need to comment, I think."

- "Access and comfort on the mobile units. Also following up DNAs [Did Not Attends]."

- "On the Five Year Forward View I was involved in coproducing (genuinely coproducing) the Six Principles for Engaging People and Communities."

- "During […] visits I can draw attention to areas that are sometimes missed by others on the panel - this does not only relate to PPI [Patient and Public Involvement] activity and involvement. I am now very experienced and am often the only other member of a visiting team."

- "A partner of my local CCG [Clinical Commissioning Group] listened to ideas I shared as part of a group on how to improve services for children and young people at a local hospital. These were taken into consideration and written into their new agreement with that hospital."

- “We have spoken a lot about changes to all sorts of documents including the 'You’re Welcome' changes and many other projects.”

Question 10. In addition to your role as a PPV Partner, what other ways are used to involve patients and the public in this group's areas of work?

- “Thinking days. Healthwatch.”
- “None.”
- “No idea.”
- “NHS England Involvement Hub which has started recently.”
- “Not aware of other avenues - please see next section.”
- “There are a great many opportunities for patients like myself to become involved in various NHS programmes which means that those who have been involved for some time in patient support programmes may not be recognised for their contribution as new members bring new ideas although some of these ideas may not be that new and could have been talked about before.”
- “Engagement events, public meetings, publicity, and the press.”
- “Group Meetings. Email. Face to face meetings.”
- “A key source of active PPV [Patient and Public Voice] is through the […] Citizens' Senate, PPGs [Patient Participation Groups] and support groups. We use [social media] to encourage further interest in the work we do, by evidencing our achievements. Public meetings and consultations are organised by the patient groups to promote service changes. These forums give us the opportunity to promote interest in the various groups. I also have regular slots in local radio and media.”
- “I do not know, I am only really contacted when I am needed for specific tasks.”
- “A number of useful newsletters are published by communications specialists. The penetration effectiveness of these needs more work and attention. Feedback to surgery level PPGs [Patient Participation Groups] is capable of enhancement. Ambassador methodology has better chance of universal coverage of all necessary groups.”
- “Locality patient group representing up to 15 GP practices. Other consultation forums e.g. at local hospital and at CCG [Clinical Commissioning Group].”
- “Not sure.”

- “For me it would be an electronic method - 75% of the population have access to the internet - it could be part of a registration at your local GP or hospital, much as NHS England already do. Information could be selected for patients who have indicated an interest in a subject / condition. Search engines on GP practice computing are now very sophisticated and can select cohorts of people at very short notice. Why do we continually try and reinvent to wheel.”

- “Consultation with stakeholders - am always keen to ensure that this extends to ‘seldom heard’ groups.”

- “Sorry, do not understand this question.”

- “None.”

- “Local Partnership Boards and networks - CTRs [Care and Treatment Reviews] advice and guidance at national level.”

- “Patient and user group involvement at the […] Member of Task and Finish Group. Will be member of Overview Group.”

- “Ask professionals about their awareness of the subject and bring relevant information to their notice, also pass on information to local groups and organisations such as Healthwatch, CVS [Council for Voluntary Service].”

- “Emails, regular contact and monthly publications.”

- “Other than doctor's interaction with their patients I do not know of another way.”

- “The work we do nationally is taken to all areas of the country by our peer network and this has helped in many ways locally and helped many individuals.”

- “Not sure.”

- “I work with different charities, local groups, service users to tell their stories, and the effect of good experiences and bad experiences.”

- “I am also a member of the […] PPI [Patient and Public Involvement] Panel. The support and encouragement of GP PPI panels is much required. GPs may have a group registered, but it is not often a 2 way conversation - and the ability to change a complaint into an understanding of a system fault is often missed.”

- “There are many ways patients and the public could be involved. Please just get out there to each home and work community so you can really appreciate the wealth of involvement potential there is.”

- “I believe that all Clinical Reference Groups and service design groups have lay involvement.”

- “Through Healthwatch. Inviting complainants to be involved in improvements. Surveys.”

- “Contributions to consultations. Active engagement with key patient groups and constituencies.”

- “The work of the […] is largely behind the scenes. We do need to do more to highlight this.”

- “The peer network I am part of is supported to do things in our own way to support service users and have an impact on other agency and NHS staff.”

- “I think it would be good to produce periodic summary information related to practitioner performance […] Although this may prove challenging produce some form of report including examples of anonymised cases that are shared with the public in: a) explaining the pressures faced today by practitioners in primary care in order to manage patients and public expectations and make them aware of the challenges facing todays practitioners. b) help patients and public better understand what to expect from practitioners and provide better advice regards the different types of service they can use and when best to use them from 'self-help', see chemist, call 111… to visit GP etc. …”

- “Find out their views on what I do. Bring their feedback to the table. Share my learning by giving information and advice.”

- “1. In the […] work, each case has separate patient evidence. It provides a good base to work from. And if we need more, I can ask the investigators to go out and get more. So it works well. 2. The […] held a very good Insight conference in Leeds in the Spring. Lots of patients there. 3. The […] has a PPE [Patient and Public Engagement] programme - but it remains to be implemented. Not sure it will be. Need to press for assurance. 4. The […] review has run a good PPE programme. Need to do more - on what will actually change. Pressing for that. 5. The CRG [Clinical Reference Group] is new, has met once - and the signs from the chair and lead commissioner, are good (at least, better than the former CRG) […].”

- “Our patient voice if anything has and is being pushed further away from the opportunity to influence any work to be done and or influence national policy and or decision making. At the moment it is rhetoric over reality.”

- “In the field of rare disease, there are a range of engagement levels: for example, through the […] at a strategic level; and through individual interactions with specific groups on particular subjects- e.g. access to specialist drugs. In addition, NHS England requires PPV [Patient and Public Voice] involvement in each specialist service commissioned- so there is an underpinning level of engagement at the service level.”

- “The CCG [Clinical Commissioning Group] do have other forms of patient involvement at various forums. For example, at the recent AGM [Annual General Meeting] of the CCG, they involved patients in a number of presentations and actively encouraged patients to attend the meeting. Support for this, from the patients, was incredibly good. It provided the patients with a good insight, not only into the workings of the CCG, but the direction of the NHS generally. Enormous benefit to the CCG and patients alike.”

- “Consultation of stakeholder groups, charities, patient groups etc. is always undertaken as part of the […] service processes.”

- “CRG's [Clinical Reference Groups] and other strategic groups. Stakeholder list. Stakeholder Bulletin. Consultation and engagement exercises.”

- “I have been asked to get involved in other workstreams, such [as] reviewing the incoming CCG [Clinical Commissioning Group] STP [Sustainability and Transformation Partnership] Plans and a group involved in patient feedback - they are both on going. Although they seem to be a little ad hoc in nature.”

- “I have set up the […] Support Group to engage other […] patients and provide information for them to engage with their health care professionals and local commissioning groups.”

- “The blanket ban to-date on seeking the views of patients and the public has prevented this from happening.”

- “None that I am aware of.”

- “Through surveys, disseminated through Children's Centres. Through invitations to conferences and events. Through smaller working groups.”

- “Consultations within the papers being assessed.”

- “On a London wide level, very little. On a PPG [Patient Participation Group] level, improved usage of social media raises awareness of our existence and function e.g. the use of blogsites, such as our PPG blogsite at […].”

- “The […] does not involve patients and public in its meetings. We are continually trying to raise our profile across the county and stimulate feedback on services: attending meetings, presenting at events, stands at key NHS hospitals and the feedback is shared with the NHS locally and at the […] when relevant. We did an engagement event in a prison prior to an NHS England clinical visit and this proved useful. We will try and repeat engagement in the justice setting.”

- “I would not know. Only recently was it suggested that I should subscribe to the NHS online newsletter In Touch, which was a good idea. I am not aware that one's opinions are listened to or acted upon.”

- “Complaints and feedback concerning clinicians is received by PAG [Performance Advisory Group] and PLDP [Performers List Decision Panel].”

- “By hosting […] meetings for [Patient and Public Voice] representatives across the region.”
- “Do not know.”
- “Not applicable.”
- “Lay member of a […] project.”
- “I chair a medical Practice PPG [Patient Participation Group]. I work in other areas of NHS England.”
- “Organising roadshow conference, workshops where they are invited for an open discussion.”
- “There are PPV [Patient and Public Voice] colleagues on other groups which feed into the process, though I am unclear what happens at region and would welcome some clarity. Newsletters, virtual groups…all the other methods of engagement.”
- “The IPC [Integrated Personal Commissioning] Programme created Collaborative Development Groups [CDGs] to ensure that all the products which would be produced in the Integrated Personal Commissioning Programme were genuinely Coproduced with not only people with lived experience of PHBs [Personal Health Budgets] but also the voluntary and community sector plus the current demonstrator sites. There were 5 CDGs in total and at least 2-3 people from the National Peer Network in each of the groups.”
- “Just the work on developing PROMs [Patient Reported Outcome Measures] so far as I am aware.”
- “Surveys, focus groups, newsletters, video conferences, free teaching workshops, PPI [Patient and Public Involvement] events around local initiatives, etc.”
- “The People and Communities Board has members from the VCSE [Voluntary, Community and Social Enterprise] sector - representing the views of many sectors of society and the public.”
- “N/A.”
- “Surveys, consultations.”
- “An example of our involvement with others is we attended conferences throughout England where […] were meeting and discussed our plans and projects with them to gain a wider audience and see what young people really want.”

Question 11. What other ways could be used to involve patients and the public in this group's area of work?

- "Actually [being] listened to and used to influence agenda [is] currently an issue."
- "Being prepared to actually listen to what is being said as opposed to listening to the comments that you want to hear. I started out in the process with enormous amounts of energy and now feel that a pin has been pushed into the balloon. So, for me, deflated is probably quite appropriate."
- "Social media."
- "As I have said, I do not know if this 'group' even exists anymore."
- "Make it easy to be involved. The NHS England Involvement Hub needs to be more proactive in increasing capacity in the Hub to involve patients, carers and public."
- "I have always thought that despite the excellent input I have been offered - mine is a lone view and thus open to bias. Many of the patient representatives I have met are of a similar age and background to me - we do not represent the population as a whole. I think that having input from just a small number of patient representatives is therefore 'dangerous' and I am very keen to promote any other avenue that can gain input from large numbers of patients (i.e. 1000+ minimum). We use online surveys (such as this!) in our local area with good results. Similarly the communications team reaches out to schools and colleges etc. with road shows etc. I think these methods could be adopted at a national level more - so that a better cross representation of views is obtained rather than just relying on a small number of patient representatives' input."
- "NHS England could seek to prioritise the work of patient involvement in a much more substantial way that supports the requirements to deliver better support to all areas of the service."
- "Understand what is needed and set up area groups who have an interest in the work then hold interviews with a panel that includes an active partner to fill that panel."
- "Presentations and road shows. Perhaps promote through established community groups, such as […] and hobby groups."
- "Keeping PPV's [Patient and Public Voice members] up to date with what is happening would be a good start."
- "Much improved use of social media and forums."
- "Wider advertising of opportunities; paid leave for full-time workers."

- “Asking PPV [Patient and Public Voice Partners] if they have the time to go around various community groups and asking them a set of questions directed from engagement England to get the fuller picture.”

- “Not sure.”

- “Direction [needs to] come from NHS England as [the] more need [there is] for patient involvement the [more] areas of interest are publicised and the [patient and public] voices express interest. The more the need [for] expressions of interest will follow.”

- “Direct liaison or a network for carers of people who are detained so that peer support can be developed and good quality carer assessments supported for adult social care to sign off on. PHBs [Personal Health Budgets] are still inadequate in their knowledge of the law around them and who is responsible for assessments. If the statutory bodies do not have a clue how should families understand the processes?”

- “Have relevant meetings. Try to get other people involved.”

- “Product placement in TV programmes e.g. soaps and medical series such as […] etc.”

- “Perhaps conference calls on a regular basis to gather opinions and keep people updated and involved.”

- “Locally via GP surgeries.”

- “As guidance [is] published this could be easier for people to find and learn about. CCGs [Clinical Commissioning Groups] could promote PHBs [Personal Health Budgets] to a greater extent. Peer networks should be set up around the country and funding available to make this happen. PHBs are the way forward to attain a high standard of care for patients.”

- “If it is not happening - perhaps some regional events on PHB's [Personal Health Budgets] would be useful.”

- “Meeting people in groups already taking place, involving group leaders to organise [the] meeting with you. Providing the additional support needed by some of our groups to take part equally. Reward and recognition of their time.”

- “More public engagement at local health events. The public do not know what is happening, even the clinicians are unaware of some of the changes in services taking place and patients are being sent to non-existent services or to the wrong place with long delays in the process.”

- “See above. Give more notice of events etc.”

- “As this national panel develops I feel it would be useful to have frequent reviews of its decision making to ensure that policies are being adhered to and consistency is being achieved.”

- “More involvement at consultation stages.”

- “Hard one because often very few patients affected but we are often too reliant on the word of the organisation coming with a proposed service on its word that PPV [Patient and Public Voice] has been played in.”

- “More patient involvement in setting goals for PPV [Patient and Public Voice].”

- “If more funding were made available then we would be able to attend more meetings and events and see things through from start to finish rather than only being able to dip in and out. People would get to know and hear about us more and have confidence in us to know that by working together we all can make an effective difference.”

- “Ensuring that people are involved right from the start. Get people around the table with leaders planning what a programme should be and do.”

- “1. It would be good to have a reference panel for each of the […]. 2. I have suggested a standing group of […] patients to feedback on patient experience in […]. Remains to be seen if that is incorporated in the conclusions. 3. A similar body could be set up to service the […] CRG [Clinical Reference Group]. 4.The investigations carried out as part of the […] work already involve audits of patient records, so in effect we are taking on board other patient experiences. That works well and broadens the evidence base.”

- “Hear what is being said and positively discriminate for patient representation.”

- “It would be good to continue to embed the patient / carer experience into service design and commissioning; and to ensure that there is a strong PPV [Patient and Public Voice] at the strategic implementation level, in addition to the oversight role on the […].”

- “I do believe that the PPG's [Patient Participation Groups] could be used more extensively. As I have seen in other parts of the country, some PPGs are extremely active whilst others are still in their infancy. As they progress, it would be a genuine source of feedback not only for the CCG [Clinical Commissioning Group] but for the NHS generally.”

- “Better use of NHS Citizen Assembly events?”

- “To be honest I am not sure! I just feel that whilst the local team listen there is little that goes past local level as they are governed from above with little apparent local autonomy to carry out change. In other words all is driven by a national agenda. This is exacerbated by the painfully slow process for enacting change and the apparent lack of any oversight with regards to the current top down changes being demanded particularly at primary care level. Too much in too short a time seems to be the norm, with no prioritisation to help guide GP Practices in particular."

- "Triangulating evidence with patient survey results."
- "Spend time developing good peer networks. Give out key information at the right time, communicate using simple language. Listen to feedback."
- "On decision-making boards such as the Equality and Diversity Council, NHS England Board and PPI [Patient and Public Involvement] boards."
- "The blanket ban to date on seeking the views of patients and the public has prevented this from happening."
- "Better openness and transparency and more information on websites."
- "I would like to see the group taking their work out into local communities more, e.g. perhaps holding a roadshow which could travel around to Children's Centres, community groups and maternity hospital foyers etc., as I feel that most of the general population having babies are not aware of the work this group is doing or would ever have a chance to input their views. Also, some more general PR [Public Relations] - such as features in local press on the work of this group and any NHS groups, would be great as the general public would not ever hear about it in any other way."
- "Attending focus groups, structured engagements with practitioners and patients we serve to see the world as they experience it, structure and directional CPD [Continuing Professional Development], assigned mentor/s."
- "Improve awareness of the organisations' existence and services they provide."
- "Need to attract younger PPVs [Patient and Public Voice members] and provide the necessary support to enable them to become fully involved in the work of the group."
- "Difficult in the context of the […]. We need to gather as much feedback as possible to contribute to the meeting agendas."
- "It would be useful to have a gathering of other PPV [Patient and Public Voice] representatives a couple of times a year so that we can meet and exchange views. Surely NHS England could organise that at a central venue?"
- "Workshops, events, discussion hub / […] where public are provided with information to deepen their understanding and expectation of interaction with clinicians. Informed users would work both ways to perhaps reduce uninformed complaints yet also encourage the public who may feel clinicians must always be right and have the monopoly."
- "Not relevant to […] as these are strictly confidential."

- “I would like more direct participation in the revalidation programmes.”
- “Many ways a review of patient involvement should take place.”
- “Same as above.”
- “Specific questions, use PPG [Patient Participation Group] networks, virtual groups.”
- “Many different areas. I really think we now need to be out there collecting real evidence of how PHB's [Personal Health Budgets] are working locally for people. CCG's [Clinical Commissioning Groups] quite often say they are doing well with PHB's and hitting the figures but I think it would be really interesting to speak to real people to see if PHB's really are being kept true to the key features.”
- “1) Anybody in our […] area that has experienced any […] surgery should be given my email address so that they can relate their experiences - good or bad. I could provide undertakings about patient confidentiality and if absolutely necessary I could communicate via a secure NHS email address. 2) I never meet anybody doing a similar role to myself. It would be good if there was some sort of annual meeting to permit a bit of networking and sharing of learning. 3) Virtually all patient involvement in commissioning lacks transparency. Other than CCG [Clinical Commissioning Group] meetings in public I do not know who the patient representatives are even if they exist. I cannot feed questions into them. I am unaware of the constraints that they are under and I am certainly unaware of any summaries that they might make in relation to their take on meetings. Meetings in public are generally not public-friendly and guidelines should ensure that members of the public can get questions responded to straight away if they are non-personal and directly related to the issues just discussed.”
- “Schools and college work, working with local industry occupational health professionals and targeting meetings where business men and women can have a voice.”
- “[…] needs to have VCSE [Voluntary, Community and Social Enterprise] representatives and more PPV [Patient and Public Voice] representatives, as it is top heavy with NHS England management members.”
- “Encourage Trusts to recruit more PPI [Patient and Public Involvement members].”
- “Create more local groups that are focused on certain issues to create bigger impact and change in a specific area.”

Question 12. Do you have any further comments?

- “Yes get away from thinking only university graduates and company director types and let some ordinary patients in as partners. I have not got past long listing since partners came […].”

- “Some feedback on PPV [Patient and Public Voice] would be welcome! And notification of future opportunities.”

- “Make it easy to want to be involved. Standard application forms for NHS England CRG's [Clinical Reference Groups] are complex and are usually applied for by individuals with high health literacy skills leaving a lot of potential patient leaders behind.”

- “It would be good if NHS England could recognise those patients who have given long term support to programmes since the service first talked about patient involvement back in 2013 at the September AGM [Annual General Meeting].”

- “How many people are becoming PPV's [Patient and Public Voice members] because NHS England gives a £150 a day payment?”

- “It is heartening to know that NHS England is serious about improving PPV [Patient and Public Voice] through this and other surveys. Important to act on the feedback, I will look forward to the reports.”

- “No.”

- “It would be useful to have advance notice of volunteering opportunities.”

- “Yes - involve the voluntary sector a lot more to deliver and improve your service, such as […] etc. to feed, change beds, elderly buddy and even local school students to come on the wards and read etc. There is such a massive source that can be tapped into which could free up some of the time [of the] nurses so they can do what they need to do.”

- “No.”

- “Midlands and East lead the way in understanding the need to involve people and their families. They are a pleasure to work with and one does feel valued.”

- “Only public and patients, and I include NHS staff in that when they are off duty, know what the PPV [Patient and Public Voice] is and are able to have their say without fear of repercussions.”

- “Apologies for leaving many blank comment boxes, I feel I am not well informed enough and experienced enough being a PPV [Patient and Public Voice] representative in order to make well considered and thought out answers to all the questions asked. However, I hope with future involvement I will be able to provide more detailed and considered answers if this survey was to be repeated.”

- “No.”

- “I have always been listened to with respect and consideration. I do sometimes feel on the periphery of the group but that may be because of the technical element of discussions and there are two patients and twenty clinicians!”

- “The work of involving patients has a far greater value than anyone realises. Only when commissioners and CCGs [Clinical Commissioning Groups] listen to the needs of people will care improve for the individual.”

- “No.”

- “[…]”

- “I feel recently that I have not had many opportunities to be involved and particularly with sufficient notice to be able to diary or rejig my diary to accommodate. At the end of the day I am self-employed and do not wish to have to ‘let people down’ by changing prearrangements which actually may be detrimental for their health. The reason I would like to be sufficiently involved is because I do feel times are changing and that can have potential for developing many genuine home and work healthcare communities. […].”

- “[…].”

- “Share the common approach of coproduction with NHS. Understand how people need support to be involved.”

- “1. There is a proposal to limit an individual's PPV [Patient and Public Voice] roles to no more than two - behind which I can see the logic - but I and my fellow PPV representative on the […] are arguing strongly against this. The more I do in PPV work, the better I get at understanding what is going on in different parts of the NHS, the more I come into contact with patients and other PPV representatives, the stronger my personal evidence base becomes and the better the contribution I can make to each of the groups I contribute to. 2. In other words, I think there is a case for a group of ‘expert patients’ who live and breathe the NHS (and the way it makes decisions) every week, not just once or twice a quarter. There is not enough shared decision making, either clinician to patient or PPV representative to NHS England group/panel. Cut us down to two groups and we become almost invisible and almost certainly ineffectual.”

- “No.”

- “I have only been a patient leader for barely 12 months. From a quiet start I do feel my voice is being listened to at the CCG [Clinical Commissioning Group] and have now developed a good working relationship with them. We are encouraged as a group in the southern area and have regular meetings with NHS England where our views do have an impact. The involvement of patient leaders is a positive move and will prove more productive as time goes on.”

- “The initial problems related to accessibility, the induction process and access to taxis as part of the expenses policy very nearly caused me not to take up the post. I could not believe that a modern public service could be so unresponsive and fail to apply common sense, unless I made a fuss. It soured the initial relationship but hopefully has improved now.”

- "I think I have probably said enough. I understand the constraints that all the NHS operates under but find it difficult to be sympathetic entirely when I see examples of apparent poor planning, no impact assessments or implementation plans in evidence. Perhaps I am not close enough to the coal face to have a complete view and understanding of the difficulties. But I cannot help thinking that as long as the boxes are ticked to please the ministers and NHS leadership all is seen as fine."

- "Very little communication, not in regular contact with team, and feels a bit like a tick box exercise."

- "I would like to see how more diversity of PPI [Patient and Public Involvement] can be addressed as this has been a key issue I have been observing not only NHS England but also other bodies and structures. I am also disappointed on the lack of engagement from the NHS England Equality teams for our region if it was not for the coproduction modelling group and PPV [Patient and Public Voice] then I would not have been engaged."

- "Culture change is very slow, but I seem to be getting somewhere."

- "I am really keen to get involved in PPI [Patient and Public Involvement] at a strategic level within the NHS and would be extremely interested in discussing this and working on developing new ways of engaging with patients and public. I am particularly interested in the language used to describe PPI involvement and how this could be made more inclusive. I was particularly struck by one senior NHS clinician who was speaking at one of our network events, who very much included himself in the PPI description and shared some of his own story of […], which immediately opened up a much more open and honest discussion and reminded the whole group that we are all patients!"

- "Annual reporting of the performance of Boards."

- "The QSG [Quality Surveillance Group] is sub regional (question 2 I think)."

- "It would be good to have the opportunity to talk face to face to a really senior executive of NHS England. As an organisation it needs more help for its public profile and image of a huge and unwieldy machine. […]. We PPVs [Patient and Public Voice members] know how to reduce costs."

- "I think that this is a very important role. However, I am concerned about accessibility and whether it should be better remunerated to encourage [a] wider pool of applicants. It is a voluntary role and will only ever attract those that are well off or on state benefits."

- "This survey does not match the role I play as a lay person in the work of NHS England."

- "The […] which was funded by NHS England has been invaluable to me and many others within the National Peer Network. It has been a chance to really develop our skills and knowledge of the programmes we work alongside. It has allowed us direct access with the programme leaders and we have been supported to [ask] questions and challenge in really productive way. I cannot stress enough how important the relationships have been between our group and the NHS England team. They have been the key to our successful working paths being parallel and adjoined instead of an ‘us and them’ relationship. All credit to the team and our group.”

- “1) Confidentiality is far too often used as a screen to hide behind when NHS managers do not want to disclose that things are not quite going as they should. 2) Although I can get my expenses paid easily for my […] involvement, my contrasting experience with […] is unfavourable and I feel that I have to make a real pest of myself to get any expenses paid at all. Why can there not be a uniform system across NHS England? 3) I am genuinely interested in the technical clinical issues associated with […] yet I have no way of finding out any more other than brief chats with surgeons and interventional radiologists. Some sort of open day organised nationally but aimed at non-medical people would be particularly helpful. 4) I have attended many excellent lectures and presentations on other topics such as diabetes, stroke and cardiology. Without exception none of these have been video recorded. With modern technology it should be possible to design a video library so that volunteers and members of the public can educate themselves based on these presentations.”

- “Perhaps there should be appraisals of PPV [Patient and Public Voice] members by the chairs of each group. I would value that. And maybe there should be an effectiveness review of each group as a whole on an annual basis, with specific contributions from PPV members highlighted?”

- “I have become very disillusioned with PPV [Patient and Public Voice] work in NHS England, as it seems to be tokenistic and disingenuous.”

- “This is a developing area. The big problem is that medical revalidation is poorly understood by the public and requires much more publicity.”

Appendix 3 – Responses from committee chairs

Question 1. Name of Group / Committee / Board you are a chair of?

Due to the low number of completed surveys received from committee chairs, responses to this question are not included because of the high risk of identifying individuals.

Question 2. Please select the category most relevant to your role with NHS England, or 'national' as appropriate? If you work with NHS England both nationally and regionally you can select two options.

Response	**Total**	**Percentage of responses**
National	0	0.0%
South	6	85.7%
Midlands and East	1	14.3%
North	0	0.0%
London	0	0.0%
Total	**7**	**100.0%**

Question 3. NHS England Directorate, if known?

Response	**Total**	**Percentage of responses**
Commissioning Strategy	1	33.3%
Transformation and Corporate Operations	0	0.0%
Medical	1	33.3%
Nursing	0	0.0%
Operations and Information	1	33.3%
Finance	0	0.0%
Total	**3**	**100.0%**

Not Answered	4

Question 4. Broadly speaking, to what extent do you feel that patient and public involvement is valued by NHS England?

Response	**Total**	**Percentage of responses**
To a great extent	5	71.4%
To some extent	1	14.3%
Hardly at all	1	14.3%
Not at all	0	0.0%
Don't know	0	0.0%
Total	**7**	**100.0%**

Question 5. If possible, please provide examples of how the views of the Patient and Public Voice Partner have been listened to, taken into account and acted on, and the difference this has made?

- “This group plans how the local impact of proposed service changes will be assessed that is appropriate to the demographics of affected populations as well as geographical considerations. Lay insight into local situations and / or the best methods for engaging specific patient groups has been invaluable to this work.”

- “The PPV [Patient and Public Voice] Partner is a key member of the […] group. […]. Our group is not quorate if our PPV Partner cannot attend / dial into the meeting. The PPV Partner, as with other partners on the group, can ensure that their feedback has been heard as reflected by meeting documentation e.g. minutes and in revisions of draft documents to ensure that their views have been taken into account. It has been invaluable to have a patient perspective on this working group to ensure that we undertake engagement that is accessible and meaningful to those whose views we are seeking on proposals.”

- “Original PPV [Patient and Public Voice] representative on group has been very supportive and made suggestions but due to lack of resource we were unable to act upon these. He wished to lobby for more funding for the group but sadly stood down due to illness before he was able to do this.”

- “Our PPV [Patient and Public Voice] Partner is an equal member of the group and makes a very valuable contribution to the group and its agenda. This has influenced our work programme. She has also brought us into contact with [people] with lived experience keeping the group well connected to the experience of […].”

- “Chair is the only truly public member (i.e. not a medical professional) and has a casting vote.”

- “The PPV [Patient and Public Voice] Partners may provide a different perspective from those employed by NHS England. They bring a variety of views and can challenge the group to think differently.”

- “The PPV representative has been very supportive around service development and […]. He is well informed and always makes sure the patient’s perspective is at the centre of any decision making.”

Question 6. In addition to the contribution of the PPV Partner, what other ways are currently used to involve patients and the public in this group's area of work?

- “The Chairs and host managers of local Healthwatch, local authority scrutiny committees, public health, social service and CCG [Clinical Commissioning Group] engagement leads are also members of this group. They contribute by sharing lay perspectives and insights from their own constituencies and experiences with the group and help to design, advertise and advise on local service-specific public and patient engagement."

- "The working group develop robust PPE [Patient and Public Engagement] planning templates to support each phase of engagement activity. Feedback obtained during engagement is used to inform activities being undertaken at the time and in planning for future activities."

- "Healthwatch groups are invited to the steering group but rarely attend due to other pressures. PPV [Patient and Public Voice Partners] involved in the first stages of the […] project that we were supporting."

- "When we have had a specific piece of work we have involved [people] with lived experience, for example when we were mapping […] and developing a strategy for […]. Our PPV [Patient and Public Voice] working group member has also taken part in wider […] network events e.g. chairing on of our annual events."

- "None."

- "We also use PPV [Patient and Public Voice] Partners in the quality assurance processes of the team."

- "We link to Healthwatch who provide us with monthly comments on patients' experience of […] in our area."

Question 9. Do you have any final comments?

- "PPV [Patient and Public Voice] involvement has been invaluable in getting us to the position where we are now launching a […] with a funded clinical lead and programme manager. This is a great legacy of the […] working group."

- "As a team we try to take forwards our work in conjunction with PPV Partners and to role model this approach. We encourage all the organisations we work with across […] to consider developing PPI [Patient and Public Involvement] and this is moving forwards with an increasing number of organisations now involving lay people in the processes for […]. I am keen to gain more information on the impact of PPI."