Nurses and Patient and Public Involvement:
A Consultation in Four Strategic Health Authorities in England

Summary Report:
An Overview of Key Findings and Recommendations

July 2009

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This Report was commissioned by the Royal College of Nursing
Acknowledgments:

We would like to thank all the participants, senior nurses working in different organisational settings in four Strategic Health Authorities in England for giving up their time to take part in this study. We would also like to thank Professor Bob Sang for his initial contribution and his comments on the project and Dr Sophie Staniszewska for her comments on the final report. Ms Helen Caulfield of the RCN Policy Unit negotiated access within NHS organisations to enable focus groups to be conducted. The project was commissioned by the Royal College of Nursing, supported by Dr Peter Carter and Professor David Sines and the initial groundwork completed by Professor Bob Sang and Helen Caulfield.

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Dedication

This report is dedicated to the late Professor Bob Sang for his initial contribution and his comments on the project. Professor Bob Sang was a pioneer in Patient and Public Involvement in the UK and had a passion for these issues. Bob wrote:

'It is clearly time for a constructive challenge to the direction and substance of healthcare reforms. Who better to lead this challenge than patients themselves as active, effective partners in the transformation of health and social care?'

Furthermore:

Essentially, I am arguing for a much more ‘bottom-up’ approach to healthcare reform, based on a working partnership between Citizens and Professionals, enabled by the new system of Patient and Public Involvement. The policy drivers ‘talk the talk’ of engagement and empowerment, but it is at a local level where creative practitioners are beginning to make a real difference to both the commissioning and provision of care, based on their empathy and ability to work collaboratively with other professionals and with ‘clients/service users’.
Envoi: Reflection on Partnership

‘And if you look at true partnership with any organisations coming together, you develop a mutual understanding of what's in scope, what you can do, what's out of scope and what each of us role is when you come to the table, to have discussions, don't you? And I think that we need to develop a relationship with patients, the public and their carers, so that they are absolutely clear about what our terms of reference are, what their terms of reference are in that partnership and that is the bit that is really difficult because it's going to be different for different levels of engagement, isn't it? So if we're talking about true partnership, we are both entitled to have our say and to have expectations that are managed within that scope and it's how you actually set that out and what competencies do we need to be able to develop that relationship with patients and the public and how do we decide then, how much control do we have over who is allowed to come to the table to express their views, so what sort of selection process would we have? But in a partnership we do have a selection process and I think that there would be a reasonable way of getting a process to pull together that we could manage in that way.’

(Focus Group 1, P5, p20, 12-28)
1. Introduction

1.1 Current NHS policy places patients at the centre of the health care system and has set out a vision of a service in which patients and public have more of a say about the provision of health care in their communities. Since 2001, this has been formalised as a statutory duty to involve and consult the public and an increasing body of evidence has reinforced the benefits which can result from this.

1.2 The recent review by Lord Darzi in 2008 emphasised the need to give patients and the public better information, more control and influence. These developments raise questions regarding the approach which nurses have in place for effective PPI and towards patient focused projects and in setting priorities for PPI as part of the World Class Commissioning agenda.

1.3 This report presents findings of a national consultation project with the central aim of exploring nurses’ experiences of Patient Public Involvement (PPI). Specific objectives were to clarify what is required to enable nurses engaged in practice and in commissioning to involve patients and the public in the improvement of services and health care decision making and to clarify priorities for effective nursing practice in PPI.

2. Representation and consultation methods

2.1 All ten Strategic Health Authorities (SHAs) in England were invited to send representatives to take part in focus group discussions. Four SHAs were able to send fifteen representative senior nurses who had direct experience of PPI and were employed in eleven Primary Care Trusts. Participants took part in three focus groups conducted between September and October 2008.

2.2 Focus groups lasting 80-120 minutes were digitally recorded; transcribed verbatim and anonymised transcripts were returned to participants for validation. Following this, the transcripts were analysed thematically; six core and 37 sub themes were identified. The main themes were ‘patient and public involvement: definitions and context’; ‘experience of PPI’; ‘barriers for PPI’; ‘facilitators for PPI’; ‘building effective PPI’ and ‘ideal scenarios for PPI’.

3. Selected key findings and recommendations

The key findings and recommendations arising from this consultation with a few selected extracts from the focus groups are presented below.

3.1 Patient and Public Involvement - definitions, context, experience

(i) Most participants were aware of patient and public involvement definitions and context, the different levels of PPI and the continuum of involvement. Some recognised the main elements of PPI as being patient-centred and working in partnership with patients, empowering and informing them. Different levels of PPI
were identified, ranging from informing and listening to consulting and working in partnership in commissioning. A cultural shift in PPI was also indicated.

*Well it's an absolute must, it's one of the big pushes in NHS reform around patient centeredness and having the patients at the heart of everything that we do, which we feel we've always done but they have a much greater involvement in the planning and prioritising and development.*

(FG3, P1, p1, 17-19)

(ii) It was believed by some that services and subsequent PPI were influenced by patients, service users and the public in many informal ways. These were not necessarily labelled or recognised as PPI, for example, involvement of community groups, changes based on complaints, incidents and patients feedback were mentioned.

*If you were to ask teams, ‘how do they, in PPI?’ ‘Well we don't really do any of that’, because they think formal process but in actual fact when you really drill down, ‘we're engaging with them all the time’ and we've made significant changes in our services based on complaints and individual responses and incidents and all of those have involved patients and public, so I think we've been doing it for a long time and we don't always formalise it and I don't think we should always formalise it…*

(FG2, P1, p4, 46-50)

(iii) Formal public involvement approaches experienced by participants included public engagement events and talks, good partnership working at the community level, patient and public panels, MORI polls and surveys. Formal service user involvement routes included involvement of users in health panels and as Non-Executive members of boards; involvement in sexual health commissioning through interviews with service users. Formal patient (and carer) involvement routes included discovery interviews and patient stories to support developments or changes, a monthly patient or carer forum in wards, a patient experience survey, patient involvement in Essence of Care and working in partnership with carers.

*And then I did facilitate one of the regional Darzi groups and was involved in some of the public engagement events there and ….*

(FG1, P1, p16, 32-35)

*…each of our wards has a monthly patient or carer forum, so inpatients at the time are invited and their visitors are invited into a forum where we are just talking about, sometimes when there are things on the agenda to talk to them about, as I say something's been picked up within the survey we particularly want to find something out about then we will do but if not then it's their agenda really, about anything that they want to pick up…*

(FG2, P1, p9, 42-48)

(iv) Participants reported significant involvement with specific groups of patients, carers and service users, i.e. specific networks, maternity services, children and young people, diabetes, urgent care, and end of life care.

*In [locality] we've got a Children's Trust and we've got to shadow Children's Trust Board, which is made up of young people and that's replicated in each of the districts and they're being set up and they feed into school councils, special school councils,*
youth service etc, so we're kind of developing a network to be able to speak to the young people.

(FG1, P3, p11, 29-33)

(v) PPI in commissioning included involvement of people in strategic discussions, taking on board service users’ views and shaping the services accordingly. Within the practice-based commissioning area, having truthful conversations and partnership, managing expectations in relation to budgets was considered the way forward. PPI experience in commissioning and strategy was demonstrated in various ways, i.e. in a general context, in improving specific services, involvement in strategic boards and committees, and practice-based commissioning.

We've got a small team in communications and public patient involvement. We've got a signed off engagement strategy…And we've got, within that team a number of individuals who can go to overview and scrutiny, who can run focus groups, who know what the local population needs because obviously we're three PCTs with very different health sort of needs and communities, who know the local communities and I think that's essential.

(FG3, P2, p31, 43-50)

From a personal perspective engaging with the public, we try to engage the public in a lot of commissioning processes that we're doing at the moment, for instance accrediting GPs with a specialist interest, we have lay assessors on a panel to give the patients an overview and we let the patients walk, they walk through the surgery to see what it's like from the patient's perspective. We have them on interview panels for GP appraisers.

(FG3, P1, p9, 25-30)

(vi) PPI in nursing practice highlighted the characteristics of nursing as a profession, such as the caring side of nursing, one to one rapport and engagement with patients. These were felt to shape the services and constitute important PPI characteristics. Expressed views were that nurses carry out PPI pragmatically, for instance, when delivering care they need the patients’ cooperation. However, nurses in practice may not recognise some activities, such as patient satisfaction surveys or evaluations as PPI; they view them as improving the patient experience, part of their day to day nursing activity.

As a profession I think it is, I think it is that caring side of nursing, that one to one rapport that you get when you're caring for a patient and the feedback and I'm not sure whether that feedback that you see, I mean I'm not at the bedside anymore but I still have involvement in clinic, so I still have that engagement and I know as leaders we're very conscious of the fact that we need to be taking onboard patient stories and we need to be identifying good and bad comments, you know, that we're getting back from the patients and acting upon them and I think that's how we're going to shape our services.

(FG1, P4, p2, 24-32)
3.2 Barriers for effective nursing practice in PPI

A number of barriers for PPI were identified, including limited resources and time, difficulties in representation and recruitment, difficulties and complexities of carrying out PPI and changes in national PPI policy and structures. Limitations in commissioning, PPI evidence-based practice and staff awareness of PPI were problematic as were, in some instances, negative staff attitudes and failures to adequately respond to patient and public feedback.

Diagram 1. Barriers for effective nursing practice in PPI

(i) Resources, capacity and time were experienced by many as the main barriers for PPI.

*I mean I think resources is a big thing, ..... but I also think if we're going to do this properly, we have got to have an identified resource which is specific to actually engaging and working with these people, otherwise we're never going to be able to do it. We can come up with ways of doing it and we've got good examples like [colleague] says but we just haven't got the capacity.*

(FG1, P3, p23, 32-41)

*Because in a busy ward environment, you know, where you've got 28, 30 patients being cared for, a limited number of staff available to them actually the patient and public involvement bit could be seen as the icing on the cake really, rather than what needs to be done on a day to day basis, I think it is about actually allowing, allowing nurses to take time to do it and not feel that actually it's an extra, that actually it's part of what they do on a day to day basis....*

(FG2, P2, 24, 45-51)

(ii) Patient representatives were identified most often to be people who have time, are most vocal, appear to be more active and perhaps have a special interest in a specific problem. Lack of guidelines, difficulties in recruiting and influencing a wide range of people to participate were identified. Involving the public, *'the man in the street'*, in particular, presents a special challenge.
…I think some, when you're doing kind of wider public consultation and you're going to village halls and, you know, you're doing that kind of activity to try and bring people in, you get a varied response really and, but you do get the person who's very active and everybody knows and you know, of course will turn up and have their opinion, you do occasionally get some people that, you know, have got a particular interest or just walk in off the streets, if you're at the right place but it is very difficult to capture the man at the bus stop.

(FG2, P1, p10, 17-24)

(iii) Other barriers related to the complexity of carrying out PPI, taking into account that involvement may be linked with people’s personal experiences, the many dimensions and areas of involvement as well as and managing patients and public expectations effectively. Challenges of involving seldom heard communities, such as the black and ethnic minority communities and the disabled were identified.

Set up a consultation event, here's the ground rules, here's the parameters, here's what we will do with your information, here's what we (it is easy), but we're talking about day to day lived experiences that pop up when you least expect them, or you get put in a situation where you hear something.

(FG1, P1, p19, 19-22)

I think a couple of challenges from my perspective, the BME community and the deaf, the hard to reach communities, because there's nothing more terrifying than standing up doing a presentation, seeing it sign languaged, hearing it being interpreted in Cantonese and seeing somebody else, you know, and are we equipped and trained to do that?

(FG3, P1, p17, 6-10)

(iv) Concerns were also expressed that changes in national PPI policy and structures, with the abolition of PPI Forums and the creation of new LINKs, have brought wider engagement to a halt.

I think some of the systems and some of the changes that have happened recently, for instance the abolishment of PPI forums and the creation of the new LINKs, that, certainly from our perspective on the [locality] has been, has almost brought wider engagement to a grinding halt because we had a very active Patient and Public Involvement Forum, the LINKs host wasn't appointed until the beginning, their contracts started at the beginning of August, then the Manager within the host who was identified, you know, host organisation was identified to start the work went off sick, you know, and now we're here into September and really, and there's a sense of frustration building amongst particularly the old PPI forum members, so here we are six months on from the abolishment of the forum and they still haven't got an engagement group.

(FG2, P2, p20, 44-51 and p21, 1-4)

(v) In relation to commissioning, with some exceptions, PPI work programmes were considered to be still very tokenistic and world class competencies not to have yet been achieved. The participation culture of an organisation can be a barrier to involvement: control and representativeness are key issues to be considered here. PPI which is controlled was not considered to be ‘real’ PPI. Challenges existed within some general practice cultures where engagement with the PPI agenda was limited.
And the patient and public engagement sort of work programmes are still very tokenistic so there isn't necessarily anywhere to put things, you know, we're all saying these honourable intentions and there's some pockets of really good practice but most organisations, most PCTs I think would really struggle to say they're class four, the world class competencies on patient and public engagement, so there's a bit about when it's not structured and thoughtful, it's still relevant.

(FG1, P1, p19, 23-29)

You touched on something with regard to GPs, I mean in practice-based commissioning in various things … and GPs see more people than probably anybody else and yet engage less, that's my experience, you know, and don't believe they need to engage and decisions that have been made, we've made, in partnership with the public, GPs are trying to overturn because it doesn't fit with their plans.

(FG2, P1, p17, 15-21)

(vi) Negative staff attitudes and limited awareness of PPI were also identified. The view was expressed that nurses perform PPI relevant activities which they do not, however, recognise as PPI. This is related to the fact that PPI activities – which are not recognised as such – are not captured, fed back to the senior level and thus not evidenced. This hinders the process of developing evidence on which to base effective nursing practice in PPI.

And I find it, like I say having worked with GPs and some of our consultants are fabulous, absolutely fabulous and we've got certain dynamic groups, diabetes and various other things but we've got others where the patients would never have, have a voice if it was down to the doctor. Whereas I don't think nurses think like that, so I think it is very relevant about how boards are made up, where we're going with all of these new Trusts….

(FG2, P1, p19, 40-47)

…actually sometimes it's very hard to find the evidence to actually demonstrate that and say for instance there might be notice of a meeting but they might not say ‘xx is the patient representative’, you know, so it maybe just had a list of names, you know, so it doesn't actually say that, you know, ‘xx said, you know, so and so, so’. You're not actually, you can't actually call necessarily when somebody comes and says well ‘what's the evidence? You know, how can you demonstrate this for your, this particular assessment process or that process?’ Actually because it's part of what we do on a day to day basis…..

(FG2, P2, p14, 15-24)

(vii) Not responding to patient and public feedback and expectations, either by not using the feedback or information on outcomes because issues have been resolved elsewhere, or resources are not sufficient, or by not being able to fulfil certain expectations because they are outside an individuals’ jurisdiction, were also barriers for PPI.

P3: My concern is that we can sort them and don't necessarily use the information we get to shape the service if we're not careful.
P2: Or that we don't have the resources to provide.
P3: Yes, which is where the honesty bit comes in.

(FG1, p12, 38-44)
3.3 Facilitators for effective nursing practice in PPI

The main facilitators for PPI were identified as the specific characteristics of the nursing role and informal personalised PPI activities, changes in NHS policy and structure and subsequent cultural change, the commissioning PPI competencies, other frameworks relevant to PPI, awareness of PPI benefits, and providing feedback to staff.

(i) The nursing role and nurses’ informal personalised activities, including the professional attributes of being of a caring nature, continuous rapport with patients, ongoing feedback, and listening, were reported to facilitate PPI. It was also reported that the PPI elements are all integral to a nurse’s role at different levels and within different settings.

As a profession I think it is, I think it is that caring side of nursing, that one to one rapport that you get when you're caring for a patient and the feedback .... so I still have that engagement and I know as leaders we're very conscious of the fact that we need to be taking onboard patient stories and we need to be identifying good and bad comments, you know, that we're getting back from the patients and acting upon them and I think that's how we're going to shape our services.

(FG1, P4, p2, 24-32)

(ii) It was recognised that most recent NHS national policies and documents were patient-centred. It was also recognised that the inception of LINKs would shape services; although lack of clarity about involvement and membership in relation to them was identified. It was recognised that these changes would facilitate a change in culture, including a focus on self-care and self-management.

I think we were getting there anyway. I think there’s been a change in culture and I think we were well on the way there and then that commissioning of patient by the NHS came out and that was the tipping point and....

(FG3, P1, p1, 49-50)
(iii) The world class commissioning competencies relating to PPI, which are about the organisational structure as a commissioning PCT and engaging the public, have influenced and facilitated PPI, together with the push for integrated services and the recognition of the third sector.

"Well, yes, one of the world class commissioning competencies is around Patient Public Involvement and it’s about…It’s about your structure as a commissioning PCT and how you’ve structured yourself and what your hierarchy looks like and how you’re going to engage the public in, right at that front end, your health needs assessment work because at the moment they’re kind of brought in after that, aren’t they? And we, we’ve got a big Darzi project going on at the moment where these health centres are going up and we’ve had the community, because obviously [small locality] the big one for us, where that’s going and they know what they want."  

(FG3, P1, p32, 28-36)

(iv) Some participants referred to the utility of existing frameworks which encompass PPI or relevant competencies, for example, the Essence of Care Standards, the Knowledge and Skills Framework and customer care standards. Overall these were found to be helpful and sufficient for PPI; the view was expressed that no more frameworks are needed.

"….because you’ve got the continuum of involvement that is recognised and actually in a sense you could put your different levels of involvement as with the gradings, you could make a model basically, you could use the continuum of involvement and then you’ve got your Essence of Care Standards, you’ve got your KSF, your Knowledge and Service Frameworks, you’ve got your standards of nursing, some areas have got additional ones using, based on the Essence of Care, you’ve got your customer care standards, which is all integral into a nurses role at different levels in different ways, wherever they may be working in the community or in an acute setting or in a community hospital. So actually there is a kind of framework there already, it’s how you apply it."

(FG2, P4, p29, 25-36)

(v) Some benefits of PPI were recognised, including empowerment and influence, providing arguments for change and having a re-energising effect. Other benefits were better understanding of the NHS and its bureaucratic blockages for patients and the public, challenging NHS staff, bringing about simple change, speeding up procedures, making the NHS more transparent and accountable.

P4: And I think nothing’s more powerful is it, than a patient or a carer challenging a consultant or a doctor or a nurse or a Social Worker?  

P2: It’s very powerful.  

P4: To, or the Head of Social Care, it is much more powerful and it actually speaks volumes, you know, that they will turn and pull something up…  

(FG3, p4, 36-42)

(vi) Providing feedback to staff on various aspects of patient involvement and feedback on patients experiences, surveys and complaints linked perhaps with action plans was considered another facilitator for PPI.
3.4 Building effective PPI – recommendations to overcome barriers and achieve effective PPI

(i) Dealing with limited resources, capacity and time for PPI

(Diagram 3a)

Larger PPI teams with additional capability and capacity, additional resources to enable staff to do more PPI activities and deliver the PPI commissioning competencies were put forward as suggestions. Other suggestions were the provision of lower level assistance and alternative approaches for resource allocation, either in integrated consultation with other organisations or equipping every nurse to engage in PPI.

**P4:** Because we have PPI that work across the four PCTs for [locality] and that group is in my opinion very small….It will direct people as to how they hold their public and patient involvement, it will become involved in the Darzi, but nothing else. Because they don’t have the capacity as a team and so the work still is falling on us and to re-develop services and commission services this needs to be continuous……

**P2:** I agree that we probably do need additional capacity and capability.

(FG3, P33, 19-40)

Diagram 3a. Suggestions for dealing with limited resources, capacity and time for PPI

- Bigger PPI teams
- Extra resources for PPI
- Assistance at the lower level
- Resources allocation: integrated consultation / every single nurse
- Resources for PPI commissioning competencies

(ii) Improving representation / selection / recruitment

(Diagram 3b)

Approaches to improve representation of various sub-groups encompassed involving parents' forums and people who have current experience. Adopting more formal recruitment processes, ensuring openness, accountability and confidence could be helpful as would reaching people through different venues, i.e. pubs, nightclubs, shopping centres. Recommendations to improve recruitment encompassed working closely with PALS, LINKs, local self-help groups; local contacts and networks. Payment for involvement and organising transport for representatives may also demonstrate a strong level of PPI commitment. Incentives such as training and provision of NVQ qualifications may support greater recruitment.

*I think, a sort of more formal, sort of almost like an interview kind of process, so that you can try and sort of identify if somebody is just coming along because … certainly I don't want to keep banging on about Foundation but certainly the Governors are all elected so a global community, obviously you're into then all sorts of people would*
vote in that kind of election but, you know, at least there is the openness there to say that these people had to be elected out of a pool of certain people…

(FG2, P6, p22, 16-23)

I think we’ve still got to work really hard to reach those communities and to do that in different ways, whether it be taken on sort of mentors or that kind of aspect or, you know, being able to train, I liked your NVQ idea, train individuals who could then become a resource for the organisation.

(FG3, P1, p17, 19-23)

Diagram 3b. Suggestions for dealing with representation / selection / recruitment issues

- **Representation & selection**
  - Recognising that people are individuals
  - Involving parent’s forums
  - Adopting a formal recruitment process
  - Taking chair’s action & changing group format

- **Recruitment**
  - Listening to many voices
  - Involving people with ‘raw’ experience
  - Reaching people through different venues
  - Using personal stories & views fit for purpose

- **Incentives & payment**
  - Working more with PALS
  - Working more with LINKs & local groups
  - Using contacts, colleagues & networks
  - Being legally enforced, such as jury panels

(FG3, P2, p23, 23-36)

(iii) **Dealing with limitations in commissioning** (Diagram 3c)

Suggestions for removing organisational barriers included raising PPI on the commissioners’ agendas at board meetings; this could also bring about changes in organisational cultures. The importance of PPI could be demonstrated by not accepting papers or bids in Boards and committees that could not truly demonstrate PPI. Forward planning for involvement in consultations to inform national strategies and greater involvement by nurses in practice-based commissioning were also recommended to enhance organisational change.

….and I was delighted to note that it (PPI) was higher up the agenda than finance…And I made that point to all the non-execs in a joking way that I was delighted that it was up there, absolutely the forefront. And I was amazed at the impact that that had on some of the non-execs where we were using the analogy of the double decker buses and how many people have injuries as patients in hospitals and how many double decker buses that would be for the Trust and there was three or four non-execs spoke to me afterwards and I heard about it and repeated it in different forums.

(FG3, P2, p23, 23-36)

….so I think there’s a whole culture change that needs to happen (in practice-based commissioning) and I think nurses need to be at the centre of actually developing
that culture change and leading that culture change but that is going to be a very
difficult thing to do because traditionally we've taken a back seat, haven't we?
(FG1, P5, p7, 27-31)

Diagram 3c. Suggestions for dealing with limitations in commissioning

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(iv) **Improving staff attitudes and awareness of PPI** *(Diagram 3d)*

Nurses’ awareness should be raised with regard to the need to empower and work in partnership with patients. Understanding how PPI information is used and reinforcing ownership of the process so that nurses can initiate changes were suggested. PPI activities, however, should remain natural and an integrated part of all processes; excessive PPI labelling can be a barrier.

...people need to be very conscious of working in partnership, I think historically the NHS has had a very closed culture and very disempowering culture to patients and I think the trend now is very much around patient focus, patient needs first and some, no doubt if one was to observe a whole range of different nurses functioning you'd get some working brilliantly and some lower...Yes, less aware and conscious of that need to empower and work in partnership...

(FG2, P4, p28, 7-17)

Other recommendations to improve staff attitudes and awareness included raising understanding that PPI takes many forms and all health professionals should engage in it as part of their jobs. Using game techniques to influence cultures and flag messages for staff could be helpful.

...labelling it patient and public involvement actually probably isn't going to help the situation if you like but it is about getting people to understand that actually patient and public involvement comes in that whole range of forms and it's not something that's done to you by people who've got it in their title actually it's something that everybody's engaged in and should be part of whether they're a nurse or whether they're a clinician or whatever, actually should be part of the day job for us all.

(FG2, P2, p7, 11-17)

(v) **Improving PPI evidence-based practice** *(Diagram 3d)*

It was suggested that PPI should become more formalised so that its value can be reported and monitored, thus developing the evidence base for practice. However,
evidenced PPI should be undertaken using process indicators rather than outcome indicators with minimum bureaucracy.

...I think that for us at the moment is actually a key challenge to create that evidence because what an individual said, it's difficult always to identify, it could tip, you know, it could lead on to all sorts of other discussions and something would change at the end of it but to say this led to that change is not always so easy to demonstrate. 

(FG2, P3, p6, 20-24)

Diagram 3d. Suggestions for improving staff PPI attitudes and awareness, and PPI evidence-based practice

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<thead>
<tr>
<th>Suggestions for Improving Staff PPI Attitudes and Awareness</th>
<th>PPI Evidence-Based Practice</th>
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<td>Improving Staff PPI Attitudes and Awareness</td>
<td>PPI Evidence-Based Practice</td>
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<tr>
<td>Nurses being conscious of the need to work in partnership</td>
<td>PPI should become more formalised</td>
</tr>
<tr>
<td>Reinforcing ownership of the PPI process to nurses</td>
<td>Evidence without creating bureaucracy &amp; paperwork</td>
</tr>
<tr>
<td>Nurses understanding of use of PPI information</td>
<td>Looking at process indicators rather than outcome indicators</td>
</tr>
<tr>
<td>Staff's understanding of many PPI forms</td>
<td>Staff's understanding that PPI is part of everyone's job</td>
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<td>Staff's understanding that PPI is part of everyone's job</td>
<td>Using game techniques to influence culture</td>
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(vi) Improving responses to patient and public feedback and managing expectations

Presenting plans for PPI which do not raise unrealistic expectations by patients and the public was considered essential. Staff should manage expectations by working in partnership, with effective consultation and information gathering. It was recognised, however, that there are cases, where issues cannot be dealt with from those who consult or work in partnership with the public. In such instances, these cases should be redirected to other services.

Yes. It's really, really hard isn't it? You know and you feel a responsibility to the people because they have an expectation of us that we're going to fix it and if we're going to hold these consultation events what is it that we can realistically do to manage their expectations of what we're going to be able to do as a result of it, so they don't think it's a waste of time and they don't say well I went last year and I haven't done anything about it, you know, so we won't bother again in the future. So there's definitely something that we keep coming back to about managing our expectations and the patients and public's expectations of what we're going to be able to do with that information so how do we tailor what it is we can use …

(FG1, P5, p18, 3-13)
(vii) Offering PPI education and training
Embedding an involvement culture with younger age groups, through raising awareness in schools and Youth Councils and integrating PPI as part of children’s citizenship and health education was suggested. Universities should offer and integrate PPI education and training at different levels; for example, pre-registration training to foster skills in communication and partnership working, ideally delivered through inter-professional learning units. At post qualifying level, PPI awareness and partnership working should also be offered within all programmes as explicit units or integrated within the general content. In addition, training should move towards a more integrated customer service approach.

Diagram 4. Offering PPI Education and Training

And I think, to be honest, we are going down the academia path and I think local universities have a role to play around PPI as well, you know, that could be something that's built into training if it is. ..Undergraduate training.

(FG3, P3, p40, 37-43)

It has to start with pre-registration training, doesn't it? So it has to start with, you know, from day one, those skills in communication and partnership working have to be embedded in pre-registration, nursing training, you know......and other professional training as well, so that actually you've got that partnership working going from day one.

(FG2, P2, p29, 11-27)

(viii) Involvement of nurses with specific groups
Involvement of nurses with specific local groups or people who are not patients or in care, such as Age Concern/Help the Aged would be helpful. This interaction, listening to people belonging to specific subgroups could enhance the practitioner’s understanding of their needs. In addition, those who are not in care can voice more general concerns without being frightened of consequences or ramifications. PPI leads could facilitate this connection; they can support staff and visit groups together.

Yes, who may not be patients at the time, may not be in that role of being a patient and not very keen on kind of telling you quite how it is at the time because they think it will affect their care, you know, and listening to people that, you know, don’t care
what, you know, that will make a comment, you know, whether you agree with it or not or, you know, or whether they've got a right understanding of it or not but it's quite challenging I think going to community groups and being able to stand up and say well actually you do it this way because or you know, you've got a point, I mean you could do it.

(FG2, P5, p31, 6-14)

(ix) Changing organisational cultures
Changing organisational cultures to give a stronger PPI focus could be achieved by using patient stories, experience and complaints to influence commissioning decisions; sharing PPI information and feedback; nurses being proactive and perhaps more challenging and innovative and through effective change management procedures. In general practice, positive shifts towards a stronger patient protection – patient focused culture are recommended.

I think we're much more challenging as well as a profession, we're very challenging I think naturally, I think not just nurses but I think we're actually sitting in the roles that we're sitting in, it's probably because we are challenging and vocal and probably see a bigger picture and really want to be innovative and it's looking for those opportunities I think, instead of waiting for something to happen, we want to make it happen.

(FG3, P4, p36, 40-45)

(x) Integrating PPI in all roles and responsibilities
Some participants suggested making PPI part of everyone’s job, as part of customer care training and through KSF competencies. If the acquisition of PPI knowledge and skills becomes part of everyone’s personal development plans, it will enhance practice, service and also inculcate a sense of ownership of the PPI agenda.

And another thing is about making sure that it's vested in everybody's job descriptions and again it's back to if you've got a communications team they can't do that single handed. We, every contact with members of the public should be, you know, the key message opportunities.

(FG3, P1, p17, 24-27)

(xi) Other recommendations to increase PPI awareness and activities in nursing
a) Strong leadership in nursing and in commissioning should be facilitated in order to increase awareness of PPI.

b) Highlighting to the government the activities that nurses already perform in PPI and making a more strategic commitment to PPI would be helpful.

….should be highlighting to the government as a result of these consultations is 'guys, we already do this, we do an awful lot of it, it's fundamental almost to our nature as nurses that we do this and at different levels'. A band five ward nurse will do it in a very different way to a band eight community matron for example but they will all do it so rather than shove another load of frameworks on top of us, how about we just acknowledge that we already do do it and then maybe have more of a strategic commitment to PPI and let people run it.

(FG2, P6, p32, 45-50)
c) PPI awareness could be facilitated through diverse conference events and seminars, i.e. on world class commissioning and PPI.

P4: They need to be putting on things around world class commissioning and PPI, we don't want to know how to catheterise or how to do something that is, quite often either community focussed or just acute because we're working across all of the areas, so we need them to present us with something bigger.

P2: I'm not sure about that, I'm not sure about whether is a market or a need to go further into world class commissioning because I think it's a market that's become very, very quickly and heavily populated.

(FG3, p37, 36-44)

d) Both profile and awareness of PPI should be raised by supporting the involvement of nurses in practice-based commissioning and facilitating active involvement of nurses in major NHS consultative exercises, such as the NHS Constitution for England.

...well in a way the vehicle for the coffee room moans to the change for patients could be practice-based commissioning; and nurses get, there are so many blocks to getting in to practice-based commissioning and I've done a few sort of national conferences where I've talked to nurses about practice-based commissioning and said why don't you just go to the meeting, what's the worst that could happen? You know, why don't you start trying to create those mechanisms and those discussions but it's those individuals having to knock on doors that are sometimes shut, learn a whole new set of language and then wait their moment to drop in their, you know, this service needs changing because and, you know, carry on having those discussions but I don't think nurses are recognising practice-based commissioning is their business and I think that's a good proxy for public engagement and involvement...

(FG1, P5, 30, 39-50)

e) Other events could be considered such as a PPI campaign, along the lines of the recent successful privacy and dignity campaign; a PPI conference, covering issues such as patient diaries and customer care. The participants suggested that one day focused regional and local events were preferable.

d) Suggestions were also given for PPI information to be included in websites, including innovative PPI examples that people could add to or share and a PPI toolbox that people could use, linked to other websites, such as Patient Choices or the Department of Health.
3.5 Effective PPI – ideal scenarios

(i) The ideal scenario for PPI comprised many elements, for example, being patient-centred, working within a true partnership, having shared vision; clarity of purpose, aims, rules, actions and deliverables; knowledge, empowerment, positivity, honesty, openness and transparency. A holistic and integrated approach to PPI, good representation, selection and recruitment of people, moving away from tokenism, and leadership and commitment were considered as other effective and important PPI characteristics.

The trick is to be completely honest about what it is that we’re asking them and about what we can do and what we can’t do and if we are going to empower and going back to the point that was made earlier that they have to appreciate some of the, some of the decisions are incredibly difficult and we might find that actually they don’t want to know, they don’t want to go into it in that depth because actually they don’t want to have to be making decisions because then we can be the bad guy and they’re not having to be involved and I think, I think we will get quite a bit of that and I can understand that, why should they have to be made to feel like that when it’s much easier if it’s us……

(FG1, P3, p12, 1-19)

(ii) Being very open and very honest as to what the NHS can and cannot do and why, was suggested for effective PPI in commissioning. An increasing understanding of how the NHS works in the community and relevant resources
would help the public. A focus ‘on the who, what, where and when’, a strategy, an action plan and additional resources are needed.

**P3:** You know, it's between a lot of.... It's true, I am not an academic, give me the who, what, where, when bit of paper.

**P4:** That is world class commissioning, the who, where, what and when. So we need to focus and we need chief execs to say I want a two page document, I want a strategy, want two pages that tells me what's what.

**P3:** That's true.

**P4:** And I want an action plan to go with it, so, yes.

(FG3, p19, 31-40)

PPI should be integrated in everyone’s job, should be evidenced and be part of everybody’s practice for to achieve effective PPI in nursing.

Well it is kind of required now, isn't it, increasingly by regulators in that it has to be evidence that needs assessment has been done, you are evidencing that actually this is the public view but this is where you get the community being very cynical about the NHS because plans are developed and then the consultation happens and decision are actually made and what…

(FG2, P4, p33, 26-31)

Diagram 6. Effective PPI

- **Leadership & commitment**
- **Moving away from tokenism**
- **Representation / selection / recruitment**
- **Holistic & integrated approach**
- **Ideal scenarios**
- **Nursing practice: being integrated within all jobs & evidenced PPI**
- **Commissioning: open & honest, strategy & action plan, resources**
- **Knowledge, positivity, honesty, transparency**
- **Clarity of purpose, rules, actions, deliverables**
- **True partnership & shared vision**
- **Being patient-centred**
4. Conclusions

4.1 This report presents an attempt to explore ‘an emerging productive partnership’, nurses enabling patient and public involvement in health. Notwithstanding the limitations of this consultation - lack of engagement by some SHAs and smaller numbers of groups and participants than anticipated - the focus group interviews produced rich data. Although not generalisable, the findings provide insights into PPI experiences of fifteen nurses working at strategic level in eleven PCTs in England.

4.2 Findings correspond with those of the only two other relevant studies identified, both from Picker Institute (2007 and 2009) and provide some evidence that progress towards achieving meaningful and effective PPI is still very slow. A strong message was that another framework is not needed, as PPI or similar competencies are covered elsewhere. The question remains how the recommendations of this report will be used to increase awareness of PPI, facilitate PPI nursing networks and other strategic developments amongst nurses. Specific recommendations are made about offering relevant training and events to nurses in a proactive and interactive manner.

4.3 Current NHS policies place an even greater emphasis on PPI such as Section 242 (1B) of the Health and Social Care Act 2006, the Darzi Review and the NHS Constitution. The world class commissioning programme promotes integrated care and a change in organisational and staff culture; specific recommendations are suggested to assist the delivery of this policy focus. The main characteristics of effective PPI as expressed within focus groups correspond to some of the world class commissioning elements; however there is still work to be done to transform the way that health and care services in England are commissioned and to ensure that health and care services provided meet the needs of the population. Strategic and long-term approaches to commissioning services need to take into account the needs of the population more effectively.

4.4 Evidence-based services, people’s choice, control and more personalisation, informed, considered investment and PCTs partnership, are all highlighted within the world class commissioning vision; participants discussed these together with those most relevant to PPI competencies: working with community partners and engagement with public and patients. On the other spectrum of involvement, it seems that there was a consensus that nurses in practice, because of the characteristics and nature of nursing, perform PPI in its pragmatic sense, even if they do not recognise it as such. PPI, its learning and achievement has not been given sufficient recognition, nor has it been robustly shared and systematised - especially within nursing practice. Thus, PPI awareness and training for nursing needs consideration. This will ensure a move towards PPI being part of every nursing activity and assist the development of sound evidence based PPI that will improve patient care.
References