

# **Patients for Patient Safety Project in England and Wales**

**Patient Safety Champions & NHS  
Partners Meeting in London**

**2<sup>nd</sup> June 2009**

**Report : Anna Allford, Project Manager**

## Summary

Many of the volunteer Patients for Patient Safety (PfPS) Champions had travelled to the capital the day before to take some time to catch up and exchange ideas over dinner. Their passion and enthusiasm remains evident as this project completes its first year and begins to explore during this one day meeting how we can identify outcomes and outputs.

The presence of members of the project's Strategic Advisory Group added a further dimension to the way in which we are considering future plans and they are taking back with them positive views on the ways in which they can discuss involving the champions in their own organisation.

Feedback from this very packed day was positive and one participant commented:

*"The meetings really do reinvigorate our enthusiasm and so I think that they are a really good idea."* PfPS Champion

Especially important was the fact that it was felt it was a "safe space to air issues". The comments and discussion were very appreciated by the project team who will be taking forward the thoughts and ideas that emerged to discuss with the project's Accountability Group.

Peter Walsh, Chief Executive of AvMA, described the uniqueness of the PfPS Champions and their incredible energy, passion and commitment to the project. He felt it was heartwarming to witness individuals' work and the community of interest, which extends globally. He said feedback from the Patient Safety Congress was that delegates were impressed by the presentations made by champions, Anne Carvalho and Bev Hurst.

It was felt that PfPS Champions are 'pushing at an open door' now in respect of Being Open, since the National Patient Safety Agency are really enthusiastic about re-launching the policy and the Care Quality Commission have this as one of their standards.

It was agreed that widening participation through pilots to develop Patient Safety Advocates (working title) and forging links with NHS Foundation Trust (FT) Lay Governors, Local Involvement Networks (LINKs) in England and Community Health Councils (CHCs) in Wales would serve to firmly place many more patients, carers and the public as the patients' voice in patient safety improvement work. Furthermore, it would help to establish mechanisms for working with and recognising those who are already involved in patient safety.

*A full delegates list can be found in Appendix 1.*

## **Introduction**

Peter welcomed everyone and mentioned the recent changes amongst some of the NHS Partners. He emphasized the need for people to be focused as with such a packed day the participants had much to work through but with protected time for discussion also planned in the afternoon. Anna Allford, Project Manager, provided a brief update around the work of the project to date and highlighted that the Project Newsletter is on the website and available for everyone to view or download, even people that are not part of the project. She reminded people that it helped to generate interest and highlights what's happening in and around Patient Safety so it could be used to send to Trusts and other interested organisations or individuals by PfPS Champions and NHS Partners.

## **Group Discussions**

Project updates from PfPS Champions & NHS Partners had been circulated in advance of the meeting and were not discussed individually, instead the first part of the morning was spent in small discussion groups with a member of the Strategic Advisory Group to each group.

The task was to discuss outcomes and obstacles encountered in involving patients and the public in improving patient safety with the opportunity to discuss the positives as well as talk about our frustrations, the emphasis being on how we work together. Plus groups were asked to explore ways in which we could measure:

- change in 'culture' around patient safety;
- improvement in patient safety from the point of view of the involvement of PfPS Champions and the Wider Network;
- patient and public involvement in patient safety improvement work.

Additionally, each group gave feedback on their comments and suggestions and posed a question for the Panel Discussion which included members of the Strategic Advisory Group (SAG) and Project team.

## **Panel Discussion**

### **Topic 1**

***How can we support PfPS Champions in making links with Primary Care Trusts (PCTs) and in the Commissioning of services?***

***What is the focus of this project, is it patient safety or is it quality? (Is this beyond the scope of the project?)***

It was felt that the geography in a number of regions is sometimes a barrier to patient participation and in some cases this was recognised as a resources difficulty for the Strategic Health Authority (SHA) in supporting PfPS Champions.

In the South Central region this issue has been addressed by including Commissioners in their Forum as well as PfPS Champions, staff and patients. Carol Lamyman-Jones, Strategic Advisory Group member, suggested that in Wales the project and PfPS Champions need to link in to the Community Health Councils (CHCs). Cate Quinn, Strategic Advisory Group member, outlined the role the Care Quality Commission (CQC) will have in meeting new requirements and explained that it has yet to be decided how it will assess Commissioning.

The following ideas were thought to be useful in making links:

- ❖ Sharing of information.
- ❖ Every CHC (Wales) and LINK (Local Involvement Network) in England having one recognized member as a point of contact and championing patient safety.
- ❖ PfPS Champions having a role in ensuring requirements are met.
- ❖ Linking with lay members of Primary Care Trust ( PCT) Board.
- ❖ It was suggested that PfPS Champions look at the NHS National Institute for health and Clinical Excellence (NICE) Guidance – re clinical guidelines on patients safety issues and flag up the patient safety issues to the Guidance group.
- ❖ SHAs can provide a link to NHS Primary Care Trusts (PCTs) and Commissioners – perhaps PfPS Champions could help SHAs develop networks of patients involved in patient safety?
- ❖ Honing the champions role so that it is largely focused on ‘patient’ rather than the wider Patient and Public Involvement aspects.
- ❖ PfPS Champions could focus on specific issues surrounding safety
- ❖ Distinguishing safety from quality – focus on particular strategies and issues. The unique thing about the project is the focus on patient safety although other areas may overlap.

A brief discussion followed on how ‘safety’ can or cannot be distinguished from ‘quality’. It was suggested that patient safety needed to be addressed by PCTs in CQUIN (Commissioning for Quality and Innovation) [see Department of Health website [www.dh.gov.uk](http://www.dh.gov.uk)]

## **Topic 2**

***How can we be sure that we don't just tick boxes but have assurance that our recommendations reach Board level?***

The following suggestions were put forward:

- ❖ Obtain a set date for the next meeting of the Board and ensure issues are put back on the Agenda.
- ❖ Highlight at the next meeting any issues you are unhappy with.
- ❖ Request that Trusts adopt a similar procedure to that passed through the Welsh Assembly Government and put in writing any changes to recommendations along with written explanation / clarification where these occur.
- ❖ PfPS Champions can talk to SHA's about topics they feel are relevant.
- ❖ Giving honest feedback about ideas put forward, whether you agree or disagree.
- ❖ Talk about how feedback will be received – will it be recorded in the Minutes etc.
- ❖ Develop a model for the partnership with PfPS Champions/CHC/ LINKs
- ❖ Make contact with the Chairperson of relevant Groups to ascertain how, as a PfPS Champion you can contribute to the group.
- ❖ Agree 'rules of engagement' – ask for 'Memorandum of Understanding'.
- ❖ Asking how you can do more and improve patient safety, as well as obtaining feedback on how you are doing.

It was felt that this project is an opportunity to see what the role of champions will be and in particular it was felt it should not be 'tokenistic'. Role model partnership was highlighted as being the ideal to be promoted by PfPS Champions. Within the project it was agreed that we need to focus on where things are working and understand why and how they work. It was felt that mutual respect, co-operation, honesty, and trust all go a long way toward facilitating the NHS National Patient Safety Agency (NPSA) Being Open policy.

Emma Forbes, NPSA, and member of the extended project team, described plans for more patient, carer and public engagement in the work of NPSA, including computer technology to spread messages rapidly. She also outlined plans for the re-launch of the Being Open policy later this year.

### **Topic 3**

#### ***Is sustainability of PfPS Champions at a national and local approach planned?***

The following suggestions were put forward:

- ❖ PfPS Champions need to have a clear remit and set timeframes for their work (some PfPS Champions have developed personal Action Plans to help them do this).
- ❖ There should be an agreement between PfPS Champions and their NHS Partners and/or the Project team about where to focus efforts.
- ❖ DH Champion needed for Patient Safety. Ms Joan Saddler is a member of the project's SAG and it was thought she may be able to help facilitate this.
- ❖ The Project Evaluation may help focus for future years.

- ❖ Measurement of the impact of PfPS Champions involvement needs to be detailed and include rich experiences, possibly looking at how 'inclusive' PfPS Champions feel. It should be qualitative rather than quantitative.
- ❖ The Engagement Team of CQC are developing a Statement of Involvement around Health and Social Care and information relating to this is now on the website. This could be useful when planning future involvement for PfPS Champions.
- ❖ It was suggested that various national organisations could pool resources to engage PfPS Champions in their patient safety agenda.
- ❖ Making contracts longer in respect of the agency spearheading the project would help secure a firmer strategic framework.

A discussion followed on whether there should be a stated term of office for PfPS Champions and it was generally agreed that this is usually the case for other voluntary posts. Anna Lee, commented that there is a current restructure taking place within the World Alliance For Patient Safety, the programme of the World Health Organization (WHO) with which this project is closely linked. It is something they too are looking at.

A participant suggested there was a good deal of pressure on the 22 PfPS Champions as volunteers due to the sheer scale of the project and in light of the discussion on sustainability this needs to be factored in.

#### **Topic 4**

#### ***Obstacles include a lack of welcome in the NHS regarding patient safety risks (as highlighted recently in the case of whistle-blowers)***

Issues were discussed as follows:

- ❖ PfPS Champions need to demonstrate that they treat sensitive information confidentially by developing relationships of trust with NHS Partners.
- ❖ NHS Partners and NHS organisations outside of the project need the PfPS Champions assurance that their own experiences would be used in a positive way and that any individual concerns have been dealt with sufficiently emotionally, for them to undertake this wider perspective on behalf of others.
- ❖ A legal Duty of Candour (similar to that introduced in some other countries) was suggested to resolve much of this.
- ❖ Professor Albert Wu's phrase about 'non punitive culture' was mentioned as being a useful description but many participants thought that a non punitive culture is better described as a 'just culture' or open and fair culture.
- ❖ Being Open is an area that PfPS Champions can focus on to overcome barriers (Being Open is now a CQC 'standard' and providers must demonstrate it.)

Issues highlighted were not just about the NHS but about the partners the NHS work with and the skills these partners bring. There exists barriers to people coming forward to speak out about patient safety risks because of anxiety and concerns about how they will be received and the consequences. The answer was felt to be to develop a just culture. It was agreed that a 'just culture' must come from the top down in any NHS organisation.

It was felt that the Project team could collect and disseminate examples of good practice to share with NHS healthcare professionals and patients. Case studies and examples will be asked for by the Project Manager and suggestions for these are welcome.

It was commented that PfPS Champions are independent people working within NHS rules and it must be acknowledged that there is always a tension around developing working partnerships in this way if volunteers are to remain independent.

### **What measurements do we need?**

Participants discussed measuring patient and public involvement in patient safety both from the point of view of improvement in patient safety due to involving PfPS Champions and the Wider Network and also by virtue that little or no work has been done to date to measure patient and public involvement in patient safety in England and Wales. Measuring a 'change in culture' in the NHS was also explored.

It was felt that by changing attitudes towards patient safety then a very real shift could be measured. This could probably be through collecting qualitative data and it was suggested that patients need firstly to have information provided to them to outline how staff should be dealing with them safely. Cate Quinn explained that the CQC has been using in the past a number of measures to look at this. Marcia Kelson, Strategic Advisory Group member, commented that NICE use patient stories to help change attitudes and understand better the patient perspective. She said they are very powerful and could be shared with Boards as it is essential to include the 'human' aspect as well as facts and figures relating to patient safety incidents. NHS Yorkshire & Humber have made a film based on things that worked well for patients – looking at why it worked well. This will be used as a training tool but has not yet officially been launched. Anna Allford requested a copy for dissemination after its launch.

During lunch there was an opportunity for further networking and to view Poster presentations showcasing pieces of work that some PfPS Champions/NHS partners had brought along. Anna asked for feedback around this and suggested this could be a regular feature at national meetings of this kind if people generally found it useful.

## **New role to widen participation of patients and the public in the project**

The Project Manager outlined the future development of 'Patient Safety Advocates' to support existing PfPS Champions (participants had been provided with the Role description in their packs). The Project team had recognised during the first year of the project the need to ensure that PfPS Champions were not over-stretched in some regions either geographically or from the considerable amount of work being offered to them. The need for more 'Champions' had always been something that had been called for by some SHAs and also in Wales, from the beginning of the project. Anna explained that as the project did not have the remit or capacity to recruit more volunteers and run an Induction Workshop for further PfPS Champions, then a national role in support of the current 22 PfPS Champions that was flexible for local requirements had been developed by the Project team.

The term 'Advocate' was discussed and it was agreed that it was only a working title and a better term could be adopted. Anna asked that suggestions for the title be sent to her.

Discussions with East Midlands SHA and the Project team to recruit volunteer Patient Safety Advocates (working title) to three of the five counties in the region have resulted in a proposed pilot which will be based on the newly developed national role for 'affiliates' to the project. Patient Safety Advocates would need local agreement with NHS organisations for travel/other expenses in place before being recruited but they would be facilitated by the Project Manager in terms of information, contacts, networking etc. This pilot scheme would bring the capacity up to 5 volunteers in the East Midlands area i.e. 2 Champions and 3 affiliates.

The East Midlands SHA are working with the project to recruit a replacement Champion (to be known as an Associate Champion) to the existing vacancy before considering recruiting 'affiliates'. An Associate Champion would be a replacement for PfPS Champion vacancies (currently 2 nationally) and would be fully part of the project i.e. for travel expenses, training etc. with the proviso that when an appropriate Induction Programme became available from the World Alliance For Patient Safety then the Associate would access this and have the opportunity to be entitled PfPS Champion (once they'd met the criteria stipulated by the World Alliance).

NHS Northwest said they were also considering a pilot in their region and had recently discussed this with the Project Manager. It too would be based on the project's national Role description but at the time of discussion with Anna the Trusts that might be interested in this had not been contacted so it had remained confidential.

A general discussion followed with some participants feeling that there needs to be greater clarity around the role of PfPS Champions before widening

participation. However, others felt there is a need for more people to be involved, especially in roles in support of PfPS Champions but being mindful of the need to liaise together. Earlier discussions in the morning had highlighted the increasing work for some PfPS Champions and this initiative was agreed as a useful way forward in some regions. Anna said the Project team were ready to commence widening participation in this way in areas only where Champions & NHS Partners want to go ahead and that there is no compulsion to do so otherwise. She invited any champions/SHAs/Wales to discuss plans around such pilots with the Project team. Learning from pilots that do take place may inform future planning. There will be feedback to the whole group on progress in the pilots.

It was also agreed that funding for an annual meeting where everyone involved in the project could meet and exchange views, including any affiliates, should be sought.

## **Project Update**

Anna provided an overview of the project's work to date and highlighted work undertaken by some of the PfPS Champions/NHS Partners. In particular a piece of work around Being Open by champions, June Hitchcock and Darren Tamplin, together with Alison Walton, NHS South East Coast was discussed. A spreadsheet had been developed as a matrix to examine the implementation and evaluation of the Being Open policy within all of the NHS Trusts in that region. It was still at the draft stage and June asked for feedback from other participants – to be sent to Anna at the project office for collation. There was a lot of interest and other regions looked forward to the results of the analysis and how this will feed into the work of the SHA.

It was noted that the NHSLA (NHS Litigation Authority) has a website that shows the level they have achieved in the Clinical Negligence Scheme. Having a Being Open policy is one of the criteria that is looked at. See website:  
**<http://www.nhsla.com/Claims/Schemes/CNST>**

It was suggested that it may be of interest for people to look at the *Putting Things Right* project in Wales, see website **[www.wales.nhs.uk](http://www.wales.nhs.uk)**

Barbara Wood, Strategic Advisory Group member, advised that Being Open is now part of good medical practice and that it can be used as a lever since clinicians can be sanctioned by their professional regulators for not adopting this as good practice.

Angela Brown, Strategic Advisory Group member, had recently mentioned to the Project Manager the concept of Dignity Champions. A discussion around 'Dignity Champions' that are being recruited nationally through a link on the DH website:

[www.dhcarenetworks.org.uk/dignityincare](http://www.dhcarenetworks.org.uk/dignityincare) highlighted the idea of a national campaign to recruit more people to the project's Wider Network. We already have PfPS who are the 'Ambassadors' in each region and with a page on the DH website plus a celebrity (Dignity Champions have Sir Michael Parkinson) then we could raise the profile considerably amongst the public and professionals. This idea will be discussed further by the project team.

Anna ensured participants were aware of the forthcoming Re-Tender for this project that would be announced later this year by NPSA. Current funding runs to the end of March 2010. AvMA would bid for the Tender again and participants were very much in support of this.

Additionally, Anna reminded PfPS Champions that they can utilize the Project Manager, Project Administrator and project office as a resource, for example, letters can be sent out on behalf of PfPS Champions. The new project leaflet is currently under development and when ready this will be an additional resource for everyone.

## **Potential Work Themes**

Peter and Anna highlighted the way in which PfPS Champion, Stuart Stevenson, had worked with the Wales 1000 Lives Campaign in talking about his experience on a DVD. Stuart's experience had been shown at a session at the Patient Safety Congress in Birmingham this year. Patient stories/experience could be disseminated widely in this way and it was suggested this could be useful for other PfPS Champions to do if the opportunity became available.

The project team had identified a possible mechanism for PfPS Champions to forge links with NHS Foundation Trusts (FTs). Lay Governors have an Association that could be contacted in order to raise awareness about the project and which may lead to follow-up meetings for those PfPS Champions who are interested. The project team understood that FTs hold regional or local meetings for the community they serve and invite the public to participate. This could be an opportunity for PfPS Champions to give a presentation if they were happy to do so. The project team will make an initial approach to investigate this further, with a possible planned mailing to all FTs.

Similarly, a mailing to LINKs and their host organisations in England as well as CHCs in Wales could provide opportunities for PfPS Champions to meet with and share local information about patient safety improvement work.

Anna offered to help PfPS Champions with presentations and individual meetings if these became available.

## Open Discussion

An open discussion in the afternoon ensured there was time to explore and deliberate over some of the information and ideas that had come out of the day. Everyone felt that these national meetings were vitally important for networking and exchanging ideas with others involved in the project. Peter agreed that the project team would discuss this to ensure there would be a further meeting within this current financial year.

Anna Lee, outlined the International perspective regarding what is happening elsewhere in those countries that have similarly recruited in-country PfPS Champions. She said the spotlight is on us, Denmark and Canada to demonstrate how PFPS Champions work in this way.

Peter said it was important for champions to identify individual priorities and implement their Personal Action Plans (these will be reviewed with the Project Manager in the coming months).

PfPS Champion, Narendra Mathur, commented that the General Medical Council is now made up of 50% lay people and 50% doctors and this has made tremendous improvements.

Peter noted that CHRE, The Council for Healthcare Regulatory Excellence, is an independent body accountable to Parliament. Its primary purpose is to promote the health, safety and well-being of patients and other members of the public. It scrutinises and oversees the health professions regulators, working with them in identifying and promoting good practice in regulation, carrying out research, developing policy and giving advice. CHRE oversees the work of nine health professions regulators.

CHRE have a public network that people can join – see their website for details: [www.chre.org.uk](http://www.chre.org.uk)

Peter also announced that AvMA had been instrumental in ensuring that the wording on a circular to Trusts '**Apologies and Explanations**' had been revised in line with what Champions had previously discussed in meetings. In particular it encourages NHS staff to offer earlier, more informal apologies and explanations to patients and their families.

Participants were thanked for their input and energy in keeping the day moving forward and offered the opportunity to feedback their further thoughts on the day through the evaluation form in their packs.

**Appendix 1**



**National Patient Safety Agency**

**Patients for Patient Safety (PfPS) Champions  
and NHS Partners Meeting**

Copthorne Tara Hotel, Kensington – 2<sup>nd</sup> June 2009

**DELEGATE LIST**

<b>Name</b>	<b>Surname</b>	<b>Organisation</b>	<b>Job Title</b>
Anna	Allford	AvMA	Project Manager
Valerie	Baker		PfPS Champion
Gillian	Bean		PfPS Champion
Ann	Bisbrown- Lee		PfPS Champion
Anna	Lee	WHO World Alliance for Patient Safety	Patients for Patient Safety Project Assistant,
Sue	Bothwell	NHS Northwest	Assistant Director Patient Safety Improvement
Angela	Brown	NHS Northwest	Associate Director Clinical Quality <i>Strategic Advisory Group Member</i>
Anne	Carvalho		PfPS Champion
Angela	Deacon	NHS Yorkshire & Humber	Integrated Governance Support Manager
Jenni	Dewhurst		PfPS Champion
Carol	Evans	AvMA	Project Administrator
Emma	Forbes	NPSA	European Patient Safety Network and Patient Engagement Lead
June Eng- Choo	Hitchcock		PfPS Champion
Bev	Hurst		PfPS Champion
Marcia	Kelson	National Institute for Health and Clinical Excellence	Associate Director, Patient and Public Involvement Programme <i>Strategic Advisory Group Member</i>
Chista	Kermani		PfPS Champion
Carol	Lamyman- Jones	Board of Community Health Councils in Wales	Director <i>Strategic Advisory Group Member</i>
Jean	Lowe	NHS London	Patient Safety Manager
Wendy	Martin	NHS East Midlands	Patient Safety Manager
Narendra	Mathur		PfPS Champion
Peter	Metherall		PfPS Champion
John	Morrison	Representing NHS East of England	Patient Safety Manager
Marlene	Moura		PfPS Champion
Beryl	Nock		PfPS Champion
Margaret	Ogden		PfPS Champion

<b>Name</b>	<b>Surname</b>	<b>Organisation</b>	<b>Job Title</b>
Heather	O'Neill	NHS West Midlands	Head of Patient Safety & Quality
Benita	Playfoot	NHS South Central	Patients Safety Manager, Clinical Standards
Cate	Quinn	Quality Care Commission	Safe Care Senior Policy Lead (Acting) <i>Strategic Advisory Group Member</i>
Julie	Rix	NHS Wales	Patient Safety Manager
Stuart	Stevenson		PfPS Champion
Darren	Tamplin		PfPS Champion
Gloria	Taplin	NPSA	Patient Safety National Networks Coordinator
Alison	Walne	NPSA	
Peter	Walsh	AvMA	Chief Executive
Alison	Walton	NHS South East Coast	Patient Safety Consultant
Barbara	Wood	The Academy of Medical Royal Colleges	Chair of Lay Group <i>Strategic Advisory Group Member</i>
Iain	Wordsworth		PfPS Champion
Maxine	Wordsworth		(carer for Iain)