



Formative Evaluation of Year One Patients for Patient Safety Project in England & Wales

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EXECUTIVE SUMMARY

Passionate about safety

Sometimes it makes me feel very strong and makes me feel that along with all these other people who are backing me and all these other people who are working with me and all these other people who are doing the same things...I can make a difference. PfPS Champion 1

The evaluation is largely qualitative focusing on obtaining the views of; Patients for Patient Safety (PfPS) Champions and their NHS Partners, the project team, plus the project's Strategic Advisory Group, and PfPS network members, to explore the project in its first year from their perspective. We were not asked to measure outcomes against the original contract as these are the subject of regular meetings of the project's Accountability group. A small number of semi-structured interviews were undertaken: a total of four PfPS Champions were selected together with one NHS Partner, a member of the Strategic Advisory group and a project team member. Questionnaires were sent to key informants (people strategically placed to comment with knowledge on the idea of the project and operations) and stakeholders. Relevant data from existing evaluative activities i.e. training and meetings evaluations plus new data were also examined.

Using illustrations from the interviews and surveys undertaken as part of the evaluation together with examples of partnership working demonstrating the type of involvement and levels achieved in some regions, the report outlines; achievements and learning, challenges and opportunities, and formative issues for the management of the project. It also reflects on the role of: the Champions and their NHS partners; AvMA; and the Project Manager. Views were also sought on the future direction of the project and this is discussed with conclusions and recommendations drawn from these.

Importantly findings from this evaluation will be used to shape the development of the strategy for future years. Views of all participants and stakeholders are integral to the success of the way in which PfPS Champions and NHS Partners collaborate within the project to pilot effective community engagement strategies as a broader platform for involving patients and the public in patient safety improvement in the NHS.

Background to the project

Partnership is key to the success of the project and NHS Partners from Patients Safety Action Teams of the SHAs (Strategic Health Authorities) in England plus a Patient Safety Manager from Wales joined the champions on day two of the Induction Workshop in May 2008. The positive energy and enthusiasm coupled with the commitment to openness and partnership by those who attended the Workshop ensured its success. People felt that even those who have been speaking on behalf of others already in the area of patient safety now had a 'title and a framework in which to operate.'

Although there was only a very short lead in time of six weeks for the recruitment of volunteers as prospective PfPS Champions and for the planning of the Workshop, all 22 of the patients/patient representatives were inducted as recommended in *Safety First* (DH 2006) into the WHO Patient Safety programme and some of the healthcare professionals also expressed an interest in joining the global community committed to improving patient safety. However, primarily WHO mostly has only one or two 'champions' in each country or region so the emphasis is very different to this project where in-country champions have developed rapidly due in part to the existence of an established support organisation already working in the area of patient safety (AvMA).

A participant summed up their experience as the:

Most powerful and thought provoking Workshop I have ever been on.

PfPS 'Wider' network

In addition to the 22 Champions, the project is developing and supporting a community of interest in England and Wales. This social movement aims to ensure that the patients' perspective and voice is included in the NHS improvements in patient safety. This PfPS network currently has around 250 individuals and representatives of organisations registered on a database at the AvMA office. The network has been invited to various Workshops and events and been invited to comment on national Consultations. This database was able to be further developed very quickly in the first 12 months of this project as contacts from the initial two year pilot project undertaken by AvMA on behalf of NPSA were invited to join this project.

Formative Evaluation

The objectives of the evaluation are:

- To establish whether the objectives of the project implementation have been met;
- Identify outputs/outcomes to date;
- Identify challenges and opportunities;
- Understand the relationship between Champions & NHS Partners;
- Identify how the project could be more effective in helping collaborative working between the Champions & NHS Partners;
- Identify whether there have been unintended or unexpected outcomes and what these were;
- Support the development of the project.
- To make recommendations for the development of Patient and Public Involvement/Engagement in patient safety improvement work more generally, based on the experience of the project thus far.

Project Implementation

The aims of the project (see Appendix 1 for Workplan) in the first year have largely been met as demonstrated by the;

- success of the recruitment strategy for PfPS Champions,
- development of partnership working, range and level of activities with future pilot schemes planned to test expanding the number of 'champions',
- overall satisfaction with the project management, and
- establishment of the Strategic Advisory Group.

Training and development for champions took precedence over the initial contract objective to have national workshops with different NHS healthcare professionals groups and a decision was taken by the Project Accountability Group to resource champions development as this critical point instead. Additionally, a further national meeting for PfPS Champions and their NHS Partners together with the project team took place in November 2008 to share and disseminate information.

Outcomes to date

Over the year since the induction workshop there has been good progress in developing the project overall. In at least three areas the success of the champions in bringing patient perspectives to local work on patient safety has already been truly excellent and inspiring. Evidence of passion towards improving patient safety was clear amongst those interviewed and from the survey and it was felt by PfPS Champions, NHS partners, and PfPS network members that the project sought to utilize this emotional connection to inspire others. A stakeholder commented that their reason for being involved in the project is 'because I was passionate and committed to raising awareness and ensuring that patient safety was a priority.'

Importantly it was felt by a PfPS network member that raising the profile of the need to prioritise patient safety is tangible within the project

At last the patients and their safety is taking a centre place in the treatment of patients.

Views were sought on the aims of the project and many described the way in which partnership has led to a new way of thinking around involving, and engaging with, patients and the public both

for themselves and also for NHS staff of trusts. This supports evidence that the effects on organisational attitudes to involving patients and the culture of organisations changed in a way that made them more open to involving patients, however, separating out change specifically attributable to the participation of patients is difficult (Crawford et al. 2002). This project has raised awareness of the reasons for including patients not just as good practice but for the 'added value' that their contribution brings.

they all do bring something to the table NHS Partner

Significantly the learning from the project has a much greater impact on the wider agenda for future involvement and partnership working and the way in which models for collaborative working in patient safety improvement workstreams might be further developed.

I think the role that the project has is actually un-picking it all... as to how patients might impact and support the patient safety agenda and then for people taking on those different roles what you need around them to make sure they can do it and meet the mutual expectations Strategic Advisory Group member

Challenges and opportunities

Uniquely, the project remit was to positively recruit from groups and individuals who have experienced harm. The rationale being that *Patients and their families have a unique perspective on their experience of healthcare and may provide information and insights that healthcare workers may not otherwise have known.* (Safety First, DH, 2006)

there are certain difficulties which you're gonna come across if you look at people who've been damaged by the system... but they're the ones that that have got not an axe to grind but they've got a perspective to bring which is not going to necessarily be there from someone who is only doing it from an academic standpoint. PfPS Champion 1

Patient stories about their experience are seen to be of real value providing an opportunity to engage healthcare professionals using examples they can relate to. Many PfPS Champions have developed their style of presenting their story during the project.

there is great value in the patient's story and that will have much greater impact than any policy. Strategic Advisory Group member

At the beginning of the project Patient Safety Action Teams were embryonic, each SHA developing a model in line with the needs of their region and communities. This created divergence in the way the collaboration between PfPS Champions and their NHS Partners in England had been envisaged in *Safety First*. Some SHAs (particularly those whose plans for patient and public engagement provided opportunities for champions to become involved) were more ready than others to work in this partnership. Despite those problems all but one SHA had involved champions within the first 12 months and at the time of writing this remaining SHA has proceeded to fully engage in the project with champions in that region.

Furthermore SHA staff had not been given sufficient time to prepare for lay people to become involved and this led to discussions around; personnel issues, the need for CRB checks, confidentiality; and support for volunteers. Some NHS Partners had received formal or experiential training in patient and public involvement and engagement but others were from different sectors or roles and were unfamiliar as to the processes. This project has been instrumental in testing and developing genuine partnership and collaborative working at a strategic level and has demonstrated that attitudes towards this have been changed for NHS staff by the different models developed.

Measuring change in culture around patient safety was felt to be not just about quantitative measurements that related to statistics but more about attitudes and how this reflected on care,

being open when things go wrong and a readiness to change and adapt appropriately to make NHS care safer. It was agreed more qualitative measures needed to be developed as tools for this. Interestingly, one PfPS Champion highlighted the need to consider further which groups the change is being measured for; clinicians, managers, or patients?

measuring change also depends on who you're looking at, are you looking at it through the eyes of the patient, in which case certain things will affect the improvement and other things won't, if you're looking at it from a clinician, they are seeing it through completely different eyes so when you're measuring change and you decide whose eyes is the change coming about or who are you trying to measure it for

A PfPS network member summed up the way they felt healthcare professionals could change the culture

To be open to criticism, be patient friendly and not wrapped up in professionalism with the attitude that lay people are not educated enough in medical issues to make effective contribution.

PfPS Champions & NHS Partners

The project as currently designed and resourced has been successful in establishing the network of patient safety champions and has been able to provide them and their NHS Partners with support and where appropriate training. Basic facilitation and development of the 'PfPS network' has also been possible, but the project is not resourced to do more than service and support the existing champions and their relationship with NHS Partners. The aim of the project is to provide a platform for PfPS Champions to have real opportunities to be the patients' voice in current and planned improvements in patient safety and also to promote patient involvement and engagement in this area.

I'm in a strong position but it's only because of the role of the Patient Champion where I'm in a position where I could do that
PfPS Champion 2

Inviting PfPS Champions to act as a critical friend was seen as really beneficial by a NHS Partner who stated

using them to, as part of the checks and balances process whatever we're presenting and discussing we've got somebody in that room who's just going to say 'wait a minute'.
NHS Partner

NHS professionals described planning and delivery of patient safety improvements as part of their role. PfPS Champions were seen positively as helping fulfill the requirement for patient and public engagement in the objectives of their organisation but it was recognised there is a need to involve representatives from all sections of their community. Importantly, healthcare professionals considered that it is the unique perspective of the patient experience that can contribute most to patient safety improvements.

they (patients and families) see what we don't see, they experience what we don't experience
Project team member

Effective collaborative working

As the project has evolved champions become more adept and experienced, their working practices and subsequent achievements also evolve. This evolution is dependent on many factors, not least their skills, interests and motivation but also the degree to which the patients' influence and perspective are accepted and utilised by the NHS. Additionally, there has to be a shift towards engagement in a wider sense within the NHS in line with Darzi's vision in his final report *NHS Next*

Stage Review (DH 2008) where he describes quality as clinical effectiveness, patient safety and the patient experience.

So there has to be the right kind of policy agenda otherwise you'll come up against a brick wall. You have to have open doors otherwise you come up with closed doors so there is a receptive context. Project team member

ideally I'd like to see that each organization each Trust could say we involve patients in our patient safety work...I think you could you could say yeah we've got a whole social movement. Strategic Advisory Group member

What outcomes were not anticipated?

Some champions and other stakeholders have expressed the desire for the project / champions to be given a higher profile through Department of Health and NHS communications. The example of 'Dignity Champions' who feature prominently on the DH website was quoted.

Along the way we have lost two of the original PfPS Champions; one due to the fact that the individual was not able to truly work within the ethos of partnership working, largely because their own personal case remained unresolved, and the other champion left to enable them to concentrate on their own work commitment although they remained locally involved in previous NHS patient and public involvement work they had undertaken as a volunteer. The requirement for new champions to be inducted through a WHO supported workshop is a potential complication and replacement champions to these vacancies are now known as 'Associates' until such time as they have undertaken the WHO Patient Safety Induction programme. The project has also had to act independently to establish in-country accountability arrangements such as the code of conduct for champions, without being able to wait for WHO.

Future Development of the Project

The project to date has been mainly responsive to the opportunities it has sought to develop for patient engagement and involvement. The planning of the strategy for future years is one of building on the successes and designed developments rather than organic or reactive, although of course the need for flexibility and adaptability should also be accounted for in the strategy. Growth is accepted as required and decisions around this will be considered as the NPSA develop the bid for the re-tender of the project after March 2010.

we're engaging them more and more. The difficulty is I mean they're volunteers...We can't spread them for everywhere. Strategy Advisory Group member

One of the main aims for the project was described by a respondent as 'Building a network of people with a common interest and goals, and providing support for them to have some influence.' Others from the PfPS network felt it should be more ambitious and should 'involve service users from all walks of life' and be about making 'users of the health service aware of all aspects of patient safety.' This concurs with what we already know about Patient & Public Involvement (PPI) and social movement thinking in health. Importantly an organisation is critical to support large-scale movements and cultural shift and this project could be the vehicle for the development of a social movement by building on the existing PfPS network and framing the activities to mobilise a much wider group of people. PfPS Champions and their NHS Partners could spearhead and be the catalysts for this.

I believe the project has not really got off the starting blocks the best bit is yet to happen
Stakeholder

Best practice for patient and public involvement and engagement

Key elements identified for successful involvement of patients and members of the public in patient safety include:

- Funding and resources for volunteer travel, including the travel expenses for a carer and any additional needs, for example, the cost of a taxi;
- Training and development for lay people to be involved that is tailored to meet their needs and can be delivered locally and or/nationally;
- Ongoing support and mentoring that includes not only information but advice and facilitation.

Recommendations

1. The new specification and resources for taking forward the work started by this project should include developing and supporting the wider (national) patients for patient safety network, and patient safety 'affiliates' where regions want to develop that model.
2. SHA's / WAG should be more involved in recruitment and selection of champions (and where appropriate 'affiliates'), including the setting of person specifications / competencies.
3. SHA's / WAG should be invited to integrate the PfPS project with their regional strategy for patient involvement in patient safety work. This should include the possibility of regional networks of patients already engaged with (or wanting to be engaged with) NHS work on patient safety. These could in turn be part of the wider (national) PfPS network.
4. Consideration should be given by the Department of Health and NHS to better promotion of the project / giving it higher priority.
5. The relationship between the project and WHO should be better defined. The relationship should be mutually supportive and encourage international learning and sharing of good practice whilst allowing the in-country project the flexibility it needs. Consideration should be given to a set 'term of office' and to appraisals for champions who are part of this project.
6. Social movement thinking in health should be applied to the development of an expanded PfPS network with a focus for activity that is framed within the current context for patient and public engagement in patient safety improvement workstreams.
7. Links with other organisations, particularly where lay people are already working in patient safety and quality improvement in the NHS should be strengthened for example, Community Health Councils in Wales, LINKs (Local Involvement Networks) , royal colleges' patient groups, and Foundation Trust Lay Governors in England.
8. Linking the PfPS project effectively with other NPSA initiatives and organisations such as the NHS Institute for Innovation and Improvement, and Care Quality Commission should also be explored, so as to provide consistent and high quality opportunities for patients to engage in NHS work on patient safety.

INTRODUCTION:

What is patient and public engagement?

Patient and public engagement is the active participation of patients, carers, community representatives and groups and the public in how services are planned, delivered and evaluated. It is broader and deeper than traditional consultation. It involves the on-going process of developing and sustaining constructive relationships, building strong, active partnerships, and holding a meaningful dialogue with stakeholders. Effective patient and public engagement leads to improvements in health services, and is part of everyone's role in the NHS.¹

This project aims to explore the context and climate in the NHS for including patients and members of the public in patient safety improvement work together with mechanisms for achieving effective collaborative working. A partnership between the funders, National Patient Safety Agency (NPSA), and the charity that was awarded the tender, AvMA (Action against Medical Accidents), the first 12 months has led to a number of initiatives locally, regionally and nationally. In particular positive recruitment of patients and people with experience of harm was called for in '*Safety First*'² to develop a network of 'patient safety champions' creating a unique dynamic not recorded elsewhere.

The role of Patient Safety Champions is to 'add value' to both existing and planned work by ensuring the patient voice is included in work around patient safety improvements. However, Patient and Public Involvement (PPI) in the area of improving patient safety has until recently remained poorly represented and this might be because it is perceived as difficult to engage with patients and families who have experienced medical harm for a number of reasons, some of which are identified in the report of the Pilot project (AvMA, 2008).

The key stakeholders of this project include: NPSA/AvMA; SHAs; NHS staff/policy makers; Department of Health; Welsh Assembly Government; PALS/PPI Leads; Strategic Advisory Group members/organisations; PfPS network; Patients; public; patient support organisations; Community Health Councils (Wales); LINKs (Local Involvement Networks).

Progress and project development

This report sets out to describe the progress of the project from the perspective of the participants and project team using illustrations from the interviews and surveys undertaken as part of the evaluation. Additionally examples of partnership working are included to demonstrate the type of involvement and levels achieved in some regions.

Discussions will highlight:

- Formative issues for the management of the project;
- Challenges and opportunities;
- Evidence of interaction;
- Learning and how this may affect the wider agenda;
- What the expectations are for Patients for Patient Safety (PfPS) Champions & NHS Partners;
- What AvMA and the skills of the Project Manager brings to the project;
- What we already know about Patient & Public Involvement (PPI) and social movement thinking in health;
- Financial aspects;
- Adaptation and project extension;
- Recommendations.

¹ Patient and Public Engagement Toolkit for World Class Commissioning South Central WCC Collaborative PPI Programme

² Safety first: a report for patients, clinicians and healthcare managers
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_062848

Background

AvMA and NPSA had previously worked together on a pilot project prior to this initiative and many of the lessons learned were applied to this project. The background to *Safety First* described the need for this project and shaped the way in which the remit for it was developed. A call for volunteers was launched at a meeting for patients and healthcare professionals with an interest in patient safety, in March 2008. Over 100 people completed an Expression of Interest form that was used to categorise applicants into residing in either Wales or regions covering the 10 Strategic Health Authorities (SHAs) in England. The project team consulted with the NHS Partners and a selection panel was convened comprising of NPSA, AvMA and WHO Patient Safety staff representatives. Twenty two people attended a two day Induction Workshop in London, on 20th and 21st May as part of this in-country Patients For Patient Safety Champions initiative. Additionally, 10 Patient Safety Action Team (PSAT) members from SHAs and 1 member of the Patient Safety Team in Wales joined the Workshop on day two.

Patients for Patient Safety Champions

The 22 original individuals selected included people from a variety of different backgrounds and with a range of professional and personal experience. Marginally, more women (13) than men (9) were recruited and although invited to do so not everyone supplied personal information to monitor diversity. Of the 16 who returned the questionnaire: 5 were male and 11 female; 3 people were aged between 35-49 and 9 in the 50-64 age range with 3 people over 65; 14 people described themselves as White British, 1 as Persian and 1 as Chinese. They were also asked about disability, 7 people considered themselves disabled and of those 4 are registered disabled. Almost everyone had personal experience of medical harm and in addition some were advocates or patient representatives. A few had previously worked as clinicians or healthcare professionals and one person remained a current NHS employee. Interestingly, three Solicitors and one retired Solicitor became Champions. Their interests span a range of topics and clinical specialties.

PfPS 'Wider' network

In addition to the 22 Champions, the project is developing and supporting a community of interest in England and Wales. This social movement aims to ensure that the patients' perspective and voice is included in the NHS improvements in patient safety. This PfPS network currently has around 250 individuals and representatives of organisations registered on a database at the AvMA office. The network has been invited to various Workshops and events and been invited to comment on national Consultations. This database was able to be further developed very quickly in the first 12 months of this project as contacts from the initial two year pilot project undertaken by AvMA on behalf of NPSA were invited to join this project.

Project Governance

The infrastructure of the project includes both internal and external controls to provide guidance, review and monitor the project against objectives (Appendix 1). The Accountability Group is the Patients for Patient Safety project's board. It has been set up to ensure and assure progress of the project. The responsibilities are both decision-making and to ensure delivery of plans. The current members are: Martin Fletcher, Chief Executive, NPSA; Dr Kevin Cleary, Medical Director, NPSA; Peter Walsh, Chief Executive, AvMA; and Anna Allford, Project Manager, AvMA. Former members are NPSA Directors; Dr Suzette Woodward, and Sarndrah Horsfall.

The Strategic Advisory Group consists of individuals representing NHS and other organisations already working to improve patient safety. Sharing their knowledge and expertise to guide and advise the project team in exploring further mechanisms to ensure that the patient's perspective is included and embedded in all strands of patient safety work.

PROJECT EVALUATION:

Aims

The evaluation seeks to help understand the factors affecting the implementation and uptake of the Patients for Patient Safety Champions and PfPS network involvement, in partnership with the NHS to improve patient safety. Taking a broad methodological approach that was feasible within the resources and time available, discussion based tools provided the focus to help understand what has worked well and any hindrances/barriers. The objectives of the evaluation are:

- To establish whether the objectives of the project implementation have been met;
- Identify outputs/outcomes to date;
- Identify challenges and opportunities;
- Understand the relationship between Champions & NHS Partners;
- Identify how the project could be more effective in helping collaborative working between the Champions & NHS Partners;
- Identify whether there have been unintended or unexpected outcomes and what these were;
- Support the development of the project.
- To make recommendations for the development of Patient and Public Involvement/Engagement in patient safety improvement work more generally, based on the experience of the project thus far.

Using illustrations from the interviews and surveys undertaken as part of the evaluation together with examples of partnership working demonstrating the type of involvement and levels achieved in some regions, the report outlines;

- achievements and learning,
- challenges and opportunities, and
- formative issues for the management of the project.

It also reflects on the role of: the Champions and their NHS partners; AvMA; and the Project Manager. Views were also sought on the future direction of the project and this is discussed with conclusions and recommendations drawn from these.

Importantly findings from this evaluation will be used to shape the development of the strategy for future years. Views of all participants and stakeholders are integral to the success of the way in which PfPS Champions and NHS Partners collaborate within the project to pilot effective community engagement strategies as a broader platform for involving patients and the public in patient safety improvement in the NHS.

Methodology

A small number of semi-structured interviews were undertaken. A total of four PfPS Champions were selected together with one NHS Partner, a member of the Strategic Advisory group and a project team member. Individuals who were interviewed gave permission for the interviews to be audio recorded to help with transcribing, however, one PfPS Champion was interviewed on the phone and only notes were made during the discussion. Selection was based on the need to discuss the experience of being involved in the project from all key stakeholders and particularly to explore with some champions what has worked well and why, together with some of the difficulties encountered by others.

Additionally, an email containing a link to an online questionnaire was sent to those involved in the project who have an email address. Questionnaires were designed to be easy to complete, with many of the questions being simple tick boxes. There were also a range of open ended questions where people could give more detailed and in-depth comments. All respondents were offered confidentiality and are therefore anonymous.

Questionnaire 1 was sent to: PfPS Champions; NHS Partners; Project partners; Strategic Advisory Group (SAG) Members, described throughout the report as 'Stakeholders'.

Questionnaire 2 was sent to PfPS network members. Those without an email received a postal version.

Relevant data from existing evaluative activities i.e. training and meetings evaluations were also considered and recorded meeting attendance provided a further insight into activity levels. Three case studies were collected as examples of ways in which PfPS Champions and Patient Safety Action Teams in England have developed partnership working.

Interviews were transcribed, anonymised, and thematic analysis of the information from the interviews and questionnaires was conducted by the project manager; a second researcher from the NPSA evaluation team reviewed the data.

Informal reflection after the interviews led to positive discussions of the opportunity to share experience, issues and future possibilities openly and at length with the Project Manager and was found to be enjoyable by all who had taken part.

Results

Interviews ranged from between 36 and 102 minutes in length with the median being 39 minutes. The age range of interviewees is 38 to 69 years (average age = 53 years) and their gender is 5 females and 2 males.

A total of eight responses were received for Questionnaire 1, for Questionnaire 2 there were eight on-line respondents and a further 13 postal responses. Although these figures are very low an earlier postal survey of PfPS network members in August 2008 had revealed a similarly low responses rate. Reasons for this are not entirely clear but aspects relating to membership of this network are included in the discussion around social movements in health and recommendations are made.

Emergent themes

Analysis from interview data combined with the free text responses from the surveys showed a number of themes to be present which provided a rich source of evidence around attitudes, activities and personal reflection on the experience of being involved in the project. Many respondents also gave their views on the way forward for the project or described what they felt the aims of the project should be. The following themes emerged:

- Patient and Public Involvement/Engagement.
- Project's function or aims.
- Leadership/facilitation.
- The dynamics of the partnership.
- Activities and achievements.
- Membership - with subgroups; Recruitment, Inclusion/Representation, Motivation & Commitment.
- Communication & resources.
- Patient Safety Culture.
- Future direction of the project.

FINDINGS:

The results are discussed under the following main headings to coalesce the findings and explain how the outcomes were achieved and the critical factors that determined the project in the first 12 months;

- ❖ Activities and achievements,
- ❖ Challenges and opportunities,
- ❖ Project management,
- ❖ Patient Safety Culture,
- ❖ Adaptation and project extension.

1. ACTIVITIES AND ACHIEVEMENTS

The project remit was to positively recruit from groups and individuals who have experienced harm. The rationale being that *Patients and their families have a unique perspective on their experience of healthcare and may provide information and insights that healthcare workers may not otherwise have known.*²

The context for healthcare in England and Wales do differ in the way in which they are organised. Funding and the environment in which they operate also contribute to the opportunities for involvement have been presented to PfPS Champions in these two countries. Varying levels of engagement have been observed with campaigns and national initiatives. In Wales the '1000 Lives Campaign' has provided a background for one of the PFPS Champions in Wales to have involvement. However, in general some generic issues can be useful for PfPS Champions to get involved in across a range of activities.

NHS professionals described planning and delivery of patient safety improvements as part of their role. PfPS Champions were seen positively as helping fulfill the requirement for patient and public engagement in the objectives of their organisation but it was recognised there is a need to involve representatives from all sections of their community. Importantly, healthcare professionals considered that it is the unique perspective of the patient experience that can contribute most to patient safety improvements.

they (patients and families) see what we don't see, they experience what we don't experience

Project team member

The aim of the project is to provide a platform for PfPS Champions to have real opportunities to be the patients' voice in current and planned improvements in patient safety and also to promote patient involvement and engagement in this area.

I'm in a strong position but it's only because of the role of the Patient Champion where I'm in a position where I could do that

PfPS Champion 2

From the outset the champions had expressed an interest in the NPSA policy *Being open: Communicating patient safety incidents with patients and their carers*³. It was agreed that this would provide a national theme for all champions to engage with NHS staff and discuss issues around this important policy. Training and support materials were provided by the project team and discussions within the group were facilitated to develop questions that would be challenging but not aggressive.

³ <http://npsa.nhs.uk/nrls/alerts-and-directives/notices/disclosure> accessed 22/09/09

PfPS Champions & NHS South Central

The main focus of PfPS Champions, Anne Carvalho and Chista Kermani's work to date has been membership of the NHS South Central Patient Safety and Risk Managers Forum. They have been involved in this innovative forum from the outset, under the facilitation of the Patient Safety Action Team at NHS South Central. The Forum membership includes representatives from acute, primary care, foundation, mental health and learning disability trusts and the two PfPS Champions.

The Forum meets quarterly and prepares its own agenda. The membership also devised their aims and objectives which are;

- To be a source of learning from each other's organisations and experiences
- To share best practice and lessons learned from incident reporting, investigation and regulation reviews
- To provide unified policies, procedures and processes that can be translated throughout the trusts within NHS South Central
- To ensure that patient Safety and Quality are at the top of the governance agenda
- To raise the profile of the patient safety champions and to ensure the patients view is incorporated into the whole patient safety agenda.

The Forum has given the PfPS Champions an opportunity to 'network' with representatives from all the trusts in the region and has led to invitations to be involved in other work.

Anne Carvalho presented her 'story' as part of the Annual Patient Safety Federation Conference in November 2008, which was attended by over 140 NHS representatives from with the NHS South Central area. The inclusion of a patient story at this event demonstrates how the importance of patients' stories in making adverse events very real is understood at the highest level.

The SHA is planning a Patient Experience/ involvement group inaugural meeting whereby each Trust will have a patient safety champion delegate in attendance, this will be coordinated by a PSM (Patient Safety Manager) and the two Patient Safety Champions.

1.1 What are the qualities of an effective Patient Safety Champion?

Interviewees were asked what factors make a good or effective Champion: a passion to be involved; make a difference; and improve things for others were seen as important motivational factors.

someone who is obviously very passionate about it PfPS Champion 3

and they're people who genuinely care for people, like people... Project team member

Skills and strengths included being able to communicate well and the ability to understand complex issues from the patients' perspective.

I think you need to be a good communicator. PfPS Champion 2

their lateral thinking is fantastic NHS Partner

Significantly, interviewees expressed the need for recognition of the strong emotions people who have experienced harm may feel or evoke in others. This was seen to be both a positive force and at times a barrier to developing trusting relationships between champions and healthcare professionals.

Somebody who's well-rounded, who doesn't have an 'axe to grind'... somebody who has an open mind really. NHS Partner

a really good patient safety champion is someone who can provide the emotion of the story and the depth of feeling without the people in the audience or receiving end of it feeling like they're being attacked Project team member

when they're actually telling their stories... It can become very, very stressful for them because they're re-living... That has been a blockage to engagement with some NHS Partners

NHS Partner

Champions identified with these powerful emotions and the way in which they deal with these by 'controlling' their feelings. The right balance of emotion being necessary to ensure they consider they have contributed positively and their involvement is worthwhile.

I've still got so much anger...I have to deliberately distance myself from stuff... because I start getting angry... I've still got this terrific feeling that nobody's actually listened to me... And the people who need to listen are the people who need to make sure that it doesn't happen again. PfPS Champion 1

you've got to learn from your emotional involvement as well but I also feel that you've got to keep it under control and not necessarily influence directly while you actually are a patient champion. PfPS Champion 2

if people are finding it a bit too personal they might find that hard PfPS Champion 3

Where adverse incidents had affected the life of someone being considered as a Patient Safety Champion it was felt that prior resolution needed to have taken place and support needs to be available for them.

I think it actually becomes quite important that for potential Patient Safety Champions who've had a very difficult experience...they might have the passion and determination...(but) to actually be effective as a champion... they actually need the support to recognize that that's happened to them but they need to have recovered from it. Strategy Advisory Group member

1.2 Evidence of interaction

Variable opportunities have been offered to PfPS Champions by NHS Partners in addition to the national invitations from the project team to attend events and represent the champions network at meetings or workshops.

PALS (Patient Advice & Liaison Services) and Clinical Governance departments have found the champions useful, for example, policy review and service re-design. A letter was sent by the project team to all PALS and PPI leads in trusts to highlight the role of PfPS Champions and offer to put the champions in touch with those who wished to engage with them. Clinicians and other NHS healthcare professionals have as a result contacted the project office to do so and also disseminated information locally about the project and how champions could be involved.

Local involvement does provide champions with more accessible working and it is important to include elements of this when planning collaborative working.

I am now getting much more involved and I've managed to do it in a way that suits me as well so I can do things more on a local level now and nearby, rather than doing things...based around the Strategic Health Authority which I always find quite difficult to start with just because of travel, purely out of travel and time out of work and things, so now I'm getting more involved in local things PfPS Champion 3

However, exclusively to this project, champions were placed to work closely with the Patient Safety Action Team (PSAT) belonging to SHAs in England and it was felt by an NHS Partner

in keeping it broad rather than just tailoring it to individual Trusts you get a very rich overview of how Trusts actually see patient safety...also in relation to how Trusts have engaged with the champions at a high level

Partnership working is not as developed in some areas and it's been suggested that 'success appears to be patchy', this could be due to the fact that PSATs were in the very early stages of development when the project commenced. The recommendation to align the PfPS Champions in England with came from *Safety First*.

Patient Safety Champions and NHS North East Safer Care PCPE Network

NHS North East's Patient Safety Team introduced a 3 year Patient Safety Strategy - Safer Care, in July 2008. A regional Safer Care Patient and Public Engagement (PCPE) Network was created. It has several clinical and enabling themes and involves local patients, carers and service users complementing the national Patients for Patient Safety (PfPS) Champions network.

Margaret Ogden, PfPS Champion, spoke at the Safer Care PCPE Conference in 2009 about her own experiences of healthcare and contrasted how a patient or their family feels when things go wrong, with how it can be when things go right, even if the underlying condition is a complex, serious and long term one.

PfPS Champions in this region have also been involved in some of the following initiatives together with Network members:

- Development of Safer Care Patient Leaflet
- Development of an Insulin passport
- Safe Surgery & Human Factors Theme Groups
- Patient Safety Strategic Forum
- Short-listing for the Safer Care Summit Award
- SURE Care Research

Mike Casselden, PfPS Champion, will be using his experience of diabetes in particular, to promote safe care in the region. He is focussing on patient & carer awareness & empowerment, to negotiate personal care plans.

... Safety First envisaged a group of people (PSAT) who would go around shaping and improving patient safety of which the Champions would have been a member...we envisaged a very large team... it's less about timing and more about trying to link with something that's not ready yet. Project team member

Raising awareness of the project and the role of champions has been core to the work of the Project Manager and project team. Acting as a central contact point for organisations who want to engage with volunteer champions has been a vital responsibility, particularly in relation to ensuring that organisations know they have to help with travel and possibly other expenses (e.g. childcare) for volunteers when asking for their involvement.

And I know outside of the SHA individuals do contact the Champions on a one to one basis, which is very important for Champions to have that accountability and responsibility within themselves and it also makes them feel that they have ownership... Of this agenda, not the SHA they have the ownership NHS Partner

PfPS Champions have attended a number of high level national events including those on behalf of: CHRE (Council for Healthcare Regulatory Excellence); Health Care Commission (now Care Quality Commission); Patients Summit; National Patient Safety Forum; and 2 champions gave presentations at the Patient Safety Congress in 2009, in addition to having a champion as a panel member at the NPSA's 'Clean Your Hands' day.

I think there've been highlights for me like the 'Clean Your Hands' day when we had...about 300 people in the room and one of our Patient Champions sat on the panel and was really eloquent and added value to that conversation and was really brilliant. Project team member

Many champions have also attended local workshops and events and during a series of 5 workshops for THOTH (now NHS Training for Innovation) PfPS Champions gave presentations to healthcare professionals and patients developing resources around 'Managing the Consequences of Adverse Incidents' in the NHS. Feedback from these workshops was extremely positive in relation to having champions describe experiences and tell stories from the patient perspective and their contribution towards the overall materials and reports produced as a result of the workshops was greatly appreciated.

1.3 Patients for Patient Safety (PfPS) Champions & NHS Partners

In developing and defining their role PfPS Champions have found their niche as both champions of patient safety and also of patient involvement in patient safety. Satisfaction is gained from the feeling that being involved in patient safety improvements has benefits for everyone, including NHS staff.

there's been a huge amount of interest in us (2 PfPS Champions in a SHA region) from lots of different sources, any meeting I go to now I get approached by one or two other people saying could you help us with something...it expands the more things you go to, it's sort of exponential, the more you pick up and you get involved which is really nice. PfPS Champion 3

This project has raised awareness of the reasons for including patients not just as good practice but for the 'added value' that their contribution brings.

they all do bring something to the table NHS Partner

Recognition of the need to understand the context of current health policy and to work within economic and political constraints is essential.

in the current climate that we've got is to align it with something that is already happening so don't put them in to do something new or different, you know, or out of sync with whatever the SHA's doing. Project team member

Inviting PfPS Champions to act as a critical friend was seen as really beneficial by a NHS Partner who stated

using them to, as part of the checks and balances process whatever we're presenting and discussing we've got somebody in that room who's just going to say 'wait a minute'. NHS Partner

At the start of the project volunteers were asked to make available one day a month as their minimum time commitment. PfPS Champions described their workload and involvement in this project as varying between one day or two days a month to 3 or 4 days a week in total. One PfPS Champion described the role as being far busier than expected and commented;

far busier than I have anticipated from the one day a month to typically about 3 days a week... The amount of paperwork involved is possibly an hour or two a day and there's reading involved as well. And that was something I had not anticipated. PfPS Champion 2

The Patients for Patient Safety Champions; the partnership in the Northwest.

Bev Hurst and Ann Bisbrown-Lee were recruited as PfPS Champions to work with the Northwest Patient Safety Action Team.

Where are we now?

'Ann and Bev are going to be a very valuable resource to the patient safety agenda, whatever groups they sit on..... I feel sure that our group would benefit from their membership' Assistant Director of Nursing, North Cumbria University Hospitals NHS Trust

PfPS Champions;

- Were invited to help with a Healthcare Commission Hygiene Code pre-inspection visit at a PCT. It was a great success; the PCT passed their hygiene code inspection and acknowledged the role Bev and Ann played in putting patients at the centre of their activities,
- Contributed to three regional projects; Privacy and Dignity, Eliminating Shared Sex Accommodation, implementing the Care Indicators and testing an integrated risk management system for children and young people.
- Are becoming embedded in the Patient Safety Campaign by routinely attending regional workshops and meetings.
- Will become part of our patient safety improvement infrastructure eg managed networks led by providers.

How did we start?

- By building relationships that were based on openness
- Being pragmatic; testing approaches with our partners, keeping it simple and focusing on adding value.
- Promoting their role to partners
- Communicating with each other regularly
- Keeping them uppermost in our minds and work; explaining their role at every opportunity.

Why we think it's working

- Leadership; the Patients for Patient Safety Champion role has been recognized and promoted at all levels in NHS Northwest
- The experience and knowledge of the Northwest Patients for Patient Safety Champions; they have moved beyond their personal experience and want to work constructively with the NHS.
- Teamwork and experience; Bev and Ann are part of our extended team, we understand the positive impact they have and vice versa.
- Respect and trust; we're all working for the same aims and have a vast range of different but invaluable experience and knowledge.

We know this is a journey and we aim to build on our success!

2. CHALLENGES AND OPPORTUNITIES

Often those who challenge are excluded. PfPS network member

The perception that if patients seeking involvement challenge healthcare professionals they could be excluded from the consultation process remains palpable amongst those who have experienced harm, however, evidence of optimism by champions and stakeholders was found in the interviews and surveys suggesting this project is viewed as a very real "opportunity to truly engage patients and families and healthcare providers" where "lay people are given a chance to raise issues with professionals".

The acknowledged dynamics of the relationship between lay people being involved in healthcare improvements and lay people actually becoming team members remains challenging.

And the great difficulty of wanting to keep somebody fresh in the role that they're in and enabling them to work effectively...But the more you involve them in the group the more they take on the organisational responsibilities And I think the value I saw in this project is actually being able to make that work. Strategic Advisory Group member

Part of the personal and professional development sessions undertaken by the project team at meetings and training sessions for champions throughout the project has sought to explore and uncover some of the issues and concerns belying this reality. Continuing independence is seen as essential to the champions

I think that a lot of this role is trying to work things out for yourself, so I think we get plenty of support when we need it but at the same time we get left to do our own things which is nice, you don't want too much intrusion, you want a little bit of freedom to do what you want

PfPS Champion 3

However, independence does present some difficulties around identity and affiliation, and a sense of belonging to organisations involved in the project. For example, when designing business cards and compliments slips for use by the champions, WHO (World Health Organization) Patient Safety (formerly known as the World Alliance For Patient Safety) declined a request for their logo to be used and since it was not appropriate to use either AvMA or NPSA logos, plain cards and stationery were developed. WHO champions in other countries or regions have different needs, often only one or two champions represent their country as national figureheads but in England and Wales this project has actively engaged and developed a model for in-country champions facilitated by an existing patient support organisation (AvMA).

Patient stories about their experience are seen to be of real value providing an opportunity to engage healthcare professionals using examples they can relate to. Many PfPS Champions have developed their style of presenting their story during the project. A template for PowerPoint presentation has been provided for champions who want to use this computer software to give presentations and the project manager provides one-to-one mentoring for champions to support them around content and delivery.

Some champions prefer to use cue cards or notes to remind them of what they want to say but essentially it is the narrative that engages hearts and minds.

there is great value in the patient's story and that will have much greater impact than any policy. Strategic Advisory Group member

it's nice to have your own story, it's nice to have a story to tell people, because I think when you go to a meeting often people want to have an example of something that will stick with them and make them think really what we're aiming at today is to stop these things happening, so I think really a good story is effective... maybe the alternative is to have two or three stories because then people get more of a mix or a variety of things, different settings where things go wrong rather than just one PfPS Champion 3

A barrier to involvement includes the specialist language used by communities of practice within the NHS, with its terminology and multitude of acronyms, even bewildering to healthcare professionals themselves as they move between specialties and sectors.

I've got thirty years experience in acute and coming in to this Strategic Health Authority... The first day it was like everyone was speaking a foreign language because everybody uses a phenomenal number of abbreviations which didn't mean anything to me
NHS Partner

Additionally, differentiating between organisations and acquiring knowledge of the roles these organisations have in patient safety does take champions a long time to build up. The project manager is researching training packages and publications aimed at the lay public to provide a working background. One PfPS Champion stated:

I have a real problem with trying to distinguish who does what and what role they're in and whether they're you know a charity, or... a governmental body or part of the NHS, it's just so vast... it's a mine-field isn't it.

2.1 Training

A gap analysis to determine the training and skills of PfPS Champions was undertaken by the project manager following the Induction Workshop in order to identify what types of training people felt was required. Short sessions between 4 and 6 hours with high quality training were felt to fulfil the needs of champions in relation to managing their travel, health and work issues. Champions prioritised training in *Being open* (NPSA Policy) and Root Cause Analysis (tool for investigating incidents from NPSA), therefore workshops for these were developed and held including a further Masterclass in *Being open* where presentation skills were also introduced.

I found the Being open training was helpful in understanding it. PfPS Champion 1

that was very good the Root Cause Analysis PfPS Champion 2

Feedback after the training events was mainly positive but there was an emphasis on champions wanting to spend more time discussing the subjects as a group and also having more time to network with each other. This was strongly expressed after national meetings between the PfPS Champions, NHS Partners and project team also.

Having the NHS professionals and PFPS Champions meet together is a very useful exercise and serves as a positive way to share experiences and learn from each other.

PfPS Champion 4

The need for continual regular training to be provided was evident in some of the interviewees

regular training maybe on at two to three month intervals for everybody would be a good top-up PfPS Champion 3

I don't think we can under-estimate the amount of support and training they potentially might need NHS Partner

3. PROJECT MANAGEMENT

AvMA is an independent charity with more than 25 yrs of experience specifically supporting people affected by medical accidents and working for better patient safety and justice when things do go wrong. AvMA has made sure that the experience and insight of patients is taken account of by policy makers.

You cannot tell people that have been hurt that something didn't happen and that nothing is to blame, it's nonsense NHS Partner

A two year pilot project in conjunction with NPSA provided the basis for learning for this current project. AvMA's Chief Executive has direct management responsibilities within the project for the Project Manager and is also a member of the Accountability Group.

I was aware of the group of AvMA what you did and therefore it seemed very sort of appropriate and sensible that you were going to pick up the Patient Safety Project and how it would work. Strategic Advisory Group member

AvMA has developed a database for this project of around 250 individuals; patients, carers, patient support group representatives, and NHS professionals, building on previous contacts. Known as the PfPS network it is a resource for the project to draw upon lay and expert knowledge in consultations and seeks their involvement in meetings and workshops. An interviewee described the network as also being a source of support for champions.

AvMA's contacts as well in relation to medical accidents and when harm has occurred to people and how they are a resource also to support other patients and also to support the champions if necessary NHS Partner

Furthermore, AvMA hosts the website for the PfPS project, featuring articles, reports and newsletters in addition to the biographies and photos of the individual champions
www.avma.org.uk/champions

the other thing that's really useful is having the AvMA website and the AvMA link because if people say they haven't heard of a patient safety champion, I'll say well go to the link and everything is on there which is great PfPS Champion 3

The experience and background of the Project Manager lends itself well to this project where building and maintaining relationships is essential. The project manager originally trained as a nurse and has worked in the voluntary and health sectors, including as Convenor in Complaints for a large NHS Trust. A former Chief Officer of a Community Health Council (health watchdog), she has worked with volunteers in a number of settings and has project management skills as well as a background in Patient and Public Involvement (PPI) developing strategy regionally and nationally in the NHS genetics services.

I think that works well {referring to the role of Project Manager as facilitator}. I think there has to be a central figure... Facilitator yes I think that's the word. PfPS Champion 1

The importance of relationships is key to a project where the greatest resource is the PfPS Champions themselves and investment in them both financially and emotionally is paramount. The Project Manager, in particular, has spent a lot of time on the telephone speaking with both Champions and NHS Partners to encourage and support partnership working. Additionally, where concerns have arisen her role has been to manage these and seek resolution with the project team when appropriate.

I think that we get a huge amount of support from you {referring to the Project Manager} which is great...I think you smooth things out very well because as we have spoken about, there's a lot of passion, a lot of emotions going around, I think you're very good at dealing with those

PfPS Champion 3

they're individuals who need that support, they need the basket of support cos they can't do it on their own cos it's all new stuff and it's all scary stuff and so the conditions are kind of going ahead of them, to say with your banner going 'these are really fantastic people and this is why you want to use them and these are their stories', then to follow-up but also the conditions you've created are around developing them, informing them and keeping them up-to-date. And always being there to listen to them when they come back. Project team member

3.1 Communication and Resources

Stakeholders reported the amount of information sent by the project team is both useful and appropriate however, there is a 'tendency for information overload'. Champions are offered printed copies of documents if they wish but generally emails are used to transmit information initially.

I'm quite happy with emails cos there's no point running up postage costs and then just pile on your mat that you're just going chuck in the corner. PfPS Champion 2

For some of the PfPS network members and a couple of the champions, communication using computer technology (emails/website) is not suitable, largely due to a lack of home computers and/or IT skills. Hard copies of information and materials are sent out by post for individuals who cannot access electronic documents but the project manager also offers coaching in using computers and email technology for those who wish to develop their skills.

The project newsletter particularly was very positively received. Produced 1-2 monthly, people feel it provides a summary and feedback of what's happening around the project. A member of the PfPS network commented that they used the newsletter to pass on information about the project to a health committee they belong to. However, another member found the newsletter 'dry and vague'. WHO Patient Safety also provide a forum for champions together with email bulletins and a newsletter which has featured the work of our 'in-country' champions and the project. The international perspective it provides was commented on as being interesting but not necessarily applicable by one interviewee.

CRB (Criminal Records Bureau) checks were provided for PfPS Champions after discussion took place at the Induction Workshop and as a matter of good practice for volunteer recruitment. These are administered by NPSA staff. Development of a Code of Conduct for the project was also deemed necessary to support the WHO Patient Safety 'Statement of Case' and 'Action Framework' which were adopted by the project and champions together with their NHS Partners at the Induction Workshop. The Code of Conduct refers to these two latter documents (which together set out the way in which partnership working which is fundamental and vital for champions should be fostered) but also gives guidelines for working within the project and how to address issues should they arise.

Champions need a Code of Conduct definitely and I know you've delivered on that and that's been really important NHS Partner

3.2 Financial aspects

Initially investment in the Induction Workshop led to a larger budget in Year One for the project with a subsequent decrease in funds available in Year Two. Volunteer expenses for travel and other expenses are currently provided in line with AvMA's volunteer policy. No payments are made to the PfPS Champions.

Recognition of the need for investment to facilitate and support PfPS Champions early in the project led to revisions to the terms of the contract. This enabled funding to be used for training and development in support of the PfPS Champions and for further national meetings between the project team together with champions and their NHS Partners instead of the 4 proposed events with healthcare professionals from acute, primary and mental health care settings.

Some members of the PfPS network have expressed disappointment at not being able to have travel expenses fully reimbursed when attending meetings or workshops advertised by the project.

Couldn't attend cos of financial constraint in funding my journey and conference fee being a pensioner living on pension credits.

Furthermore the need to provide training for champions and others involved in patient engagement has been noted:

I don't think we can under-estimate the amount of support and training they (Champions) potentially might need NHS Partner

Lay people/patients who get involved need to be trained to enable them perform effectively and feel more at ease with the professionals when working together. PfPS network member

Moreover, cost implications of expanding the project to widen participation needs careful consideration and forms part of the discussion in this report.

4. PATIENT SAFETY CULTURE

A question relating to how we can measure patient safety culture was included in the interviews and surveys. Both broad aspects and more specific measures were seen to be useful but crucially it was stated that quantitative measurements and statistics alone are not enough to gauge a change in culture and qualitative metrics (measurements) needed to be developed.

you can look at safety culture from across the breadth from the leadership's involvement to the way that they treat staff when things have gone wrong, the way that they talk to patients when things have gone wrong. All of these, the way we report incidents, the way they learn from it, and the way they develop solutions, all of these things, this multiple package of things tells you whether you've got a patient safety culture or not or how good it is.
Project team member

You can measure it just by direct results as far as there (are) statistics available. You can measure it directly just pure numbers... It would give you an operational change...so it was taken onboard and so how do you measure it, is the activity on the groups...and the people you deal with and their attitude and whether they're actually taking onboard suggestions and changes...and more to the point whether they actually do it as a matter of course and spontaneous PfPS Champion 2

one way would be to measure the incidents reported by staff and compare and contrast with incidents reported by the public. Stakeholder

Walkarounds are very useful to give immediate feedback about concerns and issues around patient safety. PfPS Champion 4

Interestingly, one PfPS Champion highlighted the need to consider further which groups the change is being measured for; clinicians, managers, or patients?

measuring change also depends on who you're looking at, are you looking at it through the eyes of the patient, in which case certain things will affect the improvement and other things won't, if you're looking at it from a clinician, they are seeing it through completely different eyes so when you're measuring change and you decide whose eyes is the change coming about or who are you trying to measure it for

Finally, even with the means to measure change (NPSA provide tools and other organisations also have tools available) then the way in which behaviour change is required alongside organisation change means that it could take time for patients and staff to see a marked difference.

you can put all processes in place but the culture shift always takes longer.
Strategic Advisory Group member

there is just a gulf between what's been written down and what's actually happening
PfPS Champion 1

When asked what members of the PfPS network wanted to achieve they highlighted feeling safe, having trust in healthcare services and a fair system for investigating incidents together with putting in place the necessary changes, as their priorities.

A PfPS network member summed up the way they felt healthcare professionals could change the culture

To be open to criticism, be patient friendly and not wrapped up in professionalism with the attitude that lay people are not educated enough in medical issues to make effective contribution.

5. ADAPTATION AND PROJECT EXTENSION

One of the main aims for the project was described by a respondent as 'Building a network of people with a common interest and goals, and providing support for them to have some influence.' Others from the PfPS network felt it should be more ambitious and should 'involve service users from all walks of life' and be about making 'users of the health service aware of all aspects of patient safety.' Greater agreement was around the aim to 'change the safety culture to openly reporting safety incidents and learning from them.'

It is generally agreed that there needs to be a widening of the project to include more people and part of the discussion may hinge on the issue of representativeness, whether a small group of champions can adequately represent and reflect the views of the wider body of patients, public and support group members and act as a conduit for them. Some champions have health and personal needs that limit the amount of involvement they can have and others have family and work commitments that need to be balanced against this voluntary role.

I think there's probably, as we know, not enough champions. PfPS Champion 3

I think...we should have Champions and we should have a bigger mass of people who can add that value. Project team member

we're saying to everyone this has got to be cohesive and it's got to be involved, much more local, and acknowledge that lots and lots of people already are very, very involved and very passionate about this NHS Partner

5.1 Expansion

Views on proposed pilot schemes to recruit more volunteers within the project were sought at interview. One such development has been discussed with NHS East Midlands. This SHA had felt from the commencement of the project that 5 champions would be needed rather than only the 2 allocated, due to the wide geographic spread covering five counties with very different communities. Congruence within the champion group interviewed also supports expansion.

I would certainly welcome it because in this area particularly...that's another issue that two champions for the whole of (name of region)...it would still be very difficult geographically...so yes to actually have somebody else in {refers to this locality} just for the sheer psychological support. PfPS Champion 2

I think it's worked very well in achieving its aim but if you had more people or more support I think you could do even more PfPS Champion 3

The project team developed a national template for a model to recruit and facilitate 'affiliates', volunteers who could work with the existing champions in support of them. However a limited budget means that local support for these additional champions would have to be negotiated and in place in order for them to have access to travel and other expenses.

Although the suggestion has been positively received consideration of the way in which group size and equity amongst champions affects the group dynamics has raised concerns.

I think maybe its value is there is such a small number of us PfPS Champion 1

I would worry about the number of people in a meeting because I think it's a close, personal group now and I think the more you add to it, the more it takes away from that
PfPS Champion 3

you've suddenly got these Patient Safety Advocates (working title for the proposed new affiliates)... who don't carry the same title...I think everybody should be actually of the same value of the same title.... Call it what you like we should be all be equal or if one person leaves and or suddenly if you've got twenty and you're changing it to forty and so on we should all have equal status. PfPS Champion 2

Additionally, champions and NHS Partners felt it important to be wholly involved in the selection process of any further volunteers. This had been recognised as necessary during the first wave of champion recruitment but unfortunately time had not been built into the early part of the project to fully develop this aspect prior to the Induction Workshop in May 2008.

DISCUSSION:

Learning and how this may affect the wider agenda

In developing and defining their role PfPS Champions have found their niche as both champions of patient safety and also of patient involvement in patient safety. Evidence of passion towards improving patient safety was clear amongst those interviewed and from the survey and it was felt by PfPS Champions, NHS partners, and PfPS network members that the project sought to utilize this emotional connection to inspire others. Reasons for being involved in the project included

because I was passionate and committed to raising awareness and ensuring that patient safety was a priority Stakeholder

Positivity and receptivity towards patient involvement in work to improve patient safety in the NHS is gaining momentum and this is especially welcomed by those who have experienced harm. Importantly it was felt that raising the profile of the need to prioritise patient safety is tangible within the project

At last the patients and their safety is taking a centre place in the treatment of patients.
PfPS network member

Uniquely, the project remit was to positively recruit from groups and individuals who have experienced harm. The rationale being that *Patients and their families have a unique perspective on their experience of healthcare and may provide information and insights that healthcare workers may not otherwise have known.* (Safety First, DH, 2006)

there are certain difficulties which you're gonna come across if you look at people who've been damaged by the system... but they're the ones that that have got not an axe to grind but they've got a perspective to bring which is not going to necessarily be there from someone who is only doing it from an academic standpoint. PfPS Champion 1

Views were sought on the aims of the project and many described the way in which partnership has led to a new way of thinking around involving, and engaging with, patients and the public both for themselves and also for NHS staff of trusts. In support of this Crawford et al.⁴ discussed the

⁴ Crawford M. et al Systematic review of involving patients in the planning and development of healthcare. BMJ: Vol. 325 1-5; 2002.

effects on organisational attitudes to involving patients and that the culture of organisations changed in a way that made them more open to involving patients, however, it was noted that separating out change specifically attributable to the participation of patients is difficult. Significantly the learning from the project has a much greater impact on the wider agenda for future involvement and partnership working and the way in which models for collaborative working in patient safety improvement workstreams might be further developed.

I think the role that the project has is actually un-picking it all... as to how patients might impact and support the patient safety agenda and then for people taking on those different roles what you need around them to make sure they can do it and meet the mutual expectations Strategic Advisory Group member

Frustrations for champions, NHS Partners and project team early on in the project were largely centred around the project being unique and innovative. At the time only two other countries globally had attempted to set up 'in-country' patient safety champion projects in line with the WHO model. Canada and Denmark had both organised their efforts differently and shared some of the issues that this project has highlighted. The main difference is that in England and Wales, AvMA as an existing voluntary body had the advantage of already being independent and operating as a support network for patients. Whereas in the other countries the structures for the project led to new support organisations being developed and much of their early work was to enable this to happen. Without the necessity to do this for this project, some champions were soon able to develop partnership arrangements and commence activities in some regions almost immediately after the May Induction. This does however raise the question of how to integrate the needs of the project as it develops with the desire to continue to have close links with WHO. It may be fruitful to have a discussion regarding whether future champions should belong to WHO or rather just sign up to the same principles, particularly as we've already recruited two replacement champions who aren't currently recognised as Patients for Patient Safety Champions but known for now as Associate Patient safety Champions.

Overall activities across England and Wales have been relevant, highly significant and valuable, although the levels of activity are not consistent in all areas. There are some excellent examples of partnership working in at least three or four regions but in other areas it has taken longer to establish relationships and build the trust necessary to develop meaningful collaborative working.

At the beginning of the project however, Patient Safety Action Teams were embryonic, each SHA developing a model in line with the needs of their region and communities. This created divergence in the way the collaboration between PfPS Champions and their NHS Partners in England had been envisaged in *Safety First*. Some SHAs (particularly those whose plans for patient and public engagement provided opportunities for champions to become involved) were more ready than others to work in this partnership. Despite those problems all but one SHA had involved champions within the first 12 months and at the time of writing this remaining SHA has proceeded to fully engage in the project with champions in that region.

I think that it initially was a bit confusing knowing what our roles were because they weren't defined but I think in each, each Strategic Health Authority seems to, or each set of champions seem to have found their own niche PfPS Champion 3

Partnership working is key for the success of this project. Building relationships with NHS Partners as well as PfPS Champions required a longer period of time before the Induction Workshop and much of the first year has been spent by the project manager in developing the foundation for this. An early discussion around recruitment policies before champions were selected would have been best practice. Positive recruitment of people who have experience of harm has been unquestionably the right way forward. However, the level of support needed was not anticipated and should in future be built in.

Along the way we have lost two of the original PfPS Champions; one due to the fact that the individual was not able to truly work within the ethos of partnership working, largely because their own personal case remained unresolved, and the other champion left to enable them to concentrate on their own work commitment although they remained locally involved in previous NHS patient and public involvement work they had undertaken as a volunteer. Both of these vacancies have now been filled with 'Associate' Patient Safety Champions recruited with the full involvement of the relevant SHAs and following a national template for the role developed by the project team.

Some champions have continuing health issues and feel thwarted by these in their attempts to fully engage in the process or participate in the project but their enthusiasm and drive has not erred. Support from the Project Manager, other champions and in some instances NHS Partners has enabled them to continue to have an input and worked with them to meet their needs.

right from the start I think it's been accepted that (I) have a disability and well more than one disability and that everything is being done that's possible to accommodate that.
PfPS Champion 1

The absence of a key member of the project team due to long-term illness also meant changes to the team were necessary and a period of uncertainty relating to this led to priorities around workload, discussions and leadership being reviewed. This was resolved and strengthened by the addition of an extended project team whereby more NPSA staff became involved and had responsibilities within the project.

Widening the agenda

The project to date has been mainly responsive to the opportunities it has sought to develop for patient engagement and involvement. The planning of the strategy for future years is one of building on the successes and designed developments rather than organic or reactive, although of course the need for flexibility and adaptability should also be accounted for in the strategy. Growth is accepted as required and decisions around this will be considered as the NPSA develop the bid for the re-tender of the project after March 2010.

we're engaging them more and more. The difficulty is I mean they're volunteers...We can't spread them for everywhere. Strategy Advisory Group member

Additionally, there has to be a shift towards engagement in a wider sense within the NHS in line with Darzi's vision in his final report *NHS Next Stage Review*⁵ where he describes quality as clinical effectiveness, patient safety and the patient experience.

So there has to be the right kind of policy agenda otherwise you'll come up against a brick wall. You have to have open doors otherwise you come up with closed doors so there is a receptive context. Project team member

Support for the project is tremendous as respondents reflect on what the next steps are.

So the Project must be seen I think as part of a bigger movement. PfPS Champion 1

It is a great project with good aims and it should go on continuously. PfPS network member

One member of the PfPS network suggested they'd like to see 'the input of ethnic groups' at meetings as they felt that people from ethnic minority groups were under-represented. Conclusively, the discussion about how to move forward together with consideration on

⁵ Darzi A. High quality care for all: NHS next stage review final report. London: Department of Health, 2008.

representativeness is timely. There is clearly a need to recruit more people in support of the PfPS network and champions could together with NHS Partners spearhead and facilitate this development.

What we already know about Patient & Public Involvement (PPI) and social movement thinking in health suggests that an organisation is critical to support large-scale movements and cultural shift. This project could provide the basis for such an organisation to ensure that the PfPS network develops and grows as a social movement.

some form of enabling organisation is required for a movement to survive and grow; movements with access to other organisations and policy-makers will act differently to those that do not; resources (financial, time and human) are important to mobilisation and survival.⁶

Emotional input and passion are pre-requisites for social movements to be successful but other ingredients also need to be in place.

What I know about social movement is that actually if you want to bring about a culture change you don't need necessarily to give people a toolkit, although that might be helpful... you have to do is touch the heart and inspire people... get them engaged in the values and principles of what you're trying to achieve... and once you've got that huge engagement and interest and principles you then underneath that put say 'well what might help you do this x,y,z?'... that's where we are now and social movements are about changing culture... these are actually the next steps... it would be entirely appropriate Strategic Advisory Group

Bibby et al.⁷ give the following definition of a social movement 'A voluntary collective of individuals committed to promoting or resisting change through co-ordinated activity.' The authors stress that 'social movements produce a lasting and self-generating effect, and create, as they do this, a sense of shared identity.' The 'story' is seen as ultimately important and it's noted that when people share stories they are communicating emotionally as well as verbally, a quality that many of our champions have developed. Interestingly the storyteller is also empowered when doing so. Facts are additionally required 'to connect rationally with people's motivation'. Building mass is the essential stage and recruitment strategies to do so need to be designed and implemented. Campaigns with explicit action are required to get people to sign up.

You need to create your mass Project team member

ideally I'd like to see that each organization each Trust could say we involve patients in our patient safety work...I think you could you could say yeah we've got a whole social movement. Strategic Advisory Group member

Whilst the project has maintained occasional contact with the wider PfPS network members (newsletters, invitations to events etc) there remains potentially great potential to be developed. The idea at the core of this is that there are already a number of people who are working with NHS bodies at a local or national level, and more still who are interested in doing so. The role for champions as 'championing' patient involvement and engagement in patient safety improvement work could be further scoped, perhaps developing the PfPS network in line with social movement thinking in health, with champions spearheading this. Importantly, it is noted that many lay people are already involved in improving patient safety and the champions could aim to engage with them, for example, LINKs (Local Involvement Networks) in England, CHCs in Wales, Foundation Trust (FT) Lay Governors and Patient groups/patient panels belonging to trusts and PCTs.

⁶ Bate S. P., Bevan H., and Robert G. 'Towards A Million Change Agents' A Review of The Social Movements Literature: Implications For Large Scale Change in the NHS . NHS Modernisation Agency 2004

⁷ Bibby J. et al. The Power of One, The Power of Many: Bringing Social Movement Thinking to Health and Healthcare Improvement. NHS Institute for Innovation and Improvement 2009

The wider PfPS network could bring all these people together as a 'social movement' and provide mutual support and sharing of good practise. This could be organised at the regional (SHA) level as well as a national level for England and Wales. At present, there is no such mechanism and those who are involved tend to work more or less in isolation. A starting point might be the identification of at least one member from each LINK and CHC (in Wales) to be a member of the wider network. The role of the PfPS champions would continue to be a champion for patient safety and patient involvement at a strategic / regional / national level and a point of contact and role model for members of the wider network in their region / country.

Limitations of this evaluation

Time constraints were one of the main difficulties as this evaluation and report formed part of Project Manager's workload. Day to day priorities took precedence at times leading to an increased and pressured period of activity for the project manager. If similar activities are to be incorporated in future protected time for this would be required. Furthermore, a budget for the evaluation was not identified and transcribing of interviews was by necessity done by the project manager and project administrator.

Selection of interviewees was made after discussion within the project team and based primarily on the smallest number of interviews that would be representative of the different groups involved in the project and which reflected a cross-section to correspond to different stakeholders and different partnership approaches. Additionally, possible interview bias is acknowledged as the Project Manager conducted all of the interviews, however, this is recognised as part of the process in qualitative research and positive reflection after the interviews indicated that it was this existing relationship that allowed people to open up and say what they really felt during the interview.

Response rates to the questionnaires for this evaluation were very low and a previous postal survey of PfPS network members in August 2008 had revealed a similarly low response rate. It was hoped that by providing a simple link via email for people to take part in an anonymous web-based survey this would encourage them to take part. When considering and planning future surveys it may be necessary to incentivise the process in order to maximise response rates.

For future evaluation work consideration needs to be given to externally conducting such reviews. This would also strengthen the research methodology however, despite selection bias and qualitative techniques used in this evaluation does not preclude it from being effective and valuable.⁸

⁸ Long L. et al. Engaging Consumers in safety and quality at Royal Adelaide hospital. *Int J Evid Based Healthcare* 2008; 6: 119-134

CONCLUSION:

As a consequence of AvMA and NPSA having worked together on a two year pilot prior to the commencement of this project on 1st April 2008, it was possible to make a 'flying start' to implementing recommendation 13 of *Safety First*. By the end of May 2008 22 Patients for Patient Safety 'champions' had been recruited and attended an induction workshop together with NHS Partners from Strategic Health Authorities and Wales. Over the year since the induction workshop there has been good progress in developing the project overall. Champions have been engaged in a variety of different ways at a national level, and with their SHA and Welsh Assembly Government colleagues at a regional and local level.

The level of engagement between PfPS Champions and NHS Partners has not been consistent in every area. In one region the amount of engagement was minimal (but at the time of writing, an action plan had been agreed for remedying this). However, after just one year every other area had something they could refer to as a success story from the project and patient and public involvement in patient safety had been given a bigger profile and priority. In most areas, the progress was very significant and the ground was set for further development. In at least three areas the success of the champions in bringing patient perspectives to local work on patient safety has already been truly excellent and inspiring.

As the project has evolved champions become more adept and experienced, their working practices and subsequent achievements also evolve. This evolution is dependent on many factors, not least their skills, interests and motivation but also the degree to which the patients' influence and perspective are accepted and utilised by the NHS.

As is to be expected, the kind of commitment and contribution that individual champions have been able to make has varied according to their own circumstances and priorities. Two champions dropped out of the project: one because of feeling unable to work in the context of close partnership with the NHS after all, whilst their case remained unresolved; the other, because of other commitments and not being able to commit to the project. The rest of the champions remained committed to and enthusiastic about the project (although one champion – from the area which had seen little or no engagement – expressed understandable frustration). As far as the NHS partners are concerned, the vast majority have expressed support for the project and satisfaction with it. However, several have commented that they would have liked to have been more involved in the design of the project and in the selection of champions. Some had found it very challenging 'factoring in' this project to their region's existing work on patient safety, including patient and public engagement.

It has been expressed that champions need to move beyond their own personal experience and broaden the agenda.

Is there is something about the immediate experience of what they {referring to PfPS Champions who have experienced harm} have had... that they can feedback from an incident. That has a time limit on it. Strategic Advisory group member

Support for PfPS Champions and NHS Partners is crucial and during the course of the project so far, the role of PfPS 'champions' has become more clearly defined as championing the cause of patient safety and of patient involvement in patient safety work. There is a growing appreciation that there is a danger of placing too great an expectation on the limited number of 'champions'. It has become clear that the concept of a wider 'social movement' of patients for patient safety, incorporating the 'champions' as figureheads and facilitators but also building on a PfPS network of patients and the public already engaged with NHS work on patient safety (or wanting to be), has great potential. In some areas, patient safety 'affiliates' are also being recruited to complement the role of champions.

Additionally, training and facilitation for SHA and NHS staff to collaboratively work in genuine partnership with lay people should be considered as fundamental if the expertise and perspectives

patients, and their families bring to the table can be fully appreciated and for them to have a real influence. This was highlighted as a challenge early in the project and PfPS Champions, NHS Partners and the project team have all sought to develop not just relationships to meaningfully work in this way but also mechanisms to do so. The experiences of those involved in the project should be captured as part of the learning to take forward in future training. The satisfaction from working in this true partnership way is exponential, the more it happens, the more patients and NHS staff feel change and patient safety improvements in particular is really happening.

The project is aligned, as recommended in *Safety First*, with the WHO Patient Safety initiative. Each of the champions who are part of this project has also been appointed as a patient safety champion as part of the WHO initiative. Whilst this has certain advantages, the requirement for new champions to be inducted through a WHO supported workshop is a potential complication. The project has also had to act independently to establish in-country accountability arrangements such as the code of conduct for champions, without being able to wait for WHO.

The project as currently designed and resourced has been successful in establishing the network of patient safety champions and has been able to provide them and their NHS Partners with support and where appropriate training. Basic facilitation and development of the 'PfPS network' has also been possible, but the project is not resourced to do more than service and support the existing champions and their relationship with NHS Partners.

Some champions and other stakeholders have expressed the desire for the project / champions to be given a higher profile through Department of Health and NHS communications. The example of 'Dignity Champions' who feature prominently on the DH website was quoted.

The aims of the project (Appendix 1) in the first year have largely been met as demonstrated by the;

- ❖ success of the recruitment strategy for PfPS Champions,
- ❖ development of partnership working, range and level of activities with future pilot schemes planned to test expanding the number of 'champions',
- ❖ overall satisfaction with the project management, and
- ❖ establishment of the Strategic Advisory Group.

Training and development for champions took precedence over the initial contract objective to have national workshops with different NHS healthcare professionals groups and a decision was taken by the Project Accountability Group to resource champions development as this critical point instead.

Key elements identified for successful involvement of patients and members of the public in patient safety include:

- Funding and resources for volunteer travel, including the travel expenses for a carer and any additional needs, for example, the cost of a taxi;
- Training and development for lay people to be involved that is tailored to meet their needs and can be delivered locally and or/nationally;
- Ongoing support and mentoring that includes not only information but advice and facilitation.

Feeding in the findings of this evaluation into the strategy which is currently under development will ensure that it is realistic, achievable and shaped by all stakeholders as well as being framed in the right context for the current climate and planned changes within the NHS.

I believe the project has not really got off the starting blocks the best bit is yet to happen
Stakeholder

RECOMMENDATIONS:

- 1. The new specification and resources for taking forward the work started by this project should include developing and supporting the wider (national) patients for patient safety network, and patient safety 'affiliates' where regions want to develop that model.**
- 2. SHAs / Welsh Assembly Government (WAG) should be more involved in recruitment and selection of champions (and where appropriate 'affiliates'), including the setting of person specifications / competencies.**
- 3. SHAs / WAG should be invited to integrate the PfPS project with their regional strategy for patient involvement in patient safety work. This should include the possibility of regional networks of patients already engaged with (or wanting to be engaged with) NHS work on patient safety. These could in turn be part of the wider (national) PfPS network.**
- 4. Consideration should be given by the Department of Health and NHS to better promotion of the project / giving it higher priority.**
- 5. The relationship between the project and WHO should be better defined. The relationship should be mutually supportive and encourage international learning and sharing of good practice whilst allowing the in-country project the flexibility it needs. Consideration should be given to a set 'term of office' and to appraisals for champions who are part of this project.**
- 6. Social movement thinking in health should be applied to the development of an expanded PfPS network with a focus for activity that is framed within the current context for patient and public engagement in patient safety improvement workstreams.**
- 7. Links with other organisations, particularly where lay people are already working in patient safety and quality improvement in the NHS should be strengthened for example, Community Health Councils in Wales, LINKs (Local Involvement Networks) , royal colleges' patient groups, and Foundation Trust Lay Governors in England.**
- 8. Linking the PfPS project effectively with other NPSA initiatives and organisations such as the NHS Institute for Innovation and Improvement, and Care Quality Commission should also be explored, so as to provide consistent and high quality opportunities for patients to engage in NHS work on patient safety.**

Appendix 1

Patients for Patient Safety Project, England and Wales

Workplan

Goal	Output	Month
To have a communications strategy that integrates this work stream with other across NPSA to maximise value	<ol style="list-style-type: none"> 1. AvMA to develop a communications strategy aimed at patients and activists 2. NPSA to build on the strategy by proposing communications activities aimed at NHS staff and clinicians 	End May 2008
<p>Champions workshop arrive Monday evening 19th May and work Tuesday 20th of May.</p> <p>Wednesday 21st May NHS Partners arrive and work with Champions.</p> <p>Opportunity to attend Patient Safety Congress 22nd and 23rd May</p>	<ul style="list-style-type: none"> • Articulation of wants and needs and expectations • Established consensus for future approach and work with champions via report • Dissemination to SHA Patient Safety Action Teams, NPSA in Wales, champions, PPI leads in trusts 	<p>May 2008– workshop</p> <p>July - report</p>
Develop ongoing support for Champions	<ul style="list-style-type: none"> • Project Manager and p/t Assistant to facilitate Champions • Develop AvMA website and Discussion Forums • Communications and In-house newsletter to be developed.. 	June and ongoing
Develop relationships with key stakeholders	Identify national workstreams and organisations involved in improving patient safety that Champions can add value to e.g. Patient safety Campaigns in England and Wales	June/ongoing
Training and Development Mapping exercise for Patient Safety Champions	<ul style="list-style-type: none"> • To explore what skills and training/relevant professional qualifications volunteers currently have • To determine future training/ further 	July

	development required.	
Training event – ‘Being Open’	<ul style="list-style-type: none"> To provide training and develop presentation skills of Champions who will be discussing this with healthcare professionals as their National focus 	July
Advisory Group established	Good governance and engagement	July
Refine and develop database of wider Network contacts (from previous pilot study)	<ul style="list-style-type: none"> Survey of database contacts Develop role of network 	July ongoing
Develop plans / proposals post first year of the project	<ul style="list-style-type: none"> Prepare project plan 09/10 Scope future 3-5 year plan 	August/September
Review meeting with Champions and NHS Partners (residential)	Review progress to date. Share experience and disseminate good practice/learning.	November 2008
Building Knowledge events. Skills and confidence of patients and champions	Further events as identified by Champions and their NHS partners/national organisations	TBC 2008/09