

Formative Evaluation of Year One

Patients for Patient Safety
Project
in England & Wales

Executive Summary

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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.

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Copies of the full report can be viewed or downloaded at www.avma.org.uk/champions