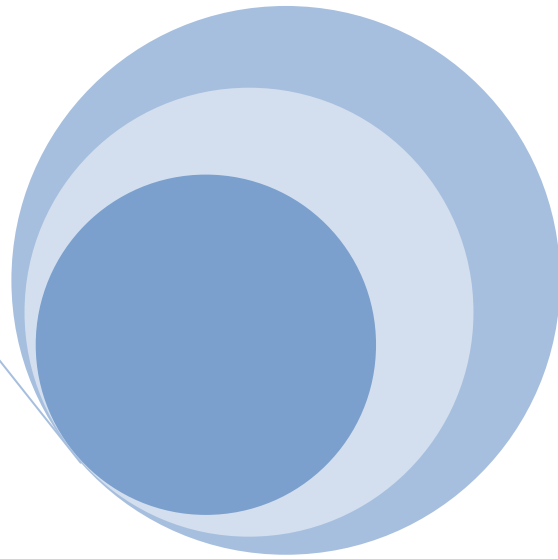


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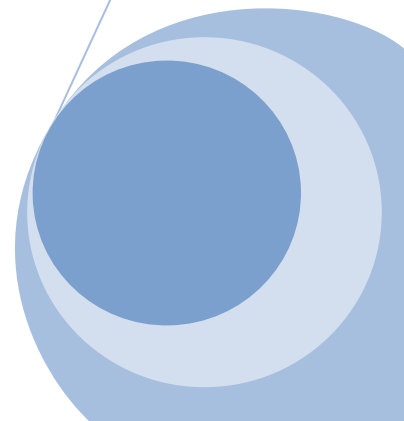
National Patient Safety Agency



Patients for Patient Safety Project England and Wales

**Report
April – September 2008**

Anna Allford, Project Manager, AvMA



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Introduction:

This report considers the qualitative as opposed to the quantitative estimates of the progress and impact on working to develop partnerships between Patients for Patient Safety Champions and NHS partners in England and Wales between its commencement in April 2008 and September 2008. It involves description, interpretation and a seeking of understanding of the mechanisms, structures and tensions that exist in this shift of involving patients and the public in improving patient safety. Where relevant, evidence is provided for determining the outcomes and outputs against objectives set, some of which is discussed quantitatively.

Background

Recommendation 13 of *Safety First*¹ (Department of Health, England, 2006) called for the development of a network of 'patient safety champions' drawn from patients and the public, to work with the NHS to improve patient safety by bringing patient experience and perspectives to this work. The rationale was that experience around the world shows that it is in the countries where there is such involvement of patients that work on patient safety is most successful. The recommendation was that the initiative has close links to the Patients For Patient Safety (PFPS) workstream of the WHO World Alliance for Patient Safety which has pioneered the concept of patient safety 'champions'.

Project Update:

A call for volunteers was launched at a meeting for patients and healthcare professionals with an interest in patient safety, in March by the charity AvMA (Action against Medical Accidents) in partnership with the funders, National Patient Safety Agency (NPSA). Twenty two people attended a two day Induction Workshop in London, on 20th and 21st May as part of this first wave of in-country Patients For Patient Safety Champions selected to represent England and Wales. Additionally, 10 Patient Safety Action Team (PSAT) members from Strategic Health Authorities (SHAs) in England and 1 member of the Patient Safety Team in Wales joined the Workshop on day two.

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."* One participant summed up their experience as the

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

A further follow-up event is planned for 28/29th November 2008 to share experiences and disseminate information and learning. The report of the Workshop is available at:

http://www.avma.org.uk/pages/induction_workshop_for_patient_safety_champions_may_2008.html

Patient Safety Champions

A project leaflet *Can You Be A 'Champion' for Patient Safety?* produced in English and Welsh provided the background information and was made available to support the recruitment of Champions. Over 100 Expressions of Interest were received following advertisements on the AvMA website and through mailings to organisations known to AvMA and NPSA. PSAT contacts were invited to consider the applicants within their geographical area and give feedback to the project team. Final selection took place at a Project team meeting and at this stage a further opportunity was provided for the PSATs to make any comments regarding those candidates selected to attend the Induction Workshop.

The first 6 months of the project has been extremely busy and already Patient Safety Champions are emerging as a positive driver engaging and working in partnership with healthcare professionals in the need to deliver safe healthcare and 'challenge the current culture of denial'².

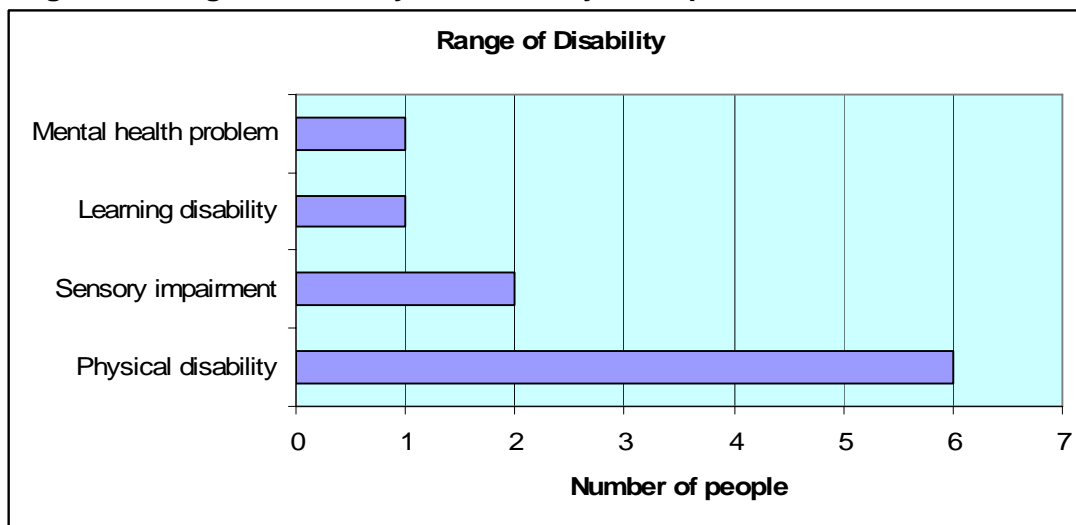
^{1,2} Safety first: a report for patients, clinicians and healthcare managers

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_062848

Diversity

The 22 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. The categories of disability and number of people who fit these are represented below (Diagram 1); a few other health disorders were given by people as supplementary information.

Diagram 1 Range of disability described by Champions



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 is a current NHS employee. Interestingly, 3 current Solicitors and one retired Solicitor became Champions. Their interests span a range of topics and specialties including:

- Infection Control
- Corporate performance and quality
- Reporting systems for Serious Untoward Incidents (SUIs)
- Cancer/palliative care
- Obstetric Care
- Primary Care
- Chronic long term illness
- Psychiatric/mental health care
- Anaesthesia
- Diabetes
- Prevention of pressure sores
- Being Open
- Consent
- Psychological consequences of medical harm
- Cardiology
- Paediatrics
- Community care
- Care of the Elderly
- Radiology
- ME/Fibromyalgia
- Epilepsy
- Nutrition

Partnership Working

Patient Safety Champions will be supported to provide the patients' perspective in improving patient safety at all levels; locally, regionally and nationally, throughout England and Wales. The current focus is on **Being Open - communicating patient safety incidents with patients and their carers** and the first training session with Champions for this NPSA policy took place in July. The training

generated much discussion and also prepared Champions for how to present their role to NHS staff and focus on the importance of Being Open when things go wrong for patients. Feedback was extremely positive and a future Masterclass in the subject has been on November 12th for all Champions in England and Wales. One participant said

“...very informative, interactive and worthwhile. I would recommend it to others.”

Other national initiatives are being discussed, including the Patient Safety Campaign in England and the 1000 Lives Campaign in Wales and the NHS Partners involved in this project are being encouraged to invite the Champions to help them include the patient perspective in their work streams for improving patient safety. A plethora of patient safety work is taking place but we know from the previous AvMA pilot study that tensions exist around Patient and Public Involvement in this area when NHS staff and those patients who have experienced harm open up the agenda together. It is extremely difficult for both parties, emotionally, to talk about what went wrong and how this could be prevented from recurring – the barriers are recognised and we must work together to address and overcome these. The role of Patient Safety Champions is to ‘add value’ to both existing and planned work.

Local, Regional and National role for Patient Safety Champions

Almost all Champions have met with the PSATs with only a few remaining to meet in September and three yet to arrange a date. The majority have started to plan together areas for involvement and schedule further meetings. The role is extremely varied for example, the North East SHA has had a very positive meeting with the Champions, Margaret Ogden and Mike Casselden, and forged ahead with its plans to involve Champions in their agenda to improve patient safety. While in the West Midlands region, for example, the Patient Safety Champions have been working locally. Brian Osborne has been looking at the Privacy & Dignity Policy for a PCT and is on the Worcester PCT Complaints/Incidents PALS Group. Beryl Nock sits on the Themed Action Group which is a cross-provider network from the Acute and Primary Care Trusts and the Directorate of Adult, Community and Housing services in Dudley, to improve services for the elderly.

As awareness of the project has spread, opportunities have been made available to include Champions. Nationally, Patient Safety Champions have officially attended four events:

- The Department of Health (DH) on behalf of the National Advisory Group for the Council for Healthcare Regulatory Excellence, organised a Workshop where 8 Champions were present;
- The Healthcare Commission held an event around reducing the risk of healthcare associated infections, attended by 4 Champions;
- The Hand Hygiene Summit re-issued an NPSA alert and one Champion was invited to be part of the Discussion Panel as a patient representative. It was an extremely positive endorsement of how Champions can work in partnership with healthcare professionals, adding value to the day's presentations and discussions.
- The Being Open Review led by Professor Albert Wu brought together healthcare professionals, DH, medical defence organizations, and other organizations with an interest to examine the findings of his review and to make recommendations for how to promote the Being Open Policy in the future. 2 Champions participated in this extremely important event.

There are a further 7 events up to November where Champions will be attending or giving presentations and this does not include those organised by individuals themselves.

A local Acute Trust in Northampton participating in the national patient safety initiative, LIPS2, has also consulted the Champions through this project. They were interested in their views around what patients/carers consider to be safety priorities, how they can present safety information to patients/carers, and how active people can be in making their own care safer. This Trust was

delighted with the responses given by the Champions and have accepted an offer from one of the Champions to go in and help them locally. Other organisations interested in consulting with the Champions include: Nursing & Midwifery Council; and The Advisory Committee on the Safety of Blood, Tissues and Organs.

Wider Network

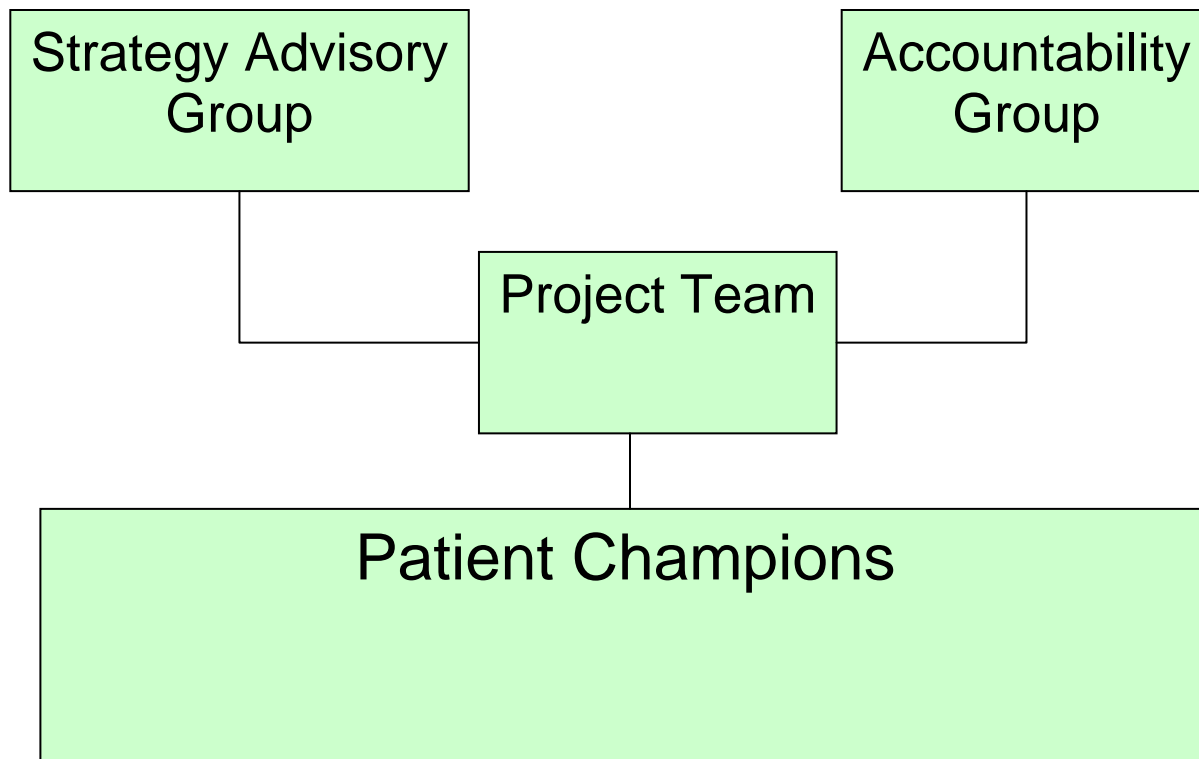
The number of individuals on the wider Network database increased by around 80 following the call for Expressions of Interest. It has steadily continued to grow during the project and now has approximately 250 individuals and representatives of organisations registered. Further refinement of the database has been carried out and currently a survey to obtain up-to-date contact information and ask people how they want to be involved is underway. Results of this will be used to develop further mechanisms for involving patients and the public in improving patient safety. Organisation contacts who do not respond to the survey will no longer be deemed active and further contacts will be sought.

The network has been invited to various Workshops and events and been invited to comment on national Consultations. The in-house newsletter and email bulletins are circulated to this group and the AvMA website/forums provides a further mechanism for their involvement. It is envisaged that the group will also provide a platform for development of future Patient Safety Champions.

Project Governance:

The infrastructure of the project (Diagram 2) includes both internal and external controls to provide guidance, review and monitor the project against objectives. 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 membership are: Martin Fletcher, Chief Executive, NPSA; Suzette Woodward, Director, NPSA (standing in for Peter Mansell, Director, NPSA); Sarndrah Horsfall, Director, NPSA; Peter Walsh, Chief Executive, AvMA; and Anna Allford, Project Manager, AvMA.

Diagram 2 – Infrastructure



Strategic Advisory Group

The process of establishing a Strategic Advisory Group was discussed by the Accountability Group. Suitable representation from specific organisations was decided upon and the following members selected:

- Dr Jonathon Gray, Joint Director 1000 Lives Campaign, Wales;
- Carol Lamyman-Jones, Director, Board of Community Health Councils in Wales;
- Kate Jones, Head of Programme - Leading Improvement in Patient Safety, NHS Institute for Innovation and Improvement;
- Maggie Kemmner, Head of Safety Programme, Healthcare Commission;
- Dr Marcia Kelson, Associate Director-PPI, National Institute for Health and Clinical Excellence;
- Angela Brown, Associate Director of Clinical Quality, NHS North West.

Two further members have been invited and their decision is awaited;

- Ms Joan Saddler OBE, Director of Patient and Public Affairs, Department of Health
- Barbara Wood, Chair of the Lay Group, The Academy of Medical Royal Colleges.

The Strategic Advisory Group will help guide the development of this project in England and Wales. It will be a 'virtual' group with one planned face-to-face meeting per year, and occasional liaison by email and telephone. The aim is to advise NPSA and AvMA on development of the project and help it link with other relevant initiatives in the field of patient safety and patient & public involvement.

The project team comprises: Suzette Woodward, (standing in for Peter Mansell); Peter Walsh and Anna Allford plus a part time Assistant.

The project Workplan (Appendix 1) outlines the goals and outputs for the current year and the progress to date.

Resources:

Materials and resources to support Champions and their NHS partners are being developed and information being collated, some of which is already available on the AvMA website www.avma.org.uk/champions together with private and public Discussion Forums.

Champions have requested resources to aid their work such as business cards, leaflets and compliments slips and discussions with the World Alliance for Patient Safety (WAPs) as to the availability of these suggests that they are not ready to produce these globally. Therefore, a decision has been made to develop and print these for those Champions who would like to have them. A discussion is planned for the meeting in November with the Champions to determine what, if any, other resources could help them.

A guidance document to help people understand the mechanisms for patient and public involvement (PPI) in patient safety with examples of how they can help the NHS improve this is also planned.

Communication

As a new initiative it has been extremely important to form a group community and identity, sharing ideals and developing a professional collective approach to the role undertaken by Champions. Through the following communication tools a shared mechanism for disseminating information, sharing ideas and good practice, discussing relevant topics and sounding out issues and concerns has been established.

- Email bulletins to the Champions/NHS partners and the wider Network

- PFPS specific pages and content on the AvMA website
- Discussion forums on the AvMA website

Furthermore, WAPS has a forum and network to disseminate information across Europe and Internationally. Two recent WAPS Newsletters have also included articles about this project written by the Project Manager and as a result contact has been established with other Champions. The Denmark Champions group has been particularly interested in how Champions are working with Being Open and have shared information resources with the project.

The external communications strategy includes raising awareness with local hospital Trusts and PCTs through a proposed letter from the project office informing PPI Leads/Patient Safety Leads about the project and the role of Champions. Additionally, a series of regional events that THOTH (NHS Training Hub for Operative Technologies in Healthcare) have run have included presentations from AvMA's Chief Executive and the Project Manager, together with a Champion speaking about the patients' perspective when things go wrong. These have been very well received by the participants and helped to not only give people information about the project but see at first hand how the Champions are working in partnership with NHS professionals to improve patient safety. It has also been a really useful mechanism for the Champions to explore presenting their story and introducing their role.

Funding for travel expenses will also be made available for those Champions in England who wish to engage with their Local Involvement Network (LINKs) and the Welsh Assembly in Wales in order to establish links with others working in patient and public involvement with a view to promoting patient safety.

Training & Development

In addition to the 'Being Open' training and 'Presentation skills' attended by 10 Champions (plus a carer) other opportunities are being offered to Champions following the mapping exercise to assess their needs in this area. 19 Champions responded to the survey and evidence strongly suggested a need for the 'Being Open' Masterclass with 12 Champions placing this as their top priority and a further 4 as their second priority. 'Tools and Analysis of Safety Data' was felt to be their next most important training requirement closely followed by 'Root Cause Analysis'. 'Presentation Skills' and 'NHS Structure' were dependent much more upon the previous knowledge and skills of each individual and therefore variation between Champions was far greater for these two areas.

Other areas that were felt might be useful included: training on the subject of 'Infection Control'; supporting and listening skills; assertiveness training; and skills around taking part in meetings.

IT training and mentoring to support Champions is also being arranged on an individual basis where identified, with one Champion having already attended the AvMA office for IT and Email training with the Project Manager.

Policy and Procedures

Discussion took place during the Induction Workshop in May around use of the title 'Patient Safety Champions' and when it was or wasn't applicable to use it. Clarification from WAPs was sought early in the project (email 3/07/08) to ensure the exact wording of the title for Champions. This was explained as "They can call themselves 'Patients for Patient Safety Champion, England and Wales'. They can not say a WHO champion or a WHO Patient champion – They are a Patients for Patient Safety Champion. In addition to this they could say that – Patients for Patient Safety is one of the programme areas of the World Health Organization's World Alliance for Patient Safety."

It has been further emphasized to Champions that it is not appropriate to use the title when seeking personal information, or communicating, about their own case or that of a family member or individual.

Mechanisms for payment of agreed travel/other expenses to Champions when attending meetings/events on behalf of the project have been developed. Champions wishing to claim expenses need to have these approved by the Project Manager prior to booking a meeting or purchasing tickets etc.

CRB checks for Champions as requested by the NHS Partners at the May meeting have been initiated by NPSA and will be provided to Champions as good practice for volunteers involved in the project.

Confidentiality around information that Champions may be a party to whilst carrying out their voluntary role, for example, details regarding patients or staff, was also discussed at the Induction Workshop by Champions and NHS Partners. It was agreed that everyone understood the nature of maintaining confidentiality in such circumstances, although some further clarification has been sought through the project and it has been suggested that NHS Partners developing Volunteer Policies will share these within the project.

A Code of Conduct policy for Champions has been similarly discussed and whilst the Action Framework belonging to WAPs lays down the guidelines for Patient Safety Champions there is currently no existing policy within the project.

Conclusion:

Patient and Public Involvement defines the ways in which patients, carers, and the public have a *voice* in decisions about how healthcare services are planned, designed, delivered and evaluated. This 'collective' form of involvement which seeks to influence decision making at a strategic level is distinct from the exercise of individual patients' *choice* or influence on the course of their own treatment.

NHS National Centre for Involvement, July 2008²

Having no one model on which to base the work of the Champions in England and Wales it remains an iterative process. The spirit of collaboration and partnership working is described within the WAPs Collaborative Agreement (Appendix 2) which all Champions signed up to. 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 complexity of this group of volunteer Champions requires sensitivity to the needs of the group whilst ensuring that partnership working is effective in supporting the objectives of the project. The Champions are passionate and committed individuals but many are at different stages in their personal experiences in terms of understanding what went wrong for them or their families. Finding that very fine balance of using that emotion to positively motivate healthcare professionals is something that we aim to foster through training events, peer discussion, mentoring and support. 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.

² A baseline assessment of the current state of Patient and Public Involvement in English NHS Trusts.
<http://www.nhscentreforinvolvement.nhs.uk/docs/Annual%20Survey%202007%20report.pdf> accessed 12/09/07

Recommendations:

Partnership:

- Build on and foster the developing partnerships with organisations working in the area of patient safety to ensure Champions have the opportunity to provide the patients' perspective.
- Continue to build and develop the Wider Network to inform the work of the Champions.

Resources:

- Develop business cards, leaflets and compliments slips in liaison with Champions.
- Develop a loose-leaf folder of policies/information for current and future Champions.
- Collate examples of good practice and publish to share and disseminate knowledge.

Training:

- Offer mentoring in presentation skills for those Champions requiring this.
- Development Workshops for Champions.
- Provide materials and links to resources on NHS structure.

Policy:

- Develop a Code of Conduct for the project.
- Develop recruitment protocols with NHS Partners for future Champions.

Future work

- Recruit further Patient Safety Champions to enhance current working and ensure the community is reflected in terms of diversity. In particular targeting people from under-represented ethnic minority groups and younger people below the age of 50.
- Ideally, a Pilot to recruit and develop a Young Persons Patient Safety Champions Network could be considered if funding for year 09-10 permitted.

Appendix 1

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 development required. 	July
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)	<p>Review progress to date.</p> <p>Share experience and disseminate good practice/learning.</p>	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

Appendix 2



PATIENTS FOR PATIENT SAFETY COLLABORATIVE AGREEMENT

Purpose

This collaborative agreement sets out the roles and responsibilities of Patients for Patient Safety Champions and the WHO World Alliance for Patient Safety. This agreement is intended to clarify roles, expectation and behaviours of all parties so that patients are at the core of the global movement for improved patient safety.

This agreement can be terminated by either party at will upon notification to the other.

Who are the Patient for Patient Safety Champions

Patient for Patient Safety Champions are an integral part of the WHO World Alliance for Patient Safety. They have demonstrated themselves to be a group of people committed to positive, appreciative, informed, and passionate work on patient safety through:

- A commitment to build positive, trusting relationships and to work in partnership with other health care players to promote learning from their own experiences of health care errors and system failures. This acknowledges that a culture of blame and retribution can itself lead to harm and prevent commitment to safety from flourishing. It recognises that fear, denial and defensiveness also seriously impede learning and progress;
- Participation in an International or Regional Patients for Patient Safety Workshop
- A commitment to the values expressed in the London Declaration and willingness to promote this vision
- Willingness to support the objectives of the World Alliance for Patient Safety
- Willingness to develop and share personal goals for action
- Active participation in a wider International Patients for Patient Safety network.

Who is the WHO World Alliance for Patient Safety?

The World Health Organization is the international agency within the United Nations' system responsible for health. WHO produce health guidelines and standards and help countries to address public health issues. 192 countries are members of WHO. They meet every year at the World Health Assembly to set policy for WHO and approve programmes of work and the budget.

The World Alliance for Patient Safety fulfils the requirements of WHA Resolution 55.18 on patient safety and quality of care. The Alliance aims to provide international leadership and create an over-arching strategy, action programmes and a coalition of nations, stakeholders and individuals to transform the safety of health-care worldwide. The Alliance believes that patients and their experience should be at the heart of patient safety strategies and programmes at all levels in a health care system.

What do Champions do?

Championing a fundamental change in the culture of safety in health care systems around the world requires new and creative approaches.

Champions will:

- Raise awareness and understanding of patient safety and the work of the World Alliance for Patient Safety within their own country and within WHO regions;
- Develop ways that the health care system can learn from their own experience and that of other patients and families;
- Build relationships with other key players who want to improve patient safety
- Inform the Patients for Patient Safety Project Manager of their activities and patient safety issues and needs in their country and region
- Contribute to other action areas of the World Alliance for Patient Safety and global activities
- Act in accordance with the Patients for Patient Safety Action Framework
- Convey accurate and consistent messages about the Patients for Patient Safety programme and the World Alliance for Patient Safety

How will the Alliance support the Champions?

- Support Champions to develop personal goals for action and review resource possibilities
- Provide advocacy and communication tools in the form of an Advocacy Toolkit. This will be updated as the project develops so that tools remain valuable and relevant to the changing situation.
- Promote networks for sharing and learning new information amongst champions by establishing and moderating an electronic workspace for information exchange among Champions.
- Keep champions updated on the work of the Alliance.
- Promote opportunities for active involvement of patients and their families in all aspects of Alliance work and broader linkages with WHO regional offices.
- Work with a patient led Steering Group to ensure that the champions initiative is further developed
- Provide advice and guidance on the activities of Champions consistent with the framework outlined in Table One.
- The Alliance will also act with integrity at all times in representing the Patients for Patient Safety Champions and the work of the Patients for Patient Safety programme.

In country activities	Regional activities	Global activities
Strategic objectives agreed by Patients For Patient Safety Steering Group	Objectives agreed by Patients For Patient Safety Steering Group, WHO Regional Office and World Alliance secretariat.	Objectives and activities agreed by Patients for Patient Safety Steering Group and World Alliance secretariat.

TABLE 1

What does success look like?

Patients for Patient Safety identifies, organizes and orients like-minded consumer patient safety champions who collectively embrace a common foundation of values. We develop a shared mental model of partnership and consistent messages. Together we provide the world's largest geographically and culturally diverse pool of patient wisdom on patient safety, ensuring authenticity and sustainability for the World Alliance for Patient Safety. This will ultimately save lives and prevent injuries.

Evidence of success will be demonstrated as patients and advocates are embraced as an integral component of the healthcare system and are viewed as a valued resource to inform improvement strategies and initiatives in relation to all aspects and levels of healthcare.

Please confirm your commitment to the collaboration outlined above, with the World Alliance for Patient Safety and the Patients for Patient Safety Programme by emailing Rachel Heath, Patients for Patient Safety Project Manager at safety@patientsorganizations.org

For Further Information:

**Action against Medical Accidents (AvMA)
44 High Street
Croydon
CR0 1YB.**

DX 144267 Croydon 24

Tel:+44 (0) 20 8688 9555

Fax: +44 (0) 20 8667 9065

Email: safety@avma.org.uk

Website: www.avma.org.uk

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