



Patients for Patient Safety Induction Workshop England and Wales



20 & 21 May 2008, at Hilton Docklands Hotel, London

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Executive Summary

Introduction

Recommendation 13 of *Safety First* (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'.

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 National Patient Safety Agency (NPSA). Twenty two people attended a two day Induction Workshop in London, England, 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 healthcare professionals from Strategic Health Authorities (SHAs) in England and 1 member of the Patient Safety Action Team in Wales joined the Workshop on day two.

Induction Workshop

Patients, their carers or patient advocates met together on day one of the Workshop to share their personal stories and experience of what happens when things go wrong in the care provided by the NHS (National Health Service). Common themes emerged around errors in treatment, diagnosis and care, and many people expressed dismay at the culture of denial which persists among healthcare professionals in the aftermath of a serious incident. Much discussion featured on the failures in policy and process to address the issues and prevent similar incidents and accidents from recurring. In future, through this initiative, 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 work of the WHO World Alliance for Patients Safety was introduced by Martin Fletcher, Chief Executive of the NPSA and further information was presented by Rachel Heath, the International Patients For Patient Safety Project Manager. Suzette Woodward, Director, NPSA, provided an overview of the structure of healthcare organisations across England and Wales and set the context for discussions around how Champions can be involved. Anna Allford, as the Project Manager for **Patients For Patient Safety in England and Wales** outlined the project and stated that AvMA already has a network of about 150 individuals who have experience of medical harm, or an interest in improving safety for patients. It is anticipated that their concerns and issues will also contribute to the broader agenda around patient safety and be highlighted through the work of the Champions. One participant commented at the end of a very busy first day; *"I feel good. I feel powerful. I feel important."*

On day two eleven healthcare professionals and policy makers joined the group representing the ten Strategic Health Authorities in England together with one representative for Wales. International Patient Safety Champions, Nagwa Metwally (Egypt) and Rebecca O'Malley (Ireland) gave presentations about their own involvement in this global movement: their reasons for becoming Champions; their work to date; and their hopes and aspirations for the future.

Participants felt that *“the inspiration taken from personal experiences”* contributed to their overall satisfaction and a further positive comment included: *“Marvellous speakers!”*

Peter Walsh, Chief Executive of AvMA, together with Anna facilitated the Workshop sessions, ensuring time in small groups and partnership working was incorporated in addition to the full group meeting. This mix worked well and allowed the Champions to open the dialogue with their healthcare professionals and policy maker partners.

Tickets for the 2 day Conference ‘Patient Safety Congress 2008’ were arranged for all participants who wished to extend their stay in London and attend. The hotel had been selected for its accessibility and proximity to the Conference venue. A formal announcement was made at the Congress by Peter Walsh regarding the future role of the Patient Safety Champions.

Conclusion

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.”*

All 22 of the patients/patient representatives have become Patient Safety Champions and some of the healthcare professionals also expressed an interest in joining the global community committed to improving patient safety. One participant commented *“The use of patients’ personal experience to promote improvements in patient safety is a very powerful tool.”*

The next meeting is planned for late Autumn when there will be an opportunity for the Patient Safety Champions and healthcare professionals to come together again to share their work, highlight their progress and disseminate good practice.

Evaluation

Twenty seven participants completed evaluation forms and of these 65% considered themselves either a patient or patient representative. The remainder felt they belonged to the groups of Health Professional or Healthcare Policymaker, however, some participants ticked more than one box, with some having both a personal and professional role and involvement. The dialogue and exchange of ideas over the course of the Workshop was agreed to be extremely valuable by the majority of participants and the opportunity to work together in ‘Regional Teams’ (Champions with their respective NHS partners) was very well received.

Overall the Workshop was felt to have met the expectations of the participants (Diagram 4) and positive comments were received including; *“I think everyone who wished to contribute was able to do so.”* And, *“It made me realise just how much could be achieved by the Champions.”* (Patient Safety Champion). However, given that this was the first Workshop of it’s kind in England and Wales it was acknowledged that a number of participants felt unsure of what to expect; one person commented *“I’m not sure what my expectations were but it was an excellent couple of days!”* One participant summed up their experience as the ***“Most powerful and thought provoking Workshop I have ever been on.”***

Introduction

Background

Recommendation 13 of *Safety First* (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'.

The launch of the call for patient safety champions (two for each Strategic Health Authority in England and two for Wales) took place at a conference in Birmingham on 18th March 2008 to which stakeholders; patients, carers, patient activists, and healthcare professionals were invited. Selection criteria included: agreement with the principles of the WHO PFPS program as set out in its 'London Declaration' (Appendix 1); the ability to work constructively in partnership with the NHS; evidence of passion and commitment to improving patient safety; ability to devote a reasonable amount of time to the role; and the ability to attend this Induction Workshop.

Using the WHO model, it is a requirement that people have successfully completed an induction and 'signed up' to the Collaborative Agreement setting out the approach of patient safety champions working in partnership with the health service before being accredited as a patient safety champion.

Any candidates who it was decided not to invite to the first Induction Workshop have been encouraged to join the wider network of individuals interested in or already working with the NHS in England and Wales to improve patient safety. This wider Network was developed during the two year pilot project preceding the current initiative which was managed by AvMA (Action against Medical Accidents) in partnership with the NPSA (National Patient Safety Agency) It is expected that patient safety champions will work with members of this wider network in their regions as well as other patients' organisations.

Workshop - Day One

Sharing experience

Introductions and practicalities around expenses were briefly discussed following an overview of the Workshop content by Peter Walsh, Chief Executive of AvMA. Importantly the group, comprising patients, carers and patient activists with an interest in improving patient safety in the health services, developed their own set of ground rules (Appendix 2) to: ensure confidentiality; respect others' opinions; and avoid using discriminatory language or jargon.

The first part of the day was spent getting to know each other in small groups of 5 or 6 people with the purpose of exploring: their reasons for applying; personal stories and experiences of healthcare; and hopes and fears for improving patient safety. Notes were collated and grouped

by the Facilitator for each of the 3 areas of discussion and a feedback discussion was then led by another Facilitator for the whole group.

Reasons for applying to be a Patient Safety Champion stemmed from a wish to stop the same mistake or harm happening again and to challenge the culture of denial that prevails when things go wrong for patients. Participants' comments included:

- Personal experience of harm
- Improving care and safer care
- Partnership and inclusiveness (including with Primary Care providers)
- Patients' needs must come first
- Putting the positive in Patient Safety
- Want to be effective
- Change the wrongs
- Already working in Patient Safety
- Acknowledgment of harm
- Working from the inside
- Dialogue and discussing ways forward
- Strong motivation to make things better
- Can bring something special
- Great passion, enthusiasm, energy, dedication
- Build Partnership.

This led to a discussion on equality and payment for volunteers who felt that this volunteer role while requiring passion and commitment needed to have equality with the different partners **and** retain the independence of the Patient Safety Champions. It was generally agreed that the power of their story was especially important. Some participants suggested the cost of attending conferences (registration and travel in particular) might prove difficult to fund if people had a special interest in a subject and a few muted a tendency to undervalue volunteers.

Sharing personal stories helped to build bonds between the participants and many empathised with the concerns expressed within their groups. Most people had been directly affected personally or through family, by medical harm but stressed that balance is required as 99% of health care has a positive outcome. What people wanted was; accountability, lessons learnt, openness and honesty. However, it was also recognised that by relating personal stories one could get labelled as a difficult patient/person and could turn some people off from wanting to understand their reasons for highlighting their negative experience. It was agreed that the 'message' has to go across in a certain way, aiming to win hearts and minds through partnership and willingness to improve safety across the board.

Clear themes emerged from people's experience, in particular a focus on diagnosis, care and treatment revealed errors or poor care resulting from:

- Misdiagnosis
- Poor Care – lack of dignity
- Discharge procedures
- Violence
- Poor communication
- The power of personal stories
- Medication Safety is an important issue for many patients
- Policies not followed (difference between guidelines and policies was noted).

Participants strongly felt that they didn't want anyone to have to experience what they have been through ever again. Areas around denial were explored and many participants discussed the necessity to acknowledge the culture of denial to tackle:

- Poor complaint handling
- Records being incorrect or going missing
- The requirement to follow up or provide reassurance it won't happen again.

Policy and Process failures were raised including:

- Failure to adopt recommendations
- No support for people during the process of making a complaint
- Processes when things go wrong needed explanation and support for staff as well as patients
- Plethora of policies, guidelines and procedures exist
- Role of 'guidance' - when should they be mandatory?
- Whole health economy needs to be considered – that comes down to legislation – greater understanding and performance management needs to be taken more seriously
- Role of 'core standards'

It was concluded that we are all potential users of healthcare and that no-one is immune to medical error. Therefore we all have a stake in it being improved and whilst participants also have positive stories we can learn from they want to avoid being 'labelled'. It was agreed that *how* they share their experience is important. A 'fair and open' culture was called for. A further issue discussed was Death Certificates and a need for clarification was deemed important if unsafe and/or poor quality of care were to be identified as contributory factors in the cause of death.

Participants' hopes and fears were centred around improving safety, seeking to instil a 'Can Do' culture both for the individual staff member and corporately within the NHS. They wanted to see: the reintroduction of common sense; systems that empowered patients and educated others (patients and staff); high standards of Competencies and Qualifications; and lessons to be learned when things go wrong. Additionally, support is needed for staff in order to be open and honest together with the ability to challenge superiors. A degree of accountability also

needs to be accepted to prevent fear of reporting and cover ups. **Communication** was felt to be very important for Openness and Honesty to exist.

The requirement in the NHS for Patient and Public Involvement (PPI) emerged as a vehicle for participants to engage in partnership and open the dialogue around patient safety. The power of patient representatives working in collaboration and partnership is not be underestimated but barriers to engagement need to be considered so lessons can be gained. The recently published AvMA report on the pilot project had been included in the participants' pack and this highlights some of the difficulties faced by patients who have experienced harm seeking to be involved. It was stated that there is a need to forge links with other patient involvement activities and connect with others who have expressed interest and also who are already working in patient safety throughout England and Wales.

Personal reflection about their own involvement in this initiative included:

- Will anyone listen to me?
- Where do I go from here?
- I don't know what to do?
- Will I have enough time for this role?
- Will I understand the hierarchy in the NHS?
- How will we share the improvements in health care and share information between champions?
- Am I being labelled as a troublemaker?
- Will I damage my career?
- Will it jeopardise my healthcare?

In conclusion participants agreed that the NHS needs a period of stability as it undergoes a change from a 'providing National Health Service' to a 'commissioning NHS'. It was also suggested that "*It's about attitudes, behaviours – outside of the policies and procedures*". However, the role of the Chief Executives and the Board was an important aspect of accountability and responsibility as it was felt that "*We're up against a defensive culture!*" Pressures on the system in terms of quality were recognised and it was speculated as to how the public could be involved (feed into) in the retraining system. Although issues of understaffing and it's affect on quality and safety cannot be ignored, the important thing is that when something goes wrong for a patient it doesn't happen again. There are lessons are to be learnt, they need to be implemented and enforced. One participant commented that information on patients rights on Clean Care Safe Care are on the Department of Health (DH) Website.

Presentations

The work of the World Alliance for Patient Safety (WAPS), World Health Organisation (WHO)¹, was introduced by Martin Fletcher, Chief Executive of the NPSA and further information was presented by Rachel Heath, the International Patients For Patient Safety Project Manager. Martin informed the group that this initiative is part of a global programme and is gaining

¹ Patients For Patient Safety, World Alliance for Patient Safety website <http://www.who.int/patientsafety/en/>

momentum. WHO formed 60 years ago, and includes 193 countries. With the help of the Chief Medical Officer (CMO) of England, the patient safety resolution was adopted in 2002, 2 years later in 2004, WAPS was formed. Sir Liam Donaldson (CMO) ensured patients were included as part of WAPS, acknowledging that patients have a very unique perspective. Areas of focus include: promoting awareness and political commitment; strong leadership; technical advice; research; sharing knowledge; working in partnerships; guidance and standards; and patient engagement. A participant commented that WHO produces statistics on the burden of different notifiable diseases and raised the question as to whether *Clostridium Difficile* (C.Dif) is a notifiable disease and that if these healthcare associated infections were notifiable, then we could start to monitor the problem more affectively.

Rachel provided an overview of the Patients for Patients Safety (PFPS) Global Programme and highlighted the power of the patient story and the humanity of patient safety. She stated that Susan Sheridan is the global lead who has experienced 2 serious medical errors to close family and formed a Non-Governmental Organisation (NGO) in United States, working in partnership. The London Declaration, the foundation of the PFPS programme was developed at a regional workshop and through the commitment to this very powerful partnerships have been created. Previous participants have viewed these workshops as a safe place to discuss difficult issues and shift the balance towards patients in a supportive environment. There is a network of over a 100 champions globally, who are working individually – some creating new patient led partnerships and setting up new NGOs. As a result Advocacy, awareness raising and networking, teaching, sharing experiences, and changing legislation have all been achieved. In country workshops similar to this one have already been held in Denmark and Canada. Rachel also told participants that support is available as WHO Patients For Patient Safety Champions in the form of resources such as: toolkits; information materials for publicity; an Electronic Community System; PFPS Newsletter; and through Rachel as the International Project Manager.

Suzette Woodward, Director, NPSA, provided an overview of the structure of healthcare organisations across England and Wales and set the context for discussions around how Champions can be involved. She explained that in Wales the Welsh Assembly Government (WAG), feed into Department of Health (DH) and that Wales consists of 3 regions. There is currently a group working on the Healthcare Quality Improvement Plan (QUIP)² in which the current focus is Patient Safety. In England 10 Strategic Health Authorities (SHAs) report to DH, and each SHA has a recently formed Patient Safety Action Team (PSAT). WAG and DH sponsor around 600 organisations such as; NPSA, Healthcare Commission, NHS Institute for Innovation and Improvement (NHSII), Health Protection Agency (HPA), and The National Institute for Health and Clinical Excellence (NICE). Each agency carries out its own work in patient involvement, but there is no one body which oversees this work. Suzette concluded that this is a great time to start influencing and informing as Patient Safety Champions.

Peter provided an insight into the work of the current Champions in the UK: Peter Mansell; Ian Hayes; Josephine Ocloo; and Peter Walsh himself. He highlighted that the existence of NPSA and AVMA means the UK is a huge step ahead of many other countries. He speculated that the role that litigation has had to play has helped to push patient safety higher up the agenda in the UK and felt that the direct support by AvMA during the past 25 years to patients has led to the charity having a good insight into patients' issues. Peter gave an overview of the 2 year

² Healthcare Quality Improvement Plan: Designed to Deliver, Welsh Assembly Government, November 2006

pilot project completed in March by AvMA in partnership with NPSA including: the formation of a wider Network which means that 200 other people are now committed to patient safety in England and Wales; and the project outcomes which evidenced the need for support / training for patients plus the issues of time and expenses. It was also found that NHS employees feel anxious about dealing with patients who have experienced harm or their families/carers. However, it was shown that patients with particular knowledge – working on specific problems – works quite well but patients don't want to be constrained. It remains imperative to tackle the culture of denial.

Anna Allford, as the Project Manager for Patients For Patient Safety in England and Wales outlined the project and stated that it is anticipated that the concerns and issues offered by the wider Network will also contribute to the broader agenda around patient safety and be highlighted through the work of the Champions. Although initially the platform is to explore partnership work with the PSATs there will be opportunities locally, regionally and nationally for Champions to feed in to issues brought to their attention or areas where they already have an ongoing interest, by providing the patient perspective. This might include; raising awareness of 'Being Open'; participating in NPSA workshops; getting involved in training for new doctors or training to local health authorities; or giving talks and presentations. Anna confirmed that although this is a voluntary role, AvMA and NPSA will offer support, information and contacts together with appropriate resources. She suggested that participants were Ambassadors for patient safety and their personal experience and passion demonstrated this. The Project goals were defined as exploring what safe NHS services look like from different perspectives and it was agreed that a further meeting would be arranged with Champions and SHA/Wales representatives to find out what has been achieved in late Autumn. It was confirmed that there would be group work within their respective SHA regions and for Wales on day two.

The London Declaration

A discussion in the afternoon regarding the 'London Declaration' was led by Peter; some participants found the language and terms used were too 'American' and sounded somewhat 'evangelical' in places. Other participants wanted more emphasis on 'reducing the number of healthcare errors', it was felt that this was a "*basic human right*" and should be central. It was suggested that it could also include a statement that 'Patient Safety must come first, and overrule Cultural sensitivities'. Peter explained that this is the global declaration so Champions need to agree to the principles rather than the wording. The group were reminded the declaration is also in place for people to understand their work. The concept of developing a local version was suggested to be discussed at a point in the future.

The role for Patient Safety Champions in England and Wales

The group discussed their role and how they might contribute to improving patient safety. It was agreed that they can help put issues on the table as they have "*have a fresh perspective – we have common sense!*" It was felt that this is an opportunity to share best practice and areas of success but some participants wondered how far do they go in their role as Champions? They highlighted a need to support a joined up thinking process between this project and the new Patient Safety campaign in England and the current '1000 Lives' campaign in Wales. The Darzi review consultation document was also felt to point the way to further local involvement in safety issues. Suggestions for their role included: Advisory role; advocacy role; and possibly a performance management role. Partnership working was agreed as the way forward and it was felt that any contentious issues can be brought to the group, particularly if there was a danger of being 'used'. Peter clarified these are some of the potential roles, and that Champions would

be able to take on what they were able and suited to. Emphasising that the Champions purpose is not to act as an individual support to individual patients but it's about liaising on a broader level i.e. representing the patient perspective but not all patients' individual experiences.

Peter agreed that there would be a range of resources and support offered to Champions locally according to the work that SHAs/Wales and NHS Trusts might ask them to be involved in and nationally through AvMA and NPSA. It was agreed that a glossary (Appendix 3) of useful organisations and websites provide in the delegates pack would be expanded upon and any suggestions from the group would be added. Furthermore AvMA's role would be to connect Champions with the 200 other patient 'activists but he pointed out that it would be useful to discuss with representatives of the PSATs on day two how to find out where problems lay that led to medical harm and share experiences. A possible starting point might be to look at the current work around Lord Darzi's Review³ to find out what involvement patients had in developing local plans to improve services in the nine English SHAs taking part. In Wales, the PSAT representative has links with both the Welsh Assembly and the current patient safety campaign office and will be able to help set up initial meetings.

The expectation is to liaise and share information etc. but to work independently. However, their status doesn't mean they have the right to speak for all PFPS Champions and they must be accountable otherwise they could be removed from WAPS. Finally, in clarifying the role Peter said it's not a performance management role - it's an advisory/advocacy role, working in partnership with NHS staff and bodies, and other organisations with an interest in patient safety to identify poor practices and seek to work towards solutions, and also sharing and disseminating good practice where available. Some participants felt that their incomplete understanding of internal workings of NHS was going to act as a barrier but they agreed by the group that their fresh perspective would in fact be a positive contribution. One participant commented at the end of a very busy first day; *"I feel good. I feel powerful. I feel important."*

Workshop - Day Two

Introductions to NHS partners in England and Wales

A representative from Wales and one for each of the 10 Strategic Health Authorities (SHAs) in England introduced themselves and briefly outlined their job role and responsibilities to the group. It was agreed that the existence of the DH document, *Safety First*, is an achievement in itself – citing a direct commitment to tackle the culture of denial. A question arose as to whether information on incidents reported to NPSA will be made available to the Champions. A representative of NPSA responded that there is a department at the NPSA that deals with each request for information on a case by case basis. The NHS partners commented that they are not always privy to as much information as the public expect.

Verbal agreement was given by everyone to photographs being taken during the day and some individuals had their photo taken separately to accompany their biography.

³ DH website <http://www.dh.gov.uk/en/Healthcare/OurNHSourfuture/index.htm> accessed 17/06/08

Presentations

Nagwa Metwally, Patients for Patient Safety Champion, Egypt, described her work to improve standards in the only large public hospital in Egypt. She has been instigating 'walk arounds' – noting areas of concern, and suggesting ideas for improvement in meetings with the hospital. Nagwa believes you don't need to be a specialist to see things that are wrong in hospitals. She has helped build up a team of volunteers and their group is now recognised as an independent part of the Egyptian Red Crescent. The group aims:

- To improve the relationship between doctors, nurses, management and patients.
- Provide patient advocacy.
- Foster the development of human rights which is difficult in Egypt, and other developing countries. Patients need to understand they have more rights than just to receive treatment.
- To change the existing culture and attitude towards patients.

Nagwa feels that they have already made a difference: Improving IT / documentation systems; hospital renovation; poster campaigns for hand hygiene; and the acquisition of infection control supplies. The current group of 50 volunteers has also; attracted medical school students, gained the confidence of nurses and doctors to work more closely, helped with training courses and worked in partnerships with other organisations. They conducted a survey of all sections of the hospital and detailed recommended action plans. At a recent presentation Nagwa found herself telling the hospital not to be afraid of criticisms...take the help! Some of the difficulties encountered around patient safety issues include: under-staffing; non involvement of key members of management; and no economic incentives. Future work for the group will be; integrating patient safety into the curriculum of students, fundraising; establishing reporting systems, and raising community awareness. Nagwa feels that by dealing with the patient as a case of humanity - not a study, health professionals can improve care for patients. She wants them to engage the patients in evaluating hospital performance and encourage leadership among the healthcare workers.

Rebecca O'Malley, Patients for Patient Safety Champion, Ireland, recounted her personal story. She felt that common themes run between all the patient stories. Rebecca's story is one of misdiagnosis followed by being asked not to make the matter public when she approached her healthcare provider for information about what had happened in her case. She questioned whether she had a voice and could speak out but the report she was given was insufficient. Rebecca wanted to ensure the report's findings would be acted upon. Eventually after huge pressure put on the health providers by the media coverage, a full independent report was commissioned which gave 15 excellent recommendations to improve safety and accountability.

Rebecca would like to see the creation of an Independent register for reporting errors and also feels something has to change to make it easier for patients to engage with doctors. In terms of education, she thinks Patient Safety should be included on the first day of medical training. A policy to admit mistakes, report on them and analyse the errors is required otherwise nothing will change if mistakes are not recognised. Rebecca described a huge strength and determination from the International Patient Safety Champions. The following has been developed by fellow Champion Ryan Sidorchuk:

- Tell me what happened in a way I can understand
- What you will do to address this
- How I will know it is being investigated and that it wont happen again
- Apologise to me.

Rebecca stated that there are no statistics on how many patients are informed of medical errors, and errors do not have to be reported if they are related to an existing medical problem. She commented that there is a great amount of satisfaction from the working as a Champion. Everyone can make a difference, in their own way. Her message to the SHA and Wales representatives present was to *“use this fabulous resource [Champions] - they can provide countless information and suggested improvements. Engage patients, nurture the partnerships that are created today”*.

Regional group work

The Champions and NHS partners worked together in their regional groups to discuss how they can begin to work together. The SHA/Wales representatives gave an overview of the communities and geographic area they represented and described their current work in improving patient safety. Following this each group fed back their discussion and shared with the whole group any areas where they could see partnership working adding value.

Feedback by area:

NHS South Central:

Discussed the basic structure of the SHA and invited their 2 Champions to the Federation meeting planned for June where they will be introduced to each leader of the workstreams. It was felt important that the SHA and NPSA are both identifying areas for Champions to focus on. This group also looked at the interests of the Champions and where they best fit.

NHS North West:

This SHA stressed their commitment to partnership working with the Champions and said that the Champions will be introduced at the next PSAT meeting. Sharing best practice was agreed to be essential. They also planned a formal launch for the Champions in the region.

NHS South East Coast:

Common themes were identified and there was a general information exchange. It was planned to introduce key SHA contacts to the Champions. An Induction for their Champions (including visits to certain organisations – reflecting personal interests of the Champions, and their time allowances) was discussed. It was also agreed to build a mechanism for information sharing. Champions realised that SHAs don't have as much information as previously thought. Therefore they discussed what information they think would be useful and the SHA representative agreed to pull together a resource pack which will give them a heads up profile on the local NHS.

Yorkshire and the Humber:

This group looked at the overall structure of NHS and the Strategic Health Authority, including the work they do and where the PSAT fits into their structure and Incident reporting processes.

The SHA representative stated that there is already a lot going on around patients and the public in their region and gave the Champions some information and publications. This group also recognised the commitments and time constraints for individuals. It was agreed to further explore ways of partnership working and that a structure chart would be useful. The next step would be to meet other members of the PSAT.

South West:

Following an introduction to the role and structure of the SHA this group shared their passion for patient safety and their past experiences. They discussed plans for taking the work forward and expressed the need to clarify roles. It was felt that by working in partnership it offered a logical rational challenge and shared understanding of how to take forward work to improve patient safety. It was also agreed that there are lots of ways to engage.

East of England:

The group discussed that there is not currently a patient on the steering group for the proposed Academy of Patient Safety associated with Cambridge University. It was felt it would give security of tenure in face of possible government changes. The belief is that education is central for improvements and funding for this is in place. This was seen as an opportunity for Champions to get involved in the early stages. The SHA has 8 Care Pathways; all have patients involved with these pathways and they would like to work with LINKs (Local Involvement Networks) to include patients and the public in the wider sense. The Champions will be invited to meet the PSAT team and learn more about these pathways.

North East:

Regional priorities and any broader potential opportunities for the Champions to get involved with was discussed. The Patient Safety Strategic Forum have 8 themes they are promoting and other key areas to enable and support patient safety work including; patient safety culture, processes and procedures. Future partnership with all Patient Safety Champions and the NHS included developing relationships with wider Network of 200 interested patient people. It was suggested that there could be involvement in the 8 Patient Safety themes through flexible mechanisms and also opportunities for representation at meetings (perhaps even teleconferences). A North East Patient Safety Seminar was mentioned as being a further opportunity.

Champions could be involved in raising awareness, and again education at an early stage was identified as vital - targeting universities might be one way. Community awareness sessions and local authority/councillors, plus community and voluntary organisations were all possible areas for future involvement. In terms of broader opportunities, it was felt important to have good communications and cascade information so that the 2 Champions didn't feel on their own. It was suggested that setting up a website could be an efficient way of working and also to let people know they are there. It was agreed necessary to begin with small steps to measure actions. Engaging with local MPs/MEPs and members of the regional TUC might also promote their role and raise awareness.

London:

A discussion around the experience and knowledge that the Champions will bring led on to the SHA representative sharing the vision for London. It was felt that Champions have a real opportunity to contribute as nothing is set yet. They want to promote patient involvement and

patient awareness as central and Champions can become part of a flexible network for engagement. The SHA want to create a website and explore ways to involve people that can't come to formal meetings. It was agreed that it is important to share learning across the board and the intention is to make a tangible difference.

Wales:

Introductions to key groups and an induction with campaign leads were proposed as an initial way forward in Wales. It was agreed to look at key documents and share these as well as arranging for an Induction/awareness session (risk management, clinical governance) for the Champions. Sharing available information was felt to be vital whilst at the same time being cautious not to overload the Champions. It was agreed to address specific issues and focus on the right issues for maximum impact. The '1000 Lives' Campaign is key to sharing patient's stories and focuses on good examples of improvement in patient safety.

East Midlands:

The group discussed the structure and processes of the SHA. Again it was found to be surprising how little information the SHA have access to and this had been discussed earlier in the Workshop. The SHA representative agreed to discuss with the PSAT ways the Champions can be involved as several different streams of work already exist within the Clinical Governance Network. It was also considered how this will be promoted centrally. Education was identified as key to improving patient safety and ensuring it is high on the agenda. East Midlands commented that the SHA would like additional Champions for their region.

West Midlands:

'Seven Steps to Patient Safety' (NPSA) was suggested as the origin for the current work around patient safety and it was felt that 7 steps had now been identified by this group to enable partnership working. A launch was discussed and a commitment from the SHA to lead to a statement. Champions will be given an induction about the SHA. CRB checks will be required before going out to visit trusts. The Patient Safety Quality Group was identified as a possible group where the Champions could be involved. Project work and 'walkabouts' were also suggested as possible methods for involvement. 'Being Open' and Root Cause Analysis training would be useful for Champions. Communication, websites, and emails were also felt to be ways of involving the Champions. Business cards and information leaflets could help raise the profile for Champions but there was an issue of funding around this suggestion.

Further discussion:

Comments generally from participants included the agreement that patient safety needs to be embedded into education centrally for health professionals. The issue of CRB checks and ideas around this were discussed. Some participants had heard of a 'CRB passport' that allowed a person to work anywhere within an authority without having to have a new CRB check each time, additionally, some Champions noted they already had one for work they do currently. It was agreed that AvMA/NPSA would investigate CRB checks further to find a suitable solution.

A discussion around expenses took place and Peter confirmed that any work of the Champions requested by the project team, will be covered by the project for expenses relating to reasonable travel and out-of-pocket expenses. When Champions are working as requested by the SHA/NHS or other local organisation to attend meetings or get involved then expenses are to be negotiated directly with them. It is also important to get clarification around the budget

and to ask them 'Who pays for what?' It was suggested that AVMA and the NPSA ensures that leaders at level 1 have agreed levels of engagement for Champions with PSATs.

A question was raised by a participant regarding liability insurance and Peter explained that Champions will not be covered by liability insurance because of their position. Should they somehow become liable then they are responsible as individuals. If anyone is at all concerned then they should take further advice, get information and make sure all parties are clear about this.

It was agreed that being open when things go wrong should be put onto every agenda no matter where you are and it was noted that 'Consent' is part of the 'being open' work. It was suggested that the 'right to know, right to ask', should become the core of the NHS constitution and that Champions could be involved in bringing this patients' perspective into the processes for the SHAs in England and for Wales.

Resources could be usefully shared and Anna asked for policy documents around working with volunteers to be forwarded to her so that she can disseminate these. Other areas where information can be accessed include the DH website which has issued guidance for Consent and also has some information about what people are entitled to and their rights to healthcare. One Champion asked a question around Trade Union sand the perspective from the workforce but it was felt that we already work with patient groups and don't need the formal staffing structures.

What support do Champions and their NHS partners want from AVMA and NPSA

It was agreed that Anna would circulate a list with telephone numbers/emails once everyone had agreed to their details being used by other members of the group. However, it was decided that it would remain confidential to the group and participants were requested not to share details with anyone outside of this group without prior permission of that individual. Confidentiality and a Code of Conduct was already part of the agreement provided by the ground rules (Appendix 2) that the group had developed.

A glossary of terms to help understand commonly used jargon around healthcare and useful organisations would be further developed and articles of interest would be forwarded to Champions. Other resources would be developed on the AvMA website for the initiative and the Champions. The publication from NPSA, *A Compendium of Patient Safety in Practice* due to be launched at the Patient Safety Congress would also be sent to participants as this contained information on 'Seven Steps to Patient Safety' and 'Being Open' together with case studies.

AvMA and NPSA agreed to discuss training and development for Champions and provide appropriate opportunities for this.

National agencies such as the Healthcare Commission might be interested in the work of the Champions in providing the patient perspective and it was agreed that AvMA would make contact with these and similar bodies to help ensure Champions and the wider Network would have opportunities to be engaged in work around patient safety, locally and nationally.

Finally, it was concluded that working in partnership with PSATs could be a very positive way forward and that today's discussions had paved the way for further exploring the mechanisms by which the patients' voice can be included in future improvements in patient safety. Participants were reminded that NHS and PSAT partners were also eligible to become Patient Safety Champions after attending this Induction Workshop and everyone should now send an email or write to Rachel to confirm that they are committed to the Collaborative Agreement after which a Certificate would be issued and access to the forum and resources of the World Alliance For Patient Safety would be made available.

Conclusion

*"Most powerful and thought provoking Workshop I have ever been on."
(Patient Safety Champion)*

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."*

All 22 of the patients/patient representatives have become Patient Safety Champions and some of the healthcare professionals also expressed an interest in joining the global community committed to improving patient safety. One participant commented *"The use of patients' personal experience to promote improvements in patient safety is a very powerful tool."*

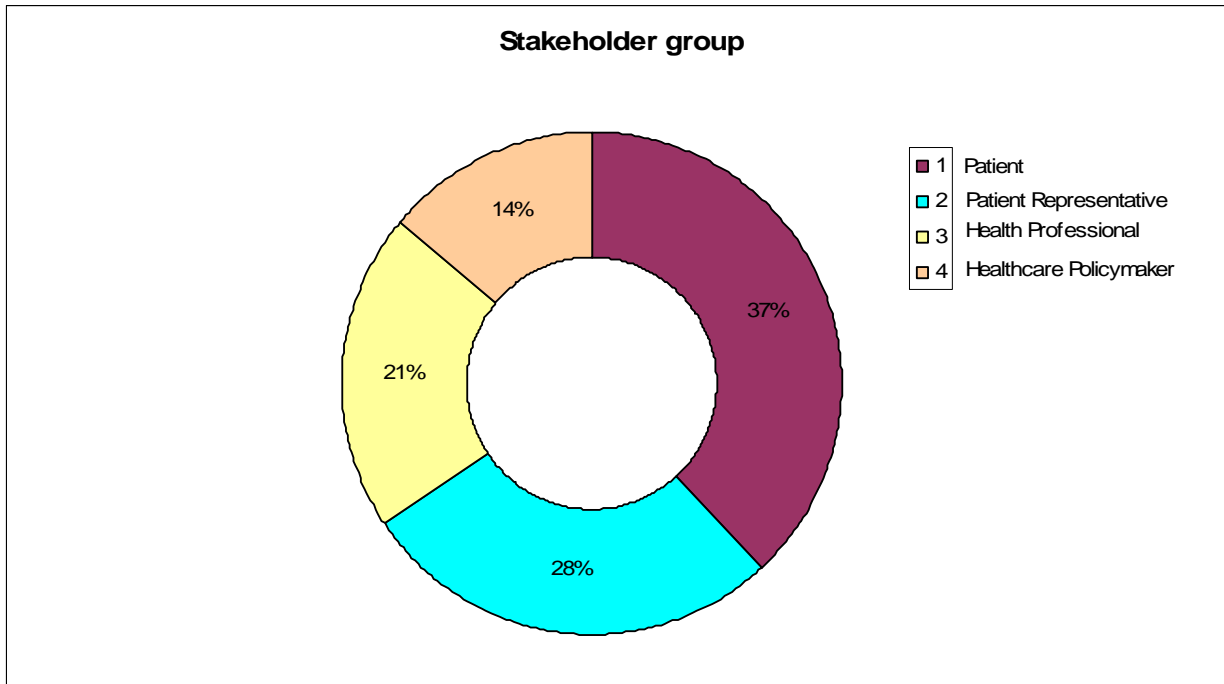
A participant described their next step as to *"Network with others associated with the project to afford mutual support and tap knowledge."* and another person suggested *"The Workshop has given a good overview of the issues that need to be addressed, and how we can go forward with our NHS colleagues."* A further participant agreed to use their energy and vision *"To move our SHA forward on its commitment to involve patients in real, effective ways, and to place patient safety to the top of the agenda for all organisations in our area."*

The next meeting is planned for late Autumn when there will be an opportunity for the Patient Safety Champions and healthcare professionals to come together again to share their work, highlight their progress and disseminate good practice.

Results of the Evaluation

Twenty seven participants completed evaluation forms and of these 65% considered themselves either a patient or patient representative. The remainder felt they belonged to the groups of Health Professional or Healthcare Policymaker, however, some participants ticked more than one box, with some having both a personal and professional role and involvement (Diagram 1).

Diagram 1



The dialogue and exchange of ideas over the course of the Workshop was agreed to be extremely valuable by the majority of participants (Diagram 2) and the opportunity to work together in 'Regional Teams' (Champions with their respective NHS partners) was very well received. *"Ideas came forward from group and class discussions which I had never thought of."* Most participants found it beneficial and rewarding and enjoyed the experience of learning more about the plans for improving health where they live (Diagram 3). One participant commented that it *"Gave the opportunity to get ideas on the table."* Some people did not feel they had gained a good understanding of the work of the project or the role of the Patient Safety Champion by the end of the Workshop. It was stated by them however, that as it is such a unique and new initiative it is understandable that it has yet to evolve and embed itself into working practice. Importantly it was felt that the discussion about the role during the Workshop was necessary, *"It was also useful to consider the role of regional UK Patient Champions."* (Patient Safety Champion) and one participant said they would have liked *"Perhaps more direction as to the role."* (Patient Safety Champion).

Diagram 2

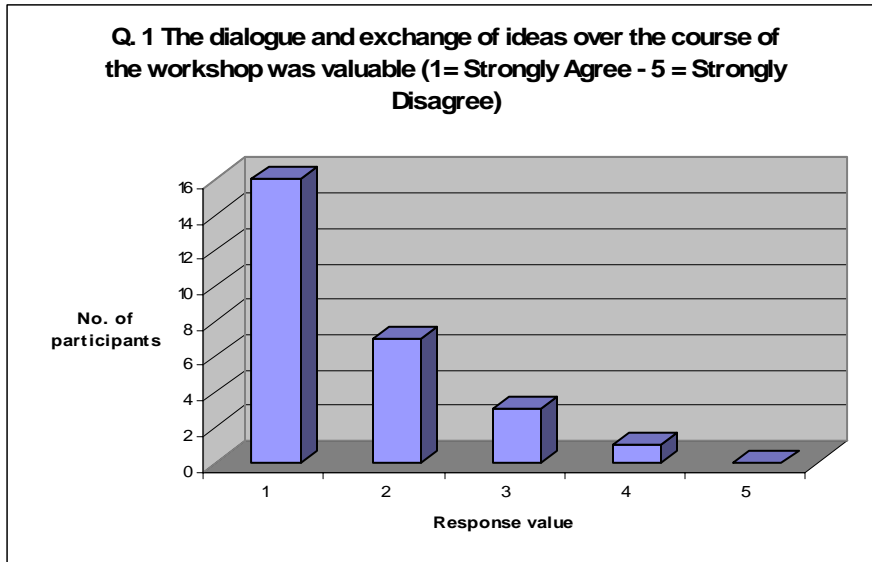
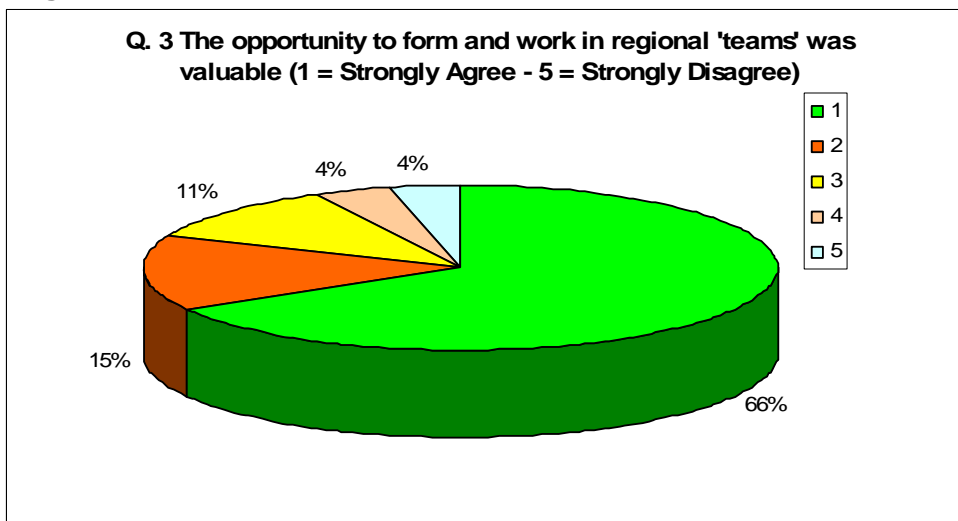


Diagram 3

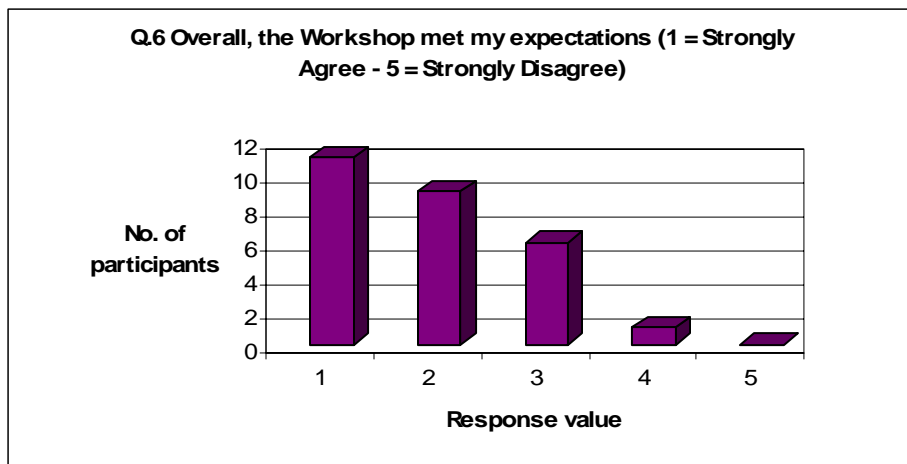


The information in the participants pack was intended as a resource and contained documents that can be read as further background. For many there had not been time during the Workshop to read this information as the packs were issued during the Induction. A couple of people commented that it would have been useful to have had the packs before the Workshop, however, this is not borne out when looking at how people perceived the activity or workload prior to the Workshop. The majority of respondents (17) felt that an appropriate amount of time had been spent on activities leading up to the Workshop and only six people felt there had been too little time spent in this way.

Whilst most participants appreciated the opportunity to attend the Patient Safety Congress after the Workshop just under half did so. A few people felt splitting up the Workshop and Congress dates would have enabled them to have attended as they felt that 4 days together out of their schedule was too much to take at one time.

Overall the Workshop was felt to have met the expectations of the participants (Diagram 4) and positive comments were received including; *“I think everyone who wished to contribute was able to do so.”* And, *“It made me realise just how much could be achieved by the Champions.”* (Patient Safety Champion). However, given that this was the first Workshop of it’s kind in England and Wales it was acknowledged that a number of participants felt unsure of what to expect; one person commented *“I’m not sure what my expectations were but it was an excellent couple of days!”*

Diagram 4



Contact details for Information

For further copies of this document or for more information please visit the AvMA website [www. avma.org.uk](http://www.avma.org.uk) or contact Anna Allford, Patients For Patients Safety Project Manager by emailing safety@avma.org.uk or write to AvMA, 44 High Street, Croydon, CR0 1YB
Tel: 020 8688 9555 Fax: 020 8667 9065

Appendix 1

The London Declaration

We, Patients for Patient Safety, envision a different world in which healthcare errors are not harming people. We are partners in the effort to prevent all avoidable harm in healthcare. Risk and uncertainty are constant companions. So we come together in dialogue, participating in care with providers. We unite our strength as advocates for care without harm in the developing world as well as the developed world.

We are committed to spread the word from person to person, town to town, country to country. There is a right to safe healthcare and we will not let the current culture of error and denial, continue. We call for honesty, openness and transparency. We will make the reduction of healthcare errors a basic human right that preserves life around the world.

We, Patients for Patient Safety, will be the voice for all people, but especially those who are now unheard. Together as partners, we will collaborate in:

- Devising and promoting programs for patient safety and patient empowerment.
- Developing and driving a constructive dialogue with all partners concerned with patient safety.
- Establishing systems for reporting and dealing with healthcare harm on a worldwide basis.
- Defining best practices in dealing with healthcare harm of all kinds and promoting those practices throughout the world.

In honor of those who have died, those left disabled, our loved ones today and the world's children yet to be born, we will strive for excellence, so that all involved in healthcare are as safe as possible as soon as possible. This is our pledge of partnership.

March 29, 2006.

Ground Rules

1. Confidentiality.
2. Respect others' opinions.
3. No discriminatory language.
4. Ensure everyone has chance to speak.
5. New friendships.
6. Good time keeping.
7. No Jargon!

Appendix 3

Glossary of terms and abbreviations

AvMA	Action against Medical Accidents
BMA	British Medical Association
CMO	Chief Medical Officer
DH or DoH	Department of Health
FT	Foundation Trust
HCC	Healthcare Commission
HPA	Health Protection Agency
LINKs	Local Involvement Networks
NGO	Non-Governmental Organisation
NHSIII	NHS Institute for Innovation and Improvement
NICE	National Institute for Clinical Excellence
NPSA	National Patient Safety Agency
PALS	Patient Advice and Liaison Service
PCT	Primary Care Trust
PfPS	Patients for Patient Safety
PSAT	Patient Safety Action Team
PSI	Patient Safety Incident
QUIP	Healthcare Quality Improvement Plan (Wales)
SHA	Strategic Health Authority
SUI	Serious Untoward Incident
WAG	Welsh Assembly Government
WAPS	World Alliance for Patient Safety
WHO	World Health Organisation

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