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NHS
National Patient Safety Agency

Patients for Patient Safety Project in England and Wales

Patient Safety Champions & NHS Partners Meeting in London

30th November 2009

Report : Anna Allford, Project Manager

Summary

This meeting is the third national meeting of Champions and NHS Partners following on from the Induction Workshop that took place in May 2008. The last two meetings have also been attended by members of the Strategic Advisory Group. It was felt important for everyone to meet with the project team in this way on a six monthly basis initially to network and share experience of developing partnership working in patient safety improvement work.

Updates from Wales and each of the 10 SHA regions in England were provided in the delegate packs to inform participants about events and workstreams where champions had been, or were planned to be, involved.

Speakers included Martin Fletcher, Chief Executive NPSA, who proposed 10 areas where champions could get involved in the work of the NPSA. General discussion also took place about NPSA policies and Martin provided background to their planned activities. Emma Forbes from the NPSA extended project team, described the strengthening of the *Being open* policy and the recent events around the re-issue of the NPSA Alert for this.

Anna Allford, Project Manager, discussed the way in which the Formative Evaluation of the first year of the project had been conducted and the findings that had emerged. People involved in the project had responded to surveys and also given interviews that provided a narrative of their experience of being involved in the project. AvMA has made recommendations in the report of the evaluation to inform the project. The report will be made available as soon as it is finalised.

International Speakers; Helle Eckeroth, Project Manager for the PFPS in-country project in Denmark, and Stine Elkjaer Larsen, a new Danish Champion, spoke about the way their project is working and Stine kindly shared her experience of being a patient. It was felt that there is much to learn from each other about the differences in the way the projects have developed but also it was agreed that there are some strong commonalties between the two. One participant said "*I loved the Danish presentation and the insights they brought with them*."

Peter Walsh, Chief Executive of AvMA, led champions and NHS Partners in further discussions around the topics. Additional opportunities to discuss issues and concerns around patient safety with the project team had been built into the day. Importantly it was felt that looking forward to the future possibilities for partnership working, not only regionally/locally but nationally across agencies that have patient safety remits, is most valuable during these meetings.

The day was an exceptionally full one as always but much of the feedback has been about people reflecting on the role of champions and the way in which they can be involved in patient safety workstreams. This has been extremely positive and we look forward to hearing from NPSA on their plans to take the project forward.

Introduction
Peter Walsh, AvMA's Chief Executive, welcomed all those present and offered a special welcome to Martin Fletcher and the new Associate Patient Champions, Amanda Pearce and Alan Horsell. International Speakers from the PFPS in-country project in Denmark, Helle Eckeroth and Stine Elkjaer Larsen, were especially welcomed to this national meeting.

Keynote Speaker
Martin Fletcher, Chief Executive NPSA, announced that he will be leaving to return to Australia just before Christmas and has a new post there in healthcare professionals regulation.

Reflecting on where we are currently in patient safety Martin felt that we'd come a long way in England and Wales. Lord Darzi's dimensions of; patient experience, quality, and safety have firmly set the agenda for the way in which NHS services can transform patient care. Senior leaders and Board members in NHS organisations are driving this agenda. However, he stressed that there is still a lot more to do.

The partnership of Patient Safety Action Teams (PSATs) and Patient Safety Champions has been a very important part of the project. The challenge he suggested, is that there is knowledge about safer practices but there is a need to sustain the focus on some key priority areas, looking at how we can put into practice what we have learnt. Already it was evident that Patient Safety First Campaign (**http://www.patientsafetyfirst.nhs.uk**)had addressed some of this.

Martin commented that openness within the healthcare system still presents a challenge and just having the guideline isn't enough. Emma Forbes later described the strengthening of the NPSA policy *Being open* in her presentation.

A further area of importance Martin told delegates, is the way in which NPSA identify hazards and use data analysis to make sense of it. Addressing this with strategies, setting priorities for action and evaluating these to close the loop are all essential. Martin posed the question; *"Are we really learning from local events?"* He felt it was necessary to enhance what the PSATs have done and continue to build upon what local teams have achieved.

The NPSA has 10 priorities for the coming year **'10 for 2010**'.

1. Surgical checklists
2. Matching Michigan with Johns Hopkins
3. Suicide prevention
4. Intrapartum care toolkit
5. Learning disabilities campaign
6. Patient deterioration
7. Patient falls
8. Pressure ulcers
9. Insulin
10. Anticoagulants

For the NPSA it is very much a sense of building on a strong platform and taking it forward in 2010.

In terms of the champions work Martin noted that a one-size to fit all approach would not have been right. The NPSA want to look at how champions can get involved in some of these key areas. Martin suggested that it would be useful to discuss with champions what their interests and areas of expertise are, as there are opportunities here for champions to be involved in small working groups.

Finally, Martin referred to the tough economic climate and challenges facing healthcare, he felt there is a need to ensure that patient safety is part of the agenda, commenting, it is not just about good patient care but also good use of resources. The Matching Michigan initiative that NPSA is now piloting has specific interventions that not only improve patient care but frees up resources.

Peter thanked Martin and a general discussion with delegates took place. Comments and a question relating to suicide in hospital were raised by a champion who acknowledged that on some general wards staff with psychiatric training could be beneficial. Martin responded that the risk factors around suicide are well known but suicide prevention measures need to be implemented within services and safety issues together with risk judgements have to be made.

Martin responded to a question around the *Being open* policy being put into legislation, saying that he believes there are a lot of areas that can be addressed without legislation. Organisations need to have mentors available for staff to be helped and supported through the process. However, he felt many of the current barriers can be addressed without the need for legislation. Another champion expressed the concern that the patient's perspective needs to be understood better too.

Issues around a 'blame culture' were discussed and Martin suggested it is more about building a system of an open and fair culture, although what this means in practice is yet to be fully realized.

One champion asked how a balance can be had, for example, in the expenditure on pressure ulcers in the NHS, with the current requirement for the NHS to save money in these economic circumstances. Martin stated that pressure ulcer prevention can release resources and cash for the NHS but a business case needs to be built for this. A champion who has been working closely with the Matching Michigan project group supported the cost savings that could be made through interventions such as preventing catheter related infections. Martin agreed but stressed that more work is needed to demonstrate this in cash terms.

A comment was made by a champion that more sharing of best practice, as happens in some industries, could lead to improvements and Martin replied that the 1000 Lives Campaign in Wales has done this by highlighting exemplar sites.

Formative Evaluation
Anna Allford, Project Manager, described the beginnings of the project and how it had developed in the first 12 months. Anna commented that everyone, champions and NHS Partners, had come a long way during a very short time and that the Strategic Advisory Group

had come on board to advise the project team and discuss approaches that could be used to further involve champions in national patient safety work within the organisations they represent.

The evaluation has involved all stakeholders including the Wider Network to gauge opinion about what has emerged as the project has evolved, what has worked work and what lessons we can learn. A strong emphasis was placed on partnership throughout the evaluation interviews and surveys and it was recognised how important this is for a truly collaborative approach. Where partnerships had been formed quickly, champions have developed working relationships that are already showing added value and outputs that can be demonstrated. However, it is acknowledged that in some areas it has been more difficult to establish such relationships and has taken longer, for a variety of reasons.

In addition to the results of the evaluation three case studies have been included in the report (currently only in draft version at present) to share what has worked well and disseminate different aspects of the different approaches used.

The findings so far are mainly positive with a focus being on the personal story and experience that many champions bring being not only useful but inspiring when this is related to healthcare professionals. The need to move beyond this and work strategically also emerged but this must be balanced by keeping the champions fresh and retaining them as the patients' voice, and not part of an NHS organisation they're working with. This latter aspect is something that as a project we have had to balance right from the start.

AvMA has made the following recommendations in the report:

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.

The role for champions as 'championing' patient involvement and engagement in patient safety improvement work could be further scoped, perhaps developing the Wider Network in line with social movement thinking in health, with champions spearheading this. Importantly, it was agreed that many lay people are already involved in improving patient safety and the champions could aim to engage with them, for example, LINks (Local Involvement Networks) in England, CHCs in Wales, Foundation Trust (FT) Lay Governors and Patient groups/patient panels belonging to trusts and PCTs.

Further discussion around the recommendations took place in the afternoon.

Being open
Emma Forbes, Lead for Patient Engagement at the NPSA, announced that the NPSA has published strengthened guidelines for NHS organisations on *Being open*, which describe the importance of open and effective communication with patients. *Being open* is a set of principles that healthcare staff should use when communicating with patients, their families and carers following a patient safety incident in which the patient was harmed.

NHS Trusts have until 22nd February to inform the NPSA that they have actions underway and until 23rd November 2010 to complete the actions in the framework. The revised Being open framework is available at **www.nrls.npsa.nhs.uk/beingopen**

Emma stated that policies in Trusts need to be aligned at Board level. The role of 'Senior Clinical Counsellors' was outlined as providing mentoring and support to their colleagues. They should not be asked to lead on *Being open* discussions but their primary role is to support colleagues and help staff through the process in implementing *Being open* following an incident. It is important to make the information about *Being open* visible to everyone, staff and patients.

Emma gave feedback on the Workshops and listening exercise that took place in September. She commented that a number of NHS Trusts did not have a policy, or staff did not know about *Being open*.

A series of 5 'Webinars' had taken place during the launch and the discussions from these are available on the NPSA website. Some delegates had taken part in these and it was felt

that there was a great excitement around these events and a huge amount of support for the policy.

PfPS Champions, Anne Carvalho and Peter Metherall were invited to the recent Summit Meeting for *Being open* and Peter Walsh was a Speaker at this. Anne stated it was amazing, and feels that it is really possible now to be open. Peter Metherall said he was inspired by the healthcare system in New Zealand. One of the NHS Partners who had also attended the event found it very useful and was looking forward to hearing more about research in this area.

Emma noted that a representative of the Care Quality Commission (CQC) has confirmed that the Guidance regarding registration will include *Being open*. All health and adult social care providers, who provide regulated activities, will be required by law to register with the Care Quality Commission. To do so, providers must show they are meeting new essential standards of quality and safety across all of the regulated activities they provide. More about this can be found on their website **www.cqc.org.uk**

Additional resources and support will be available throughout the year for *Being open*. Patient stories could be a part of this and it mat be possible for champions to get involved by providing their experience and patient stories.

Questions from delegates included asking for assurance that there will be support for nurses in the process and Emma confirmed that Senior Clinical Counsellors will be available to all staff not just doctors. Another champion suggested that patients too need support during the process. Emma agreed that the work now needs to move forward to show organisations how this process can work in practice. She felt it was time to shout out 'Let's change the culture!'

A further champion pointed out that much of being open is already in the NHS Constitution. Emma responded that as the Constitution starts to embed then there should be more *Being open* appearing in the operating framework.

Peter Walsh proposed that a Legal Duty of Candour, called for by AvMA, would resolve issues around reporting of incidents and the difficulties faced by patients and staff. He commented that there are a number of countries world-wide that already do this and there is nothing to fear, feedback he's received has been positive from those countries.

A discussion took place regarding the definition of a serious untoward incident and Kate Beaumont, Head of NHS and Patient Engagement, NPSA, added that a consultation has just finished around this so there will be a national definition in the near future.

One champion commented that doctors sign a Pledge that places an obligation upon them to report if they or a colleague has made a mistake or is practicing in an unsafe way. Peter Walsh, related news of a recent meeting he'd had with the Department of Health (DH) in which he had received news of forthcoming regulations around reporting. One champion felt that unless they were statutory and legislated for then they would not be effective. Peter felt that the regulations are being gradually replaced until there is more informed guidance.

International Speakers
Helle Eckeroth, Project Manager for the PFPS in-country project in Denmark gave a presentation on the work of their project and champions to date. Helle felt that there were comparisons to be made with our project after listening to the concerns and comments at the meeting but there was also a lot to learn from each other. Helle said the first Danish Workshop took place in 2007 and 13 champions were inducted into the project at that time. She said that they were eager for change and wanted it immediately, however, during this 2 year period there was still some resistance to champions by healthcare professionals. Where champions had existing networks this had given them more successes.

Following a further Workshop in September 2009 eight more champions joined the project bringing the total to 21. Some were recruited from cases in the Danish media. In Denmark Patient Safety is high on the political agenda and the champions together with the organisation lobby and make speeches. The project is privately funded and they have received substantial funding to take forward their work programme and for future developments.

Helle says that around 50% of champions are able to go out and talk about their experiences but the remaining 50% need more training and personal development to support them. The strategy for 2010 – 2013 is to form partnerships between health care professionals, patients and their relatives. Their mission is to strengthen patient safety through open dialogue and to encourage and educate patients / relatives to be active partners in the health care team. They want to encourage health care staff to be active listeners and embrace the empowered patients and relatives. Additionally, they would like to expand the network to 60 Champions.

Patient Champion activities planned for 2010 – 2013 include:

- Talks at local, regional, national and international level;
- Represent patients voice in parliament and Health Care Committee;
- Participate in Patient Safety Rounds (at hospitals);
- Collaborate with local risk managers in both primary care and on hospitals;
- Participate in public engagements;
- Distribute patient handbooks at venues, conferences set;
- Write articles to the media about relevant subjects on the political agenda;
- Be members of relevant working groups;
- Teaching patient safety in patient schools all over Denmark.

Their publications include '***10 Patient Tips***' and a resource for healthcare professionals, '***Say Sorry***'. Additionally, they have produced a '***Patient Handbook***', which has been evaluated in Denmark. These resources can be downloaded freely from the website:
www.patientsikkerhed.dk/en/about_the_danish_society_for_patient_safety/activities

Stine Elkjaer Larsen is a new Danish Champion aged 26, who has been a patient since she was a very young child. She told her story movingly and frankly and we are very grateful for her personal reflections. Stine gave an account of the effects of using a contrast dye called Omniscan during imaging investigations a few years ago. As a patient who'd already had a successful kidney transplant as a young person she was surprised to find a rapid deterioration

in her health and kidney function but for a couple of years no-one made the connection between the contrast medium and her failing health.

Stine felt very unwell and suffered severe pain and loss of mobility but she could not get any answers. In 2006 a nurse suggested she had symptoms relating to NSF (nephrogenic systemic fibrosis) which had been linked to Omniscan (contrast medium) and she was put in touch with a researcher investigating this incurable illness. In Denmark the product Omniscan was taken off the market and elsewhere it is now recognised that it should not be used in people with severe kidney disease. Omniscan and comparable products contain the potentially toxic metal gadolinium. Healthy kidneys filter out gadolinium but patients with severely impaired kidneys can become victims of NSF according to the FDA (Food and Drug Administration) in the US.

Gradually, Stine started to improve and regain her strength and in January she got a new kidney transplant. Since then she has felt well enough to re-commence her studies and nurse training but there is no certainty what the future consequences of being injected with this drug are for her. Stine hopes that nurses will be more open and honest with patients and wants to work with them to enable them to do so.

Delegates commented that having a perspective from other projects outside of England and Wales was really valuable and they were really grateful to Stine for sharing her story.

Potential Work Themes

Peter Walsh, summarised the recommendations made in the Evaluation Report and reminded delegates of the opportunities for champions to work on NPSA Working Groups. A discussion took place around these ideas.

One champion was concerned about the proposal within the NHS Constitution to develop 'Constitution Champions' and whether they may be asked to advocate for patient safety? The consultation can be found on the Department of Health (DH) website
www.dh.gov.uk/en/Consultations/Liveconsultations/DH_108012

Peter asked if champions thought it was a role for them to become Constitution Champions but it was generally agreed that it would not be appropriate as there was already so much to do in patient safety and "it would blur the edges."

A query was raised about the project evaluation which referred to the Recommendation 2. Clarity was provided by Anna around the process that had already been put in place when recently recruiting to champion vacancies. The involvement in the recruitment process had been with the SHA and champions in the regions of East and West Midlands. This had been recognised as necessary during the first wave of champion recruitment but unfortunately time had not been built into the early part of the project to fully develop this aspect prior to the Induction Workshop in May 2008. A champion felt that people with disability may be marginalized in the recruitment process and able-bodied candidates selected preferentially. Anna reminded delegates of the initial process which remains in place now whereby people who submit an Expression of Interest form are not asked about disability. In fact emphasis is made during the recruitment advertising that we should like to hear from people who have direct experience of medical harm. This could, in fact, lead to more people with disability and a range of health conditions being included in the champions network.

A further question was raised about the suggestion that a fixed term of office for champions could be introduced into the project. Peter said that WHO Patient Safety were already discussing this possibility for champions and within the project it would be reasonable to provide a guide for volunteers regarding how long they would serve.

One champion commented that a contact at the NPSA would be helpful in providing information to champions and asked who might be the person to contact. Kate Beaumont agreed that for general advice around patient safety then she could help in this way. The project team at AvMA can pass on any queries champions may have to Kate.

Another champion was concerned about the term 'appraisals' being used in Recommendation 5. Anna explained that it is less formal than it sounds and that this process was started a year ago when champions were invited to develop personal Action Plans and share these with their NHS Partners and the project team. Reviewing an Action Plan with a champion recently gave Anna the chance to highlight just what had been achieved in such a short period of time as this champion had in fact met all of the goals they had set themselves. A champion commented this was appropriate and a good thing to reflect on and see that progress and objectives had been fulfilled. A further champion asked if there will be a budget to support training and development if appraisals identify a need with individual champions. Peter explained that there is no budget set for next year but some training has been made available to champions and additional training can be considered. Anna added that the analysis of the survey of champions skills and training needs identified training that has been already provided; Being Open and Root Cause Analysis plus presentation skills.

Raising funds for the project or for AvMA was proposed by one champion. Peter agreed that he would welcome such practical help if anyone wanted to offer this. Additionally, this champion felt that awareness raising could help the project if a higher media profile could be commenced. Peter agreed and noted that it would be helpful to have a higher profile with the Department of Health (Recommendation 4).

Peter asked what delegates thought about individual champions working at a national level with the NPSA. This is already happening with *Being open* and was seen to be a positive way forward by champions. Kate Beaumont requested champions to let the Project Manager know what areas of interest they have in the 10 themes outlined by Martin and AvMA will pass this onto the NPSA.

A champion asked for feedback on 'Never Events' following some earlier involvement by champions. The concern was around pressure ulcers in particular and the champion felt it would be a good opportunity to work with the Royal College of Nursing (RCN) on such issues. Kate said that NPSA already work with the RCN.

An NHS Partner outlined the regional network the SHA in the North East had set up to work on some of the 10 key areas highlighted by Martin and another NHS Partner suggested that the 'Top 10 Safety Tips' (Danish project leaflet) mentioned by the Denmark Project Manager could be discussed with a view to taking these forward by champions. Emma responded that in 2006, NPSA had developed a similar checklist of top 10 tips and it may be possible for champions to be involved in reviewing these. Peter also suggested that the Patient Handbook from the Denmark project could be considered in future discussions in England and Wales.

A further NHS Partner noted that champions in the North West had given a presentation to anaesthetists and surgeons around the WHO Safe Surgery Checklist and the notes from the meeting might be useful for patients. A champion said she'd recently been an in-patient in hospital and had seen quite a lot of information on the wards to help patients keep safe, e.g. tips such as what questions to ask the doctors, washing of hands etc. Peter agreed there was a lot out there and it would be helpful to know what exists already.

An NHS Partner from the West Midlands described how a champion had asked a pertinent question at a recent Safe Surgery Checklist meeting about why this is not mandatory. This has led to the SHA's Medical Director taking forward talks with the PCT's Commissioners how they could include this in the commissioning process and monitor it. Anna mentioned that although this champion could not be at the meeting today she'd made a good suggestion that it was really important to make progress with PCT commissioners and establish relationships with them because of their new role with all providers, including Foundation Trusts.

A champion requested feedback on the champions recent input into *Being open*. This champion had been invited by the NPSA together with another champion to the *Being open* Summit meeting. She said she'd found it inspiring and that it was felt clearly possible to have a culture of being open – sharing examples of good practice – and evaluating sites that are doing this well. Emma agreed that organisations that are doing this well in practice could celebrate their success and share best practice with others. Another champion stated that they believe healthcare professionals do apologise when things go wrong in general but the media highlights issues when they are on a much bigger scale. A further champion gave an example of how in industry a lot of sharing takes place and Kate said that through the **Patient Safety First** campaign they organise insight days to do this.

Peter felt that by expanding the Wider Network there is a potential for a bigger social movement, linking in people who are involved in patient safety locally. A champion working with the SHA in the South Central region commented that the Patient Safety Federation in this region has emailed their contacts to request that champions can get in contact with the patient representatives.

One champion suggested that there is a need for champions to collectively campaign for the secondary legislation needed to get the NHS Redress Act through parliament. Peter explained that champions had not been given the remit to act in a campaigning role within the project but could individually do so (or even some champions could get together outside of the project if they wished). A discussion took place around this as some champions felt this could be a role for them but other champions disagreed as they felt it would be difficult to reach a consensus on which campaigns champions would want to support and not all champions wanted to act politically in this way.

Peter thanked everyone for their valuable contributions and especially the speakers who had provided information for the champions, NHS Partners and project team to reflect on.

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