PATIENTS FOR PATIENT SAFETY

REPORT ON THE PILOT PROJECT
APRIL 2006-MARCH 2008

NHS
National Patient Safety Agency

avma
action against medical accidents

Table of Contents

Appendices

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1) Introduction

The ‘Patients for Patient Safety (PfPS) Project’ is a joint project of the National Patient Safety Agency (NPSA) and Action against Medical Accidents (AvMA) which aims to develop the role of patients and the public in patient safety work in the NHS in England and Wales. Following a tendering exercise, the NPSA contracted with AvMA for it to project-manage the project on a pilot basis from 1st April 2006 to 31st March 2008 in order to inform further work in this area. This report has been produced by AvMA, to report on the progress and findings from the pilot project over the two years of its operation and plans for the ongoing Patients for Patient Safety project, including the recruitment and support of ‘patient safety champions’ from April 2008

2) Project Management and Governance Arrangements

Following agreement on a contract for project management of the project, AvMA appointed Josephine Ocloo and Louise Price as project managers on a job-share basis. Josephine has considerable experience of involvement in patient safety work as a result of her own personal experience of being affected by medical harm. She had also been working previously with AvMA on a voluntarily placement as part of undertaking a PhD on medical harm and patient empowerment within the NHS. This work involved leading on the development of a network of self-help groups (eventually called the Medical Harm Self-Help Network - MHSHN), whose members had been affected by medical errors, in order to empower these groups to become more involved in the wider patient safety agenda. Louise is an experienced manager within AvMA who has been directly involved in AvMA’s own client support and involvement work. Josephine and Louise have been responsible for the day-to-day project management and administration of the project, with back-up from other members of AvMA's staff. AvMA’s Chief Executive, Peter Walsh, acts as the responsible officer for the contract with the NPSA and oversees the project on behalf of AvMA.

Peter, Josephine and Louise have all met on a regular basis with Peter Mansell, who managed the contract on behalf of the NPSA, and provided a wider link with the WHO World Alliance for Patient Safety, Patients for Patient Safety Project.

3) Project Objectives

The four objectives set for the project in the contract specification are:

1 To identify and recruit a network of individuals and Trusts involved or wanting to be involved in patient safety work at the local and regional levels, and to provide the infrastructure for mutual support, shared experience and good practice.

2 To develop and deliver a core training module to help individuals acquire the confidence, knowledge and skills to play an influential role in patient safety work.

3 To develop networks of self-help and support groups/patients organisations and patients and those close to them concerned with improving patient safety to provide opportunities for sharing information and experiences.

4 To disseminate learning from the approaches used in the project and make recommendations for how patient and public involvement in this area, and self-help/ mutual support of patients affected by medical accidents could be supported, maintained and fostered in the longer term.

4) Project Outputs

March 2006	-	Recruitment of Development Worker
April - June 2006	-	Meetings of those participating in the self-help/support group network
	-	Establishment of advisory group and contacts with self- help/support groups
	-	Call for interested participants
	-	Development of database
June – April 2007	-	Adaptation of the core training module
	-	Continued call for interested individuals
	-	Continued facilitation of self-help/support network
	-	Development of website and newsletter
	-	First core training for individuals interested/involved in clinical governance
	-	First meetings of network for individuals

In addition, Peter Mansell during the course of the first year authorised the amendment of the objectives to include direct work with local NHS trusts (‘pilot sites’), to work with those Trusts on their work on involving patients in their own patient safety work at the local level. It was agreed that this would make a practical and valuable contribution to objective 1 of sharing experience and good practice.

5) April 2007 - Priorities for the project’s second year included:

- Continuing work with the ‘pilot sites’ through the implementation stage of some of the work that has started, and collection of good practice examples in involving patients in patient safety work.
- Further development of the network in terms of increasing members and exploring strategies for supporting individuals in patient safety work.

- Delivering the ‘core’ training module to network members and follow-up session on PPI in clinical governance.
- Holding a one-day event for network members on complaints and regulation.
- Publicising the work of the project through speaking at patient safety related events and conferences, liaising with organisations such as the Healthcare Commission to develop partnership approaches to the project's work and publishing material on the project's findings.
- Evaluating and disseminating learning, by holding a one-day conference for patients and the public and healthcare professionals.

6) The Establishment of a Patient Safety Network

The PfPS project was launched at a highly successful conference 'The Patients Agenda for Safety and Justice', organised by AvMA in partnership with the MHSHN, in May 2006. At the conference a 'call of interest' was made to individuals and organisations who might be interested in getting further involved in the project and in forming a wider network for patient and public involvement (PPI) in patient safety work. This call led to some 45 individuals initially expressing an interest. This incorporated people from a range of backgrounds and included both those individuals affected by harm and those from the MHSHN and patient representatives more generally, particularly those from Patients’ Forums and other voluntary patient groups. As the network has developed over the last two years, interest has grown considerably and membership of the network now includes more than a hundred individuals who have regularly attended network events.

In order to develop the network and its focus, a number of events have been held to date.

- An event held at the NPSA on 22 September 2006, to enable individuals to meet and explore ideas about how a patient safety network could be developed.
- Following a request by the Department of Health, several members of the Network attended a workshop discussion facilitated by the Department in the winter of 2006, as part of its review of organisational arrangements for patient safety leading to the report *Safety First.*[1]
- Some network members also attended a meeting with the NMC set up by AvMA, to discuss Fitness to Practise issues. These issues were raised at the conference 'The Patients’ Agenda for Safety and Justice'.
- A second meeting of the network was held on the 13 February 2007, which covered specific training on Being Open, the NHS Redress Scheme, with the afternoon set aside to look further at network development.
- The next meeting of the network was held in June 2007 and consisted of a one-day training event on patient safety for PPI representatives and those affected by medical harm.
- The training included a follow-up half-day event held on 25 January 2008 to look at PPI in clinical governance processes.
- A one-day conference was also held on 13 December 2007 to look at complaints, regulation and PPI in the Annual Health check.

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[1] Safety First A report for patients, clinicians and healthcare managers, Department of Health, Dec 2006

ISSUES IDENTIFIED:

Diverse representation and involvement

Those attending network meetings were either individuals directly affected by medical harm and/or involved with organisations and/or patient representatives or patient forum members more generally. Whilst the meetings held have been productive, it is of note that people came to the safety agenda with a wide range of backgrounds either as a result of their personal experiences or through experiences gained in groups or organisations. This diversity of experience posed a challenge in trying to meet the needs of those attending meetings. Some issues to note in particular for future working, are:

- Whilst many active patient representatives were knowledgeable about healthcare issues and the policy agenda, this was not necessarily the case when it came to having knowledge about patient safety initiatives.

- Those directly affected by medical harm had more knowledge of safety concerns, either because of their personal story or because they had become more involved from a campaigning or activist perspective. However, because these individuals had had very difficult experiences or had not been listened to in the past, their views could be expressed very strongly and emotionally. This input was not always well received or understood by those who had not experienced medical harm.

- Whilst there appeared to be a fairly broad representation of members attending meetings in terms of gender and age, this was not the case in terms of disability and ethnicity.

Knowledge and capacity building

In order to provide a focus for the meetings, it was found helpful to concentrate on giving individuals specific information on a range of areas with respect to patient safety. Participants themselves determined the type of information and topics for discussion at various meetings. This type of focus helped to encourage individuals to engage in discussions constructively, rather than getting bogged down in certain areas. Individuals identified the need for them to be given specific training and support if they were going to get properly involved in patient safety work. It was acknowledged that without appropriate training and support, there was a danger of reinforcing NHS stereotypes of 'difficult' and misinformed patients and of setting people up to fail or being used in a tokenistic type of way.

Some barriers to involvement

- A number of issues were consistently raised about the need for individuals to be able to be properly reimbursed for their expenses in attending meetings. Without this issue being addressed, individuals were either not able to attend meetings, or because of their commitment to the issues, individuals travelled to meetings at great cost to themselves, which was often made clear that they could not afford.

- What also came across from individuals at meetings was that they were keen to be involved in the patient safety agenda but found it very difficult to get involved. This was because either they were not being given the correct information they needed to access certain areas, and/or because they were experiencing more overt resistance to involvement either in getting onto a committee or whilst involved in the committee process.

- Other more general barriers appeared to relate to the way in which those with negative experiences of healthcare could be treated at network meetings, because of a lack of knowledge by individuals not affected by harm about the issues concerned. These issues could be about an experience of medical harm or an experience occurring as a result of discrimination. This issue raised the problem of how to give these individuals the appropriate space to raise specific issues, whilst not allowing the agenda to become dominated by overlong accounts of personal experiences.

The patient safety focus

What was clear from the breadth of discussions that took place in network meetings was that individuals saw patient safety concerns in very broad ways. This meant that they did not just confine themselves to looking at issues to do with prevention and improvement, but also focussed on issues such as governance, justice and accountability. These latter areas were particularly seen as an issue when individuals had been directly affected by medical harm. Tackling all of these areas was seen as important in ensuring lessons were learnt about preventing medical harm and building a safer culture of care in the future.

Recommendations

Preparation at the start of meetings is essential, by setting ground rules and by acknowledging that individuals because of their personal experiences of medical harm might become angry or emotionally affected. It might be important to find ways to acknowledge these experiences as part of the debate whilst pointing out the limitations of the meeting in allowing the details of personal issues to be discussed.

In developing networks for the future some thought needs to be given to how best to explore ways in which those directly affected by medical harm could be supported in getting involved in patient safety work given the barriers and hostility they will often face in this process. For example, we need to determine whether the network has a formal structure and resources, what types of issues it focuses on, whether it is made up of individuals and groups, how it achieves diverse representation of people from different backgrounds, how it will work with patient safety champions etc.

In developing training in the future, thought will need to be given to how one can organise this to meet specific needs. One suggestion is to develop more specific detailed training for those already involved strategically in clinical governance and patient safety, because they are already more active and knowledgeable about patient safety work. Those not already involved in this area may need other types of training on patient safety at different levels or on specific topics and themes.

7) Identifying Good Practice Examples

In order to identify good practice in involving patients and the public in patient safety in the NHS, every NHS Trust and PCT in England and Wales was written to with information about the project. The letter invited them a) to tell individuals who were already engaged with their Trust's patient safety work about the opportunity to join the network and b) to send in examples of good practice involving patients and the public in patient safety work. The aim was to attract additional expressions of interest in the Network and in providing examples for a compendium of good practice from Trusts already involving patients in patient safety work. The response from NHS Trusts was, however, disappointing, with very few responses received.

Recommendation

For the future, more research needs to be done to identify what good practice exists for involving patients and the public in patient safety and what this involvement constitutes, together with strategies used for achieving this.

8) Work with NHS Trusts

The decision to pilot some of the work of the national PfPS Project at a local level with two NHS Trusts, arose out of a meeting at a conference on patient safety, 'Patient Safety - The Challenges for Trust Management', held in June 2006. The meeting involved the project managers and the Chief Executive of what is subsequently referred to in the report as Trust A, a local acute hospital and foundation hospital Trust and the Chief Operating Officer of what shall be called Trust B, a local mental health Trust. The PfPS project managers were keen to take forward some of the PfPS project work at a local level and both Trusts expressed a strong commitment at the conference to developing a patient safety culture within their hospital work. Both Trusts were particularly keen to explore how they could develop the work they were doing in patient safety to achieve more patient and public involvement.

It was therefore agreed that Trusts A and B would become pilot sites for exploring strategies for gaining more patient and public involvement in patient safety work at a local level. In developing this work, it was left to each Trust in partnership with the project managers of the PfPS project to decide how to take the work forward. This meant in practice that the work developed differently and organically at each site, taking into account Trust priorities and the current infrastructure in terms of PPI. In terms of management of the projects work each PfPS project manager led on the work with one NHS site in partnership with Trust staff, with support where needed from the other project manager.

The work is set out below, with the Trusts involved, in accordance with the different ways the work developed over the life of the PfPS project.

9) Work with Trust A

As background context in developing their patient safety work, within Trust A some very serious patient safety incidents had occurred over recent years, which had provided the momentum for looking at the way the Trust responded when such incidents occurred. This review of their work had led the Trust to recognise that, as an organisation, they had on occasions responded to serious incidents in a reactionary and defensive manner that in turn had impacted upon staff. This had led to an organisational-wide commitment to stimulate change within the area of patient safety that included addressing the way in which staff were involved and supported in the aftermath of an incident.

The Trust was also keen to explore how they could involve patients and families in raising awareness of potential safety issues, prevention and support. A further area the Trust was looking at in some detail was implementation of the NPSA's Being Open Guidance. In January 2006 a target had been set for a minimum of 35% of senior managers and clinicians within the Trust to undertake the NPSA’s Being Open training. Over the next year the Trust then intended to monitor the effect that implementing the Being Open initiative with staff would have on patient/user and carer satisfaction, complaints and incidents and staff satisfaction. Exploring what would be needed to incorporate PPI involvement into the Being Open policy was seen as an integral element of this work.

In order to develop the work of the national PfPS project at a local level with the Trust, a number of initial meetings were set up to look at how strategies could be developed organically out of the work and priorities that the Trust had already identified as key issues. It was eventually agreed to focus primarily on the area of suicide and to identify the issues and factors associated with this when a patient commits suicide whilst under the care of the Trust, the circumstances in which it took place and the issues specifically:

- from the perspectives of relatives/carers bereaved through suicide;
- from the perspectives of staff involved with the aftermath of a suicide, including responsibility and oversight of the process and dealing directly with bereaved relatives.

In order to take this work forward it was agreed to work with the Trust at one of their main hospital locations and to hold two workshops off-site of the Trust with independent facilitation provided by the NPSA, in order to look separately at these perspectives. The workshop with staff was entitled - 'Learning about ourselves - a meeting exploring the experience of patient suicides for staff' – and the workshop on patient experiences was called 'Learning about ourselves - a meeting exploring the experience of patient suicides on patients' relatives'.

Key objectives of the workshops were to:

- enable the Trust to improve its services in managing the risk of suicide and its response to its aftermath particularly in the light of the NPSA's 'Seven Steps to Patient Safety'[2] and 'Being Open – communicating patient safety incidents with patients and their carers' guidance[3];

- enable patients’ relatives and carers and staff to gain a better insight into the issues and understanding about each other's experiences in the aftermath of a suicide;

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[2] http://www.npsa.nhs.uk/patientsafety/improvingpatientsafety/patient-safety-tools-and-guidance/7steps/ website accessed 05/05/08

[3] http://www.npsa.nhs.uk/patientsafety/improvingpatientsafety/patient-safety-tools-and-guidance/beingopen/ website accessed 05/05/08

- enable patients' relatives and carers to become further involved in the future with the work of the Trust in developing their patient safety agenda; and

- consider future joint initiatives to bring both staff and patients' relatives and carers together to develop a partnership model for PPI in patient safety.

Workshop with Patients' Relatives and Carers

Despite a lot of work taking place to organise this workshop, eventually it did not take place because of the lack of sufficient numbers to make it worthwhile as set out below;

- 22 relatives identified by Trust for contact,
- 2 relatives expressed interest in being involved (later contacted by 3rd relative),
- 2 relatives provided written accounts of their experience but did not wish to participate in person,
- 3 said did not wish to be involved,
- 15 did not respond and could not be contacted by telephone.

A key issue in preventing the workshop happening, as the figures above demonstrate, was in not being able to make direct contact with families in the first place. The Trust went back three years as a starting point for identifying next of kin. This measure was taken was in order to ensure that relatives/carers were not contacted who might have been recently bereaved and therefore might find it difficult to be involved. A minimum of 30 people who had committed suicide were initially identified; however, a number of these were defined as having no fixed abode and some individuals were screened out as not being suitable for other reasons. The final numbers were scaled down to 22 potential participants, who were written to and responded as indicated above.

It is difficult to be clear, because of the non-response rate to the workshop, exactly what other issues may have prevented relatives from wanting to attend the workshop. One lady, who was spoken to on the phone, had wanted to attend, but also spoke about continuing to have major unresolved issues with the circumstances surrounding the suicide of her son. Two other possible participants, however, were struggling with trying to get time off to attend the workshop. Overall some general conclusions in thinking about organising such a workshop for the future might be that individuals bereaved as a result of a suicide may be less likely to want to get involved where:

- they have been unable to obtain resolution and closure;
- there has not been an ongoing relationship with the Trust;
- there are still unresolved issues with the Trust;
- they do not feel that there is going to be a personal benefit as a result of their input or that they are going to be properly compensated for expenses/time incurred; or
- they have moved. It may well be that families/carers are identified going back 1 year rather than 3 to avoid the problem of being unable to identify accurate contact details.

Careful thought should also be given when identifying families to participate in order to ensure that families are not excluded who may be perceived as too difficult to work with as these experiences may provide invaluable learning for the trust.

Additional approaches for the future in seeking the views of patients' relatives and carers might also be done through individual interviews, relatives invited more informally to share their experiences with staff or to attend a meeting with staff members and written stories. Involving people at risk of suicide and their carers could also be a more effective approach to developing PPI in this area, as these patients will have a stronger incentive to get involved if it would help them manage their own situation more effectively as well as helping others.

Developing further strategies for PPI

As a result of the lack of progress in this area some further attempts were made to try to achieve PPI in the patient safety agenda at the Trust. This involved:

a) making contact with a number of user support groups. This raised the issue that user support groups were more likely to be in contact with those at risk or expressing suicidal feelings rather than relatives and friends bereaved by suicide. It was particularly useful to meet up with two groups whose objectives are to enable user involvement in the planning, development and monitoring of mental health services within the catchment area of Trust A.

In the latter part of 2006, one voluntary group ran a series of focus groups with service users and carers to look at the need for health care staff to help patients deal with suicidal feelings. The feedback from the focus groups was written up for an information booklet published in January 2007, called 'Dealing with Suicidal Feelings'. This information was subsequently fed into Trust A's Suicide Prevention Strategy. However, the voluntary group also felt that it would be a good idea to take this work forward in more depth by discussing the issues raised in more detail with Trust A. From our discussions with this group we gained the impression that whilst they felt there were some good initiatives taking place around user involvement within the Trust, this was not necessarily in relation to user involvement, patient safety and suicide. Therefore some proposals suggested by the voluntary organisation for developing this work were for the Trust to explore the idea of setting up a strategic meeting with key professionals, user groups and some users to discuss the document produced on the views of those dealing with suicidal feelings. Another proposal was for some thought to be given to how a bigger PPI event could be held to allow for more user-staff dialogue to be developed in the area of suicide.

b) Meetings were also held with key members of staff to try and identify what PPI in patient safety already existed within the hospital. Meetings were held with the team manager in the Community Mental Health Team (CMHT), the Trust lead on PPI and the Trust lead on suicide prevention. A number of attempts were also made to meet with the Chair of the Trust Patient and Public Involvement Forum which were unsuccessful because of his carer responsibilities. From these meetings it was difficult to obtain clear details about PPI in the patient safety aspects of the Trust's work. From our meeting with the Team Leader of CMHT we were informed of the SUN (Service Users Network) based within the Trust for people with personality disorders. However this is therapeutically led by a psychotherapist.

The meeting with the PPI lead was useful in providing us with an overview of the commitment to PPI in the Trust; however, it was difficult to ascertain from the PPI Strategy the aspirations in terms of PPI and actual involvement. We were also not able to get any information about PPI in patient safety, but were referred instead to the Trust lead on suicide prevention. This meeting was helpful in clarifying that in order to take this work forward there needed to be better co-ordination of all the people involved with this work and what they were trying to achieve in terms of PPI. An important suggestion made at this meeting was the idea of exploring the perspectives of relatives and carers bereaved by suicide by inviting them to tell their story as part of a training video for Trust staff. This proposal has now been pursued with monies identified to take the project forward. This initiative will be taken forward by putting together a steering group made up of Trust staff and patient representatives and will also include some input and involvement from Josephine Ocloo (as someone affected by medical harm) after the PfPS project has finished in March 2008.

Recommendations

In order to take the work forward in developing PPI in patient safety within the Trust, a number of areas of work could be considered. These relate to the need to:

- identify a range of Trust staff who could help to take this work forward in partnership with patient and user groups;
- identify clear PPI opportunities in patient safety in Trust activities;
- identify what the barriers are to involvement and how these can be tackled; and
- write a section in the PPI strategy for taking this work forward long term at the Trust.

Workshop with Staff

The staff workshop took place on March 28th 2007 and its key aim was to explore with participants what further steps might be taken within the Trust with regard to the management of risk of suicide as well as how best to respond when suicides happen. Staff were identified from each of the 5 boroughs under the Trust who were both community- and hospital-based and who had experience of dealing with the aftermath of a patient suicide, including responsibility and oversight of the process, dealing directly with family members and close friends and investigation. In total, 11 staff members attended the workshop who were ward and team managers from the Community Mental Health and Assertive Outreach Team and the Assistant Director of Nursing. The participants worked in two groups with independent facilitators and the sessions were taped and a report produced from the transcript on key issues.

Key Issues from the Workshop

a) Prevention and risk assessment

It was noted that

- staff were having to deal with patients with more severe levels of mental illness than in the past and with far more disturbed behaviour;

- there was a need to ensure that features of the physical environment could not be readily used for the purpose of suicide;
- during dangerous periods it was important to ensure suicidal patients were closely monitored, particularly with new admissions and in the early days after discharge;
- there was a need to attend to those patients or partners close to someone who had committed suicide as there could be a knock-on effect;
- there was a need to address the disparity in the attention given to patients already in the system (where procedures existed for an immediate response) and those who were not, where it was much harder to respond quickly;
- Risk Assessments (RA's) were seen as essential but it was noted that they could not always prevent suicides, but that it was important for staff not to become complacent. RA's were found to be more effective if the patient was engaged with services;
- fears of litigation were viewed as placing general pressures on staff to cover themselves even where this action was not necessary;
- some problems were found to arise when agency staff were on duty and did not know the patients, the structure of the wards or the policies and procedures.

Some Recommendations

Training and feedback

- The need for new staff to be alerted to how to recognise risk.
- The need for more help to be given to front-line administrative staff (who often took calls from distressed patients in the first instance) on how to handle these situations appropriately.
- The need for more diverse training opportunities for recognising risk factors and what can be changed and what can not.
- The need for staff to be given feedback on learning after incidents.

Procedures and documentation

- The need for caution in too rapidly discharging patients from hospital.
- The need for new staff to be prepared for carefully documenting suicide risks.
- The need for mental health risk assessments to incorporate procedures for people likely to harm themselves, but not commit suicide, as well as how to cope with a suicidal colleague.

Working closely with families

- The need to work more closely with families and other carers in dealing with suicide and for their concerns to be taken seriously, as well as educating them about risk factors.

Better liaison

- The need for better links with other agencies so that mental health teams would know if a patient had been to a hospital.

Mental health promotion

- The need for better mental health promotion in schools and in the community as a preventative exercise in getting people to look at practical coping skills in dealing with their feelings.

After a suicide:

- The need to recognise the devastating impact of a suicide on staff, who will often know the patient very well;
- The need to recognise that staff often blame themselves after a suicide because of the sense that some action on their part might have made a difference;
- The need to recognise that staff also often feared being blamed by others after a suicide, whether informally by other staff or more formally through an inquiry;
- The need to recognise that most participants had had some involvement with families after a suicide and had found this exceptionally difficult because of the high level of emotions and concerns involved. There was a concern about saying the wrong thing and a fear of litigation;
- The need to recognise that most participants felt that they or their colleagues had not been offered enough support in these situations, although the situation was seen to vary across the Trust. It was also acknowledged, however, that even if support was offered it could be difficult to take up because of work pressures and that taking time out would impact on colleagues. It was also felt that some individuals just tended to feel they should be very stoical and be able to cope, which hindered their willingness to ask for help.

Some Recommendations

Support

- More and better support should be provided for staff in the aftermath of a suicide and policies that exist for providing support should be put into practice.
- Staff also need to be encouraged to take up what support is on offer without feeling that this will compromise their colleagues.
- Continue to develop an open reporting non-punitive culture so that staff do not feel inhibited when dealing with serious patient safety incidents.

Resources and staffing

- There was a view that more resources needed to be made available generally to prevent incidents and that this meant being able to get the right staff in place with the right skills.

Training and advice

- There is a need for more training for staff on how to cope with families and other patients in the aftermath of a suicide. This needs to include things like breaking bad news to a worker close to the patient. Some participants also wanted to see more legal advice and assistance to help managers when they need to go to court.

Patient and public involvement

A further recommendation came from the PfPS project managers who sat in on the staff workshop but did not comment or get involved in the sessions. As a result of listening to the discussions it was felt that participants were not really sure how to involve patients' relatives and families after a suicide and seemed very concerned about saying something they shouldn't. This situation was seen as having implications both for implementing the NPSA's guidance on Being Open after an incident has occurred and in developing more ongoing partnerships with patients and the public in terms of their health care.

As a result of the workshop and additional observations made by the PfPS project managers, a proposal to the Trust was that they hold a follow-up workshop to explore in more detail what types of support staff needed in the aftermath of an incident and in implementing Being Open. In addition, the Trust needs to explore how strategies could be developed for gaining greater PPI after an incident and in patient safety work at the Trust.

Follow-Up Workshop

On 11 December 2007, a workshop took place with (approximately 50) senior members of staff and managers in one of the boroughs covered by Trust A to explore the issues mentioned above in more detail. The workshop organisers were particularly keen to hold the workshop in the light of a spate of suicides that had taken place in the borough and therefore the need to learn the lessons from these incidents. Josephine Ocloo from the PfPS project gave a presentation on the project's work with the Trust and Peter Mansell from the NPSA was invited to lead on a workshop with Josephine, on supporting staff following an incident and implementing the Being Open guidance.

The workshop was called 'Learning from Incidents: Supporting Staff and Improving Practice' and key presentations on the day covered:

- National and Trust Suicide Prevention Strategies;
- Suicides and Patient and Public Involvement;
- Implementing “Best Practice in Managing Risk”.

Workshops sessions which all participants attended were on:

a) Learning from incidents and implementing best practice in managing risk; and
b) How staff can be better supported following an incident and implementing the Being Open guidance.

Some key findings were:

Supporting Staff

- That different individuals will need different levels of support depending upon their relationship to a patient affected by a PSI.
- That staff need space to debrief and reflect upon their feelings after an incident, which can be facilitated in different ways, deemed most appropriate by staff involved.

- That staff should be supported through access to a psychologist/psychotherapist (which should be offered as a matter of course), through a group support or in one-to-one sessions with a supervisor.
- That staff felt they were not always properly informed on what was happening after an incident, nor were they interviewed, and therefore could not properly and appropriately support relatives.
- That staff/ teams affected by an incident were not always part of a wider investigation or root cause analysis process after an incident so did not know what was happening in relation to key outcomes and learning from the events.

Implementing Being Open

- Staff wanted to know who was responsible for implementing Being Open and exactly how open they should be. For example who should give information to families/carers, how much and what type.
- It was felt that this process needed to be clearer at team level, so that everyone knew 'who knew what' and 'who was doing/saying what'.
- It was seen as important to involve families in any root cause analysis or investigations, but there needed to be clarity on how this was done, who was doing it and for feedback to be given to the wider team.

Recommendations

After an incident, all staff involved should be:

- Offered a choice of support in order to help them cope with their feelings;
- Provided with proper opportunities for briefings about how an incident was being dealt with, who was doing what and who was responsible and what liaison was taking place with families/carers;
- Involved or informed about investigations and root cause analysis so proper learning could take place after the incident;
- Given proper guidance about implementing Being Open and who was responsible for carrying this out;
- Given proper guidance about the strategy for involving families/carers in any investigations/root cause analysis and/or giving them feedback about this process.

10) Work with Trust B

Once agreement had been reached with Trust B that they would become a pilot site for the PfPS project, a key aim with the work was to develop a plan for exploring strategies for patient and public involvement in patient safety work. The original intention was that the project work would run from October 2006 until June 2007. This was later extended because three members of the project-planning group had accepted their proposal to speak about the projects work at the eighth annual Risk and Patient Safety Conference on the 27-28 November 2007. The project work with Trust B was therefore carried out over 15 months and covered a range of activities. These included:

- ▪ Holding a launch event for staff and patients and the public to tell them about the project and to discuss how it could be taken forward.

- Setting up a small project planning group comprising of key staff members involved with patient safety and some PPI representatives.
- Josephine Ocloo speaking at the Trust's Patient Safety Conference on her personal experience of medical harm and involvement in patient safety work.
- Developing small pilot initiatives for lay involvement in each of the Trust's five workstreams linked to their Safer Patients Initiative (SPI) project.
- Organising a talk given by Peter Mansell from the NPSA for staff and PPI members on how to involve people directly affected by PSIs (Patient Safety Incidents) in safety work. This led to a commitment at the Trust to explore the possibility of building upon work carried out previously with head and neck cancer patients, in which they were encouraged to tell their stories about care received. The aim of a new project would be to involve patients affected by MRSA (a bacterial infection that is usually acquired in hospital which is difficult to treat with antibiotics) who had not been happy with or had concerns about their care and treatment.
- Holding an event aimed specifically at patients and the public to tell them about safety work at the Trust and to explore how they could and might want to be involved. A follow-up event was subsequently held to look at the patient safety context and key risks in more detail and to identify any barriers to PPI and how these could be dealt with.
- Submitting a proposal to speak at a conference on 'Risk and Patient Safety' in November 2007 to disseminate the project's findings.

These activities raised a number of issues throughout the life of the project, which are discussed further in the section below.

The Launch Event

The launch was held at the Trust on 24 October 2006. The aim was to bring together key staff members and patients/patient representatives to tell them about the project goals and to discuss ways in which patient and public involvement in patient safety work could be engendered within the Trust. Originally, it was envisaged that the event would have roughly even numbers of staff and patients participating, in order to develop a partnership approach to the work. In practice however, the event was dominated by staff members (13) compared to PPI member's (3). Notwithstanding this situation, the discussions at the event were positive and wide-ranging and demonstrated a strong willingness from all participants to take the PPI agenda in patient safety work forward.

Overall the workshop was divided into two parts. The first part consisted of a fairly open-ended discussion about a range of issues to do with involving patients in patient safety work and the second part of the workshop looked at how the project work could be taken forward at the Trust.

Issues from part one:

First of all there was some discussion about where the current PPI strands of work were located in the Trust. Some of the work strands identified were through PALS, the PPI Representative Group, and the PPI Forum, through the Trusts Foundation Trust membership and governors and with engagement with the local community. Through these strands, patients were involved in developing new services, sitting on various internal committees, participating in the National Patient Survey Programme for the

Healthcare Commission, Discovery Interviews (e.g. finding out about the patients' experience of care pathways) and gaining the patients' perspectives in ward and departmental reviews.

It was acknowledged, however, that there was little active involvement of patients in patient safety work and therefore this strand needed to be developed. Some key questions to emerge about PPI in patient safety were:

- Can patients be more involved in recognising and identifying problems and alerting staff?
- What is the evidence for patient involvement in improving patient safety? (It was noted that there was some evidence on the Clinical Governance Support Team (CGST) website.)
- Could the cancer head and neck co-design work be transferred to other areas and to patient safety work and did this process empower these patients?
- How could patients who have experienced an adverse event at the Trust be more involved?

Further key points from the discussion were about the need to:

- ➢ provide a protected environment to enable patients to talk.
- ➢ have meetings for patients and staff to discuss experiences.
- ➢ build upon the good practice model from the Confidential Experience Forum given to patients in the maternity service.
- ➢ explore if this type of forum could be used on the general ward environment in order to obtain feedback from patients?
- ➢ set the scene at the first appointment with the clinician i.e. for the doctor to invite/encourage the patient to inform him/her/staff if they have any problems.
- ➢ provide information to patients asking them to inform the hospital about their experiences (good or bad).
- ➢ provide information on patient safety that would go out with patient admissions information.
- ➢ share the Patients' Rights Information but also being aware that the giving of these rights did not mean that patients were empowered to use them.
- ➢ recognise the need for staff to be empowered to report mistakes.

These points naturally seemed to lead on to a wider discussion about patient empowerment. This discussion raised a number of interesting questions at the outset and noted that a model needed to be adopted to include empowering patients, addressing any imbalances of power between patients and staff and looking at what this meant in the context of partnership. It was felt that a patient empowerment model also needed to include the concept of empowering staff as well.

A key issue raised was about the way that patients could be made passive and disempowered in their own care by simply coming into hospital as a patient. Examples given included the way that a patient's medication could be taken away, despite the patient being competent in self-administration. This could have the effect of disempowering that person and making worse their current medicine's management routine. Another example was that patients could find it very difficult to challenge staff about washing their hands, unless they were actively given permission to do so. This could be because they were afraid of antagonising staff and/or could also be from groups who were not used to challenging or speaking out. The latter point meant that the project needed to be aware of the needs of different groups and how power and discrimination could jeopardise patient safety. It was therefore seen as very important to empower patients to be actively involved in their own care and treatment, for example agreeing and signing off care plans with staff, giving patients information before and when they are in hospital and looking at different ways and types of communication.

Some of the issues that came up about empowerment in relation to staff were focussed on how it could be difficult for staff from professional groups to challenge others or for junior staff to challenge more senior ones. This could be an issue for example in trying to achieve compliance with hand hygiene. Other issues focussed on training staff to empower patients, empowering staff to talk to patients and giving staff enough time to spend on direct patient care.

A note of caution expressed about an empowerment model and key questions asked were whether the organisation could cope with the empowerment of patients? And, whether empowering patients meant more or less work for staff?

The second part of the workshop focussed on the practical aspects of developing the project idea. This meant exploring how patient and public involvement could be achieved through the Trust's main patient safety programme the Safer Patients Initiative (SPI) and its five workstreams in: Medicines Management; General Ward Care part of which included infection; prevention and control; peri-operative care; critical care; and Leadership walkabouts. As well, how could wider strategies be developed at the Trust, for achieving patient and public involvement in patient safety work?

The workshop therefore agreed to:

- set up a project-planning group to take the work forward.
- identify a wider group of patients and the public to be involved in patient safety activities.
- give some thought to identifying patients affected by a patient safety incident (PSI) with a view to involving them in the work.
- consider what training could take place with staff and patients in developing an empowerment model for PPI in patient safety work.

Learning:

One key point of learning from this event was the recognition that PPI in healthcare generally does not necessarily mean that individuals are involved in patient safety and that a different strategy may be required to achieve this involvement. Identifying the issue of empowerment was also important and the recognition that to involve patients and the public in healthcare they may need particular types of help and support to be properly involved. It was also important to recognise how staff need to be empowered in this process as well.

Recommendation

Overall consideration needs to be given to what empowerment means in practice and how it can be achieved in different ways and on different levels, depending on the groups of people involved.

The Project Planning Group

A project-planning group was therefore set up to give strategic direction to the project. It was agreed that the project would be directly managed jointly by a senior member of the Trust staff and a manager from the PfPS project. Other individuals who were then invited to join the group were key Trust staff who headed up the different Safer Patients Initiative workstreams as well as other staff members involved in patient safety work, such as the Risk manager and the PALS (Patient Advice Liaison Services) manager. In addition, the Chair of the Trust's Patient and Public Involvement Forum (and patient representative group member) was invited to be part of the group as a patient representative.

Later on however, as a result of the issue being raised of an imbalance between the numbers of staff and patients and how this might be affecting the discussions, it was agreed that two further patient representatives would be invited to join the planning group.

Learning:

In terms of learning for the future, the experiences in the project planning group highlight the importance of trying to get a balance between lay and health professional views when developing a partnership approach to involvement. In trying to achieve this balance thought also needs to be given to what the issues are in terms of gaining diverse representation. This will clearly vary given the circumstances of the work being undertaken, but will range on the one hand from giving thought to representation on the grounds of race, disability, gender etc, to, on the other hand, exploring whether individuals or groups need to be specifically targeted, such as those who have been affected by patient safety incidents or who have had other particular healthcare experiences.

Some issues to take into account in developing a partnership model in this respect will be:

- tackling barriers to participation;
- issues of power and discrimination;
- issues of support in enabling involvement.

The Safer Patients Initiative

The Safer Patients Initiative (SPI) was being carried out in partnership with the Health Foundation and the Institute of Healthcare Improvement (USA) at the Trust. The initiative aimed to develop a patient safety culture by addressing five workstreams: Leadership; Medicines Management; Critical Care, General Wards, and Peri-Operative Care. The Trust aimed to reduce adverse events by 50% through concentration on elements within each of the workstreams e.g. the prevention of ventilator-acquired pneumonia as part of critical care or ‘on time’ antibiotics at the point of surgery. Other organisations and Trusts participating in the Safer Patients Initiative also shared these objectives. Alongside the SPI work, the Trust had been working to reduce its Hospital Standardised Mortality Ratio (HSMR) which was 111 in 2003 and had currently fallen to around 90 each quarter. The Trust had also been successful in reducing Clostridium Difficile (a bacteria causing antibiotic-associated diarrhoea) cases from around 40 per month in 2007, to no more than 12 per month in 2008.

In relation to the PfPS project work, each workstream lead was therefore encouraged to think about how patients could be involved in that area of work. Falls were added to the list of five workstreams as an aspect of general ward work and because falls were commonly reported on incident forms.

It was therefore decided that:

- The critical care workstream would seek to get families involved in an aspect of the care bundle to avoid ventilator-acquired pneumonia.
- The peri-operative workstream would deliver a questionnaire to patients and begin to change the culture of surgical patients as passive recipients of theatre services.
- The falls nurse specialist would devise a way of working more closely with hospitalised patients and their families.
- The medicines management workstream would revisit patient self-administration of medicines as patient representatives cited staff administration of regular long-term medicines as disempowering.
- Patients would be asked for their views during leadership walkarounds.

Later it was also decided to add work in relation to patients and staff being able to question and challenge each other about compliance with hand hygiene procedures.

Success in relation to work on each workstream was variable and sometimes limited.

- The falls nurse specialist successfully developed a partnership way of working to involve patients and their families in keeping those at risk of falling safer while in hospital through discussion, advice and information.

- The critical care team tested involving families in monitoring the angle of the patients head in relation to his chest as one aspect of the care bundle to prevent ventilator-acquired pneumonia but struggled with this at times when there were other concerns with relatives. Relatives also admitted that if the patient should subsequently acquire pneumonia and they had witnessed that the patient had not been consistently nursed at a 30 degree angle they would relate this to that one factor, not appreciating that there were other factors involved. Staff felt it was still possible to involve relatives in this way but that it would need to be made clear each time that positioning was one of a number of measures used in combination to make ventilator-acquired pneumonia much less likely.

- Self-administration of medicines was explored in some depth, examining the literature, visiting other sites, counting the number of patients in a care area who would meet the criteria set for self-administration, assessing the time required and assessing the safety of self-administration in an acute hospital setting. However, it was found that only one or two patients a month, at most, in a ward would be eligible for self-administration of their medicines. It was also found that most other hospitals, although keen on doing this ten years ago, had stopped as patient acuity had risen and self-administration was no longer viable.

- In relation to leadership walkabouts, two or three patients were asked each time for their views during rounds. In terms of their response it was found that they generally had little or nothing to report and did not seem aware when asked of patient safety concerns. Those doing the leadership walkabouts have continued with the practice of asking patients their views and will see if these views change over time so that they can be incorporated into the learning process.

- The peri-operative workstream delivered their questionnaire to patients who attended frequently for day surgery and found that their main concerns were related to the environment e.g. too cold at times in the waiting area. They created a patient safety display in the waiting area and began to draw patients' attention to this and to discuss the content with them.

Learning:

Trust staff learned that the patient views on the walkabouts seemed to corroborate other evidence discussed later from the workshops, that patients may be generally unaware of safety concerns and risks within hospitals. This provides important information in thinking about raising awareness more generally with patients and the public around patient safety issues.

The Trust also learned that a multi-faceted approach needs to be taken to develop patient and public involvement in patient safety, seeking to involve people individually in their own care, in project work and at a more strategic level in the Trust. It was recognised that stimulating involvement clearly takes time as relationships build and some trust develops and that once involvement is started it needs to be maintained.

With regards to the SPI workstreams, it was recognised in Trust B that this work tended to concentrate on building the culture but also on the technical aspects of adverse event prevention. Therefore it was noted that this may well have been why it was so difficult to get patients and families involved in the workstreams themselves as originally envisaged at the launch event.

The staff team also learned that they might be putting a burden on families in trying to gain involvement in some patient safety areas such as monitoring aspects of critical care.

Involving those with a Poor Healthcare Experience

The specific issue of involving those affected by a patient safety incident was an important area that the planning team wanted to consider given the overall remit of the project. In order to take this forward a number of avenues were explored.

This included first of all trying to identify what some of the issues were for those with poor experiences by looking at some of the data within the Trust. This led to a couple of team members searching the database of patient complaints to find any related to the identified SPI workstreams. However, there were surprisingly few complaints that could be linked directly to the workstreams. Complaints commonly focused on aspects of communication and omission in personal care. Some thought was also given to searching the risk adverse event database but it was not possible to search using the same key words. It was recognised that falls made up a large proportion of reported incidents.

The project team then decided to look at the idea of writing to some patients identified through the complaints/PALS audit who had made a complaint, in order to explore whether these individuals might be interested in becoming further involved in Trust activities. In the discussion about how to take this piece of work forward, different perspectives emerged from staff and lay representatives. On the one hand, Josephine Ocloo (the PfPS project manager) felt that before an attempt could be made to involve those with poor experiences of the Trust's services it was important to allow them first to be given an opportunity to talk about their experiences and to feel listened to. It was felt that this could be done by inviting individuals to attend a workshop with a view to not only learning about these patients experiences but also through this approach attempting to build trust. It was felt that this was important to do before moving on to ask for something from these patients in terms of PPI, which might be particularly sensitive if they still had unresolved issues with the Trust.

This suggestion, however, seemed to provoke some discomfort amongst Trust staff, although there was never any in-depth discussion about what these feelings were about. Some of the reservations put forward related to the specific purpose of conducting this type of activity and the difficulties of how it could be achieved. The discussion also generated further views about how patients were already involved in Trust work and what systems were in place around this and whether any new systems were needed. Ultimately the planning group were not able to agree on taking a decision to move forward with a workshop. They did, however, also agree that simply writing a letter to those who had made a complaint, without being able to spell out what PPI opportunities were available in the Trust and how they could be accessed, was not appropriate.

It was therefore decided that one way to move forward was to start by asking people who already had some contact with the hospital, such as governors and volunteers, for some help with ideas about involvement in patient safety. The planning group also accepted Josephine's suggestion to invite Peter Mansell, Director of Patient Experience at the NPSA to come and talk to the Trust about his experiences and approach of holding workshops with those affected by different types of patient safety incidents.

Meeting with Peter Mansell (NPSA)

A meeting with Peter Mansell was organised and took place at the Trust on 23 March 2007. This meeting was well attended by both staff and patients/patient representatives, leading to a lively debate about involving those affected by medical harm. What eventually became clear was that the model being used by Peter Mansell to involve patients with poor experiences of healthcare was not dissimilar to the model of Experience Based Co-Design tested out at the Trust with patients and staff in head and neck cancer services. It was acknowledged in discussing the similarities, however, that this model had only been used with cancer patients who had generally not complained about their healthcare.

Some of the key points to emerge from the meeting are set out below concerning the model being used by the NPSA to work with those affected by medical harm.

Key Components of workshop model:

- ☐ To not put patients and staff together too soon in the process;
- ☐ That it was advisable to bring together a mixture of patients from different Trusts and to have a workshop off the Trust site;
- ☐ In organising a workshop, to identify Trust areas where harm is most likely to occur to patients and then to select/profile patients according to these areas;
- ☐ To draw upon the voluntary/community sector to identify patients from diverse groups;
- ☐ That staff attending these type of workshops are there to listen only and not to defend the Trust;
- ☐ The focus of the workshop is on learning rather than on accountability, although this does not preclude patients from fully expressing what they think went wrong;
- ☐ Independent facilitators are used;
- ☐ Permission letters from patients allow them to indicate if they would like further involvement;
- ☐ Learning from the workshops to be shared more broadly with Trust staff to see if the stories resonate and to allow for reframing and clarification of the problem(s).

In talking about this model Peter Mansell made the important points that working with those who have suffered harm, genuinely hearing their stories, and using the information to improve patient safety, can lead to those individuals becoming great allies. He also noted that whilst the nature of this type of engagement could be messy, in terms of emotional cost, it was very worth doing, because of the increased levels of trust gained by patients and their families in the organisation.

After reflecting upon the learning to come out of this meeting, the planning group decided to proceed in two ways. Firstly, the group would explore how a project could be taken forward within the Trust aimed at working with patients who had been affected by MRSA. Secondly, the group would hold a workshop with patient and public representatives with whom the Trust already had a relationship in order to explore involvement in patient safety. The focus of this workshop was to be aimed mainly at governors and volunteers, as well as existing Forum members. Later on, it was also decided to hold a second workshop with these individuals to build upon the issues from the first workshop.

Learning:

What was useful about the work in this area was that although it was not possible within the life of the project to actually engage in some work with those affected by medical harm, it was possible to open up a wider debate about this area. This debate has been important in bringing out into the open a number of issues. For example:

- The importance of engaging with those affected by harm when building a patient safety culture.
- The way that these patients can be excluded because an organisation is uncomfortable in working with them.

- The need to develop proper strategies for involvement in this area which are likely to be different from those used to engage with patients who have had positive experiences of healthcare.

Some questions that might be useful to consider in developing this work in the future are:

- How comfortable are health professionals in working with those who have had poor rather than good healthcare experiences, have been affected by a patient safety incident and/or have made a complaint or taken legal action?
- What are the fears and other barriers preventing work in this area?
- How can these barriers be addressed?
- How can models that are currently being used in the organisation be adapted for work with different groups of patients?

Project with Those Affected by MRSA

For the future, the Trust has made a commitment to take this work forward by undertaking a piece of work that incorporates the shared principles of experience based co-design and workshops with those affected by harm, as described above. This will involve interviewing both staff and patients to understand their experiences of MRSA and then facilitating the two groups to work together to improve care delivery and reduce harm.

The Workshops with Patient Governors

Workshop One

This workshop took place on 15 March 2007 and the key aims were:

- to explore the types of patient safety issues important to patients and patient representative, and,
- to explore how to get more patient/public involvement in patient safety work.

Key activities in the workshop involved clarifying definitions regarding patient safety and giving out key information on building a patient safety culture, such as the NPSA's 'Seven Steps for Patient Safety'. The workshop also explored questions such as a) what a patient coming into hospital would want from staff and the organisation to feel safe, b) How patients could be assisted to feel comfortable in challenging staff about hand hygiene and c) how patients and the public could be encouraged to get more involved in patient safety work.

Some of the responses in the workshop to the questions above were:

A) Expectations from staff:

- ❑ To ensure there is good communication with patients ('explain/communicate keep us informed');

- To have good organisational procedures that work properly concerning arrival of patients and discharge, quick assessment and problem identification and good history taking;
- To ensure compliance with both small rules as well as the bigger ones.

Expectations from the organisation:

- To have a culture of safety;
- To have ongoing testing of procedures to make sure they work;
- To have all parts of the organisation communicate and work together systematically rather than to have areas/departments working in isolation;
- To have a partnership approach with patients;
- To have enough qualified staff and to ensure they are properly supported.

B) Hand hygiene and challenging staff

In this area it was noted that:

- It is not easy for most patients to challenge staff;
- Patients do not have the confidence to challenge;
- There is a fear of intimidation or of being branded troublemakers.

Some expectations from staff were:

- To make patients feel comfortable about challenging by telling them they welcome feedback;
- To develop a partnership approach and dialogue between patients, families and staff, thereby encouraging families to be part of the safety agenda;
- To reassure patients there will be no adverse comeback if they raise an issue;
- To give patients appropriate information about the safety risks.

C) Some suggestions from participants for involving patient and the public were:

- To give information on safety to patients in different ways, through posters and leaflets, public meetings and other events and to develop a patient safety checklist;
- To encourage individual patient involvement through the keeping of patient diaries, dialogue with families/carers taking into account the diverse needs of patient groups, building patient involvement into care plans, asking for feedback from patients; involvement in specific projects in relation to stroke, cancer etc;
- More strategic PPI activities could relate to involvement in clinical governance, observations carried out on wards to identify safety issues, and involvement in staff training.

The workshop did not have the time to look at barriers to patient involvement and the Trust were not able to say at that point, in any detail, what they saw as key opportunities for PPI in patient safety work. Some of the above mentioned opportunities such as diary keeping had previously been used by the Trust and been identified in workstreams and committees; however, the workshop suggested PPI opportunities in patient safety work needed to be spelled out more clearly and in more detail.

Learning

Overall some key learning from the workshop to emerge was that patients and the public have not been properly involved in the patient safety debate. This meant that they were often not aware of the risks involved in healthcare, or might be relying on small bits of information gleaned from the media, which might not be entirely accurate or complete. The perception at the workshop was that being suddenly exposed to this information could come as quite a shock to patients and the public. Therefore, that there was a need to open up a wider debate in which PPI representatives could be given apt information and allowed to become better informed about the broader safety context. In developing this approach the workshop also highlighted the need to look at strategies for how individual patients and their families could be involved in making their own healthcare safer and in contributing more generally to building a wider safer culture of care within the NHS.

Two further matters to come out of the workshop were that the Trust needed to be able to spell out more specifically what the opportunities were for patient and public involvement in patient safety and that the Trust needed to look at how they could work with patients to identify the barriers to involvement and how these could be addressed.

In order to move forward with these matters, a second workshop was held with the same constituency of patient and public representatives on 11 June 2007, as well as extending an invite to any other PPI members identified as having an interest.

Workshop Two

The key aim of the workshop was to build on the learning from the previous workshop by focussing on:

- enabling participants to understand key risk factors at the Trust in terms of patient safety; and
- trying to identify any barriers to PPI and how these could be addressed.

About 10 governors of the Trust and patient representatives attended the workshop. A number of these participants had attended the first workshop, but not all. The first hour of the workshop was spent looking at the patient safety context nationally and key risks within the Trust. This information was received with interest and led to a very lively debate. Like the previous workshop what was noticeable was the way that participants reacted to the information about the risks at the Trust. Participants were very keen to have more details about the issues and to offer suggestions and solutions, as well as criticisms. What seems important to remember for the future is that patients and the public are keen to engage in the safety debate, but need to be given proper information so that they can engage with the issues in a well informed manner that takes into consideration some of the wider thinking about how errors and risks occur in a modern context in healthcare.

The second hour of the workshop had been set aside to give participants an opportunity to work in small groups to explore opportunities for PPI in patient safety and to look at any barriers to involvement and how these might be addressed. However, whilst some action points emerged concerning involvement in the patient safety context, participants focussed mainly on raising a number of issues more generally about barriers to PPI at the Trust. Most of the participants felt that these issues needed to be addressed before they could consider further involvement in other areas such as patient safety.

Some of the issues/points made in the workshop are summarised below and have been grouped into three main areas: developing patient and public involvement more generally, committees and communication, jargon and language.

Developing PPI more generally

- For the Trust to reinforce their commitment to PPI more generally.
- A need to develop a partnership approach with PPI members in which members feel properly listened to and supported.
- The danger of tokenism and the importance of ensuring that PPI members feel their input/contributions are valued by the Trust.
- Developing an inclusive approach.

Committees

- The need to identify what committees exist in the Trust and their role/function.
- A need to spell out the role of PPI members on committees and how they can participate, including the time commitment and the knowledge/background required of PPI members.
- The problem of inaccessible meeting places at difficult times.
- To address the question if PPI members become part of these committees about what guarantees exist for ensuring follow through on issues raised by PPI members and of their being able to make a difference.
- The need for PPI members to receive feedback from the Trust about initiatives being put in place or changes made as a result of their input and contributions.

Communication, jargon and language

- The need to ensure patients can make their points and are listened to.
- For communication to be two way and more of a partnership.
- To ensure that language is not a barrier because of someone's ethnic background or because of the culture of the organisation.
- It was noted apathy might exist from lay members because they lack appropriate knowledge of the issues.

As a result of the feedback from the workshop and after discussion amongst planning group members, it was decided that a letter should be sent to workshop participants thanking them for their contribution and comments. The letter also set out what action would be taken as a result of the feedback. These actions were, firstly, that the PfPS project team would be devising a framework to enable patient representatives and governors to understand the patient safety agenda at the Trust better. This would include identifying the key committees in the Trust with a patient safety component and looking at how patient representatives could become more involved in them. Secondly, some guidelines would be produced for chairs of committees for inducting, communicating with and supporting patients and members of the public when involved in those committees (see Appendix 2 of the report for these guidelines). In developing the guidelines, the intention was also to look at issues of communication and use of language and terminology and how these impacted upon lay representatives. The letter confirmed that when this work was completed workshop participants would be informed of the outcomes.

Learning

Overall conducting the workshop provided important opportunities to build upon the learning from the first workshop. This related firstly to the importance of giving patients and the public strategic information about the patient safety context and key risks and finding ways to continually involve them in the patient safety debate. The workshop also highlighted important issues about the sorts of barriers that patients and the public can face in trying to get involved in Trust activities and how they can be disempowered. This suggests that more ways need to be found in the future to develop partnership approaches to involvement and how patients and the public at both an individual level and in working strategically can be empowered. The workshop also highlighted the need for more thought to be given to what the PPI opportunities are in patient safety at the Trust and how these opportunities apply at the different levels of involvement identified below, in discussing the review of the Trust's PPI strategy.

Reviewing the Trusts PPI Strategy

Given the project’s focus on PPI in patient safety, it was agreed that there was a need to review the Trust's PPI strategy. This was seen as important because although there was PPI in Trust work more generally, this was not the case in patient safety, which it was acknowledged might need a different strategy. Building upon the learning from the project work, three main streams emerged for involving patients and the public in patient safety as set out below:

- ☐ The need to raise awareness generally amongst patients and the public about patient safety and risks through the distribution of key information. This could be done for example through the distribution of leaflets, putting up posters, through website information and through events targeting patients and the public;

- ☐ The need to involve individual patients in their own care by giving them information and providing opportunities for them to take action or be involved in safety related activities;

- ☐ The need to involve patients and the public in strategic Trust patient safety, clinical governance and risk committees;

- The need to work with specific community and voluntary organisations that have a focus on health or with organisations who work with specific communities of interest, to make these groups more aware of safety issues in healthcare and how they can become involved.

It was agreed that these streams should form the basis for involving patients and the public in different ways in patient safety. It was also noted that it would be useful for the strategy to set out the PPI opportunities at the Trust in patient safety and how these can be regularly communicated more widely.

Additions to Project Plan

During the lifetime of the project several other initiatives started to develop. For example, the Trust considered how the website for staff and the public was used and is developing, with patients, information to help people to know about patient safety work in the Trust and how they can help to keep themselves safe. A video is being produced to show both on the website and in other situations, the importance of patient safety.

The Trust also held a Public Seminar on Patient Safety in October 2007 with 90 attendees. This was widely advertised. Those who attended were told about the Patient Safety Initiative work at the Trust and had opportunities to ask questions although there were fewer questions than in smaller workshops held as part of the PfPS project work.

Patients have also been involved in some other areas such as outpatients and in audits of staff hand hygiene compliance. In relation to the latter issue, it became evident in the project work that one of the ways that patients could become more involved in patient safety, was through training staff not to react negatively if a patient raised an issue about hand washing. This was seen as important in then enabling patients to be encouraged to feel able to raise any concerns in this area without fear of any negative comeback.

In order to take this forward, a small sub group of staff and patients, including staff from training and development and from an elderly care ward was set up. They met and designed a customer care/communications training session to be used on the ward with a range of staff. The training focused on a scenario where a patient was uncomfortable that a staff member had not washed their hands and challenged them. Staff were shown ways to deal with this positively and also to think about how they might approach colleagues to raise concerns about hand washing or similar matters.

Feedback from the Risk and Patient Safety Conference 2007

The feedback from the Risk and Patient Safety conference 2007 (mentioned earlier) was very positive. The three members involved in the presentation found that other conference participants were very keen on hearing about the practical issues involved in getting PPI in patient safety work, as they were struggling with similar issues. The presentation was well received, as it was the only presentation related to PPI work in patient safety and which involved patient representatives directly. This suggests that more presentations of this type are needed in the future to open up more of a dialogue about developing this aspect of patient safety.

Way Forward

In concluding the project's work at Trust B, a final report was written up in partnership with the Trust on key areas of learning and developing the area of PPI in patient safety in Trust work in the future.

These areas are set out below.

1) In considering its approach to PPI in Trust work, ongoing consideration needs to be given to how PPI in patient safety can specifically be embedded in all aspects of the Trust's work and service provision. The project’s work has shown that whilst PPI activities are taking place in a range of different areas in the Trust's work, this has not necessarily been the case in relation to patient safety activities. In order to address this situation the PPI opportunities in patient safety should be spelled out more clearly.

2) In order to further support PPI in patient safety work, the Trust should continue to take a range of measures such as giving patients and the public more specific information about the patient safety context at the Trust and how to avoid key risks in their healthcare. Different ways should be explored for communicating this information. Other ways should also be explored for empowering patients to be more involved in their healthcare such as through the work taking place on empowering patients to challenge poor practice around hand hygiene or to get involved more strategically through committees related to all aspects of the patient safety agenda.

3) Further consideration needs to be given to what empowerment means for patients and staff in building a partnership approach in patient safety and in healthcare generally. The project identified a number of issues about empowerment. These relate to how patients are made more passive when they come into hospital, how they can lack the confidence or feel too intimidated to raise concerns or to challenge poor practice and how various barriers in relation to communication and in committees can inhibit and prevent PPI more generally. Further thought also needs to be given to how staff can be empowered to support and assist patients.

4) A key area that needs to be looked at further is how those with poor experiences of care and/or who have made a complaint or experienced a patient safety incident can be given the opportunities to feed their concerns and experiences into the Trust's learning processes. These patients may also belong to groups who have particular needs in terms of empowerment and who may be able to play a particularly useful role in enabling the Trust to look at what could be done differently in terms of providing safer healthcare. Proper consideration also needs to be given to tackling the fears and barriers that are preventing this work from happening in the first place.

5) Further consideration should be given to how PPI can be achieved in the Trust's SPI programme, as this area of patient safety work did not seem to produce the opportunities for PPI that should have been more possible to develop.

6) In moving the PPI agenda in patient safety forward it would be useful for the Trust to identify what next steps can be taken which should be set out in an action plan. This plan should focus on the learning from each activity strand in this report and identify next steps for service improvement work at different levels within the Trust.

Key Actions

When the planning team met on 20 December 2007, they agreed that some key action points should be identified in order to take the project work forward now that the project had formally come to an end.

These are summarised below as falling under four headings:

1) To continue to give information to patients and the public about patient safety matters and to feed this back to patients through a variety of methods and media (website, patient information booklet, seminars and workshops, newsletters, meetings etc). A particular challenge will be to find ways to convey information to patients and the public in a sensitive way about the key risks that they face when coming into hospital care.

2. To promote and develop PPI in key Committees (including the new patient experience committee) with a patient safety remit. This will include inviting a PPI representative to sit on the Trust Risk Committee. This committee work will also be used as an opportunity to test out the guidelines produced from the workshop with governors about tackling barriers to involvement, with the findings fed back to those attending the workshop.

3. To continue service improvement work which involves patients and in particular to take forward the project work mentioned earlier with patients affected by MRSA.

4. To empower staff to continue service improvements through training initiatives such as the programme to empower patients to raise issues with staff about their hand hygiene.

Further examples of the way that the Trust is continuing to develop its work in this area are also set out in the appendix.

11) Work with other Trusts

The original intention with the project's work was to have four Trusts as ‘pilot sites’ – an acute Trust, a Primary Care Trust (PCT), a mental health Trust, and an ambulance Trust. Therefore in addition to the work carried out with the Trusts mentioned above, contact was also made with two other NHS Trusts during the latter half of 2006 and quite a bit of work was done over several months. These involved meetings with key individuals involved in patient safety and risk management, the production of papers on how PPI in patient safety could be developed and liaison with the Patients’ Forum for one of the Trusts. For various reasons, eventually the PfPS project team felt that it would not be possible to take forward the work with these sites. However the proposals developed about possible ways of developing PPI in these Trusts, provide some interesting suggestions for how work could be developed in this area in the future as mentioned briefly below.

Trust C

The proposal for work with this Trust was to mainstream throughout the Trust the NPSA's Being Open Guidance and to link this with reforming the Trust's Complaints Procedure. Strategies proposed for achieving this work included:

- Taking a “whole systems” approach in which complaints investigation, outcomes analysis and risk analysis were examined as components of a single system;
- Getting user involvement in the Being Open implementation team and in examining the process and outcomes of the team's work;
- Carrying out interviews or running a focus group with patients who had made a complaint to gain their views on the workings of the Trust's complaints system.

Whilst this work did not proceed for various reasons, the project managers did note that there did appear to be some fears with this Trust in working directly with individuals who had made a complaint and in engaging them in terms of wider user involvement.

Trust D

With this Trust there was an initial interest in looking at the implementation of the NPSA's Being Open Policy and how this was being implemented in GP surgeries. This area was seen as particularly interesting in terms of being able to ascertain what the position was in terms of telling patients about patient safety incidents when they occurred. However, it was also acknowledged by this PCT that GPs were independent contractors of healthcare, and there was therefore evidence that they were not implementing Being Open and that the PCT were not able to enforce compliance.

With this PCT there was also an interest in carrying out a small piece of research with patients with long- term conditions, who were deemed most at risk of readmission to hospital. This proposal involved the suggestion of working with Community Matrons around the 'Virtual Ward' programme, where the objective was to enable patients to manage their conditions effectively at home, thus reducing the risk of acute exacerbations and minimising the need for readmission to hospital. The aim of the research was to gather data via the Community Matrons from patients in the Virtual Wards about what the key issues were in relation to managing their condition and any safety concerns. For example, the PCT explored whether individuals had experienced a patient safety incident (PSI), why this had happened and whether it had been reported and whether patients understood key medical information given to them about their care and medicine's management. The information would then be used to explore how patients could be empowered to better self-manage their care and to ensure that the occurrence of PSIs and adverse drug reactions were less likely or could be picked up more easily if they occurred.

Unfortunately this proposal was not able to be taken forward for various reasons to do with the organisation having more pressing priorities to deal with and some issues to do with resources and availability of staff time.

Conclusion

Overall the project has been very well received by various stakeholders and has provided valuable learning that has been disseminated in a range of ways. By informing the implementation of recommendation 13 in *Safety First* and through publishing the projects findings at conferences aimed at both NHS professionals and patients and in the journal Health Care Risk Report.

The partnership approach between the NPSA and AvMA - an independent patients' charity - has worked well and, we believe this has helped the project have credibility by practising what it preaches. This has also meant that the project has been able to draw on each organisation's knowledge and expertise and existing relationships. The two Trusts that agreed to become involved in the project as 'pilot sites' have also shown considerable commitment from management and key staff in allowing the PfPS project to see their work from within, including some quite sensitive issues. We are very grateful for their co-operation.

In spite of adding a substantial additional objective of working with local NHS Trusts as 'pilot sites', the project has achieved the objectives and targets set out in the contract and paved the way for innovative new work in patient safety. This work arises out of the publication of *Safety First* and particularly its recommendation 13 which calls for the development of a national network of 'patient safety champions'.

The Future

Following a competitive tendering exercise, the NPSA have appointed AvMA to manage the Patients for Patient Safety project covering England and Wales from April 2008. As mentioned above, the new project specifically addresses recommendation 13 of *Safety First.* Planning for the new project has benefited from being able to draw directly on the learning from the pilot project due to the close involvement of the NPSA and AvMA staff and network members involved in the pilot. The pilot project culminated in a partnership event for NHS staff and patients and the public in Birmingham on 18 March 2008 (see summary in Appendix 3) which also served as the platform to launch the new project and the call for 'patient safety champions'. The first 22 'champions' will attend a residential induction workshop in May leading up to the Patient Safety Congress in London, where the network of patient safety champions will be launched. Anna Allford has been appointed project manager, based with AvMA.

Key Findings and Recommendations

Overall, from the project's findings, a number of key themes have emerged about the issues associated with achieving patient and public involvement in the emergent patient safety agenda in the NHS. These themes and some recommendations for the future are set out below.

A) Current Patient and Public Involvement in Patient Safety

The findings from the project suggest that patients and the public are willing to work in partnership with NHS organisations in patient safety work but face substantial barriers in getting involved. Patients and the public working with the project were motivated by various reasons for wanting to get involved with the patient safety agenda. Key factors related to having had a personal experience of medical harm or experiencing its impact on a family member, or wanting to make the NHS function better and to see it operating more generally from a more patient-centred perspective. However, despite this willingness to become involved, evidence from the NHS Trusts the project had contact with and from PPI members in the Patient Safety Network, suggested that NHS Trusts were struggling to achieve PPI in the patient safety agenda. Evidence from the project suggested that NHS Trusts had made progress in gaining PPI in Trust activities more generally, but this did not necessarily appear to be the case in relation to more patient safety focussed activities and areas.

There also seemed to be a number of fears related to this type of patient engagement as well as a lack of knowledge and strategies for achieving it. Particular fears in this area related to working with those individuals who had had poor experiences of healthcare and who had made complaints and/or been affected by a patient safety incident. There also appeared to be considerable resistance to involving PPI members in more strategic areas of patient safety on boards and on clinical governance or risk committees.

Recommendation:

More work needs to be done to develop different strategies for involving patients and the public and particularly those affected by harm, in the patient safety agenda. These strategies should enable Trusts to find ways to involve and engage patients and the public on both an individual and strategic level.

B) Patient and Public Perspectives on Patient Safety

Patients and the public who became involved in the project's patient safety network did not make the same distinctions between ‘improvement’ and ‘accountability’, when talking about patient safety as different parts of the NHS does in practice. Individuals often drawing upon their personal experiences of harm were as concerned with issues of justice and accountability as they were with preventing and learning from patient safety incidents. This meant that they wanted to actively have a role in holding organisations to account and not just to be involved from a distance or in a tokenistic way or simply to be asked to comment on policy documents. PPI members talked about their work as Patient Forum and input into the Annual Health Check and expressed an interest in checking that systems, policies and procedures, including those that deal with patient safety incidents that have occurred, were robust and fair. For example, there was considerable interest in the *Being Open* policy and how network members could ensure it is taken up appropriately by the NHS organisations they work with.

Recommendation:

It is therefore recommended that any new arrangements for involving patients and the public in patient safety work allow individuals to be involved in the whole range of work connected to patient safety, both in relation to improvement, learning and the regulation of standards and medical performance.

C) Barriers to Patient and Public involvement in Patient Safety

Overall the issue of partnership has been an interesting area to look at within the project and a number of issues in this area have been observed.

Evidence from the pilot Trust sites and in speaking to patient representatives has highlighted that there is an unequal balance of power between NHS staff and patients and the public that often appears to be not well understood. These issues were reflected in various ways in the project. Two examples were a) the way in which patients could be made passive in the healthcare relationship through having their medicine routine disrupted when they came into hospital, or b) not feeling able to raise an issue about hand hygiene with staff, out of fear the concern would be treated negatively. Patients might also not be given important information about risks and safety in a hospital, or worse find themselves affected by serious PSIs, where the consequences were made even worse by the way individuals were treated after the incident. This treatment could occur regardless of whether individuals had made a complaint or taken other action against a Trust or health professional. Some of these issues about power and inequality also reflected themselves in different ways when patients became involved as PPI representatives and then they could face a range of barriers to working in partnership with trained professionals. For example, patients were concerned about being able to access appropriate information and training, about safety and risks, gaining membership of patient safety, risk and clinical governance committees and once on these committees having opportunities to raise issues about discrimination and inequality and to challenge from a patient's perspective etc. A particular issue raised from PPI representatives in the project was about patients being expected to be involved as volunteers in their own time without being properly reimbursed for expenses both for travel and time incurred.

Dealing with these power imbalances is therefore crucial if partnerships are to be developed with patients and the public and healthcare professionals and organisations, which avoid tokenistic relationships and one-off consultations that are designed mainly to benefit organisation involved rather than to genuinely address patient concerns.

Recommendations:

There is a need to find more ways to address imbalances of power between healthcare professionals, healthcare organisations and patients and the public and to develop more equal relationships based upon real partnerships in the healthcare process.

Trust Boards need to clearly set out the ways and opportunities for patients and the public to become involved in patient safety work in Trusts, both on an individual patient level and at a strategic level at board meetings and on clinical governance and risk committees.

Steps need to be taken in particular to explore the issues associated with the way that patients who have had poor experiences of healthcare are negatively treated and excluded from PPI activities.

It is also recommended that proper information and training is developed to enable patients and the public to develop their knowledge and skills at appropriate levels to enable them to become involved in patient safety activities in the way that they choose.

Clear policies need to be developed by NHS Trusts in line with the Department of Health's guidance 'Rewards and Recognition'[4] which sets out clear procedures for reimbursing patients and the public for their involvement.

The project's experience so far in recruiting people to the network and from some of the pilot site work also suggests that there are barriers for some groups to getting involved in the patient safety agenda, particularly people from Black and minority ethnic or disabled communities. Wider evidence suggests that these groups also tend to have poorer experiences of healthcare than other sections of the wider population. More work is therefore needed to understand what these barriers are and how they can be addressed in order to achieve genuine diverse involvement in developing a national network and safety work more generally.

D) Supporting Staff to Support Patients

A key issue to emerge in the project, with both pilot sites in different ways, was the importance of supporting staff to support patients in becoming involved. This might relate to supporting staff after a serious incident has occurred in order that they can properly support and engage with patients and their families and implement the Being Open guidance. Staff also need to be given the time, guidance and training to support patients their families and the public to become involved in patient safety in a range of other ways.

Recommendation:

Healthcare professionals need training on what it means to genuinely involve patients on an equal footing and to be reassured that this is 'safe' to do organisationally, and that they will be supported in doing this work by arrangements set out at a senior management level.

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[4] Reward and Recognition The principles and practice of service user payment and reimbursement in health and social care. A guide for service providers, service users and carers. Department of Health., August 2006

Appendices

Appendix One

Continuing Work at Trust B in Developing Patient and Public Involvement

The Trust plans to continue to develop patient and public involvement in patient safety work.

The following list indicates the new work that has started in the Trust this year in relation to patient involvement in aspects of care:

- Patient involvement in work to improve the amount of time that staff have to devote to patients on the wards (productive ward, releasing time to care initiative). For example, this is taking place on a surgical ward with help from members of the cancer users group.

- Changes in committee structure (December 2007) with a move away from the performance and quality committees to a set of three committees (including one patient safety committee and one patient experience committee). The patient experience steering group is chaired by a Non-Executive Director; it includes the Director of Nursing and Clinical Services and is growing a 50/50 staff and patient membership.

- The acquisition and implementation (February 2008) of a patient feedback system using a hand-held device allowing responses from several patients in many departments to five questions designed by staff and patients.

- Emergency care and short stay work to improve safety, efficiency and flow, commenced October 2007 which involves 1) collecting stories from staff and patients about their experience of delivering and receiving care, and 2) patients and staff working together on the design of emergency care structures, processes and environment (February to June 2008).

- Staff who go out and meet regularly with patient and carer groups and with sections of the community are beginning to talk with those groups about their patient safety issues.

Appendix Two

Work with Trust B - Patient Representatives on Committees

Guidelines for Working in Partnership with Patient Representatives Co-opted onto hospital committees.

Any committee or working group needs to enable its members to participate fully. This paper aims to help NHS staff enable patient representatives to play their full part.

Patient representatives who are asked to join hospital committees can feel disempowered by the committee process for a number of reasons. They may feel they have little to contribute to a committee because they are not familiar with the context they are in, or find it difficult to participate because they are the only lay person on the committee and can feel in a token position. It is therefore important to ensure that patient representatives are made to feel valued and that their opinions are listened to and that they are given the confidence and the tools to fulfil their role as partners in the committee process. This can be done efficiently by thinking through and implementing a series of measures.

A patient representative can be identified through the Patient Affairs & PALS Manager or, if appropriate, a volunteer from a particular patient group may be approached. However, if this is the case it is important that they be registered as a hospital volunteer (if they have not already done so). This ensures that they are CRB (Criminal Records Bureau) checked and issued with a hospital ID badge.

Some questions to consider before identifying a patient representative for a particular committee are:

- What is the Committee's purpose?
- Are terms of reference available?
- Do you want patients with direct experience? Carers or members of the public?
- Do you want them to have particular health or information expertise
- Do they need particular knowledge or skills?
- What are you asking them to do/What does participation involve?
- How often will the committee meet and how long will the meetings last?
- What are future dates/location?
- How will expenses be paid?
- Does the patient representative have any special needs?

Once a patient representative has agreed to join a committee the following steps must take place:

- The patient representative should first be given the terms of reference of the committee and other relevant information to read to enable them to decide whether they wish to be part of the group.* Yes ☐ No ☐

- An effort should be made to ensure that all committees have a minimum of at least two patient representatives on them to avoid tokenism and to better allow for patient participation into the committee process. Yes ☐ No ☐

- The chair of the committee (or a nominated member of the committee) should introduce themselves to the patient representative and spend some time giving them a "plain English" explanation of the role and purpose of the group prior to the first meeting. Yes ☐ No ☐

- Consideration should be given to whether the patient representative would benefit from any particular training courses that are offered by the Trust to help them fulfil their role. Yes ☐ No ☐

- At the first meeting, the patient representative must be introduced to the other members of the committee. The committee should also be given an explanation of the role of the patient representative. Yes ☐ No ☐

- Every effort should be made not to use unnecessary jargon or acronyms during the meetings unless they are explained to the patient representative. It may be useful to produce a list of commonly used acronyms for the patient representative to refer to. Yes ☐ No ☐

- The Chair should ensure the patient representative is given adequate opportunity to contribute to the group discussion, to ask any questions they may have or to place an item on the agenda if requested in advance of the meeting. If the patient representative has not spoken in the meeting, if appropriate they could be asked if they wished to add anything or make any suggestions. Yes ☐ No ☐

- The patient representative must be supplied with the telephone number and/or email address of a nominated member of the group who will be able to answer any questions they may have following the meetings. Yes ☐ No ☐

- Minutes and agendas should be sent out to the patient representative two weeks prior to the meetings to ensure they have time to familiarise themselves with the content of the meeting. Yes ☐ No ☐

- Expenses for attending meetings should be properly reimbursed and within a reasonable time-scale. Yes ☐ No ☐

Recommendations:

- It would be useful to pilot these guidelines with committees generally, but in particular to test them out with clinical governance/patient safety committees, given the current desire to achieve more patient and public involvement in this area.

*It might be useful to compile a short pack of useful information to give to the Patient representative. This could include information such as a diagram of strategic Trust committees to help them understand the committee structure of the hospital and current patient and public involvement in them.

Signed by Chair/Staff rep …………………………………..

Signed by Patient rep ………………………………………..

Appendix Three

Briefing report on the Event 'Patients for Patient Safety - Empowering patients in patient safety work' held at Birmingham City Hospital on March 18 2008.

Purpose of the Event

The purpose of this event was to:

1. Promote awareness to patients and NHS staff of the Patients for Patient Safety Initiative in England and Wales and the development of the 2008 program implementing recommendation 13 of *Safety First;*
2. Share the learning from the pilot project and patient safety within the West Midlands;
3. Run a partnership event with the Healthcare Commission (HCC) to test out with patients what aspects of the safety standards patients value and how they express them and to explore patients' views regarding where/what HCC new priorities/focus should be in regard of future work in patient safety; and
4. Launch to call for patient safety champions.

The programme for the Day reflected the above objectives

10.30–12.30	**Welcome and Introduction:** Peter Walsh, Chief Executive (AvMA) and Nigel Barnes, Patient Safety Project Manager (NHS West Midlands)
10.40	**Patients for Patient Safety – the National and International Context:** Peter Mansell, Director of Patient Experience (NPSA)
11.10	**The Patients for Patient Safety Pilot Project – what have we Learnt:** Josephine Ocloo (Project Manager, Patients for Patient Safety pilot project, AvMA)
11.55	**Launch of the Call for Patient Safety Champions:** Peter Walsh, Chief Executive (AvMA)
12.20	**Patient & Public Involvement in the Regulation of Patient Safety:** Richard Elson (Healthcare Commission)
12.35	**Questions and Discussion**

12.45–13.45	**LUNCH**
13.45	**Breakout Session 1 (for patients & public only)** ▪ Break out session 1: Helping the HCC test what the aspects of the safety standards are that patients value and how they express them. ▪ Exploring patients’ views regarding where/what HCC new priorities/focus should be in regard to future work in patient safety. **Breakout Session 2 (for staff and patients & public)** ▪ Sharing with patients and NHS staff the findings and experiences following the two year pilot project working with patients and NHS Trusts to improve patient safety and listening to their experiences and suggestions.
14.45	**TEA BREAK**
15.00	**Feedback from the Workshops & Discussion**
15.40	**What does Partnership in the approach to Patient Safety mean in West Midlands?:** Nigel Barnes, Patient Safety Project Manager (NHS West Midlands)
16.0	**Next Steps: What will happen next nationally and locally – how to get involved**
16.20	**Questions and Discussion**
16.30	**CLOSE**

Participants

Ninety three participants registered for the conference and sixty attended. Of these, forty were classified as patients and 20 as NHS staff.

Key Points from Conference Discussion:

Partnership

That the partnership approach taken was a good thing and that it means trying to create a more equal and level playing field between patients and health professionals in which patients are properly valued. This meant there was a need to further identify the issues that stopped people participating equally.

Some examples of partnerships being equal were administrative in nature – e.g., the need for payment for time/expenses; preparing & supporting individuals properly – while others were more cultural – e.g., communicating appropriately with jargon seen as disempowering; training staff to work with PPI representatives; building trust and allowing those with poor health experiences to be involved and to challenge from their own perspectives without being negatively labelled.

Nigel Barnes concluded that partnership is key to the success of the PfPS project & described how lay members of the W/Midlands Patient Safety Action team are supported by a Lay Reference Group.

Patient Safety

A range of issues and concerns were highlighted that raised issues about patient safety related to prevention, improvement, the monitoring of incidents, litigation and tackling the culture of denial. Some examples of these issues were about: creating a cultural shift in the NHS towards one of openness and honesty; developing an open reporting culture particularly in Primary Care; considering if there should be mandatory reporting of incidents; getting staff to feel confident enough to report incidents without fear of blame and making sure the NPSA's National Reporting and Learning System (NRLS) makes reporting easy; recognising that whilst staff had fears about litigation, harmed patients also felt that they had a right to take legal action and to have justice & accountability; tackling the issue of missing medical records after a Patient Safety Incident and the way that harmed patients can be denied medical treatment; addressing issues to do with tackling racism and promoting equality and diversity; and finding ways to support staff who are 'whistle-blowers'.

Conclusion

In developing a strategy for tackling the barriers to the involvement of patients and the public in patient safety, consideration should be given to identifying and setting out the different ways that a partnership model can be implemented both at a strategic level and in terms of involving patients on an individual level and in communicating with the wider public. This should also include identifying the support that is needed both for staff and patients.

Steps should be taken to work with health professionals in addressing their fears and concerns about involving and working with those with poor experiences of healthcare and those directly affected by medical harm or who have made a complaint.

Lastly, third-party feedback suggests that one or two NHS staff present felt that the patients’ experiences were disconcerting to hear and even that some patients were still aggressive towards the NHS and NHS staff and this felt somewhat strange to them. This suggests that the champions’ work will have an important role to play in making space for patients and NHS staff to come together to explore patient safety in all its aspects from a variety of perspectives.

Peter Mansell
Director for Patient Experience and Public Involvement
NPSA
Wednesday, 09 April 2008