Making the safety of patients
everyone's highest priority

Leadership for safety, 'How to' guide supplement:

Using patient stories with boards

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www.patientsafetyfirst.nhs.uk

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Introduction

Patient Safety First's 'Leadership for safety' intervention suggests that organisations working to improve patient safety should bring the patient's voice to the Board. Whilst the idea of starting each Board meeting with a patient story may initially sound easy to accomplish, in reality it is a challenging goal that requires careful planning, consideration of a number of ethical issues and skilled presentation.

Everyone has experienced the power of narrative and storytelling at some time or another in their professional or personal lives, or both. True stories engage the listener in a way that hypothetical scenarios can not and at times trigger significant emotional responses. Such emotional reactions are often even more powerful when the listener feels some kind of personal connection with the experience described. This might be due to them having had a similar personal experience (or knowing someone who has), relevance to an area of personal interest or a sense of responsibility for those in a similar position.

The Leadership for safety intervention also highlights the importance of the Board's responsibility for patient safety, not in a generic sense where the responsibility is that of 'the Board' and therefore diffuse but in highly personal sense. Each leader should recognise their personal accountability for patient safety and know their own role in improving it. Patient stories can help forge and maintain a connection between an organisation's leaders and their primary purpose; providing high quality, safe care. Patient Safety Leadership Walkrounds (see useful links) also serve to bring leaders into contact with patients and their stories and experiences, but in these situations the function of the walkround is wider and time limited. Using a patient story with a Board is more focused on one event or episode and really understanding what happened and why.

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About this guide

This guide is aimed at senior leaders who wish to embark on using patient stories at Board level and those staff members who will be involved in the process. It outlines the process of selecting and gathering stories and guidance on presenting them in the boardroom. There are a number of issues involved in using patient stories such as consent, storage, confidentiality and safeguarding the emotional wellbeing of patients. At the end of each chapter of this guide there is a section entitled "Take care" which highlights some of key issues or tips for consideration to ensure the process is carried out in an ethical way.

For conciseness this document refers to the person sharing the story as the patient but when taking and sharing stories it may not actually be the patient who is directly involved in the process. If the patient would like their story to be used but does not wish to participate personally it could be anyone they choose such as a relative, care or friend.

Why use patient stories?

- Connect with patients and relatives. All healthcare leaders care about what happens to patients in their organisation but the detail of patient experiences of harm can help them to connect on a more emotional level
- Connect with front line staff. Leaders should never underestimate the emotional impact that staff involved in incidents of patient harm can experience. It can be an opportunity for staff to talk in depth about an event and discuss with senior leaders their thoughts and opinions on why it happened and how it could be avoided in future
- Improve understanding of human factors in harm and error. Boards are advised to concentrate on strategy but an in depth story can give useful detail that provides a window into the workings of the system. This can be particularly useful in building understanding of what it means to have a culture that is just; one that recognises why people make mistakes and exactly what they are asking of their staff when they put them to work in their organisation
- Make patient safety personal. When stories of patient harm appear in the media it is not uncommon for healthcare leaders to feel such an event would not happen in their organisation. Hearing stories of their patients who have been harmed or had a near miss brings it into their own sphere of accountability – 'this is here, **we** did this'.

> *"The Board is committed to learning from actual patient experience. Board members actively listen to the real experiences of patients and relatives in each Board meeting; to learn how problems in care provision affect and impact upon patients and their families, and to maintain a focus on continually improving patient safety and experience. Patients and relatives have shown a willingness to share their stories so that the Board is aware of and learns from their experiences of care at Bedford Hospital."*
>
> Bedford Hospital NHS Trust

Take care

- Don't rush in - stories should not be taken simply to 'tick the box' or because other organisations are using them. If the time is not right to do this in a well planned way, make this explicit but start to work up a plan and timeline to start using them in the future.
- Think about why you want to use the stories. As senior leaders, what is it you want to find out?
- Consider what will be done with this information when it is obtained. How will the Board support actions arising?

Finding and choosing which stories to tell

There are different approaches that can be taken to identify patients. You could set yourself criteria for the identification process, for example have been an inpatient for a minimum period or you may have a number of methods of accessing possible stories that may already be available to you.

Suggestions for consideration could include

- Promotion within a service area such as a ward or GP practice by displaying posters, providing information leaflets or asking patients whether they want to take part
- Inviting a random selection of patients that have received care from your service to take part
- Incident forms
- Serious Untoward Incidents/Deaths
- Complaints
- Suggestions from clinical or operational management staff.

A good time to approach in-patients is during the time following a decision that they are ready for discharge and before they leave the hospital. Allow patients adequate time to consider the information that you provide and to ask any questions about the process. If a patient agrees they can then decide whether they would prefer to tell their story before they leave or give permission for contact to be made after discharge.

It is also worth considering patients different abilities to tell their stories. It is easier to approach patients who are able to talk but those that find communication more difficult may have different experiences that are incredibly valuable. In these situations consider who may be able to help the patient tell their story, for example a relative or carer, or a speech and language therapist.

Take care

- Provide the patient with adequate information that is easy to understand and explicit about what will actually happen; how you will take the story (notes / tape recorder / video), what type of questions they may be asked. Make it clear that if you hear something that puts others at risk that you may have to take immediate action. Most

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hospitals have teams that assist with the development of good quality patient information.

- Don't pressurise the patient into telling their story
- Be careful about the ethics of contacting people after they have been discharged from care. Discuss any such plans with your senior colleagues as it may be considered unethical to use the information on your systems for a different reason
- It is vital that patients feel free to choose whether to tell their story, and have the capacity to make that decision for themselves.
- There is a real fear amongst patients that if they make negative comments their future care may be affected and therefore may find it difficult to discuss negative experiences openly
- Over time, if no action is seen to be taken as a result of using patient stories it will become seen as a waste of time.

Specific notes on consent
It is worth regarding the stories as remaining the property of the patient. Make sure that you get consent from the patient before you start which clearly states how and where the story may be used and by which method(s). If you think you may wish to use the story for another purpose in the future you will need to get the patient's permission to contact them again to discuss this and obtain their consent.

You will need to be clear that you may have to retain some information from the story in order to remember the range of issues described, but that you will not keep the whole story.

Taking the stories

Taking a story takes time. Allow a couple of free hours to take the story and schedule in time to listen and reflect on the story afterwards.

Who
Most people can take a patient story. The essential requirement is that they need to be able to listen. It is however recommended that the person taking the story should have no involvement in the patient's care. The storyteller may need prompts to continue or explain something a little better but it is not the listener's role to give opinion, advice or recommendations; it is to help them talk. Some people are naturally better than others at taking stories and as with any meeting between two personalities; some patients will immediately feel more comfortable with some listeners than others.

It is advisable that whoever is taking a story fully understands the process and has insight into the communication issues involved such as recognising when the storyteller is feeling uncomfortable or upset, reluctant to discuss certain details and how to manage these situations sensitively. They need to be aware of personal reactions and how they can influence the storyteller. For example, looking shocked at something they say may

encourage them to make more or less of that issue. Conversely no reaction would appear strange so a healthy balance of empathy is required to encourage the story to be told.

Different people will hear different things from the same story. A team that is made up of people with different professional backgrounds can help to get the most out of the story. Whilst it is easier to do this in a conversation you need to consider how a particular patient may feel if they are outnumbered by hospital staff in the discussion.

Training is available in this area. Many NHS organisations will have a team of people who have been through the Royal College of Nursing Clinical Leadership Programme. A key part of this programme is around patient stories and these people are a valuable resource to tap into.

Where
Meet somewhere away from the patient's treatment area that is quiet and free of interruptions. If the patient prefers to meet in their own home consider the organisation's policy on lone working and make sure this does not put either party at any risk.

Take care

- Maintain the patient's confidentiality and if agreed, their wish to remain anonymous
- Make sure that the patient feels able to talk. The person taking the story should not be someone involved in providing direct care to the patient, either in the past or in the foreseeable future
- Be able to offer support after the story if needed. Story telling can be an emotional experience for both the patient and the person taking the story. This could be in the form of access to counselling support or a debrief session if required
- Allow the patient to stop at any time. Ensure the patient is aware that they can withdraw their consent for the material to be used further at any time after the story has been taken.

Methods of taking and sharing the stories

There are a number of ways of collecting and presenting stories. Ideally once Boards are familiar with the use of stories it might be helpful to vary the method so the Board get to hear or consider stories in different ways. The presenter can also find other ways to help the Board see deeper into the story. For example different tools are used in the process of investigating incidents or complex processes – use of an issue tree/driver diagram as part of the discussion following a patient story can really bring a problem to life, help the Board to see all of its complexity and stimulate a more detailed discussion.

Written notes
This is the simplest way to take the story and can be later prepared into a written case study or PowerPoint presentation. You may need to consider having a scribe in the room if you think your notes may be hard to decipher after the event!

Audio recording
This allows you to concentrate solely on the discussion instead of worrying about keeping accurate notes of what is being said. It also allows you to re-listen to the story with a colleague who may identify different things to you. Patients can be asked to tell their story independently onto a tape or write it down but where this happens important details may be missing and can leave the listener with a host of important questions unanswered later as it is harder for the patient to talk in isolation.

Filming
This approach requires a lot more planning and resources therefore it may be that you decide to take stories initially via another mechanism and film specific ones afterwards. Your communications department should be able to provide basic filming equipment and would need to spend time afterwards helping with the editing process. The editing process can be quite time consuming as there will be a lot of footage and it takes considerable skill to extract all the necessary clips of information that give the full picture of the story whilst retaining its emotional impact. Remember also that the storyteller and the facilitator may be more nervous in front of camera as they know they will be watched by others and recognised.

If you have a specific story that you would like to use more widely in the organisation for training and education purposes then it may be advisable to secure funds and use a company that specialises in this type of media in healthcare settings. The issues around consent become even more crucial when using this method.

Presenting in person
This means the patient or relative tells their story in person. Whilst this can be the most powerful way of presenting a story it is also the most difficult and high risk – particularly for the patient or relative doing it. This is because it is hard to prepare someone for how it will feel to stand in front of a board and talk about an experience that is deeply personal and may still be traumatic for them to discuss, even if they want to. Their emotional response may occasionally be unpredictable and depend on other factors such as how the patient is feeling and the mood in the boardroom on that day, and the thread and tone of the discussion. Some factors will always be out of your control no matter how well you prepare the patient and Board. For this reason there will be very few occasions where this method will be appropriate or the patient would want to go into the boardroom. A patient could be identified during collection of their story using another method and if they agree, a decision made to spend more time together preparing for this.

Take care

- Double check that equipment is working correctly and at the right volume – there is nothing worse than taking a story only to find out that the tape did not work or you cannot clearly hear what is being said
- If presenting in person, even a confident patient will require a great deal of support in preparing and presenting the story. There is a particular risk if the Board have a lot of

questions as a constant stream of challenging questions could come across as aggressive or make the patient feel they are being interrogated

- The Board will also need preparation and guidance in terms of how to deal appropriately with patients and staff in the boardroom. They need to be acutely aware of how intimidating an environment the boardroom can be. Their tone of voice and style of questioning could exacerbate this. Phrasing of questions is important; any suggestion that they are seeking to justify what happened or apportion blame will make the patient feel uncomfortable and reluctant to talk openly.

After the story has been used

Actions should result from the use of a story. This may require agreeing actions to be taken or revising an existing ones. If a suitable action plan is already in place then there needs to be a more depth review of its progress. Previous actions may have been meant to have been implemented earlier to prevent recurrence. If this is the case then it is helpful to find out what the barriers were to implementation so that steps can be taken to improve the likelihood of the changes being fully implemented and sustained.

If the patient has stated they would like to be given feedback then they should be called and or written to outlining the outcomes and thanking them for their participation. If any staff members have inputted into the overall story they should also get feedback. Whether or not the area involved in the incident was named, feeding back to its staff is a great opportunity to connect directly with them and have a detailed discussion about the story and what can be learned from it.

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Case studies

Winchester & Eastleigh Healthcare NHS Trust

Choosing and taking patient stories is an executive led process. All serious untoward incidents (SUIs) are presented to the Board focussing on what has been learnt and what is being done next. However the CEO also sees all letters of complaint and compliment so the stories chosen are not purely based on incidents, they can include positive feedback. If a death has occurred then any related story wouldn't be used until the outcomes of any inquest and related disciplinary proceeding were known. Stories from completed inquests are easily accessible.

Where stories are collected from a patient or relative this is done by the Chief Nurse who then follows up the discussion with a letter. All stories used are fully anonomised which means the narrator and the Trust have fewer concerns about the ethical issues that can result from needing to store the story and use it in other ways.

On one occasion a video story was used and again it was fully anonomised. On that occasion the process was led by the Education centre and developed for training purposes but it was also shown to the Board. As this story was filmed and going to be widely seen in the Trust the CN spoke to the staff on the ward involved and went to show them the video. This was a good opportunity for the staff to discuss what had happened and learn from it.

Using patient stories is not seen as a separate raft of work, they just draw on what they already have available to them. They want to keep any process as simple as possible, they feel the simpler and less effort involved in doing it the more likely it is that they can sustain it over time. This is particularly important within the current financial climate where resources may become more constrained. If other hospitals are just starting out using patient stories that's the advice they would give – keep it simple. If the process is complicated, overly bureauocratic or labour intensive from the beginning "it gives them a reason not to start".

They have seen great impact from using these stories. There is a different feel at the Board, they talk in more detail about safety and related mortality measures. "It focuses their minds for the day".

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United Lincolnshire Hospitals NHS Trust

The Chief Nurse (CN) chooses which stories are presented to the Board. It may a choice based on a particular policy driver but when using an SUI or incident of avoidable harm often one is chosen that is related to a specific strand of their safety strategy. The Trust has participated in the Leading Improvement in Patient Safety (LIPS) Programme so the story may be relevant to a stream of work being undertaken as a result of that. Occasionally it will be a story taken at the patient's request. Mostly the stories are about patients who experienced harm.

The CN takes the stories herself. She calls the patient to make the arrangements then makes notes before the meeting. All interviews are audiotaped and consent issues are discussed at the start such as how they want to use the story, how the patient /relative wish to be referred to in the story (full name or anonymous) and whether they are happy to be contacted in the future if they'd like to use the story for a different purpose. They also agree if and how she will feedback to them after the story has been presented. They do not use a paper based consent form as it's all on the tape.

After the discussion the tape or its transcript is edited so the story is an appropriate length and to ensure the patient's wishes around disclosure of their identity is honoured. Where appropriate the perspectives of staff involved are included in the final presentation.

After the story has been used the CN gives feedback to the patient if this has been agreed and where necessary, information passed to the Trust's Sharing Lessons Learned Forum. Feedback is also given to ward/unit staff.

The use of patient stories has helped to keep the meetings focussed on patient safety.

The CN feels that if Trusts are just starting out with using patient stories it is important to be very clear how the patient wishes to be referred to – the level of anonymity. Some patients very much want to have their names used but obviously some do not. Preparation of the Board also needs to be considered. Actions need to result and there may be a tendency for Non Executive Directors to focus on the story told, the related assurances and how it will be seen.

In the future the Trust are considering giving patients/relatives the opportunity to talk directly to the Board but recognise this will require much greater preparation of the patient and the Board.

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Useful links

1000 Lives Campaign
See the document Wales produced on using patient stories
http://www.wales.nhs.uk/sites3/page.cfm?orgid=781&pid=41303

Institute for Healthcare Improvement
Copy of the notes produced by Delnor-Community Hospital, Geneva, Illinois, USA on using patient stories with Boards.
http://www.ihi.org/IHI/Topics/LeadingSystemImprovement/Leadership/Tools/GuidelinesforUsingPatientStorieswithBoardsofDirectors.htm

Patient Safety First
Information regarding the Leadership for safety intervention and a copy of its related How to Guide.
http://www.patientsafetyfirst.nhs.uk/Content.aspx?path=/interventions/Leadership/

Patient Safety First
Short films on safety walkrounds and a copy of the related How to Guide supplement.
http://www.patientsafetyfirst.nhs.uk/Content.aspx?path=/interventions/Leadership/walkrounds/

Patient Safety First
Download a copy of the How to Guide on Human Factors in Healthcare.
http://www.patientsafetyfirst.nhs.uk/ashx/Asset.ashx?path=/Intervention-support/Human%20Factors%20How-to%20Guide%20v1.2.pdf