



Creating a Revolution in Patient and Customer Service Experience

Using Patient Stories



Executive summary

As part of its commitment to create a revolution in patient and customer experience, NHS Midlands and East has been keen to understand the role patient stories are playing within organisations and the extent to which this is helping deliver a Patient Revolution.

During the Summer, an on-line survey together with a series of deep dive case study interviews were commissioned by NHS Midlands and East to understand how patient stories are being used by NHS organisations across the cluster and in particular how they are being used by Boards in support of improving quality and patient experience.

This report summarises the findings of this review and concludes with a series of key observations and hints and tips for organisations using patient stories. Featured within Annex A is a copy of a 'Patient Stories Checklist', developed by the Burdett Nursing Trust and identified by a number of Trusts across the West Midlands NHS as a common useful resource for organisations considering taking stories to Boards.

Key observations as a result of the survey and interviews concluded that;

The use of patient stories across the Midlands and East is a relatively new technique with widespread use amongst Trusts but limited evidence of use by commissioners.

Patient stories are deemed as valuable in supporting quality improvement discussions at both strategic and operational levels (Board to Ward).

A wide range of methods for capturing and disseminating patient stories are in place across the Midlands and East NHS.

Hearing directly the 'voices of patients' enables greater understanding of the issues affecting patients and brings reported experience to 'life'.

Celebrating and learning from positive experiences is as valuable as learning from examples of less positive experience.

Tried and tested good practice advice is readily available.

The benefits of patient stories are wide reaching.

Stories provide 'real' insight in support of service improvement.

Embedding patient stories is key to creating a patient and customer services culture.



Introduction and background

During the summer of 2012, an online survey was carried out by NHS Midlands and East to capture information from around 100 organisations on the use of patient stories to deliver the Patient Revolution. In total, 40 organisations completed the survey, a 40% response rate. A detailed breakdown of organisations is listed below.

Trust type	No of respondents	% of respondents
Acute Trusts	30	75
Primary Care Trusts	5	13
Mental Health Trusts	2	5
Ambulance Trusts	1	3
Community Trusts	2	5
Total	40	100

This report looks at the information collected from the survey and aims to address the following key questions:

- How are organisations using patient stories?
- How are patient stories captured and conveyed?
- How are patient stories influencing service improvements?
- What advice do organisations currently embedding patient stories have for others starting in the process?

In addition to the survey, this report is supported by the findings of a series of case study interviews undertaken with eleven NHS Trusts across the Cluster, a number of which focus on the use of patient stories. The case studies report 'Creating a Revolution in Patient and Customer Services Experience; 11 Journeys From Across The Cluster' should therefore be read in conjunction with this report.

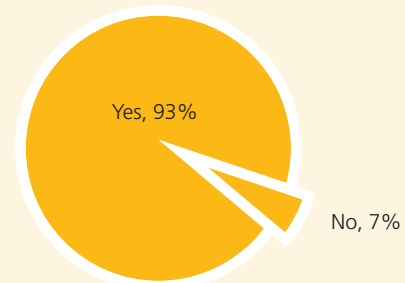
Using patient stories

The majority of Trusts who responded to the survey (37 out of 40) make use of patient stories within their organisation, with 43% of respondents having only done so for the last two years. A further 35% have only been using patient stories in the past 12 months.

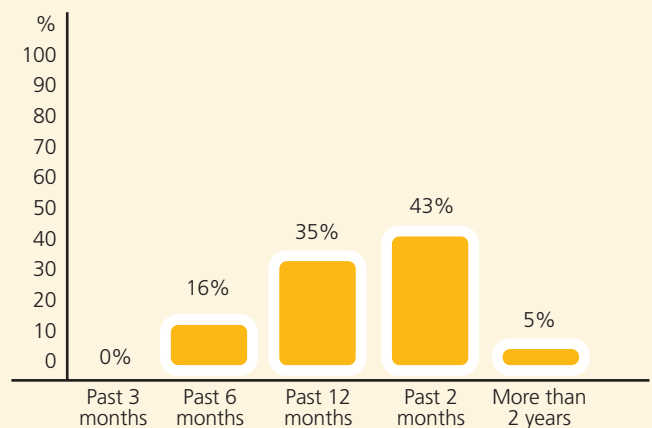
The highest proportion of patient stories relate to acute care and care of the elderly. Other frequent topics covered by patient stories highlighted by Trusts were:

- Maternity care
- Ambulance service (pre-hospital care)
- Drug and alcohol services
- Dental services
- Transition and adolescent care
- Community services.

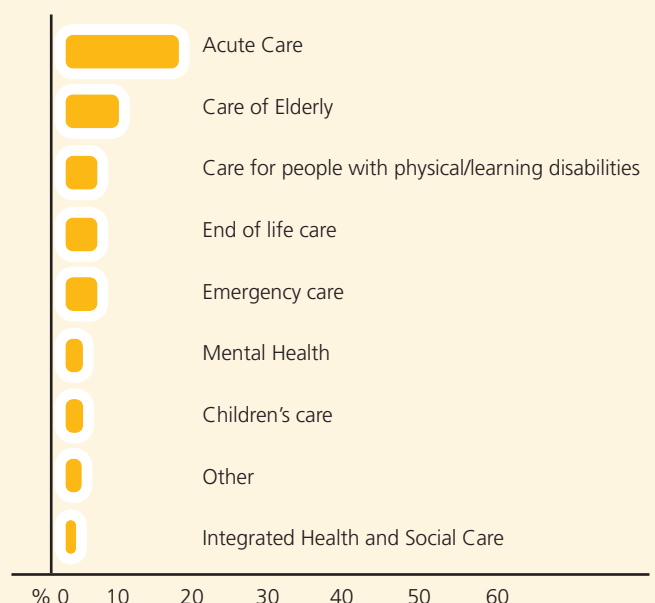
Q5. Do you make use of patient stories within your Trust?



Q6. How long has your Trust been using patient stories?



Q7: Could you indicate in which setting patient stories were used over the past 6-12 months?



Capturing patient stories

Trusts across the NHS in Midlands and East use a variety of tools to capture patient stories. However Trusts seem to be moving away from the more traditional methods such as using written documents (written stories/interviews, letters) to more visual methods such as recorded materials (face to face interviews, DVD or audio recordings or using photographs) when relaying stories.

According to the survey results, many patient stories appear to come from patient feedback (e.g. complaints register, PALS – the Patient Advice and Liaison service, Complaints and NHS Choices), suggestions or untoward incidents, with patients contacting the trust to report a complaint or to provide compliments on the service they received;

“Patients who complain, complete surveys, provide compliments or use the PALS service are asked if they would be interested in telling their stories to our Board. Patients who express an interest are then contacted and usually met at their own homes by the Director of Nursing and/or Head of Patient Experience. Details of their story including some background are recorded and a story drafted which is agreed with the patient before submission. In most instances, the patient and their family attend the Board meeting when their story is discussed.”

(Ambulance Service Trust, East Midlands)

Despite this, most Trusts do not solely rely on the complaints register to capture patient stories. Instead, there is a move to capturing stories through NHS staff. These methods include capturing stories through:

- Training staff to collect stories from patients
- Asking staff to identify examples of where services have worked well for patients or where challenges to provision of services have been noted
- Ward visits
- Feedback from ward sister meetings
- Feedback from members of Patient Panels.

“Volunteer or staff member tell their story of a patient they have helped care for/support and the developments that have resulted, e.g. development of PICTOCOM tool for patients with communication and language difficulties following work of a Health Care Assistant with patients on stroke unit with communications difficulties.”

(Acute Trust, West Midlands)

A number of Trusts identified that patients are keen to share their stories, and this is something that is consciously enabled by these organisations. For some, such as University Hospitals Coventry and Warwickshire NHS Trust, there is a waiting list of patients who have signed up to tell their stories, from which the Trust is then able to select stories to present at various forums such as Board Meetings or directly to frontline medical staff.

For some Trusts, active ‘story gathering’ is undertaken and is something which represents an alternative way of capturing patient stories. For example, within a number of Trusts such as Leicestershire Partnership NHS Trust, Board Members undertake unannounced walkabouts on wards throughout the hospital, in order to both observe customer care on the wards and also to speak directly to patients to find out more about their experience within the Trust and to gather stories to relay back to staff and the Board in general.



Conveying patient stories

Face to face

Trusts report that the most powerful impact of patient stories is when the latter are conveyed by patients themselves. Patients are given a voice and invited to present their stories in different settings including:

- To the Board
- At conferences and professional forums
- In patient focus groups
- At local ward meetings
- At appreciative enquiry workshops.

Staff training and induction

It is common practice among several trusts to use patient stories and invite patients to staff training and induction. For example, patients are invited to tell their story to staff involved in delivering care, to clinical teams and to doctors in training. e.g. dignity days and staff development days, attend staff training days or take part in training videos.

The use of patient stories in staff training is something which was reinforced throughout the Trust case study interviews, with a number of Trusts routinely incorporating these into their staff training and, in some cases, staff induction programmes.

The use of patient stories in this context, particularly during the early stages of joining an organisation was seen to enable an in-depth understanding of patient experience, and to establish organisational expectations in relation to this. This approach reinforces and embeds the core values of the Patient Revolution, by providing staff with an insight into 'real' patient stories and outlining the Trust's own approach.

The use of patient stories relating to specific medical conditions, such as dementia, within staff training was another area which was highlighted in both the survey and case study interviews. This was seen as a particularly useful application of patient stories as this not only enables greater level of understanding amongst staff in relation to meeting the needs of individuals with complex needs but also allows patients and carers to have a direct impact upon service design and to share their views regarding what would improve their experience within a hospital environment.

Third party reporting/written word

Trusts still most commonly report patient stories through third parties. These include:

- Stories presented in reports (e.g. Care & Compassion report, Chief Executive Advisory Group Report)
- Stories presented at meetings (e.g. Board, Integrated Governance Committee, Quality and Safety Committee)
- Stories and letters included in staff stories, intranet, hospital newsletters and bulletins.

"Patient stories are captured through ward visits undertaken by members of the Board of Directors, patient panel and the PALS manager. The patient stories are presented to the Quality and Safety Committee which is attended by both Executive and Non executive members of the Board. The minutes of the Quality and Safety Committee are presented to the Board of Directors and includes details of the patient story discussed"

(Acute Trust, West Midlands)

Examples of Innovation

Leicestershire Partnership NHS Trust's use of live patient stories in a 'chat show' format is one example of the innovative use of patient stories delivered to Board Members. In this instance, patients are invited to attend the Trust's Board meetings and are then 'interviewed' by the Trust's Director of Nursing in order to provide a detailed insight into their story. This approach was seen as particularly useful as this allows the patient story to be delivered in a way which keeps it 'personal', yet allows a thorough and detailed account of the patient's experience to be explored within the Board Meeting.

Whilst the use of patient stories presented via DVD was fairly routine within a number of Trusts, one example of which offered a new approach to this was that adopted by Heart of England NHS Foundation Trust. Here, patient story DVDs are used throughout staff training sessions, but also the Trust films staff responses to patient story DVDs as they are shown. This cyclical approach, emphasises the importance of reflecting on staff responses to patient stories and the importance of patient stories in supporting individual and organisational learning and behavioural change in relation to the broader patient revolution agenda.

Ensuring that face-to-face patient stories are engaged with and fully understood by those to whom they are delivered is another key consideration also highlighted by Leicestershire Partnership NHS Trust's 'Complaints and Compliments Analysis' process. These are staff training sessions within which patient stories relating to a particular comment or complaint received by the Trust are delivered to staff members by the patient themselves. A key principle which underpin such session is that staff are required to listen to the patient's story without speaking, in order to fully engage with the experience. Staff are then asked to repeat the story in order to establish their level of understanding and interpretation, followed by a more thorough discussion of this as a team activity. This form of patient story delivery highlights how such initiatives can enable staff to go beyond simply listening to patient stories and seek to develop a deeper understanding of patient experience within their Trust from this perspective.

Choosing which stories to tell

Whilst positive experiences are an effective way of sharing examples of good practice in terms of customer service and patient experience, the use of negative examples is another way in which patient stories are used to educate staff members and instigate change and improvements.

A high proportion of patient stories come from complaints or feedback. Therefore it is not surprising that trusts select stories from those avenues. Some trusts choose stories from complaints or investigations while others take suggestions from patients' council, service reference groups, volunteers and direct approaches from patients.

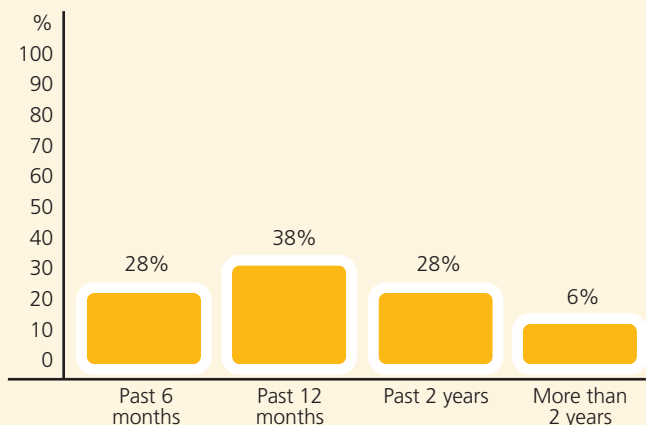
When asked, most trusts claim stories generally get selected to reflect all services provided by the Trust. In some cases, stories are based on key priorities or used to illustrate the Trusts corporate objectives.

A number of respondents reported a conscious decision for trusts to select both positive and negative examples of patient stories, in order to reflect a balanced view and the range of patient experiences. This is something which was particularly highlighted within responses received from Worcestershire Acute Hospitals NHS Trust, University Hospitals Coventry, Leicestershire Partnership NHS Trust, Warwickshire NHS Trust and Sherwood Forest Hospitals NHS Foundation Trust.

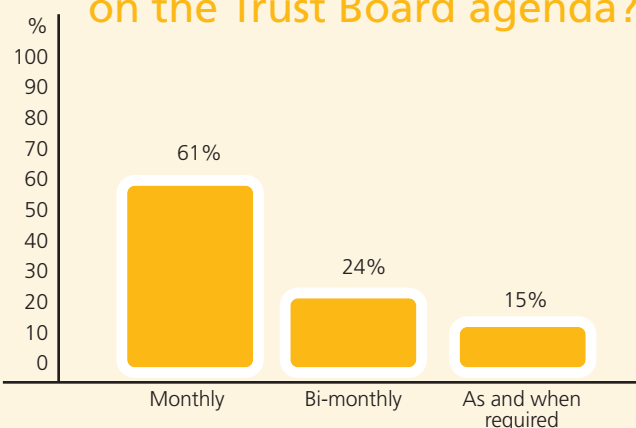
Patient stories and the board

In 84% of cases, patient stories appear as a formal item on the Trust Board agenda. Of the 16% who do not have stories as a formal item (6 trusts), five are Acute trusts and one Primary Care Trust.

Where patient stories are used, in around 6 in 10 cases patient stories appear monthly on the Board's agenda. However, in line with the length of time that patient stories have been used in trusts, the trend seems recent with only 6% of trusts saying they have had stories as an item at Board level for over two years.



Q14. How frequently do patient stories appear as an item on the Trust Board agenda?



Q15. How long have you had a formal patient story item on the Trust Board agenda?

As discussed above, patient stories across the Trusts who responded appear to feature in many instances on the Board as a dedicated agenda item. However, there is no one standard format for conveying patient stories. In many cases, patients, carers and/or relatives are invited to put their story in person. Where this is not the case, stories are presented on their behalf in various ways:

- Staff, volunteers, Ward Sisters, Nurse Specialists or Matrons present stories of patients
- Matrons share patient stories and how the experience changed their views and the practice of their teams
- Letters, feedback, web postings and/or any trends are read out and in some cases followed by discussion
- Written stories/papers conveying a patient story/stories are discussed
- Patient story videos and film
- Stories are included and discussed in deep dive sessions or Board Development Workshops
- Discussion of key themes/trends relating to patient stories
- Verbal reports from Board Member visits to clinical areas.

“At the private Board meetings, a matron presents an incidence or series of incidences which resulted in a poor experience and (Acute Trust, West Midlands)

“Whilst we do not currently use individual patient stories within the PCT we do regularly review patient opinion websites and use soft intelligence gained through PALS and the patient and public engagement team to feed key themes and trends to our Board”
(PCT East of England)

“Patients, carers, ex carers attend the private lunch session (1 hour) before every PCT cluster public board meeting and share their story with the full Board, allowing time for them to talk about their experience and then for the Board members to ask questions.”
(PCT Cluster, West Midlands)

Benefits of using patient stories

Undeniably, all Trusts who responded to the survey see patient stories as a powerful tool in improving care with benefits extending not only to the organisation (at staff and Board levels) but also to patients themselves. Patient stories are ‘memorable’, ‘real’ and can have profound impact on staff and other stakeholders.

Benefits to staff

A reality check - the main benefit to staff of patient stories is its ability to ground staff; by listening to patients, staff are made to “stop and think” of the way they are delivering care. This process can bring about focus, raise awareness and understanding among staff.

Empowering and motivating staff – positive patient stories also help to boost staff morale and empower staff to act on feedback received and make changes in practice;

“Personal contact always refreshes the impact on nursing care being delivered. The importance of ‘humanising’ contact cannot be underestimated and the impact on staff is a forceful visual impact. They return to their ward environments re-invigorated into wanting to ‘make the difference’ - ultimately with the intention of improving patient experience.”
(Acute Trust, East of England)

“A Trust Volunteer, who has been integrally involved in improving the experience for patients who have difficulty feeding themselves, told his story of one of the patients he worked with who can now feed himself, and of the success of the Trust's work using appropriately trained

volunteers supporting patients (appropriately risk assessed by nursing staff) in feeding. This story has also been featured in the local press.”
(Acute Trust, West Midlands)

Benefits to organisations

Catalyst for behaviour and culture change - Most importantly, patient stories can bring about a change in culture through exposure to patients and patient stories. Staff are immersed in the culture of involving, listening, hearing, responding to feedback and with this comes acceptance, realisation, reflection acceptance and with this comes acceptance, realisation, reflection and acceptance of the impact their care delivery has on patients and reflection. Staff hear what is important to patients and which may not have been otherwise apparent and this can be a powerful driver for change.

“We have had consultants admit it was they who had not responded to a particular patient as they felt that someone else would see to them, their reflection was that the story would change their future behaviour. More strategically, the key benefit is for an increasing number of frontline staff getting exposure to the reflections of patients and carers that they did not have access to previously, thus influencing a change in culture.”
(Acute Trust, West Midlands)

Benefits of using patient stories (continued)

"It gives staff time to listen and an appreciation of what is important to patients. It promotes a culture of involving, listening to, hearing and responding to feedback."
(Acute Trust, East of England)

"Compilation of patients who had recent experience of the Acute Medical Unit – Patients were interviewed at home after discharge. The film was used for a Transformation planning day to show staff how patients perceive their service - the film was well accepted and used in the planning process"
(Acute Trust, West Midlands)

The main benefit of patient stories at Board level is that they help ground discussions in the reality of patient care. Patients are put at the heart of decisions as the stories are powerful reminders of the context within which Board Members are making decisions. Board Members are able to see how their decisions impact on patients.

Forging a connection - Some trusts mention that patient stories allow the Board to understand better the complexities of day to day life at an operational level. This helps forge and maintain a connection between the leaders and their primary purpose of providing high quality care.

"One of the key benefits identified by Board members, particularly Non Executive Directors, is that they find hearing direct from local people using health services a very powerful indicator of local experience, which supports them to make more informed choices and decisions, as members of the Board. One Non Executive Director said it was the 'most useful hour of the meeting'. "
(PCT Cluster, West Midlands)

"Patient stories used in meeting settings serve as a reminder to the meeting participants about the context in which they are making decisions and can often stimulate discussion about doing things differently for the benefit of patients."
(Acute Trust, East Midlands)

"The key benefit is that the Board start their meeting grounded in an awareness of the patient/carer - 'customer' - and this focuses their attention on the quality of care above all else. Board members report that they find meeting patients/carers in this way deeply affecting and that it influences their outlook for the rest of the meeting"
(Acute Trust, East of England)

"Trust board are informed from a perspective of the person using our services. This qualitative information has allowed increased scrutiny of performance data. An example would be the changes to care pathway for CRISI services following a patient story at board."
(MH Trust, East Midlands)

"From a cluster perspective, there is some assurance that providers are taking patients views seriously. All trusts are engaged in some way in this, which suggests effective provider development, and in taking this to CQRM there is an opportunity to inform commissioning decisions"
(PCT Cluster, West Midlands)

"Service user's experiences of using maternity services at XXX and paediatric services for her son. Her experiences were shared at the same session as the Board made their decision about whether to go out to formal consultation over maternity and paediatric services at these hospitals"
(PCT Cluster, West Midlands)

Benefits of using patient stories (continued)

Board commitment to improving experience - having patients come in and tell their story is an effective tool not only for the organisation but for the patient themselves. Using patient stories demonstrates the commitment of the organisation to patients and the continual improvement and shows that the Board is taking patient experience seriously.

Empowering patients as partners - furthermore some respondents clearly feel that patient stories create empowered patients and greater partnership working as patients feel listened to and as a result, are willing to become active stakeholders in the engagement processes by joining user groups or becoming ambassadors.

"Patients/carers report they find the process cathartic and empowering - more so than just getting a letter - the process of coming in to the formality and gravitas of the Board meeting means a great deal to participants. Participants stay in touch and some have joined user groups/continued to be engaged. They are also excellent ambassadors."

(Acute Trust, East of England)

"The power of a patient telling their own story is more powerful than a management argument. Patients therefore feel more empowered which can lead to greater partnership working"

(Acute Trust, West Midlands)

Benefits to patients

Patients' level of engagement and participation with sharing their stories was evident across a number of organisations who agreed that patients find this process beneficial. This was further supported by case study interviews at Heart of England NHS Foundation Trust and University Hospitals Coventry and Warwickshire NHS Trust (UHCW), where patients are keen to have their stories heard and, in the case of UHCW, a waiting list is currently in place for patients wanting to share their stories. This demonstrates patients' enthusiasm for sharing their stories and experiences in such instances, inferring that this is something they find to be both a beneficial and positive experience.

Patient stories and service improvements

Of the 40 organisations who took part in the survey, 32 organisations answered the question about whether the use of patient stories has had an impact on service improvements. All, except for one of those that answered the question claimed that the use of patient stories has had a direct impact on service improvements.

"The complainant was offered the opportunity to come in and tell their story to staff involved in delivering care. Once this had happened a number of changes were put in place as a direct result. These were communicated to the complainant so they could see real action had been taken as a result of them telling their story. This was shared with the executive team via a report."

(Acute Trust, West Midlands)

Whether at Board level or more generally across the organisation, a wide range of service improvements have arisen from discussions of patient stories;

Staff training and development

As a result of using patient stories, many trusts have now altered the structure, content and delivery methods for

staff training. Responses confirmed that a number of trusts now run awareness sessions, customer care development sessions or use stories and involve patients themselves within the delivery of customer care training.

"Mr B, a patient who raised many issues with us regarding care on one of our surgical wards, offered and has now been working with our Chief Nursing Officer and nursing staff on wards in workshop settings to improve the services in line with some of his suggestions for improvement: as well as the DVD capturing his experience being mandatory awareness training for ALL staff and dementia training (different levels of detail and duration) being mandatory as well."

(Acute Trust, West Midlands)

In some trusts, the dissemination of patient stories has resulted in changes to the core procedures and processes within the organisation. Some examples include revised complaint handling procedure, new call categorisation procedure and changes to recruitment process.

Patient stories and service improvements (continued)

“Professional Development Nurse XX gave key lessons to the Board. XX provided details of a patient who was a regular user of the Trust’s services because of a complex medical history. Whilst complimentary of the medical care received, he raised concerns with regard to infrequent visits to the side room in which he was placed and not being provided with discharge information. XX provided details of how the particular incident had been addressed and how this had been addressed more widely across the Trust. This focussed on improved leadership, using the 10 point dignity plan, providing consistency of carers and involving the patient in the discharge process.” (Acute Trust, East of England)

Service changes

As well as changes to staff training and changes in processes, many trusts have used patient stories to trigger major service re-designs, new service introductions as well as re-evaluation of services. Some examples include new acute oncology nurse service and an enhanced recovery programme.

Many trusts have also seen changes to their care pathways including those of maternity services, mental health and learning disability services and older person’s services;

“Parents of a child with Down’s Syndrome spoke about the lack of information available – the outcome was a clinician attended the Down’s Syndrome group and the parents were involved in the redesigning of the Down’s care pathway - and supported the launch” (MH Trust, East Midlands)

Changes have happened at both strategic levels and operational levels with many changes directly happening at ward level. Amongst many of the examples cited these include changing noisy apron dispensers, upgrading shower facilities, increasing access to single room accommodation and upgrading menu cards.

Other improvements and outcomes from patient stories have centred on:

- New improved environment and/or equipment
- Staff post creation or staff/team re-organisation
- Development of new tools and aids such as improved communication tools .

“Particular themes have also emerged e.g. that fluid balance was not being well addressed for some patients which led to both policy and practice changes throughout Trust” (Acute Trust, West Midlands)

“Examples are the development of 4 trust wide projects all based on patient feedback - noise at night, pain and comfort, attitudes and behaviours of staff and patient information. Improved outcomes have been evidenced by improved patient survey results in these areas.” (Acute Trust, East Midlands)

“Ward nursing team reorganised and split into 3 distinct teams to enhance continuity of care and communication. Staff attended bespoke customer care training sessions. In response to the complainant saying she was not aware how to escalate concerns through medical/nursing channels, a communication notice has been displayed at the end of each bed and information placed in the admission/discharge information booklet. This information advises that concerns can be raised with the nursing and medical staff on the ward. If not resolved these concerns can also be discussed with the Ward Manager, Matron or Consultant.” (Acute Trust, West Midlands)

“Patient complaint which was investigated as an SUI related to a patient admitted with learning disabilities resulted in the development of pictorial communication tools on all ward areas, full time employment of a learning disability nurse for the acute trust, a fast track identification and referral pathway for all patients admitted with L&D, in-house education programme for MDT staff.” (Acute Trust, East Midlands)

Moving forward

In many cases, organisations have already integrated patient stories within their organisation, especially so at Board level. In those instances, respondents said they are mainly keen to integrate patient stories more widely internally and promote a wider range of stories. Respondents suggested areas for further development including:

- Encouraging Clinical Commissioning Groups to include patient stories in their wider work
- Developing the range of stories presented (e.g. including children and young people)
- Disseminating stories wider than Board level (e.g. local ward level, sub-committees, equality and membership committees)
- Standardising the approach – Inclusion of patient stories in all staff development and customer care training programmes

Given the limited number of responses, it is suggested that there are many organisations that appear to have as yet integrated and embedded patient stories within their organisation.

Whilst those surveyed agreed that the use of patient stories can act as a catalyst for improvement and change it is clear that for some organisations the use of Patient Stories is still at its infancy and with the first step being taking patient stories routinely to the Board.

Collaborative working with other agencies

From the survey responses most confirmed that they currently have no plans to develop joint stories with health and social care colleagues, although many agreed this is a good idea and would consider this in the future.

There are however organisations who have and do engage local authorities and other local agencies in learning from patient stories when relating to a specific condition or age group e.g. Age UK, Alzheimer's Society.

Resources and support for organisations

Many organisations did not rely on specific documents or resources when developing the use of patient stories within their organisations. Many relied on the information gleaned through complaints and other patient experience sources and as such processes and approaches have evolved over time.

However, there appears to be some key resources that were used by a small number of organisations in developing their approach. These include a 'How to' guide to using patient stories with Boards (by Patient Safety First) and the Burdett Nursing Trust Patient Stories Checklist (attached within Annex A).

Organisations were also asked what support and/or materials would be most useful to support their work in this area. Clearly, the largest need from organisations was to hear about how other organisations are using patient stories and also, how this is driving service improvements.



Useful lessons learnt and advice from organisations

There were a number of key hints and tips from organisations about what is important for trusts and Commissioners looking to develop patient stories as part of a broader patient experience strategy. These include:

Supporting patients and the Board

Undeniably, the most recurrent advice is that the right level of support needs to be given to both patients and the Board when discussing patient stories at the Board. Patients need to understand the context they are stepping into, understand the expectations and get enough support both before and after they attend the Board Meeting to ensure they feel comfortable. In the same way, the Board needs to be supported and educated to prepare to receive patient stories as well as understand their validity and purpose.

“You need to allow adequate time to support individuals to share their experiences. It can be daunting for lay people to be confronted by a full Board and I meet with all of the people beforehand to help them plan what they are going to say. I also make notes of the most important points that they want to make sure they cover, so that if they become distressed, or forget something on the day, I can remind them of what they wanted to emphasise.”
(PCT Cluster, West Midlands)

“Time spent with the patient/carer ahead of the meeting is well spent as they feel empowered and engaged to a greater extent than if left to just appear on the day. Following up is also vital - to ensure they are thanked and also to know what happened next.” (Acute Trust, East of England)

“If we ask patients or relatives to come to the Board we need to be very clear with them about what to expect and what the purpose of telling the story is. They need to be properly greeted and made to feel at home and not intimidated by the setting or style of the Board meeting/room. Simple things like a more informal room layout and making sure everyone introduces themselves. Patient stories from 'the horses mouth' are very powerful but also very emotive and sensitive for those individuals”
(Acute Trust, West Midlands)

“If you are going to have people at the board you need to pick the 'right' people as it can be very intimidating for them. They need to have a key person to link with who will help them through the process.”
(Acute Trust, East Midlands)

“Be prepared to invest enough time in your patient stories (working with the patients/carers and staff involved). Prepare your Board well before doing any patient stories - it's not a witch-hunt or about sacking people!” (Acute Trust, West Midlands)

Creating a balance of stories

As referenced in previous sections, a large number of trusts also feel that it is very important to have a good balance of patient stories to cover both positive stories and negative stories. There are lessons that can be learnt from both and positive stories can be very motivating for staff at all levels. Interestingly some organisations take both the positive and less positive stories to the same meeting to understand and address variation of experience.

“Try to have a balance, e.g. I once read out 2 stories – one good one bad – from same ward and same period. NEDs were shocked.”
(Acute Trust, West Midlands)

Some trusts advised that it is important that trust do not solely focus on stories obtained through complaints, incidents or ward visits – which appears to be the current tendency by a number of respondents. Instead, there should a structured methodology for accessing patient stories that come from all services and are linked back to the organisations strategic drivers/goals. As many people as possible should be involved to ensure that stories are made part of the strategic approach of an organisation, that these are embedded at all levels and become part of the culture for improving the customer services experience.

“My advice would be to ensure that there is a balanced approach to patient stories used and that using complaints is not always the best way although this does have its place. Ensure that the stories are from all services to ensure that context and understanding of impact of what the organisation does and contributions made by teams is evident. Link back to strategic drivers and goals of the organisation and allow time to ensure the board then discusses what if any learning there is” (Community Trust, West Midlands)

Face to face interaction (added value)

A large number of organisations also detailed the need to use face to face patient and Board interaction as far as possible as opposed to written, auditory or visual formats. While the latter are helpful, inviting patients to come in and giving them the ability to ask questions can be a more powerful experience for both the organisation and for patients.

“Interestingly the use of DVDs is less successful. The ability of the patient to ask direct questions of the board and the board to question (if the person is happy to receive questions) is far more powerful. The process we use is, I as Chief Nurse have a conversation with the patient with the board listening in and that works really well.”

(MH Trust, East Midlands)

“We wish to move from purely staff-identified stories and towards inviting patients or their family/carer to represent these stories (either face to face or via recording), and to integrate this type of feedback into existing mechanisms to drive service change.”

(Community Trust, East of England)

Resource commitment

Another key learning from organisations is not to underestimate the amount of time needed to use patient stories in a way which enables maximum benefit. Organisations should be prepared to invest enough time and resources into embedding patient stories within the organisation. For example, the impact of using patient stories in training and/or when communicating issues around patient experience is powerful, but the time investment can be considerable.



Other advice and examples of innovation

Trusts who responded to the survey also suggested the following as key sources of advice for organisations wishing to use patient stories;

- Aim for stories to showcase the contributions made by local teams and the impact on the organisation
- Be careful that one story does not become a single focus for an organisation
- Encourage local experience events to enable local teams to experience a wider group of service users
- Use wide range of media to keep momentum going
- Have a framework which clearly explains what you trying to achieve
- Incorporate patient stories into the existing mechanisms to drive change.

In addition, some key examples of innovation and how stories are being used in practice include;

- The use of ‘Live Patient Stories’ presented in a chat show format at Board Meetings (Leicestershire Partnership NHS Trust)
- The presentation of patient story DVD’s, and filming of staff responses to these, at training events (Heart of England NHS Foundation Trust)
- ‘In your shoes’ events incorporating patient stories, generally delivered directly by patients themselves, to facilitate greater understanding of patient experience amongst staff members (Walsall Healthcare NHS Trust, Nottingham University Hospitals NHS Trust, South Essex Partnership NHS Trust)
- ‘Complaints and Compliments Analysis’, whereby patients are invited to share their stories and experiences relating to a particular compliment or complaint and staff are encouraged to first solely listen to the patient and then subject this to further analysis in a team training session (Leicestershire Partnership NHS Trust, Heart of England NHS Foundation Trust).

These highlight approaches to patient stories which could be adopted across organisations and which offer potential benefits such as improvements to services, staff training and, overall, an increased focus on patient experience in line with the broader patient revolution agenda.

Conclusion

There are a number of clear observations relating to the use of patient stories across the Midlands and East NHS as a result of the online survey and the deeper dive case study interviews;

The use of Patient Stories across the Midlands and East is a relatively new technique

Of all trusts reporting the use of patient stories, only a small number of trusts stated that they had been using patient stories for more than 2 years. For most trusts patient stories are a relatively new technique for capturing and learning from patient experience and is something which has been introduced as part of a longer term strategic approach to improving patient experience. From the limited number of responses from PCTs, it is unclear as to how committed commissioners are in taking patient stories to the Board.

Patient stories are valuable in supporting quality improvement discussions from Board to Ward.

Patient stories are used across a range of clinical areas and cover a range of issues, such as patients with specific care needs, particular social groups such as children or older people, and other issues relating to patient requirements and experience. Within these areas, patient stories are incorporated into both departmental and ward specific feedback, staff training and Board level discussion/presentations.

A wide range of methods for capturing and disseminating patient stories are in place across the Midlands and East

A range of methods are employed to capture patient stories, from paper based methods such as feedback forms to more visual approaches such as video and audio recording or photographs documenting patient experience. The way in which these are collected varies across the Trusts, with some indicating that they principally rely on patients offering these through feedback mechanisms such as compliments or complaints, whilst others seek to gather such information themselves through staff trained to collect patient stories, feedback received by staff on wards and in departments and ward visits conducted by senior staff and Board Members. Patients are keen to share their stories examples cited where registers of stories are in place to manage the number of patients who wish to share their story with the Trust.

Hearing directly the 'voices of patients' enables greater understanding of the issues affecting patients and brings reported experience to 'life'

Conveying patient stories was also an area in which a range of methods were employed across the Trusts. A

sense that face-to-face, or 'live', patient stories were a particularly effective way of presenting these was evident from the survey and reinforced in trust case studies. The key benefit to this method was identified in terms of making the story 'real' for those listening to it and bringing this story to life for the audience. This was consequently seen to enable greater understanding, particularly were additional engagement and analysis was undertaken by the Trust.

Integrating patient stories, whether delivered 'live' by the patient or through another medium such as written feedback or DVD's, into staff training was another principal way in which patient stories were conveyed and utilised. This was highlighted as a key application of patient stories, and one which offered great potential in terms of instigating change and, most importantly, improvements in terms of service delivery and patient experience.

Celebrating and learning from positive experiences is as valuable as learning from less positive patient stories

The need to select patient stories which reflect both positive and negative experience was something which was reflected in the survey results and reinforced in case study findings. Despite trusts generally stating that a balance should be struck between positive and negative experiences in order to reflect all aspects of services and feedback, examples provided by trusts tended to focus on stories which capture negative experiences.

Evidently, the method of feedback collection can impact on the nature of patient stories e.g. those sourced from complaints tending to lead towards negative experience, however feedback from some trusts suggests that different approaches towards story gathering, such as ward visits, actively engaging various groups of patients across hospitals or presenting anecdotal stories or feedback given to staff members during their day-to-day work, may therefore enable a more balanced view. The importance of striking this balance was reflected within supporting case studies, with a number of trusts stating that they consciously try to achieve this balance between positive and negative feedback, and use this to identify both good practice and areas for improvement.

There are some tried and tested good practice tips readily available for taking Patient Stories to the Board

A range of methods for presenting patient stories at Board level was evident throughout the survey findings, and also supported by case studies from individual trusts. Face-to-face, or 'live' patient story presentations, with the

patient themselves relaying their experiences, was something which was often used and felt to be positively received as a means of sharing patient stories at Board Meetings. Other methods used include staff presenting a particular story relating to one of their patients, reading patient letters or written feedback, DVDs or the thematic presentation of patient experiences and stories by a member of staff.

Whilst most approaches were developed through experience, some NHS Trusts across the West Midlands benefitted from engagement in the Burdett Trust for Nursing Board Development Programme which as part of its approach to strengthening the focus on quality amongst NHS Boards developed and tested a range of checklists including a checklist for taking patient stories to the Board. (See Annex I)

The benefits of Patient Stories are wide reaching

Patient stories were seen to be beneficial for staff, Board Members and patients across the Trusts. For staff members, these benefits principally related to an enhanced understanding of patient experience, learning and development as a result of this on both an individual and organisational level. Such benefits were echoed at Board level, with this having the additional impact and benefit of helping to ground high level decision making in patients' realities and experiences. For patients themselves, sharing their stories was seen to be beneficial in terms of empowering the individual and enabling them to have a 'voice' and to consequently have an impact on the services they use. Supporting case studies suggest that in some trusts patients were particularly keen to share their stories with the organisation. This therefore demonstrates that this is something that patients see the benefit of and wish to be involved in.

Stories provide 'real' insight in support of service improvement

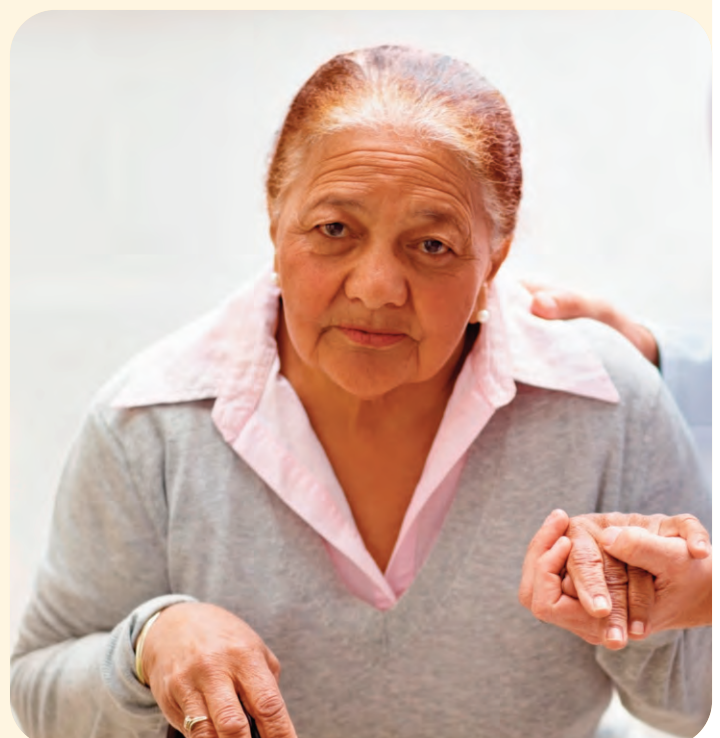
Insight from the review confirms that patient stories have a valuable role in influencing service changes and supporting quality improvements. Respondents were clear that changes and improvements as a result of using patient stories were evident in the development of staff training and development, organisational processes/procedures and improvements to service delivery. The influence of patient stories was characterised by the level of insight into 'real' patient experience that this method of feedback offers, highlighting both areas of good practice from which learning can be shared/spread and areas for improvement.

Changes and improvements as a result of the use of patient stories were identified throughout the trusts, from Board to Ward level. This demonstrates the wide ranging impact that patient stories can have in terms of instigating positive changes and improvements within NHS Trusts and aligning these with the broader Patient Revolution Agenda.

Embed patient stories to create a patient and customer services culture.

Patient stories are seen to be in the process of being integrated and embedded across many of the Trusts, particularly at Board level. Whilst being evidenced as taking place in some of the Trusts, ensuring that patient stories are utilised to their full potential and wholly integrated into all aspects of service delivery and improvement is therefore a key focus for many trusts moving forward.

Individual Trust case studies highlighted a range of innovative approaches to using and embedding patient stories as part of approaches to create a patient and customer services culture. This includes going beyond simply presenting stories to the Board and seeking to animate these experiences for staff at all levels through embedding into staff development and training, departmental and ward feedback discussions and encouraging enhanced engagement of patients and carers as part of their overall approach to creating a patient/customer services centred culture.



Annex A

Patient Stories Checklist for Boards

Background

During 2009-2011 NHS West Midlands commissioned a Burdett Board Development Programme within NHS organisations across the West Midlands. The aim was to strengthen the Boards focus on quality and safety during transition.

The West Midlands SHA programme report 'Sustaining quality during turbulent times; Helping Boards within the West Midlands to Focus on Quality During Turbulent Times', outlined a number of keystones, in the form of checklists that can help anchor a board's attention to quality.

One of those keystones: The Patient Stories Checklist was developed and tested with NHS Trust across the West Midlands as a series of prompts designed to provoke conversation and reflective review of the attention given to quality and the use of Patient Stories by boards.

The Patient Stories Checklist was been suggested by a number of respondents to the 'Online Survey of Patient Stories across the Midlands and East NHS', cited as a valuable resource in supporting the use of Patient Stories within Board meetings.

In light of key recommendations from the second Francis Report into Mid Staffordshire NHS Foundation Trust and in the transition to new structures within NHS, it has never been more timely that organisations and CCGs remind themselves of The Patient Stories Checklist and consider its application in support of the use of Patient Stories with Board meetings.

Whilst originally developed for NHS Trusts, this Patient Stories Checklist is equally applicable to both commissioners and providers moving forward.

Taking Patient Stories to the Board

Patient stories can reveal a great deal about the quality of services, the culture of an organisation, and the effectiveness of mechanisms to manage, improve and assure quality. They also serve as a powerful reminder to organisational leaders of their accountability for quality.

Patient stories can be delivered by patients or their relatives, or staff can tell the story from a patient's perspective, together with what it is like to be a member of staff involved in that persons care.

Good practice is to start the board meeting with a patient story. There is a risk, however, that by hearing a patient story at the start of a meeting, it will take place before the board has settled into its task. Stories can also trigger strong emotional responses in the listener, which need to be anticipated and managed. Patient stories may be more likely to meet with resistance during times of upheaval, as staff become anxious about their futures and less able to respond constructively to stories that show the organisation, or their practice, in a negative light.

It is therefore essential that patient stories are preceded by careful planning, so that everyone is prepared for the story they are about to hear and understand the purpose of sharing it.

Good, well-structured facilitation by the Chair should help in priming the board to listen to patient stories and for the anxiety they may evoke. Executive clinicians should be instrumental in helping to facilitate the session, manage board members' responses to the stories they hear, and help the board identify the actions and learning that fall out of the story.

The Patient Stories checklist that follows is designed to help support good preparation for and facilitation of patient stories in board meetings.

Patient stories checklist

Preparation

What is the purpose for our board of hearing patient stories?

- To understand the impact of causing harm to a patient?
- To use stories to set priorities?
- To nurture a quality-centred culture?
- To road-test the organisation's quality assurance mechanisms?
- To explore how decisions made by the board impact on patient experience?
- To improve our understanding of how harm happens?

Why are we hearing this particular story?

- What sort of story is it?
- How has the story been selected?
- What type of emotional response might the story evoke?
- Will the story show the organisation/staff negatively?
- What questions need to be surfaced from this story?

How is the item going to be managed?

- Who is going to lead this item?
- How is the story going to be told (e.g. verbally, PowerPoint, audio recording, film)?
- If a patient or relative is going to tell the story in person, what preparation have they been given and what support do they need during the meeting?
- If a staff member is going to tell the story what support might they need?
- What preparation will board members need to ensure their questioning is appropriate?
- How much time will be needed for this item?

Discussion

What does this story add to our understanding of the quality of our services?

- How does the story relate to the information contained in our quality or performance report?
- What does this story tell us about progress towards our quality improvement goals?
- What additional information does the board require to help it make sense of the story / put it in context?

What does this story reveal about our staff?

- What does it suggest about morale and organisational culture?
- What does it reveal about the context in which clinicians work?

- What does it reveal staff attitudes to harm?

What actions need to be taken as a result of what we have heard?

- What needs to be done immediately to make things right for the patient and prevent a recurrence for other patients?
- What implications does it have for board decisions?

Review

How did we do in hearing this story?

- Did we give enough time to this item?
- Were we sufficiently prepared?
- What could we have done differently?

Does this story raise any learning needs for board members?

- What additional support do board members need in hearing patient stories?
- Do board members wish to find out more about the processes for examining failures (e.g. significant event analysis, root cause analysis)?
- Has the story evoked anxieties that members wish to talk through outside of the meeting?

Additional key considerations for Boards arising from feedback from organisations in the use of Patient Stories;

- What additional support do board members need in hearing patient stories?
- Do board members wish to find out more about the processes for examining failures (e.g. significant event analysis, root cause analysis)?
- Has the story evoked anxieties that members wish to talk through outside of the meeting?



Other Useful Resources

Using patient stories with boards, Patient Safety First Campaign

<http://www.patientsafetyfirst.nhs.uk/ashx/Asset.ashx?path=/Intervention-support/Patient%20stories%20how%20to%20guide%2020100223.pdf>

Guidelines for telling 'patient stories' with boards of directors, Delnor-Community Hospital, Geneva, Illinois, USA. Institute for Healthcare Improvement

<http://www.ihl.org/IHI/Topics/LeadingSystemImprovement/Leadership/Tools/GuidelinesforUsingPatientStorieswithBoardsOfDirectors.htm>