

In their shoes

Building a culture of listening



Why listen?

The system must have a stronger focus on improving patients' experience of care.

Targeting Zero: Supporting the Victorian hospital system to eliminate avoidable harm and strengthen quality of care

Patient stories bring experiences to life and make them accessible. They encourage focus on the patient as a whole person rather than just a clinical condition or an outcome. Collectively, stories can help us build a picture of what it is like as a service-user and how we can improve the service we provide. Using specific patient stories to complement quantitative data reports can be a powerful way of increasing focus and engagement with quality and safety issues.

1000 Lives: Learning to use patient stories

Improving patient safety and quality of care is an ongoing imperative supported by the efforts of the entire public health sector. In the Victorian system, there is an increased focus on recognising and supporting users of the health system as active participants, not only improving their own care, but improving the systems and delivery of care to benefit others as well.

This toolkit draws on international experiences and local examples to provide a practical guide to incorporating the patient's voice to improve board governance and strategic management, in line with the Victorian Clinical Governance Policy Framework. Patient stories assist boards to better understand their core business – that of providing healthcare where the experience of care will have an impact on satisfaction and better patient outcomes.

The strategy of stories

The need to continually build a culture of listening is not a new one. Throughout history, society has relied on stories to pass on learnings, share experiences, entertain and educate. What is less understood is the role of stories in strategic oversight of complex organisations. In essence, stories create an experience that lets strategy be understood at a personal level and provides a powerful platform to achieve a number of strategic objectives.

Embracing patient stories and building a focus on the patient voice enables Boards to gain a more complete understanding of the impact of their strategic direction and increases engagement across all levels of the organisation.

Matching stories to strategies

| Objective | Method | Example |
|---------------------------------------|--|---|
| Sparking action | Description of a successful change implemented in the past, allowing the audience to imagine how it might work in their situation | A new team member reveals a change to the layout of the waiting room at their previous hospital and the glowing patient feedback it received |
| Personal identity | Providing personal experiences that may reveal strength or vulnerabilities from your past | A leader recalls a time they were unsure about the best course of action and outlines the discussion with a patient to decide on the best course of action |
| Transmitting values | Using familiar situations and responses to prompt discussions about the values being promoted | During an outpatients clinic appointment, a patient shares their frustrations with the blunt language used in letters advising of follow up needed after discharge |
| Corporate identity | Normally delivered through third-party feedback such as patient's word-of-mouth | An email from a patient after their recent stay praises the nursing staff on a particular ward for their pleasant nature and the feeling of care they received |
| Improving collaboration | Recounting a shared experience that prompts the audience to also share their own stories about the topic | A patient's family recall the manner in which the surgical teams caring for their son made sure everyone knew what was planned as part of their son's care |
| Taming the grapevine | Highlighting aspects of rumours that may reveal it to be untrue or unreasonable, often through the use of funny or exaggerated stories | Long-term patients with chronic conditions are asked about rumours that the clinic will be reducing its hours |
| Sharing knowledge | Spending time to focus on mistakes made and lessons learned from correcting the mistake or ensuring it does not recur. | A clinician shares a story of harm to a patient that could have been prevented and outlines the steps taken to ensure it never happens again |
| Leading people into the future | Evocative or inspirational stories about the desired future state, being careful not to use excessive detail that may turn out to be incorrect | A research team visits a local facility considered to be offering best-practice service and hears from patients about the differences in their own service offering |

Adapted from Adamson, 2006.

The impact of a story

Background

Mildura Base Hospital introduced the #hellomynameis campaign after the hospital reviewed feedback from one of its emergency patients, Sheryl.

“She explained to me that she had come into the hospital with her 18-month-old grandson, with her daughter and son-in-law, and the experience she had when she went through the emergency department was quite negative,” explained Jenni Lloyd, the project lead for implementing the campaign.

“There was no introduction from the hospital staff to Sheryl herself, or her daughter. Sheryl said that because of this, they didn’t know who to ask about her grandson’s care, so they didn’t.”



The Executive Team at Mildura Base Hospital

Action

Staff at Mildura Base Hospital introduced a new program to improve communication between carers and patients following discussion of the patient’s story.

The hospital adopted the #hellomynameis campaign founded by Dr Kate Grainger in the United Kingdom, which encourages carers to introduce themselves and their role to each patient.

Outcomes

The program has been credited with improving organisational culture, as well as improving communication with patients.

“It is such a simple idea. It is so easy to forget to say your name,” said Dr Alison Walker, Director of Medical Services. “When patients come in, they are often anxious or nervous, but just seeing a friendly face and having someone tell them who they are is really vital to putting them at ease.”

The culture of introductions was also improving communication between carers, she said.

“We have a lot of doctors that rotate through here, and they don’t know anyone here. Having that culture of saying who you are and why you are there is really important,” Dr Walker said.

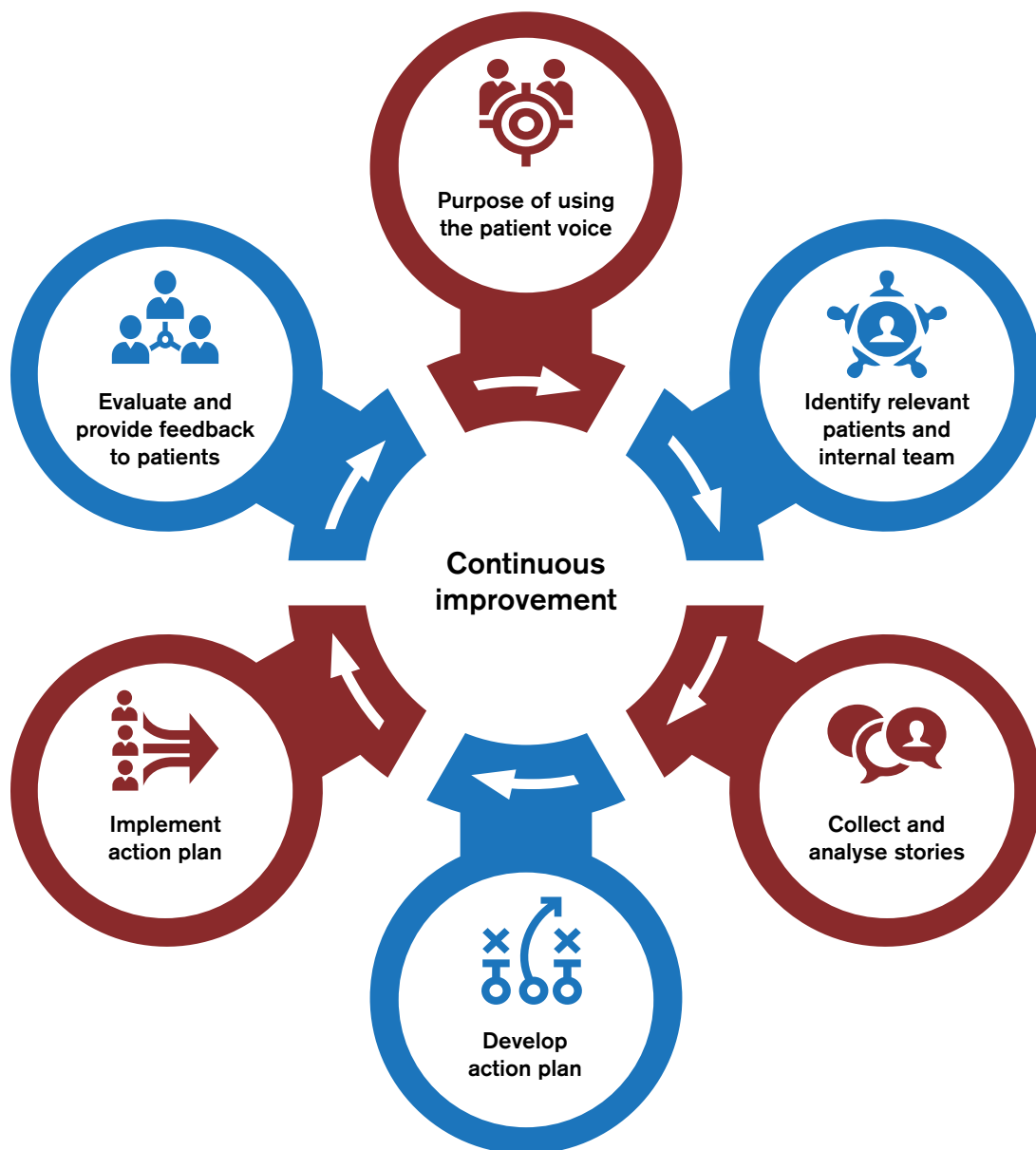
The program has been fully embraced by all levels of the organisation from the Board to operations.

View the full story at www.vmia.vic.gov.au/patientvoice

How to listen

The use of patient stories compliments other methods used to capture the patient voice. The stories can compliment, contrast, amplify and contradict other sources available to the board (for example, patient satisfaction surveys). Including patient stories as a structured and formalised component of board meetings requires an operational framework to increase effectiveness.

The following serves as an outline for establishing a framework.





Purpose of using the patient voice

Patient stories are an effective way to understand the patient experience, however they may not be suitable for all situations.

Before commencing, ensure the use of patient stories will assist and support your strategic objectives. Establishing a well defined aim of the project will ensure you attract the right team and build a strong platform for action.

Questions for Executive and Operations

Is the use of a patient story **appropriate** for this situation?

Have we considered **other means of patient feedback** such as questionnaires, focus groups or diaries?

Are we looking at a **broad issue** that may have many patient voices, or focusing on a specific aspect of our service?

Questions for Board

Would it be useful to **hear directly** from our end-users in relation to this issue?

What part of the story are we **'missing'**?

Who is likely to be **most impacted** by the decision we are making?



Identify relevant patients and internal team

Collecting appropriate patient stories does not need to be complex and will be more efficient and effective if a team approach is used. Including a variety of disciplines in the collection process will enable team members to offer different perspectives from the same story and maximise the potential impact of each story.

Identifying possible story tellers can come from a variety of sources, and it is important to remember the possible contributions of different groups involved in a patient's care such as the patient themselves, the patient's family, carers, clinicians and other hospital staff.

The following may assist:

- Utilise existing networks where possible, and consider including opt-in options in existing consumer feedback channels as a possible source of patient stories.
- Remember, everyone involved in caring for patients is equipped to gather patient stories – involve team members from different professional roles to get a broad range of perspectives.
- It's best if the person collecting the story has not had direct involvement in care for the patient, to more accurately retell the story and remove the patient's fear of retribution if the story is not as positive as it could be.
- Consider partnering separate areas of the hospital to collect stories for each other.

Questions for Executive and Operations

What is the **most efficient** method for identifying patients for follow up?

How should we **'spread the load'** of collecting patient stories?

Is our purpose better served by a **variety of stories**, or from targeted **'deep dive'** captures of the patient experience?

Questions for Board

How are we ensuring that we receive patient stories from a **good cross section** of our patient population?

Are we hearing patient stories reflecting **all aspects** of the patient experience?

Is the feedback we are getting skewed in a particular direction? Is this a result of cognitive bias or an **accurate reflection** of reality?





Collect and analyse stories

Once patients have been identified to share their story, decisions need to be made on how to capture the story, for example, through filming or in written form.

Consider the logistics of timing, locations and methods of recording stories, as highlighted by the experiences of the 1000 Lives campaign in Wales (see references for further reading).

Timing should allow a sufficient gap between the incident/s and the story telling to enable the patient to feel comfortable sharing – if it is too early, some may feel that sharing their story may influence the care they continue to receive.

The 1000 Lives project also showed that the physical location of the story telling was a key factor, with many patients unwilling to return to the environment associated with the story. This meant that some patients told their stories in managers' offices instead of the ward, for example, or in other more neutral locations.

The medium for recording also contributes to the effectiveness of the story. An audio recording allows the story teller and recorder to concentrate on the story at hand, while a video recording may provide a more complete capture of the story telling process it is also a more intrusive experience for the story teller.

In some cases, a balance may be found between recording the story and re-recording stories or recreating stories in other mediums if needed in specific instances. The experience from the 1000 Lives campaign revealed three to six patient stories normally provided sufficient material for the projects delivered.

Questions for Executive and Operations

What is the **best location** for stories to be told?

Do we need **special equipment** to capture or record the stories?

What **timeframe** is most appropriate to record the stories?

How can we **work with the story teller** to ensure that the stories are captured appropriately?

Have we been **open and honest** with the story teller about what outcomes we are expecting as a result of their story being shared to ensure their expectations are met?

Questions for Board

Is there a format that makes it **easier to receive** the stories? Is this format easy to deliver?

Does this patient story deserve a **wider audience** (perhaps as a service improvement tool)?

Does the patient story have **enough context** to be effective?



Established networks

Utilising established networks, such as community advisory committees, can provide strong support as a source of patient stories and through established processes to ensure patients are as comfortable as possible providing feedback and sharing their insights.

The ethics of stories

It's important that the process of collecting and using patient stories is conducted ethically. Your organisation may already have guidelines for collecting and analysing feedback in an appropriate manner.

Unless the patient stories are being collected for a research project, it is unlikely the process of collecting stories will need formal ethics committee approval, however the following may assist:

- *Patients should receive information about why the story is being collected, where it will be used and how they will receive feedback about any outcomes from the use of the story.*
- *Stories should be collected without the story teller feeling any direct or implied pressure to share.*
- *Formal consent to collect the story should be obtained.*
- *Privacy and confidentiality of patient stories should be clearly defined and respected.*
- *Make sure the story teller is aware that if they raise issues that highlight risks to others, then action will need to be taken to address those risks.*
- *Provide support to the story teller, if they need it. Allow the story teller to stop at any time.*
- *Allow the story teller to withdraw their permission for the story to be used at any time.*
- *Do everything possible to ensure the story teller is comfortable telling their story, whether it be through providing good communication in the lead up to the story telling, a comfortable setting to tell the story and appropriate follow up once the story has been told.*

Adapted from *1000 Lives : Learning to use patient stories*



Develop action plan

As a team, it's important to discuss the key learnings from each patient story and identify a possible action plan for changes or improvements. Mind mapping processes or discussion among multi-disciplinary teams will allow for a variety of perspectives to be included in this process.

Presenting an evidence based action plan supported by a well-aligned patient story is a compelling presentation to a board and will improve the effectiveness of the use of patient stories in a governance setting.

Questions for Executive and Operations

What are the obvious **opportunities for improvement** raised by issues in this patient story?

Have we ensured that we have captured a wide range of perspectives on this story to **maximise its usefulness**?

Where does this story fit in the health service's overall quality improvement program – does it **confirm our actions** or suggest a wider scope or **different direction** is required?

Questions for Board

To what extent does this story represent a **wider issue** at our health service?

What are the **key learnings** from this story?

Is an **immediate response** required to issues raised by this story?



Implement action plan

Once an action plan is developed, implementation is supported through the use of a patient story, particularly in those instances where organisations are seeking to create a 'burning platform for change'.

Consider if the patient story could be used in the following ways:

- to **inspire** team members to remember that patients are at the core of what we do and why we do it, and to realise the strong impact that our actions will have on the patient's experience
- to **educate** our team members about the need for patients to be considered an equal partner in delivering quality healthcare and to highlight the value they add to this
- to **reinforce** positive cultural and behavioural programs within the healthcare organisation through continued demonstration of the impact of these programs on patient's lives.

Questions for Executive and Operations

Is there a **story behind the story**, where one patient's experience highlights a wider cultural or systemic issue?

Does this patient story make it clear exactly **why** changes are being made?

Does this story highlight a **'burning platform for change'** at an emotional level?

Questions for Board

Is this improvement program limited to the team where it originated, or are their wider implications **across the organisation**?

What can we **learn** through the implementation of this program?





Evaluate and provide feedback to patients

Although it is unlikely that every patient story will lead to wide ranging system or culture changes, it is important to provide feedback to every patient who has been willing to share their story.

This process need not be exhaustive, however thanking the patient for their willingness to share and expressing an ongoing desire to improving the quality of care is the bare necessity of acknowledgement.

Questions for Executive and Operations

Has **anything changed** as a result of this story being shared?

Have the **messages** from the patient's story been delivered to the right audiences?

What is the most **appropriate form of follow-up** with the patient after they have shared their story?

Questions for Board

What is an appropriate form of **acknowledging the patient's contribution** to the oversight function?

What can be done to demonstrate the **value of patient stories** to the board's governance at the health service?



Getting started

Your organisation may already have established processes for collecting and using patient stories, or this may be done on a more informal or ad-hoc basis. Take the time to consider the possible benefits of increased use of patient stories in your healthcare organisation and see what lessons can be learned from the stories already shared.

VMIA has a range of online materials available on its website to support organisations in increasing their focus on the patient voice, available at www.vmia.vic.gov.au/patientvoice

The site also features a number of case studies and examples where the patient voice has been used to improve healthcare.

In their shoes

The *In their shoes* video series features three patient stories:

It could be me follows a typical patient journey through the health system from consultation to surgery and rehabilitation. At each step of the journey, the healthcare clinician becomes the patient in the subsequent step, reinforcing the concept of caring for others as you would wish to be cared for yourself.



Experienced general practitioner Dr Philip Worboys shares his story of survival in *It was me*. Dr Worboys was riding a bicycle when he was hit by a car at high-speed, leaving him in the complete care of healthcare workers to save him from his critical condition. He offers rare insight into what it is like to be a patient from the perspective of a doctor.

Dr Rachel Rosler shares her story in *It was my daughter*, as she considers the patient experience from a mother's perspective. Dr Rosler's daughter was born prematurely at 26 weeks, resulting in a range of ongoing health issues. The importance of caring for patient families as well as patients is highlighted in this story.

James Titcombe webinar

James Titcombe is a consumer and patient safety specialist from the United Kingdom, who shares his personal story of losing his newborn son in 2008. Since his son's death James has been a tireless campaigner to improve the healthcare system and is an excellent example of the power of the patient's voice to influence widespread change.

#hellomynameis

The #hellomynameis campaign was introduced at Mildura Base Hospital as a direct result of a patient sharing their story at the health service. A series of videos examines the reason for the campaign and the practical aspects of using patient stories to influence systemic and cultural change.

References and further reading

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