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Cover Page Footnote

Conflicts of Interest DPR is a full-time employee of Five02 Labs, Inc., and is under contract to a number of not for profit organizations to provide patient engagement support. She received an honorarium and consulting fees for involvement in the Working Group and for leading writing of this manuscript. KS received honoraria for involvement in the Working Group and the manuscript writing. IJ was employed HEC's embedded Patient Partner when the Storytelling Working Group was struck and developed the recommendations. IJ received an honorarium for involvement in the manuscript writing. Authors' Contributions DPR and CAF led the conception of the manuscript. DPR led writing of the manuscript. DPR, KS, LH, IJ, CAF made substantial contributions to the design, analysis of the work, and in writing and revising the manuscript. Authors' information We have not filled in the Guidance for Reporting Involvement of Patients and the Public for this commentary and instead would like to note that authors (DPR, IJ, KS) identify as patient partners. Acknowledgements The authors would like to thank Storytelling Working Group members Dr. Arika Lafontaine and Ms. Barbara Sklar for their contributions to the work that is presented in this publication, and to Ms. Maria Judd for her review and editorial advice. This article is associated with the Infrastructure & Governance lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_InfraGov

Storytelling at board meetings: A case study of co-developing recommendations

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Abstract

In healthcare, stories shared by patients often provide details and insights into experiences of illness and care. Stories are a way to educate healthcare providers and others to improve care and systems to become more patient and family centred and to better meet patients' needs and priorities. Telling stories may bring benefits to both storytellers and audience members but also presents risks of harm. A reflective storytelling practice aims to honor stories and storytellers by ensuring there is time to prepare, reflect, learn, ask questions, and engage in dialogue with the storyteller to explore what went well and where there are learning and improvement opportunities.

Healthcare Excellence Canada (HEC) is a pan-Canadian health organization focused on improving the quality and safety of care in Canada. HEC commits to engage patients, caregivers, and communities and aims to develop practices and structures to enable engagement activities. At the request of the HEC Board, the Patient Engagement and Partnerships team co-developed recommendations on the process for how best to meaningfully share stories at Board meetings, including stories from those leading, providing, and receiving care. This Case Study outlines the process HEC used to co-develop storytelling recommendations, focusing on a trauma-informed approach to create safe spaces for preparing, learning from and reflecting on stories, to clearly articulate their purpose, and to ensure the locus of control for storytelling rests with the storytellers. This Case Study shares these recommendations and invites other organizations to use these recommendations and/or adapt them within their own context.

Keywords

Patient and caregiver stories, patient experience, storytelling recommendations, leadership, governance, patient engagement

Introduction

Storytelling is an act of human connection and has been part of human nature in cultures around the world. In healthcare, stories shared by patients often provide personal details and insights into experiences of illness and of care, and increasingly have been used as a means to educate healthcare providers and others to improve care and systems of care that better meet patients' needs and priorities.¹⁻⁶ The word 'patient' used here may include individuals with personal experience of a health issue (who may also prefer to call themselves clients or residents) and informal caregivers, including family and friends.⁷ The active sharing of stories, by both those receiving and providing care, can and has led to opportunities for improvements in quality and safety of care by putting a 'face' to the data that is typically used to monitor quality and safety. Real-life stories can provide an opening to critically reflect on experiences from others' perspectives,

and may offer an opportunity to engage in dialogue and interactions that prompt learning at affective, cognitive and experiential levels that are often not possible through other means.^{4,5,8-10} Patients and their caregivers who share their stories have identified the therapeutic benefit of feeling listened to and validated, as well as a sense of catharsis and satisfaction knowing that their experiences may contribute to improving the health care system and ultimately the experiences of other patients.^{4,11} However, patient stories also highlight an emotional vulnerability that comes with their sharing and potential harms and risks to patients and caregivers when sharing painful or difficult experiences⁴ include their increased stress and anxiety, possible negative physical effects, decreased quality of life, and even re-traumatization especially if it is felt that the experience is unacknowledged or dismissed, with no discernible action or learning as a result.^{9,11} The act of storytelling is not a simple one, and its potential

benefits must be carefully considered together with its potential risks to maintain the respect and safety for all.⁶

Creating a safe space for all involved in the storytelling experience needs thoughtfulness and careful planning, particularly when those with lived experience are invited to share their experiences. It requires ensuring the audience is prepared to be active listeners to receive the story, and considering the intended purpose of asking individuals to re-live their healthcare and life experiences.² This reflective practice for storytelling contemplates the purpose of the practice, aligns intentions of the audience with the storyteller, and ensures that stories are not co-opted or appropriated in ways that do not serve their original intent.^{1,9} A reflective practice for storytelling aims to honour stories and storytellers by ensuring there is time to reflect, to learn, to ask questions, and to engage in dialogue with the storyteller to further explore what went well and where the opportunities are for learning and improvement.^{6,8} Importantly, ‘closing the loop’ with storytellers allows them to understand what listeners did with, or as a result of hearing, their story.¹²

Background

Sharing of patients’ stories was an early feature of patient engagement efforts, a movement that has continued to evolve over the past decade.^{13,14} The sharing of stories provides insights into patients’ experiences, and stories are often featured at conferences, workshops, and other meetings.¹⁵ Hawthornthwaite *et al’s* work shows that stories were categorized as offering lessons, inspiration, and reminders of compassionate patient- and family-centered care.² At the health governance level, patient stories are encouraged as a way to connect hearts and minds to issues being attended to by boards, particularly as they relate to patient safety concerns.^{4,16-18} In 2021, the Canadian Patient Safety Institute and the Canadian Foundation for Healthcare Improvement formally amalgamated to create Healthcare Excellence Canada (HEC), a newly formed pan-Canadian health organization with a focus to improve the quality and safety of care for everyone in Canada. HEC’s legacy organizations had a longstanding commitment to patient, family and caregiver engagement, partnering with patients and caregivers within their organizations and recognizing their valuable contributions to the quality and safety of care. HEC seeks to build on its strength for engagement and partnership, and as a new organization, is determined to ground its work in the experiences of those receiving and providing care. In particular, HEC’s transition Board (in place for the first year of the new organization) expressed a desire to hear experiences of the health system directly from those receiving care, providers and leaders, and to do so in meaningful ways that will continue to influence the work of the organization. As such, HEC’s Patient Engagement and Partnerships team was tasked with developing

recommendations on the process for how best support those receiving, providing, and leading care to prepare for and share stories at board meetings. It is recognized that these recommendations may also be used for other venues where storytelling is a tactic, such as at healthcare conferences, in patient and family advisory committees, and more.

This Case Study outlines the collaborative process HEC used to co-develop storytelling recommendations and highlights the recommendations that emerged. It is noted that stories may include a range of positive and negative experiences and be from the perspectives of those receiving care, providing care, and/or leading care. The recommendations highlight the need to use a trauma-informed approach to create safe spaces for learning and reflection, and to ensure the locus of control for storytelling rests with the storytellers. This Case Study serves as an invitation to other health organizations to use these recommendations and/or adapt them within their own context.

Co-Development Approach for Storytelling

To model its collaborative approach (Figure 1), HEC developed a ‘Storytelling Working Group’ tasked with co-creating storytelling recommendations for its Board using a consensus-driven model. The Working Group was purposefully comprised of individuals from various parts of Canada who brought a mix of health care perspectives, experience, and interest in storytelling methods. Two staff members from HEC were appointed as co-chairs (embedded Patient Partner and Director, Patient Engagement and Partnerships). Membership included three patient partners, a healthcare provider/physician leader, and a patient experience specialist, all invited by and external to HEC. As part of project onboarding, the Working Group was provided with a draft terms of reference document and was given the opportunity to refine and amend to ensure clarity of purpose, roles, and expectations. The Working Group met several times over a 2-month period to co-develop these recommendations, providing feedback and input to the recommendations as they were developed iteratively. Patient partners had the option to receive or decline an honorarium for their contributions to the Working Group.

Figure 1: Approach to Collaboration

- Inclusive
- Flexible
- Diversity of perspectives

HEC supported the Working Group logistically and administratively. Meeting agendas and previous meeting notes were provided in advance of meetings, and members had the opportunity to contribute to both and amend meeting notes as needed. Based on the discussions of the Working Group, the co-chairs then created and updated drafts of the storytelling recommendations with each consecutive meeting. Key items on which consensus was not reached were discussed until consensus was reached, which sometimes meant that topics carried over from one meeting to another. All members of the Working Group were able to express their perspectives, and every effort was made to create a safe environment to enable open, honest dialogue amongst members. This work occurred during a global pandemic, during which many members had competing priorities, so efforts were made to ensure contributions could be provided. For example, virtual meetings were scheduled when the majority of Working Group members could attend, however, if a Working Group member was unable to attend a scheduled meeting, they could provide feedback via writing or via a call with one of the co-chairs. This approach to co-development ensured everyone had an opportunity to contribute even if not able to attend meetings.

Co-Developed Storytelling Recommendations

The recommendations discussed below have been built upon the lived experiences of the Working Group members who brought varying perspectives of storytelling to the fore and are grounded in emerging evidence related to storytelling practices in healthcare. They are highlighted in Figure 2.

Foundational principles for storytelling

Underpinning the recommendations are two foundational principles for storytelling to ensure stories and storytellers are honoured in the spirit of sharing and safety.

Figure 2. Co-Developed Storytelling Recommendations

Foundational principles for storytelling

1. Clear understanding of the purpose of storytelling
2. Locus of control remains with storyteller

Recommendations for storytelling

1. Articulate the why: what is the purpose of storytelling?
2. When/how often should stories be shared?
3. How should stories be shared?
4. How to identify storytellers?
5. How will stories promote learning and change?
6. What happens after the story is shared?
7. Evaluation of storytelling

1. **Clear understanding of the purpose.** A clear intent is required for stories to be shared at any meeting as a deliberate tool to inform work, and to offer an opening for ongoing learning, reflection, and action.
2. **Locus of control.** There is a real importance for individuals who share their stories to remain in control over decisions regarding what is shared and how and where their story is shared.¹⁹ The storyteller maintains choice and control regarding if and how they share their story, their ongoing involvement in discussions and ongoing work that may ensue as a result of sharing their story, and how they would like to be recognized for sharing their experiences.²⁰⁻²⁶

Below, we further articulate how these principles underlie the recommendations in action. These principles are consistent with many best practices emerging from engagement practices, particularly starting with clarity of purpose that supports understanding expectations for all involved.^{27,28} Storytelling is a highly personal endeavour and ensuring that the storyteller has control of their experiences is paramount to ensure authenticity and respect for the story and storyteller.

Recommendations for Storytelling

Building from these foundational principles, and to maximize the potential of storytelling for learning and improvement, the Working Group co-developed the following recommendations that focus on the why, when, and how of storytelling, ensuring preparation of both storyteller and audience, and considerations for learning and evaluation.

1. **Articulate the why: what is the purpose of storytelling?**

It needs to be clearly articulated why a board wishes to have a story or stories shared at their meeting(s) and what purpose stories will serve to inform the board's actions and decisions.¹¹ Boards are asked to consider stories being presented to move beyond inspiration or to serve as a 'connection to the work,' by taking an action-oriented focus to consider what the organization will do with knowledge gained from the story. Storytellers want to know that their lived experiences have the potential to incite change and to contribute to improvements. The 'why' needs to be considered from the storyteller's point of view to ensure that it is connected to that of the board. When 'why's' are aligned and shared purpose and goals for storytelling identified, the potential for harm, including tokenism, is minimized.²⁹ Having storytellers share stories without clear purpose runs a risk of tokenism for both the storyteller and for the organization asking them to share their story.^{15,30}

2. When/how often should stories be shared?

Stories should only be shared at board meetings when there is a clear articulation of the purpose that links with the agenda of what is to be discussed, rather than as a standing agenda item. This maintains using storytelling strategically to prompt learning, reflection, and action at board meetings when enough time is granted for storytelling. Storytelling should be seen as a unique tool given the time and energy required to create a safe and welcoming environment to support people in preparing their stories and to prepare the audience to receive the story.

3. How should stories be shared?

There are a number of considerations for how stories may be shared.

Format: The locus of control should remain with the storyteller(s) in terms of if and what they choose to share and how they would like to share it (e.g., in person/virtual format, videorecording, written, read by someone appointed by the storyteller).¹⁹ Any media that is created (e.g., PowerPoint slides, videos, podcasts, etc.) to share the story must remain the property of the storyteller so they can choose to share later in their own way, and in their own time as they wish, or provide consent for their use. The preference is not to 'brand' the story as one that belongs to the organization to which the individual is presenting unless the storyteller chooses and consents to do so.

Confidentiality: Confidentiality of the story must be maintained and is part of creating a safe space in which storytellers may share. Consent from the storyteller is required if the story is shared outside of the original session in any manner.³¹ The storyteller's preferences regarding consent must be solicited, documented and shared with those involved. Consent may be revoked at any time by the storyteller.

Preparation for storytellers: Storytellers require preparation before, during, and after sharing their story.^{2,27,32} A liaison/staff role is helpful for this purpose and should be fulfilled by a staff member with the required expertise to operationalize how stories are introduced at the board and to support the storytellers. This may be a role best suited for a staff member within an organization's patient engagement (or equivalent) team. Board members who have comfort and expertise with storytelling may be involved in facilitating discussion following the sharing of the story, if appropriate.

In advance of storytelling. The storyteller should be clear about the shared purpose of telling their story and provided with details on logistics (e.g., estimated size and composition of the audience, time allotted for

storytelling and discussion, date and time of the session). The storyteller should be supported to choose what they focus on in their story and to ensure the story remains authentic to them in their own words.^{2,14} If required, storytellers should be coached to ensure confidentiality of those involved in the story and in how the story may be framed for learning (e.g., not 'blame and shame,' focusing on patterns rather than people).³³ A budget is required for storytelling and is part of an equity-based approach to ensure barriers to participate are removed. The budget may be in the form of a staff liaison's time or in forms of offering recognition to (e.g., monetary and non-monetary compensation) and at a minimum, covering expenses for (which are separate from compensation, and as much as possible, should be paid in advance to minimize out of pocket expenses for the storyteller) the storyteller. If the organization has a policy or framework for recognition, this should be discussed with the storyteller and options provided in advance.²⁰⁻²⁶ If a storyteller does not wish to receive compensation, it remains important to earmark a budget for this purpose or disperse it to other areas of an organization's patient engagement activities. This approach helps organizations adequately budget for patient engagement efforts overall, signalling the importance of engagement work and recognizing the value of those involved. Storytellers should be provided the option to participate in discussions following the sharing of their story if they wish to be and are comfortable with doing so. For some storytellers, this may be important while others may not wish to be involved in such activities.

At the time the story is shared. The organization's employee liaising with the storyteller(s) should be responsible for ensuring the storyteller(s) is introduced and is comfortable in the environment. They may act as a support person as needed.²

After the story is shared. The organization's storyteller liaison should provide support as needed and debrief on the experience with the storyteller(s), including providing support on how the storyteller wants to improve their impact at an appropriate time. The storyteller(s) may require further support (peer or professional) at a later time which should be provided by or facilitated by the organization if this is needed. The organizational liaison should ensure that the outcomes as a result of storytelling are communicated to storytellers in a timely manner. This 'closing the loop' with the storyteller(s) is often missing from engagement activities, can influence how storytellers perceive their experience¹² and may help storytellers understand how their experiences have influenced the work of others.

Preparation for the audience. To make the storytelling experience meaningful for all involved, preparation of the audience is also required. Similar to storytellers, there are three timepoints at which to prepare the audience.

In advance of the storytelling. The organization's storytelling liaison should support the audience (in this case, the board) to articulate the purpose of the story/stories to be shared and to acknowledge the vulnerability of sharing a story that is open to the reality of trauma. The audience needs to be aware of the potential dynamics that may be created with the storyteller and to minimize any power imbalances by creating a safe space for sharing. For example, if the storyteller is a patient or caregiver, they may have experienced power imbalances in healthcare, which should not be replicated when sharing their story. Engaging with an audience that is listening with intent and asking questions at appropriate times helps to create a safe place for someone to share what may be very vulnerable and personal experiences.²

During the storytelling session. The storytelling liaison should support the audience to take an active approach to engaging with the story and storyteller, that helps a storyteller feel listened to rather than watched.⁹ A facilitated discussion (led by the storytelling liaison or other appointed person) further supports learning and intentional dialogue to engage with the story.² Learning from a story means accepting the lived experience of the storyteller as *their truth* of the experience; it does not mean interrogating or invalidating their experience(s), but rather explores the lessons that can be learned from the experience and how things can be made better.

After the storytelling session. Supports may be required for the audience given that stories may trigger feelings of discomfort or even trauma based on their own experiences. The staff liaison may need to support board members following the session.

4. How to identify storytellers?

Matching the storyteller to the purpose of storytelling is emphasized. In some cases, storytellers may be those involved in an organization's current/past initiatives. An equity approach will help understand more experiences broadly within the health system and recognizes that different individuals may need different supports to be engaged, especially if they have experienced structural barriers within the health system. Intentional outreach to communities most affected by the topic area being covered will provide additional and new insights to connect to the work of the organization.³⁴ Establishing relationships proactively with diverse communities that bring a

range of lived experiences (including those that are underserved in the health system) may help develop trust and allow a network from which to invite storytellers rather than doing so close to deadlines (which may be more acceptable when storytellers are already engaged with the organization). Ideally these communities are also engaged in other ways with the organization, rather than only for storytelling purposes which risks tokenism. An ethic of 'bringing in new voices,' along with those who are more experienced in sharing their lived experience is encouraged and emphasized.

5. How will stories promote learning and change?

Rather than only time for hearing a story, time needs to be built into the agenda for facilitated discussion and intentional dialogue to enable learning and to consider actions to be taken as a result of the story.^{5,8} It is the choice of storyteller(s) as to whether or not to be involved in these discussions. The organization's storytelling liaison may work with the storyteller in advance to develop guiding questions for discussion after the storytelling and to focus on lessons learned as a result of their story.

6. What happens after a story is shared?

Beyond expressing appreciation for the storyteller's time and energy, follow up is required to share any outcomes that may have resulted from the sharing of their story.^{12,27} Ideally, and if the storyteller wishes to, there is opportunity for them to remain engaged with the organization in improvement efforts or other efforts that result from the storytelling engagement. Not all storytellers will want or expect continued engagement, but this should be an option for them to decide upon.

7. Evaluation of storytelling

Evaluation is not meant to evaluate the storytellers or their stories, rather to reflect upon the process and impacts of storytelling and should consider how an evaluation will be used and what purpose the evaluation serves.³⁵⁻³⁷ Evaluation needs to consider varying perspectives, including that of storytellers, the audience (including board members) and the staff liaison. Evaluation is important to demonstrate the value of storytelling within an organization and to justify it being sustained over the long term.

Evaluation may occur at levels that serve different purposes:

Iterative learning on the process of storytelling: From storyteller, audience, and staff liaison perspectives, this type of evaluation considers what went well with the sharing of stories and how things could be improved. For example: What impact did hearing the

story have for you? Were diverse storytellers engaged using an equity, diversity, inclusion lens that welcomed many voices? Were the storytellers and audience well prepared (that is, ensuring that the act of storytelling is not performative)? Was there a good fit to match storyteller with purpose? Was there shared purpose for storytelling? Was a safe environment created? Was the loop closed with storytellers?²

Immediate impacts of storytelling: This type of evaluation explores what learnings the board took away at the time of the story.

Longer term impacts: This type of evaluation examines the impact of stories in the longer term, for example, for board functions on mission/vision/strategy and financial accountabilities. This considers if the stories influenced deliberations by the board and subsequent work of the organization, that is, did the sharing of stories help the board carry out its role?

Lessons learned through storytelling may also be aggregated over time and shared with the board, and potentially more broadly to influence storytelling practices. This may include sharing practices and lessons learned through publication or conferences. Further, it is good practice to share gathered feedback with storytellers about their session.

Next Steps for Storytelling

As a newly formed organization with a five-year strategic plan that articulates its commitment to ground the work of improvement and safety in the lived experiences of those using and working within the health system, listening and responding to these experiences shared through storytelling approaches will be central to the work moving forward. At the time of this writing, the transition Board of HEC endorsed these recommendations, to ensure there is shared purpose in inviting stories at the Board and intentional learning and action that will result. As a relatively new organization, HEC has recently moved from a transition Board to its permanent Board composition. While the recommendations have not been fully implemented, stories have been shared at the Board level which were supplied through a partner organization, and which were delivered in the spirit and philosophy of these recommendations. The storytelling included space and time for facilitated discussion and guiding questions for board members to discuss and consider in relation to current work being proposed within HEC. The same exercise was undertaken with staff to provide an entry point for discussion regarding new work at HEC, and to understand the 'why' from many perspectives, including those with lived experience of the system. HEC is currently developing processes to implement these

recommendations to support future requests by the Board for storytelling at their meetings.

These storytelling recommendations will also be taken and adapted for work within HEC more broadly (e.g., programming, communications, etc.) with ongoing iterative evaluation to ensure that various areas within HEC continue to meaningfully listen to the voices of those who deliver and receive care, and to refine and augment HEC's engagement practices. HEC has already taken the step of offering externally facilitated storytelling workshops to all staff as a means for staff to consider how stories may be honoured and respectfully shared in the work of the organization. There is opportunity to contribute to the growing body of literature regarding storytelling in healthcare, and to ensure practices honour and create safety for the stories shared and storytellers.

Conclusion

Storytelling in healthcare provides an opportunity for learning and improvement, albeit one that requires consideration and planning to create a safe space for storytellers and listeners. A thoughtful and intentional structure to a storytelling approach respects storytellers who share intimate experiences that may re-expose them to potential benefits and harms, and demonstrates the commitment that organizations are making to better understanding lived experiences. This Case Study shares newly co-developed recommendations for a process to be used at Healthcare Excellence Canada Board meetings to share stories from those delivering, leading, and receiving care. The collaborative process by which these recommendations were co-developed, through a consensus-driven approach with a Storytelling Working Group that was purposefully comprised to include a variety of perspectives, models the way in which HEC aims to engage and partner in meaningful ways with patients, caregivers, providers and leaders. The recommendations aim to ensure storytellers are honoured through creating a safe space in which learning is intended. Others are invited to use and adapt these storytelling recommendations within their own contexts (which may also include for conference or other committee purposes) to help formalize processes, to ensure the goal is well articulated and intentional, and to make certain that safety for sharing and learning is created for all involved.

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