
Tell Me a Story: How Patient Narrative Can Improve Health Care



Executive Summary

This report assesses the United Kingdom's Care Opinion initiative, an online platform that facilitates the collection and use of patient feedback to drive culture change and improvements in health care delivery, and shares recommendations for how U.S. health systems can incorporate some of the model's unique attributes into their own efforts to elicit and act upon patient feedback. It was funded by the Robert Wood Johnson Foundation which is learning from promising solutions from around the world as it works to build a Culture of Health in the United States.

How Patient Narrative Can Improve Health Care

When you have a child in the intensive care unit, you try to spend as much time as possible at your baby's side. But parents need to shower, eat, sleep—they can't be with their infants around the clock. So what if staff recorded short video clips to share with parents, showing them what their baby is up to when they can't be there? That idea was submitted to a hospital in Scotland, through the United Kingdom's Care Opinion website. The hospital is now piloting the idea, with positive feedback from other parents and interest from hospitals in other parts of the United Kingdom.

Patient feedback shared through the Care Opinion platform (www.careopinion.org.uk) has also helped a hospital in England rethink how to staff its emergency department and has encouraged a hospital in Scotland to alter its procedures around documenting patient allergies.

These stories offer great promise for the United States, where public and private health systems are embracing efforts to increase the level of transparency and are in the nascent stages of exploring how to elicit, report, and use patient feedback to improve care.

Seeking Patient Feedback

Narrative feedback is familiar to anyone who has provided comments about a product or service that they purchased (e.g., Amazon.com, TripAdvisor, etc.). In essence, organizations ask their customers, "What did you think of our product/service?" or "What can we do to improve?"

More than 100 large U.S. health systems are collecting and reporting patient reviews online. To date, all the activity in the United States to collect and report patient narrative has been voluntary.

Not only are consumers providing feedback, they are also increasingly seeking information online about their health care providers. By 2013, 31 percent of Americans had read patients' comments online, and 21 percent used them when selecting a clinician.¹

There is huge potential for health systems to include patients more thoughtfully as partners in change. Innovative approaches abroad, including Care Opinion from the United Kingdom, can help spur creative thinking and continuous evolution in how care is being delivered.

Eliciting and Using Patient Stories

Asking for basic feedback (e.g., "how did we do?") is a relatively simplistic endeavor. The mechanism for collecting feedback can be as simple as a comment box. At the other end of the spectrum—representing a more focused line of questioning and providing richer, more detailed information—are methods like in-depth interviewing and structured focus group discussions. A new method of eliciting narratives through a carefully structured sequence of open-ended survey questions also shows considerable promise.² These more rigorous techniques are useful for eliciting complete and balanced stories about patients' experience.

Irrespective of how patient narrative is captured, it can be valuable. Patient feedback can improve health care quality beyond what conventional "report cards" accomplish by enhancing clinicians' understanding of encounters that their patients consider problematic.³ Further, patients can provide a level of insight, wisdom, and ideas not available from any other source.

1 Health Research Institute. Scoring healthcare: Navigating customer experience ratings. Delaware: Pricewaterhouse Coopers, 2012.

2 CAHPS Patient Narrative Elicitation Protocol: <https://www.ahrq.gov/cahps/surveys-guidance/item-sets/elicitation/index.html>

3 Schlesinger, M., Grob, R., Shaller, D., Martino, S. C., Parker, A. M., Finucane, M. L., Cerully, J. L., & Rybowski, L. (August 2015). Taking patients' narratives about clinicians from anecdote to science. *The New England Journal of Medicine*, 373(7). doi: 10.1056/NEJMs1502361

Learning From Abroad: Care Opinion

Care Opinion is the United Kingdom's leading independent, nonprofit online platform for people to share their experiences of health care in ways that can lead to learning and change. The Care Opinion model is a mechanism that both allows patients to tell their story and allows providers to listen, gain insight, respond, and act.

Key Features

The United Kingdom's Care Opinion website has aspects and functionality that make it a stark contrast to the health system-initiated websites comprising the majority of efforts to publicly report narrative information in the United States. These differences make a particularly compelling case study that may provide some out-of-the-box thinking about how efforts in the United States could evolve. Distinctive features of Care Opinion include:

- Anyone involved in the care of a patient can provide feedback (family, caregivers, hospital staff, etc.).
- Providers can see comments and obtain feedback in almost real time, in comparison to more clinical or standardized survey-based measures.
- The public can check on progress and whether:
(1) a new story has been posted, (2) the story has been read by the health care provider, (3) the story has a response from the provider, (4) a change is planned, or (5) a change has been made by the provider.
- A robust feedback loop enables comments to be tagged, synthesized, and tracked over time.
- Staff within the health care provider organization are offered extensive training by Care Opinion about how to listen and respond to patients' comments.

Its core differentiating functionality—the ability for providers to respond and for the public to see their response, and any corresponding changes they make—reinforces the need for the health care system to be patient-centered and for providers to actively listen.

Upper Right: The Care Opinion website makes it easy for the public to check on the progress of their story.

Lower Right: Using Care Opinion, the public can easily learn about other people's experiences with a health provider and how that provider is responding.

The image displays three sample story cards from the Care Opinion platform. Each card features a patient's story, a status indicator, and the provider's response.

- Card 1:** Story: "It was **a huge relief just to be understood** - let alone being given the tools to cope better on my own." Status: **STORY HAS A RESPONSE**. About: Ealing IAPT.
- Card 2:** Story: "**I feel like I have been left in limbo**. My GP, who is thankfully a great support, is patiently awaiting a response from the Consultant to see what to do next." Status: **STORY HAS A RESPONSE** experienced by 2 others. About: Raigmore Hospital / Gynaecology.
- Card 3:** Story: "I find it very illuminating being with others with the same condition as myself and who are willing to share and talk about the problems we have. **Talking about them helps to solve them.**" Status: **CHANGE MADE**. About: Westerlands Care Home (Stirling).

The image is a screenshot of the Care Opinion website interface. At the top, it says "109 stories have been told about Ealing IAPT". Below this, there are tabs for "Latest stories", "Latest responses", and "Latest changes". The main content area shows a list of stories with their progress status and response time.

Story	Progress	Activity
"Grateful for her support"	STORY HAS A RESPONSE	Response last week
About: Ealing IAPT		
"depression due to work"	STORY HAS A RESPONSE	Response 3 weeks ago
About: Ealing IAPT		
"Looked after by Ealing IAPT"	STORY HAS A RESPONSE	Response 3 weeks ago
About: Ealing IAPT		
"Great Treatment from IAPT"	STORY HAS A RESPONSE	Response 4 weeks ago
About: Ealing IAPT		
"She helped me overcome my demons"	STORY HAS A RESPONSE	Response last month
About: Ealing IAPT		
"Getting over the feeling of not being good enough"	STORY HAS A RESPONSE	Response last month
About: Ealing IAPT		

At the bottom, there is a pagination bar: FIRST | PREV | 1 | 2 | 3 | 4 | 5 | 6 | ... | 18 | 19 | NEXT | LAST

Why Narrative?

In a series of interviews with more than a dozen researchers, government officials, and health care providers in England and Scotland, participants continually pointed to the profound value that patient narrative generates, and how it can uniquely catalyze staff and organizational efforts to improve quality and patient-centeredness:

- Information is unadulterated by survey questions, (i.e., it is in the patient's own words). It can surface their values and expectations.
- Providers see the care process through the patient's or family's eyes. At its best, narrative can increase empathy for the patient's journey through their care and treatment, which sometimes includes multiple providers and organizations. Narrative helps providers step into a patient's shoes, which can be "transformative and consciousness raising."
- Narrative gives quantitative data context, "heart," and specifics.
- Narrative can identify problems or common experiences (positive or negative). It can shed light on what to improve. It can also help identify solutions and ideas, or how to improve.
- Narrative is hard to ignore. Combining patient stories with quantitative data is compelling, especially for clinical staff and leadership.
- Narrative can often touch on both the concrete and the emotional components of care.
- Comments can span beyond a specific organization or provider and address experience across a continuum of care, or multiple specialists or departments. This is a particularly significant feature of narrative in view of efforts to develop new approaches to performance measurement that encompass the full range of patient care.

Aspects That Differentiate Survey and Narrative Approaches

1 Representativeness: How well do the responses reflect the patient population or panel?

2 Richness of Information: How robust or detailed is the information?

3 Audience: To whom is the respondent speaking? For whom is the story intended (e.g., a recommendation to friends/family or to give feedback to a provider)?

4 Structured Questions: How structured or focused are the questions (i.e., are they completely open-ended or do they provide prompts and suggested areas on which to focus)?

5 Synthesis of Information: To what extent do providers and others see the "raw" stories, as opposed to synthesized or edited feedback?

6 Specificity of Information: At what level of accountability are the comments directed [e.g., an individual physician (more granular), or a hospital unit (the organizational level)]?

7 Timeliness of Data: How recent are the data? How much time has passed between care and feedback?

8 Ability to Respond to Comments: To what extent are providers able to respond to comments?

9 Ability to Track Impact or Change: To what extent is the public able to track whether a change has been implemented or impact realized? How accountable are providers to acting on the feedback?

Opportunities for the United States

The Care Opinion model offers six game-changing ideas that could boost nascent efforts in the United States to capture patient narrative and use it to truly transform organizational culture and care systems and advance patient-centeredness:

1. Allow Two-Way Communication and Responses

Websites could allow providers to respond (authentically and empathetically) to patients' comments. Reorienting the health care system to one that puts patients' needs first and foremost must start with active listening. Allowing the public to see a level of responsiveness (both in terms of timeliness and thoroughness) would reinforce a significant and important culture change.

Several U.K. providers noted their organization's evolution in how they respond to patient comments. Initially, it was perfunctory at best (i.e., "thank you for your feedback, we'll look into it"). Providers wanted to privately "circle the wagons" and explore what exactly happened before getting back to a patient. This mentality has evolved over time. Now, provider responses more often start with an apology or a recognition that the patient experience wasn't "up to snuff." There's usually a suggested course of action (e.g., "please come in," or "we'll follow up with you via phone," or "we're going to do XYZ to solve this").

2. Encourage 360-Degree Feedback

Allowing other people involved in the care process to provide feedback (e.g., families of patients, other caregivers, staff within the provider organization, social services agency personnel, etc.) essentially shifts the feedback process to a more comprehensive, 360-degree perspective.

There are many areas in which proxies and others are integral to observing, reflecting, and commenting on the care experience (e.g., maternity care, pediatrics, end of life, and care coordination). The Care Opinion model and patient narrative in general may be uniquely suited to gathering multiple perspectives that could help paint a better picture.

3. Extract Key Themes Without Losing The Full Story

Patient narratives are often about a particular unit, service line, department, provider, or staff. This specificity helps target resources to improve precisely where an organization needs to make improvements. A helpful analytic methodology used by the UK Care Opinion model is "story tagging." Users can tag stories by providers, service lines, departments, locations, conditions, treatments, and pull up sets of related stories to identify key themes. The richness of narrative data provides a great deal of information, especially for those who are working to improve processes, systems, infrastructure, or operations.

The analysis of text/narrative can be labor-intensive. Many in the United States are exploring natural language processing, as it seems to offer some efficiencies; however, it pre-supposes patterns, since the algorithms are programmed to look for those patterns. The U.K. Care Opinion model wants to infuse the patient perspective into the fabric of the National Health Service. Care Opinion would argue that solely providing a synthesized version of a story to health care providers dilutes its transformative power. Providers need to hear these raw comments and stories. The details embedded in narratives can provide clinicians with vital insights about practice improvement, though it can be difficult for them to interpret a substantial ongoing stream of narratives without sufficient time and appropriate support from within their practices.

4. Provide “At-A-Glance” Syntheses

Creating a graphical, easy-to-digest snapshot summary that synthesizes feedback over a period of time can make it easier for providers and other decision-makers to spot themes and also point to system issues. The UK Care Opinion model uses a number of visualization tools to help providers summarize and explore the stories people are sharing, using tags to filter stories.

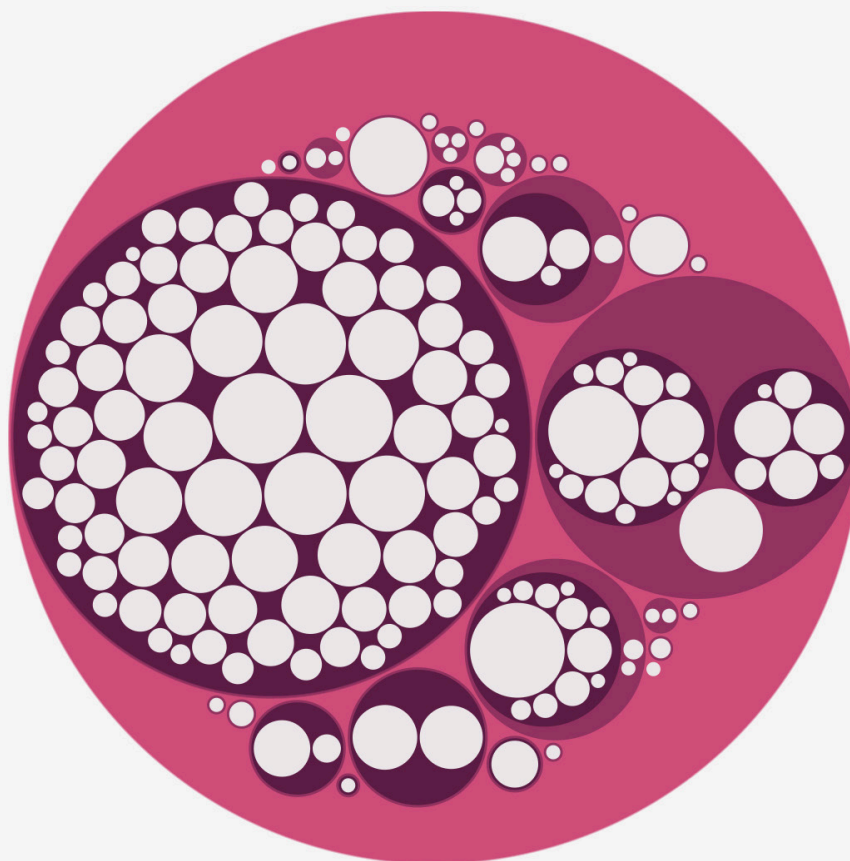
Many in the United Kingdom create reports on a monthly basis. A more comprehensive summary on an annual basis could assist with organizational budgeting, training, and oversight.

Below: Lily pad visualization. The circles in the lily pad represent different healthcare services, or groups of services. The bigger the circle, the more stories there are about that service. This lily pad shows which services people in Liverpool are posting stories about. Hovering over a circle will reveal the individual stories that map to that circle.

Stories from Liverpool

Created by Care Opinion on 19 December 2017

About: all stories on this site from people in NHS Liverpool CCG

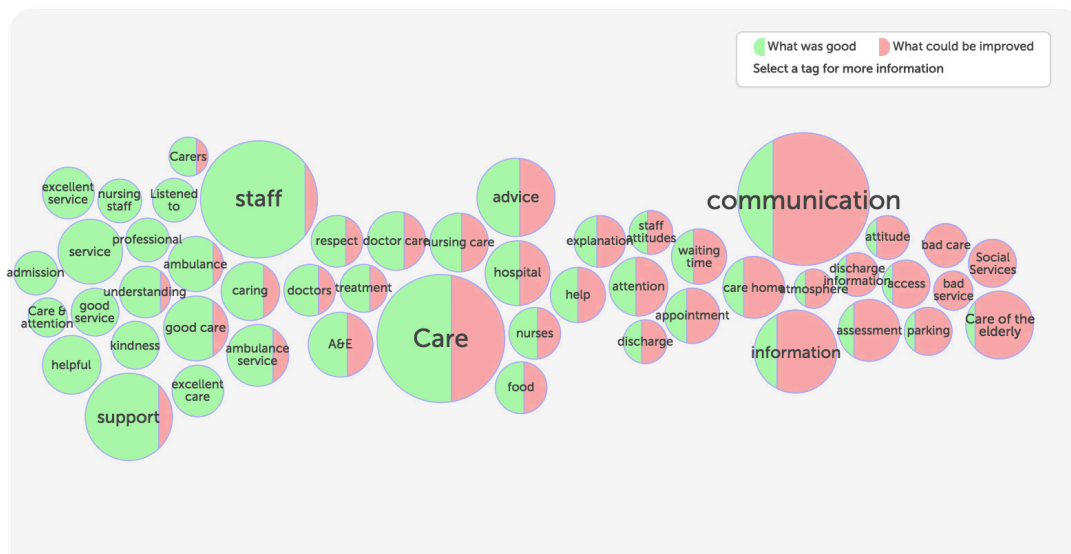


Select a service to get started

Experiences of dementia care

Created by **James Munro**, Chief executive, Care Opinion on 10 July 2016

About: Interactive tag bubbles about stories tagged with any of dementia, alzheimer's



Tag bubbles.

These visualizations give providers an informative overview of the aspects of care people are tagging in their stories as "what was good" or "what could be better". By clicking on a bubble, you can navigate to the stories which inform it.

Anxiety and depression

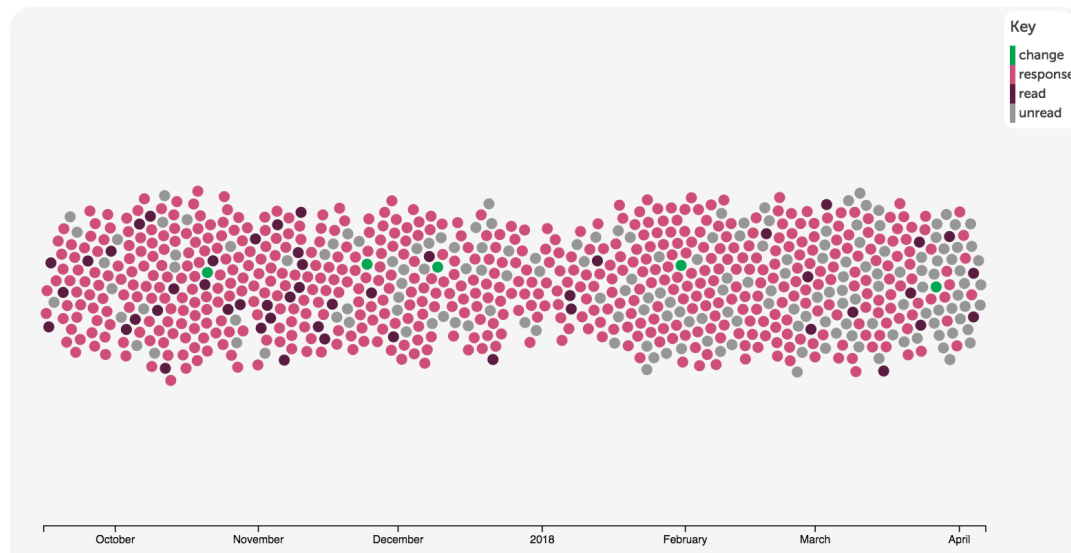
Created by **James Munro**, Chief executive, Care Opinion on 05 April 2017

About: Story swarm showing criticality and progress of recent stories

Progress

Together Expanded

Note: we have limited the number of stories in your swarm to 800.



Story swarms.

In a story swarm, each dot is a story. They are shown horizontally by time, and colored in this swarm by the criticality of the story. Hovering over a dot will reveal the individual story that maps to that dot in the swarm.

5. Use Narrative to Drive System-Level Change

Narrative has the ability to identify a problem, concern, or breakdown in care or service that can lead to broader, system-level changes. For example, individual patient stories might inform policy decisions such as changing visiting hours, altering staffing levels, or shifting organizational investments (e.g., increasing training budget, improving physical building, changing information technology, altering clinical/staff bonus or compensation).

Stories that connect staff and patients can also boost morale. While feedback about the health care system is generally positive, stories that identify the root cause of a compliment (not a complaint) are as important as the compliment itself and allow a provider to build from an asset-based mindset, rather than from a more traditional starting point of what went wrong. Given the workforce challenges that the health care system will be experiencing in the future, it would be interesting to explore whether narrative and the ability to respond to patient concerns can improve job satisfaction, reduce turnover, or improve recruitment.

6. Create An “Upside” for Providers Who Are Responsive Change Agents

The United Kingdom has a robust and disciplined complaint mechanism that can be used by patients seeking non-monetary redress from health care providers and there is some evidence that listening and responding promptly to patient feedback reduces the likelihood patients feel it necessary to escalate complaints to a formal oversight body. While there is not an exact parallel in the United States, our malpractice and insurance systems may provide additional incentive for providers to actively use narrative as both a mechanism to respond, as well as to demonstrate their ability to fix the issue with minimal patient/family frustration and escalation.

Narrative can also be helpful in improving individual physician or staff communication skills. Notably, in the United States, many health systems are now using shadowing and individual coaching for physicians who want to improve based on receiving negative feedback.

Conclusion

Delivering patient-centered care is a central aim of the U.S. health care system. Patients, policy makers, health care providers, insurers, and employers all want to make our health system more focused on the goals, needs and priorities of the people and communities they serve. Eliciting patient narratives and being responsive to the concerns, needs and ideas—which are generated by the lived experience of how patients and families interact with the health care system—is critical to meeting that goal.

Many U.S. health systems actively seek out patient feedback, often in the form of patient experience surveys,

focus groups, or online reviews. The United Kingdom’s Care Opinion model has several unique aspects and functionality that are noteworthy and our analysis of these differences points to six areas where both countries could learn from each other, evolve, and innovate.

Learning from the experience and lessons derived from Care Opinion and pursuing these six game-changing ideas can help health care systems in the United States better leverage patient narrative to transform their organizational culture and operations so that patients are truly at the center of care.

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