

# Narrative Respect and SOGI Data Collection: How Patients' Charts Can Tell Their Stories

Across the health care industry, new requirements and initiatives for collecting data about patients' sexual orientation and gender identity (SOGI) have increased over the last few years. Clinical needs, concerns about patient safety, epidemiological and population health efforts, and regulatory demands have all contributed to these new developments. Many Catholic health care ministries have already found ways to respond to this environment, and others are discerning their own path forward.

Mercy has recently charted its own course through these waters and found them, perhaps predictably, somewhat tumultuous. We began the process with a long questionnaire covering SOGI data thoroughly and including questions about sexual orientation, an organ inventory, and so on. One plan suggested that this questionnaire be incorporated into the electronic medical records system and administered to every patient who came into our care. Concerns soon arose about this approach. Some co-workers and clinicians felt that they were being pressed into taking sides in polarizing cultural conflicts; others wondered how it all intersected with our Catholic identity; and still others worried that the questionnaire was too invasive and would make many patients uncomfortable, especially since some of the data points didn't seem to align

directly with clinical needs.

In response to these concerns, we shifted course and found a way that works for us to address the fundamental concerns driving these SOGI data collection initiatives, while taking the concerns of our co-workers and clinicians into account. The ethical heart of this approach centers on the demands of what one could call narrative respect. In this essay, I will explain that concept, drawing on Wayne C. Booth's ethics of fiction; indicate how we applied it to the issue of SOGI data collection; and briefly summarize the benefits of that approach.

Each patient's chart tells a story. It includes the essential elements that narrative theorists have identified as definitive of a narrative: a teller and a tale.<sup>1</sup> The tale is sometimes front and center; consider all the notes that include a "History of the Present Illness." Even beyond those histories, the chart as a whole is an ongoing presentation of the patient's course through disease processes, recoveries, efforts at health maintenance, and so on, all made intelligible through their linking in a narrative moving from beginning to middle to eventual end.<sup>2</sup>

The mark distinguishing a narrative from a drama is its indirect presentation of the actions and events through the perspective of a teller.<sup>3</sup>

A patient's chart, along with its tale, features a plethora of tellers, as each clinician presents the narrative from a particular professional and personal perspective; and, if clinicians are sufficiently attentive, the patient's own telling will be represented in the chart as well. If a robust alliance has formed between the patient and the caregivers, one might even find that the tale is ultimately told by a team whose contributions achieve some unity of perspective. But in any event, the chart offers its readers a narrative representation of the patient's experience.<sup>4</sup>

The literary scholar Wayne C. Booth draws readers' attention to a feature of stories that suggested a path forward for our SOGI data collection initiative. Booth points out that every story presents the reader or auditor with a set of fixed norms, "beliefs on which the narrative depends for its effect but which are also by implication applicable in the 'real' world."<sup>5</sup> For example, writes Booth, "The Goose that Laid the Golden Egg" suggests many 'nonce beliefs,' only to be accepted as obtaining in the world of the story—such as that geese can lay golden eggs—but also many fixed norms, such as "Greed is self-destructive."

Careful readers can identify a story's fixed norms and understanding them is crucial to a full appreciation of a narrative. The effort to understand a narrative in terms of its own fixed norms, however, does not necessarily entail the reader's own endorsement of that norm as applying in both the world internal to the narrative and the world external to it. For example, a riveting piece of sports journalism may imply the norm that athletic excellence is a preeminent human good, and a reader may understand the story in those terms, without

agreeing that, in the "real" world, athletic excellence is so central to human flourishing.

Different tales and different tellers structure their stories according to different fixed norms, and this applies to patients and their charts as well. Some fixed norms are common across almost all patients' stories—such as that health is generally preferable to illness—but others are less universal. In the present case, for example, the stories that some patients tell about themselves include fixed norms that present the relation between gender identity and biological sex as accidental; but other patients structure their narratives around opposing fixed norms. Attempts to standardize the narratives contained in patient charts, beyond the scope of those very general and nearly universal fixed norms, present the danger of imposing on all patients the fixed norms that belong only to some patients' telling of their stories.

Recognizing this reality allows one to frame the difficulty of SOGI data collection in a new way. The problem is how to elicit every patient's story in the chart, as each would tell it, without imposing controversial fixed norms on any patient, at least as far as possible. From this perspective, it becomes apparent that the misgivings co-workers expressed about our original process reflected a reasonable intuition: that requiring all patients' charts to identify them in categories such as "transgender" or "cisgender" represented a kind of narrative imperialism, forcing patients to tell stories in accord with fixed norms that they would themselves reject. In that case, their charts would stifle their own telling of their stories rather than giving them an honored place.

This form of imperialism acts on the

assumption that local or individual differences are not relevant and that authority—in this case, narrative authority—must ultimately rest in a higher, more expert perspective. What we needed to counteract that narrative imperialism was an attitude of narrative respect. Narrative respect requires care teams to recognize patients' authority to tell their own story by making place for the telling of their stories in their charts and by avoiding, as far as possible, the imposition of controversial fixed norms that the patients may not endorse. Without this kind of respect, caregivers will often find themselves unable to discern the coherence of patient narratives, because they will lack access to the fixed norms that underpin their intelligibility.<sup>6</sup> However, the fact that caregivers exercising narrative respect will engage a variety of patient stories with diverse and conflicting fixed norms raises another perplexity. It suggests a kind of incoherence in their own perspectives with caregivers careening from one fixed norm to a contrary one in the course of a few minutes with the electronic medical record (EMR).

But Booth's reflections again suggest a way out. He writes, "[W]e may finally, on reflection, reject even the fixed norms: that is precisely what much ethical criticism does."<sup>7</sup> Narrative respect does not require careful readers to endorse the fixed norms in the stories they encounter, but only to recognize them and consider how they provide the structure for the meaning the teller finds in the tale. Clinicians experience this kind of tension in many different circumstances. Consider the expectant mother whose birth plans strike the caregiver as excessively risky but also as understandable in terms of fixed norms rooted in holistic approaches to health or cultural mores. Or think of those types of counseling in which the

therapist helps clients to uncover unrealized fixed norms in their own stories and reflectively evaluate them.

In some cases, a patient's chart will remain a site of tension, because the multiple tellers of the tale it contains will not share important fixed norms, even if each can understand the others' stories in terms of their respective commitments. Not every chart attains that unity of perspective that comes from integrating telling of the tale that are distinct and yet share central fixed norms. Narrative respect does not require every teller of the tale in the chart to endorse the same fixed norms, but it does require a place for those diverse tellings to be heard and the effort to understand them in their own terms.

The applications of this understanding of the patient's chart as a story turned out to be fairly straightforward. SOGI data collection that requires every patient to declare a gender identity arguably imposes fixed norms about the relation between gender and biological sex on all patients—and perhaps on the providers as well, who must present the questions, with their implied narratives, as if their fixed norms were universal. A promising alternative is to focus instead on open-ended, clinically focused questions. Providers might ask, "is there anything about your gender identity or sexual orientation that you would like us to know as your health care provider?" Or, more specifically but still without assuming the patient endorses any particular fixed norm, "Have you ever received, or do you plan to receive, hormonal or surgical treatment for gender incongruence or dysphoria?" Affirmative answers to inquiries like these would trigger a question set in the EMR that

drills down into further details, allowing patients who endorse fixed norms affirming the accidental relation between sex and gender to have narratives that make sense to them represented in the chart—and ensuring that information important for patient safety is included. Negative answers would result in the interview continuing without demanding that the patient's narrative conform to fixed norms alien to that patient. In each case, the provider would remain a careful witness to the stories patients want to tell but would not be committed to endorse every fixed norm they entail.

We eventually moved in this direction, working with a version of those sorts of open-ended questions. We believe the benefits are significant. It allows all patients to tell their stories according to fixed norms they endorse. It lowers hurdles for providers reluctant to engage these conversations, because it provides a way for them to be respectful while not committing them to endorsing, or appearing to endorse, controversial fixed norms. For the same reason, it is consistent with our Catholic identity. It does not assume any fixed norm that may be in conflict with those implicit in a Catholic anthropology;<sup>8</sup> and, at the same time, it compassionately welcomes patients to tell their stories their way, as Our Lord did in conversation with the woman at the well.<sup>9</sup> Finally, while achieving all these benefits, it also procures the relevant clinical, epidemiological, and population health data and meets regulatory requirements. Using open-ended questions to express narrative respect for our patients in these fraught conversations, then, is an approach that we believe deserves wider consideration. ✚

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**RANDY COLTON, PHD, HEC-C**

*Director, Ethics*

*Mercy Northwest Arkansas*

*Rogers, Arkansas*

## ENDNOTES

1. Robert Scholes, James Phelan, and Robert Kellogg, *The Nature of Narrative*, 40th anniversary ed., rev. and exp. (New York: Oxford University Press, 2006), 4.
2. Alasdair MacIntyre, *After Virtue: A Study in Moral Theory*, 2nd ed. (Notre Dame, IN: University of Notre Dame Press, 1984), 205.
3. Scholes and Kellogg, 4. See also Randall G. Colton, *Repetition and the Fullness of Time: Gift, Task, and Narrative in Kierkegaard's Upbuilding Ethics* (Macon, GA: Mercer University Press, 2013), 73.
4. See Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (NY: Oxford University Press, 2006), 146-148.
5. Wayne C. Booth, *The Company We Keep: An Ethics of Fiction* (Los Angeles: University of California Press, 1988), 142-143.
6. See Booth, *The Company We Keep*, 149: "In whatever form we take the story, as long as it is intelligible to us we will have seen it in a matrix of its fixed norms."
7. Booth, *The Company We Keep*, 143.
8. See the United States Conference of Catholic Bishops' "Doctrinal Note on the Moral Limits to the Technological Manipulation of the Human Body," March 20, 2023 (<https://www.usccb.org/resources/Doctrinal%20Note%202023-03-20.pdf>).
9. John 4:1-26.