

Episode: *Author Interview: "What Arts and Health Practices Teach Us About Participation, Re-presentation, and Risk"*

Guest: Sofie Layton, MRes

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[bright theme music]

TIM HOFF: Welcome to another episode of the *Author Interview series* from the *American Medical Association Journal of Ethics*. I'm your host, Tim Hoff. This series provides an alternative format for accessing the interesting and important work being done by Journal contributors each month. Joining me on this episode is Sofie Layton, an artist whose practice includes installation, site-sensitive performance, and theater. She's here to discuss her article, coauthored with Drs Jo Wray, Victoria Walsh, and Giovanni Biglino, *What Arts and Health Practices Teach Us About Participation, Re-presentation, and Risk*, in the July 2022 issue of *The Journal*, [Arts-Based Research in Health Care](#). Sofie, thank you so much for being on the podcast with me. [music fades out]

SOFIE LAYTON: It's a pleasure. Thank you very much for inviting me.

HOFF: To begin with, what's the main ethics point that you and your coauthors are making in this article?

LAYTON: I'm particularly interested as an artist in how disease and illness can be translated, not purely sort of, it's not really the medical practitioners sort of to preserve, but it can go beyond that. But if you're working in this way with patients who are potentially quite vulnerable and at points of illness on their journey, that we need to think very carefully how we navigate this journey. And so, the article really helps set out some of the risk and some of the ethics questions that we need to look at when we're sort of going through that process, particularly if we're looking at how we use medical data and the ethics around using somebody's medical data, whether that's anonymized. And that you may have ethics sort of license to use it because you're working with a researcher, but you also need to be aware that you can, you're using it in a different way as an arts practice.

HOFF: Mmhmm.

LAYTON: Therefore, somebody could, a heart could be recognized through the medical imagery, or particularly if it's a sort of special condition.

HOFF: Mm.

LAYTON: And then I suppose it's about how we have one-to-one interactions with people and what those, how we navigate those interactions and how we assess the appropriateness of what we're asking and how we just hold that information in those ways. And I mean, what we did within the article is we set out eight specific dimensions of risk.

HOFF: And what do you see as the most important thing for health professions students and trainees to take from this article?

LAYTON: I think that a transdisciplinary approach to thinking about medical narratives is, gives a much more rich and varied...sort of possibility. We've, obviously, there's amazing authors, and I sort of cited Virginia Woolf that did an amazing essay on being ill. And within medical humanities there's a lot of literature and Boyer's recent book on cancer. And so, there are areas to tap into, but those tend to be much more from an individual, personal perspective. Whereas if you can actually work with a patient group and explore your ideas with a patient group, but through an artistic sort of medium, it allows for narratives and metaphors that you wouldn't necessarily expect. And that becomes, I think it teaches both the health professional, but it also can allow patients a space in which to voice their health issues in a very different way and that sort of transdisciplinary approach. And obviously, there are amazing people also like Rita Charon that has sort of created a narrative approach, but I think this is about looking at different methodologies and then also how that work can be taken into a much more public arena.

So, the work I did with, particularly with Jo Wray and Giovanni Biglino, we worked with patients with congenital heart issues and worked with 3D printed imagery and then literally asked people to explore what it felt like to hold their heart in their hands.

HOFF: Mm.

LAYTON: And there was one extraordinary situation where I was working very closely at a hospital called Great Ormond Street Children's Hospital in London. And I was working with a mother who had, her daughter was born with something called hypoplastic left heart syndrome. So, it's only half of her heart had developed properly. And I had shown her a heart print that I'd made in bronze, and she said, "Oh, I'd really like to see my daughter's heart." And so, I worked with Giovanni, and we had ethics approval to do this. And I was able to show her her daughter's heart, and she held her daughter's heart. And she said, she looked, held this tiny little three-month-old heart in her hands, and she said, "I feel like I'm holding snow in my hands."

HOFF: Ah.

LAYTON: And that moment of this medical data became something much more expansive and poetic and gives a very different way in to exploring a person's narrative or a parent's narrative about their health or their daughter's health.

HOFF: Mmhmm, mmhmm. To wrap up, if there was a point that you could add to your article that you didn't have the time or space to fully explore, what would that be?

LAYTON: So, if I could add one more point to my article, it would be for the artist and the clinician and the scientist working through a transdisciplinary process offers extraordinary insights and a richness, but it has its own risks. And the need to enter to the foreign land of each other's process and to try and understand each other's way of articulating illness is what produces meaningful, engaging work. The artist is not there to merely illustrate the medic's vision or to illustrate the patient's narrative, for that matter. She gives color and depth and new layers of meaning that makes something new from the tender process, while still respecting and being ethically appropriate within her practice. [theme music returns]

HOFF: Mm. Sofie, thank you so much for your time today on the podcast and for you and your coauthors' contribution to the Journal.

LAYTON: Thank you very much for inviting me. It's lovely.

HOFF: To read the full article as well as the rest of the July 2022 issue for free, visit our site, [JournalofEthics.org](https://www.journalofethics.org). We'll be back soon with more *Ethics Talk* from the *American Medical Association Journal of Ethics*.