SOGI Data in EHR
Lessons from Taussig Cancer Center

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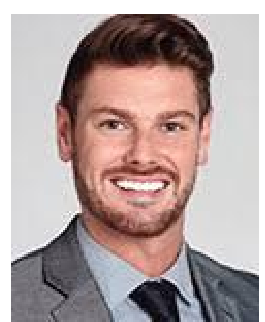

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The following are excerpts from an interview between three people above conducted on May 9, 2022.

S: From your experience working through SOGI data collection at the Taussig Cancer Center, what do you think are the steps a cancer center needs to go through in order to successfully collect SOGI data?

GR: From the biggest, broadest concept, I think the pre-work and deciding what's going to be collected where it's going to be collected that's part one. Part two is really helping people to understand the overall why. And then part three is sustaining, and making sure that as new people come into the fold, that we are providing that education, and that we are periodically reminding people that this exists and is important.

The Pre-Work

TS: First and foremost, you need buy-in from executive leadership and from stakeholders throughout the cancer continuum of care, because this is obviously a tool that can and should be used throughout the entirety of the cancer center.

GR: At the Cleveland Clinic, they updated our mission, vision, and values, and the value of inclusion was one that was highlighted. So this fell directly within that, and they built the data collection tool. You've got to get IT involved, and you've got to get executive leadership bought into it. Half the battle, I think, was the pre-work that they did for quite some time in troubleshooting what information they wanted collected, where it would be collected in the electronic health record.

TS: A lot of that work was done in collaboration with IT, our center for LGBT care, our transgender medicine and our surgery program. So, really getting buy-in from those key stakeholders was key. Of

course this is going to look different for different health institutions but because we are such a large organization, I think the first place that executive leadership went of course, were those LGBTQ specific points of care or lines of service

GR: That was part one, and that was a huge step. All of that work was done, and completed and the build occurred before it ever got to my hands to say, "All right, we've got it. It's here. We built it. Now make the people come and use it."

2 Sharing the Why

GR: Part two, I think may have even been more difficult. It was getting the training and education out there, getting people comfortable with it, and then getting them comfortable enough that they were actually going to use it. Use what they've learned.

TS: Once that initial tool was developed, other institutions, including the Cancer Institute looked at this tool, and knew it had been rolled out, knew that it was being used in LGBT specific service lines. However, it was still available for the rest of our institutes throughout Cleveland Clinic yet was not rolled out in a way that gave us enough training, information, understanding of it even. So, that's really where we came in and said, "Okay, this tool already exists. How do we get people comfortable with it? How do we teach people how to use it?"

One thing that Gigi managed from that developmental perspective is getting those stakeholders together and creating this committee that would be able to provide input from all different levels of care from nurses to front desk workers, so that we have the perspectives of each of these groups represented so that we can work through any barriers that they foresaw that from our points of view, we would not have seen coming.

GR: So, they had built SOGI into the electronic health record within the history section of the patient. So, you've got your medical history, your surgical history, and then supplementally in there, it's got a sexual orientation and gender identity history. And that group developed questions, and it's point and click questions that are available. So, sexuality, gender identity, it even would drill down into if you're in a surgical suite, or if you're dealing with a patient that is transgender, then you can select any modifications that have been made any supplemental hormones, any surgeries, and an organ inventory. And so, there's that section in the history. And then for the front end folks, meaning like the schedulers, front desk, check-in folks, they have a section in registration where they can enter a patient's preferred name. If somebody voluntarily gives that information, we chose not to have it be blasted out upon registration. But if somebody voluntarily gives that information, they've got sections within registration that they can record that information.

TS: For example, if a pronoun or name is corrected at the front desk, they are given that ability to edit that piece of the record. They did do a pilot as to how this would roll out, who should be asking these questions, and we actually found a kind of discrepancy there because of the pilot location, having actually kind of a private suite style check-in areas. So in that location, it made sense for that check-in person to be asking some of those questions because they're going through and doing in some ways what a

rooming nurse would in most of our other locations. So, it was important for us to look at, okay, why are we saying that asking these questions in a front desk situation is appropriate? One thing that we made sure was implemented was the ability for patients to self-identify some of this information in their MyChart, which gave them more privacy. Then the rest was mainly the responsibility of the rooming nurses and or PAs.

Then Georgina's committee became the trainers for this module that we would meet with different groups or departments within the Cancer Center to educate them. And obviously, that education was pretty comprehensive because we didn't want to just educate on SOGI. We also needed to create some objectives around why this information is important. What barriers to care that LGBT people face specific to healthcare and even more specific to cancer, explain to these providers and these different departments why this group is considered medically underserved, and overall just understanding the relevance of the SOGI tool in cancer care.

GR: It was like peeling layers of an onion, and I think that the why is really when we hit the turning point because people thought they understood. Here's a tool, here's what you should do, but it seemed like there was a disconnect between why, and the more we asked why, the more information that we gave people, regarding the importance of it, and continually asking the question why, that's really when you saw the light bulbs kind of go off. People were able to connect the dots and really connect with the initiative.

TY: We targeted everyone everywhere with the training. We had Institute town hall meetings that included everyone, then we did individual staff meetings with key groups, grand rounds for oncology nursing, the staff physician meeting, everything. I think a really important, almost key piece of this is that pre and post test survey that we gave folks before and after the training.

GR; The one that broke my heart. While it was overall a very positive result, with almost everyone reporting more skills and comfort post training, one of the questions was "LGBT people deserve to have quality healthcare" and there were a couple of people who outright said they just disagreed. It still makes me want to cry.

TY: There was also a tier level. Maybe we should talk a little bit about that tier level? We had tiers one and two.

GR: We had people that we deemed as primary focus that it would truly be almost a metric for them to make sure that is part of their physical assessment of the patient, or part of the routine conversation with the patient, and tier one people were our physicians, research nurses, the research department, oncology care coordinators, our regional locations, Mansfield, Sandusky, and then tier two were front desk, admin assistance, cancer answer line, financial navigators, patient service, etc.

TS: The evaluation allowed us to see the post training shift. We had a big chunk of folks that just felt neutral or maybe even uncomfortable before the training, and we saw that shift much closer to comfortable and, or very comfortable. So, that was the positive piece of that despite some of those outliers.

GR: We had some physical indicators of welcome too. When we would complete the DEI training with the Office of Diversity, they would give us a little rainbow badge. That would be a nice visual cue. We always have the small print signs that are out and about, but I still think that there's probably more work to do where we could have more signage.

TS: We did use this opportunity to also drive people to that DEI training, which is related to the Human Rights Campaign's Healthcare Equality Index. Through that training we were able to provide more of those organizational indicators of welcome. Also we had pronoun pins, the badge pulls, and things like that.

3 Sustainability

GR: Part of sustainability is continuing to offer the education. I have several new training requests I'm working on now. And I try on at least a quarterly basis to send a broad update out to our Institute on the statistics on the total number of patients that are populating on our SOGI report. And the good news is that it's steadily increasing with each quarter.

TS: TS: One thing I also want to emphasize is that data and metrics piece, because being able to keep track of that has been something that's allowed us to see, not only the results of our efforts, but also where we can improve and how we can do better. I'm not going to say it's easy, but it may seem easy to implement the tool and then the education, but part of that sustainability piece is also keeping track of the metrics.

GR: Overall lessons learned? I think finding the right people to champion it is very, very important because if you don't have the right people, their heart's not going to be a hundred percent in it. And we found as we moved through this project that we really did have some folks that were truly passionate about it, and that they were going to do everything that they can to make sure that their work groups understood. So, they made our lives so much easier because you didn't have to drag them into it. They ran with it. So, finding the right people is very important.

TS: I think that's a great point Gigi, because I did point out before having people from different parts of the cancer care continuum is important. But I think that is just as important, if not more, having people that are... They don't even have to necessarily be comfortable with their own DEI efforts. But of course, having the willingness to learn and being able to champion this from that committee perspective is so key.

Also it's important to make sure we keep up with this. One thing that happens across many, many DEI efforts is the one and done mentality. And we see it now with the amount of staff turnover and caregiver turnover in healthcare and across all organizations, it's important to remember that your employee employees today are not going to look the same as in a year or two. So, it's important to keep up with this and continue to educate on SOGI.

GR: Yes, sustainability is maybe the most important part of the whole initiative.