Dr. Jessica Mazerik

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Richie**:** Good morning. My name is Jason Richie. I'm a volunteer with the NIH Office of History and Stetten Museum. Today is July 17, 2023. I am speaking with Jessica Mazerik. You currently work for the NIH HEAL initiative?

Mazerik: Yes, I currently work for the NIH HEAL initiative—Helping to End Addiction Long Term.

Richie**:** Okay, great. You serve as the Director of the data ecosystem?

Mazerik: Yes, that's right.

Richie: Okay, great. Well, now that we have that out of the way, and you've provided the Deed of Gift, I'm curious what brought you to focus on data science in Ohio State and at Vanderbilt? What was your journey?

Mazerik: Yes, I have always been interested in how the body works at a cellular level. I ended up studying cell biology, and I went to grad school for that. It turns out that I also really like interacting with people. I ended up moving towards a science communication career. My first work experience in Washington DC was an internship with the Woodrow Wilson Center. With support from the Wilson team and others, I authored a report on science communication. Then I got a fellowship at National Cancer Institute working in the Center for Cancer Genomics. I came in as a communication fellow, but the office was a program office that was overseeing complex cooperative agreements related to reuse of The Cancer Genome Atlas (TCGA) data. I ended up working more on programs than on communication and became a program manager in that office. That sort of took me down the data science and program officer route. I found that I really loved that aspect of working with the investigators and helping them to communicate their research and hearing about their research and understanding what was going on in the awards, and then trying to translate that information back to colleagues at NIH or to materials for our websites, and for other outreach and education stuff that we were doing at NCI. I've been moving around NIH ever since, always with one foot in the data science door. That's sort of how I got here.

Richie: Would you say that your role now involves more education and communications than data specifically?

Mazerik: In HEAL, we've really tried to tie data and outreach together under the HEAL data ecosystem. We have a couple of other transaction authority awards that are building data sharing infrastructure for HEAL and also providing support for investigators funded through HEAL to get their data ready to share and reuse through our HEAL data ecosystem. We also have a couple of awards under the HEAL data ecosystem that are focused on results dissemination. In HEAL, we've always been very interested in the translation of research to knowledge and implementation where appropriate. We've had these data sharing awards, and we've been encouraging people to share their data, but there's a there's a gap. Data aren't the way that everyone will ingest and understand information coming out of research. We wanted to do something more translational. The other two

awards that our HEAL Ecosystem team oversees make up a program called HEAL Connections. Connections' intent is to bridge that gap between the data and the translation to more community- and culturally-specific materials that can be disseminated. That is a really cool set of awards because they help us work with association partners and community partners and multiple lived experience panels. Even though we have a lot of technical work going on in the ecosystem, we also really have that tie back to outreach, translation, and uptake in communities, which I love.

Richie: Sure. That makes sense. It sounds like you're really gathering data from a variety of different perspectives.

Mazerik: Yeah and putting results out for many different audiences. Exactly.

Richie: That's great. That's great. Tell me about a little bit about the team that you work with at HEAL, and what their roles are?

Mazerik: Sure, so Dr. Rebecca Baker is the HEAL director. She works very closely with the NIH leaders to steer the ship. We have amazing program staff, and grants management staff, and comms staff, from across NIH institutes who make HEAL what it is. Our HEAL office team is also amazing. We are small in number but make a big impact. Guiding the HEAL Data Ecosystem work with me are Anthony Juhene, a data scientist, and Janet Oputa, a program manager. They bring expertise and dedication, and I learn a ton from them.

Richie: Okay, so do you then have the ability to scale up and scale down your data, depending on the audience?

Mazerik: The data being generated is dependent on what that research program looks like. I mentioned the program officers from across NIH - they are developing funding concepts for HEAL. The investigators from the research community come in and apply for those. Sometimes they're big consortiums that are working together to come up with very coordinated, harmonized data sets, and sometimes there are individual investigators who are doing research projects more independently. The data from each of those scenarios looks very different. Our challenge in the central data ecosystem has been to try to build something that fits the needs of everyone. HEAL all started in 2018 with supplement awards. In 2019, we started building some programs, and so a lot of the data and publications are just starting to come out. While we've been working in the HEAL data ecosystem to build infrastructure and provide that support, we are just now starting to see data start to come through. One of our big pushes in this next year is going to be to really get those investigators to share their data as they're publishing papers.

Richie: Okay.

Mazerik: The data look a little bit different depending on what kind of research program they're coming from as well as what stage the program is in.

Richie: That's interesting. In your position specifically at the HEAL initiative, how did you find your interaction with the NIH [changing], and what's been that evolution?

Mazerik: HEAL reaches across and depends on input from across NIH. That makes it somewhat unique, and our data programs are somewhat unique too. When we were talking about setting up the HEAL data ecosystem, Dr. Baker was getting guidance from many different data leaders across NIH. We wanted to understand what the landscape was and how to really set up the best data sharing infrastructure for HEAL. Sometimes it makes sense to set up a central team to take all the data, process it in the same way, get it ready to share, and then put it out to the world. In the case of HEAL, that didn't make sense because there are so many different types of data being generated, and different types of research projects, and so much varying knowledge about data management and sharing from the different kinds of awards. In HEAL where we've landed, based on this guidance of all of these really incredibly smart people around NIH, who helped us with this decision, we are building what we call a data mesh. It's all based on metadata, or descriptors of the data and of the study. That information is pulled into a central search engine to look for data or HEAL studies. Once you find what you want, you can connect out to the places where the data are stored. We have workspaces where you can pull data in and compute on it and do analyses, we have analysis tools. It allows investigators and HEAL to put their data in a place that makes sense for them long term and still be connected to the central infrastructure that we're building.

Richie: It sounds like it also offers continuity between projects as well?

Mazerik: Exactly. With the study level metadata, we have outlined several fields , most of which are relevant to every program across HEAL. This increases the capacity for search, increases the ability to compare studies and datasets that are related that you might not have realized were related . We're doing the same thing with the data dictionaries as well, which holds different kinds of descriptors about the actual data (versus the study). That will provide a deeper level of connection between the data sets.

Richie: Sure, that makes sense, especially as a layman not really understanding data at all but understanding interpretation of what comes out from data. I'm also curious, given the fact that we're still emerging from the pandemic, how your work changed during the pandemic? What did the pandemic accelerate with your research with the opioid initiative given the toll opioids have taken after that?

Mazerik: The opioid crisis has evolved quite a bit since HEAL started. At the beginning, there were concerns around prescribing and prescription opioids, opioid overuse, leading to addiction and overdose, but now, there are synthetic opioids and polysubstance use that are unfortunately contributing to the increasing overdose numbers. COVID conflated all of that. Dr. Volkow is an expert and if you've listened to HEAL events, you may have heard her talk about it. But the crisis has evolved. That has led the research that we're putting out through HEAL to change, and other things have affected it as well. Being home for COVID meant that researchers and providers had to think about more telehealth options, including on the pain side of treatment, how treatment might differ when you can't go into the office, and how co-existing conditions like depression or other mental health conditions might play into the pain that you're feeling or into the way that you're using opioids. It added a lot of complexities that have shaped what we're doing today. Then from a personal level, the HEAL team grew substantially during COVID. The two folks on my team in the HEAL data ecosystem, Anthony Juhene, and Janeyt Oputa, who work really closely with me; we hired both of them during COVID. We don't see each other much in

person but talk on Teams many times a day. Even now we go into the office sometimes, but it's just a different work environment. Centrally the team expanded during COVID, and it's a really great team. But you know, different because we never really all sat together in the office before.

Richie: Right, that makes sense. Do you have any interaction with the state opioid stewardship programs that have been started to distribute money? Have they requested access to data at all in informing their decisions?

Mazerik: Not yet through the ecosystem. Again, I think that's because some of the studies are not complete, and we're just starting to see those publications come. We hope those are the kinds of people that will come and look at the data and that we will be able to inform decisions at many different levels with the data and other materials and results that are coming out of HEAL.

Richie: Are there any other target audiences, long term, that you see being the consumers of this information and accompanying data?

Mazerik: We've always thought that we wanted to make it more of a place that was easy for people who are good with data, not only bench researchers, to come and use data or explore the findings. I do think that there's that the interest of bringing in people from different agencies, policymakers who are working on opioid and pain related issues, [and] payers [like] CMS [Center for Medicare and Medicaid Services]. I mentioned the two awards that are helping with dissemination and so we can partner with the communities to understand exactly how we can translate and share the results and have that bi-directional relationship with them. That's the intent of HEAL: to really help those communities.

Richie: They all have their own stories, I understand. Yeah, definitely. I was curious, can you tell me about an average day in your life at work? What issues that you work on in your role and expand upon that a bit?

Mazerik: On the technical side, we have the University of Chicago Center for Translational Data Science. Bob Grossman and Phil Schumm are the PIs [principal investigator] of that award. Then the Renaissance Computing Institute at University of North Carolina in Chapel Hill and RTI [Research Triangle Institute] are the other awardees. Stan Ahalt is the PI for that award and has several amazing co-PIs. They are doing the work, and sharing with us for guidance and input as they build – so we spend a lot of time working with the awardee teams. I'm also constantly interfacing with them to help navigate the HEAL space and understand the HEAL research portfolio so that they can build infrastructure, products, [and] guidance documents that are tailored to HEAL. I help make those connections between those awardees and the HEAL investigators who are funded centrally through HEAL, but also, those awards are all being overseen by different institutes and centers. I do a lot of work with other program officers to make sure that everybody's on the same page. Another piece is having touchpoints with other HEAL program officer colleagues but also with the folks on the data science side to make sure that what we're doing in HEAL is integrating and aligned with NIH and its overarching vision. There's coordination with institutes and centers because, again, we're using all these different repositories to store the data. A lot of them are managed by the institutes and centers, so we need to collaborate with them and partner with them to connect our system. It's a lot of phone calls.

Richie: Phone calls, Zoom meetings, all the ways that our world has evolved over the past few years. I wanted to touch on this as well because of the health data in the data ecosystem, from my understanding, is findable, accessible, interchangeable, and reusable in that it's publicly available?

Mazerik: The FAIR acronym [Findable, Accessible, Interoperable, and Reusable]. The data ecosystem is really focused on findable and accessible. The interoperability piece is very challenging because of the diversity of science and data types being generated across HEAL. We have a lot of consortiums that are doing that interoperability piece on their own, and then we're also able to do some centrally in the ecosystem. As we're putting guidelines in place, we are thinking about FAIR. In fact, we have a “Fresh FAIR” webinar series, led by the RENCI/RTI team, that we talk about guidelines for managing and sharing data. They are very informative and well-done.

Richie: Very interesting, so much information about data ecosystems. I never really knew, but I think you know your website is really informative.

Mazerik: Thank you.

Richie: For my last question, is there anything else you'd like to share with us that we haven't covered about either your journey before being at the NIH or your current work?

Mazerik: I'll just touch again on the collaborative and trans-NIH nature of HEAL and how that's really helped shape what we're doing on the data side. We learn from our data science leaders to understand the landscape, and how HEAL can fit in and play a part. Then we have this amazing support from all of the institutes and centers who are administering the research of HEAL and wonderful support from the HEAL initiative team and staff and Dr. Baker in standing up resources centrally. This massive team effort will help get HEAL data, results, and findings out to many different stakeholders who can then use the information in different ways to do what they need to do and make those implementation changes on the ground.

Richie: Great. Well, thank you so much for taking the time to speak with us today.

Mazerik: Absolutely. Thank you for having me.