TEXAS Health and Human Services | **Texas Department of State Health Services**

MEETING SUMMARY
Advisory Committee to the Texas Cancer Registry
Friday, May 19, 2023, 11:00-1:00

Members/Designees/Guests Participating:

Sandi Pruitt, PhD, MPH, UT Southwestern Medical Center, **ACTCR Chair**
Caitlin Murphy, PhD, MPH, CPH, UT MD Anderson Cancer Center, **ACTCR Vice Chair Elect**
Christopher Webb, PhD, MPH, Research Advancement Manager, DSHS Office of Practice and Learning
Laura LarsenStrecker MPH, Program Specialist IV, DSHS Office of Practice and Learning
Jayne Rollison, Program Specialist, Data Analytics and Performance
Lee A Spangler, JD, Texas APCD
Kelly Merriman, MPH, PhD, CTR, UT MD Anderson Cancer Center
Laura Wood, American Cancer Society
Michael Scheurer, PhD, MPH, Baylor College of Medicine
Zuber Mulla, MSPH, PhD, Texas Tech University Health Sciences Center El Paso
Jessica Chacon, PhD, Texas Tech University Health Sciences Center El Paso
Sharon Giordano, MD, MPH, University of Texas M.D. Anderson Cancer Center
Rohit Ojha, DrPH, FACE, JPS Health Network
Diedre Watson, CTR, Baylor Scott & White Health, Round Rock
Erika Thompson, PhD, MPH, CPH, FAAHB, University of North Texas Health Science Center
Philip Lupo, PhD, MPH, Baylor College of Medicine
Daikwon Han, PhD Texas A&M University
Ramona Magid, CPRIT
Dimpy P Shah, MD, PhD, UT Health San Antonio Cancer Center
Sanjay Shete, PhD, UT MD Anderson Cancer Center

Texas Cancer Registry:

Natalie Archer, PhD, MHS, Registry Branch Director, TCR
Alison Little, MPP, Epidemiology and Analysis Branch Manager, TCR
Adrianne Moreno, MPH, Epidemiologist, TCR
Paige Miller, PhD, MPH, TCR
Kristen Smith, BS, Information Specialist, TCR

I. Welcome and Administrative Items — Sandi Pruitt, PhD, MPH, Caitlin Murphy, PhD, MPH, ACTCR Chairs	
Call to Order Welcoming Caitlin as Vice Chair	• **Sandi Pruitt (Input)** Called meeting to order ◦ **Caitlin Murphy (Input)** recognizes • **Sandi Pruitt (Input)** recognizes Caitlin Murphy in her first official meeting as acting ACTCR Vice Chair • **Caitlin Murphy (Input)** introduces herself
II. General Updates — Natalie Archer, PhD, TCR Branch Director, Alison Little, MPP, Epidemiology & Analysis Group Manager	

• New Staffing Update	• **Natalie Archer (Input):** Thanks, Sandi, and welcome as vice-chair, Caitlin! Thanks so much to you both for your service and leadership as chair and vice-chair – the Texas Cancer Registry greatly appreciates it!
	• **Natalie Archer (Input):** For General updates, the first thing I wanted to mention were some staffing updates of our own.
	    ◦ I'm grateful to now *officially* be the Cancer Epidemiology and Surveillance Branch Director; I was the interim Director from December – March, and then accepted the Director position permanently starting in April. I've really enjoyed working alongside all of our hardworking and dedicated TCR staff members for the past few months – getting to know them and seeing how passionate they are about the important work that TCR does for the cancer community and for the state of Texas helped made my decision to apply for the permanent Director position an easy one. I'm still learning a lot about the cancer registry (and the operations side in particular!), but our TCR staff and others from ACTCR, CDC, CPRIT, and other organizations have been so supportive and helpful – I appreciate it! I'm looking forward to getting to know each of you better, and to continue to work together with this Advisory Committee to ensure that TCR maintains a very high-quality cancer registry whose data help to make significant contributions in the fight against cancer.
	    ◦ **Archer (Question):** Next, I'd like to introduce Alison Little, who started as our Epidemiology and Analysis Group manager in December 2022 – just after the last ACTCR meeting. She and I both started working with TCR at the same time, and I'm so grateful she's been there to help with grant reports and lots of other activities. Alison, would you like to tell everyone a little bit about yourself?

	○ **Alison Little (Input):** Worked at TCR for 2 years 10 years ago. In the time since she's been away she's worked with Medicaid data. Mel's cultivation of a mission at TCR is part of drew her back ○ **Archer (Question):** Last but not least, please join me in welcoming (or more accurately, welcoming *back*) Dr. Paige Miller. She left us for about a year, but we are thrilled she's back with TCR! Paige is a Senior Scientist with Alison's group, and she's managing the epidemiologists in the group. Paige, for those who may not have worked with you in the past, could you please share a bit about yourself too? ○ **Paige Miller (Input):** Was at TCR in 2012 as the Epidemiology Manager. Now as Research Specialist, she more oversees the data requirement, IRB applications, and stats.
• Round Robin ACTCR Introductions	• **Archer (Input):** Since Alison and I are new and would like to get to know everyone a little bit, we were wondering if we could take a few minutes for each of the ACTCR members to introduce yourselves as well. Would you each be willing to share your name, your job title and institution/affiliation, how long you've been a part of ACTCR, and how you (or your institution/organization) use TCR data? I'll put these pieces of info into the Teams chat as well, in case that's helpful! And we'd love for you to turn cameras on for introductions as well, if you feel comfortable doing so! If it sounds OK, I'll just go through the list of participants that I have here in Teams. • **Jessica Chacon** – new to ACTCR, TTUHSC, looks at research for medical students • **Dr. Han** – TAMU school of Public Health • **Dr. Lupo** – Prof. Baylor College of Medicine, been part of ACTCR since 2016, considered Super User due to the many uses for he has for TCR data • **Dr. Merriman** – MD Anderson, Former chair of ACTCR, works with clinical facility • **Caitlyn Murphy** – uses fertility data, TCR data used for own research, works with students using data for class • **Dr. Ohja** – JPS health network, new ACTCR member, uses data for benchmarks • **Dr. Pruitt** –ACTCR member since 2014, uses data for disparities research • **Dr. Scheurer** – Professor at Baylor, longtime ACTCR member, past chair, Use data for many different projects and administrative reasons. • **Dimpy Shah** – UT Health San Antonio. ACTCR member for 7 years now, mainly use data for student projects. • **Dr. Shete** – MD Anderson, been part of ACTCR since 2016, Looked at survivorship issues

	• **Dr. Thompson** – Fort Worth UNT, new member, Use data from data visualization side, use with students. • **Dr. Mulla** – Texas Tech El Paso, been with ACTCR 4-5 years, use limited use dataset. • **Ramona** – CPRIT, uses data to update Texas Cancer Plan • **Laura Wood** – ACTCR member for 3 years, Part of American Cancer Society, Use data to educate local field teams, also to look at state landscape and understand trends.

• NAACCR Gold Certification	• **Archer (Input):** Continuing with program updates, I'm so happy to announce that TCR has achieved North American Association of Central Cancer Registries <u>Gold Certification</u> for the most recent Call for Data this past fall (2020 data)! The team did an incredible job collecting and working with cancer data that were affected by the pandemic, and all of this in the middle of changing our central registry software over to SEER*DMS.
	• **Archer (Input):** So in this table, TCR's stats/measures are shown in the 'actual measure' column that's highlighted in yellow.
	    o With the adjustment that NPCR/NAACCR settled on for this year (which was more complicated than the across the board raise in percentage that SEER had used), we had an adjusted completeness estimate of 102.1%!
	    o 0% missing for unknown age, sex, and state/county/province at diagnosis
	    o 0 duplicate primary cases
	• **Archer (Input):** And we're very proud of the fact that we had only 0.5% of cases with missing/unknown race, compared to U.S. average of 1.4% with missing/unknown race across all registries!

• 2023 Data Dissemination Plan	• **Archer (Input):** Next, we wanted to share our 2023 data dissemination plan with y'all – I'll turn it over to Alison for her to give info about this. • **Little (Input):** This year we are doing screening amenable cancers since each year we switch between that and modifiable. Liver will be included in our current reports plan to have out by end of Summer, beginning of September • **Merriweather (Question):** Fascinated by cause specific survival and cause of death. What's the completion rate? • **Miller (Input):** For reasons you mentioned we aren't doing that. It's a typo • **Merriweather (Input):** Tell me about Legislative Representation

	• **Little (Input):** There's a thing we've done every year, so there's not a ton of info, but I'll drop a link in the chat. Despite challenges of missing members we'll get it done over the next few months (referring to the TCR Legislative Report)
• New Legislative Rule Change, Utilizing BRANY IRB	• **Archer (Input):** Finally, I wanted to mention that a new legislative rules change (to the Texas Administrative Code) has been recently implemented and was effective March 20, 2023. This rules change will allow for the DSHS IRB to designate another IRB to be able to approve the release of confidential TCR data for research studies. When going through this rules change process, the IRB we had in mind was the National Cancer Institute's BRANY Central IRB, which reviews IRB applications for several states that participate in Virtual Pooled Registry (VPR)-Cancer Linkage Studies (CLS). We are moving forward with designating BRANY IRB to be able to review/approve multi-state cancer linkage studies that include TX data. This should definitely streamline the IRB process for researchers, which is great news! However, investigators will still be requesting and receiving *the data for these studies* from TCR. This means that DSHS will still require an MOU to be signed prior to release of data for these BRANY IRB-approved studies, very similar to the MOU process that Laura, our new IRB coordinator, will be describing more in-depth in her presentation. TCR is currently working with DSHS Legal and our contracts management section to come up with an MOU template that's specific to these BRANY IRB-approved cancer studies. This process will likely take some time, so the first few central IRB-approved studies will encounter a slowdown before their institution/institutions are able to actually receive and sign an MOU and they subsequently receive the requested TCR data. However, after the template has been approved, the MOU process should move much more quickly for these BRANY IRB studies, especially (we've been told) if no changes are made to the template. • **Archer (Question):** Does anyone have any questions about the legislative rules change or our plans to use the BRANY IRB? [*BRANY = Biomedical Research Alliance of New York]
III. DSHS IRB Update – Laura Larsen-Strecker, Program Specialist IV, Office of Practice & Learning	
• New DSHS IRB MOU Overview	• **Archer (Input):** And that's a good segue into our next agenda item, an overview of the new DSHS IRB MOU process by our new IRB Coordinator with the DSHS Office of Practice and Learning, Laura Larsen-Strecker. Laura has a Master's degree in Kinesiology with a focus in Exercise Science from UT-Austin, and a

| | Bachelor's degree in Earth and Planetary Science from Harvard University. Laura is an expert rower – she coached the Varsity Women's Rowing team at UT while getting her Masters' degree there, and has previously coached at the Austin Rowing club as well. Laura, thanks so much for taking the time to talk with us today!

- **Larsen-Strecker (Input):** Welcome! We're going to talk about MOUs. There are 2 institutional review boards: the DSHS IRB and HHSC IRB. We're going to focus on the DSHS IRB. The 2 main purposes of the IRB is to provide oversight of human subject research and provide protection for human subjects. Some studies can be expedited when there is minimal risk.

- **Larsen-Strecker (Input):** The basic process when going through the IRB review board is Program review > IRB review > Research Executive Steering Committee review > Contract Section. Program staff determine how or if data gets released so lots happens under the program umbrella before it even comes to the IRB. Contract Management Section is responsible for MOUs, they will need to be renewed every 5 years. MOUs that are created by new research studies but are amended to the MOU should not have the amendment change the language.

- **Larsen-Strecker (Input):** MOU is another step before data is released. There will be some changes to the forms. You can email Laura Larsen-Strecker at her IRB email or the Contract Management Section with further questions.

- **Archer (Question):** Who is the authorized signatory

- **Larsen-Strecker (Input):** My understanding is it's determined by the program

- **Webb (Input):** It's unlikely to be the researchers themselves

- **Zuber (Input):** (Gave description of process change of who signs these things at Texas Tech)

- **Archer (Input):** Thanks for working to get it to the Institutional Level

- **Pruitt (Question):** What's the expectation for existing open IRBs

- **Larsen-Strecker (Input):** At this time it's just new applications and there's no date to include older ones

- **Webb (Input):** The implementation is it would be renewals and we'd give programs lots of notice. We currently only have one going through right now so we're not going to push everything through. |

	• **Merriweather (Question):** I know it's dependent on staff process and it takes awhile now, but wouldn't they want to hold their monthly meetings more often then to speed up the process?
	• **Webb (Input):** We haven't discussed it and don't think it's likely, but we have taken measures to move things along faster. When we say things take 6 months to get approved, IRB probably only has it for 1 month. We've spoken with program to see what's hanging things up. We know they're prioritizing renewables, implementing an online application system which would allow researchers to know where their applications are and IRB to know what's in the queue and what's taking too long for further discussions. Just trying to streamline and adjust.
	• **Archer (Input):** Thanks again, Laura! We're excited to welcome another guest speaker, Mr. Lee Spangler, to talk with us today about the Texas All-Payer Claims Database and their anticipated timeline for use of these data. I know that this is something that several folks have expressed interest in knowing more about and utilizing in the future.
IV. APCD Update – Lee Spangler, JD, Executive Director Texas APCD	
• Texas All Payer Claims Database Overview	• **Archer:** Lee is an Associate Professor with the UT Health Science Center School of Public Health, and he's the Executive Director of the Texas All Payor Claims Database. He joined the Center for Health Care Data in early 2022. Prior to this, he's served as Vice President of Government Relations at Blue Cross and Blue Shield of Texas (BCBSTX), where he directed the company's state advocacy efforts. He also worked for many years at the Texas Medical Association, where he served as Vice President of Medical Economics. Mr. Spangler currently serves on the board of the National Association of Health Data Organizations, he's a past President of the Texas Association of Health Plans, and he's a past chair of the State Bar of Texas Health Law Section. We're so happy to have you with us today, Lee!
	• **Spangler (Input):** For an APCD, the data base collects claims from all payers in the state using standardized data formatted and then organized into a researcher accessible format (no matter who you go to you'll still give data). This started in the 90's in New England, we'd be about the 23rd-25th state to begin this process.
	• **Spangler (Input):** This creates transparency in charges in the data base and what is paid. Quality improvement can track the patient to see their record.
	• **Spangler (Input):** As for state regulation for All Payers and if it's included, there was a Supreme Court case on APCD regarding Vermont request for data and it was a 6-2 decision that you can't mandate EISA plans. So this is where the legislature

wants us to go. After estimates from the state of Texas, it's believed the APCD will have around 67 million patients. We could know as much data as whether or not the patient is employed by their insurance plan. Race is also something that is not regularly collected by providers working with uncovered peopled (not by Medicaid etc). The APCD is also working with hospitals to see if they can get info about paying program to better collect race information.

- **Spangler (Input):** Policy making is very curious about the public health implications, so they are making a portal where they can pull things up by county with a cost label data set called community factors. Legislature hasn't provided funding yet but it is on a wish list so it may go unfunded but it won't go away. They're also in talks with others to establish it or work for next legislative session.
- **Archer (Question):** Is the intent to put data in the portal for linkages?
- **Spangler (Input):** The answer is kind of both; The center is good at linking data, all of it is public health survival efforts that can help with that, then if you're amenable it could be presented as well as you guys have your own dashboard center, we have our own budget to do the same thing as well

V. Deidentified Data Update – Natalie Archer, PhD, TCR Branch Director	

• Asking requestors to utilize SEER Research data sets	• **Archer (Input):** On TCR's side, I just have one more item. I wanted to mention again the change that TCR is making in the process to obtain de-identified record-level cancer data for Texas, which was mentioned in an email that Kristen sent out a couple of weeks ago. Now that we are a SEER registry (and we are so thankful for your help and support with achieving this goal!), our de-identified TCR data are now available in two datasets that SEER provides, called SEER Research and SEER Research Plus, along with cancer data from all other SEER registries. To try to reduce duplication of effort for our staff, since these data are available elsewhere, we do not plan to update our TCR Limited-Use Dataset with this latest year of data (2020) or future years of data, and we're no longer listing the limited use dataset as a data product on the TCR website. Information on SEER's Research and Research Plus data products and how to request access to them can be found on SEER's website, and I'm going to paste these links into the chat as well.
	
	    • [How to Request Access to SEER Data - SEER Datasets (cancer.gov)](#)
	    • [Comparison of SEER Data Products - SEER Datasets (cancer.gov)](#)

	• **Archer (Input):** We've also decided to make this transition this year because our DSHS Data Governance section is beginning to put more stringent review processes in place for any agency datasets where individual-level data are released, regardless of whether they contain personal identifiers or not. If we were to continue our own LUD process, our agency would require either an MOU or DUA to be in place before we could send these data, and we think that at that point, it would probably be easier for researchers to request our de-identified cancer data from SEER.
	• **Archer (Input):** It sounds like several ACTCR members (or their grad students) use TCR's limited-use dataset. We definitely want to try to help make this transition as smooth as possible for y'all and for and all others who've used the TCR LUD file in the past. We've included some information in the email that Kristen sent out, but if there's any other information that we can provide that you think could be helpful, please let us know!

VI. Member Updates/New Business — Sandi Pruitt, PhD, MPH

• Member Updates	• **Wood(Input): Laura –** Texas Biomarker legislation has been passed! Link: Expand Access to Biomarker Testing in Texas	American Cancer Society Cancer Action Network (fightcancer.org)
• Next Hybrid Meeting in Fall 2023	• TBD in Fall, will do a hybrid meeting; **Action Items (Kristen Smith):** Send poll for next meeting time; Send minutes for vote

VII. Adjourn