



**MEETING SUMMARY**

Advisory Committee to the Texas Cancer Registry (TCR)  
Friday, April 5, 2019, 11:30 AM – 2:30 PM

**Members/Designees/Guests Participating:**

- Maria Hoang Tran, MPH, CTR, Memorial Hermann Healthcare System, **ACTCR Chair**
- Philip Lupo, PhD, MPH, Baylor College of Medicine, **ACTCR Vice-Chair/Chair-Elect**
- Harem El-Serag, M.D., MPH, Baylor College of Medicine
- Kelly Willis Merriman, M.P.H., Ph.D., C.T.R., University of Texas M.D. Anderson Cancer Center
- Laura Wood, CHES, American Cancer Society (delegate for Amanda English) (via phone)
- Menghua Tao, MD, PhD, MPH, University of North Texas Health Science Center (via phone)
- Michael Scheurer, PhD, MPH, Baylor College of Medicine
- Sandi L. Pruitt, PhD, University of Texas Southwestern Medical Center (via phone)
- Sharon Giordano, M.D., MPH, University of Texas M.D. Anderson Cancer Center (via phone)
- Zuber Mulla, PhD, M.S.P.H., Texas Tech University Health Sciences Center El Paso (via phone)

**Texas Cancer Registry (TCR)/Other DSHS Staff Present:**

- Melanie Williams, PhD, Branch Manager, TCR
- Paige Miller-Gianturco, PhD, Epidemiology Manager, TCR
- Susan Perez, CTR, RHIT, Registry Operations Manager, TCR
- Katie Dahlquist, MEd, Information Specialist, TCR
- Erin Gardener, MPH, Epidemiologist, TCR
- Keisha Musonda, MPH, Epidemiologist, TCR

**Note:** Please refer to the ACTCR webpage for handouts and presentations from the meeting (see links under December 2018: <http://www.dshs.texas.gov/tcr/actcr.aspx>)

<b>I. Welcome – Maria Hoang Tran, MPH, CTR, ACTCR Chair</b>	
Call to Order and Approval of Minutes	<ul style="list-style-type: none"> <li>Called meeting to order.</li> <li>Approved minutes from December 2018 ACTCR meeting.</li> </ul>



**II. General Update — Melanie Williams, PhD, TCR Branch Director**

Action Item Summary	Outstanding action items whose completion wasn't shared during ACTCR monthly updates will be discussed during the meeting.
Reorganization and Staffing Update	<ul style="list-style-type: none"> <li>• TCR staffing structure has been updated.             <ul style="list-style-type: none"> <li>• Registry Operations Manager (Susan Perez) oversees registry operations groups, quality assurance group and trainer.</li> <li>• Reclassifying some registrar positions to allow progression of career with TCR.</li> <li>• Upgraded some epidemiology group positions to align with skills and knowledge for specific roles.</li> <li>• Considering additional positions to help with operations tasks (e.g., IRB coordination and reporting compliance).</li> </ul> </li> <li>• There is still a shortage of CTRs nationwide.             <ul style="list-style-type: none"> <li>• Number of CTRs is increasing but still not meeting the demand.</li> <li>• Melanie Williams is working with National Cancer Registrars Association to address shortage, including facilitating a plenary session on the topic at the NCRA conference in May 2019.</li> <li>• TCR has had success with foreign-trained MDs who are not interested in getting licensed in the US. TCR is also pursuing RNs who no longer want to work in direct patient care.</li> <li>• Group discussed the possibility of using contract CTRs. TCR has used contract CTRs in the past. Some registries have had good experiences with contract CTRs while others have not been as positive.</li> </ul> </li> </ul>
CDC National Program of Cancer Registries (NPCR) Site Visit	<ul style="list-style-type: none"> <li>• Three CDC NPCR staff visited TCR in February 2019: program consultant, IT team lead and epidemiology team lead. Melanie Williams is awaiting the site visit report.</li> <li>• TCR leadership shared constructive feedback about the registry software. CDC NPCR IT staff will work with TCR to resolve issues that will benefit all registries using the software.</li> </ul> <p><b>Action Item:</b> TCR will share information from site visit report when it is available.</p>
2018 Reporting Delays	<ul style="list-style-type: none"> <li>• Due to delays for standard setters, the TCR is still unable to process cases from 2018. The TCR reporting calendar has been updated to reflect these delays, with January 2018 cases due in June 2019.</li> <li>• Hospital registries are already aware of the delay as it's directly impacting their current work.</li> </ul>



	<ul style="list-style-type: none"> <li>Group discussed how delay could potentially impact data consumers. One researcher is having to amend study protocol because cases aren't available within six months of diagnosis. Consensus of group:             <ul style="list-style-type: none"> <li>Share information on a case-by-cases basis when delay affects a specific research project or proposal.</li> <li>Share information with a broader audience once more information is known (e.g., when data will be available for 2018 cases).</li> </ul> </li> </ul>
<p>86<sup>th</sup> Legislative Session Update</p> <ul style="list-style-type: none"> <li>DSHS Legal Review of Texas Cancer Registry Statutes</li> <li>CPRIT Continuation</li> </ul>	<ul style="list-style-type: none"> <li>There are no proposed changes to the TCR statutes this session.</li> <li>There are conflicting bills proposed for the continuation of the Cancer Prevention and Research Institute of Texas (CPRIT), which provides 2/3 of TCR budget. One bill, which passed committee vote earlier this week, proposes a ballot initiative to fund CPRIT for another 10 years. Another proposed bill would end CPRIT in 2021. There is a contingency plan to fund the TCR if/when CPRIT ends.</li> </ul>
<p><b>III. Epidemiology Update – Paige Miller-Gianturco, PhD, MPH, RD, TCR Epidemiology Manager</b></p>	
<p>New TCR data products published January–March 2019</p>	<p><i>See handout: TCR Data Products Jan-March 2019</i></p> <p><b>Action item:</b> Katie Dahlquist and Melanie Williams will find out if reports for unique visits and downloads are available for individual web pages and documents.</p>
<p>Upcoming TCR data products for 2019</p>	<p><i>See handout: 2019 TCR Data Dissemination Plan</i></p> <p><b>Action item:</b> Add uterine cancer two-pager to Data Dissemination Plan for 2019.</p> <p><b>Action item:</b> Consider adding HIV-related cancer report to Data Dissemination Plan for 2020.</p> <p><b>Action item:</b> Add ICC3-3 recode to SAS limited-use dataset in 2020. In the meantime, Paige Miller-Gianturco will provide a SAS program used by TCR epi team as needed.</p>
<p>Non-Compliance Issues for DSHS-IRB Approved Studies Discussion</p>	<p><i>See handout: Non-Compliance Issues for IRB-Approved Studies</i></p> <ul style="list-style-type: none"> <li>Patient contact studies: There was consensus to contact the PI's institution's IRB if the PI isn't complying with guidelines or isn't responding to TCR staff's emails about requirements such as the recruitment report.             <ul style="list-style-type: none"> <li>Should requirements for patient contact studies be added to the confidentiality agreement where administrative officer signs?</li> <li>Should the institution's privacy officer or HIPAA lawyer be required to sign section of application acknowledging patient contact study requirements?</li> </ul> </li> </ul>



	<ul style="list-style-type: none"> <li>Data security: There was consensus that TCR should not fulfill data requests for PIs that have outstanding data security compliance issues. If a PI with a history of data security compliance issues submits a new IRB application, it should include a plan with their institution’s IRB to make sure PI complies with data security measures.</li> </ul>
<p><b>IV. Registry Strategic Planning – Group Discussion</b></p>	
<p>SEER Model for Partnerships with Academic Centers</p>	<p><i>See handout: Registry Strategic Planning</i></p> <ul style="list-style-type: none"> <li>Questions to consider:             <ul style="list-style-type: none"> <li>What will the cost be for academic partners?</li> <li>What are the benefits to academic centers who partner with SEER registries in other states?</li> <li>How will responsibilities be divided between TCR and academic center partner(s)?</li> </ul> </li> <li>Suggestions for partnership models:             <ul style="list-style-type: none"> <li>Divide task areas among different NCI-designated Comprehensive Cancer Centers who are interested in partnership. (e.g., one works with VRT, another Patterns of Care/Quality of Care studies)</li> <li>Epidemiology consortium with an academic center</li> <li>TCR staff don’t need to be on site at academic center (TCR would remain part of DSHS in Austin)</li> </ul> </li> </ul>
<p>Ancillary Studies and Additional Projects</p>	<p><i>See handout: Registry Strategic Planning</i></p> <p><b>Action item:</b></p> <ul style="list-style-type: none"> <li>Include TCR-supported studies being conducted by PIs at NCI-designated Comprehensive Cancer Centers in SEER application.</li> <li>Include NCI-funded studies by PIs utilizing TCR data in SEER application.</li> </ul>
<p>Virtual Tissue Repository (VRT)</p>	<p><i>See handouts: Registry Strategic Planning, SEER Virtual Tissue Repository Initiative Current Status and Future Goals; Virtual Tissue Repository Overview</i></p> <ul style="list-style-type: none"> <li>Many institutions already have tumor banks. Would just need to figure out how to create and manage a virtual network.</li> <li>A statewide VRT would probably include less than 50% of tumors diagnosed in Texas.</li> </ul>



Virtual Pooled Registry (VPR)	<p><i>See handouts: Registry Strategic Planning, Virtual Pooled Registry Fact Sheet</i></p> <ul style="list-style-type: none"> <li>Members supportive for TCR participating in some form of VPR. Providing aggregate counts of matches between researchers' cohort studies and TCR cancer data will help PIs identify which center registries to approach for data requests (instead of submitting applications to all 50 states).</li> <li>TCR will still require DSHS IRB approval before providing record level data for matches.</li> </ul>
Patterns of Care/Quality of Care Studies	<p><i>See handouts: Registry Strategic Planning, Patterns of Care Studies</i></p> <p>Topic not discussed due to time, but members are welcome to submit suggestions and feedback.</p>
<b>V. Member Updates/New Business – Group Discussion</b>	
Member Updates	<ul style="list-style-type: none"> <li>Kelly Merriman – MD Anderson was able to add nine new staff to the registry, bringing the total of registrars up to 30. MDA is looking into automating abstracting from EPIC as much as possible.</li> <li>Michael Scheurer – Baylor College of Medicine is starting competitive renewal applications. Dr. Poplack transitioned from the Director of Texas Children's Cancer and Hematology Centers to the Director of Global HOPE (Hematology-Oncology Pediatric Excellence); his replacement is Susan Blaney.</li> <li>Maria Tran – Memorial Hermann completed their CoC survey and will have their survey for National Accreditation Program for Breast Centers soon. They are also looking into the National Accreditation Program for Rectal Cancer. Merger between Memorial Hermann and Baylor Scott &amp; White was called off.</li> </ul>
Next Meeting	<p>Date: October 16, 2019 Time: 11:30am–1:30pm Conference call only</p>
<b>VI. Adjourn</b>	