



## **MEETING SUMMARY**

Advisory Committee to the Texas Cancer Registry (ACTCR)

Friday, April 20, 2018

Austin, Texas

### **Members/Designees/Guests Participating:**

Kelly Willis Merriman, M.P.H., Ph.D., C.T.R., University of Texas M.D. Anderson Cancer Center, **ACTCR Chair**

Maria Hoang Tran, M.P.H., C.T.R., Memorial Hermann Healthcare System, **ACTCR Vice-Chair/Chair-Elect**

Theresa Byrd, D.Ph., R.N., Texas Tech University Health Science Center

Sharon Giordano, M.D., M.P.H., University of Texas M.D. Anderson Cancer Center

James Goodwin, University of Texas Medical Branch, Galveston

Daikwon Han, Ph.D., Texas A&M University Health Sciences Center

Zuber Mulla, Ph.D., M.S.P.H., Texas Tech University Health Sciences Center El Paso

Debra Patt, M.D., M.P.H., M.P.A., Texas Oncology

Sandi L. Pruitt, Ph.D., University of Texas Southwestern Medical Center

Dimpy P. Shah, M.D., Ph.D., UT Health San Antonio Cancer Center

Sanjay Shete, Ph.D., University of Texas M.D. Anderson Cancer Center

Elaine Symanski, Ph.D., University of Texas Health Science Center at Houston

Menghua Tao, M.D., Ph.D., M.P.H., University of North Texas Health Science Center

Karen Torges, Past Chair, Cancer Alliance of Texas

Yu-Tin Huang, Ph.D., M.P.H., UT MD Anderson Cancer Center (Guest)

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

Melanie Williams, Ph.D., Branch Manager, Texas Cancer Registry (TCR)

Heidi Bojes, Ph.D., Section Manager, Environmental and Epidemiology Section

Paige Miller-Gianturco, Ph.D., Epidemiology Manager, TCR

Maria Vega, M.P.A., Core Business Operations Manager, TCR

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

### **Welcome—Kelli Willis Merriman, M.P.H., Ph.D., C.T.R., ACTCR Chair**

Ms. Merriman called the meeting to order, and attendees introduced themselves.

Members approved the meeting minutes from the October 20, 2017 meeting.



Dr. Williams also reviewed the status of the more substantive action items from the March 2017 ACTCR meeting, including the following:

- Dr. Williams indicated that there had been discussions about the need for a statute change related to linked Texas Health Care Information Council Inpatient/Outpatient cancer data sets. The statute change has internal support and will be suggested for next legislative session; please see discussion later in these meeting highlights.
- Dr. Williams updated ACTCR members on the issue of minimum data elements needing to be reported and her discussions with the New York Cancer Registry. She also informed members that the TCR decided to no longer require the reporting of non-US citizens to the registry.
- Dr. Williams provided a staffing update to members. The Epidemiology Team is fully staffed, some vacancies within the registry have been repurposed for other uses within the TCR, and TCR has made progress in filling vacant positions throughout the registry. Filling of positions remains a critical focus given the increased number of data requests and IRB requests received and processed and changing reporting requirements. The TCR continues to face challenges in recruiting and retaining certified tumor registrars (CTRs).
  - ***ACTION ITEM: The TCR will send job opening announcements to ACTCR members so that they can share with their networks to include recent graduates.***

Dr. Williams provided an update on the Centers for Disease Control and Prevention-National Program of Cancer Registries (CDC-NPCR) non-competitive grant application for the 2018-2019 federal fiscal year. The TCR submitted a reapplication in January 2018 and anticipates that the TCR will hear about FY 18-19 funding in May or June. The TCR asked for additional funds for the coming year.

- ***ACTION ITEM: The TCR will share funding amounts received with members in the monthly ACTCR email to members.***

Dr. Williams provided an update on the annual data submission. The TCR has met the CDC-NPCR data quality standards and anticipates that the North American Association of Central Cancer Registries (NAACR) certification results will be available in May/June 2018.

- ***ACTION ITEM: The TCR will share the NAACCR results with members in the monthly ACTCR email to members.***



## **Member Requested Topics – Group Discussion - Discussion led by Melanie Williams, Ph.D.**

The following briefly summarizes the topics Dr. Williams discussed:

### *Data Dissemination Plan Draft Overview*

Dr. Williams reviewed the TCR Data Dissemination Plan with members and solicited their input and suggestions. She welcomed members input on the draft. Dr. Williams provided an overview on the new statistical web reports and tables that are being prepared and published on the TCR website. She indicated that the TCR welcomes members' feedback on the reports, tables and other needs that they have. Members had questions about the timely availability of data and how records are processed. Dr. Williams updated the group on how records are processed and when data becomes publicly available.

- ***ACTION ITEMS:***
  - ***Members will review and provide feedback, if any, on the data dissemination plan by the end of May 2018.***
  - ***Members to share ideas they have on web reports and data with the TCR.***
  - ***The TCR will make publicly available the PowerPoint slide presentations with the TCR data from published web reports for their potential further use and dissemination.***
  - ***The TCR will provide updates on what products on the data dissemination plan are updated/available via the ACTCR monthly email.***

During the data dissemination plan discussion, members were updated on what the current review process is for journal articles. The TCR does not provide formal review of journal articles that include TCR data that are not co-authored by a DSHS staff member. When a DSHS staff member is listed as a contributor/author to the article, the journal article is reviewed and approved formally within the DSHS.

### *86<sup>th</sup> Legislative Session*

Dr. Williams further expanded on the discussions about the proposed public and research linked Texas Health Care Information Council in-patient and out-patient data sets. The discussions regarding this topic have been positive and it is anticipated that the Department of State Health Services (DSHS) will suggest modifications to the enabling statute for consideration in the upcoming session.

- ***ACTION ITEM: TCR to provide a copy of proposed language to members.***

### *SEER Registry Benchmarking*

Dr. Williams updated members on several efforts that are underway to look at registry operations and/or to identify opportunities to improve them. These efforts include:

- CDC-NPCR Evaluation Plan Draft – Dr. Williams provided an overview of the mandated plan and indicated that it is a document that will be modified and updated during the current grant cycle dependent on both members’ feedback and feedback from the CDC-NPCR. ACTCR efforts and collaboration are specifically mentioned in the plan as a critical element of how the TCR evaluates its work and efforts. The TCR anticipates feedback from the CDC on the plan in Spring/Summer 2018.
  - ***ACTION ITEM: Members to review plan and provide input.***
- CDC-NPCR Data Quality Indicator Report – Dr. Williams highlighted critical indicators throughout the report.
- CDC-NPCR Program Evaluation Instrument – The TCR recently received this instrument and will be responding to it in May.
- TCR Registry Software IT Assessment Project – The TCR and DSHS IT contractors are working together to assess the existing registry software (Registry Plus) and its capacity to meet the needs of a state that collects and disseminates large amounts of cancer data. This review is also assessing the availability, scope and requirements of other available cancer registry reporting software and how they do or do not meet TCR’s and reporters’ needs. The project will end in Summer 2018.
  - ***ACTION ITEM: The TCR to send out copies of the system replacement assessment overview to all members.***
- Cancer Prevention, Control, And Research Activities Supported – Dr. Williams updated ACTCR members on the breadth and frequency of how TCR data is used to support cancer prevention, control and research activities. She welcomed members input and encouraged them to interact with the TCR when they need TCR data to help support their efforts.

### *Patient Contact Studies*

There was discussion about the TCR’s policy and procedures (P&P) for research studies involving patient contact. The TCR is revisiting its current P&P, and reviewing those of other state registries. The TCR would like input from ACTCR members on opportunities for improvement or modification.



- ***ACTION ITEM: TCR to host a conference call in June/July with interested members to review and evaluate the TCR's P&P related to releasing data for patient contact studies, and to determine what modifications, if any, to current policy and procedures would be recommended.***

### **Member Updates/New Business—Group Discussion**

- No members provided updates from their respective institutions.
- Next meeting will be held in October 2018.
  - ***ACTION ITEM: TCR to send out a doodle poll to determine exact date in October 2018.***
- Members suggested the following agenda items for the next meeting:
  - Program Evaluation Instrument overview and results
  - Update on changes/updates, etc. on Data Dissemination Plan (requested update for every future meeting)