



## MEETING MINUTES

Advisory Committee to the Texas Cancer Registry (TCR)  
[DSHS Central Campus](#), 1100 West 49th Street, Austin, TX 78756  
Wednesday, March 25th, 2015  
11:30am – 2:30pm  
Room T-607

### Members and Designees Present:

Michael E. Scheurer, Ph.D., M.P.H., Baylor College of Medicine, **ACTCR Chair**  
David Auzenne, M.P.H., Breast and Cervical Cancer Services, DSHS  
Stephanie Nutt, M.A., M.P.A., **LIVESTRONG** Foundation  
Roberto L. Rodriguez, M.D., M.P.H., Health Promotion & Chronic Disease Prevention Section, DSHS  
Karen Torges, Cancer Alliance of Texas (CAT)

### *Via Phone:*

Sandra Balderrama, M.P.A., Cancer Prevention and Research Institute of Texas (CPRIT)  
Dan Goldberg, Ph.D., Texas A&M University  
Kelly Willis Merriman, M.P.H., Ph.D., C.T.R., UT MD Anderson Cancer Center  
Maria Tran, M.P.H., C.T.R., Memorial Hermann Healthcare System  
Deidre Watson, C.T.R., Oncology Network Consultants

### Texas Cancer Registry Staff Present:

Ashley Dixon, M.P.H.  
Beatriz Gutierrez, M.P.H., C.T.R.  
Leticia Nogueira, Ph.D., M.P.H.  
Maria Vega, M.P.A.  
Melanie Williams, Ph.D.

### Minutes:

#### **I. Welcome—Melanie Williams, Ph.D., Branch Manager**

Dr. Williams called the meeting to order and attendees introduced themselves. Minutes from the June 3, 2014 meeting were approved as presented. Nominating a Vice-Chair was also discussed.

#### **II. ACTCR Governance—Melanie Williams, Ph.D., Branch Manager**

Dr. Williams thanked Dr. Ruth Rechis for her service as ACTCR Chair and Dr. Michael Scheurer was introduced as the new ACTCR Chair. Also introduced was Stephanie Nutt as the new **LIVESTRONG** representative. Nomination ballots for Vice-Chair were passed out for those attending in person. Members also discussed an online nomination process was also discussed to include those who could not attend today.

***ACTION ITEM: Email full membership online Vice-Chair nomination survey.***



### **III. Texas Cancer Registry Update—Melanie Williams, Ph.D., Branch Manager**

#### *Overview of recent activities—*

Dr. Williams discussed the recent CDC grant award and that TCR received a slight increase in funding over last year. This additional funding, in part, helps to support Meaningful Use activities.

The TCR anticipates regaining NAACCR Gold Certification after narrowly missing Gold last year due to issues such as participation in CER and IT issues, which have since been resolved.

***ACTION ITEM: Send email announcement to members of certification results (when available).***

Dr. Williams discussed the TCR's use of the business intelligence software Tableau to visually present TCR performance measures. Karen Torges suggested doing a webinar on how to use the Tableau dashboard for targeted audiences (researchers and data users) or doing a short 10-minute "infomercial" presentation at relevant stakeholder groups' meetings.

***RECOMMENDATION: TCR to conduct Tableau dashboard webinar and/or stakeholder group presentations (e.g., CAT Quarterly Meeting, CPRIT Annual Meeting)***

***ACTION ITEM: Add link to dashboard(s) on TCR website.***

#### *Legislation potentially impacting TCR—*

TCR has provided feedback on several bills this session; each is briefly described below.

HB 1319 relates to use of Health Information Technology (HIT) in Texas; if passed it will allow public health programs to receive data through a Health Information Exchange (HIE). The proposed amended statute does specifically name the registry, and if passed will require a rule change to specifically state that the TCR can accept data via HIEs.

HB 764 relates to the use, collection, and security of health information collected by state agencies including DSHS. HB 764 directs DSHS to remove sensitive patient identifying information; to provide written notification to parties of data collection; prohibits the sale of data; and directs DSHS to provide an annual report to the Legislature of security breaches, security prevention efforts, and plans. Implementation of this bill may decrease the value of Texas Health Care Information Collection (THCIC) data; may increase cost to state and health care facilities due to possible duplicate reporting (if it inhibits our access to the data); and would likely prohibit THCIC from charging TCR for access to its data.

DSHS has also been asked to look at a few CPRIT related bills. HB 1952 relates to striking provisions from CPRIT statutes that currently allow CPRIT grants to be used for things such as product development or other private sector entities and not to fund those activities in the future. SB 197



relates to CPRIT developing a plan for self-sufficiency upon the distribution of all bond funds. Currently, two-thirds of TCR's funding is from CPRIT.

HB 2766 relates to the confidentiality of Date of Birth in Texas.

TCR staff verified and is continuing to monitor that the rider that provides the majority of TCR's funding is attached to CPRIT funding in the appropriations bill.

#### *Virtual Pooled Registry—*

Dr. Williams attended a meeting at the National Cancer Institute where they allowed states to participate in some of their planning and surveillance meetings. Normally these meetings only include SEER registries. One topic of interest at the meeting was the concept of a Virtual Pooled Registry. The goal of the Virtual Pooled Registry is to create capacity similar to the National Death Index but without aggregating patient data. This would be different from the NAACCR dataset in that nothing below county level is reported to NAACCR.

Potential benefits of a Virtual Pooled Registry include creating an unprecedented resource for cancer research; saving years of time in getting approvals for access to data across multiple states; saving taxpayer dollars; allowing a more rigorous and comparable scientific research by adopting a standardized methodology; potentially eliminating the need to negotiate data release and IRBs if no matches are in the pooled registry; and allowing some registries who may not have the resources to participate in research. This process would likely yield a more convenient method for de-duplication of data in state registries.

If implemented the Virtual Pooled Registry would most likely be built into funding requirements, so that SEER registries would be required to participate in the Virtual Pooled Registry. Research using the Virtual Pooled Registry would still need to go through the DSHS IRB process.

#### **IV. Facilitated Discussion on Data Needs—Group Discussion**

Dr. Williams led an open discussion with members on the data needs of TCR data users. Members shared the following ideas and suggestions:

- Capturing parents' names and contact information to facilitate contact studies in pediatric cancer.
- Capturing names and contact information for next of kin (e.g., foster parents, uncles/aunts, grandparents).
- Including established biomarkers (TCR refers to them as "Site Specific Factors" (SSFs). It was suggested that since TCR collects some established biomarkers that TCR should make data users more aware of this collected data. Members shared that the American College of Pathologists would have the best list of biomarkers.



- Enhancing collection of co-morbidities, history of tobacco use, environmental exposures, and CER forever seven

***RECOMMENDATION: Make it more “known” which biomarkers TCR collects***

***ACTION ITEM: Email members article on cancer clusters***

## **V. Facilitated Discussion on Supporting Survivorship Care Plans—Group Discussion**

Members provided updates on some of their activities related to supporting Survivorship Care Plans, which included the following:

- Baylor Passport for Care is a collaboration between Texas Children’s Cancer Center, Baylor, and Children’s Oncology Group that includes an electronic version of screening recommendations for childhood cancer survivors. This effort has received a CPRIT grant to develop a survivor portal with the goal of creating a sense of community among cancer survivors (social media context). This project also includes developing guidelines to enable conducting research through the portal. The collaborators are also working on developing a Passport for Care for breast cancer patients.
- **LIVESTRONG** Survivorship Care Plan Tool is an effort led by the **LIVESTRONG** foundation working with the University of Pennsylvania OncoLink, a well-established online resource for cancer information. Together they are developing a tool that allows for doctors, nurses, and patients to enter demographics, diagnosis, and treatment information that is used to deliver a customized survivorship care plan. A major challenge faced is actually getting users to enter information into the tool. They are working to identify solutions to prepopulate the information. Stephanie will give an update on progress at the next ACTCR meeting.
- Colorado Care Plan Pilot is a similar approach to **LIVESTRONG**’s tool in that it uses cancer registry data to prepopulate breast cancer care plans. This tool needs cancer registries to participate, but have not yet allowed any other states access.
- DSHS is working to develop an application for a new CDC Survivorship Funding Opportunity Announcement (FOA). The application is being developed by the DSHS Health Promotion & Chronic Disease Prevention Section with other areas of DSHS participating or providing input. TCR is providing support for DSHS’s application for these funds.

***ACTION ITEM: Stephanie Nutt to present an update on Survivorship Care Plan progress at next meeting***

***ACTION ITEM: Dr. Michael Scheurer to give an update on Passport for Care – Breast Cancer at next meeting***

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



Members provided general updates about the work of their organization.

Baylor College of Medicine—Dr. Dr. Michael Scheurer reported that Baylor submitted a NCI grant application and applied for comprehensive status NCI designation for the Dan L. Duncan Cancer Center.

Cancer Alliance of Texas—Karen Torges reported that the CAT is working on increasing tobacco control efforts, encouraging efforts associated with attaining the workplace CEO gold standard, evaluation of the Texas Cancer Plan, and increasing education/information about the Affordable Care Act as it applies to cancer. There will be a survivorship panel at next CAT meeting on May 21, 2015.

**LIVESTRONG**—Stephanie Nutt reported that **LIVESTRONG** has a new CEO, Chandini Portteus. **LIVESTRONG**'s current research initiatives include conducting a survey on survivorship care plans. Stephanie will give an update at the next ACTCR meeting regarding the results.

Health Promotion & Chronic Disease Prevention Section—Dr. Roberto Rodriguez reported that DSHS is awaiting notification about a CPRIT grant for colorectal screening targeting Federally Qualified Health Centers (FQHCs) in HSR 2 and 3 (North Texas). DSHS is also co-applying with MD Anderson Cancer Center and the University of Texas School of Public Health for a CDC FOA to promote colorectal screening also targeting FQHCs.

UT MD Anderson Cancer Center—Dr. Kelly Merriman reported that she started a new position as Registry Director of the Tumor Registry at MD Anderson (MDA). She also reported that the MDA Cancer Network usually averages 4900 new patient registrations per month, but this past January that number tripled to 15,000 new patient registrations. This increase was due to MDA's new contract with Memorial Hermann for screening mammography. It's projected that in 2 to 5 years MDA will be screening 50% of breast cases in the area.

Memorial Hermann Healthcare System—Maria Tran reported on the partnership with MDA for breast cancer screening. They are also moving away from traditional hospital registries to registries in the community in order to serve all the new outpatient centers.

***ACTION ITEM: TCR to schedule next meeting for September 2015***

## **VII. Adjourn**

There being no further business, the meeting was adjourned at 2:32pm.