



MEETING MINUTES

Advisory Committee to the Texas Cancer Registry (TCR)
LIVESTRONG Foundation, 2201 E. 6th Street, Austin, Texas 78702
Tuesday, June 3, 2014
11:30am – 2:30pm

Members and Designees Present:

Chair: Ruth Rechis, PhD, LIVESTRONG Foundation
Karen Torges, Cancer Alliance of Texas
Deidre Watson, CTR, Oncology Network Consultants

Via Phone:

Xianglin Du, MB, MS, PhD, University of Texas Health Science Center at Houston
Lewis Foxhall, MD, UT MD Anderson Cancer Center, UT Medical School, DSHS Council
Dan Goldberg, PhD, Texas A&M University
Sandi Pruitt, PhD, UT Southwestern
Michael E. Scheurer, MPH, PhD, Baylor College of Medicine
Sumihiro Suzuki, PhD, University of North Texas Health Science Center
Maria Tran, MPH, CTR, Memorial Hermann Healthcare System

Texas Cancer Registry Staff Present:

Ashley Dixon, MPH
Maria Vega, MPA
Melanie Williams, PhD

Minutes:

I. Welcome—Ruth Rechis, Ph.D., Chair

- a. Call to order
- b. Introductions, welcome new members
- c. Approval of minutes

Dr. Rechis called the meeting to order. She introduced new members Sandi Pruitt, PhD, Sarah Mendoza, and Scot Maitland and thanked Dr. Keith Argenbright, Brad Pollack, MPH, PhD, and Sarah Taylor, MPH, CTR for their service on the committee. Minutes from the September 17, 2013 meeting were approved as presented.

II. Texas Cancer Registry Update—Melanie Williams, Ph.D., Branch Manager

- a. National Program of Cancer Registries (NPCR) Call for Data results
- b. TCR staffing and funding, requests for additional assistance
 - i. NPCR
 - ii. State
- c. Review of progress on ACTCR input and recommendations

- i. Most relevant cancer reporting sources, Stage 2 Meaningful Use
- ii. Public member
- iii. Patient contact studies
- iv. Discussion of potential alternatives for TCR Strategic Planning Project

NPCR Call for Data Results—

Dr. Williams discussed the NPCR call for data results, as provided in the Data Evaluation Report. The registry faced challenges in data collection last year, including it being the first year after system conversion to the Web Plus platform, as well as additional workload from CER data collection. The data were slightly less complete than in previous years, but the data are still sound and the registry has included footnotes for our researchers. The TCR has not yet received its NAACCR certification results, but results are expected soon. The completeness estimates may be adjusted for high Hispanic population. *(Editorial Note: NAACCR announced on June 17, 2014 that the Texas Cancer Registry attained the Silver standard for quality, completeness, and timeliness for the 2011 reporting year data submission.)*

TCR staffing/funding, requests for additional assistance—

Dr. Williams discussed the registry's need for additional resources as the registry has seen a significant increase in the volume of work, yet is currently funded at \$150,000 less than 2006 funding levels. There are over 250,000 records in backlog that are pending processing. The newly formed Non-hospital Group's productivity has increased by 300%, however the volume of reports that the group handles has increased by 400%.

TCR recently requested, via the exceptional item process for above base-line funding, additional state dollar funding to support the registry work associated with the growing volume of reports. The request included asking for three additional positions to support physician reporting. Because the amount of the overall request was \$1.2 million for the biennium, DSHS leadership decided to meet TCR's needs within current DSHS appropriations. This will facilitate the funding and resources being available prior to the beginning of the next biennium (FY16-17). An additional funding request was also submitted to the CDC; preliminary results included an award of an additional \$80,000 over previous year's funding.

Review of progress on ACTCR Input—

During the discussion of TCR's progress, suggestions for improving physician reporting were made, including reaching out to the Texas Medical Association (TMA) to see how the TCR can message to physicians about reporting their cancer cases to the registry. The committee's review of licensure lists proved helpful as the registry was able to better target the types of facilities that would provide missing cases. Stage 2 Meaningful Use is progressing slowly both at the registry and nationally; it seems that physician EHR reporting will likely progress at the same pace as pathology reporting (which took about 10 years to be fully functional).

A public member was added to the committee; this will hopefully bring more transparency to the committee as well as opportunities to discuss issues that include patient contact studies and survivorship. Regarding patient contact studies, the committee's previous recommendations on patient contact studies were incorporated into TCR's internal requirements and approved by DSHS

Commissioner. The TCR is currently involved with six studies involving patient contact. To date, only eleven patients requested to no longer be contacted; one individual was unhappy about being contacted and his information was flagged for non-release, and it was determined that another patient should no longer be contacted. On a positive note, many patients expressed gratitude for being contacted, as they appreciated the need for further study of patient survivorship issues.

The Strategic Planning project has not progressed as hoped; the Scope of Work previously developed is still good. The cause of delay on this project revolves around resource and timing issues. The TCR has not been able to move forward with the procurement, but may be able to move forward in the next fiscal year, if the registry obtains the additional funding that was requested.

Discussion on potential alternatives for conducting the Strategic Planning project included:

- Administering a survey (not preferred)
- Focus groups with selected partners, (e.g., LIVESTRONG Board, TMA Cancer Committee)
- Use professional facilitators; DSHS has a facilitator contractor
- Conduct when these group (such as TxTRA, NCRA) are already meeting to ensure better feedback and response rate
- Cancer Alliance of Texas Department of State Health Services
- Town Hall with University Representatives/Academic Centers

III. Data Sharing and Accessibility—Group Discussion

- a. Legislative and DSHS Strategic Priority
 - i. House of Representatives Interim Charge
 - ii. DSHS Sunset Review and Strategic Plan
- b. Current TCR Accessibility
 - i. Web Query Tool
 - ii. Ad-hoc data requests
 - iii. SeerStat, SAS Limited Use Data Sets
 - iv. Custom data sets involving the DSHS-IRB
- c. Current overall TCR Process and Data Availability
 - i. SWOT Analysis - Identifying strengths, weaknesses, opportunities, threats
 - ii. Suggestions for improvement
- d. Potential New Data Accessibility
 - i. Texas Health Care Information Collection Inpatient/Outpatient Linked Data
 - ii. Medicare and/or Medicaid Linked Data
 - iii. Birth Certificate Linked Data
 - iv. New Dashboards, e.g., Tobacco-Related Cancers, Obesity-Related Cancers
 - v. Others

Dr. Williams updated the group on the focus in part, on data and registry issues, in such venues as the House of Representative Interim Charge related to registries and the DHS Sunset Review and HHSC led strategic plan development activities. Melanie also discussed enhancements to the TCR WebQuery Tool (<http://www.cancer-rates.info/tx/>) along with other information concerning ad-hoc data requests; SAS limited use data sets and custom data sets involving research approved via the DSHS-IRB process.

The group discussed data sharing and accessibility. Highlights of the discussion included:

- Focus on quality, technology, and exchange
- Hospital discharge data linked dataset
- New version of the web query tool, with enhanced features
- Greater ability to select and aggregate data by specific service areas
- Expanded dashboards for selected cancers (smoking related, obesity related)
- Improvements to data request process
- New linked datasets, permissions may be an issue
- Largest number of missed cases were from large healthcare systems' outpatient data
- Be proactive/anticipatory about requests according to National Cancer Calendar

ACTION ITEM: TCR to create a tobacco related cancers dashboard

ACTION ITEM: TCR to send members list of data elements contained in the hospital discharge data for input on creating a consolidated list of fields needed

IV. Member Updates / New Business— Ruth Rechis, Ph.D., Chair, Group Discussion

- a. Election for Vice Chair/Chair Elect
- b. Next meeting—discuss preference for 2 or 3 times per year, timing

The committee still needs a vice-chair; TCR will be soliciting for volunteers in the post-meeting follow up email. Election may be held online.

Regarding the timing and frequency of meetings, participants agreed to have two standing meetings each year (a third as needed or an issue comes up), with the next meeting scheduled for October 2014, and another in the first quarter of CY 2015. Additionally, it was proposed that a nice improvement would be to do a regular quarterly email update to the members (on non-meeting quarters).

Member Updates—

Karen Torges (Cancer Alliance of Texas)—focus on tobacco control and CEO gold standards, which encourages companies to have tobacco control in the workplace; evaluation of Texas Cancer Plan.

Deidre Watson, CTR (Oncology Network Consultants)—moving offices

Ruth Rechis, PhD (LIVESTRONG)—Symposium on the delivery on patient centered cancer care

ACTION ITEM: TCR to solicit volunteers for a vice-chair for the committee

ACTION ITEM: TCR to do a twice yearly update to members in quarters in which the committee is not meeting.

V. Adjourn

There being no further business, the meeting was adjourned at 1:40pm.