Advisory Committee
To the Texas Cancer Registry

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Branch Manager

Texas Cancer Registry
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• Texas Cancer Registry became legislatively mandated in 1979.

• Eliminated in 1987 through a legislative error.

• Statewide data begins with 1995 diagnoses

• High volume of data in large state agency

• Not meeting national data standards is a recent memory

• Tremendous variation of stakeholders and interests in the Registry
Background

- Began as the Texas Cancer Data Work Group in 1997

- Since 2007 called the Advisory Committee to the Texas Cancer Registry (ACTCR)

- Founded on premise that the Texas Cancer Registry (TCR) and Texas cancer community as a whole, needed better interaction and communication with one another

- Needs of the TCR, reporters, cancer control, and research community were not being met
There were diverse and sometimes conflicting points of view about goals, priorities, and how progress could be attained.

The TCR also very much needed external support in order to gain the resources needed to become statewide and meet national data quality standards.

This group became and still is a very strong advocate for the TCR.
Membership

• Not to exceed 30 members

• Represents various interests in cancer data reporting and use, such as hospitals, cancer treatment centers, ambulatory surgery centers, pathology laboratories, physicians, professional associations, advocacy groups, other state cancer programs, and universities

• Strive for balanced regional and organizational representation

• Meets 3 times per year in Austin
Advisory Committee to the Texas Cancer Registry (ACTCR)
List of Current Members

- ACTCR Officers -

Brad Pollock, Ph.D., M.P.H. (ACTCR Chair)
Dielmann Distinguished University Endowed Professor and the Chairman
Department of Epidemiology and Biostatistics
University of Texas Health Science Center at San Antonio

Karen Torges (ACTCR Vice-Chair)
Director
Strategic Collaborations
High Plains Division
American Cancer Society

Lauri Kalanges, M.D., M.P.H.
Medical Director
Community Health Services Section
Texas Department of State Health Services

Ramona Magid, M.B.A.
Executive Director
Austin Affiliate of Susan G. Komen for the Cure

Kelly Merriman, Ph.D.
Program Manager
Department of Epidemiology
University of Texas M.D. Anderson Cancer Center

Andy Miller, M.H.S.E., C.H.E.S.
Vice President for Programs and Policy
Lance Armstrong Foundation

- ACTCR Members -

Sejong Bae, Ph.D.
Associate Professor
Department of Biostatistics
School of Public Health
University of North Texas Health Science Center

Debra Patt, M.D., M.P.H.
Physician
Medical Oncology and Hematology
Texas Oncology Cancer Center and
Assistant Professor at
University of Texas M.D. Anderson Cancer Center and
Enhancements to the Registry

• What does the advisory committee do to enhance the Registry?
Examples of Benefits to the Registry

• Significantly contributed to the TCR meeting national data quality standards

• Obtained $1.2 million in FY 06 and $1 million in FY 07 to improve TCR infrastructure to achieve and maintain national data standards

• Now recurs as $1.875 million every 2 years.

• Improvements in Staffing:
  • Vacancy rate 2% compared with 15-20
  • Increased number of CTRs on staff by 50%
Examples of Benefits to the Registry

- New Regional Registries
  - South Texas – Texas A&M School of Rural Public Health
  - East Texas – UT Health Center – Tyler

- Other Academic Support
  - Contract CTRs – MDACC, UTMB
  - Path Lab Reporting in South Texas - UTSPH - Brownsville

- Other Non-Hospital Source Reporting
- Automation and other business improvements
- Stakeholder support!
Benefits for Advisory Committee Members

• How does advisory committee membership benefit members?
  – They feel as though they are custodians of an incredible valuable resource
  – Opportunity to see “bigger picture” of cancer reporting
  – They feel as advocates this way they have greater strength in numbers
  – Tremendous value to hear their points of view, and have opportunity to openly discuss
  – Face-face dialogue is invaluable, along with developing important relationships
  – This provides them an opportunity to contribute towards and protect a critical resource that they need, in order to be successful in their work
Committee Revisited

- In 2007 reviewed and revised advisory committee based on member and TCR staff strategic planning meeting/process

- Advisory Committee had become somewhat “stale” and had not been reviewed or significantly revised since inception 10 years prior

- The group reviewed the committee’s history, mission and goals, as well as the NPCR program standards
Committee Revisited

Identified items in need of revision:

- The group’s goals and future direction
- The organizational structure of the group
- How to increase member mutual benefit
- The need to more clearly articulate what members should advocate and promote
- Improve group collaboration and linkages to other stakeholders
Committee Revisited

As part of review and strategic planning also considered consequences of an ineffective advisory committee:

• The group could become disengaged and stagnant
• May lose opportunity to capitalize from group collaboration
• The TCR could lose additional resources resulting in not meeting NPCR grant requirements or NAACCR certification, thus exposing an even greater risk for further budgetary reductions
Committee Revisited

The following items were identified as trends:

- Low meeting attendance
- Disproportionate information provided from a limited number of members (unbalanced membership)
- Meeting agenda items were repetitive
- Subcommittees tended to silo data and have varied effectiveness
- Lack of performance measures for project progress made
- There was a lack of formal organizational structure
- Clarity was needed in terms of the group’s niche
Committee Revisited

The following items were identified as working well:

• Input from the group regarding funding, law and rules effectiveness
• Providing the TCR with input/advice about new initiatives (i.e. National Provider Identifier, non-hospital reporting sources)
• Providing the TCR with realistic impressions and direct communication channels that represents various viewpoints of Texas cancer related professionals
• TCR updates on data use, particularly for researcher
Committee Revisited

Other items listed as working well:

- Collaboration; it is an essential element for the group
- A diverse group of stakeholders, that are invested and educated on current events are strong advocates and can provide good advice
- Current issue documentation and reports essential to providing the group with information
Welcome to the Texas Cancer Registry

The SOURCE for Cancer Data in Texas

The Texas Cancer Registry (TCR) is a statewide population-based registry that serves as the foundation for measuring the Texas cancer burden, comprehensive cancer control efforts, health disparities, progress in prevention, diagnosis, treatment, and survivorship, as well as supports a wide variety of cancer-related research. These priorities cannot be adequately addressed in public health, academic institutions, or the private sector without timely, complete, and accurate cancer data.

The TCR is the 4th largest cancer registry in the United States, and currently meets the National Program of Central Cancer Registries, Centers for Disease Control and Prevention high quality data standards and is Gold Certified by the North American Association of Central Cancer Registries.

The ultimate goal and purpose of the TCR is to collect and disseminate the highest quality cancer data that will contribute towards cancer prevention and control, improving diagnoses, treatment, survival, and quality of life for all cancer patients.

Learn more about the Texas Cancer Registry.
Advisory Committee to the Texas Cancer Registry (ACTCR)

Our vision is to contribute significantly to the knowledge of cancer for use in improving the health of Texans

Our mission is to advise and support the Texas Cancer Registry in achieving its Mission

The ACTCR (formerly known as the Texas Cancer Data Work Group), consists of a diverse group of highly experienced and dedicated individuals that represent Texas’s Institutions of Higher Education, Hospitals, Cancer Treatment Centers, Ambulatory Surgery Centers and other Non-Profit Organizations. ACTCR Members typically meet three times per year; their collaboration greatly benefits the Texas Cancer Registry regarding important legislative, research, funding and data quality and initiatives.

- Current Member Listing
- ACTCR Operating Principles (.pdf, 51.7 KB)
- Members Enter Here
Overview
• Exceptional Item Funding from 79th Legislative Session
• NAACCR Certification and Texas Results
• Registry Improvements and Cancer Data Work Group
• Cancer Reporting Rule Changes
• New Reportable Data Items for 2006 Cases
• Trainings
• Compliance Monitoring and Current Reporting Status
• Data Quality Audits
• Data Utilization
• Miscellaneous Mentions

Advisory Committee to the Texas Cancer Registry (ACTCR) - Member Website

Operational Committee Projects:

Urgent / Short Term Projects

• Data Sharing and Access to Texas Health Care Information Collection Data
• UT Brownsville Cancer Information Management Program ~ Student Practicums

Intermediate to Long Term Projects

• Dermatopathology / Melanoma - Data Acquisition Planning
• Planning for Improved Process for Researchers Conducting Patient Follow-back Studies
• TCR Data Utilization Marketing Efforts

Contact TCR
Advisory Committee to the Texas Cancer Registry (ACTCR)
Member Website

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Meeting Information

- 1/14/09 ACTCR Meeting Materials

Operational Committee Projects

- View Current Projects

ACTCR Information

- ACTCR Operating Principles (.pdf, 52 KB)
- ACTCR Member Contact Information (.pdf, 54.7 KB)
- TCR Statistical Cancer Data
- Newest TCR Publications
- New and Ongoing Studies Utilizing Texas Cancer Registry Data
- New and Ongoing Epidemiologic Studies
- TCR Staff - Contact Information
- ACTCR Member Donated Hours Tracking Form
- American Cancer Society Directions and Map
Not Just Another NPCR Requirement

• What works best in making the committee effective and not just another NPCR requirement?

  – Active participation
  – Open discussion about needs – everyone’s needs
  – Diversity of organizations and interests
  – A sense of purpose
  – A sense of accomplishment
  – A lack of tolerance for complacency
Questions