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Greater Austin Region Cancer Care White Paper *Executive Summary*

Cancer Care in Bastrop, Caldwell, Hays, Travis, and Williamson Counties

Submitted to:

Central Health

LIVESTRONG Foundation

Shivers Foundation

ACCS Advisory Committee



Health Resources in Action
Advancing Public Health and Medical Research

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Introduction

Central Texans share a strong sense of community pride. There is a deep belief that the Austin area represents the “gold standard” in many factors that determine livability, such as economic development, revitalization, and population growth. Residents in greater Austin expect similarly high quality health care.¹

Cancer has overtaken heart disease as the number one cause of death in the Austin Metropolitan Statistical Area (MSA) - including Bastrop, Caldwell, Hays, Travis, and Williamson counties - and is one of the top health concerns cited by Austinites.²

Health Resources in Action (HRiA), a public health consulting firm headquartered in Boston, MA, was commissioned by a collaborative of three funders - Central Health, the LIVESTRONG Foundation and the Shivers Foundation - to develop a white paper to describe the availability of quality clinical cancer care and support services in the greater Austin region. HRiA has extensive experience conducting community health assessments to identify the needs and strengths of a particular community in order to: improve its health status, inform funding decisions, and help prioritize program development and implementation.

The ***purposes of this Executive Summary are to provide an overview of the main elements of the Greater Austin Region Cancer Care White Paper.*** This Executive Summary is organized around collaborative “Consensus Statements” agreed upon by Austin-area cancer care experts (i.e., Advisory Group). Importantly **this Executive Summary and the complete White Paper** are not **intended to be comprehensive reports** of all aspects of cancer care in the greater Austin area and there are limitations to how these data should be considered given the **limited data available**. We recognize that there is more work to be done to elucidate the full picture of cancer care in the greater Austin area and envision this white paper as a starting point for collaborative regional improvement efforts.

Overview of Methods

Approach

In order to understand how cancer patients experience the full continuum of care, we considered: barriers to accessing clinical and supportive care; the availability of quality clinical care and support services; the infrastructure enabling quality measurement and improvement processes; and the dynamics of the healthcare market.

A total of 40 key informant interviews and 15 focus groups representing providers, patients, support groups, community leaders and policy makers, were conducted. In addition, data from five patient focus groups, previously conducted by the LIVESTRONG Foundation, were reviewed. Six subject matter experts in cancer care were interviewed. Overall, feedback was gathered from a **total of 158 stakeholders**. In addition, patients, caregivers and providers were surveyed to collect perceptions of care as well as information on various other parameters. All major provider groups and institutions in the greater Austin area were invited to participate via interviews, focus groups and surveys to maximize opportunities for inclusion of all perspectives. For each area of interest, patient and provider perceptions are compared to available quantitative data sources and published literature to assess whether or not prevailing perceptions are supported by existing evidence.

Oversight and guidance was provided by an Advisory Group of local cancer care providers as well as healthcare and community leaders. (See Appendix B for list of Advisory Group members.)

Sponsors of this white paper decided to focus inquiry on: cancer care provided to adult patients, age 18 and above, because the vast majority of cancers occur in the adult population; and on the four most common cancers in the region (colorectal, lung, breast, prostate), as well as two additional cancers frequently cited by Austin area informants as representing gaps in care (pancreas, leukemia).

Cancer care in the greater Austin area is compared to four of the largest cities in Texas (San Antonio, Dallas, Houston, and El Paso) as well as to two demographically comparable markets (Denver, CO and Charlotte, NC, respectively), per available data.

It is important to acknowledge the limitations to these methods. Most notably, the information gathered through interviews, focus groups and surveys represents opinions from a small sample and may not be generalizable to the entire population.

For a detailed description of methods and limitations, please refer to Appendix A.

I. Consensus Statement #1:

We agree that our region deserves the best in oncology care. We strive to ensure that the greater Austin area demonstrates the excellence in comprehensive cancer care its residents expect and deserve.

Over 10% of the population of the Austin-Metropolitan Service Area (MSA) has been diagnosed with some type of cancer at some point in their lives; this is 28% LOWER than the state average. For the greater Austin area, the **number of new cases per year** for the six cancers reviewed is **just slightly lower than the state rate.**³

There are disparities in the distribution of cancer: most regional and statewide cancer patients and survivors are white; the next highest group is of Hispanic/Latino descent.

For each of the six specific cancer sites, the age-adjusted **cancer mortality rates in the greater Austin area are lower than for any of the Texas comparison cities and lower than the statewide average.**⁴ In fact, **for lung/bronchus, the most common cancer, Austin residents fare better** (in terms of mortality) **than residents of cities with NCI-designated comprehensive care centers.** However, conclusions regarding the quality of care cannot be drawn based on mortality rates alone.

“I think people need to know that people do well here.” – Nurse Educator

II. Consensus Statement #2:

We agree that all residents of the greater Austin area should have access to timely high quality comprehensive cancer care and support services, regardless of insurance status.

Texas has the largest percentage of uninsured residents in the country: 28% lack health insurance, compared with 17% nationally.^{5,6} Within the Austin MSA, Bastrop and Caldwell counties have the highest percentages of uninsured adults under age 65. **Among patients seeking cancer care, the uninsured rate is significantly lower,**



estimated at 5% - 15%, largely resulting from the age group most affected by cancer – those over age 65 who are Medicare-eligible.⁷

Individuals without health insurance tend to have more advanced disease when they present for care. There is a strong consensus among providers and patients **that uninsured people in Central Texas are dying at disproportionate rates** and concern that there is “nowhere for these patients to go.”

There are significant **disparities in insurance status by race and ethnicity**. The growing **Hispanic population has the highest uninsured rates**.⁸⁹ The cost of health insurance will continue to rise, making coverage even less affordable for all residents.

The soaring costs of healthcare challenge all sectors. National and local policies try to address this concern. The U.S. **Patient Protection and Affordable Care Act (ACA)** aims to **improve access to health care services** and to **hold providers accountable** for delivering higher quality and lower cost services.¹⁰ The **Texas Medicaid Transformation Waiver** enables expansion of Medicaid managed care, provides funding for uncompensated hospital care, and rewards healthcare providers who improve prevention, management, and coordination of care. These reforms may pave the way towards a health care delivery system that is more accessible, more coordinated, and higher quality.

III. Consensus Statement #3:

We agree that *all* residents of the greater Austin area should have equal access to quality comprehensive cancer care and support services, regardless of whether they reside in rural, suburban or urban areas.

Distribution of oncology services in the five-county area is unbalanced. Primary care providers and clinical cancer treatment services are **concentrated in Travis and Williamson Counties** while the largest population growth is in Bastrop, Hays and Caldwell Counties. Almost 25% of cancer patients live in Bastrop, Caldwell and Hays counties, and do not have adequate transportation to access clinical and support services.¹¹ Some provider groups are making efforts to establish satellites to expand their reach beyond the urban center.

IV. Consensus Statement #4:

We agree that *recruitment efforts are needed* to increase the supply of general and sub-specialized oncology providers and that recruitment could be facilitated through a continuum of undergraduate to graduate medical education.

Demand for cancer care is increasing as the population grows and ages. Austin is the fastest growing city in the nation. This **population trajectory is outpacing the capacity of the health services sector**. Significant shortages of healthcare providers, including oncologists and nurses, are predicted.¹²

There are not enough oncology providers in the region to meet the growing need for cancer care services.^{13, 14} Currently, there is one full-time equivalent (FTE), medical oncologist serving the region's indigent population. The greater Austin area has a lower saturation of medical oncologists than the national average and other cities in Texas. **The greater Austin area is at a deficit for subspecialty cancer care providers as well.**^{15, 16}



Specific concerns cited were lack of sub-specialization within pathology and surgery. Specialized services for mental health, bone marrow transplants, leukemias and lymphomas are particularly lacking. Yet, despite these deficiencies, **the greater Austin area has the highest breast cancer and lung cancer survival rates** in the state.

An **academic medical center with a medical school** is being created in the greater Austin region to **attract, train, and retain new physicians and medical researchers** in the community.¹⁷ There are also local initiatives underway to recruit physicians in areas of need and build bone marrow transplant capacity.

V. Consensus Statement #5:

We agree we need to address the perception that patients must be referred out of the greater Austin area to receive high quality cancer care.

Most cancer patients in Texas, including those from greater Austin, receive care in the metro area closest to their homes. Austin has the highest rate of outmigration for cancer care among the Texas comparison cities and Denver: 12% of greater Austin area cancer patients seek care outside of their home area while 88% stay close to home for their care.¹⁸

Reasons given by a small sample of migrating patients for seeking care in another city included: advanced stage cancer; rare cancer; need for bone/marrow transplant; perception of better care or better reputation elsewhere; and desire to be treated in an academic medical center, by a particular specialist, or at a recommended facility. Of note, there are no National Cancer Institute (NCI)-designated centers in the greater Austin area.^{19,20}

VI. Consensus Statement #6:

We agree that we must maintain and improve access to prevention and screening services for all patients in order to decrease the prevalence and late stage diagnosis of cancers in our region.

As 40% of cancer cases are preventable and prognosis improves dramatically with early detection, the **importance of prevention and screening cannot be overstated**. There is consensus among providers regarding the need to address known behavioral risk factors associated with cancer (i.e., reduce obesity and smoking, improve diet, and increase exercise) across Central Texas communities, particularly in low-income and minority populations. Reducing high obesity rates among adults in Texas (67%), for example, would decrease cancer rates substantially.²¹

The greater **Austin area is doing relatively well in the area of prevention and screening**. The **Austin MSA breast cancer screening rate** (77%) is on par with the national average as well as with Dallas and Charlotte, and exceeds screening rates in Denver, El Paso, Houston and San Antonio, despite the relatively low number of mammography providers. Although **Austin has the highest concentration of free/low-cost mammography** providers, the breast cancer screening rates increased along the income gradient.^{22,23}



Among the five comparison cities in Texas, **Austin MSA has the highest rate of colorectal cancer (CRC) screening (71%)** among Texas comparison cities, despite the **lower per capita density of CRC screening providers.**^{24,25}

Despite the impressive screening rates, identification of and outreach to those subpopulations least likely to obtain recommended screenings should be pursued.

VII. Consensus Statement #7:

We agree that *quality cancer care resources exist in our community.*

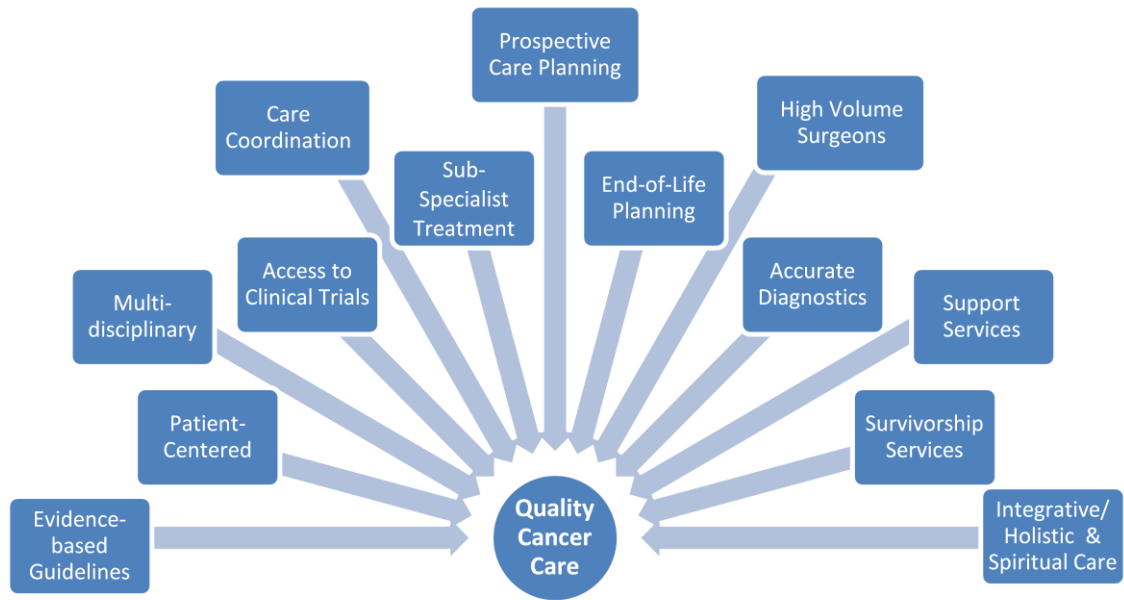
Inconsistencies in the delivery of quality cancer care are common in communities across the nation, yet knowledge of what makes cancer care better or worse is still fairly limited. While there is not a universal set of quality standards, methods to measure quality cancer care encompass a broad set of characteristics, which are still evolving through medical literature review and by national leaders in cancer care

In 2006, the American Society of Clinical Oncology (ASCO) summarized 10 goals for all cancer centers to include: Access to Information; Privacy, Confidentiality, and Dignity; Access to Medical Records; Prevention Services; Nondiscrimination; Consent to Treatment and Choice; Multidisciplinary Cancer Care; Innovative Cancer Care; Survivorship Care Planning; Pain Management, Supportive, and Palliative Care. As researchers' understanding of cancer patients' needs and preferences evolves alongside scientists' understanding of the disease itself, and as policy and technology changes improve the health care's ability to measure, assess, and improve, the definition of quality cancer care will continue to evolve.

In addition, the Institute of Medicine's (IOM) domains of quality health care aim to ensure that care is safe, effective, patient-centered, multidisciplinary, timely, efficient, equitable, and integrates evidence-based practice to continuously improve care.²⁶ Twelve quality elements are reviewed in this paper and illustrated on the graphic below.²⁷ **Consistent integration of major quality elements provides a strong foundation for quality cancer care in the region.**



Key Elements of Quality Cancer Care (Selected Examples)



In the Austin cancer care market, evidence-based elements of comprehensive cancer care have been adopted by the private sector to varying degrees, yet are less reliably implemented by providers in public care settings.

From a patient's perspective, the cancer care experience depends on relationships with providers, connections to supportive care, and understanding treatment options in order to make informed decisions. Particularly key is the degree to which the provider is respectful, and engages the patient in collaborative planning, based on the patient's expressed wishes and needs.²⁸

VIII. Consensus Statement #8:

We agree that working *collaboratively* among regional cancer care providers and patients could lead to better care outcomes and a better *patient experience*.

There is a pervasive perception of a very competitive professional culture across the oncology landscape in the greater Austin area. The information necessary to fully define the cancer care market in the greater Austin area is considered proprietary by most local oncology care providers and was not available for this report. The majority of informants expressed that **more cooperation among practitioners is essential to improve services for the community.**

"We all know what excellent care is but we don't get there because we don't play nicely in the sandbox together. There are long-standing [issues] that preclude collaboration."
- Physician Leader

Growth of collaborative efforts will create opportunities for Austin's cancer care providers to improve clinical care quality, care delivery systems and the way in which patients experience care.

“This is [about] everybody working together to make sure people are treated well and that cancer care is excellent, that everyone in the community recognizes what everyone is trying to do.” – Nurse Educator

In terms of satisfaction with cancer care services, seeing one’s own doctor is primary to patients. Communication, understanding treatment options, being a partner in care decisions, and respect for one’s time and one’s person all influence a patient’s satisfaction with his/her cancer care provider. Among support services, satisfaction was most evident for support groups, by far the service most often accessed.

IX. Consensus Statement #9:

We agree that we need to commit to *continual improvement* of our health care system, and establish, track, and share common *metrics for quality, prevention, care coordination and supports* for the most prevalent cancers in our community, in order to demonstrably improve quality.

The local oncology community as a whole would benefit from coordinated efforts to consistently and systematically implement continuous quality improvement strategies. The complex multi-variable nature of cancer care management has provider and payer communities struggling to identify valid measures of improvement.

Electronic systems implemented by greater Austin’s private sector facilitate care coordination, measure quality, and improve outcomes. Austin’s largest provider of private oncology care, Texas Oncology, is an example of a practice that embeds quality initiatives within their oncology-specific electronic health record to foster compliance with evidence-based guidelines. In addition, all of the Commission on Cancer accredited hospitals must monitor and perform quality improvement efforts each year. Seton, for example, has a nationally recognized effort to prevent blood stream infections in patients with central lines. Electronic medical record (EMR) systems enhance communication and care coordination by enabling providers across care settings to share real-time information about patient care. The Integrated Care Collaboration’s unique ICare health information exchange (HIE) system is a cutting edge tool that will expand the ability of all providers to provide better care with greater efficiency and lower cost for all patients. Regular assessment and sharing of how greater Austin is doing in providing cancer care (e.g., tracking common metrics across providers) would be a significant step towards enhanced collaboration and accountability.

X. Consensus Statement #10:

We agree that patients benefit from better access to *clinical research* across the continuum of care. We need to leverage existing, build new, and integrate all assets into cutting-edge, technology-supported research to innovate care, and ultimately increase patient knowledge of, and access to, clinical trials.

Cancer Research/Clinical Trials offer patients the prospect of participating in scientific advancement and provide an opportunity for novel treatment that may be successful when standard treatments have failed. There **are several open clinical trials within a 50-mile radius of Austin for each cancer type targeted in this white paper.**²⁹ Access to some



industry-led trials is available in the Austin region, yet **more research led by area clinicians is desirable**. Some cancer care providers in the Austin area expressed unease with their perception that clinical trial choices in private practices may be driven by earning potential.

There has been a growing movement to expand support for cancer care research across the state. In 2007, the Cancer Prevention and Research Institute of Texas (CPRIT) was established and launched the Clinical Trials Network of Texas (CTNeT) which recently opened its first trial. Political support for expanding medical research has been growing as well.³⁰

XI. Consensus Statement #11: **We agree that there are resources for palliative care and advanced care planning, but we have more work to do.**

Healthcare costs escalate exponentially during the last 30 days of life. **Advanced-care planning results in a 35% reduction in total cost of care during the last week of life, with no measurable impact on longevity.**³¹ Provider-initiated discussions, focused on end-of-life planning with the terminally ill, **empower patients** to choose care options consistent with their values. Oncologists should begin conversations with patients about end-of-life preferences and initiate referrals to hospice care earlier in the treatment course.

The **greater Austin area compares favorably with Texas and other comparison cities in terms of reducing futile care and expenses while improving quality of life during the last month of life for cancer patients**. Cancer patients in the Austin MSA spent the fewest days in the intensive care unit (ICU), had the fewest life sustaining procedures performed, were least likely to die in a hospital setting, and had the highest enrollment in hospice care during their last month of life, compared with other Texas cities.³²

Un/underinsurance, and financial constraints for those who have health insurance, are significant barriers to appropriate end-of-life care for cancer patients. The importance of culturally appropriate end-of-life care was raised as well.

XII. Consensus Statement #12: **We agree that more work needs to be done to increase awareness and expand the breadth of support services in our community across the cancer continuum.**

Good services are being offered in the community but there is a lack of awareness of what they are and how people (both those affected by cancer and the professionals who treat them) can access them. Psychosocial and financial supports are critical to assisting patients with the stressors associated with cancer.^{33,34} Few patients surveyed felt that their emotional, physical and day to day needs were fully met.

Currently, a great number of **cancer support services are available, especially for breast cancer, but supports are described as largely limited to Travis County and for other diagnoses**. Other gaps noted include: bereavement support, post-treatment support, groups for men, peer matching, caregiver supports and supports for clinical providers.

Support groups are the most commonly accessed support service, with lifestyle counseling (23%) and pain management information (18%) in second and third place.³⁵



The least frequently accessed service was long-term planning, followed by transportation, end-of-life planning, and mental health counseling. **Services to assist patients with financial needs are scarce and not often accessed.** The ability to understand, be sensitive to, and be respectful of patients' belief systems, cultural norms and linguistic needs is an essential part of effective quality care.

Needs are not well met as survivors transition out of active treatment.³⁶ Support service **providers urge an enhanced focus on survivorship.** Cancer survivors can become powerful resources for the community.

"It would be really great if at the doctor's office they told you about a monthly cancer orientation – 'welcome to the rest of your life' " – Survivor

Three *suggested next steps* are to: 1) Educate providers and patients about existing resources and how to access them; 2) Create a central resource clearinghouse; and 3) Develop a support services work force expand capacity to provide the supportive services.

XIII. Consensus Statement #13:

We agree that clinical *coordination and patient navigation* are critical services that would benefit from expansion and enhancement.

Concerns are common about fragmentation of care, care coordination, and the need for medical and social service navigation. Most patients in the Austin area are in charge of coordinating their own care. **Patient navigators appear to improve quality of cancer care in uninsured populations and may help decrease care disparities.**³⁷ Assistance with logistical coordination would allow people affected by cancer to focus on their health.³⁸ Outcomes of patient navigation programs include: "increase in timely screening and prevention services, increase in timely treatment after abnormal findings, improved adherence to prescribed treatment, decreased halt on quality of life, improved patient satisfaction with care provided, and decreased anxiety and fears over treatment and the future."^{39,40,41,42}

Although there is increasing provision of navigation services by hospitals, the LIVESTRONG Foundation, and other support providers in the community, the community's knowledge of these services is not widespread and the need for such services still greatly outweighs the supply.

XIV. Consensus Statement #14:

We agree that there is still a lot of work to be done to improve cancer care in the Greater Austin region.

Opportunities exist to leverage expertise to increase efficiency and improve outcomes through collaboration, and progress has already been made. Patients recognize and acknowledge that improvements are underway to address gaps. Some selected examples include:

- A collaborative endeavor to establish a local bone marrow transplant service.
- Recruitment of oncologic subspecialists and clinical researchers.
- Engagement in prospective care planning (Multidisciplinary Conferences) by some institutions.



- Implementation of sophisticated information systems by the dominant outpatient oncology provider in greater Austin, Texas Oncology.
- Launch of satellite oncology offices to meet the needs of Austin's rural population.
- Creation of a new medical school with the possibility to increase the number of providers and enrich the landscape of cancer research with investigator-initiated clinical trials.

XV. Next Steps: A Call to Action

“This needs to be a community effort and an integrated system. There needs to be an alignment in the physician community. We have everything we need (smart people, passion, resources, etc.), but the fact that folks can’t work together is really the problem. The various players have got to come together for the good of the whole.” – Local Cancer Care Provider(s)

Central Texas has a great opportunity to innovate cancer care as it reconfigures community health and builds academic medicine. A successful system aligns with patient-centered care, focuses on system efficiencies, and keeps people out of the hospital.

Collaboration is essential! There are areas of expertise in Austin that could be raised to higher levels if integrated across provider systems. Area experts have already begun this process by agreeing upon the Consensus Statements outlined in this paper and committing to continue the collaborative work initiated by the development of this white paper.

Immediate next steps that the Collaborative should consider include:

- **Define a vision** for oncology care in the greater Austin area. Where does Austin want their cancer care to be in five years? Develop metrics for assessing and tracking progress.
- Agree on a **process for sharing de-identified proprietary information** to gain deeper insight in the oncology care market in the greater Austin area.
- **Develop a public communication strategy** to share the findings of this report and raise awareness of the high quality cancer care available in the greater Austin area.

Commitment to ongoing collaboration among cancer care leaders in our community is a vital first step toward expanding and further elevating the quality cancer care that the flourishing Austin region deserves.

Austin Cancer Care Study White Paper

The complete Austin Cancer Care Study White Paper is available upon request by emailing research@livestrong.org.

Appendix A: Detailed Approach, Methods, and Limitations

A. Overview of White Paper Development Process

In order to understand how cancer patients experience the full continuum of care, this white paper considers: barriers to accessing clinical and supportive care; the quality of available clinical care and support services; the infrastructure enabling quality measurement and improvement processes; and the dynamics of the healthcare market.

These realms are investigated along parallel tracks: 1) looking at patient and provider perceptions of the cancer experience in the greater Austin area; and 2) analyzing published literature and quantitative data to identify and measure relevant quality indicators. For each area of interest, **patient and provider perceptions are compared to available quantitative data sources** to assess whether or not prevailing perceptions are supported by existing evidence. An assessment of supply, demand, and capacity related to cancer care is also included in the scope of this paper.

While the writers and sponsors of this white paper recognize that all cancer types across the spectrum are important to prevent, diagnose, and treat, the decision was made to narrow the focus of this white paper in order to chart a trajectory for excellence in the areas where community needs are greatest. Therefore, this report addresses cancer care provided to adult patients, age 18 and above, because the vast majority of cancers occur in the adult population. This report also focuses on the four most common cancers in the region (**colorectal, lung, breast, prostate**), as well as two additional cancers frequently cited by Austin area informants as representing gaps in care (**pancreas, leukemia**).

For the purposes of this white paper, cancer care in the **greater Austin area is compared to four of the largest cities in Texas** (San Antonio, Dallas, Houston, and El Paso) as well as to **two demographically comparable markets**, one with and one without a comprehensive cancer center (Denver, CO and Charlotte, NC, respectively), for those domains with available and accessible comparable data. Unless otherwise noted in the report, data provided are for each city's MSA.

As noted above, the **Austin MSA is comprised of Bastrop, Caldwell, Hays, Travis, and Williamson counties**.

B. Methods

The approach to the development of this white paper was multi-pronged, including:

1. Literature Review

This report includes an extensive literature review on key elements and indicators of quality cancer care.

2. Key Informant Interviews & Focus Groups

A total of 40 key informant interviews representing 28 organizations, and 15 focus groups with a total of 83 participants, representing providers, patients, support groups, community leaders and policy makers, were conducted. Additional interviews were completed with 6 national subject matter experts on cancer care models and key components of high quality, comprehensive cancer care. Data from five patient focus groups (with a total of 29 participants), previously conducted

by the **LIVESTRONG** Foundation, were reviewed to broaden representation of the patient perspective.

Overall, feedback was gathered from a **total of 158 stakeholders**. Key informants were identified by funders, Advisory Group members, and by referral from early informants. All Advisory Group members, and all informants recommended by Advisory Group members, were invited to participate. Participants were assured that they would not be identified by name in any reports generated by the qualitative component of this effort without their explicit permission. Several cancer-related organizations volunteered to host focus groups and to assist with recruitment of participants. Using an inductive content analysis procedure, interview and focus group notes were reviewed, themes were identified, text was coded, and occurrences of each theme were tallied. Emergent recurrent themes and areas of consensus were extracted. (See Appendix A for detailed breakdown of informant and focus group constituencies.)

3. Patient and Caregiver Survey

Patient and caregiver surveys were developed to examine primary cancer site, stage at diagnosis, treatment location and rationale, percent who sought second opinions for diagnosis or treatment, insurance status, patient satisfaction with care, referral to and use of support services, perceived influences on quality, care coordination, and suggestions for improvements in cancer care. The survey dissemination process was approved by an external IRB. All healthcare providers represented on the Advisory Group were invited to distribute surveys to their patient and caregiver populations. The survey was distributed electronically to patients/survivors and caregivers through the following venues: Cancer Connection, Casting for Recovery, Komen Austin, Lone Star Circle of Care, M.D. Anderson Support Group, and Single Jingles. These institutions distributed the surveys online through clinical and supportive cancer care providers in English (Spanish and paper versions were also made available if requested).r. Survey results were entered into a database and analyzed.

A total of 66 responses were received electronically: 39 from patients and 27 from caregivers. Survey results were analyzed using PASW 18 (SPSS). Demographics for cancer patients and cancer caregivers are provided. For each question, the percent or mean was estimated. Data were first analyzed for patients and caregivers separately. Tests for differences in responses for cancer patients and caregivers were not conducted due to small sample sizes. In areas where findings were consistent between patients and caregivers, data are presented for patients and caregivers, combined.

4. Patient Forum Survey Conducted by the LIVESTRONG Foundation in 2010

Results of this survey of 31 patients and providers were reviewed. Findings relevant to this white paper were incorporated herein.

5. Provider Survey

A survey was distributed to all providers of cancer care services in the greater Austin area to gather information on market share, payer mix, wait times for treatment initiation, and various indicators of quality care. Providers were surveyed electronically. Response rate was 0%. See Appendix D for the provider survey.



6. Quantitative Data Review

Collection and analysis of quantitative data for the Austin MSA were completed to measure:

- Incidence and mortality rates for colorectal, lung, breast, prostate, pancreatic cancers and leukemia;
- Supply and capacity of cancer screening and treatment services;
- Variables impacting access to care;
- Treatment locations for cancer diagnoses, including the proportion of “outmigration” (i.e., those residents who seek care outside the greater Austin area market); and
- Available measures of clinical quality.

Identical measures were collected and analyzed for the comparison cities of Denver, CO, and Charlotte, NC, as available.

7. Advisory Group

Oversight and guidance was provided by an Advisory Group of local cancer care providers as well as healthcare and community leaders. A Data Working Group subcommittee was created from the Advisory Group to provide input and oversight of availability, reliability and access to quantitative data sources. (See Appendix A for list of Advisory Group and Data Working Group subcommittee members.)

Collectively, Advisory Group members agreed to 15 Consensus Statements to improve cancer care in the greater Austin area. The findings of this white paper were reviewed with the Advisory Group prior to finalization of this report.

C. Limitations

Given the limitations inherent in healthcare assessment, this report is **not intended to be exhaustive or definitive**. Rather, it is a snapshot of the current state of cancer care in the Austin region, based on stakeholder perceptions and the data accessible and available within the constraints of the project, as a starting point for continuous improvement. Given the time allotted and scope of this project, this report does not capture all aspects of cancer care in the greater Austin region, but rather provides information that can be used to foster conversations and encourage further investigation into what needs to be done to improve outcomes for people affected by cancer.

Currently, **standard metrics to measure the quality of cancer care have not been established**. There are multiple definitions of “quality” in the healthcare arena, as well as various approaches to measuring Quality care. The most basic definition is based on the mathematical equation: $Quality = Value/Outcome$, yet this calculation fails to take the various interpersonal and psychosocial aspects of healthcare quality into account. Further, there is **no universally accepted definition for “comprehensive” cancer care**. In this report, we review elements considered central to both high quality and comprehensive cancer care based on support by published evidence, quantitative data, and/or qualitative consensus among stakeholder groups. Given the **complexity of cancer care** - including diversity of diagnoses, stages, side effects, prognoses and personal beliefs – this white paper **cannot answer the question: “Is the quality of cancer care in the greater Austin area adequate?”**

While all of the major provider groups and institutions in the greater Austin area were invited to participate via interviews, focus groups and survey, as well as conduct outreach to their patient populations to enable the process to be as inclusive as



possible, respondents self-selected and therefore comprise a convenience sample. The same is true for patient and caregiver focus group participants. As interview, focus group and survey participation was dependent on convenience sampling, information gathered may not be representative of all subgroups of the population. In addition, the uninsured population was over-represented among participants in the patient/caregiver survey (45% of survey respondents were uninsured as opposed to the 5% uninsured rate among all Austin area cancer patients). The qualitative data summarized here represents the subjective opinions and perspectives of a **small sample** of particular individuals who participated in interviews and/or focus groups. Results of the qualitative data may therefore not be generalizable to the entire population.

We have found consistency in themes across groups and individuals. Where possible, we have balanced subjective opinions with interviews with national cancer care leaders (unaffiliated with the Austin market) as well as with independent data on Quality care indicators from peer-reviewed, published literature.

There are significant limitations on the objective quantitative data sets available as well. Not all systems track data the same way or use the same measures. Many data sets are prohibitively expensive. Cost effective **data sets are often outdated**. In addition, some key metrics were not tracked in a way that was useful for the purposes of this white paper.



Appendix B: Advisory Group Members

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References

- ¹ Health Resource in Action. Health and Health Care Trends & Innovations in Central Texas. Nov 2011. Created for Central Health, available upon request.
- ² San Antonio Metropolitan Health District. Health Profiles 2010. Released May 25, 2012. <http://www.sanantonio.gov/health/pdf/healthprofiles/Hp2010/2010%20Health%20Profiles.pdf>
- ³ Texas Cancer Registry, 2005-2009. age adjusted site-specific cancer incidence per 100,000 residents.
- ⁴ Texas Cancer Registry. 2005-2009 age adjusted cancer mortality per 100,000 residents.
- ⁵ America's Health Rankings, United Health Foundation, 2012. Accessed December 21, 2012 at: <http://www.americashealthrankings.org/TX/HealthInsurance/2012>
- ⁶ Gallup Healthways Well-Being Index survey January through June 2012. Accessed December 21, 2012 at: <http://www.gallup.com/poll/156851/uninsured-rate-stable-across-states-far-2012.aspx>
- ⁷ Integrated Care Collaborative (ICC), 2010-2011. Texas Cancer Registry, 2009.
- ⁸ American Community Survey, 2009-2011, US Census Bureau
- ⁹ Texas Department of Insurance. State Planning Grant Project. 2006. Accessed online: <http://www.tdi.state.tx.us/reports/life/documents/spgint061.pdf>.
- ¹⁰ Public Law 111-148 – Patient Protection and Affordable Care Act. Approved March 23, 2010. <http://www.whitehouse.gov/healthreform/healthcare-overview>
- ¹¹ Integrated Care Collaborative: Number of Patients Treated and Monitored, 2012
- ¹² Health Resource in Action. Health and Health Care Trends & Innovations in Central Texas. Nov 2011. Created for Central Health, available upon request.
- ¹³ Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists: challenging to assuring access to oncology services. J Oncol Pract. 2007;3:79–86.
- ¹⁴ Association of American Medical Colleges Center for Workforce Studies. Forecasting the Supply of and Demand for Oncologists: A Report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies. Washington, DC: Association of American Medical Colleges; 2007.
- ¹⁵ Oncology Solutions. **LIVESTRONG** Foundation Cancer Study: data points for discussion, for Seton Healthcare Family.
- ¹⁶ While data is not available to measure the number and type of all specific oncologic subspecialists in the greater Austin area, the Texas Medical Board lists self-identified surgical oncologists, medical oncologists, radiation oncologists and palliative care providers.



¹⁷ Endorsed by State Senator Kirk Watson (District 14, Travis County, TX) and outlined in the “10 Goals in 10 Years” initiative <http://www.healthyatx.org/learn/10-in-10/> and <http://www.watson.senate.state.tx.us/>

¹⁸ Texas Cancer Registry, 2009; Colorado Central Cancer Registry, 2009.

¹⁹ http://cancercenters.cancer.gov/cancer_centers/index.html

²⁰ The four designated centers in Texas are located in San Antonio (Cancer Therapy & Research Center at the University of Texas Health Science Center at San Antonio), two sites in Dallas (Dan L. Duncan Cancer Center at Baylor College of Medicine and Harold C. Simmons Cancer Center at UT Southwestern Medical Center), and Houston (M.D. Anderson Cancer Center at the University of Texas at Houston)).

²¹ Health Resource in Action. Health and Health Care Trends & Innovations in Central Texas. Nov 2011. Created for Central Health, available upon request.

²² Texas Cancer Information, 2012. Accessed July, 2012 at: www.texasancer.info.

²³ Health Resource in Action. Health and Health Care Trends & Innovations in Central Texas. Nov 2011. Created for Central Health, available upon request.

²⁴ Behavior Risk Factor Surveillance System (BRFSS), 2010.

²⁵ Texas Cancer Information, 2012. Accessed July, 2012 at: www.texasancer.info.

²⁶ Institute of Medicine. Crossing the Quality Chasm: A new health system for the 21st century. National Academies Press. 2001.

²⁷ References for elements of this graphic are found throughout the narrative

²⁸ Patient and Caregiver Survey, 2012. LIVESTRONG Survey, 2010. Focus groups, 2012.

²⁹ Emerging Med, December 19, 2012.

³⁰ <http://www.healthyatx.org/learn/10-in-10/> and <http://www.watson.senate.state.tx.us/>

³¹ The Advisory Board Company, Oncology Roundtable. Six Imperatives for Driving Value in Cancer Care. 2011. <http://www.advisory.com/~media/Advisory-com/Research/COB/Resources/Six-imperatives-for-driving-value.png>

³² Dartmouth Atlas of Healthcare, 2003-2007.

³³ Zabora J, et.al. The prevalence of psychological distress by cancer site. Psychooncology. 2001;10(1): 19-28.

³⁴ Steinberg T, Roseman M, et.al. Prevalence of emotional distress in newly diagnosed lung cancer patients. Support Care Cancer. 2009; 17(12): 1493-7.

³⁵ Patient and Caregiver Survey, 2012.



³⁶ **LIVESTRONG** Patient Forum Survey, 2010.

³⁷ Chen F, et.al. Improving breast cancer quality of care with the use of patient navigators. *Am Surg.* 2010;76(10): 1043-6.

³⁸ **LIVESTRONG** Patient Forum Survey, 2010.

³⁹ Dohan D, Schrag D. Using Navigators to Improve Care of Underserved Patients. *Cancer,* 2005;104:848-854.

⁴⁰ Battaglia T, Rologg K, Posner M, Freund K. Improving Follow-Up to Abnormal Breast Cancer Screening in Urban Population. *Cancer,* 2007;109:359-367.

⁴¹ Steinberg M, Fremont A, Khan D, Huang D, Knapp H, Karaman D, Forge N, Andre K, Chaiken L, Streeter O. Lay Patient Navigation Program Implementation for Equal Access to Cancer Care and Clinical Trials. *Cancer,* 2006;107:2669-2677.

⁴² Ell K, Vourlekis B, Xie B, Nedjat-Haiem F, Lee P, Muderspach L, Russell C, Palinkas L. Cancer Treatment Adherence Among Low-Income Women With Breast Cancer or Gynecologic Cancer. *Cancer,* 2009;4606-4615.

