

St. Jude Children's Research Hospital

2016 COMMUNITY HEALTH NEEDS ASSESSMENT

June 30, 2016

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EXECUTIVE SUMMARY

Introduction

St. Jude Children's Research Hospital in Memphis, TN, is a specialty hospital that treats pediatric catastrophic diseases with a focus on cancer and blood disorders. Patients at St. Jude are referred by a physician, diagnosed with a disease currently under study, and eligible for a research protocol. St. Jude is the only pediatric research center for children with catastrophic diseases, including cancer and blood disorders, where families never pay for treatment not covered by insurance. In fact, no family ever pays St. Jude for anything. Transportation, housing and food are among the no-cost services provided to ensure families coming to St. Jude can focus on their child. No child is ever denied treatment due to race, sex, nationality, ethnicity, religion, or the family's ability to pay.

The community served by St. Jude can best be defined by understanding St. Jude's patient population and scope of clinical services. St Jude serves as a national referral center for children with catastrophic diseases, such as cancer as well as a local referral center for children with cancer, blood disorders, and HIV/AIDS. It does not admit children for any diagnostic groups outside of these services and does not offer medical services beyond those necessary to care for children with these diseases. St. Jude does not have an emergency room (ER). A referral from a medical professional external to St. Jude, typically the child's pediatrician or a pediatric subspecialist, is necessary prior to accepting a patient for treatment to St. Jude.

The purpose of the CHNA was to provide an empirical foundation for future health planning and review progress in community benefit priorities identified in the 2013 community health needs assessment. These purposes were identified to meet the community health needs assessment (CHNA) mandate for non-profit institutions put forth by the IRS.

Community Health Needs Assessment Methods

The CHNA process included:

- Engaging an advisory committee of St. Jude staff
- Reviewing secondary social, economic, and health data
- Conducting interviews and focus groups with internal and external stakeholders, leaders in public health, patients and family members
- Review of current community benefit efforts
- Prioritizing needs to be addressed by community benefit initiatives

St. Jude's 2016 CHNA builds upon the 2013 CHNA and reflects the activities identified in St. Jude's 2013 Community Benefit Implementation Plan. The 2016 CHNA was led by an internal team of St. Jude staff members. The leadership of this team engaged Health Resources in Action (HRiA), a non-profit public health consultancy organization, to conduct the CHNA. In an effort to develop a social, economic, and health portrait of the community served by St. Jude for the greater Memphis area and nationally, HRiA reviewed existing data drawn from local, state, and national sources. HRiA conducted qualitative research with internal and external St. Jude stakeholders as well as patients and family members served in order to

supplement quantitative findings with perceptions of community strengths and assets, their priority health concerns, and suggestions for future programming and services.

Key Findings

The following provides a brief overview of key findings that emerged from this assessment. As a highly-specialized and world-renowned hospital, St. Jude was seen by focus group and interview participants as having three service communities: The U.S. and international patients and their families; the Memphis community which surrounds it; and the larger community of cancer researchers and cancer care provider institutions. For the purposes of the 2016 CHNA process and community benefit planning, St. Jude has defined its community by geography in the United States and principal function, which is to serve children with catastrophic illnesses.

General Findings

- It is estimated that St. Jude's current economic impact on the Memphis area and the State is \$2.5 billion, a figure that could increase upwards to \$3.5-4 billion in the future.
- Focus group and interview participants described St. Jude as a major contributor to the greater Memphis community.
- Many respondents noted the quality of care provided at St. Jude, including innovative care as well as connection to specialists.
- Across internal and external providers in the Greater Memphis area partnerships between St. Jude and other institutions were noted as a strength, particularly the following relationships:
 - o Le Bonheur Children's Hospital
 - University of Tennessee Health Science Center
 - Hope House HIV clinic and Smile Program
 - o National Institute of Patient Family Centered Care
- Patients expressed appreciation for the compassion and dedication of St. Jude's staff.
- All of those served by St. Jude, as respondents described, are dealing with catastrophic or chronic disease, which creates substantial personal challenges.
- Many respondents also noted the substantial stress, fatigue, and fear experienced by families and children that comes with a serious illness.
- Transitioning care from St. Jude was mentioned as a concern by family members and St. Jude staff. These transitions include patients who "age out" (transition to adult care) and those who return to their communities after receiving care at St. Jude as inpatients (local to Shelby county) and as outpatients (outside the Shelby county area).
- Several respondents shared that enhanced collaboration across organizations would also be beneficial, such as the University of Tennessee Health Science Center.

Shelby County and Surrounding Memphis Area

- St. Jude is located in Shelby County, in the City of Memphis, Tennessee, which has a predominantly African American, non-Hispanic population.
- Many respondents who participated in interviews pointed to substantial health disparities in the county, with African Americans in particular experiencing higher rates of poorer health and lower life expectancy.

- Interview and focus group respondents identified the following strengths in Shelby County: a Mid-South hub; moderate climate; low cost of living; strong health care infrastructure; good jobs in the health care sector, transportation, logistics, and pharmaceuticals; as well as a community spirit of volunteering and generous giving.
- The Surrounding Memphis Area is a wide region of service that touches five states in the bottom ten rankings of healthy states by United Health Foundation. Health care coverage for children in this area ranges from ~90% to ~98 and the percent of children who received care within a medical home ranges from 49% to 62%.
- St. Jude, through its location in Memphis and its affiliate sites, draws patients from all over the U.S., including from the local Memphis community. Approximately 23% of FY 2015 new patients were from the local Memphis community and an additional 33% were from the Surrounding Memphis area.
- The accessibility of St. Jude services for patients and families that need it most was cited as a substantial strength by focus group members and interviewees.
- Concerns of Shelby County and Surrounding Memphis community members and St. Jude staff included access to health care, particularly due to transportation challenges; lack of health insurance; navigating health insurance and health care; and safety while traveling to appointments.

Childhood Cancer

- Regarding childhood cancer, although leukemia has a higher incidence among children nationally, St. Jude sees a higher proportion of brain and other nervous system cancers than leukemia.
- Among FY 2015 St. Jude new patients with a primary diagnosis of cancer, the majority are
 male and white non-Hispanic. The ages of these new patients are evenly distributed across
 childhood and teenage years.

Hematological Diseases

- While the dominant focus of St. Jude is the treatment of pediatric cancer, it also serves as a
 primary hematology hospital for patients in the Surrounding Memphis area, with the largest
 program being treatment of sickle cell disease.
- A recent study of prevalence of Sickle Cell Disease in African Americans in the Surrounding Memphis area found a prevalence of 1/287, significantly higher than the national reported 1/350-1/500.
- Among FY 2015 St. Jude new cases of hematological disorders or sickle cell disease, the majority of these patients are male, black non-Hispanic, and nearly 50% are under two years of age.
- While these patients are only seen at St. Jude about two or three times a year, they can face substantial challenges such as transportation and housing.
- Several respondents shared that the unique population of hematology patients, almost all of whom are local, also face challenges in connecting to care.
- Because people with Sickle Cell Disease are living longer, there is a need for services to improve educational and/or vocational attainment of people with this disease as they age

into adulthood. Transitioning these patients to adult care and independence is challenging for some patients and families.

HIV/AIDS

- St. Jude also accepts pediatric patients with HIV/AIDS and serves as the area's primary provider for infants, children and adolescents with HIV infection.
- In 2014, rates of children between 0 and 19 years old living with HIV/AIDs in the Memphis area (Shelby County) ranged from 9.7/100,000 in the 0-9 year old age group to 73.5/100,000 in the 15-19 year old age group. In 2014, Shelby County had 26 new HIV cases in the 0-19 year old age group.
- Among St. Jude FY 2015 new patients with a primary diagnosis of HIV/AIDS, 80% are male and black non-Hispanic, and more than 50% are over the age of 20.
- Both poverty and transportation were identified as barriers for these patients who are local.
- Several respondents noted that St. Jude works in close collaboration with other agencies, such as the Ryan White HIV/AIDS program.

Priority Areas for Future Community Benefit Program

St. Jude works diligently to meet the treatment and related palliative care needs of children with catastrophic diseases. The population served by St. Jude is widespread and diverse; patients come to St. Jude in a time of crisis when need for treatment, education, and care for the patient and their family is high. St. Jude's contribution to the broader understanding of pediatric cancer and related diseases was cited as a strength by study participants.

In May of 2016, the St. Jude CHNA Advisory Committee met to review CHNA findings and discuss priority areas for future community benefit programs and services. Given the success of St. Jude's current community benefit activities in their patient population--children with catastrophic diseases—the Advisory Committee prioritized the following areas:

Access to care in the areas of health insurance coverage, affordable services and workforce development. St. Jude should continue efforts to improve access to affordable health insurance coverage to reduce barriers to accessing services by limiting the burden of cost on the family. The St. Jude affiliate network should be maintained to continue opportunities for services to a larger number of children. Partnerships should be maintained and expanded to support workforce development and build the capacity of the health care system to meet the needs of children and their families.

Coordination of care. With the utilization of St. Jude affiliated programs, increasing partnerships for care, and patients transitioning to care in the adult system, strategies to improve and strengthen the coordination of care should be utilized and maintained.

Sharing the knowledge and experience of St. Jude staff for prevention efforts in the community. The Greater Memphis community in general has high rates of chronic disease and poor health outcomes. While not directly related to the treatment of severe childhood illness, local opportunities exist for St. Jude staff to strengthen and support or deliver high quality, effective education programs to improve health behaviors and health literacy.

Finally, the committee noted the importance of partnerships and collaborations to build to meet the health and medical needs of children. St. Jude does not have the capacity or resources to meet all needs of all children and their families, given its focused mission and model of providing specialized services to children in crisis. Strategic partnerships with other health care providers such as Methodist Le Bonheur Healthcare, along with partnerships with schools and community based organizations allow St. Jude to create a network of resources they can leverage to meet the health and social needs of a wider community of patients and their families.

Community benefit planning and implementation efforts should be considered in the context of the mission of the hospital, existing programs and services, partnerships, and other planning efforts being conducted for the system.

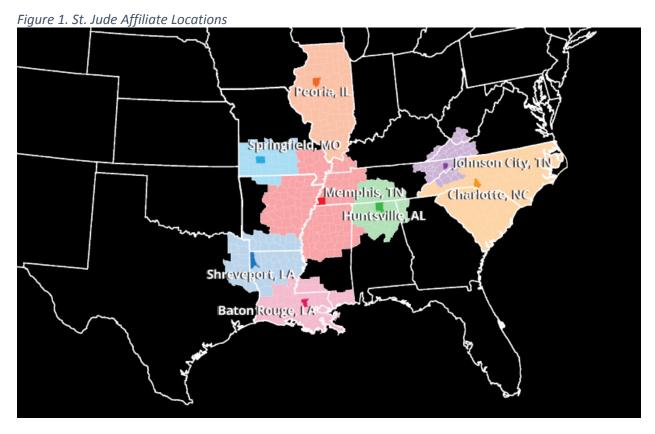
BACKGROUND

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St. Jude's primary clinical effort centers on providing ground-breaking, research-driven treatments. Specifically, more than 8,000 active patients are seen at St. Jude yearly, most of who are enrolled on clinical trials for new treatments developed by St. Jude and who are treated on a continuous outpatient basis. The hospital has 64 operational beds for patients requiring hospitalization during treatment. It should be noted that St. Jude has developed unique resources that allow a significant portion of patients to be treated as outpatients who would be admitted into inpatient units at most hospitals. This is accomplished through patient housing dedicated solely to St. Jude patient families designed with infection control measures such as HEPA filtration, infection-resistant surfaces and other medical safeguards that are not available in hotels or patients' homes.

St. Jude has a network of seven affiliated pediatric hematology/oncology clinics in the U.S., allowing St. Jude to extend care and benefits to more children and increase the number of children able to be treated on St. Jude clinical trials (see Figure 1). St. Jude also operates an international outreach program aimed at sharing knowledge and resources to improve the survival rate of children with cancer and hematologic diseases worldwide. St. Jude has partnerships with 24 medical institutions in 17 countries.



SOURCE: www.stjude.org

St. Jude is also a research organization, with research covering a broader scope of health issues than the diseases treated as a primary diagnosis. For the purposes of this report, the focus is limited to those diseases for which children are admitted to St. Jude for treatment.

Purpose of this CHNA

This community health needs assessment (CHNA) aims to fulfill the requirement by the IRS Section H/Form 990 mandate and provide a portrait of the health of a community in order to lay the foundation for future data-driven planning efforts. The CHNA process included:

- Engaging an advisory committee of St. Jude staff
- Reviewing secondary social, economic, and health data
- Conducting interviews and focus groups with internal and external stakeholders, leaders in public health, patients and family members
- Review of current community benefit efforts
- Prioritizing of needs to be addressed by community benefit initiatives

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METHODOLOGY

The following section describes how the data for this community health needs assessment was compiled and analyzed, as well as the overarching framework used to guide the assessment process.

Quantitative Data

In an effort to develop a social, economic, and health portrait of the community served by St. Jude for the greater Memphis area and nationally, HRiA reviewed existing data drawn from local, state, and national sources. Data sources include but were not limited to: The U.S Census, National Children's Health Survey, National Cancer Institute, and Shelby County Health Department, among others. Data analyses were conducted by the original data source (e.g., U.S. Census, NCFH, NCI). Patient data were also provided by the St. Jude Departments of Information Services and Childhood Cancer Surveillance in order to review a snapshot of the population served by the hospital.

Qualitative Data: Gathering Community Input

In addition to analyzing epidemiological data, HRiA conducted qualitative research with internal and external St. Jude stakeholders as well as patients and family members served in order to supplement quantitative findings with perceptions of community strengths and assets, their priority health concerns, and suggestions for future programming and services. To this end, three focus groups and 16 key informant interviews were conducted between March and April of 2016. Participants represented a broad cross-section from the St. Jude staff, patients and families, local government representatives, public health departments, community-based organizations, health care providers, and national leaders in the treatment of children with catastrophic illnesses.

Focus Groups

Focus groups were conducted with current and former St. Jude patients, patient caregivers, and St. Jude clinical, research, and administrative staff. Different topic areas were explored based on the unique experiences of each of the groups. The patient and caregiver focus groups, conducted with current patients and representatives of the Family Advisory and Quality of Life/Palliative Care Steering Councils, explored the extent to which St. Jude is meeting the needs of children with catastrophic illnesses and opportunities to bridge patient needs in the future. The clinical, research, and administrative staff focus group explored these topics as well as specific issues related to the greater Memphis community. A semi-structured moderator's guide was used across all discussions to ensure consistency in the topics covered. While similar, separate guides were used for the caregiver and patient focus groups so that they were age and developmentally appropriate.

Each focus group was facilitated by an experienced HRiA staff member, while a note-taker took detailed notes during the discussion. On average, focus groups lasted 30-90 minutes. Before the start of the groups, HRiA explained the purpose of the study to participants and participants had an opportunity to ask questions. They were also notified verbally that group discussions would remain confidential, and no responses would be connected to them personally. Patient focus group participants received a \$30 gift certificate as well as food and beverages in

appreciation for their time. Participants were recruited by St. Jude staff, who arranged all logistics for the onsite focus groups. Appendix A contains more details about focus group participants.

Key Informant Interviews

HRiA conducted interviews with 16 individuals; 6 were internal to the St. Jude hospital and 10 were external representatives. Interviewees represent a range of sectors, including leaders in health care and health research, government, and social service organizations focusing on vulnerable populations. Similar to the focus groups, a semi-structured interview guide was used across all discussions to ensure consistency in the topics covered. Interviews were approximately 30 minutes in length. A list of stakeholder interviewee positions and organizations can be found in Appendix B.

Analyses

The collected qualitative information was manually coded and then analyzed thematically for main categories. Data analysts identified key themes that emerged across all groups and interviews as well as the unique issues that were noted for specific populations. Selected paraphrased quotes – without personal identifying information – are presented in the narrative of this report to further illustrate points within topic areas.

Limitations

As with all research efforts, there are several limitations related to the assessment's research methods that should be acknowledged. It should be noted that for the secondary (quantitative) data analyses, in several instances, regional data could not be disaggregated to the neighborhood level due to the small number of children with diseases that St. Jude treats. Additionally, several sources could not provide current data stratified by race/ethnicity, gender, or age —thus these data could only be analyzed by total population.

Likewise, survey data from self-reported measures like that of the National Children's Health Survey should be interpreted with particular caution. In some instances, respondents may overor underreport behaviors and illnesses based on fear of social stigma or misunderstanding the question being asked. In addition, respondents may be prone to recall bias—that is, they may attempt to answer accurately but remember incorrectly. In some surveys, reporting and recall bias may differ according to a risk factor or health outcome of interest.

For the qualitative data, it is important to recognize results are not statistically representative of a larger population due to non-random recruiting techniques and a small sample size. Recruitment for focus groups was conducted by St. Jude staff, and participants may be more likely to have a positive opinion of St. Jude and its services. Because of this, it is possible that the responses received only provide one perspective of the issues discussed. While efforts were made to talk to a diverse cross-section of individuals, demographic characteristics were not collected of the focus group and interview participants, so it is not possible to confirm whether they reflect the composition of the region. Lastly, it is important to note that data were collected at one point in time, so findings, while directional and descriptive, should not be interpreted as definitive or causal.

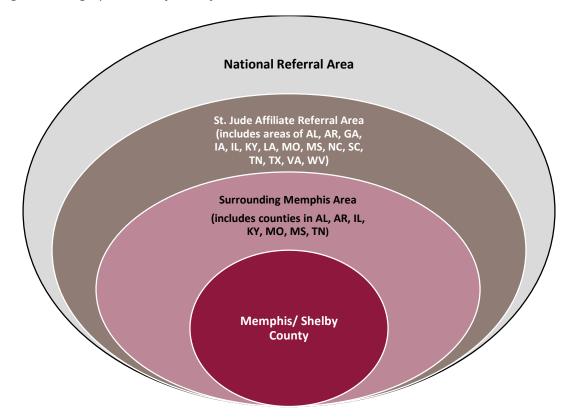
COMMUNITY SERVED

Per the IRS-990 CHNA requirements, a hospital's community for the CHNA may be defined in many ways:

- Target population served (e.g., children, women, or the aged)
- Geographic location (e.g., a city, county, or metropolitan region)
- Principal function of the hospital (e.g., a particular specialty area or targeted disease)

As a highly-specialized and world-renowned hospital, St. Jude was seen by focus group and interview participants as having three service communities: The U.S. and international patients and their families; the Memphis community which surrounds it; and the larger community of cancer researchers and cancer care provider institutions. For the purposes of the 2016 CHNA process and community benefit planning, St. Jude has defined its community by geography in the United States (see Figure 2) and principal function, which is to serve children with catastrophic illnesses; more specifically, children with cancer nationwide, and children with blood disorders (primarily Sickle Cell Disease and HIV/AIDs). Geographic areas of focus include:

Figure 2. Geographic Area of Focus for 2016 CHNA



Memphis/Shelby County

St. Jude is located in Shelby County, in the City of Memphis, Tennessee. As seen in Figure 3, Shelby County, has a population that is predominantly African American, non-Hispanic (52.8%).

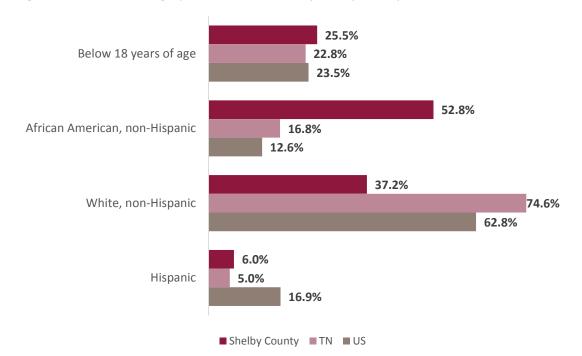


Figure 3. Selected Demographic Characteristics, By Shelby County, Tennessee, and United States

DATA SOURCE: US Census Bureau, Population Estimates Program, 2014 as cited by Robert Wood Johnson Foundation and University of Wisconsin Population Health Institute, County Health Rankings and Roadmaps

Focus group and interview participants described St. Jude as a major contributor to the greater Memphis community. As one person stated, "I see St. Jude everywhere in the community." Another echoed a similar perspective saying, "[St. Jude is] woven into the fabric of Memphis." St. Jude partners with other community and health related organizations and institutions to provide community and educational programming. A couple of respondents noted that St. Jude provides jobs with higher salaries, which contributes to the local economy and tax base. An Economic Impact Study prepared by CBIZ and Christian Brothers University (in collaboration with ALSAC's¹ Center for Excellence in Analytics) shows that American Lebanese Syrian Associated Charities (ALSAC) and St. Jude Children's Research Hospital have a significant economic impact in the Memphis area and on the state of Tennessee. It is estimated that St. Jude's current economic impact on the Memphis area and the state is \$2.5 billion, a figure that could increase upwards to \$3.5-4 billion in the future.

Shelby County neighborhoods, including those in Memphis, were described as largely lower income, with respondents reporting that many families in the area were struggling. As one focus group member stated, "the local population is very simply, families with low education."

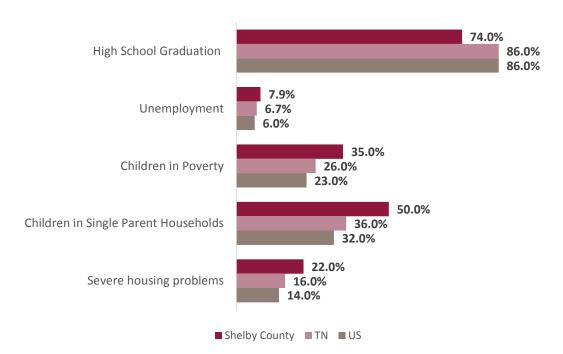
¹ ALSAC is the fundraising and awareness organization for St. Jude, and its sole mission is to raise the funds and awareness necessary to operate and maintain the hospital.

Respondents pointed to a high rate of poverty, many single-parent households, and substantial rates of homelessness and crime. Further, affordable housing was raised as a concern in the area, as was food insecurity. Respondents also reported high levels of outward mobility in the region, saying that those with higher educational attainment and skills were leaving the Shelby County.

Low levels of education, including a low high school graduation rate, also were reported in Shelby County, which contributes to lower income levels. Research show this also translates into lower levels of health literacy, and contributes to poorer health overall.

Shelby County was also described as very racially and ethnically diverse, though participants reported structural challenges in being an inclusive community. While there have been improvements in some of these structural challenges, shared one participant, racism has been a long-standing undercurrent in the county. Many respondents pointed to substantial health disparities in the county, with African Americans in particular experiencing higher rates of poorer health and lower life expectancy.





DATA SOURCE: US Department of Education, EDFacts, 2012-2013; Bureau of Labor Statistics, Local Area Unemployment Statistics, 2014; US Census Bureau, Small Area Income and Poverty Estimates, 2014; US Census Bureau, American Community Survey, 5-Year Estimates, 2010-2014; US Department of Housing and Urban Development, Comprehensive Housing Affordability Strategy, 2008-2012 as cited by Robert Wood Johnson Foundation and University of Wisconsin Population Health Institute, County Health Rankings and Roadmaps

Respondents identified several strengths of the county including the location as a hub in the Mid-South, with a moderate climate. The low cost of living also was cited as a benefit. Several respondents noted that the city has a strong healthcare infrastructure. A couple of respondents

reported economic strengths including good jobs in the health care sector as well as in the areas of transportation, logistics, and pharmaceuticals.

Respondents also described a community of generous individuals and organizations. One respondent also pointed to the strength of community organizations and volunteerism in the city, especially among the business community. As this person explained, "people support ventures that will help support the community." Similarly, family members of patients shared examples of community generosity explaining that some local families will host out-of-town family members of patients and some are tutors at St. Jude.

Surrounding Memphis Area and the Affiliate Referral Area

Because of the uniqueness of its services and its seven affiliates (Peoria, IL; Springfield, MO; Shreveport, LA; Baton Rouge, LA; Huntsville, AL; Charlotte, NC; Johnson City, TN), St. Jude has concentric service areas. These sites offer referrals to St. Jude for inpatient services and treatments developed as clinical trials at St. Jude to more children by offering care closer to home. St. Jude defines a geographic service area that surrounds Memphis and is made up of 163 counties near west Tennessee in the states of Alabama, Arkansas. Illinois, Kentucky, Missouri, Mississippi and Tennessee. Beyond the Surrounding Memphis Area is an Affiliate Referral Area of 15 states.

The Surrounding Memphis area is a wide region of service that touches five states in the bottom ten rankings of healthy states by United Health Foundation. See Table 1 for demographic, social and economic factors for the region.

Table 1. Selected Demographic and Social and Economic Factors for Surrounding Memphis Area, by State

	AL	AR	IL	KY	МО	MS	TN	US
Demographics								
Below 18 years old	22.8%	23.8%	23.2%	22.9%	23.0%	24.4%	22.8%	23.5%
65 years old or older	15.3%	15.7%	13.9%	14.8%	15.4%	14.3%	15.1%	13.7%
African American, Non- Hispanic	26.4%	15.4%	14.2%	8.0%	11.6%	37.2%	16.8%	12.2%
White, Non-Hispanic	66.2%	73.4%	62.3%	85.4%	80.1%	57.3%	74.6%	62.8%
Hispanic	4.1%	7.0%	16.7%	3.4%	4.0%	3.0%	5.0%	16.9%
Not proficient in English	1%	2%	5%	1%	1%	1%	1%	-
Social and Economic								
Factors								
High School graduation	81.0%	85.0%	83.0%	88.0%	88.0%	76.0%	86.0%	86.0%
some college	58.0%	55.0%	67.0%	59.0%	65.0%	58.0%	58.0%	56.0%
Unemployment	6.8%	6.1%	7.1%	6.5%	6.1%	7.8%	6.7%	6.0%
Children in Poverty	27.0%	26.0%	20.0%	26.0%	21.0%	31.0%	26.0%	23.0%
Children in single parent households	38.0%	37.0%	32.0%	34.0%	33.0%	45.0%	36.0%	32.0%
Severe housing problems	15.0%	15.0%	19.0%	14.0%	15.0%	17.0%	16.0%	14.0%
Violent Crime per 100,000 Population	418	484	430	235	452	267	621	199
National Health Ranking	46th	48th	28th	44th	36th	49th	43rd	

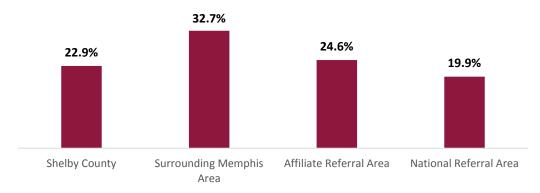
DATA SOURCE: US Census Bureau, Population Estimates Program, 2014; US Department of Education, EDFacts, 2012-2013; Bureau of Labor Statistics, Local Area Unemployment Statistics, 2014; US Census Bureau, Small Area Income and Poverty Estimates, 2014; US Census Bureau, American Community Survey, 5-Year Estimates, 2010-2014; US Department of Housing and Urban Development, Comprehensive Housing Affordability Strategy, 2008-2012; Federal Bureau of Investigations, Uniform Crime Reporting, 2010-2012 as cited by Robert Wood Johnson Foundation and University of Wisconsin Population Health Institute, County Health Rankings and Roadmaps

The Affiliate Referral Area broadens to include areas connected to all seven affiliates in all or part of 15 states in the central and south United States: Alabama, Arkansas, Georgia, Iowa, Illinois, Kentucky, Louisiana, Missouri, North Carolina, South Carolina, Tennessee, Texas, Virginia, and West Virginia.

St. Jude's Patient Population

St. Jude, through its location in Memphis and its affiliate sites, draws patients from all over the U.S., including from the local Memphis community. As Figure 5 displays, 22.9% of new patients in FY 2015 came from the Memphis/Shelby County community while another 32.7% came from the Surrounding Memphis Area.

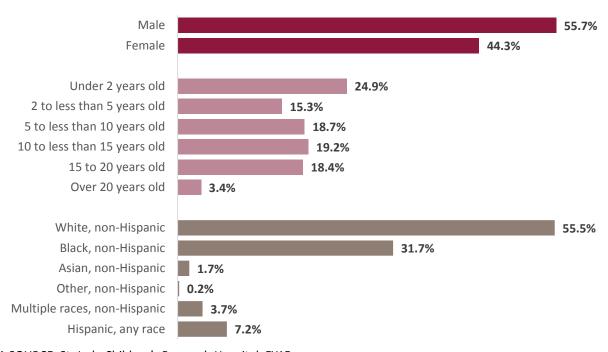
Figure 5. Geography of New Patients, U.S., FY2015



DATA SOURCE: St. Jude Children's Research Hospital, FY 2015

Of the 900 children who became patients at St. Jude for the first time in FY 2015, while they were more likely to be male than female, they varied across age, race and ethnicity, see Figure 6.

Figure 6. Demographics of New U.S. Patients, FY 2015 (N=900)



DATA SOURCE: St. Jude Children's Research Hospital, FY15

NOTE: Other, non-Hispanic includes American Indian/Alaska Native and Other; Multiple races, non-Hispanic includes American Indian/Alaskan and White, Asian and White, Black and White, and Multiple Race (NOS) NOTE: Percentages for race and ethnicity categories only include patients who indicated race and ethnicity

St. Jude's primary clinical effort centers on providing ground-breaking, research-driven treatments. While the dominant focus of St. Jude is the treatment of pediatric cancer, it also

^{*}Surrounding Memphis Area excludes Shelby County

serves as a primary hematology hospital for patients in the Greater Memphis area, with the largest program being treatment of sickle cell disease. St. Jude also accepts pediatric patients with HIV/AIDS and serves as the area's primary provider for infants, children and adolescents with HIV infection. See Figure 7.

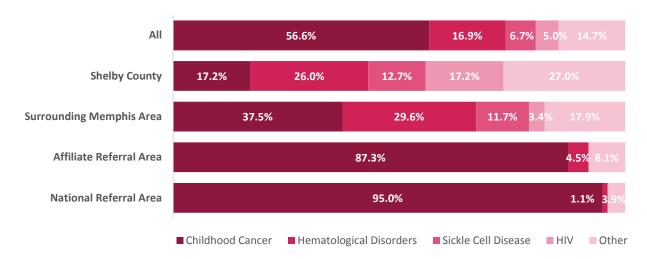


Figure 7. Primary Diagnosis of New U.S. Patients, By Geographic Region, FY 2015

DATA SOURCE: St. Jude Children's Research Hospital, FY15

NOTE: Surrounding Memphis Area excludes Shelby County; Affiliate Referral Area excludes Memphis, TN area NOTE: 0% patients within the Affiliate Referral Area with primary diagnoses of HIV and Sickle Cell Disease; 0% patients within National Referral Area with primary diagnoses of HIV and Sickle Cell Disease

All of those served by St. Jude, as respondents described, are dealing with catastrophic or chronic disease, which creates substantial personal challenges. Most are uprooted from their communities and pulled away from work, family and friends, especially those who are furthest away from home. As one member of the St. Jude provider focus group shared, "We provide all of the amenities and conveniences for them, but it is a disruptive lifestyle." An interviewee shared a similar perspective saying, "[children] have an interruption in their normal childhood, not being able to go school, looking different…"

Patients from Shelby County, especially those who are lower income, were reported to face additional challenges, such as poverty at home, or challenges with transportation. As one staff member stated, "local patients may face poverty and barriers to meet their needs day in and day out." St. Jude staff reported that they work with families to ensure that they can pay their bills and are linked to local social and educational services they need.

Focus group members and interviewees pointed to the resiliency of patients and families in the face of such devastating disease as a characteristic of those served. Another interviewee marveled at the ability of children and adolescents to tolerate the often-aggressive treatment of their diseases.

Many respondents also pointed to the quality of care provided at St. Jude, including innovative care as well as connection to specialists. As one interviewee stated, "the comprehensiveness of care is really amazing." Family members of patients described the care as "always on the

cutting edge." Others specifically mentioned the strong staff and patient services as critical components to St. Jude: "St. Jude attracts best and brightest health care staff to compassionately treat our most vulnerable." The commitment to family and keeping families together was also mentioned as a strength by a couple of respondents. Compassion was also mentioned as a strong character of St. Jude. As one person described, "there is a sense that everyone, from the person who cleans the floor to the 2:00 a.m. doctor, would be there even if they weren't being paid. It pours out. It felt like everyone wrapped their arms around me."

Youth focus group members also spoke positively about their experience at St. Jude. They expressed appreciation for the compassion and dedication of St. Jude's staff, the different activities in which they are able to participate, as well as the opportunity to make new friends. One youth focus group member specifically noted the housing, saying it feels like "home away from home" rather than like a hotel. Another shared, "I like the school, learning new things, all the kids at St. Jude."

SIGNIFICANT HEALTH ISSUES OF THE COMMUNITY SERVED

Access to Care

The Office of Disease Prevention and Health Promotion's Healthy People 2020 (HP2020) initiative cites three components of access to care: coverage, services and workforce. Data collected through the National Children's Health Survey provides some insight in to these components for children as it measures health insurance coverage and the status of having a medical home. Within the Surrounding Memphis Area insurance coverage for children ranges from 90.5% in Florida to 98.4% in Illinois. See Figure 7.

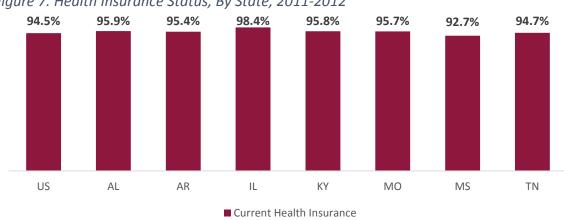


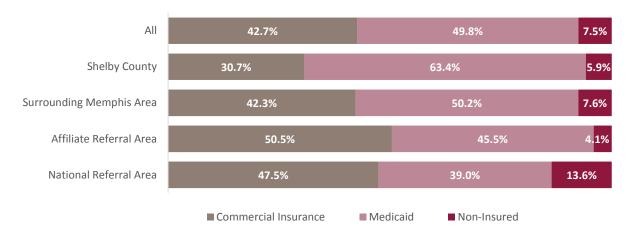
Figure 7. Health Insurance Status, By State, 2011-2012

DATA SOURCE: National Survey of Children's Health, 2011-2012

NOTE: Current health insurance is defined as percent of children insured at the time of the interview

Of the FY 2015 new patient population at St. Jude, nearly all have some form of insurance or health coverage through Medicaid, see Figure 8. New patients from the Surrounding Memphis area and Affiliate Region are more likely to be covered through Medicaid than those in the "Other" category.

Figure 8. Health Care Access, By Source of Payment, By Geographic Region, New U.S. Patients, FY 2015



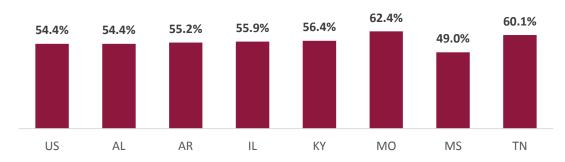
DATA SOURCE: St. Jude Children's Research Hospital, FY 2015

NOTE: Commercial insurance includes Blue Cross, Champus, and TriCare; Medicaid includes Medicaid, Medicaid Limited Pay, and TennCare

NOTE: Percentages do not include patients whose source of payment was SJ Grant or Research due to small sample size

HP2020 also describes three distinct steps for accessing health services: gaining entry into the health care system; accessing a health care location where needed services are provided; and finding a health care provider with whom the patient can communicate and trust.

Figure 9. Percent Children Who Received Care within a Medical Home, By US and Affiliate Region States, 2011-2012



DATA SOURCE: National Survey of Children's Health, 2011-2012

The accessibility of St. Jude services for patients and families that need it most was cited as a substantial strength by focus group members and interviewees. Multiple respondents spoke about the fact that financial aspects of care, including transportation and housing, are covered at St. Jude, in contrast to some other well-known cancer centers. As one interviewee stated, "anybody in the community who has a child with cancer can receive services." Another echoed this, saying, "a lot of the benefit of going to St. Jude would be very different if patients [and their families] had to worry about the payment of care." This also allows, in the opinion of an

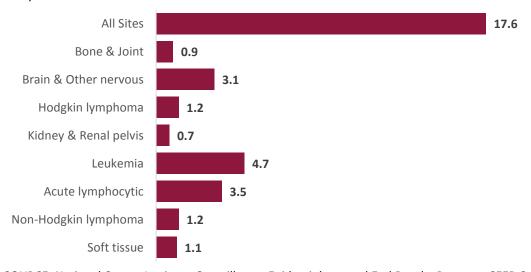
interviewee, St. Jude to concentrate on the diseases, and not the insurance and payment aspect. Numerous respondents pointed to the strength of the fundraising of ALSAC for St. Jude, that enables this to happen.

Access to health care was also reported to be a concern in Shelby County, with transportation identified as one of the most significant challenges to accessing care. An additional concern was lack of health insurance among some members of the community. Closely related to this were difficulties residents face in navigating health insurance and health care. One respondent also expressed concerns about safety when traveling to appointments. Access to health care in rural areas, according to one respondent, was reported to be especially challenging.

Childhood Cancer

As stated previously, St Jude's primary focus is on researching treatments for childhood cancers. This section provides data on current treatment needs. The next two figures (Figures 10 & 11) demonstrate that although leukemia has a higher incidence among children nationally, St. Jude sees a higher proportion of brain and other nervous system cancers than leukemia.

Figure 10. Age-Adjusted SEER Cancer Incidence Rates per 100,000 Population Under 20 Years Old in US, 2008-2012



DATA SOURCE: National Cancer Institute, Surveillance, Epidemiology, and End Results Program, SEER Cancer Statistics Review, http://seer.cancer.gov/csr/1975_2012/browse_csr.php?sectionSEL=28&pageSEL=sect_28_t able.01.html

Bones and Joints 7.7% Brain and Other Nervous System 32.9% Digestive System 1.0% Endocrine System 2.6% Eye and Orbit 4.3% Female Genital System Leukemia 22.5% Lymphoma 10.5% Male Genital System 0.8% Oral Cavity and Pharynx 0.6% Respiratory System Skin Excluding Basal and Squamous 2.2% Soft Tissue including Heart 7.3% **Urinary System** 4.1% Miscellaneous 2.6%

Figure 11. Cancer Sites of Patients with Primary Diagnosis of Childhood Cancer, FY 2015 (N=507)

DATA SOURCE: St. Jude Children's Research Hospital, FY 2015

NOTE: Diagnoses coded per SEER categories

Among FY 2015 St. Jude new patients with a primary diagnosis of cancer, the majority are male and white non-Hispanic. The ages of these new patients are evenly distributed across childhood and teenage years. (See Figure 12)

Male 57.2% Female 42.8% Under 2 years old 12.6% 2 to less than 5 years old 17.9% 5 to less than 10 years old 25.2% 10 to less than 15 years old 21.1% 15 to 20 years old 21.7% Over 20 years old 1.4% White, non-Hispanic 68.6% 16.6% Black, non-Hispanic Asian, non-Hispanic 2.0% Other, non-Hispanic 0.4% Multiple races, non-Hispanic Hispanic, any race 8.9%

Figure 12. Demographics of New Patients with Primary Diagnosis of Childhood Cancer, FY15 (N=507)

DATA SOURCE: St. Jude Children's Research Hospital, FY 2015

NOTE: Other, non-Hispanic includes American Indian/Alaska Native and Other; Multiple races, non-Hispanic includes American Indian/Alaskan and White, Asian and White, Black and White, and Multiple Race (NOS) NOTE: Percentages for race and ethnicity categories only include patients who indicated race and ethnicity

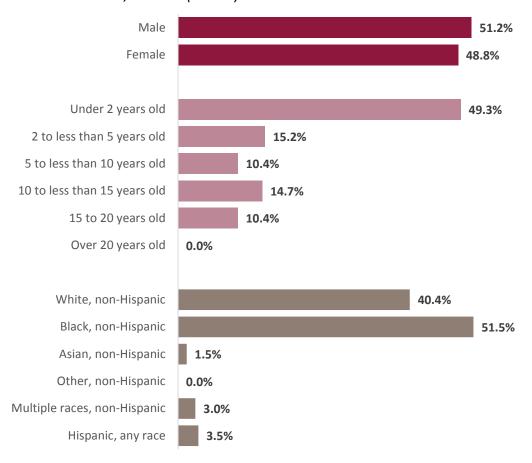
Sickle Cell Disease and Hematology Patients

St. Jude also serves as a primary hematology hospital for patients in the Surrounding Memphis Area, with the largest program being treatment of sickle cell disease. Other hematological diseases include hemophilia, immunodeficiency disorders, and anemia. A recent study completed by researchers from the University of Memphis School of Public Health and St. Jude Children's Research Hospital and published in the journal *Pediatric Blood Cancer*, aimed to obtain a more accurate quantification of the regional burden of sickle cell disease. These

researchers found a prevalence of Sickle Cell Disease in African Americans of 1/287, significantly higher than the national reported 1/350-1/500².

Among FY 2015 St. Jude new cases of hematological disorders or sickle cell disease, the majority of these patients are male, black non-Hispanic, and nearly 50% are under two years of age. (Figure 13).

Figure 13. Demographics of New Patients with Primary Diagnosis of Hematological Disorders or Sickle Cell Disease, FY 2015 (N=211)



DATA SOURCE: St. Jude Children's Research Hospital, FY 2015

NOTE: Other, non-Hispanic includes American Indian/Alaska Native and Other; Multiple races, non-Hispanic includes American Indian/Alaskan and White, Asian and White, Black and White, and Multiple Race (NOS) NOTE: Percentages for race and ethnicity categories only include patients who indicated race and ethnicity

Several respondents shared that the unique population of hematology patients, almost all of whom are local, also face challenges in connecting to care. While these patients are only seen at St. Jude about two or three times a year, they can face substantial challenges such as transportation and housing. Additionally, transitioning these patients to independence can be

² <u>Birth Prevalence of Sickle Cell Trait and Sickle Cell Disease in Shelby County, TN.</u> Smeltzer MP, Nolan VG, Yu X, Nottage KA, Davis A, Yang Y, Wang WC, Gurney JG, Hankins JS.**Pediatr Blood Cancer**. 2016 Jun;63(6):1054-9. doi: 10.1002/pbc.25936. Epub 2016 Feb 12

challenging for some because of the level of care needed. This involves education of patients and families in how to call the lab, schedule appointments, and understand insurance issues. Parents need to become health care providers and this can be challenging for some. Further, because people with Sickle Cell Disease are living longer, there is a need for services to improve educational and/or vocational attainment of people with this disease as they age into adulthood.

Similar challenges exist, according to respondents, for HIV patients. Both poverty and transportation were identified as barriers for these patients who are local. Several respondents noted that St. Jude works in close collaboration with other agencies, such as the Ryan White HIV/AIDS program.

Living with HIV and AIDS

St. Jude also accepts pediatric patients with HIV/AIDS and serves as the area's primary provider for infants, children and adolescents with HIV infection. In 2014, rates of children between 0 and 19 years old living with HIV/AIDs in the Memphis area (Shelby County) ranged from 9.7/100,000 in the 0-9 year old age group to 73.5/100,000 in the 15-19 year old age group. In 2014, Shelby County had 26 new HIV cases in the 0-19 year old age group.

Among St. Jude FY 2015 new patients with a primary diagnosis of HIV/AIDS, 80% are male and black non-Hispanic, and more than 50% are over the age of 20 (Figure 14).

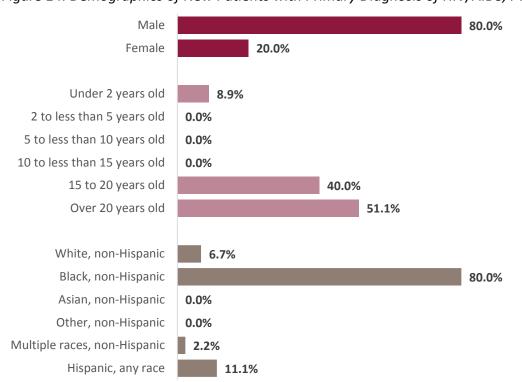


Figure 14. Demographics of New Patients with Primary Diagnosis of HIV/AIDS, FY 2015 (N=45)

DATA SOURCE: St. Jude Children's Research Hospital, FY 2015

NOTE: Other, non-Hispanic includes American Indian/Alaska Native and Other; Multiple races, non-Hispanic includes American Indian/Alaskan and White, Asian and White, Black and White, and Multiple Race (NOS) NOTE: Percentages for race and ethnicity categories only include patients who indicated race and ethnicity

Needs of the Patients' Families and Caregivers

Family members and caregivers spoke extensively about the quality of care provided at St. Jude. They appreciated the family-centered care provided and described strong relationships between staff and families. As one member stated, "the St. Jude community is one great big family." Several family members also pointed to the palliative care program and the Quality of Life team available to all families.

Commitment to their children was another strength. As one interviewee described, "they are jumping in with both feet for their children." Another interviewee marveled at the ability of children and adolescents to tolerate the often-aggressive treatment of their diseases.

Several respondents pointed to the bonds and support that form among children and families served by St. Jude. As one focus group member explained, "they get strength from other families." This translates, according to respondents, to a desire to help other families. As one interviewee stated, "their passion for sharing their experiences and improving care for others. Many sign on to ultimately help other children." One person shared that this desire to help others led to the development of a family mentoring program in response to the suggestion of patient families. However, a couple of respondents noted that these relationships form more easily among patients and families who reside at St. Jude, and is more difficult for families who live in the local community. At the same time, however, some noted that shared housing and communal activities and cooking spaces have their drawbacks. This close proximity to others can result in a loss of privacy that can be challenging to some families, according to some respondents. As one focus group member explained, "St. Jude housing is not private, so all of their flaws are seen."

Many respondents also noted the substantial stress, fatigue, and fear experienced by families and children that comes with a serious illness. As one interviewee mentioned, "parents of a sick child put things on the back burner to address needs of child." Lack of understanding of childhood cancer is an additional challenge for most patient families.

Post Treatment and Care Transition

While focus group members and interviewees pointed to the high-quality and comprehensive care St. Jude provides to patients, meeting the needs of those who "age out" (transition to adult care) was reported by several respondents to be a challenge. As one interviewee shared, "St. Jude has a thorough approach for children but then they age out." Another interviewee described the challenge in a different way saying, "a young person transitioning to adulthood now has a cardiac problem – we don't do cardiac." Several respondents pointed to the importance of working with community partners to ensure continuity of care for adult cancer survivors in Memphis and the surrounding area. One suggested that establishing these relationships is critical: "St. Jude tends to want to provide all services rather than developing relationships with other providers; this causes a problem when patients age out."

Family members shared that one of their primary health concerns is transition to care after leaving St. Jude. Three respondents pointed out the challenges of care transition for local patients when they are discharged from the hospital, especially those who have traditionally faced barriers to obtaining health care. While respondents reported that St. Jude works to

connect patients to services such as medications, nursing home care, and other services to enhance their wellness, this is not always easy. St. Jude relies on partnerships with organizations such as Methodist Le Bonheur Health Care and the Church Health Center which provide care to the uninsured.

According to staff respondents, some families also face challenges returning to their communities if they have stayed for a long time at St. Jude, in particular at Target House, which is the long-term stay residence. As one explained, "it is hard for families to go back home because Target is so beautiful; life here is better than what they had." Discharge planning and connection to services in home communities is also challenging for St. Jude patients and their families, according to some respondents. As one family member shared, "when we leave here, that's what scares me."

Health Status of the Memphis Community

Interview and focus group participants raised additional health concerns that affect Memphis and the surrounding areas. These include high rates of chronic disease, including obesity; health disparities among minority populations, who experience higher rates of chronic diseases including cancer, as well as communicable disease; and behavioral health, including heroin and prescription drug abuse. Although these concerns are outside of St. Jude's primary focus on childhood catastrophic diseases, for Memphis community members who receive St. Jude services, these concerns affect how these community members access and receive care. Further, these concerns can inform St. Jude as it examines its role in the community.

Additional Gaps for the Pediatric Population

Focus group and interview participants generated recommendations for community benefit activities that fell outside of meeting the needs of patients, they include:

Healthy Lifestyle Education and Prevention

Several respondents noted that if St. Jude wants to have greater reach in the local community, it may want to address some fundamental issues such as obesity and diabetes through healthy lifestyle programs, including working at a policy level on issues such as access to healthy food. Working with schools also was suggested such as through school health-related classes. Respondents also suggested that more could be done related to prevention education related to cancer such as HPV education.

Potential Rehabilitative and Long Term Care Services for the Pediatric Population

A couple of respondents noted a need for rehabilitative and long-term care for pediatrics in Memphis. As one interviewee shared, "we have a phenomenal oncology-based rehab group but not those who need significant rehab from other angles." A couple of respondents suggested however, that partnerships with Methodist Le Bonheur Healthcare have helped to expand rehabilitative services.

PARTNERSHIPS LEVERAGED TO MEET COMMUNITY NEED

Across internal and external providers in the Surrounding Memphis area, partnerships between St. Jude and other institutions were noted as a strength. They mentioned the relationship with Methodist Le Bonheur Healthcare, and recent partnerships aimed at attracting and retaining high quality providers and accessing state of the art equipment and technology. As one person stated, "investment in Le Bonheur Children's Hospital is a way of broadening their impact." The partnership with Methodist Le Bonheur Healthcare was also mentioned as a critical partnership, especially for transition and adult Sickle Cell Disease care and hospice and long-term care.

Several respondents also pointed to partnerships that enhance the care of those with HIV such as through the HIV clinic, Hope House and other activities funded by Ryan White HIV/AIDS program. One respondent also mentioned that work is being done to expand the Smile Program, which works to link newly-diagnosed teens with HIV to care in new locations.

St. Jude also works with other organizations that strengthen the services it provides. These include: Ronald McDonald House, the American Cancer Society's Hope Lodge, and Church Health Center. On a national level, St. Jude works with the National Institute of Patient Family Centered Care to share education resources.

Several respondents pointed to the need to continue to support youth who transition to adult care from St. Jude services. One interviewee noted a new St. Jude Transition clinic developed in partnership with Methodist Le Bonheur Healthcare that provides Sickle Cell Disease support to those ages 18-25, with support from an St. Jude case manager. As one respondent stated, "[we] need to work on transition support so that services don't drop off as children age out." Enhanced partnerships with community based organizations to help with transition age youth was suggested by one respondent.

Several respondents shared that enhanced collaboration across organizations would also be beneficial and provided specific suggestions to enhance collaboration. One respondent mentioned working more closely with University of Tennessee Health Science Center. Another suggested aligning hospital and health department health needs assessments to create a broader conversation and more comprehensive assessment of needs. A timeline of 2018-2019 was suggested for this. Partnerships with local community-based organizations to help youth

who transition to adult services, and which support local families served by St. Jude, were also mentioned.

It is important to note as well, however, that a couple of respondents cautioned about the need to stay focused on the organization's mission as different options are pondered. As one interviewee stated, "as somebody as a potential donor or to go there for my child – I would want them to be VERY focused on the clinical work...don't do too much of what you don't do best. Don't get caught up in other different things." Another respondent shared a similar thought, saying "there is not necessarily a uniform agreement on St. Jude mission being exactly in line on the health needs of the Memphis such as health insurance and immunizations, but that is not St. Jude's mission, it is catastrophic diseases." This same respondent also noted the challenge inherent in this: "their mission is relatively rare diseases as long as they stay true to their mission it is going to be hard to have a larger footprint."

EVALUATION/IMPACT OF CURRENT COMMUNITY BENEFIT INITIATIVES

Non-profit hospitals are required to complete the 990 Schedule H as part of the annual submission to the IRS. Through this form, hospitals report the dollar value of their community benefit activities. Community benefit is a program or activity that responds to a demonstrated health or community need and seeks to achieve at least one of the following:

- Improve access to health services
- Enhance population health
- Advance knowledge
- Relieve or reduce burden of government or others

Over the last four years, Ernst and Young has conducted a national review of Schedule H submissions. Their results show hospitals spending an average of 8.8% on community benefit activities with children's hospitals spending an average of 12.7%. In 2014, St. Jude reported 58.0% on community benefit activities primarily in the areas of medical research (30.8%) and financial assistance (19.8%).

As a result of their 2013 CHNA, and to meet IRS requirements, St. Jude developed a Community Benefit Implementation Plan. This plan was narrow in focus as it supplemented the medical research and financial assistance community benefit activities St. Jude is already engaged in through its mission and purpose. The plan identified three aims:

AIM #1 Improving access to healthcare services

- a) Transition of patients from pediatric to adult health care services
- b) Access to affordable health insurance coverage
- c) Palliative care
- d) Health care of childhood cancer survivors
- e) Community education

AIM #2 Improving coordination of care

a) Physician coordination of care

AIM #3 Improving child health status through behavioral modification

a) Child knowledge of cancer prevention, nutrition, obesity, and physical activity

St. Jude has provided annual reporting to the IRS on the progress and impact of these three sets of community benefit activities. The most recent report, 2015, with updates for 2016 can be found in Appendix B. Tables 2-4 provides a summary of the impact of these activities.

Table 2. Aim #1 Improving Access to Healthcare Services, Accomplishments through April 2016

	Summary Metric	Accomplishments
Transition of patients from pediatric to adult health care services Access to affordable health insurance coverage	Increase the number of patients with sickle cell disease who establish sustained adult care after leaving pediatric care at St. Jude Decrease the number of uninsured patients at St. Jude	# uninsured patients were enrolled in Medicaid or other health plans • 44 patients, FY 2015 • 22 patients, FY 2014 • 11 patients, FY 2013 • 15 patients, FY 2012
Palliative Care	Increase the number of clinicians trained in Palliative Care Medicine (PCM) and education opportunities for PCM	 4 physician fellows trained through Palliative Care Training Program (3 hired by St. Jude; 1 hired by Le Bonheur) 200+ clinicians trained in St. Jude Quality of Life Seminar and End-of-Life Nursing Education Consortium (ELNEC) 2-day seminar 50 community providers completing 3- hour Quality of Life for All Kids program
Health care of childhood cancer survivors	Provide cancer survivorship information to both caregivers and survivors via Survivors' Day conference	 St. Jude Survivor Day, September 6, 2014 St. Jude Survivor Day, September 7, 2013 16 lectures/workshops provided on survivorship issues for healthcare providers, survivors and families

	Summary Metric	Accomplishments
Community Education	Use urban radio and social media to provide information and education about health care resources and health care careers	 2 radio interviews and multiple taped 30-second educational spots Articles published in 3 issues of <i>Promise</i> magazine 20 tweets connecting viewer to health and health care career information, January - April 2016

Table 3. Aim #2 Improving Coordination of Care, Accomplishments through April 2016

	Summary Metric	Accomplishments
Physician Coordination of Care	Improve continuity of care by enhancing communication tools and efforts to provide physicians with unparalleled access to patient information	Designed and are testing a webportal to be used by referring and affiliated physicians to access patient records and improve communication

Table 4. Aim #3 Improving Child Health Status through Behavioral modification, Accomplishments through April 2016

	Summary Metric	Accomplishments
Child knowledge of cancer prevention, nutrition, obesity, and physical activity	 Increase the number of students and teachers participating in St. Jude cancer and healthy living education program 	 Increasing teacher and student participation in Educational Programs FY 2015: 250 teachers; 1621 students FY 2016: 140 teachers; 1912 students
	 Increase the knowledge that children have about cancer and healthy living topics (nutrition, exercise, sun protection, avoiding tobacco) with pre and post quizzes Improve attitudes of children toward healthy living 	
	practices (avoiding smoking, better nutrition habits, more exercise, avoiding excessive sun) using surveyinstruments	

CONCLUSION AND PRIORITIZATION OF AREAS OF NEED

St. Jude Children's Research Hospital works diligently to meet the treatment and related palliative care needs of children with catastrophic diseases. The population served by St. Jude is widespread and diverse; patients come to St. Jude in a time of crisis when need for treatment, education, and care for the patient and their family is high. St. Jude's contribution to the broader understanding of pediatric cancer and related diseases was cited as a strength by study participants. St. Jude's treatment of the patient and family was discussed as extraordinary by family members and external stakeholders. Given the focused mission and the strategies St. Jude employs to reach its goals, St. Jude's community benefit activities exceed expectations.

In May of 2016, the St. Jude CHNA Advisory Committee met to review CHNA findings and discuss priority areas for future community benefit programs and services. Given the success of St. Jude's current community benefit activities in their patient population-children with catastrophic diseases—the Advisory Committee prioritized the following areas:

Access to Care in the areas of health care coverage, affordable services and workforce development. St. Jude should continue efforts to improve access to affordable health insurance coverage to reduce barriers to accessing services by limiting the burden of cost on the family. The St. Jude affiliate network should be maintained to expand opportunities for services to a larger number of children. Partnerships should be maintained and expanded to support workforce development and build the capacity of the health care system to meet the needs of children and their families.

Coordination of care. With the utilization of St. Jude affiliate programs, increasing partnerships for care, and patients transitioning to care in the adult system, strategies to improve and strengthen the coordination of care should be utilized and maintained.

Sharing the knowledge and experience of St. Jude staff for prevention efforts in the community. The Greater Memphis community in general has high rates of chronic disease and poor health outcomes. While not directly related to the treatment of catastrophic childhood illness, local opportunities exist for St. Jude staff to strengthen and support or deliver high quality, effective education programs to improve health behaviors and health literacy.

Finally, the committee noted the importance of partnerships and collaborations to build to meet the health and medical needs of children. St. Jude does not have the capacity or resources to meet all needs of all children and their families, given its focused mission and model of providing specialized services to children in crisis. Strategic partnerships with other health care providers such as Methodist Le Bonheur Healthcare, along with partnerships with

schools and community based organizations allow St. Jude to create a network of resources they can leverage to meet the health and social needs of a wider community of patients and their families.

Community benefit planning and implementation efforts should be considered in the context of the mission of the hospital, existing programs and services, partnerships, and other planning efforts being conducted for the system.

APPENDICES

- A. List of Participants
 - o Advisory Group
 - o Focus Group
 - o Interview
- B. 2015 Community Benefit Report with 2016 updates

APPENDIX A: List of Participants

2016 CHNA Advisory Group

- Mary Anna Quinn, EVP/Chief Administrative Officer
- Robin Diaz, SVP/Chief Legal Officer
- Pat Flynn, MD, Deputy Clinical Director
- Pam Dotson, SVP, Patient Care Services/CNO
- Pat Keel, SVP/CFO
- Ron Smith, VP, Scientific Operations
- Barry Whyte, PhD, VP, Communications & Public Relations
- Cindy Lekhy, VP, Clinical Operations
- *Shari Capers, VP-Strategic Planning and Decision Support
- *Chara Abrams, Administrative Director, Psychology
- *Phyllis Hall, Director, Revenue Analysis
- *Jane Raymond, Director, Managed Care
- Jane Hankins, MD, MS, Associate Member, Department of Hematology
- Justin Baker, MD, Chief, Division of Quality of Life and Palliative Care
- Melissa M. Hudson, MD, Director, Cancer Survivorship Division
- Daniel Mulrooney, MD, MS, Assistant Member, Cancer Survivorship Division
- Patti Gust, Director, Health Information Management Services
- Tracy Dodd, Director, Physician and Patient Referral Services
- Elizabeth Walker, Manager, Print Production/Editor
- Kate Ayers, Coordinator, Cancer Education Outreach
- Kaleigh Davis, Staff Attorney
- Erin Starnes, Coordinator, Public Programs
- Dana Wallace, Associate Director, Administration and Cancer Center
- Alicia Huettel, Director, Family Centered Care
- Sheila Anderson, Case Manager
- Yvonne Carroll, Director, Hematology Patient Services
- Melissa Jones, Director, Cancer Center Operations
 - *Core Committee Member

Focus Groups

- Medical Executive Committee/Clinical Council (Internal)
 - Emily Browne, Director, Professional Development and APP
 - Andrew M. Davidoff, MD, Chair, Surgery Department
 - Pam Dotson, SVP, Patient Care Services/CNO
 - Janice English, Director, Nursing
 - o Patricia Flynn, MD, Member, SVP, Medical Director Quality and Patient Care
 - o William L. Greene, Pharm D, Chief Pharmaceutical Officer
 - o Liza Johnson, MD, Staff Physician, Hospitalist
 - o Pat Keel, SVP, Chief Financial Officer
 - Cindy Lekhy, VP, Clinical Operations

- Monika Metzger, MD, Regional Director, Central and South America Regions, International Outreach Program
- Sean Phipps, PhD, Chair, Psychology Department
- Ulrike Reiss, MD, Director, Clinical Hematology Division
- o Giles W. Robinson, MD, Assistant Member, Oncology Department
- o Victor Santana, MD, Member, VP, Clinical Trials Administration
- o Ron Smith, VP, Scientific Operations
- o Elaine Tuomanen, MD, Chair, Department of Infectious Diseases
- Family Advisory Council and Quality of Life/Palliative Care Steering Council (Internal and External, some family members and former patients are also St. Jude employees)
 - Audrey Davis
 - o Debbie Higgins
 - Casey Pappas
 - o Gabby Salinas
 - o Kelly Waddell
- Adolescent Patients, N=4

Internal Key Informant Interviews

- Carolyn Russo, MD, Medical Director Affiliate Program
- Justin Baker, Chief, Division of Quality of Life and Palliative Care
- Martha Beard, Chair, ALSAC Board of Directors
- Fran Greeson, Director of Social Work and Jana King, Director of Domiciliary Services
- Dr. Michael Link, St. Jude Advisory Board
- Alicia Huettel, Director of Family Centered Care

External Key Informant Interviews

- Dr. Johnathan McCullers, Chair, Department of Pediatrics, UTHSC/Le Bonheur Children's Hospital
- Jennifer Marshall Pepper, HIV/Ryan White, Shelby County
- Dr. David Stern, Dean UTHSC College of Medicine
- Dr. Barry Goldspiel, Acting Chief, Pharmacy Department, Chief, Clinical Pharmacy Specialist Section, NIH
- Drs. Nada Elmagboul and Robin Womeodu, Sickle Cell Disease Program Methodist Le Bonheur Healthcare
- Valerie Nagoshiner, Deputy Commissioner, TN Department of Health
- Angela Moore, PH coordinator, Community Health Planning, Shelby County Health Department
- Jennifer Myrick, Health Systems Manager, American Cancer Society mid-South
- Dee Wimberly, Carol Weidenhoffer, Hugh Jones, Sachary Hidinger, Andrea Tutor, Methodist Le Bonheur Healthcare CHNA Team
- Dr. Martin Whitside, Tennessee Cancer Coalition

APPENDIX B: 2015 Community Benefit Report with 2016 Updates

Aim #1 Im	proving access to healthcare services
Pediatric health need	Transition of patients from pediatric to adult health care services
Health facilities/Resources involved	St. Jude Children's Research Hospital, Department of Hematology, Clinical Hematology Division Diggs-Kraus Sickle Cell Center at Regional One Health Methodist Healthcare Comprehensive Sickle Cell Center (MCSCC)
Summary metric	Increase the number of patients with sickle cell disease (SCD) who establish sustained adult care after leaving pediatric care at St. Jude
Progress on action items to meet identified health need	Starting at the age of 12 the plan of care visits start to focus on planning and programming for transition. The initiatives in the plan of care that targets transition are as follows: Quarterly transition tours that are offered to our 17 and 18 year old young adults; Transition readiness multidisciplinary team meeting monthly to discuss readiness of the 17 year old based on medical stability, psychosocial, emotional and academic status. We've also implemented a Skills Lab that is in the Pilot stage, where we are teaching them how to order medication refills, how to identify the medication based on the description written on the bottle, how to schedule doctor's appointments by way of role modeling. They are also learning how to read their health insurance card and identify important phone numbers that will give them access to their benefits. At the age of 15, we start seeing the patient without the parent. The parent is asked to remain in the waiting area. At the age of 15 the adolescent completes a Personal Health Record in an effort to prepare them for completing necessary documentations after leaving the pediatric setting. In addition, the "Sickle Cell Transition E-Learning Program (STEP) for Teens with Sickle Cell Disease", a web-based education program, was developed to provide adolescents and young adults sickle cell education to help prepare them for transition. https://www.stjude.org/treatment/disease/sickle-cell-disease/step-program.html 1. Identification of possible adult medical homes for St. Jude young adult patients with pediatric hematologic conditions We have identified two Sickle Cell Centers here in Memphis where young adults with SCD transfer to post pediatric care. Diggs-Kraus Sickle Cell Center located at 880 Madison Ave. and Methodist Healthcare Comprehensive Sickle Cell Center located at 1325 Eastmoreland. 2. Create Adolescent and Young Adults (AYA) transition clinics with overlap of pediatric and adult Hem/Onc care
	increased adolescent autonomy and medical literacy Each young adult patient has an individualized plan of care. The frequency of their visit is determined by whether they are on medication therapy like Hydroyxurea or if they are receiving chronic transfusion therapy. If the young adult is not receiving therapy, they are scheduled for follow up visits every four months during the first year and every six months thereafter.

Aim #1 Imp	proving access to healthcare services
Pediatric health need	Access to affordable health insurance coverage
Health facilities/Resources involved	St. Jude Children's Research Hospital, Managed Care Department
Summary metric	Decrease the number of uninsured patients at St. Jude
	 Contract with vendor to provide Certified Application Counselor services to assist families applying for health insurance coverage through the Federally-facilitated Marketplace Apply for a grant from the Tennessee Hospital Association to assist with enrollment processes Design and implement a system to facilitate the CAC enrollment assistance process at St. Jude Identify uninsured patients and families and have CACs assist in the enrollment process An agreement was executed with FirstSource Solutions USA, LLC dba MedAssist, effective 9/9/13. This vendor assists patients in enrolling in a health plan via the Health Insurance Marketplace when eligible.
Progress on action items to meet identified health need	St. Jude Children's Research Hospital received a \$28,000 grant from the Tennessee Hospital Association, effective 11/5/13 to assist with these new enrollment processes. One hundred percent of uninsured patients and their families are referred to MedAssist personnel for evaluation via a daily report generated by registration records. In the event that they are deemed eligible, the patients and their families are given assistance with the enrollment process. This effort was initiated in FY14 and in that year 22 uninsured patients were enrolled in Medicaid or other health plans. This was an improvement over FY13 (11 patients converted to insured) and FY12 (15 patients converted to insured). While these numbers may look low as compared to a traditional hospital, it is excellent relative to our new patient population. In FY14, St. Jude accepted less than 900 new patients, and only 21% of the patient population was from the U.S. and uninsured, in other words potentially eligible for Medicaid or other coverage.

Aim #1 Imp	proving access to healthcare services
Pediatric health need	Palliative care
Health facilities/Resources involved	St. Jude Children's Research Hospital, Department of Oncology, Division of Quality of Life and Palliative Care
Summary metric	Increase the number of clinicians trained in Palliative Care Medicine (PCM) and educational opportunities for PCM
Progress on action items to meet identified health need	 Recruit and train two physician fellows in the newly formed Palliative Care Training Program The Palliative Care Training Program was successful in training physician fellows who also passed the board. Former trainees have also been successful in finding employment at St. Jude (three) and Le Bonheur (one). Provide training in Palliative Care for advanced practice health care personnel through targeted conferences and other educational opportunities. We have trained more than 200 total clinicians in our Quality of Life Seminar and our ELNEC 2-day seminar. This year we provided 25 local advanced topic presentations throughout St Jude. This is in addition to the Quality of Life Seminar and ELNEC. Create a required education series for bedside nurses involving End-of-Life Nursing Education Consortium (ELNEC) and an institution-specific Quality of Life seminar.

Pediatric health need	Health care of childhood cancer survivors
Health facilities/Resources involved	St. Jude Children's Research Hospital, Oncology Division, Cancer Survivorship Department
Summary metric	Provide cancer survivorship information to both caregivers and survivors via Survivors' Day Conference
Progress on action items to meet identified health need	 Provide workshops and speakers that offer information about available resources The St. Jude faculty provide lectures and participate in workshops related to a variety of survivorship issues. Audiences include health care providers of survivors, survivors and their families. Lectures/Workshops provided by Melissa M. Hudson

Aim #1 Improving access to healthcare services

- Heart health after cancer, Childhood Cancer Survivors Conference, University of Texas Southwestern Medical School, Dallas, TX, November 8, 2014
- Southwestern Medical School, Dallas, TX, November 8, 2014
 The spectrum of Cardiovascular Outcomes After Childhood Cancer Therapy, Pediatric Grand Rounds, Baystate Medical Center, Springfield, MA, February 16, 2016.
- Surviving Childhood Cancer, OSF St. Francis Medical Center, Peoria, IL, April 16, 2016 (keynote speaker)

Transition of Care, OSF. St. Francis Medical Center, Peoria IL, April 16, 2016

2. Give survivors and their families the opportunity to learn from other survivors

St. Jude hosts periodic celebrations of survivorship attended by survivors, families and friends. The event provides a forum to celebrate survivorship, educate attendees about health effects of childhood cancer and research progress in this area, and share information about health resources.

St. Jude Survivor Day Activities, September 7, 2013

- Survivor panel with Q & A about cancer experiences
- Google Hang-out discussion, Participants: Daniel Mulrooney, MD and Debbie Crom, PNP, PhD
 Topics: "Talking to your doctor about your unique health risks" and "The importance of staying
 healthy"
- Workshop, Presenter: Melissa Hudson, MD, "Skills for surviving after graduation from St. Jude"
- Workshop, Presenter: Cyrine Haidar, PharmD. "What medicine is right for me? It's all in the DNA!"

St. Jude Survivor Day Activities, September 6, 2014

"How does your hope grow? Adapting and changing with the seasons of survivorship" and "Practical Tools for Successful Survivorship" Moderators: Melissa Hudson, MD, Marriah Mabe, LCSW, James Klosky, PhD, Denise Williams, LCSW, Daniel Mulrooney, MD, Mary Keathley

- 3. Ensure that survivors understand how to approach healthcare post-treatment
 - Survivors and their families attending the After Completion of
- 4. Offer an online resource following the conference for continuous flow of survivorship information

Periodic brief publications feature survivor stories and educational topics:

- Long-Term Follow-Up Newsletters and Briefs (available at https://ltfu.stjude.org/) are published on a quarterly basis.
- LifeLine Newsletters (available at https://www.stjude.org/treatment/survivorship/participate-in-st-jude-life-study/lifeline-newsletter.html) are published semiannually.
- Other survivorship resources are available at: https://www.stjude.org/treatment/survivorship/participate-in-st-jude-life-study/handouts.html

Aim #1 Impr	oving access to healthcare services
Pediatric health need	Community education
Health facilities/Resources involved	St. Jude Children's Research Hospital, Communications and Public Relations Department
Summary metric	Use urban radio and social media to provide information and education about health care resources and health care careers
Progress on action items to meet identified health need	Offer radio station producers St. Jude professionals that can provide listeners details about community resources available for learning about and being tested for disorders/diseases such as sickle cell trait and HIV
	Use this platform to dispel myths and misconceptions about these two diseases and childhood cancer
	Promise is mailed to about 220,000 readers, which include donors, employees, peer institutions, CEOs of Fortune 500 companies, select media and individuals who subscribe through our online subscription form. All the articles appear online, where they have an even wider readership. We have two sickle cell articles planned for the winter 2016 issue.

Aim #1 Improving access to healthcare services

Social Media

January

- A mild #flu season? "Indicators at this stage are that we're not in for a big year" says Dr Webby to
 @business http://ow.ly/WOLZ0
- What makes a pandemic #flu virus? This answer likely to help officials spot, control emerging pandemic viruses @PNAS http://ow.ly/Xw714

February

- St Jude enhances its #sicklecell program to look beyond symptom relief to cure. Learn more http://ow.ly/Y8Tf5
- Dr Jackson, first African-American doctor at St Jude, talks about #sicklecell, integration in #Memphis in 1960s http://ow.ly/YtWhy #BHM
- We're holding 1st Science Scholars of Tomorrow for high school students #StJudeSSOT http://ow.ly/YxIRK
- High school students get glimpse inside St Jude at Science Scholars of Tomorrow #StJudeSSOT http://ow.ly/YxIRK
- A new #sicklecell program will help scientists gain insights into the disease http://ow.ly/YlguH
- 70+ high school students starting their days behind scenes at St Jude learning about our #science #stjudessot
- St Jude president, CEO Dr Downing talks about creating next generation of scientific, clinical leaders #StJudeSSOT
- St Jude translates #research findings into clinical trials and treatments, says Dr Dyer at #StJudeSSOT
- Peering into the microscopic world of #cells #StJudeSSOT
- St Jude Science Scholars of Tomorrow students gather behind the scenes of surgery #StJudeSSOT
- #StJudeSSOT students experienced spectrum of science, medicine taking place the hospital http://ow.ly/YxIRK
- We gave high school students an inside look at St Jude. Read about it:
 @WMCActionNews5 http://ow.ly/YOvcp #StJudeSSOT
- It's only 1% of all #cancer, yet #childhoodcancer is leading cause of death by disease for U.S. kids over age 1 #RareDiseaseDay

March

- St Jude hosted high school students for inaugural #Science Scholars of Tomorrow. See the photos: http://ow.ly/Z085T #StJudeSSOT #STEM
- St Jude helps teen #sicklecell patients transition to adult care. Watch to learn more: outube.com/watch?v=bEYqP8iZ8TE&index=1&list=PL4345C116C9A94457 ... #mondaymotivation

April

- Voices project helps young #HIV #AIDS patients anonymously share fears, hopes, advice in audio recordings http://ow.ly/10sFRq #NYHAAD
- T11 cancer resources: http://ow.ly/4mRRZU #abcdrbchat
- Your DNA is what makes you, you. #DNADay16 #research @TNDNADay @DNAday

Aim #2 Im	proving coordination of care
Pediatric health need	Transition of patients from pediatric to adult health care services
Health facilities/Resources involved	St. Jude Children's Research Hospital, Department of Hematology, Clinical Hematology Division Diggs-Kraus Sickle Cell Center at Regional One Health Methodist Healthcare Comprehensive Sickle Cell Center (MCSCC)
Summary metric	Increase the number of patients with sickle cell disease (SCD) who establish sustained adult care after leaving pediatric care at St. Jude
Progress on action items to meet identified health need	Starting at the age of 12 the plan of care visits start to focus on planning and programming for transition. The initiatives in the plan of care that targets transition are as follows: Quarterly transition tours that are offered to our 17 and 18 year old young adults; Transition readiness multidisciplinary team meeting monthly to discuss readiness of the 17 year old based on medical stability, psychosocial, emotional and academic status. We've also implemented a Skills Lab that is in the Pilot stage, where we are teaching them how to order medication refills, how to identify the medication based on the description written on the bottle, how to schedule doctor's appointments by way of role modeling. They are also learning how to read their health insurance card and identify important phone numbers that will give them access to their benefits. At the age of 15, we start seeing the patient without the parent. The parent is asked to remain in the waiting area. At the age of 15 the adolescent completes a Personal Health Record in an effort to prepare them for completing necessary documentations after leaving the pediatric setting. In addition, the "Sickle Cell Transition E-Learning Program (STEP) for Teens with Sickle Cell Disease", a web-based education program, was developed to provide adolescents and young adults sickle cell education to help prepare them for transition. https://www.stjude.org/treatment/disease/sickle-cell-disease/step-program.html 1. Identification of possible adult medical homes for St. Jude young adult patients with pediatric hematologic conditions We have identified two Sickle Cell Centers here in Memphis where young adults with SCD transfer to post pediatric care. Diggs-Kraus Sickle Cell Center located at 880 Madison Ave. and Methodist Healthcare Comprehensive Sickle Cell Center located at 1325 Eastmoreland.
	 Create Adolescent and Young Adults (AYA) transition clinics with overlap of pediatric and adult Hem/Onc care Create formal programming and planning processes for adolescents with hematologic and oncologic diseases, through development of disease educational curriculum and training modules to foster increased adolescent autonomy and medicalliteracy Each young adult patient has an individualized plan of care. The frequency of their visit is determined by whether they are on medication therapy like Hydroyxurea or if they are receiving chronic transfusion therapy. If the young adult is not receiving therapy, they are scheduled for follow up visits every four months during the first year and every six months thereafter.

hild knowledge of cancer prevention, nutrition, obesity, and hysical activity
Jude Children's Research Hospital, International Outreach Program (IOP)
crease the number of students and teachers participatingin St. Jude cancer and ealthy living education program
crease the knowledge that children have on cancer and healthy living topics (nutrition, kercise, sun protection, avoiding tobacco) ith pre and post quizzes
nprove attitudes of children toward healthy living practices (avoiding smoking, better utrition habits, more exercise, avoiding excessive sun) using surveyinstruments
ne program that is responsible for addressing the action items below has gone through a cansition. St. Jude has recently completed its strategic plan for the next five years which also cludes an expansion of the IOP and a new leader of the program. Under the new leader, a formal rategic planning process will be initiated during FY16 to define the overall vision for the program and the specific goals and objectives for the ensuing five years. Action item two has been addressed and action items one, three and four will be updated based on the new direction of IOP.
 Assess internal and external community resources for educational material on cancer and healthy living topics tailored to the age-specific needs of children in pre-k, elementary, middle and high school. Review current St. Jude created content to schools using teacher lesson plans, teacher training workshops, and school visits
The St. Jude Cancer Education for Children Program is a school-based outreach program that uses education and positive reinforcement to help promote healthy lifestyle choices and to reduce a child's lifetime risk of developing cancer. The program's educational objectives are to (a) educate elementary school children about cancer and dispel common misconceptions, (b) educate about and promote healthy lifestyle choices that can help children reduce their risk of cancer in adulthood, and (c) inspire an interest in science and scientific careers. It specifically addresses obesity, nutrition, smoking, and sun exposure, important issues in promoting childhood health and primary cancer prevention. The program development is overseen by a multidisciplinary team composed of St. Jude faculty and staff, local educators, and local health experts who work together to ensure that the content achieves the goals of the program while aligning to state and national education standards. The school outreach team also engages K-12 educators in the program by attending local teacher professional development conferences to provided training and materials related to cancer education (Table 1).
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Aim #3 Improving child health status through behavioral modification

 Table 1: The Number of Teachers and Students who participated in Educational Programs

School Year	Number of Teachers	Number of Students
2012-2013	65	1014
2013-2014	143	990
2014-2015	245	1621
2015-2016	140	1912

Two manuscript were published as a result of the school outreach program:

Ayers, K., Villalobos, A., Li, Z., Krasin, M. (2014). *The St. Jude Cancer Education for Children Program Pilot Study: Determining the Knowledge Acquisition and Retention of 4th-Grade Students*. Journal of Cancer Education

Ayers, K., Li, Z., Villalobos, A., Quintana, Y. & Klosky, J. (2016) The St. Jude Cancer Education for Children Program Pilot Study: The Impact of a Teacher-led Intervention on Student Knowledge Gains. Journal of Cancer Education, DOI: 10.1007/s13187-016-1010-9.

During the 2014-2015 school year, the school outreach team worked with 21 educators from 18 schools

3. Evaluate participation in health fairs and public venues to disseminate educational material and assess utility in meeting needs of the community and utilizing expertise at St. Jude.

Create an educational kiosk for the Children's Museum of Memphis