

2022

# COMMUNITY HEALTH NEEDS ASSESSMENT



# ST. JUDE CHILDREN'S RESEARCH HOSPITAL 2022 COMMUNITY HEALTH NEEDS ASSESSMENT

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## **EXECUTIVE SUMMARY**

St. Jude Children's Research Hospital (St. Jude) is a specialty hospital located in Memphis, TN that is focused on research and treatment of pediatric patients with catastrophic diseases, with a focus on cancer, blood disorders, infectious diseases, and neurological disorders. Patients at St. Jude are referred by a physician, receive a diagnosis of a disease currently under study, and generally are eligible for a research protocol. St. Jude is the only pediatric research center for children with catastrophic diseases, including cancer, blood disorders, infectious diseases, and neurological disorders where families never pay for treatment not covered by insurance. No child is ever denied treatment due to race, color, creed, disability, national origin, sex, religion, sexual orientation or preference, or the family's ability to pay.

The community served by St. Jude can best be defined by the St. Jude patient population and scope of clinical services. St. Jude serves as a national referral center for children with catastrophic diseases, such as cancer and neurological disorders, as well as a local referral center for children with cancer, blood disorders, and HIV/AIDS. It does not admit children for any diagnoses outside of these areas and does not offer medical services beyond those necessary to care for children with these diseases.

St. Jude defines its service area as Memphis and the surrounding area, which includes communities in five additional states (Alabama, Arkansas, Kentucky, Mississippi, and Missouri). In addition, St. Jude has a network of eight affiliated pediatric hematology/oncology clinics in the United States (U.S.) that expands the St. Jude market area to cover 15 states. St. Jude also operates St. Jude Global, a program committed to ensuring that every child with cancer and other catastrophic diseases will have access to quality care and treatment no matter where in the world they live.

The purpose of this community health needs assessment (CHNA) is to provide a foundation for future data-driven health planning and review progress in community benefit priorities identified in the 2019 CHNA. These purposes were identified to meet the requirement of the IRS Schedule H/Form 990 mandate.

The CHNA process and methods included:

- Engaging an advisory committee of St. Jude employees
- 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
- Reviewing current community benefit efforts
- Prioritizing needs to be addressed by community benefit initiatives

The 2022 CHNA builds upon the 2019 CHNA and reflects the activities identified in the 2019 Community Benefit Implementation Plan for St. Jude. The 2022 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.

It is important to note that when this CHNA process took place COVID-19 was and remains a primary health concern for communities, exacerbating underlying inequities and social needs. The pandemic brought to light both the capabilities and gaps in the healthcare system, the public health infrastructure, and social service networks. In this context, an assessment of the community's strengths and needs, and in particular the social determinants of health, is both critically important and logistically challenging.



To develop a social, economic, and health portrait of the community served by St. Jude, HRiA reviewed existing data drawn from St. Jude, local, state, and national sources. In addition to analyzing quantitative data, HRiA conducted qualitative research with internal and external St. Jude stakeholders as well as family members and former patients to supplement quantitative findings with perceptions of community strengths and assets, priority health concerns, and suggestions for future programming and services. The qualitative research was crucial to understanding the ongoing impacts of COVID-19 on the community since quantitative data was not yet available.

# **Key Findings**

The following provides a brief overview of key findings that emerged from this assessment. For the purposes of this report, the focus remained on the community of patients served by St. Jude and the geographic community of Memphis/Shelby County where St. Jude is located.

## Health Issues of New St. Jude Patients

Over the last three fiscal years (FY2019-FY2021) there were 2,637 new patients at St. Jude and its affiliate clinics. Just over half (52.8%) of new St. Jude patients in the last three fiscal years came from Shelby County and the surrounding Memphis area. The majority of new St. Jude patients in FY2019-FY2021 have a primary diagnosis of childhood cancer (61.3%), followed by hematological disorders (20.1%), sickle cell disease (6.0%), and HIV (3.2%). The health issues of new St. Jude patients (FY2019-FY2021) are described below.

## **Cancer Care**

- Among new St. Jude patients (FY2019-FY2021), cancers of the brain and other nervous system (32.0%) was the most prevalent primary cancer diagnosis, followed by leukemia (25.3%) and lymphoma (9.5%).
- In 2018, the national rate of new pediatric cancer cases was highest among White children (21.2 cases per 100,000 children), followed by Hispanic or Latino (19.5 cases per 100,000 children) and Asian and Pacific Islander (19.5 cases per 100,000 children) children.
- Almost two-thirds of new St. Jude patients (FY2019-FY2021) with a primary diagnosis of cancer identify as White, Non-Hispanic (64.9%), followed by Black, Non-Hispanic (20.2%).

## Sickle Cell Disease and Other Hematological Disorders

- In the last three fiscal years (FY2019-FY2021) there were 158 new St. Jude patients with a primary diagnosis of sickle cell disease. About half are male (53.2%), over three-quarters of new patients were under 2 years of age (76.6%), and nearly all new patients identified as Black (96.2%).
- Hematological disorders made up the highest proportion of primary diagnosis for new St. Jude patients from Shelby County (35.4%) and the surrounding Memphis area (35.5%).
- Nearly a third of new patients with hematological disorders are younger than 2 years of age (31.4%). Just about half of new patients identify as Black, Non-Hispanic (46.5%), followed by White, Non-Hispanic (45.4%).

## **HIV/AIDS**

In 2019 the rate of new HIV cases in Shelby County (28.2 cases per 100,000 residents) is more than double the state of Tennessee (11.4 cases per 100,000 residents). In Shelby County (41.1 cases per 100,000) and the state of Tennessee (35.6 cases per 100,000)



- residents who identify as Black have the highest HIV incidence rate of any other racial/ethnic group.
- The majority of new St. Jude patients with a primary diagnosis of HIV/AIDs are male (82.4%),15 to less than 20 years of age (63.5%) and identify as Black (91.8%).

## Mental Health

- All internal interview and focus group participants frequently noted that the resources that St. Jude provides for families is immensely helpful, but there remains a need for additional mental health resources in the broader Memphis community.
- Families coming to St. Jude experience the impact of stressful circumstances, including stressors related to the diagnosis for their child and the implications of leaving their homes and families to care for a child with cancer.
- The needs surrounding mental health existed prior to the pandemic, but the need to address the mental health of patients and their families increased substantially since the pandemic. The restrictions necessary for the health of patients during the height of COVID-19, also increased feelings of isolation among patients and their families.

## **Transitions of Care**

- Internal interview participants highlighted some of the programs and resources that St. Jude has for specific patient populations to proactively address the challenges with transitioning care such as, the Transition Oncology Program (TOP), and programs within the sickle cell and HIV programs.
- According to internal participants, the transition of care either after treatment or when patients age into adulthood is challenging.
- When patients are at St. Jude, they receive strong specialty care, and patients and their families never receive a bill for health care provided at St. Jude.
  - It can be challenging or impossible to receive the same level of care when transitioning to home in specialties such as neurology, reproductive health, orthopedic care, endocrinology, mental health, and care related to cognitive abilities, especially in rural areas far from Memphis and academic medical centers.
  - When patients transition out of St. Jude, they return to a health care system with copays and coinsurance, and other complex payment structures. According to participants, navigating this process and understanding what insurance does and does not cover can be a challenge.

## Health Issues in Memphis/Shelby County

Interview and focus group participants identified several community health concerns for children, ranging from trauma and violence in the community; to access to healthy food and childhood obesity; to mental health care access; to chronic conditions or risk factors for chronic conditions, such as heart disease, diabetes, HIV, and HPV. All participants interviewed perceived St. Jude to be an anchor and have a strong presence in the Memphis community and could play a role in helping to address social determinants of health and health care access as described below.

#### Poverty

• Approximately one-quarter (25.7%) of children in Shelby County live in households with incomes at or below the federal poverty level, which exceeds the percent of children living in poverty in Tennessee (19.4%) and across the US (17.0%).



• Internal and external interview participants identified that the root of many of the health issues in the community is childhood poverty. One internal participant emphasized, "Poverty is one of our biggest factors."

#### Education

- In 2019-2020, 79.3% of Shelby County public high school students graduated within four years, which is notably lower than percent of public high school students graduating in four years across Tennessee (89.7%).
- The percent of youth who are disconnected (meaning they are neither working nor in school) is higher in Shelby County (16.8%) than across Tennessee (12.6%).

# Food Insecurity

• In 2019, one in five (19.8%) children in Shelby County were food insecure, which is 26% higher than the prevalence of food insecurity for children across Tennessee.

# **Racial Disparities**

 Across Tennessee, the childhood mortality rate is highest for Black children, and increased by 23% from 2015 (91.0 deaths per 100,000 children) to 2019 (112.3 deaths per 100,000 children).

## Mental Health

- Like the patients in the St. Jude community, participants viewed families especially children and youth as being in particularly high need of access to mental and behavioral health services.
- There are fewer mental health providers per capita in Shelby County compared to the US. The ratio of Shelby County residents to mental health providers (669 residents per provider) is 6% higher than that for Tennessee (634 residents per provider) and 76% higher than the national average (380 residents per provider).
- In 2019, prior to the impacts of COVID-19, across the US (36.7%), Tennessee (37.5%), and Shelby County (36.2%), over one-third of students report experiencing persistent sadness. Approximately one in five students in the US (18.8%), Tennessee (19.2%), and Shelby County (20.7%) report seriously considering a suicide attempt.

## Chronic Disease

- About one in five students in Shelby County (19.2%) are classified as having obesity, and another one in five students in Shelby County (18.2%) are classified as being overweight, which are both higher than the national average.
- Among Tennessee students, the most prevalent chronic health conditions are asthma (25.1%) and ADD/ADHD (25.4%), with approximately one-quarter of students having either of these conditions.

## **HPV Vaccination**

- Across the United States 58.6% of youth 13-17 years of age have received all recommended doses of the HPV vaccine in 2020.
  - In the United States and in the St. Jude market area, the percent of youth up to date on their HPV vaccination increased from 2018 to 2020.
  - The state of Tennessee (52.9%) is behind the United States overall (58.6%) in youth up to date on their HPV vaccine
- Internal and external interview participants shared they had observed a decrease in childhood vaccinations being on time during the pandemic.



## **Priority Areas of Need**

In April 2022, the St. Jude CHNA Advisory Council met to review CHNA findings and discuss priority areas for future community benefit programs and services to supplement the medical research and financial assistance community benefit activities that St. Jude already provides. In reflecting upon the success of the current St. Jude community benefit activities, the Advisory Council and Steering Committee chose to build on the prior community benefit activities and data presented in the assessment to develop more targeted aims that continue to align with the mission of St. Jude – to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment.

The Advisory Council discussed the various communities that St. Jude serves and the target population of the aims. The community of St. Jude can best be defined by the St. Jude patient population (target population) and scope of clinical services (principal function), and the geographic community of the Memphis/Shelby County area where St. Jude is located. Not all aims are meant to address all layers of the St. Jude community.

AIM 1: Improving access to mental health supports and services in the community, beyond those related to patient diagnosis and treatment.

AIM 2: Improving access to providers, resources, and coordinated care during the transition of care from St. Jude and its affiliates to community and/or adult care.

AIM 3: Improving access and equity to clinical trials at St. Jude and its Affiliates.

AIM 4: Conducting cancer prevention work through education and HPV vaccination.

AIM 5: Increasing awareness and education of sickle cell disease and infectious diseases (HIV/AIDS) in the community.

AIM 6: Strengthen community partnerships in the greater Memphis area to address social determinants of health for local patients.

Cutting across all of these aims is the commitment to address equity and to identify opportunities for collaboration. Given its focused mission and model of providing specialized services to children in crisis, St. Jude does not have the capacity or resources to meet all needs of all children and their families. However, strategic partnerships with other healthcare providers and with schools and community-based organizations allow St. Jude to create a network of resources that can be leveraged to meet the health and social needs of a wider community of patients and their families.



## BACKGROUND

St. Jude Children's Research Hospital (St. Jude) is a research hospital located in Memphis, TN that is focused on research and treatment of pediatric patients with catastrophic diseases. Since St. Jude opened in 1962, advancements in treatment and cures have been made across a number of diseases including childhood leukemia and sickle cell disease.

St. Jude was also the first fully racially integrated children's hospital in the South, and the first and only National Cancer Institute—designated Comprehensive Cancer Center dedicated solely to children.

## Mission, Values, and Vision

The mission of St. Jude is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment. Consistent with the vision of the founder, Danny Thomas, no child is denied treatment based on race, religion, or a family's ability to pay.

The values are an integral part of the St. Jude identity and guide its daily actions and decisions. The incorporation of these values directly impacts the organization's ability to make progress towards achieving the mission of St. Jude. The seven core values that guide St. Jude are:

- 1. Always recognize that advancing treatment for children with catastrophic diseases is at the center of everything we do.
- 2. Do what is right; take ownership of what you do.
- 3. Work with purpose and urgency your efforts matter.
- 4. Embrace the challenge to create a new tomorrow.
- 5. Work collaboratively and help others succeed.
- 6. Always be respectful of your coworkers, our patients and their families, and visitors to our campus.
- 7. Make the most of St. Jude resources and be mindful of those who provided them.

The vision of St. Jude is to accelerate progress for children with catastrophic diseases on a global scale. The current FY22–27 St. Jude strategic plan lays out a vision and charts a road map to live up to the mission of St. Jude through concentrating on fundamental science, childhood cancer, pediatric catastrophic diseases, global impact, and workforce and environment.

## **Facilities Description**

St. Jude is a research-based specialty hospital that treats pediatric catastrophic diseases, with a focus on cancer, blood disorders, infectious diseases, and neurological disorders. Patients at St. Jude are referred by a physician, receive a diagnosis of a disease currently under study, and generally are eligible for a research protocol. St. Jude is the only pediatric research center for children with catastrophic diseases, including cancer, blood disorders, infectious diseases, and neurological disorders where families never pay for treatment not covered by insurance. Transportation, housing, and food are among the services St. Jude provides to ensure that families who come to St. Jude can focus on their child. No child is ever denied treatment due to race, color, creed, disability, national origin, sex, religion, sexual orientation or preference, or the family's ability to pay.

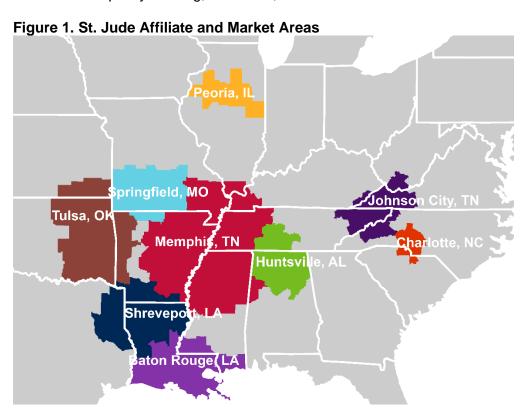
Through this care model, St. Jude provided services for more than 6,400 patients in FY2021. The main campus in Memphis has 73 operational and staffed hospital beds, multiple outpatient clinics, and a full set of ancillary and diagnostic services. The campus includes a cafeteria, on-



site school, and numerous psychosocial-based services to assist children and families. Outpatients traveling to Memphis to receive care may stay in one of the housing facilities; more than 250 rooms are either owned and operated or contracted by St. Jude, to be used specifically for families of children with catastrophic diseases.

# Geographic Areas of Service

St. Jude has a network of eight affiliated pediatric hematology/oncology clinics in the U.S., allowing it to extend care and benefits to more children and increase the number of children treated on St. Jude clinical trials (Figure 1). St. Jude and the network of affiliates cover a market area of 15 states. St. Jude also operates St. Jude Global, a program committed to ensuring that every child with cancer and other catastrophic diseases will have access to quality care and treatment no matter where in the world they live. In an effort to reduce disparities in access to care, St. Jude Global supports advancement of care through the development of comprehensive initiatives in capacity building, education, and research.



# St. Jude and Affiliate Market Areas

Because of the uniqueness of its services and its eight affiliates (Peoria, IL; Springfield, MO; Shreveport, LA; Baton Rouge, LA; Huntsville, AL; Charlotte, NC; Johnson City, TN; Tulsa, OK), St. Jude has concentric service areas. The clinical affiliate sites provide access to St. Jude clinical protocols and standards of care for patients close to home. St. Jude also defines its service area as Memphis and 145 neighboring counties in the states of Alabama, Arkansas, Kentucky, Missouri, Mississippi, and Tennessee. Beyond the Surrounding Memphis Area is an Affiliate Market Area of 15 states. The remaining areas of the United States make up the National Market Area.



# **Purpose**

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

- Engaging an advisory committee of St. Jude employees
- 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
- Reviewing current community benefit efforts
- Prioritizing needs to be addressed by community benefit initiatives

The 2022 CHNA builds upon the 2019 CHNA and reflects the activities identified in the 2019 Community Benefit Implementation Plan for St. Jude. The 2022 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.

## Context of COVID-19

It is important to note that when this CHNA process took place COVID-19 was and remains a primary health concern for communities, exacerbating underlying inequities and social needs. The pandemic brought to light both the capabilities and gaps in the healthcare system, the public health infrastructure, and social service networks. In this context, an assessment of the community's strengths and needs, and in particular the social determinants of health, is both critically important and logistically challenging. The impacts of COVID-19 were also present within St. Jude as emergency operation procedures were used at the beginning of the pandemic in March 2020 and protocols and practices were adapted to continue to meet the needs and safety of patients, their families, and the staff of St. Jude.

# **GEOGRAPHY/COMMUNITY SERVED**

## **Definition of Community Served**

Per the IRS 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)

The community served by St. Jude can best be defined by the St. Jude patient population and scope of clinical services. St. Jude serves as a national referral center for children with catastrophic diseases, such as cancer and neurological disorders, as well as a local referral center for children with cancer, blood disorders, and HIV/AIDS. It does not admit children for any diagnoses outside of these areas and does not offer medical services beyond those necessary to care for children with these diseases.

St. Jude was described by interview participants as playing an important role in pediatric cancer treatment and research, as a resource for patients and families dealing with a catastrophic illness diagnosis, and as a leader of and major employer for the local Memphis community. For the purpose of this report, the focus is the community of patients served by St. Jude and the geographic community of the Memphis/Shelby County area where St. Jude is located.



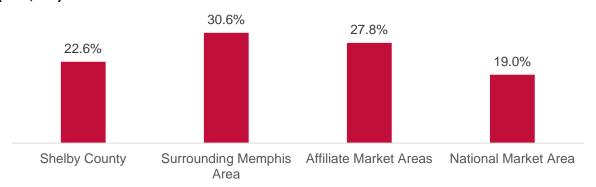
## Clinical Services Area

The primary clinical effort at St. Jude centers on providing ground-breaking, research-driven treatments. Although the dominant focus of St. Jude is the treatment of pediatric cancer, it also serves as the primary hematology hospital for patients in the Greater Memphis area, with the largest program focused on the treatment of sickle cell disease. St. Jude also accepts pediatric patients with pediatric neurological disorders and infectious diseases, including HIV/AIDS. St. Jude serves as the area's primary provider for infants, children, and adolescents with HIV. For the purposes of this report, the focus is limited to those diseases for which children are admitted to St. Jude for treatment and the geographic community of the Memphis/Shelby County area where St. Jude is located.

# St. Jude Patient Population Geography of New Patients

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. Over the last three fiscal years (FY2019-FY2021) there were 2,637 new patients at St. Jude and its affiliate clinics. As Figure 2 demonstrates, just over half (52.8%) of new St. Jude patients in the last three fiscal years came from Shelby County and the surrounding Memphis area, with approximately one-quarter (27.8%) from affiliate market areas, and about one-fifth (19.0%) of new patients from the national market area.

Figure 2. New St. Jude Patients, United States only, by Geographic Area, FY2019-FY2021 (N=2,637)

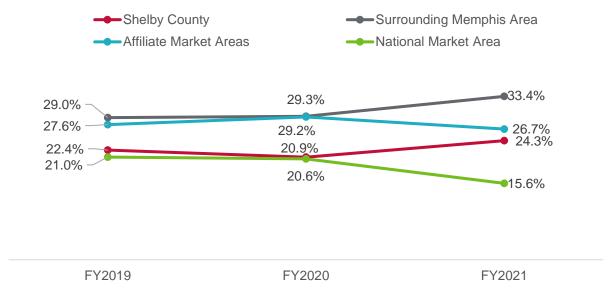


DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Surrounding Memphis Area excludes Shelby County; Affiliate Market Area excludes Surrounding Memphis Area and Shelby County

Over the last three fiscal years, there was a slight increase in the percent of new St. Jude patients from the surrounding Memphis area (29.0% in FY2019 to 33.4% in FY2021) and Shelby County (22.4% in FY2019 to 24.3% in FY2021) (Figure 3). The percent of new St. Jude patients coming from the national market area declined from 21.0% in FY2019 to 15.6% in FY2021, while the proportion of new patients from affiliate markets fluctuated from a high of 29.2% in FY2020 to a low of 26.7% in FY2021. This shift is attributed to the shutdown of national travel during the pandemic (starting in March 2020) and limitations on travel from the affiliate areas.



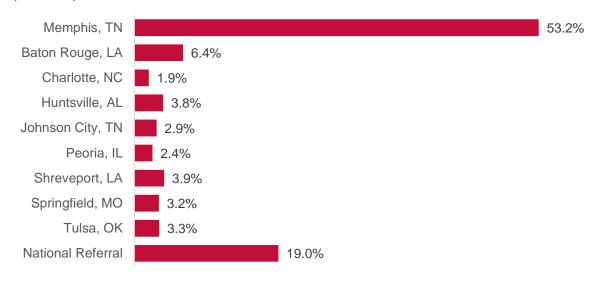
Figure 3. New St. Jude Patients, United States only, by Geographic Area and Year, FY2019-FY2021 (N=2,637)



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Surrounding Memphis Area excludes Shelby County; Affiliate Market Area excludes Surrounding Memphis Area and Shelby County

When examining the referral areas of new St. Jude patients in FY2019-FY2021, more than half (53.2%) reside in Memphis and the surrounding area (Figure 4). Approximately 21% of new patients come from one of the eight affiliates, with the Baton Rouge affiliate having the single largest percent, 6.4% of new patients. Nearly one-fifth (19.0%) came to the hospital from the national referral market, an area of the United States not covered by a St. Jude affiliate.

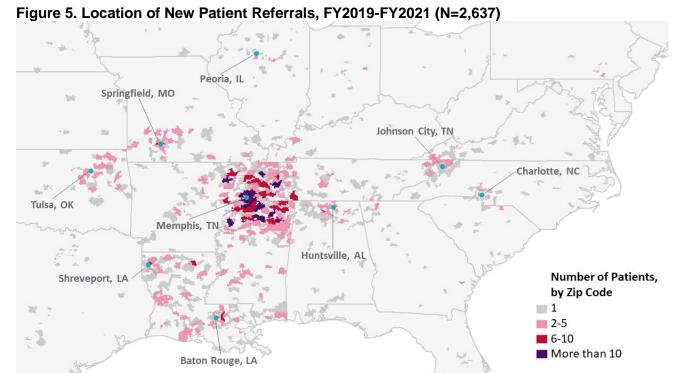
Figure 4. New St. Jude Patients, United States only, by Affiliate Area, FY2019-FY2021 (N=2,637)



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Memphis, TN includes Shelby County and the surrounding Memphis area



As shown in Figure 5, new patient referrals to St. Jude and its affiliate clinics were clustered around the geographic location of St. Jude and clinic sites. The highest density of new patients in singular zip codes (more than 10 new patients from that zip code) were all from the surrounding Memphis area and Shelby County. The reach of St. Jude extends across the nation which requires travel to Memphis, TN for patients residing outside of an affiliate market area.



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Not all 2,637 new U.S. patients home zip codes are shown on this limited map of the United States.

## Demographics of New St. Jude Patients

As illustrated in Figure 6, just over half (54.3%) of new St. Jude patients in FY2019-FY2021 are male. The age of new patients spread evenly over the age group up to age 20, with approximately one in five new patients coming from each of the age groups. Only 3.2% of new patients are 20 years and older. Approximately half (54.3%) of new patients identify as White, followed by one-third (33.9%) who identify as Black, and about one in ten (11.3%) who identify as Hispanic or Latino of any race.



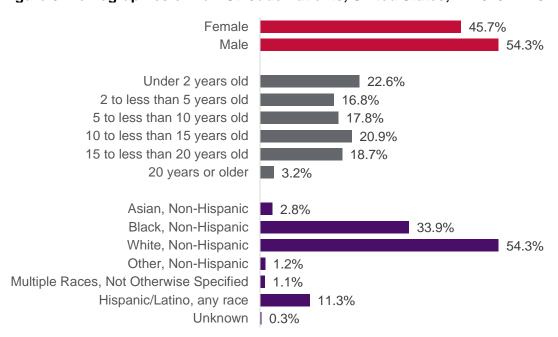


Figure 6. Demographics of New St. Jude Patients, United States, FY2019-FY2021 (N=2,637)

DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Respondents could select multiple race/ethnicity options, therefore, percentages may not add up to 100%; Other, non-Hispanic includes American Indian/Alaskan Native and Other race. Patients with known race but unspecified ethnicity were categorized as their respective race and assumed to be non-Hispanic (including 16 Black, 10 White, 1 Other). Non-Hispanic patients with unknown race were categorized as Unknown.

## St. Jude Community

When describing the St. Jude community, focus group and interview participants repeatedly spoke about the welcoming atmosphere cultivated by St. Jude staff and other patients. One Patient Family Advisory Council (PFAC) focus group participant shared, "St. Jude is like a microcosm of the way the world should be – we are all going through something, we are all kind and helpful to each other – not in a pushy way, it is all about the kids – it is really important, and a lot of people could take cues from that."

Another PFAC focus group participant characterized St. Jude as being a leader in terms of learning about the experiences of and best practices to care for transgender patients and patients of varying gender identities and sexual orientations. This participant shared, "It is heartening to see the commitment of St. Jude [...] Like caring for transgender patients. That was like wow, the proactiveness is great – I don't see it happening in my community, but it inspires me to bring it back to my community." Some internal participants also noted that St. Jude works with patients to ensure that staff can meet their needs related to religious preferences and dietary preferences and takes other steps to promote inclusion. Internal participants also described a large number of international patients on the St. Jude campus but perceived a smaller number of international patients since the pandemic.

Service providers familiar with the St. Jude community described the St. Jude patient and family population as one that is engaged from the moment they arrive on campus and always willing to participate in research and various activities in the hospital. Internal participants familiar with the



experience of St. Jude patients repeatedly noted St. Jude's philosophy of "once a patient, always a patient."

Internal interview participants frequently highlighted parents' intense commitment to their children. While they pointed out that this commitment is not unique to the parents at St. Jude, they did note that because many families need to travel to receive care at St. Jude, the impact on the family's dynamic – both financially and emotionally – can be particularly taxing. One internal participant highlighted the significant time-sensitive sacrifice and strength of St. Jude patients and families, "The resiliency, of course. Finding out your child has a catastrophic [diagnosis] on Tuesday, going to St. Jude on Tuesday evening, and starting chemo on Wednesday takes a lot."

According to internal interview participants, St. Jude staff partner with a wide range of organizations to conduct outreach and education and are viewed as a leader in the community. These participants highlighted St. Jude partnerships with schools to deliver STEM-related education, which one participant noted "encourage[s] kids to think like scientists." Staff who work closely with schools described partnerships with schools as critical to being able to educate the community. Participants also noted that St. Jude outreach and education activities provide an opportunity to share about how St. Jude provides care to the community.

Several internal participants also felt a sense of pride in St. Jude's role communicating public health information during the pandemic, particularly because St. Jude does not always speak out on community wide issues. These participants noted that seeing St. Jude take a clear and public stance on masks, vaccines, and safe school transitions was a remarkable step.

Among parents of current and former patients of St. Jude, there was a consistent sentiment that the hospital exceeds the needs and expectations of patients and their families. Participants regularly mentioned that staff at St. Jude go "above and beyond" when providing care and meeting the needs of children and their families. Several parents, and service providers noted the importance of the many resources provided to families receiving care. Both internal and external participants cited the importance of families never receiving a bill for care while at St. Jude, and also highlighted the benefits of families accessing resources and services beyond specific illness-related needs. Interview and focus group participants identified important resources such as housing, food access, transportation, technology, and healthcare referrals for other family members.

# St. Jude and St. Jude Affiliate Market Area

St. Jude has a network of eight affiliated pediatric hematology/oncology clinics in the U.S., allowing it to extend care and benefits to more children and increase the number of children treated in St. Jude clinical trials. St. Jude and the network of affiliates cover a market area of 15 states. The following section highlights key demographic information across five states that refer to St. Jude in Memphis (Alabama, Arkansas, Mississippi, Missouri, and Tennessee), five additional states covered by affiliates (Illinois, Louisiana, North Carolina, Oklahoma, and South Carolina). as well as the United States.

# Population Demographics

In terms of the market area served by St. Jude and its affiliates (Table 1), the state populations have similar proportions of children under the age of 18 and see a range in racial and ethnic diversity. The percent of residents over five that speak a language other than English at home is much lower than the United States overall in all states except Illinois.



According to Census estimates the largest population growth from 2010 to 2020 was seen in South Carolina (10.7%), North Carolina (9.5%), and Tennessee (8.9%). Mississippi and Illinois were the only states to see a decline in their population over this time.

When looking at the racial/ethnic composition of states across the market area, Missouri (75.8%) and Tennessee (70.9%) have the largest populations of residents who identify as White, with approximately seven-tenths of residents identifying as White, which is above national estimates (57.8%). Mississippi, Louisiana, and Illinois have the largest populations of non-White residents. Black residents represent approximately one in three residents in Mississippi (36.4%) and Louisiana (31.2%). The largest population of Hispanic or Latino (18.2%) and Asian (5.8%) residents in affiliate states reside in Illinois.

According to Census estimates, approximately one in five (23.2%) Illinois residents 5 years of age and older speak a language other than English at home, similar to the average across the US (21.6%). Additionally, about one in ten residents in North Carolina (11.8%) and Oklahoma (10.5%) 5 years of age and older speak a language other than English at home.

Table 1. Selected Demographics for Affiliate States, by State and United States

able 1. Selected Demographics for Affiliate States, by State and United States											
	AL	AR	IL	LA	MS	MO	NC	OK	SC	TN	US
Total Population, 2020 (in millions)	5.02	3.01	12.81	4.66	2.96	6.15	10.44	3.96	5.12	6.91	331.4
Percent Change from 2010	5.1%	3.3%	-0.1%	2.7%	-0.2%	2.8%	9.5%	5.5%	10.7%	8.9%	7.4%
Under 18 years	22.5%	23.5%	22.6%	23.7%	23.9%	22.6%	22.4%	24.3%	22.0%	22.4%	22.6%
Asian, Non- Hispanic	1.5%	1.7%	5.8%	1.8%	1.1%	2.1%	3.3%	2.3%	1.7%	1.9%	5.9%
Black, Non- Hispanic	25.6%	14.9%	13.9%	31.2%	36.4%	11.3%	20.2%	7.2%	24.8%	15.7%	12.1%
Hispanic/ Latino	5.3%	8.5%	18.2%	6.9%	3.6%	4.9%	10.7%	11.9%	6.9%	6.9%	18.7%
White, Non- Hispanic	63.1%	68.5%	58.3%	55.8%	55.4%	75.8%	60.5%	60.8%	62.1%	70.9%	57.8%
Other Race/ Ethnicity, Non- Hispanic	4.5%	6.3%	3.7%	4.3%	3.6%	5.9%	5.4%	17.9%	4.5%	4.5%	5.5%
Aged 5+ Speak Language Other Than English at Home	5.3%	7.5%	23.2%	8.0%	4.0%	6.3%	11.8%	10.5%	7.2%	7.2%	21.6%

DATA SOURCE: U.S. Census Bureau, Decennial Census of Population and Housing, 2010 and 2020; U.S. Census Bureau, American Community Survey, 5-Year Estimates, 2015-2019

Presented in Table 2 are social and economic characteristics of residents in affiliate states that are within the St. Jude market area. Across the area, a higher percent of children are living in



poverty or extreme poverty compared to the United States overall except in Illinois. A similar trend is noted in the percent of children under 18 with a disability, all states have a higher percent than the United States overall with the exception of Illinois.

According to Census estimates, in the St. Jude market, high school is the highest level of educational attainment for more than three in ten adults in Arkansas (34.0%), Louisiana (34.0%), Tennessee (32.1%), Oklahoma (31.3%), Alabama (30.8%), Missouri (30.6%), and Mississippi (30.4%), which exceeds the national average (27.0%). Approximately one-third of Illinois (34.7%) and North Carolina (31.3%) adults have a bachelor's degree or higher, similar to the national average (32.1%).

In April 2020, the early phase of the COVID-19 pandemic, the unemployment rate in Illinois (16.5%), Tennessee (15.8%), and Mississippi (15.7%) exceeded the national (14.7%) unemployment rate, whereas Arkansas (10.0%) and South Carolina (11.5%) had unemployment rates noticeably below national patterns at the time. Reflecting national patterns (4.2%), in November 2021 the unemployment rate was substantially lower in states across the St. Jude market area, ranging from a low of 2.5% in Oklahoma to a high of 5.7% in Illinois.

With the exception of Illinois (16.0%) and Missouri (17.0%), states across the St. Jude market area have childhood poverty levels that exceed the US average (17.0%). The proportion of children living in poverty in 2020 is highest in Mississippi (28.0%) and Louisiana (27.0%), where more than one-quarter of children live in households at or below the federal poverty level. The percent of children living in extreme poverty (defined as income levels below 50% of the federal poverty level) is higher than the national average (7.0%) across the St. Jude market area, with the exception of Illinois (6.0%). Louisiana (13.0%), Mississippi (12.0%), and Alabama (10.0%) have the highest percent of children living in extreme poverty. Mississippi (28.3%) and Louisiana (27.5%) have the highest percent of children living in single-parent households.

Severe housing problems refer to residences with incomplete kitchen facilities, incomplete plumbing facilities, more than one person per room, and/or a cost burden greater than 50% of household income. Across the St. Jude market area, the percent of households classified as living in units with severe housing problems is below the average across the US (18.0%). Illinois (16.9%), Louisiana (15.8%), and Mississippi (15.4%) have the highest proportion of households living in housing units that are designated as having severe housing problems.

With the exception of Illinois (5.0%), each state in the St. Jude market area has a similar or higher percent of children with a disability relative to the US average (6.2%). Arkansas (8.5%) and Louisiana (8.3%) have the highest proportion of children with a disability.

The violent crime rate is highest in Tennessee (672.7 crimes per 100,000 residents), Arkansas (671.9 crimes per 100,000 residents), and Louisiana (639.4 crimes per 100,000 residents). Only Mississippi (291.2 crimes per 100,000 residents) has a violent crime rate below the national average (398.5 crimes per 100,000 residents).

In 2020, the percent of insured children ranges from a low of 92% in Oklahoma to a high of 97% in Alabama and Illinois.

Self-reported receipt of a preventive medical visit in the past year for children 0-17 is highest in South Carolina (80.1%) and Alabama (78.2%), whereas other states in the market area have a prevalence similar to or below the national average (77.5%). Notably, Missouri (72.5%) and



Louisiana (74.0%) have the lowest percent of children who reported receiving a preventive health care visit in the past year.

Table 2. Selected Social and Economic Factors for Affiliate States, by State and United States

	AL	AR	IL	LA	MS	MO	NC	OK	SC	TN	US
High School Graduate	30.8%	34.0%	26.0%	34.0%	30.4%	30.6%	25.7%	31.3%	29.1%	32.1%	27.0%
Bachelor's Degree or Higher	25.5%	23.0%	34.7%	24.1%	22.0%	29.2%	31.3%	25.5%	28.1%	27.3%	32.1%
Unemployment (April 2020)	13.2%	10.0%	16.5%	13.1%	15.7%	12.5%	13.5%	13.0%	11.5%	15.8%	14.7%
Unemployment (November 2021)	3.1%	3.4%	5.7%	5.1%	5.0%	3.5%	3.9%	2.5%	3.7%	4.0%	4.2%
Percent Children in Poverty	21.0%	22.0%	16.0%	27.0%	28.0%	17.0%	20.0%	20.0%	20.0%	19.4%	17.0%
Percent Children in Extreme Poverty	10.0%	9.0%	6.0%	13.0%	12.0%	8.0%	9.0%	9.0%	9.0%	8.0%	7.0%
Single Parent Households	25.2%	23.9%	21.2%	27.5%	28.3%	22.2%	22.9%	22.7%	24.7%	23.3%	21.3%
Severe Housing	13.9%	14.1%	16.9%	15.8%	15.4%	13.3%	15.1%	14.0%	14.5%	14.2%	18.0%
Under 18 with Disability	4.6%	5.8%	3.4%	5.6%	4.9%	4.7%	4.3%	4.9%	4.6%	4.8%	4.2%
Violent Crime Rate (per 100,000 population)	453.6	671.9	425.9	639.4	291.2	542.7	419.3	458.6	530.7	672.7	398.5
Percent Children Insured	96.8%	95.2%	96.9%	96.4%	95.0%	94.4%	95.0%	92.0%	95.3%	95.5%	94.9%
Preventative Medical Visit in the Past 12 Months (children 0-17)	78.2%	76.5%	77.2%	74.0%	75.0%	72.5%	75.8%	75.4%	80.1%	74.6%	77.5%

DATA SOURCE: U.S. Census Bureau, American Community Survey, 5-Year Estimates, 2015-2019; Bureau of Labor Statistics, 2020-2021; Comprehensive Housing Affordability Strategy (CHAS) data, 2019; Uniform Crime Reporting, Federal Bureau of Investigations, Uniform Crime Reports, 2020; County Health Rankings; National Survey of Children's Health, 2019-2020

NOTE: High school graduate and bachelor's degree or higher data are for population 25 years and over; Unemployment data shown are not seasonally adjusted; Data for children insured at time of survey and children receiving coordinated, ongoing, comprehensive care within a medical home defines children as 0-17 years.



# Memphis/Shelby County

# Community Perceptions of the Memphis Area

When describing the Memphis area, perceptions of interview and focus group participants (both external and internal) reflected the data. Participants described Memphis as one of the larger cities in Tennessee. Several of these participants also characterized Memphis as a more progressive city in a very conservative state. The Memphis area is described as a majority minority city, with mostly Black / African American residents and a perceived growing number Latino residents.

Internal and external interview participants also described the Greater Memphis area as a welcoming community. However, many of these participants also noted that some residents and visitors perceive Memphis to have a less than stellar reputation due to past events. These participants also described Memphis as a city that is particularly aware of its roots and is working to change how other cities and states view the city. One participant explained, "Memphis is a really misunderstood community that has a lot of culture, history, and potential." Another participant stated, "It's a city that is proud and is trying to reinvent itself. [There is a] sense of pride and passionate people. [There are] [a] lot of small businesses and stores and restaurants."

Many participants noted that the greater Memphis area is also a hardworking community with "grit and grind" embedded in how residents live. Further, participants perceived significant socioeconomic inequalities that create a "haves" and "have nots" divide in the community. One internal participant perceived a strong connection between the socioeconomic divide and race/ethnicity in the community: "[There is] segregation by socioeconomic status. We have some schools that are all Black and all below poverty line." When thinking about root causes and upstream factors that influence health, internal and external participants often described children living in poverty as the "root of the problem." These participants perceived this socioeconomic divide as having substantial impacts on everything from housing and employment to education and food access. For example, one internal participant highlighted how socioeconomic inequalities affect literacy: "The area is diverse racially and economically. The latter is extreme. [There is a] wide range of education levels, so the understanding of folks varies."

Frequently, internal and external participants characterized Memphis as a city with strong ties to the faith community. Many service providers interviewed noted the importance of connecting with the various local faith communities when conducting outreach and education.

Since the pandemic, many external service providers noted that their attention has shifted to devoting resources to improve access to food and vaccines and to providing up-to-date guidance on COVID-19-related measures (e.g., masks, COVID-19 safety in schools). Some of these service providers also mentioned an increased focus on Tennessee's most vulnerable populations including pregnant women, older adults, low-income residents, and communities of color.

## Population Demographics

The population in Memphis and Shelby County is slightly younger than the population across Tennessee and the United States (Figure 7). For example, approximately 27% of residents in Memphis and Shelby County are 19 years of age or younger, compared to approximately 25% of residents in Tennessee and across the United States. Likewise, about one-quarter of residents in Memphis and Shelby County are 55 years of age or older, compared to approximately 29% of residents across Tennessee and the United States.



Figure 7. Age Distribution, by United States, Tennessee, Shelby County, and Memphis, 2015-2019



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2015-2019

As shown in Figure 8, according to 2020 Census estimates, just over three in five (61.3%) residents in Memphis and approximately half (51.1%) of residents in Shelby County identify as Black, which is more than three times the percent of residents who identify as Black in Tennessee (15.7%) and four to five times that nationwide (12.1%). Nearly one in ten residents identify as Hispanic or Latino in Memphis (9.8%) and Shelby County (8.4%), which is slightly higher than for the State (6.9%) and approximately half of the proportion of the Latino population nationwide (18.7%). The percent of Asian residents in Shelby County (3.0%) is slightly higher than the percent in Memphis (1.8%) and Tennessee (1.9%), and below that for the United States (5.9%). While residents who identify as White comprise 70.9% of the Tennessee population, approximately one-third (34.1%) of Shelby County residents and nearly one-quarter (23.9%) of Memphis residents identify as White.

Figure 8. Racial/Ethnic Distribution, by United States, Tennessee, Shelby County, and Memphis, 2020

■ Black, Non-Hispanic

■ White, Non-Hispanic

Hispanic/Latino

- Asian, Non-Hispanic
- Other Race/ Ethnicity, Non-Hispanic



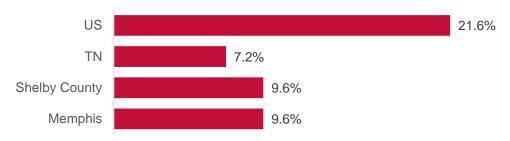
DATA SOURCE: U.S. Census Bureau, Decennial Census of Population and Housing, 2020 NOTE: Values less than 5% are not shown.

Approximately one in ten residents 5 years of age and older in Memphis (9.6%) and Shelby County (9.6%) speak a language other than English at home, which is slightly more than patterns



across the State (7.2%) (Figure 9). Moreover, twice as many residents nationwide (21.6%) who are 5 years of age and older speak a language other than English at home compared to Memphis and Shelby County.

Figure 9. Population Aged 5+ Speak Language Other Than English at Home, by United States, Tennessee, Shelby County, and Memphis, 2015-2019

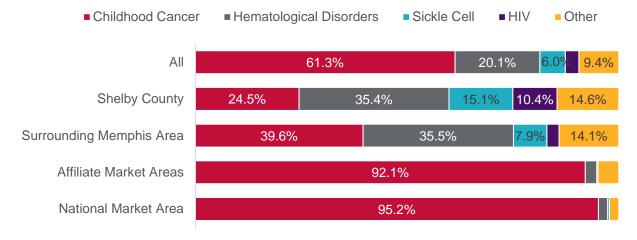


DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2015-2019

## **HEALTH ISSUES OF THE ST. JUDE PATIENT POPULATION**

The majority of new St. Jude patients in FY2019-FY2021 have a primary diagnosis of childhood cancer (61.3%), followed by hematological disorders (20.1%), sickle cell disease (6.0%), and HIV (3.2%) (Figure 10). There are notable differences in primary diagnoses across geographic areas. In Shelby County, more than one-third (35.4%) of new patients have a primary diagnosis of hematological disorders and nearly one-quarter (24.5%) have a childhood cancer, followed by 15.1% with sickle cell disease and 10.4% with HIV. More than one-third of new patients from the surrounding Memphis area have a primary diagnosis of a childhood cancer (39.6%) or hematological disorder (35.5%), 7.9% have sickle cell disease, and 2.9% have HIV. In contrast, more than 90% of new patients from affiliate market areas (92.1%) and the national market area (95.2%) have a primary diagnosis of a childhood cancer.

Figure 10. Primary Diagnosis of New St. Jude Patients, United States only, by Geographic Area, FY2019-FY2021 (N=2,637)



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Values less than 5% are not shown.

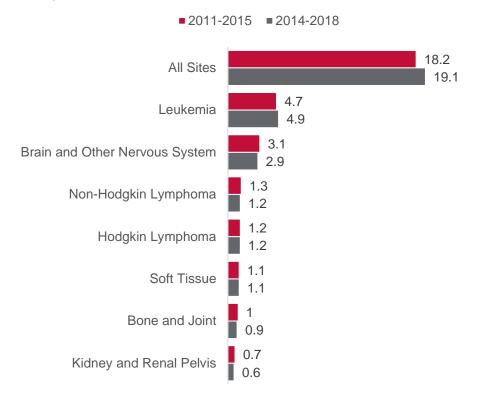


## **Cancer Care**

# Pediatric Cancer Incidence Rates

In 2014-2018, across the United States the rate of new pediatric cancer cases is highest for leukemia (4.9 cases per 100,000 children), followed by brain or other nervous system cancers (2.9 cases per 100,000 children) (Figure 11). In 2011-2015, leukemia was also the leading pediatric cancer diagnosis (4.7 cases per 100,000 children), followed by cancers of the brain and other parts of the nervous system (3.1 cases per 100,000 children).

Figure 11. Age-adjusted SEER Cancer Incidence Rates per 100,000, 0-19 Years, United States. 2011-2015 and 2014-2018



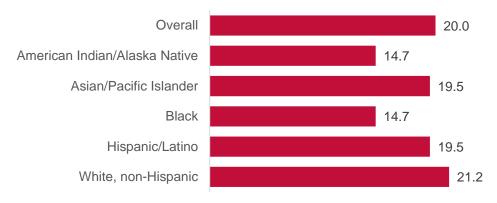
DATA SOURCE: National Cancer Institute, Surveillance, Epidemiology and End Results Program, SEER Cancer Statistics Review, 2011-2015 and 2014-2018

NOTE: This is based on the SEER 21 areas (Alaska Native Tumor Registry, CT, Detroit, GA (Atlanta, Greater GA, Rural GA), San Francisco-Oakland, San-Jose Monterey, Greater CA, HI, ID, IO, KY, Los Angeles, LA, MA, NM, NJ, NY, Seattle-Puget Sound, UT).

In 2018, the national rate of new pediatric cancer cases was highest among White children (21.2 cases per 100,000 children), followed by Hispanic or Latino (19.5 cases per 100,000 children) and Asian and Pacific Islander (19.5 cases per 100,000 children) children (Figure 12). The pediatric cancer incidence rate was 14.7 cases per 100,000 children for both Black and American Indian or Alaska Native children.



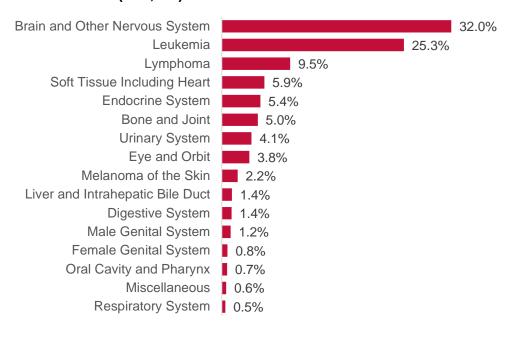
Figure 12. Age-adjusted SEER Cancer Incidence Rates per 100,000, 0-19 Years, United States, 2018



DATA SOURCE: National Cancer Institute, Surveillance, Epidemiology and End Results Program, SEER Cancer Statistics Review, 2018

Among new St. Jude patients, cancers of the brain and other nervous system (32.0%) and leukemia (25.3%) are the most prevalent primary cancer diagnoses, followed by lymphoma (9.5%) (Figure 13). These three most common types of cancer diagnosis remained the same from the last CHNA (FY2016-FY2018).

Figure 13. Primary Cancer Diagnoses Among New St. Jude Patients, United States, FY2019-FY2021 (N=1,617)



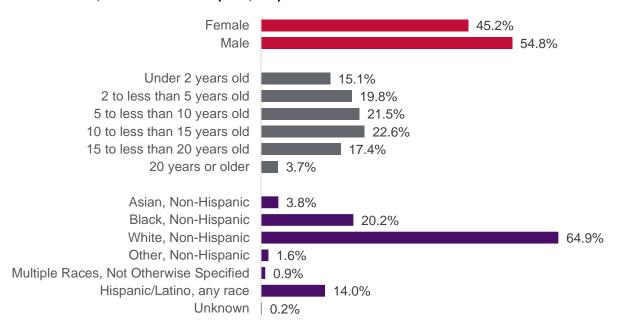
DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021



# Demographics of New Patients with Cancer

In FY2019-FY2021, among new St. Jude patients with a primary diagnosis of cancer, slightly more than half (54.8%) of patients are male, approximately one in five are 2 to under 5 years of age (19.8%), 5 to under 10 years of age (21.5%), or 10 to under 15 years of age (22.6%) (Figure 14). The majority of new patients with a primary diagnosis of cancer identify as White (64.9%), followed by patients who identify as Black (20.2%), and Hispanic or Latino (14.0%).

Figure 14. Demographics of New St. Jude Patients with Primary Diagnosis of Cancer, United States, FY2019-FY2021 (N=1,617)



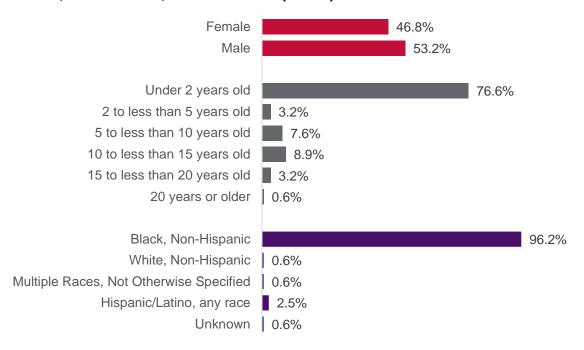
DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Respondents could select multiple race/ethnicity options, therefore, percentages may not add up to 100%; Other, non-Hispanic includes American Indian/Alaskan Native and Other race. Patients with known race but unspecified ethnicity were categorized as their respective race and assumed to be non-Hispanic (including 6 Black, 8 White). Non-Hispanic patients with unknown race were categorized as Unknown.



# <u>Sickle Cell Disease and other Hematological Disorders</u> *Demographics of New Patients with Sickle Cell Disease*

From FY2019-FY2021 there were 158 new St. Jude patients with a primary diagnosis of sickle cell disease, about half male (53.2%) (Figure 15). As expected, since sickle cell disease is often diagnosed at newborn screening, over three-quarters of new patients were under 2 years of age, and nearly all new patients identified as Black (96.2%).

Figure 15. Demographics of New St. Jude Patients with Primary Diagnosis of Sickle Cell Disease, United States, FY2019-FY2021 (N=158)



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021

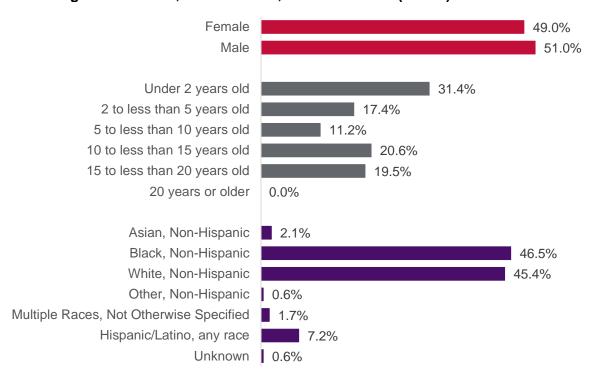
NOTE: Respondents could select multiple race/ethnicity options, therefore, percentages may not add up to 100%; Other, non-Hispanic includes American Indian/Alaskan Native and Other race. Patients with known race but unspecified ethnicity were categorized as their respective race and assumed to be non-Hispanic (including 2 Black). Non-Hispanic patients with unknown race were categorized as Unknown.



# Demographics of New Patients with Hematological Disorders

Of the 529 new St. Jude patients with a primary diagnosis of a hematological disorder other than sickle cell disease, approximately half are male (51.0%) (Figure 16). Nearly a third of new patients with hematological disorders are younger than 2 years of age (31.4%). Just about half of new patients identify as Black (46.5%), followed by White (45.4%).

Figure 16. Demographics of New St. Jude Patients with Primary Diagnosis of Hematological Disorders, United States, FY2019-FY2021 (N=529)



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Respondents could select multiple race/ethnicity options, therefore, percentages may not add up to 100%; Other, non-Hispanic includes American Indian/Alaskan Native and Other race. Patients with known race but unspecified ethnicity were categorized as their respective race and assumed to be non-Hispanic (including 7 Black, 2 White). Non-Hispanic patients with unknown race were categorized as Unknown.

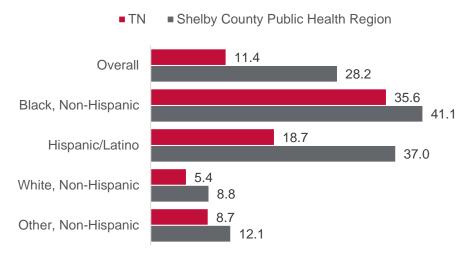


## **HIV/AIDS**

# HIV/AIDS Incidence and Prevalence Rates

The rate of new HIV cases in Tennessee (11.4 cases per 100,000 residents) in 2019 is less than half the rate in Shelby County (28.2 cases per 100,000 residents) (Figure 17). In Shelby County, residents who identify as Black (41.1 cases per 100,000 residents) have the highest HIV incidence rate of any other racial/ethnic group. Hispanic or Latino residents have the second highest HIV incidence rate, with the rate of new HIV cases among Shelby County residents who identify as Hispanic (37.0 cases per 100,000) being nearly double that for Hispanic residents across Tennessee (18.7 cases per 100,00 residents). Across all racial/ethnic groups the HIV incidence rate is higher in Shelby County compared to across Tennessee.

Figure 17. HIV Incidence Rate per 100,00 Population, by Race/Ethnicity, Tennessee and Shelby County Public Health Region, 2019



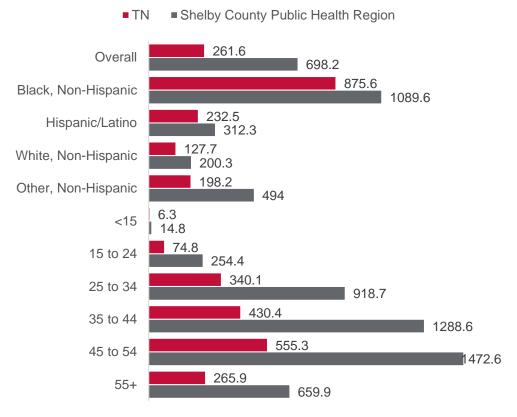
DATA SOURCE: Tennessee Department of Health, HIV Dashboard, 2019

Presented in Figure 18 are characteristics of persons living with diagnosed HIV in 2019. In both Tennessee and Shelby County, the rate of persons living with HIV is highest among Black residents. The rate of persons living with HIV is 24% higher for Black residents in Shelby County (1,089.6 people per 100,000 residents) compared to the rate for Black residents across Tennessee (875.6 people per 100,000 residents). Among Hispanic or Latino residents, the rate of persons living with HIV is 34% higher in Shelby County (312.3 people per 100,000 residents) than across Tennessee (232.5 people per 100,000 residents). For White residents, the rate of persons living with HIV is 57% higher in Shelby County (200.3 people per 100,000 residents) than Tennessee (127.7 people per 100,000 residents).

Across Tennessee and Shelby County, the rate of residents living with HIV is highest among residents 45-54 years of age (TN: 555.3 people per 100,000 residents; Shelby County: 1,472.6 people per 100,000 residents) and those 35-44 years of age (TN: 430.4 people per 100,000 residents; Shelby County: 1,288.6 people per 100,000 residents). As with patterns by race/ethnicity, the rate of people living with HIV in Shelby County exceeds that for Tennessee. For example, among persons 15 to 24 years of age, the rate of people living with HIV is 3.4 times higher in Shelby County than across Tennessee, the highest difference seen across age groups.



Figure 18. Persons Living with Diagnoses of HIV (Rate per 100,000 Population), by Race/Ethnicity, Age, Tennessee and Shelby County Public Health Region, 2019



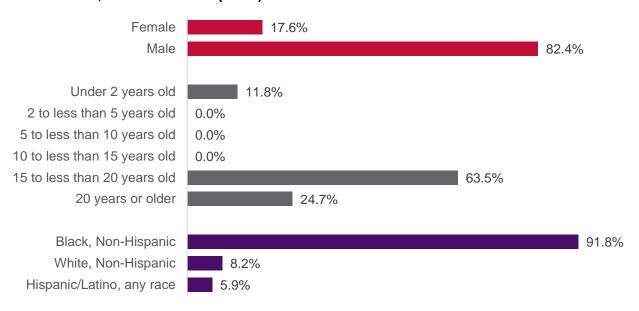
DATA SOURCE: Tennessee Department of Health, HIV Dashboard, 2019



# Demographics of New Patients with HIV/AIDS

The majority of new St. Jude patients with a primary diagnosis of HIV/AIDs are male (82.4%),15 to less than 20 years of age (63.5%), and identify as Black (91.8%) (Figure 19). Additionally, nearly one-quarter (24.7%) of new patients with HIV/AIDS are 20 years of age or older, followed by 11.8% of children younger than 2 years of age.

Figure 19. Demographics of New St. Jude Patients with Primary Diagnosis of HIV/AIDS, United States, FY2019-FY2021 (N=85)



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Respondents could select multiple race/ethnicity options, therefore, percentages may not add up to 100%; Other, non-Hispanic includes American Indian/Alaskan Native and Other race. Patients with known race but unspecified ethnicity were categorized as their respective race and assumed to be non-Hispanic (including 2 Black).

## **Neurological Disorders**

The addition of a new focus, neurological disorders, to pediatric catastrophic diseases was the most recent expansion at St. Jude with the creation of the Pediatric Translational Neuroscience Initiative. This initiative leverages the scientific strength and expertise in experimental therapeutics at St. Jude. Through this initiative, St. Jude will rise to the challenge of altering the landscape of pediatric neurological disease through investigating treatments for children with devastating neuromuscular diseases and accelerating clinical development of promising treatments. There is not yet new patient data to report on this new program.

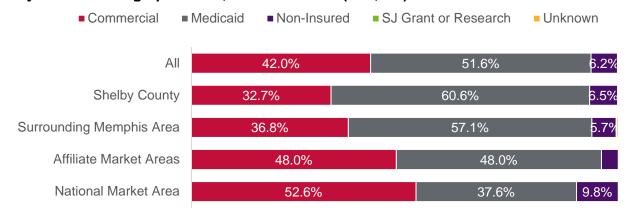
# Access and Barriers to Care

## Insurance Status

About half (51.6%) of new St. Jude patients have Medicaid coverage, followed by 42.0% with commercial insurance and 6.2% are uninsured (Figure 20). The majority of new patients from Shelby County (60.6%) and the surrounding Memphis area (57.1%) have Medicaid and approximately one-third have commercial insurance (32.7% and 36.8%, respectively). In contrast, nearly half of new patients from affiliate market areas (48.0%) and the national market area (52.6%) have commercial insurance.



Figure 20. Health Care Access, New St. Jude Patients, United States only, by Source of Payment and Geographic Area, FY2019-FY2021 (N=2,637)

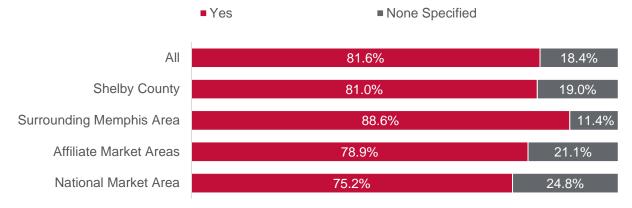


DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021 NOTE: Values less than 5% are not shown.

## Primary Care

At least four in five new St. Jude patients in Shelby County (81.0%) and the surrounding Memphis area (88.6%) have a family physician (Figure 21). Slightly fewer new patients from affiliate market areas (78.9%) and national market areas (75.2%) have a family physician, compared to 81.6% of all new St. Jude patients.

Figure 21. Family Physician Status of New St. Jude Patients, by Geographic Area, United States, FY2019-FY2021 (N=2,637)



DATA SOURCE: St. Jude Children's Research Hospital, FY2019-FY2021

# Need for More Mental Health Resources for St. Jude Patients and Families in the Community

As discussed above, all participants frequently noted that the resources that St. Jude provides for families is immensely helpful. However, these participants noted that there remains a need for additional mental health resources in the broader Memphis community. Interview participants more familiar with patient experiences noted that the needs surrounding mental health existed prior to the pandemic, but the need to address the mental health needs of patients and their families increased substantially since the pandemic. While mental health concerns were viewed



as impacting all family members, participants viewed youth and children as being in higher need for these resources.

Several internal providers noted that at the height of the pandemic, the restrictions put in place, while necessary for the health of patients, also increased feelings of isolation among patients and their families. According to participants, the usual in-person events intended to encourage community and engagement among patients and their families came to a halt and many parents experienced "isolation with a 6-year-old in a state [they are] not familiar with."

Frequently, internal participants mentioned the impact of stressful circumstances on families, including stressors related to the diagnosis for their child and the implications of leaving their homes and families to care for a child with cancer. For example, participants observed that typically, one parent must quit their job, which reduces income. One participant shared how children pick up on these stressors, "These systems drive stress. When a family is stressed, the kids feel that stress. [...] A lot of these issues are not addressed, so when they go back [home] their situation is just as terrible." Additionally, according to participants, if the parent has more than one child, the parents need to be mindful of multiple children's needs, including school, healthcare, mental health, and behavioral health.

St. Jude staff providing psychosocial services noted a need for more mental health services in the community. Participants cited issues around availability, as well as accessibility, observing that pediatric psychiatrists often have long waiting lists. One psychosocial services staff participant shared, "We are staffed to support patients when they are on campus. [We are] not involved as much after therapy. [There are] challenges in the lack of quality of [mental health] providers in the community. Some don't accept insurance or don't take public insurance." Staff noted that among patients with specific care needs (e.g., autism), access to mental health services is even more challenging, including long wait lists for specialized mental health providers. Another participant explained, "For caregivers needing [mental health] counseling, [there are] not enough local, appropriate, accessible resources."

## Transition of Care: Challenges Regarding Transitioning Care Outside of St. Jude

According to internal participants, the transition of care – either after treatment or when patients age into adulthood – is challenging. Internal interview participants highlighted some of the programs and resources that St. Jude has for specific patient populations to proactively address the challenges with transitioning care such as, the Transition Oncology Program (TOP), and programs within the sickle cell and HIV programs. Participants explained that these transitions of care challenges vary across diseases and geographic location. Staff perceived that when patients are at St. Jude, they receive strong specialty care, but for many, it can be hard to receive the same level of care when transitioning to home in specialties such as neurology, reproductive health, orthopedic care, endocrinology, mental health, and care related to cognitive abilities.

While participants recognized the critical role that schools play in supporting St. Jude patients after they receive treatment, providers familiar with the transition to care process noted that challenges can arise when children go back to school in their home school district. The primary school-related challenge identified by participants was a lack of access to the services that a child needs after their treatment at St. Jude. As one participant shared, "for local patients, what we advocate for might not be available in the school." In addition to Shelby County Schools, participants identified several services for patients outside of St. Jude that are valuable including Medicaid, Metropolitan Inter-Faith Association (MIFA) for housing assistance, Church Health Center, health centers offering sliding scale fees, legal services, and telehealth systems.



Participants also mentioned the importance of vocational rehabilitation for patients who experienced cognitive impacts from their treatment, as well as job placement assistance. Additionally, the need for legal assistance, particularly for parents who are seeking conservatorship for cognitively impacted children emerged as a need.

Another notable concern around the transition of care that emerged from interviews and focus group discussions pertained to transitioning to receiving health care services from providers and health systems that have invested less in specific programs (e.g., sickle cell disease). This may be due to inadequate reimbursement in the health care system. Participants also noted that the lack of investment in building the capacity of individuals and health care systems to care for patients of color equitably and inclusively contributed to challenges in transitioning care. One participant explained, "For our youth patient[s] with sickle cell disease, a big challenge is the transition to adulthood. They know there is a risk outside of St. Jude for discrimination and systemic racism. They know that they are not going to get care like what they get here."

Participants also cited financial challenges around the transition to care outside of St. Jude as a concern. As many participants noted, during their care at St. Jude, patients and their families never receive a bill for care provided. However, when patients transition out of St. Jude, they return to a health care system with copays and coinsurance, and other complex payment structures. According to participants, navigating this process and understanding what insurance does and does not cover can be a challenge. One internal interviewee described barriers to navigating the health care system saying, "It's hard to navigate the health care system. Parents need help learning the ins and outs. We do a lot here, but when they go home, parents have trouble navigating." Another internal participant explained, "While getting care at St. Jude, they [patients] don't pay copays or deductibles and when making that transition to payment, some [are] not sure where the money will come from. They also don't always know how much things will cost – this is part of the health literacy piece."

## HEALTH ISSUES IN MEMPHIS/SHELBY COUNTY

# Social Determinants of Health

Shown in Figure 22 are social and economic characteristics of the population across the United States, Tennessee, Shelby County, and Memphis. Similar to Tennessee (32.1%), high school is the highest level of education for 30.6% of Memphis adults, compared to about one-quarter of adults nationwide (27.0%) and in Shelby County (27.5%). In Shelby County 31.6% of adults have a bachelor's degree or higher, similar to patterns across the US (32.1%), and above the percent for Tennessee (27.3%) and Memphis (26.2%).

In April 2020, the unemployment rate in Shelby County (13.7%) was below that for the US (14.7%), Tennessee (15.8%), and Memphis (15.2%). In November 2021 the unemployment rate in Memphis (5.1%) was higher than that across the US (4.2%), Tennessee (4.0%), and Shelby County (4.4%).

Approximately one-quarter (25.7%) of children in Shelby County live in households with incomes at or below the federal poverty level, which exceeds the percent of children living in poverty in Tennessee (19.4%) and across the US (17.0%). In Tennessee, 8.0% of children live in extreme poverty, similar to children across the United States (7.0%).

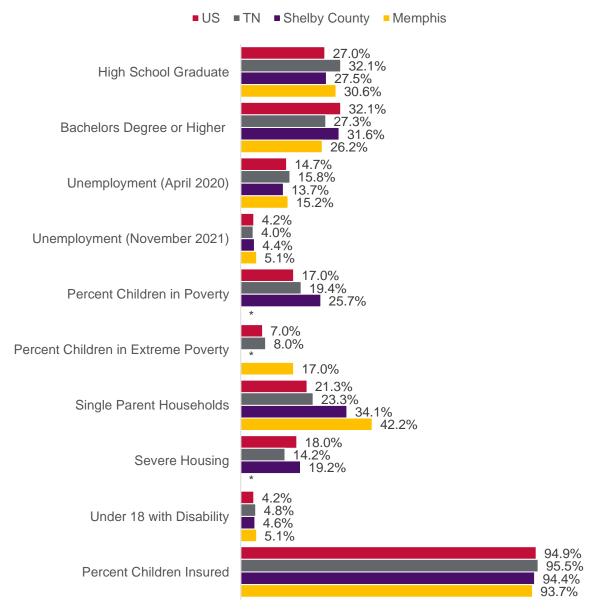
About two in five (42.2%) households with children are single-parent households in Memphis, followed by more than one-third (34.1%) of children in Shelby County, which is higher than Tennessee (23.3%) and the United States (21.3%).



Nearly one in five (19.2%) households in Shelby County are classified as living in severe housing conditions, which is slightly above the national (18.0%) and state (14.2%) average.

The percent of children with a disability range from 5.1% in Memphis to 4.6% in Shelby County, while the prevalence is 4.8% in Tennessee and 4.2% nationwide.

Figure 22. Selected Economic and Social Factors in the United States, Tennessee, Shelby County and Memphis



DATA SOURCE: U.S. Census Bureau, American Community Survey, 5-Year Estimates, 2015-2019; Bureau of Labor Statistics, 2020-2021; U.S. Census Bureau as cited by Robert Wood Johnson Foundation and University of Wisconsin Population Health Institute, County Health Rankings, 2019; Comprehensive Housing Affordability Strategy (CHAS) data as cited by Robert Wood Johnson Foundation and University of Wisconsin Population Health Institute, County Health Rankings, 2019

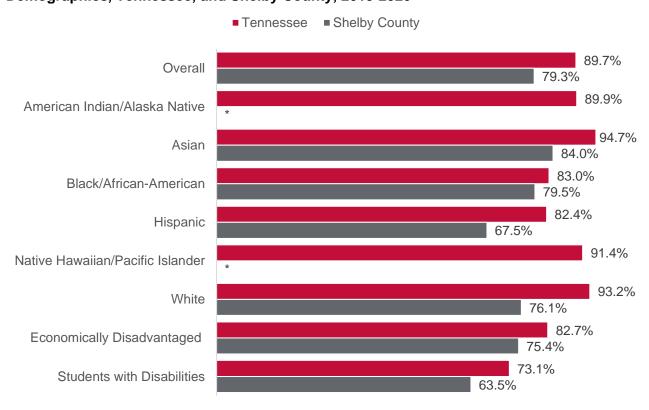


NOTE: High school graduate and bachelor's degree or higher data are for population 25 years and over; Unemployment data shown are not seasonally adjusted; Data for children insured at time of survey defines children as 0-17 years; \* Indicates data is not available.

In 2019-2020, 79.3% of Shelby County public high school students graduated within four years, which is notably lower than percent of public high school students graduating in four years across Tennessee (89.7%) (Figure 23). When looking at high school graduation patterns by race/ethnicity, the percent of students graduating high school within four years is lowest among students who identify as Hispanic, with just over two-thirds (67.5%), which is 18% lower than patterns for Hispanic students statewide (82.4%). Nearly four-tenths (79.5%) of Black or African American students in Shelby County graduated high school within four years, which is slightly lower than four-year graduation patterns for Black or African American students across Tennessee (83.0%).

During this same period, just over three-quarters (75.4%) of Shelby County students who are economically disadvantaged (defined as qualifying for free or reduced lunch) graduated from high school in four years, compared to approximately four-fifths (82.7%) in Tennessee. Under two-thirds (63.5%) of Shelby County students with disabilities graduated high school in four years, which is lower than the average statewide (73.1%).

Figure 23. Percent Students who Graduate Public High School within 4 Years, by Select Demographics, Tennessee, and Shelby County, 2019-2020



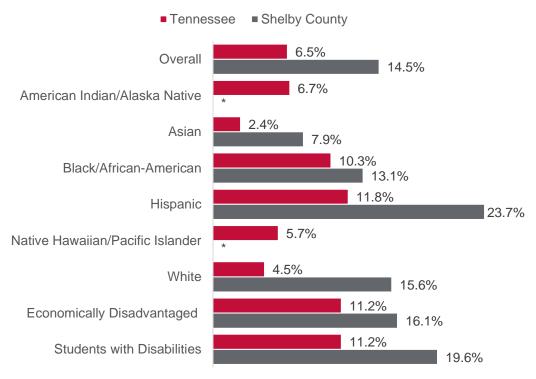
DATA SOURCE: Tennessee Department of Education, 2019-2020 NOTE: \* Indicates data is not available.

The percent of students who drop out of school is higher in Shelby County (14.5%) than Tennessee (6.5%) (Figure 24). High school dropout patterns are higher in Shelby County



compared to Tennessee in all student ethnic groups, students who are economically disadvantaged, and students with disabilities. For example, the percent of students who dropout is highest among students who identify as Hispanic, with more than one-fifth (23.7%) of Shelby County Hispanic students dropping out, which is double the percent of Hispanic students across Tennessee (11.8%) who dropped out of high school. About 16.1% of economically disadvantaged students in Shelby County dropped out of school, which is higher than the prevalence for students who are economically disadvantaged in Tennessee (11.2%). Nearly one-fifth (19.6%) of Shelby County students with disabilities dropped out in 2019-2020, compared to about one-tenth (11.2%) of students with disabilities statewide.

Figure 24. Percent Students who Dropout, by Selected Demographics, Tennessee, and Shelby County 2019-2020

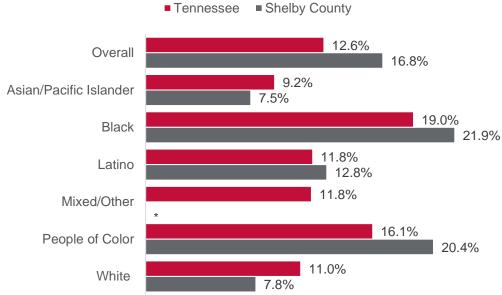


DATA SOURCE: Tennessee Department of Education, 2019-2020 NOTE: \* Indicates data is not available.

The percent of youth who are disconnected (meaning they are neither working nor in school) is higher in Shelby County (16.8%) than across Tennessee (12.6%), a pattern that holds for youth who identify as Black (21.9% vs. 19.0%), Latino (12.8% vs. 11.8%), and youth of color (20.4% vs. 16.1%) more broadly (Figure 25). Within Shelby County, the percent of youth who are disconnected is highest among youth who identify as youth of color (20.4%); this pattern is largely driven by the prevalence of disconnected Black (21.9%) youth.



Figure 25. Percent Disconnected Youth, by Race/Ethnicity, Tennessee, and Shelby County, 2019



DATA SOURCE: National Equity Atlas, 2019
NOTE: Percent of youth ages 16 to 24 not working or in school. People of color defined as race/ethnicities other than White. \* Indicates data is not available.

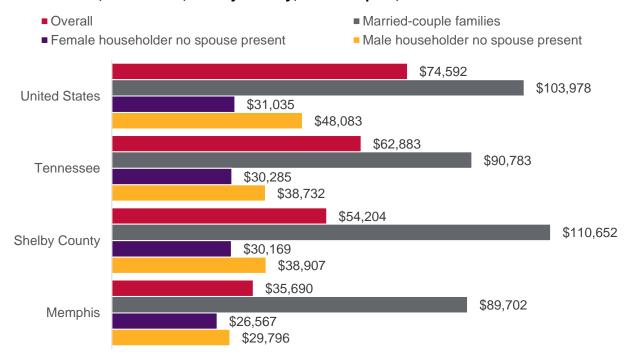
Shown in Figure 26 is the median household income for households with children under 18 years of age, by household marital status and geography. Across geographies, the median household income in households with children is highest for those with married or coupled families. Among married/coupled households with children, the median household income is lowest in Memphis (\$89,702) and Tennessee (\$90,783). With a median household income of \$110,652 for married/coupled families, Shelby County has the highest median household income, which exceeds the national average (\$103,978).

Among households with children, nationwide and in Tennessee, Shelby County, and Memphis, median household incomes are lowest for female-headed households with no spouse compared to married/coupled households and male-headed households with no spouse. The median household income for female-headed households is lowest in Memphis (\$26,567).

Among male-headed households with children and no spouse, median household incomes are lowest in Memphis (\$29,796) and median household incomes in Shelby County (\$38,907) and Tennessee (\$38,732) are well below that for the United States overall (\$48,083).



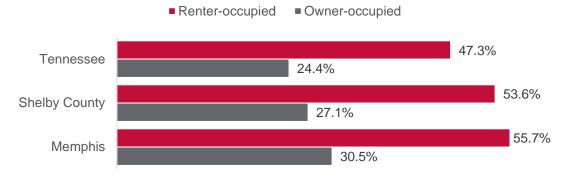
Figure 26. Median Household Income among households with Children under 18, by United States, Tennessee, Shelby County, and Memphis, 2015-2019



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2015-2019

Housing costs comprise more than 30% of household income for a larger proportion of renter-occupied units than owner-occupied units across Tennessee, Shelby County, and Memphis (Figure 27). A higher percent of renter-occupied units in Memphis (55.7%) and Shelby County (53.6%) has housing costs of at least 30% compared to Tennessee (47.3%). Similarly, a higher percent of owner-occupied units in Memphis (30.5%) and Shelby County (27.1%) has housing costs of at least 30% of household income compared to Tennessee (24.4%).

Figure 27. Residents whose Housing Costs are 30% or More of Household Income, by Tennessee, Shelby County, and Memphis, 2015-2019



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2015-2019



In Shelby County in 2020 there are an estimated 101 households without children who are experiencing homelessness who are unsheltered, and no children experiencing homelessness who are unsheltered (Table 3). Among households experiencing homelessness who are sheltered across Tennessee, 19% of households without children reside in Shelby County (637 households) and 26% of households with at least one adult and one child live in Shelby County (284 households).

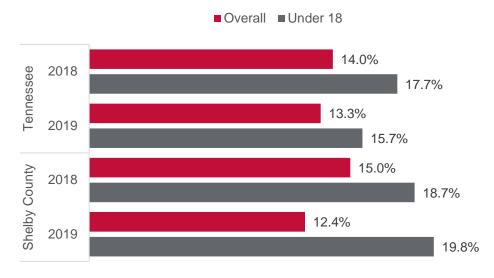
Table 3. Number of Homeless Households With and Without Children, by Tennessee and

Snelby Count	y/wempnis, z	2020				
	Unsheltered			Sheltered		
	Without Children	At Least One Adult and One Child	Only Children	Without Children	At Least One Adult and One Child	Only Children
Tennessee	2,313	471	0	3,328	1,112	32
Shelby County/	101	0	0	637	284	0

DATA SOURCE: U.S. Department of Housing and Urban Development, Continuums of Care, HUD Continuum of Care Homeless Assistance Programs Homeless Populations and Sub Populations, 2020 NOTE: Sheltered includes persons in emergency shelter or transitional housing.

As shown in Figure 28, compared to the overall population across Tennessee and Shelby County, a higher proportion of children under 18 years of age experience food insecurity, meaning they experienced limited, uncertain, and/or insufficient availability of healthy food. In 2019, one in five (19.8%) children in Shelby County were food insecure, which is 26% higher than the prevalence of food insecurity for children across Tennessee (15.7%), whereas there was a limited difference in the prevalence of food insecurity among children in Shelby County (18.7%) and across Tennessee (17.7%) in 2018.

Figure 28. Percent Population Food Insecure (Overall and Under 18), by Tennessee and Shelby County, 2018-2019



DATA SOURCE: Feeding America, Map the Meal Gap, 2018-2019

Memphis



Approximately seven in ten (69.7%) Memphis households have internet access, compared to about three-quarters of households across Shelby County (75.6%) and Tennessee (78.7%) (Figure 29).

Figure 29. Percent Households with Internet Access, by Tennessee, Shelby County, and Memphis, 2015-2019



DATA SOURCE: U.S. Census Bureau, American Community Survey 5-Year Estimates, 2015-2019

While Tennessee has fewer primary care providers per capita (1,396 residents per provider) compared to patterns across the United States (1,320 residents per provider), Shelby County supply compares favorably with 1,161 residents per primary care provider (Table 4).

There are fewer mental health providers per capita in Shelby County compared to the US. The ratio of Shelby County residents to mental health providers (669 residents per provider) is 6% higher than that for Tennessee (634 residents per provider) and 76% higher than the national average (380 residents per provider).

Across geographies, the ratio of residents to dentists exceeds that for primary care and mental health providers, indicating that there are fewer dentists available per capita than primary care and mental health providers. In Shelby County has more dentists per resident than Tennessee and the US with (1,358 residents per dentist) t.

Table 4. Ratios of Population to Healthcare Providers, by United States, Tennessee, and Shelby County

	US	TN	Shelby County
Primary Care Provider	1,320	1,396	1,161
Mental Health Care Provider	380	634	669
Dentist	1,400	1,801	1,358

DATA SOURCE: Area Health Resource File/American Medical Association as cited by County Health Rankings, 2018; CMS, National Provider Identification as cited by County Health Rankings, 2020; Area Health Resource File/National Provider Identification file as cited by County Health Rankings, 2019

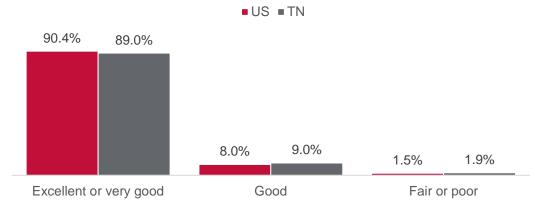


### Health Issues

### Childhood Health Status

Approximately nine in ten children in Tennessee (89.0%) and the United States (90.4%) have health statuses that are classified as excellent or very good and just under one in ten children in Tennessee (9.0%) and the US (8.0%) have good reported health (Figure 30).

Figure 30. Child's Health Status, by United States and Tennessee, 2019-2020

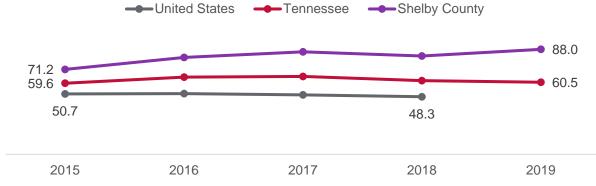


DATA SOURCE: National Survey of Children's Health, 2019-2020

### Childhood Fatality

From 2015 to 2019, the childhood mortality rate in Shelby County and Tennessee has been consistently higher than the United States (Figure 31). In Shelby County the child mortality rate has increased by 24% from 2015 to 2019.

Figure 31. Child (Ages 0-17) Mortality Rate (per 100,000 Population), by United States, Tennessee, and Shelby County, 2015-2019



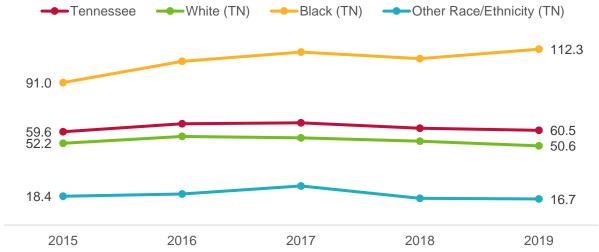
DATA SOURCE: Child Fatality Annual Reports, Tennessee Department of Public Health, 2015-2019 NOTE: 2019 Shelby County data actually for Shelby Region.

Across Tennessee, the childhood mortality rate is highest for Black children, and increased by 23% from 2015 (91.0 deaths per 100,000 children) to 2019 (112.3 deaths per 100,000 children) (Figure 32). The childhood mortality rate for Black children across Tennessee is notably higher than that for White children. For example, in 2021 the childhood mortality rate for Black children (112.3 deaths per 100,000 children) is 122% higher than that for White children (50.6 deaths per 100,000 children).



Figure 32. Child (Ages 0-17) Mortality Rate (per 100,000 Population), by Tennessee and Race/Ethnicity, 2015-2019

Tennessee White (TN) Black (TN) Other Race/Ethnicity (TN)

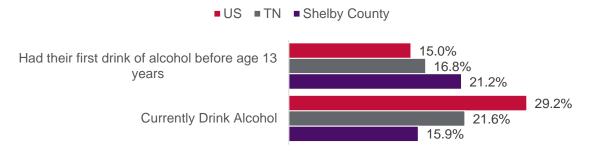


DATA SOURCE: Child Fatality Annual Reports, Tennessee Department of Public Health, 2015-2019

### Substance Misuse

In Shelby County, about one in five (21.2%) students report that they had their first drink before 13 years of age, which exceeds the prevalence for students across Tennessee (16.8%) and the US (15.0%) (Figure 33). Approximately one in six students in Shelby County (15.9%) report currently drinking alcohol, which is almost half the prevalence nationwide (29.2%) and below the prevalence of current alcohol use for students across Tennessee (21.6%).

Figure 33. Percent Students That Had Their First Drink of Alcohol Before Age 13 and Percent Students That Currently Drink Alcohol, by United States, Tennessee, and Shelby County, 2019

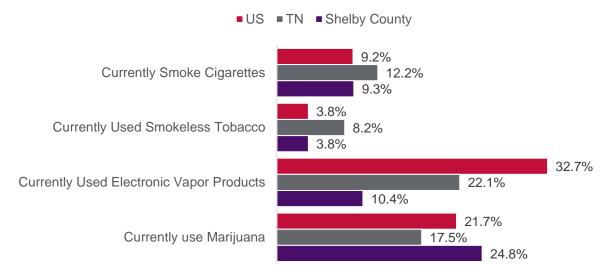


DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019

Reported current use of cigarettes and smokeless tobacco among students across Tennessee (12.2% and 8.2%, respectively) is higher than for students in Shelby County (9.3% and 3.8%, respectively) and across the US (9.2% and 3.8%, respectively) (Figure 34). In contrast, while approximately one-third (32.7%) of students nationwide report current use of vaping products, about one in five (22.1%) students across Tennessee and one in ten (10.4%) students in Shelby County report currently using vaping products. About one-quarter (24.8%) of Shelby County students report currently using marijuana, which is higher than the prevalence for students across Tennessee (17.5%) and the US (21.7%).



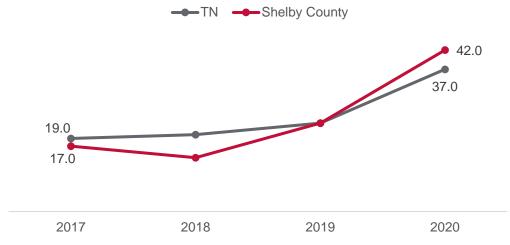
Figure 34. Percent Students Using Cigarettes, Smokeless Tobacco, Electronic Vapor Products, and Marijuana, by United States, Tennessee, and Shelby County, 2019



DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019

In Tennessee and Shelby County, the opioid drug overdose rate has increased from 2017 to 2020, with a 147% increase in Shelby County (17.0 to 42.0 overdoses per 10,000 persons) and a 95% increase in Tennessee (19.0 to 37.0 overdoses per 10,000 persons).

Figure 35. Opioid Drug Overdose Rate (age-adjusted rate per 10,000 persons), by Tennessee and Shelby County, 2017-2020

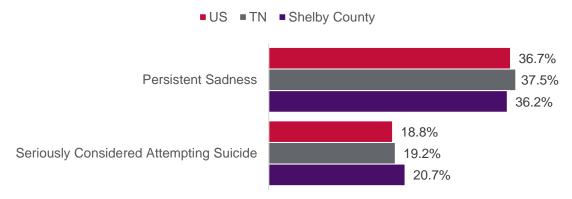


DATA SOURCE: Drug Overdose Dashboard, Tennessee Department of Public Health, 2017-2020 NOTE: Nonfatal stays and visits exclude Heroin.

Across the US (36.7%), Tennessee (37.5%), and Shelby County (36.2%), over one-third of students report experiencing persistent sadness (Figure 36). Approximately one in five students in the US (18.8%), Tennessee (19.2%), and Shelby County (20.7%) report seriously considering a suicide attempt.



Figure 36. Percent Students Reporting Persistent Sadness and Percent Students Seriously Considered Attempting Suicide during the Past Year, 2019

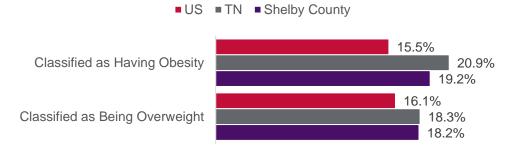


DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019 NOTE: Felt sad or hopeless (almost every day for 2 or more weeks in a row so that they stopped doing some usual activities, during past year).

# Obesity, Chronic Disease

About one in five students in Shelby County (19.2%) and Tennessee (20.9%) are classified as having obesity, which is higher than the national average (15.5%) (Figure 37). About 18% of students in Shelby County (18.2%) and Tennessee (18.3%) are classified as being overweight, compared to 16.1% of students across the US.

Figure 37. Percent Students Classified as Having Obesity or Being Overweight, by United States, Tennessee, and Shelby County, 2019

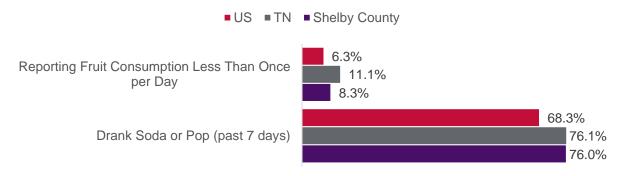


DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019

The percent of Tennessee students (11.1%) reporting less than daily fruit consumption exceeds that for students across the US (6.3%) (Figure 38). A slightly lower percent of students in Shelby County (8.3%) report less than daily fruit consumption compared to students across Tennessee (11.1%). Approximately three-quarters of students in Shelby County (76.0%) and Tennessee (76.1%) report drinking soda or pop in the past week, compared to 68.3% of students nationwide.



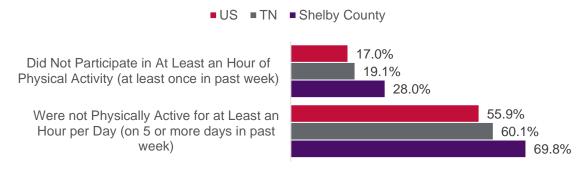
Figure 38. Percent Students Reporting Fruit Consumption Less Than Once per Day and Percent Students Reporting Drank Soda or Pop (Last 7 Days Before Survey), by United States, Tennessee, and Shelby County, 2019



DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019

Student-reported physical inactivity in the past week is generally higher for students in Shelby County and Tennessee when compared to patterns across the United States (Figure 39). About one-quarter (28.0%) of Shelby County students report not participating in at least an hour of physical activity at least once in the past week, compared to 19.1% of students across Tennessee and 17.0% of students across the US. Additionally, when asked about physical activity for at least an hour per day on five or more days in the past week, about seven in ten (69.8%) Shelby County students, six in ten (60.1%) Tennessee students, and just over half (55.9%) of students across the US report not meeting this level of physical activity in the past week.

Figure 39. Percent Students Physically Active, by United States, Tennessee, and Shelby County, 2019

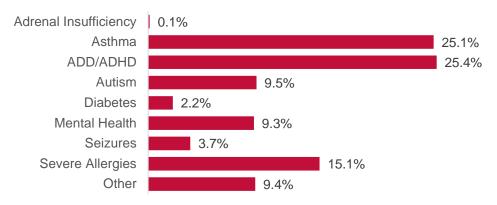


DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019

Among Tennessee students, the most prevalent health conditions are asthma (25.1%) and ADD/ADHD (25.4%), with approximately one-quarter of students having either of these conditions. Severe allergies (15.1%), autism (9.5%), and mental health issues (9.3%) are the next most common health conditions among Tennessee students (Figure 40).



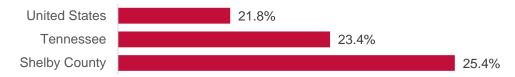
Figure 40. Chronic Illness among Tennessee Students, 2020-2021



DATA SOURCE: Tennessee Department of Education, Coordinate School Health Report, 2021

In Shelby County, one-quarter (25.4%) of students report being told by a doctor that they have asthma, slightly above the prevalence of diagnosed asthma reported by students across Tennessee (23.4%) and the US (21.8%) (Figure 41).

Figure 41. Percent Students Ever Told By Doctor They Have Asthma, by United States, Tennessee, and Shelby County, 2019

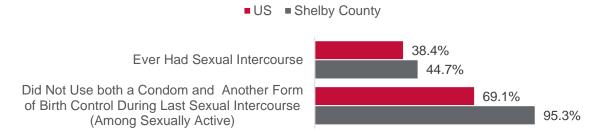


DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019

### Infectious Disease

In 2019, 44.7% of Shelby County students report ever having sexual intercourse, which is higher than that reported for students nationwide (38.4%) (Figure 42). The overwhelming majority (95.3%) of sexually active students in Shelby County report not using a condom or other form of birth control during their last sexual intercourse, compared to about two-thirds (69.1%) of students nationwide.

Figure 42. Student Sexual Health, by United States and Shelby County, 2019



DATA SOURCE: Youth Risk Behavior Survey (YRBS), CDC, 2019

NOTE: Other forms of birth control include birth control pills; an IUD (e.g., Mirena or ParaGard) or implant (e.g., Implanon or Nexplanon); or a shot (e.g., Depo-Provera), patch (e.g., OrthoEvra), or birth control ring (e.g., NuvaRing).



Across the United States, nearly 59% (58.6%) of youth 13-17 years of age have received all recommended doses of the HPV vaccine in 2020 (Table 5/Figure 43). In the United States and in the St. Jude market area, the percent of youth up to date on their HPV vaccination increased from 2018 to 2020, but importantly reflects vaccination coverage before the COVID-19 pandemic. Internal and external interview participants shared that they had observed a decrease in childhood vaccinations and on time vaccinations during the pandemic.

Only Illinois (63.1%), North Carolina (60.7%), and Louisiana (60.4%) have a higher or similar HPV vaccination coverage levels among youth compared to the United States average. HPV vaccine completion is lowest in Mississippi (31.9%), followed by Oklahoma (45.8%) and South Carolina (47.0%). Rural populations have lower HPV vaccination coverage (49.2%) for up to date than non-principal (59.1%) and principal cities (60.4%).

Table 5. HPV Vaccination Coverage, by St. Jude Catchment Area States, 2018-2020

		2018		2019		20
	<u>&gt;</u> 1 HPV	HPV UTD	<u>≥</u> 1 HPV	HPV UTD	<u>&gt;</u> 1 HPV	HPV UTD
United States	68.1	51.1	71.5	54.2	75.1	58.6
Alabama	64.7	50.2	65.6	47.3	67.3	52.9
Arkansas	60.8	42.6	67.9	50.5	70.9	49.6
Illinois	69.4	53.4	71.7	54.9	75.9	63.1
Louisiana	67.2	46.7	73.9	59.5	75.3	60.4
Mississippi	51.7	32.6	49.5	30.5	55.2	31.9
Missouri	61.6	42.1	69.0	54.3	69.9	53.6
North Carolina	68.6	52.1	71.3	49.5	80.3	60.7
Oklahoma	59.1	37.9	65.6	41.8	65.5	45.8
South Carolina	63.7	41.2	71.8	53.0	70.1	47.0
Tennessee	62.3	44.4	61.9	43.0	71.7	52.9

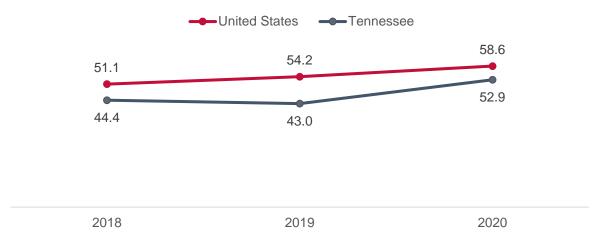
DATA SOURCE: Walker TY, Elam-Evans LD, Yankey D, et al. National, Regional, State, and Selected Local Area Vaccination Coverage Among Adolescents Aged 13–17 Years — United States, 2018. MMWR Morb Mortal Wkly Rep 2019;68:718–723. DOI: http://dx.doi.org/10.15585/mmwr.mm6833a2; Elam-Evans LD, Yankey D, Singleton JA, et al. National, Regional, State, and Selected Local Area Vaccination Coverage Among Adolescents Aged 13–17 Years — United States, 2019. MMWR Morb Mortal Wkly Rep 2020;69:1109–1116 DOI: http://dx.doi.org/10.15585/mmwr.mm6933a1; Pingali C, Yankey D, Elam-Evans LD, et al. National, Regional, State, and Selected Local Area Vaccination Coverage Among Adolescents Aged 13–17 Years — United States, 2020. MMWR Morb Mortal Wkly Rep 2021;70:1183–1190. DOI: http://dx.doi.org/10.15585/mmwr.mm7035a1.

NOTE: HPV UTD (up-to-date) includes those with ≥ 3 doses, and those with 2 doses when the first HPV vaccine dose was initiated prior to age 15 years and there was at least five months minus four days between the first and second dose. 2020 NIS-TEEN results reflect adolescent vaccination coverage before the COVID-19 pandemic. Confidence intervals are available in the original data sources.



The state of Tennessee is behind the United States overall in youth up to date on their HPV vaccine (Figure 43). While the state of Tennessee had a decrease in youth up to date on HPV vaccination in 2019, there was an increase of almost 10% from 2019 to 2020.

Figure 43. HPV Up-to-date Vaccination Coverage, by United States and Tennessee, 2018-2020



DATA SOURCE: Walker TY, Elam-Evans LD, Yankey D, et al. National, Regional, State, and Selected Local Area Vaccination Coverage Among Adolescents Aged 13–17 Years — United States, 2018. MMWR Morb Mortal Wkly Rep 2019;68:718–723. DOI: http://dx.doi.org/10.15585/mmwr.mm6833a2; Elam-Evans LD, Yankey D, Singleton JA, et al. National, Regional, State, and Selected Local Area Vaccination Coverage Among Adolescents Aged 13–17 Years — United States, 2019. MMWR Morb Mortal Wkly Rep 2020;69:1109–1116. DOI: http://dx.doi.org/10.15585/mmwr.mm6933a1; Pingali C, Yankey D, Elam-Evans LD, et al. National, Regional, State, and Selected Local Area Vaccination Coverage Among Adolescents Aged 13–17 Years — United States, 2020. MMWR Morb Mortal Wkly Rep 2021;70:1183–1190. DOI: http://dx.doi.org/10.15585/mmwr.mm7035a1.

NOTE: HPV UTD (up-to-date) includes those with ≥ 3 doses, and those with 2 doses when the first HPV vaccine dose was initiated prior to age 15 years and there was at least five months minus four days between the first and second dose. 2020 NIS-TEEN results reflect adolescent vaccination coverage before the COVID-19 pandemic. Confidence intervals are available in the original data sources.

# Health-Related Needs of the Memphis Community are Vast and Primarily Linked with Upstream Factors

Interview and focus group participants identified several community health concerns for children, ranging from trauma and violence in the community; to access to healthy food and childhood obesity; to mental health care access; to chronic conditions or risk factors for chronic conditions, such as heart disease, diabetes, HIV, and HPV. Regarding access to healthy food, internal and external participants noted the importance of not just accessing healthy food, but also knowing "how to cook that food."

As previously mentioned, the root of many of these issues, participants argued, is childhood poverty. One internal participant emphasized, "Poverty is one of our biggest factors." An external participant shared, "Memphis is a city that has a large low-income community, a large socioeconomic gap. That impacts the health of the community [and] the population's growth as well. There's a million and one challenges, like food insecurity, educational gaps, socio-economic gaps." Barriers to health and healthy living identified by internal and external participants include housing instability, high rates of adverse childhood experiences (ACEs), lack of employment,



lack of transportation, and lack of health literacy pertaining to disease diagnosis and navigating health care system. Regarding housing instability, participants noted that many residents are unable to access affordable housing and many other residents need assistance in paying for utilities and legal support for housing issues. One internal participant described what housing instability looks like for some low-income families, "[Some families are] transient where they are not homeless, but families couch surf and the kids can go from 4-5 schools in a year. This makes it hard to keep the kids engaged and having meaningful connections to what is happening in communities." Among affiliate providers, all noted that many of the structural barriers named by participants familiar with the Memphis area also exist in the affiliate areas, including, for example, transportation and lack of or limited health insurance coverage. One participant shared, "There's a need [for] employment help, and any kind of workforce development needs as well as transportation. It creates a big gap for the ability of patients to move around freely to get the services needed."

Participants and affiliate providers noted that there remain gaps in accessing mental health services and difficulties in accessing general health care resources in the broader community. Some of these participants noted that the health care system is characterized by many different types of resources, but also and significant challenges in terms of access to those services and resources. For example, an external participant noted that it does not matter how much they work with a patient to provide information on diabetes management when patients have difficulty accessing their insulin. Overall, participants viewed these barriers as having a direct connection to adverse health outcomes in the community.

Like the patients in the St. Jude community, participants viewed families – especially children and youth – as being in particularly high need of access to mental and behavioral health services. According to one external participant, "We are seeing that the stress and anxiety is impacting the health of our children and our youth." One participant noted that since the pandemic, the community has become more aware of issues related to mental and behavioral health, yet the issue of accessing services remains. Mental health service needs are discussed in further detail later in the report.

When asked about resources in the community, many internal and external participants perceived that while Memphis is a very giving and charitable community, there are not enough support services and resources to meet the needs of the community, especially since the pandemic appears to have exacerbated many issues. Some participants also highlighted the need for leadership in all Memphis community organizations to take ownership in the community regarding who will lead action and planning around community health issues.

# Perceived Impact of COVID-19 Pandemic on Preventive Care Utilization and Health Outcomes

Overall, interview participants who are familiar with preventative care noted that since the COVID-19 pandemic, screening and wellness visits have decreased, particularly for children. All of these participants noted that they either directly see, or their colleagues have seen a decrease in well child visits, childhood vaccinations, and health screenings across all populations and age groups. Interview participants familiar with cancer care noted that cancer is a "significant concern" especially in the pandemic because cancer cases are being detected and diagnosed later in the disease stage, which leads to poorer health outcomes overall.

Many service providers interviewed noted that when the pandemic first started, they became disconnected from communities as the many organizations and institutions implemented inperson restrictions. According to participants, while telehealth was available and helped to bridge the gap in care during restrictions on in-person activities, this loss of in-person connection made



it difficult to provide direct care to the community, and also created trust issues when distributing vaccines.

Overall, participants noted that while the pandemic forced many organizations to work together to meet the growing needs of the community, the pandemic also exacerbated the issues already present in the community. Further, according to participants, the lack of a uniform message around masking and school safety in the community created tension in many neighborhoods. For example, one participant described the impact of COVID-19 messaging on families: "The polarization of the world is something that is impacting families and children and having to go to school and being unsure of masking, we see impacting [the family dynamic]."

# Role of St. Jude in Memphis/Shelby County

All participants interviewed perceived St. Jude to be an anchor and have a strong presence in the Memphis community.

# Opportunities for St. Jude to Address Child Health in Memphis/Shelby County: Diversity, Equity and Inclusion Efforts

Several participants shared reflections on Diversity, Equity, and Inclusion (DEI) efforts at St. Jude and in the broader community. One external participant discussed the importance of integrating DEI efforts into each sector, noting: "Personal, business, health care, school – everyone needs to be doing it [DEI] to see the impact we want to see in the long term... Once you put a dollar on something people are more willing to focus on it. If we put them in a grant and get money for it, is more likely to get sustained attention." Another participant perceived that the COVID-19 pandemic delayed DEI efforts across the region: "The pandemic was terrible in many ways. But I think it might have derailed future progress but now that COVID is dying down, I think people will be able to think about the momentum and get back to it." While several participants lauded St. Jude's DEI efforts, some participants cited the importance of continuing to invest in DEI efforts.

On the topic of inclusive practices, one internal participant shared that their department is working to be more "intentional" about referral practices. Another participant discussed how they and their colleagues are exploring their hiring practices. This participant shared, "We have been institutionally and in our own department more inclusive in hiring practices. Our patient population is so diverse, so not reflecting that means that we have fewer creative solutions and are lacking in diverse voices to represent our patient population."

## St. Jude Can Raise Awareness of and Improve Existing Programs

Based on themes that emerged from internal and external interviews and focus group discussions, there is an opportunity and desire for St. Jude to lift up and promote the work that most benefits the Memphis community. For example, one external participant said, "I don't think many people know the work St. Jude does with sickle cell and that is obviously a huge issue in our community – they aren't well known for what they do in the Memphis community." One participant familiar with the HIV efforts in the Memphis community commented on the good work that St. Jude is doing regarding the resources and "voice" they are able to give to youth, Black men, and people in the pride community but noted that many people don't know this work is happening. Another internal participant described the continued need to equitably support patients with HIV:



"These conversations have prompted us to be more aware of how we are approaching folks. Many [HIV patients] are behaviorally infected vs. prenatally infected. Many [experience] religious and spiritual distress and religious trauma. [We] have a chaplain who is trying to embed self in the work and connect with folks."

More than anything, staff noted that they are most familiar with the fundraising efforts in the community and beyond. One participant described their perception of the current state of communicating about St. Jude programs, "I think we do a lot of work in the community, but our words are muted [...] St. Jude could use more direct communication."

Among interview participants who were not affiliated with St. Jude, many noted that they are not aware of much of St. Jude's community work and had a desire to learn more about the work. Some of these participants were aware of the HPV and sickle cell programming in the community but did not express familiarity beyond these specific efforts. One internal participant noted, "The HPV vaccination program represents great work that pertains to the entire community out there."

Many participants also noted that opportunities exist to further promote the sickle cell disease program in the community and noted that many community members may not know about the St. Jude sickle cell disease program. Some participants suggested that St. Jude could find ways to provide community education and awareness about sickle cell disease while focusing on their mission. When reflecting on how to best promote their programs, participants suggested partnering with community organizations and participating in community events and health fairs.

## Other Opportunities and Suggestions

When thinking about community outreach and education, interview participants shared a variety of suggestions for how St. Jude can add to what they perceived to be an already great job.

First, participants recommended continuing to increase and bolster presence in the schools by integrating health and STEM education in the schools and in summer programs. A few participants saw school partnerships as integral in tackling obesity and diabetes in the community. As one internal participant noted, this integration will allow children to "hone and carry skills through life." Another participant viewed St. Jude health education efforts as an important responsibility to build a more informed public: "There is a thirst for knowledge around health care and public health, but it has to come from the right messenger." Relatedly, one participant described the importance of focusing on health education related to vaccines: "[We need a] bigger voice in vaccinations. There's a need for every stakeholder to come together on this. Need to leverage the children's health expertise that St. Jude has."

Second, participants familiar with the service area and serving culturally diverse communities noted the importance of increasing culturally informed messaging. Relatedly, one participant also highlighted the importance of persistence when engaging the community, noting that community members need to see genuine concern for a few years in order to build up the trust: "Don't count people out because it did not work in the first few months. Because there is so much historic context in the community, people will just say, 'they are just reaching out because of COVID'." Another participant noted that the recent shift in dialogue around community health – specifically, an increased awareness of health equity and social determinants of health – represents an opportunity for St. Jude to intentionally engage historically underserved communities and "find new opportunities to engage and give voice to minority communities." Relatedly, this participant mentioned the importance of all stakeholders coming together to develop a uniform message regarding vaccinations in the community. One participant envisioned a St. Jude that has "more"



willingness to have difficult conversations" because the current "culture shift" that is happening presents an opportunity to step back and think about how the hospital engages the Memphis community.

Other suggestions included taking a critical look at how HIV+ patients are receiving care at St. Jude and in the community. This participant noted that there is a chaplain currently involved in this work and trying to make connections in the community. Another participant noted the importance of conducting more community-based participatory research. As one respondent pointed out, "research shows that the underserved populations benefit from these partnership programs."

One internal participant highlighted the opportunity for St. Jude to take a leadership role in addressing inequalities in the social determinants of health that impact patients before and after they seek care at St. Jude, citing the possibility of building on St. Jude's practice and reputation of leading and sharing best practices in cancer care:

"The situation that brings [families] to St. Jude is inequitable. Mom and dad are wage earners, someone loses their job to provide the care and it's hard to get the job back. [The social workers] here are extraordinary and connect to resources, but there's a limit. Four of five kids in the US survive leukemia. St. Jude has a large part in this – sharing the research, even with competitors. What if there were similar ways to address [the social determinants of health] in this way? What if we could work on and address these needs, so that when the child returns home, the whole family is healthy?"

Recommendations from affiliates included supporting affiliates in strengthening their community outreach and programming, involving affiliate programs in clinical trials based in Memphis, and taking a more streamlined approach to sharing resources in the community.



### **REVIEW OF CURRENT COMMUNITY BENEFITS INITIATIVES**

To fulfill IRS requirements, St. Jude developed Community Benefit Implementation Plans in 2013, 2016, and 2019. Over the course of three assessment cycles, the CHNA findings raised issues to accessing care, HIV/AIDS, HPV cancers, sickle cell disease, pediatric-adult health care transitions, childhood cancer survivor care, and community education. St. Jude has chosen to focus and address these needs in three general aims: improving access to care, improving coordination of care, and improving child health status (Table 6).

Table 6. St. Jude Community Benefit Areas of Focus, 2013, 2016, 2019

	2013	2016	2019
AIM 1: Improving Access to Care			
Transition of patients from pediatric to adult health care services	✓		<b>√</b>
Access to affordable health insurance coverage	✓	<b>✓</b>	<b>✓</b>
Palliative care	✓	✓	✓
Health care of childhood cancer survivors	✓	✓	✓
Community education	✓		✓
St. Jude Affiliate network		✓	✓
AIM 2: Improving Coordination of Care			
Physician coordination of care	✓	✓	✓
Transition of patient from pediatric to adult healthcare services		✓	✓
AIM 3: Improving Child Health Status			
Child knowledge of cancer prevention, nutrition, obesity, and physical activity	✓	✓	<b>√</b>

Highlights of activities from FY2019 through FY2021 include:

### AIM 1: Improving Access to Care

- Nearly 100% of St. Jude uninsured patients received assistance in enrollment: Following an audit of uninsured families in FY2019, 99.66% of St. Jude's uninsured patients were offered assistance.
- Improved availability of Tele-mental health, with wait times reduced to as little as one day: Following the transition of tele-mental health provider to iHope, time from referral to first appointment for caregivers decreased. A total of 46 patients and caregivers were referred to tele-mental health services in FY2020.
- Increased access to mental health services for caregivers: In FY2021, St. Jude increased the number of caregiver's referred to tele-mental health that scheduled and completed a first visit (56%) to above the national average (20%) first visit completion rate for all tele-mental health referrals.

# AIM 2: Improving Coordination of Care

• More than 3/4 Transition Oncology Program (TOP) patients connected to a local primary care provider: Between 12/1/2018 – 6/30/2020, 82% of transition patients secured a local provider to complete their cancer treatment.



• In adapting to COVID-19, **St. Jude's survivorship team provided 34 online/virtual forum lectures/workshops in FY2021:** Topics covered ranged from screening, risk for subsequent health conditions, and treatment innovations.

### AIM 3: Improving Child Health Status

- Over 2,000 Memphis-area K-12 students received healthy lifestyles education: The school outreach team delivered educational content reinforcing healthy lifestyle choices to reduce lifetime risk of cancer among 2,000 K-12 students in the Memphis area during the 2018-2019 school year.
- HIV staff reached 6,100 people through sixty-five 1.5-hour community educational presentations in FY2020: Attendants included youth, parents, educators, clinicians, and other community leaders. These presentations focused on HIV awareness, HIV care for youth, internalized HIV stigma, PrEP (pre-exposure prophylaxis), and mental health hygiene.
- Increased HPV program awareness and built community capacity: HPV Cancer prevention staff completed nearly 300 partner mailings and distributed a monthly email newsletter to 800 partners. In addition, staff organized and facilitated a virtual seminar on HPV cancer prevention for approximately 240 attendees.

### **CONCLUSIONS AND PRIORITIZATION OF AREAS OF NEED**

In April 2022, the St. Jude CHNA Advisory Council met to review CHNA findings and discuss priority areas for future community benefit programs and services to supplement the medical research and financial assistance community benefit activities that St. Jude already provides. In reflecting upon the success of the current St. Jude community benefit activities, the Advisory Council and Steering Committee chose to build on the prior community benefit activities and data presented in the assessment to develop more targeted aims that continue to align with the mission of St. Jude – to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment.

The Advisory Council discussed the various communities that St. Jude serves and the target population of the aims. The community of St. Jude can best be defined by the St. Jude patient population (target population) and scope of clinical services (principal function), and the geographic community of the Memphis/Shelby County area where St. Jude is located. Not all aims are meant to address all layers of the St. Jude community.

AIM 1: Improving access to mental health supports and services in the community, beyond those related to patient diagnosis and treatment.

- The assessment recognized the needs of patients and caregivers related to diagnosis and treatment while at St. Jude are well taken care of.
- The Advisory Council recognized that mental health needs of children and young adults are not limited to those related to their diagnosis and treatment – and the needs are significant and internal and external interview and focus group participants noted the increased need from the pandemic.

AIM 2: Improving access to providers, resources, and coordinated care during the transition of care from St. Jude and its affiliates to community and/or adult care.



- The activities related to transition of care have seen large successes; the Transition to Oncology Program (TOP) secured more than 80% of transition cancer patients with a local provider to complete their cancer treatment; opening a Sickle Cell clinic in Mississippi to reduce transportation barriers; and partnering with Methodist Health System and Regional One to establish an adult sickle cell clinic to assist patients in transitioning to adult care.
- The Advisory Council recognizes an opportunity to continue to build on those successes, while also expanding the work to address or further address the many barriers to transition of care found in the assessment (e.g., health literacy and understanding how to navigate insurance and the financial aspects of treatment after St. Jude; educating school personnel on how to assist patients navigating the return to school and their treatment; finding specialty providers near a patients home; etc.).

# AIM 3: Improving access and equity to clinical trials at St. Jude and its Affiliates.

• St. Jude should continue to increase efforts to improve access to clinical trials, by removing barriers to participation and addressing inequities.

# AIM 4: Conducting cancer prevention work through education and HPV vaccination.

- Internal and external interview participants highlighted the success of the St. Jude HPV vaccination initiative in building relationships with community stakeholders, disseminating educational materials, and increasing vaccination rates.
- The Advisory Council recognizes that continued work in this area, especially with a lens towards equity for rural populations, individuals on public insurance, and non-Medicaid expansion states may require additional focus.

# AIM 5: Increasing awareness and education of sickle cell disease and infectious diseases (HIV/AIDS) in the community.

- Internal and external interviewees valued the contributions and work of the sickle cell and infectious disease programs at St. Jude in the Memphis community.
- The assessment found that providers and researchers are well informed about the St. Jude programs in this area, but the broader Memphis community and populations most impacted and/or at risk may not be informed about the program or have access to educational materials and prevention efforts.

# AIM 6: Strengthen community partnerships in the greater Memphis area to address social determinants of health for local patients.

 More than half of new St. Jude patients are from Memphis and the surrounding area, strengthening partnerships in the community to address social determinants of health (e.g., housing, food insecurity, etc.) is an important component to positive health outcomes for patients during and after their time as patients.

Cutting across all of these aims is the commitment to address equity and to identify opportunities for collaboration. Given its focused mission and model of providing specialized services to children in crisis, St. Jude does not have the capacity or resources to meet all needs of all children and their families. However, strategic partnerships with other healthcare providers and with schools and community-based organizations allow St. Jude to create a network of resources that can be leveraged to meet the health and social needs of a wider community of patients and their families.



# **Appendix**

# <u>Methodology</u>

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

### Quantitative Data

To develop a social, economic, and health portrait of the community served by St. Jude in the greater Memphis area and nationally, HRiA reviewed existing data from local, state, and national sources. Data sources include but are not limited to: The U.S. Census, Tennessee Department of Education, Tennessee Department of Public Health, the Youth Risk Behavior Survey, and the National Cancer Institute. Any data analyses were conducted by the original data source. New patient data were shared by the St. Jude Department of Information Services in order to provide a snapshot of the new patient population served by the hospital.

### Qualitative Data

In addition to analyzing epidemiological data, HRiA conducted qualitative research with internal and external St. Jude stakeholders as well as with patients and family members served. This research supplements quantitative findings with perceptions of community strengths and assets, priority health concerns, and suggestions for future programming and services. Three focus groups and 22 key informant interviews were conducted between February 2022 and March 2022. Participants represented a broad cross-section of stakeholders, including St. Jude staff, patients and families, local government representatives, public health departments, community-based organizations, and health care providers.

## Focus Groups

Focus groups were conducted with patient caregivers as well as clinical, research, and administrative staff at St. Jude. In lieu of a focus group the Medical Executive Committee was given the opportunity to be engaged in qualitative data collection via an online survey. 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 Patient Family Advisory Council, 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 and the role of St. Jude in addressing them. A semi-structured interview guide was used across all discussions to ensure consistency in the topics covered. Guides were modified for different groups to ensure that they were age and developmentally appropriate.

Each focus group was facilitated by an experienced HRiA staff member; 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 assessment 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. Participants were recruited by St. Jude staff, who arranged all logistics for the onsite focus groups. Details about focus group participants are included later in the Appendix.

### Key Informant Interviews

HRiA conducted 27 interviews with 34 individuals; 13 interviews were conducted with 19 staff of St. Jude hospital, and 12 interviews were conducted 13 individuals from outside the organization.



Interview participants represented a range of sectors, including leaders in health care and health research, government, and social service organizations focusing on vulnerable populations. Additionally, two interviews were conducted with two former St. Jude patients. Similar to the focus groups, a semi-structured interview guide was used across all discussions to ensure consistency in the topics covered. Interviews were 30-60 minutes in length. A list of stakeholder interview participants positions, and organizations can be found later in the Appendix.

## Social Determinants of Health Approach to Qualitative Data Collection

While delivering quality health care to residents is an important part of maintaining community health, it is not the only factor that allows a community to thrive. In addition to individual factors (e.g., genetic makeup and personal behaviors), community health is also influenced by factors such as access to health care, socioeconomic status, community safety, and more. Where applicable, the assessment team probed focus group and interview participants on the health of the community as it relates to these factors. Additionally, the assessment team invited all participants involved in qualitative data collection to share their perspectives on how national conversations around racism, equity, and inclusion have impacted conversations and perceptions in their local communities.

### Analyses

The collected qualitative information was 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 themes within topic areas.

### Limitations

As with all research efforts, there are 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 city 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 Survey of Children's Health should be interpreted with particular caution. In some instances, respondents may over-or 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. Additionally, while there is a time lag in data analyses for data surveillance systems this lag was extended by the COVID-19 pandemic. As a result, some secondary data measures in this report are more outdated than is typical. While this lag is not ideal, it is a challenge faced by health-related organizations and agencies across the state and nation.

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 of the focus group and



interview participants were not collected, 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.

## **List of Participants**

## 2022 CHNA Advisory Council Members

- Nina Antoniotti, Director, Interoperability and Patient Engagement
- Kate Ayers, Director, STEM Education and Outreach
- Dr. Justin Baker, Division of Quality of Life of Palliative Care
- \*Kathryn Berry-Carter, Director, Family, Guest and Volunteer Services
- Dr. Heather Brandt, Director, HPV Cancer Prevention Program and Co-associate Director for Outreach, St. Jude Comprehensive Cancer Center
- Dr. Emily Browne, Transition Oncology Program
- \*Shari Capers, Senior Vice President, Strategic Planning & Decision Support
- Yvonne Carroll, Director, Hematology Patient Services
- Patricia Cathey, Manager, Family Commons
- Robert Clark, Chief Government Affairs Officer
- Dr. Valerie Crabtree, Chief, Psychosocial Services
- Jeana Cromer, Director, Clinical Trials Management
- Kaleigh Davis, Associate Counsel, Office of Legal Services
- Tracy Dodd, Director, Physician/Patient Referral Services
- Joshua Greer, Clinical Project Manager, Administration
- Patti Gust, Vice President, Revenue Cycle
- \*Phyllis Hall, Director Revenue Analysis in Managed Care
- Dr. Jane Hankins, Member of St. Jude Faculty, Hematology Department
- Andrea Harden, Administrative Manager, Psychosocial Services
- DaMaris Heidelberg, Coordinator, Nursing Education
- Jason Hodges, Director, Clinical Trials Management, Hematology Department
- Dr. Melissa Hudson, Director, Cancer Survivorship Division
- Pat Keel, Executive Vice President, Chief Financial Officer, Chief Administrative Officer
- Christy Matthews, Program Manager/Health Educator, Hematology
- Jennifer Morgan, Director, St. Jude Affiliate Nursing Program
- Krisderlawn Motley, Coordinator, Cancer Center Outreach
- Dr. Dan Mulrooney, Pediatric Oncologist, ACT Clinic
- Robyn Pennella, Science Instructional Specialist, Cancer Education and Outreach
- Samantha Ransone, Director, Medical Content/Patient Outreach
- \*Jane Raymond, Director, Managed Care
- Carina Richardson, Parent Family Advisory Council, PAIR Advisor
- Dee Roe, Vice President, Clinical Research Regulatory and Quality Management, Clinical Trials Administration
- Ashley Ross, Manager, Community HIV Program
- Dr. Carolyn Russo, Medical Director, Affiliate Program
- Dr. Victor Santana, physician and faculty in Global and in Oncology Departments
- Taylor Scult, Senior Program Designer, Office of Diversity & Inclusion
- Erica Sirrine, Director, Social Work
- Andrea Stubbs, Administrative Director, HPV Cancer Prevention
- Tangie Thomas, Vice President, Clinical Trials Operations



- Dr. Brandon Triplett, Transplant Clinical Service Chief and Deputy Clinical Director
- Leslie White, Director, Health Information Management Services

\*Steering Committee Member

## Qualitative Data Collection Participants

### Focus Groups

- Administrative Leadership 2 participants
- Parent Family Advisory Council (PFAC) 17 participants
- Psychosocial Department Directors 8 participants
- Medical Executive Committee distributed an online survey to members

# Internal Key Informant Interviews

- Dr. Nina Antoniotti, Director of Interoperability and Patient Engagement
- Kate Ayers, Program Manager, Cancer Education Program
- Dr. Nidhi Bhatt, Instructor, Hematology Department
- Dr. Heater Brandt, Director, HPV Cancer Prevention Program and Co-associate Director for Outreach, St. Jude Comprehensive Cancer Center
- · Caron Byrd, Director, Patient and Family Housing
- Dr. Hana Hakim, Associate Member, Infectious Disease Department
- Dr. Nan Henderson, Director Patient Safety, Office of Quality and Patient Care
- Dr. James Hoffman, Senior Vice President, Office of Quality and Patient Care
- Caleb Lester, Director, Office of Quality and Patient Care
- Dr. Arshia Madni, Instructor, Hospitalist Program, Oncology Department
- Diane McGarry, Administrative Director, Patient Experience Office
- Beth Anne Miller, Vice President, St. Jude Global Operations
- Julia Neely, Program Coordinator, HPV Cancer Prevention Program
- Dr. Nehali Patel, Director of Clinical Services, Infectious Diseases Clinic
- Andrea Stubbs, Administrative Director, HPV Cancer Prevention Program
- Dana Wallace, Associate Director for Administration, Comprehensive Cancer Center
- Shayla Williamson, President and Administrative Director, Home Health
- Former Patients interviews conducted with two former patients

## **External Key Informant Interviews**

- Dr. Susan Aguillard, Pediatrician, Pediatrics East
- Dr. Debra Bartelli, Research Associate Professor, Division of Epidemiology, Biostatistics, and Environmental Health
- Dr. Reginique Green, Chief Clinical Officer, Christ Community Health Services
- Shantelle Leatherwood, CEO, Christ Community Health Services
- Lauren McCann, Director of Operations, Le Bonheur Children's Hospital
- Dr. Morgan McDonald, Deputy Commissioner for Population Health, Tennessee Department of Health
- Dr. Michelle Taylor, Director, Shelby County Health Department
- Jeneba Winfrey-Porter, Medical Operations Director, Church Health
- Dorcas Young Griffin, Director of Community Services, Shelby County Government