

# 2022

# COMMUNITY HEALTH NEEDS ASSESSMENT 2022-2024 IMPLEMENATION PLAN

Report Date: October 12, 2022



#### **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.



#### 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.

#### 2022-2024 IMPLEMENTATION PLAN

The implementation plan was developed during the fall of 2022 with input from the Advisory Committee members. Actions have been developed for each AIM. The anticipated impact, resource commitment, and planned collaborations are identified for each action. The implementation plan will be monitored, and accomplishments reported at the end of each year and presented to leadership.



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

The assessment recognized that the needs of patients and caregivers, related to diagnosis and treatment while at St. Jude, are well met.

The Advisory Council also recognized that the mental health needs of children and young adults are significant and not limited to those related to their diagnosis and treatment; participants in internal and external interviews and those in a focus group noted increased mental health needs due to the pandemic.

Action 1	Expanding telemental health options for St. Jude patients and caregivers when the need is not related to diagnosis and treatment.
Description	St. Jude currently partners with an external entity to provide telemental health services, at no charge to caregivers with pre-existing or new mental health disorders, who live outside the Memphis area and temporarily reside at St. Jude for their child's treatment. The program also provides telemental health counseling sessions to bereaved caregivers. This action item aims to expand the existing telemental health program, including eligibility and duration of care for families residing within our local catchment area and when the need is unrelated to diagnosis or treatment.
Anticipated Impact	Improved mental health, social–emotional functioning, and overall well- being for patients and caregivers. Increased access to care where current barriers exist.
Resource Commitment	Continued funding for the current telemental health program and increased budgetary allowance for the expansion of services. Additional staffing resources may be needed (1.0 FTE to coordinate telemental health and other supportive resources for caregivers and their families).
Planned Collaborations	Expanded partnership with current telemental health provider. Explore partnerships with additional telemental health organizations.



	Enhance and expand available community mental health resources
Action 2	for patients and caregivers by leveraging partnerships and
Description	collaborative efforts.
Description	Patients and families often struggle to locate and access mental health resources in their communities. St. Jude patients come to Memphis from various locations across the country that often lack resources or qualified mental health clinicians. This Action item aims to help eliminate some of these barriers by participating in legislative advocacy to promote the adoption of interstate licensure compacts for mental health providers (e.g., psychology, social work).
	St. Jude will also launch a branded version of "Find Help," a directory of community resources, to be integrated within the electronic health record. This will equip and empower families to locate and access existing supportive and mental health resources in their local communities.
	This Aim will also enhance collaboration with our St. Jude Affiliate Clinics to promote patient and family access to mental health resources in their local communities.
Anticipated Impact	Improved mental health, social–emotional functioning, and overall well- being for patients and caregivers. This Action item will increase access to care where current barriers exist.
	Interstate licensure compacts help eliminate barriers and access to care, especially in underserved, under-resourced, or geographically isolated communities.
Resource Commitment	Continued annual funding for the Find Help database.
	Explore the feasibility of funding legislative action groups to promote the passage of interstate licensure compact legislation.
	Support from the St. Jude Office of Government Affairs; Office of Legal Services; and local, state, and national legislators to enhance mental health support.
	The 1.0 FTE (noted in Action 1) will contribute to the completion of this Action.
Planned Collaborations	Social Care Network, www.findhelp.org
	Collaborate with the Affiliate Program to empower St. Jude affiliate institutions to leverage and enhance mental health resources in their own communities.
	St. Jude Office of Government Affairs/Legal Services.
	Explore collaborations with the Council of State Governments, PSYPACT Commission, National Association of Social Workers, and the Clinical Social Work Association.



# 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.

Activities related to the transition of care have largely been successful: more than 80% of patients followed by the Transition to Oncology Program (TOP) had identified a primary care provider at the completion of their anticancer treatment. A sickle cell clinic was opened in Mississippi to reduce transportation barriers, and we are partnering with Methodist Health System and Regional One to establish an adult sickle cell clinic to help patients transition to adult care.

The Advisory Council recognizes the opportunity to continue building on these successes, while also expanding the work to address (or further address) the many barriers to transition of care identified during the assessment (e.g., health literacy and understanding how to navigate insurance issues and the financial aspects of receiving treatment after patients leave St. Jude, educating school personnel about how to assist patients as they return to school, and finding specialty providers near a patient's home, etc.).

Action 1	Continue to improve transition opportunities for St. Jude patients after completion of therapy.
Description	Implement a clinical pathway to support the transition back to the home community after completion of cancer-directed therapy.
Anticipated Impact	Alignment with national transition standards of practice Increased staff awareness and knowledge of transition guidelines and resource availability
	Increased transition readiness of the patient family
	Increased staff, patient, and family satisfaction with the transition of care to the home community
	Decreased total number of off-therapy patients who see SJ subspecialists and decreased number of visits per off-therapy patient
	Increased scores on Health Care Transition Process Measurement Tool and Current Assessment of Health Care Transition Activities
Resource Commitment	Leverage existing TOP, Care Coordinators, Affiliate Patient Navigator
Planned Collaborations	Primary oncology clinics; ACT Clinic; Office of Quality & Patient Safety; Strategic Communication, Education, & Outreach Department; Affiliate Program; Patient and Family Advisory Council



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

St. Jude Children's Research Hospital has the first and only National Cancer Institute–designated Comprehensive Cancer Center devoted solely to children. The designation reflects leading excellence in laboratory, translational, clinical, and survivorship research, as well as leadership in education and community outreach.

The St. Jude Affiliate Program makes treatments developed as clinical trials at St. Jude available to more children by offering much of the same care close to the patients' homes. The physicians and staff at these sites work in collaboration with the staff of St. Jude to deliver state-of-the-art care and innovative clinical trials to children with cancer or nonmalignant blood disorders.

These two aspects of St. Jude partner to provide equal access to clinical trials in Memphis, at Affiliate locations, and nationwide. Current (and future) initiatives target increasing our understanding of factors involved in parents' decision to enroll their child in a trial and continue to increase access to clinical research for all appropriate pediatric populations. This includes further understanding the barriers associated with clinical trial participation across all population groups.

Action 1	Launch the U-DECIDE trial at the Affiliate Clinics (The Decision to Enroll in Therapeutic Clinical Trials in a Pediatric Cancer Clinical Network).
Description	Understanding why parents decide not to enroll their child in a primary therapeutic clinical trial can inform the design of clinical trials and maximize enrollment. The U-DECIDE trial aims to describe the sociodemographic characteristics of pediatric oncology patients treated through the St. Jude Affiliate network. In addition, the trial will examine the associations between social determinants, decision-making factors, and trial-related attitudes of parents of newly diagnosed pediatric oncology patients in the Affiliate network and the decision to enroll or not enroll their child in a therapeutic clinical trial. Also, it will seek to understand individual preferences, reasons, and factors influencing parents' decision to enroll or not enroll their child in a therapeutic clinical trial.
Anticipated Impact	Understand the associations between social determinants of health, decision-making factors, and trial-related attitudes among parents of newly diagnosed patients.
	Understand the reasons, individual preferences, and factors influencing parents' decision to enroll or not enroll their child in a therapeutic clinical trial.
Resource Commitment	Funding for the U-DECIDE trial. The trial launched in summer 2022.
Planned Collaborations	Partnership with Affiliate Clinic providers.
	Continued partnership with the St. Jude Comprehensive Cancer Center leadership and program medical directors.



Action 2	Continue to implement operational strategies to increase local access to and enrollment in clinical trials at the Affiliate locations.
Description	Operational and strategic efforts have been pursued over the past 4–5 years to increase enrollment in clinical trials at the Affiliate locations. Some Affiliate locations are better prepared and supported locally to enroll patients on St. Jude trials, while others require additional support. Several initiatives are being pursued to support increased enrollment at Affiliate locations:
	<ul> <li>New Affiliate Clinic model implementation – Huntsville, AL location</li> <li>Telehealth use in trial informed consent and other support</li> <li>Partnership with Clinical Trials Administration to ensure appropriate staffing models at Affiliate Clinics</li> <li>Agreements needed for local enrollment efforts</li> </ul>
Anticipated Impact	Increased access to trials in Affiliate Clinic communities.
	Increased enrollment in volume on clinical trials.
Resource Commitment	Funding is provided through the current Affiliate Clinic models.
	Additional resources have been provided in the St. Jude Strategic Plan for Affiliate Clinic model development.
Planned Collaborations	Partnership with Affiliate Clinic providers.
	Partnership with St. Jude Clinical Trials Administration and
	St. Jude Comprehensive Cancer Center leadership and program medical directors.



# 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.

Action 1	Strengthen partnerships with local education agencies to disseminate educational programs on cancer control and prevention.
Description	Partner with local education agencies to disseminate educational programs on cancer control and prevention.
Anticipated Impact	Increase the number of students and teachers participating in the St. Jude cancer control and prevention educational programs.
Resource Commitment	Funding from the National Cancer Institute of the National Institutes of Health, under Award Number P30CA021765
Planned Collaborations	Continued partnership with Memphis Shelby County Schools, University of Tennessee Health Science Center, University of Memphis, Lemoyne- Owen College, the Memphis Public Libraries, and Affiliate site school systems

Action 2	Serve as a leader, convener, and catalyst for implementing evidence-based interventions to increase HPV vaccination coverage and prevent HPV-associated cancers.
Description	The HPV Cancer Prevention Program will engage with external advisors and collaborators on the local, regional, and national levels to identify opportunities and inform programmatic activities to increase HPV vaccination coverage and prevent HPV-associated cancers.
Anticipated Impact	Increase the number and network of partners engaged.
	Expand the period that partners are engaged.
	Measurable number of meetings, staff participation, and resulting actions.
Resource Commitment	Allocation of staff time and direct and indirect expenses related to the activities.
Planned Collaborations	Key partners (local, state, regional, and national), including the Healthy Children's Advisory Council, Unity Consortium, Immunize.org, American Cancer Society, National HPV Vaccination Roundtable, , HPV Cancer– Free Tennessee, Memphis and Shelby County HPV Cancer Prevention Roundtable, University of Memphis, and others.



Action 3	Engage in strategic implementation of evidence-based interventions to increase HPV vaccination coverage.
Description	The HPV Cancer Prevention Program will partner with key organizations in the community, clinical, and policy/advocacy settings to implement evidence-based interventions.
Anticipated Impact	Increased number of programmatic activities and interventions implemented.
Resource Commitment	Allocation of staff time and direct and indirect expenses related to the activities.
Planned Collaborations	Key partners (local, state, regional, and national), including the Healthy Children's Advisory Council, Unity Consortium, Immunize.org, American Cancer Society, National HPV Vaccination Roundtable, Southern HPV Vaccination Roundtable, HPV Cancer–Free Tennessee, Memphis and Shelby County HPV Cancer Prevention Roundtable, University of Memphis, and others.



# 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 St. Jude sickle cell disease (SCD) and infectious diseases (HIV/AIDS) programs in the Memphis community.

The assessment found that providers and researchers are well informed about the St. Jude programs in these areas, but the broader Memphis community and populations most affected and/or at risk may not be informed about the programs or have access to educational materials and prevention efforts.

Action 1	Develop online educational modules on sickle cell testing and genetic counseling for TN Department of Health nurses to enable them to complete the training at their convenience.
Description	St. Jude is the state-designated sickle cell center for West TN to follow up newborns who screened positive at birth for SCD or sickle cell trait (SCT). SCT is the carrier condition for SCD. Approximately 600 newborns who screen positive for SCT or other hemoglobinopathies are referred to St. Jude each year. Parents of newborns who screened positive for SCT require genetic counseling to understand their risk of having a child with SCD and the inherent risk for a child with SCT. Although most newborns with SCT and/or other hemoglobinopathies referred to St. Jude reside in Shelby County (with proximity to St. Jude), ~20% reside in rural areas of West TN. St. Jude has had an ongoing relationship with nurses throughout the mid-south region that are in the catchment area to provide confirmatory testing and genetic counseling to those families within the mid-south. St. Jude provides in-person training and educational material for nurses and families. Unfortunately, due to the COVID-19 pandemic, St. Jude has not been able to provide in-person training, and there has been a large turnover in local health department personnel. In response to the changes required by COVID-19 guidelines, St. Jude will develop online educational modules for local health department nurses that will enable them to complete the blitz training at their convenience. St. Jude nurse- educators and healthcare providers will be available to answer any questions and consult on complicated cases.
Anticipated Impact	Increased access to confirmatory testing and genetic counseling for families at risk of having a child with SCD. Improved awareness of caregivers of complications and inherent risk for their child with SCT.
Resource Commitment	Sustained funding for the Learning Management System (LMS) to assess the participation and completion/mastery of course materials by local health department nurses. Funding for an eLearning training tool to develop educational modules. Additional manpower resources (1.0 FTE) and LMS funding, which depends on the number of participants, to expand the educational modules to local TDH nurses.



Action 1	Develop online educational modules on sickle cell testing and genetic counseling for TN Department of Health nurses to enable them to complete the training at their convenience.
Planned Collaborations	Continued collaboration with rural TDHs. Collaborate with organizations that have a similar interest in newborn screening and genetic counseling for SCD and SCT, e.g., American Society of Hematology Sickle Cell Disease Coalition.

Action 2	Create and execute a communication campaign that addresses the gaps in knowledge and awareness of HIV and the HIV Prevention and Care Program at St. Jude that provides related prevention and treatment.
Description	The communication campaign will have three target audiences: women (to prevent and treat mother-to-child transmission of HIV), youths at risk of or living with HIV, and the healthcare systems that they access (physical and virtual) in the communities where they live.
	The strategy of the communication campaign will be multicomponent, using different platforms for communication (social media, emails, billboards, commercials, radio, etc.), and tailored using any available incidence data (e.g., zip codes) to reach the noted target audiences.
	Campaign planning will be informed by input from community stakeholders, including those from the faith-based community, and will use existing relationships the St. Jude HIV Prevention and Care Program has with members in the community, as well as targeted outreach to seek additional opinions.
	Note: We anticipate an overlap in the target audience, with that of the Sickle Cell Disease Program, based on race/ethnicity. This overlap will provide many opportunities for using communication approaches that serve both programs, which will be mutually beneficial and cost effective.
Anticipated Impact	Increased awareness that St. Jude is leading the fight against many potentially catastrophic illnesses of children and youths. Bend the curve of new HIV infections amongst children and youths in Shelby County by affecting key measures, such as the number of individuals at risk of HIV who get tested, that of individuals with an HIV- negative diagnosis who, if eligible, begin HIV pre-exposure prophylaxis, and reducing the time from HIV-positive diagnosis to first medical appointment and initiation of treatment. The impact of the campaign will be measured via periodic assessments of its mention by randomly approached samples of the noted target audiences.
Resource Commitment	A comprehensive multiyear communication strategy plan and related budget will be developed with the St. Jude Strategic Communication, Education, and Outreach department.



Action 2	Create and execute a communication campaign that addresses the gaps in knowledge and awareness of HIV and the HIV Prevention and Care Program at St. Jude that provides related prevention and treatment.
Planned Collaborations	St. Jude Communication and Media Relations Group, Connect to Protect Memphis Coalition in-conjunction with its 25 plus stakeholders, which include the local and state health departments, faith- based leaders, and community advisory boards.

Action 3	With a coalition of community stakeholders, identify the gaps in the continuum of HIV prevention and care and address those gaps with a focus on structural change
Description	St. Jude founded and has led the "Connect to Protect" Memphis (C2P Memphis) community coalition since 2008. C2P includes community- based organizations and brick-and-mortar healthcare facilities, schools, the local health department, and other individuals and organizations interested in improving HIV prevention and care in Shelby County. From 2008 to 2015, C2P Memphis worked under the auspices of an NIH-funded Adolescent Trials Network Grant; since 2015, it has continued as an unfunded coalition whose members unanimously agreed was good to maintain for our community.
	The C2P Memphis coalition is set up to assess the pulse of HIV prevention and care in Shelby County, identify what is working and what is not, and propose structural changes and advocate for them. This was done as part of the initial grant-funded activity of the coalition. As part of the proposed Action item 3, this interactive, interventional ability of the coalition will be leveraged and deployed.
	The C2P Memphis coalition developed the "End HIV 901 Ending the HIV Epidemic: Health and Harmony in the 901," community action plan in 2019, which is now a CDC-funded effort with TDH oversight. The proposed action plan will compliment and inform the TDH-funded Ending the HIV Epidemic activities in Shelby County.
Anticipated Impact	Structural changes, including at a procedural and policy level, that bring about sustained, improved HIV prevention and care in Shelby County. These structural changes will highlight the efforts put forth by individuals and organizations within C2P. It will also showcase St. Jude's ongoing efforts to take a collaborative approach to change and develop recorded policies that enhance HIV treatment and prevention or eliminate barriers to treatment and care through community input.
	This Action item is anticipated to bring its own type of awareness and recognition of St. Jude and its HIV Prevention and Care Program as a thought leader, recognition that will compliment what we anticipate achieving within Action item 2.
	The anticipated impact will be assessed annually, as the number of structural change objectives and applicable changes are identified and addressed by the C2P Memphis coalition.



Action 3	With a coalition of community stakeholders, identify the gaps in the continuum of HIV prevention and care and address those gaps with a focus on structural change
Resource Commitment	\$7,500 dollars per year for C2P Memphis coalition activities.
Planned Collaborations	More than 25 community members of the C2P Memphis coalition, St. Jude legal counsel and government relations colleagues (when applicable)



# 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; thus, 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.

Action 1	Collaborate with other healthcare organizations; local, state, and national government agencies; and local community organizations to improve identification and utilization of resources.
Description	Through increased advocacy and community engagement, identify resources to help ensure equitable access to health care and other services for children and youths with catastrophic diseases and help childhood cancer survivors improve and maintain their quality of life.
Anticipated Impact	Improved health outcomes for historically marginalized patients and families, as well as improved community engagement.
Resource Commitment	Leverage existing staff for this endeavor.
Planned Collaborations	Tennessee Department of Health, Shelby County Health Department, local hospital systems, Metropolitan Inter-Faith Association (MIFA), Memphis Area Legal Services, The Works, Inc., Blue Cross/Blue Shield of TN