# Casey DeSantis Cancer Research Program Long-Range Plan

December 1, 2024



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## 1. Acknowledgements

This Long-Range Plan was developed based on input from the Cancer Connect Collaborative, cancer centers, research institutions, biomedical education institutions, hospitals, and medical providers both funded and not currently funded under the Casey DeSantis Cancer Research Program.

The Florida Department of Health would like to thank the Florida Agency for Health Care Administration and those individuals, organizations, and institutions who attended the stakeholder meetings and provided input for the Casey DeSantis Cancer Research Program's Long-Range Plan.

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## 2. Executive Summary

In 2024, the Florida Legislature codified the Cancer Connect Collaborative with a purpose of advising the Florida Department of Health and the Legislature on developing a holistic approach to the state's efforts to fund cancer research, facilities, and treatments. The Cancer Connect Collaborative may make recommendations on proposed legislation, proposed rules, best practices, data collection and reporting, issuance of grant funds, and other proposals for state policy relating to cancer research or treatment.

Further, the Florida Legislature charged the Cancer Connect Collaborative with developing a long-range comprehensive plan for the Casey DeSantis Cancer Research Program. In the development of the plan, the Cancer Connect Collaborative must solicit input from cancer centers, research institutions, biomedical education institutions, hospitals, and medical providers.

The plan must include, but need not be limited to, all the following components:

- Expansion of grant fund opportunities to include a broader pool of Florida-based cancer centers, research institutions, biomedical education institutions, hospitals, and medical providers to receive funding through the Cancer Innovation Fund.
- An evaluation to determine metrics that focus on patient outcomes, quality of care, and efficacy of treatment.
- A compilation of best practices relating to cancer research and treatment.

The Casey DeSantis Cancer Research Program, with state funding of more than \$187 million, can fund eligible institutions and leverage opportunities to strengthen cancer research in Florida, and ultimately improve the lives of those impacted by cancer in the state.

Two state funding streams for cancer research have seen dramatic growth in recent years under the Casey DeSantis Cancer Research Program. Nearly \$128 million is allocated to cancer centers that meet criteria established by the National Cancer Institute. Additionally, the Cancer Innovation Fund received \$20 million in Fiscal Year (FY) 2023-2024. With the \$20 million from the Cancer Innovation Fund, the Florida Department of Health awarded 30 grants to 15 Florida-based institutions addressing innovative research across a broad range of cancer types (e.g., bladder, blood, brain, breast, colorectal, liver, and lung). In FY 2024-2025, funds for the Cancer Innovation Fund increased to \$60 million.

Currently, the bulk of cancer research funding is distributed to four facilities meeting criteria set by the National Cancer Institute. In addressing the expansion of cancer research funding to include additional facilities, the Governor and Legislature could consider other types of cancer centers, such as facilities designed as Florida Cancer Centers of Excellence, biomedical education institutions, and pediatric cancer centers. In transforming Florida's approach to cancer prevention, treatment, and research, leaders could consider the opportunities for a Florida Cancer Research Network, potentially housed within, and administered by the Florida Department of Health.

Additional cancer data reporting requirements will ensure Florida's focus on patient outcomes, quality of care, and treatment. In addition to an overview of current cancer data reporting, various metrics to standardize cancer data collection and evaluation are described. Finally, to ensure rapid uptake of best practices, the report describes methods for understanding,

collecting, and reporting cancer best practices across several categories, including screening and risk reduction, clinical management, clinical trials, and survivorship.

#### Recommendations

The following recommendations will transform Florida's approach to cancer prevention, treatment and research and will provide funding for a broader range of facilities, improve cancer care, and further drive innovative research. To achieve a meaningful expansion of cancer research opportunities, the Governor and the Legislature could consider the following options:

- 1. Expand funding opportunities. Expanding funding through the Casey DeSantis Cancer Research Program to a broader pool of facilities to increase access and establish a funding structure based on project merit and potential return on investment of state dollars, ultimately building greater access for Floridians seeking high quality and innovative care across the state. This approach ensures opportunities for funding to build capacity for rural, pediatric, and smaller research and/or health care facilities. Research indicates that greater distance from cancer care has a negative impact on patients affected by these diseases, in terms of stage at diagnosis, appropriate treatment received, and ultimately prognosis and survival. Further, cancer funding models from many other states prioritize research and grant funding rather than funding for specific facilities. Expansion would be supported using current funding under the Casey DeSantis Cancer Research Program by removing the tiered structure and allocation methodology in section 381.915, Florida Statutes, to allow access to the \$127.5 million for other entities based on merit, return on investment, and patient care needs.
- 2. Create a statewide entity with the purpose of issuing cancer research funding and providing oversight and transparency of data, best practices, and patient care in Florida. Establishing a comprehensive program at the Florida Department of Health under the direction of the Cancer Connect Collaborative dedicated to advancing cancer research and access to care is vital to improving patient care and fostering innovation. This entity would fulfill this charge by building competitive funding programs with grant-based programs focused on:
  - Groundbreaking cancer research including, but not limited to, laboratory research, clinical research, and dissemination and implementation research;
  - Cancer prevention and screenings;
  - Fostering collaboration across public and private sectors;
  - Ensuring innovative care and access for all Floridians;
  - Cancer data and trend analysis; and,
  - Recruitment of outstanding cancer researchers.

This entity will be housed at the Florida Department of Health with the Cancer Connect Collaborative as central drivers in transforming cancer research, treatment, and care. Rooted in the Casey DeSantis Cancer Research Program, this initiative will unify statewide efforts, promote groundbreaking innovation, and elevate Florida as a leader in the fight against cancer. With a focus on collaboration, accountability, and measurable impact, the program will advance cutting-edge research, improve patient outcomes, and improve access to cancer care across all corners of the state. It will serve as a beacon of

excellence, fostering a robust ecosystem of innovation that aligns public and private stakeholders in the shared mission of eradicating cancer.

Further, this comprehensive program would create a resource and knowledge-sharing platform to house data and best practices collected from funded research and making funding opportunities available to interested facilities and organizations. Compiling best practices in cancer treatment and care is essential for improving patient outcomes and ensuring that health care providers have access to the most effective strategies. The Cancer Connect Collaborative will be responsible for driving the direction of patient care metrics, clinical outcomes and reviewing and assessing best practices to be available on the platform.

This plan is provided by the Cancer Connect Collaborative in conjunction with the Florida Department of Health in fulfillment of its 2024 legislative directive.

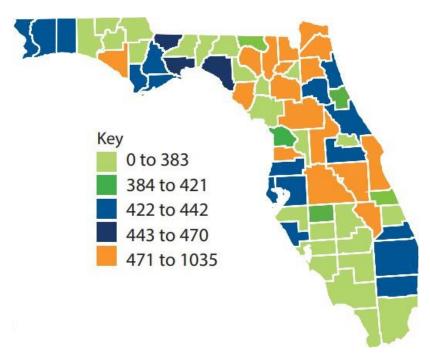
## 3. Introduction

## Overview of Cancer Burden in Florida

Cancer, also called malignant neoplasm, is a class of diseases in which a cell or a group of cells display uncontrolled growth (division beyond the normal limits), invasion (intrusion on and destruction of adjacent tissues) and sometimes metastasis (spread to other locations in the body).<sup>1</sup>

According to Healthy People 2030, while the cancer death rate has declined in recent decades, over 600,000 people still die from cancer each year in the United States.<sup>2</sup> In Florida, cancer is the second leading cause of death after heart disease.<sup>3</sup> Florida also has the second-highest cancer burden in the nation, despite having the country's third-largest population.<sup>4</sup>





<sup>&</sup>lt;sup>1</sup> National Cancer Institute. Understanding Cancer > What is Cancer? <a href="https://www.cancer.gov/about-cancer/understanding/what-is-cancer">https://www.cancer.gov/about-cancer/understanding/what-is-cancer</a>

<sup>&</sup>lt;sup>2</sup> National Cancer Institute. (2019) Annual Report to the Nation on the Status of Cancer, Featuring Cancer in Men and Women age 20-49 Years. *Journal of the National Cancer Institute*, 111(12), 1279-1297. https://doi.org/10.1093/jnci/djz106

<sup>&</sup>lt;sup>3</sup> Florida Department of Health, FLHealthCHARTS. *Leading Causes of Death Profile*. https://www.flhealthcharts.gov/ChartsReports/rdPage.aspx?rdReport=ChartsProfiles.LeadingCausesOfDeathProfile

<sup>&</sup>lt;sup>4</sup> Centers for Disease Control and Prevention. United States Cancer Statistics: Data Visualizations. *Cancer Statistics at a Glance*. https://gis.cdc.gov/Cancer/USCS/#/AtAGlance/

<sup>&</sup>lt;sup>6</sup> 2020-2025 Florida Cancer Plan. Florida Cancer Control & Research Advisory Council.

In addition to the higher per-capita occurrences of cancer across the state, more than 130,000 new cancer cases are diagnosed and reported each year to the Florida Cancer Data System (FCDS), which serves as the statewide cancer registry.<sup>6</sup>

FCDS receives information from 254 hospitals, 108 radiation therapy centers, 515 surgery centers, and 5,688 physician offices, which report over 239,000 cases annually. When unduplicated, the number of new cases translates to approximately 148,500 newly diagnosed cases per year, of which approximately 134,000 are malignant; the remaining cases, although suspected of being malignant, are not.

## 4. Expanding Grant Opportunities for Cancer Innovation

This section explores Florida's state-led cancer funding initiatives with a focus on the Casey DeSantis Cancer Research Program and the Cancer Innovation Fund. It also highlights other states' approaches to cancer research funding and outlines pathways to broaden eligibility under section 381.915, Florida Statutes.

## Florida's Cancer Research Funding Landscape

## **Casey DeSantis Cancer Research Program**

In 2014, the Florida Legislature created the Florida Consortium of National Cancer Institutes (NCI) Centers Program and later renamed it the Casey DeSantis Cancer Research Program in 2022.

## **Exclusive Funding for NCI-Designated Cancer Centers**

In FY 2024-2025, \$127.5 million were appropriated exclusively for Florida's four NCI-designated cancer centers.<sup>7</sup> This represents a consistent increase in state investment since the program's inception in 2014. These institutions have been the primary beneficiaries of the Casey DeSantis Cancer Research Program since its inception in 2014, as there is a formula to determine a participating cancer center's allocation fraction (see equation 1).

#### **Equation 1: Current Tier-Weighted Allocation Fraction Formula**

CAF=  $[0.4 \times (CRC \div TCRC)] + [0.3 \times (CPC \div TCPC)] + [0.3 \times (CBE \div TCBE)]$ Where:

CAF = A cancer center's allocation fraction.

<sup>&</sup>lt;sup>6</sup> Florida Statewide Cancer Registry, Florida Cancer Data System, *Annual Cancer Reports*: 2016–2020. Florida Department of Health. <a href="https://fcds.med.miami.edu/inc/publications.shtml">https://fcds.med.miami.edu/inc/publications.shtml</a>

<sup>&</sup>lt;sup>7</sup> The National Cancer Institute recognizes cancer centers that meet rigorous standards for transdisciplinary, state-of-the-art research focused on developing new and better approaches to preventing, diagnosing, and treating cancer.

CRC = A cancer center's tier-weighted reportable cases.

TCRC = The total tier-weighted reportable cases for all cancer centers.

CPC = A cancer center's tier-weighted peer-review costs.

TCPC = The total tier-weighted peer-review costs for all cancer centers.

CBE = A cancer center's tier-weighted biomedical education and training.

TCBE = The total tier-weighted biomedical education and training for all cancer centers.

After the allocations are calculated, if the calculation results in an annual allocation that is less than \$16 million, that cancer center's annual allocation shall be increased to a sum equaling \$16 million, with the additional funds being provided proportionally from the annual allocations calculated for the other participating cancer centers. Meaning, each of the four participating facilities receive a guaranteed funding allocation annually.

The four centers receiving these funds are:

- 1. Moffitt Cancer Center (Tampa)
- 2. University of Florida Health (UF Health) Cancer Center (Gainesville)
- 3. Sylvester Comprehensive Cancer Center, University of Miami Miller School of Medicine (Miami)
- 4. Mayo Clinic Comprehensive Cancer Center (Jacksonville)

During the 2024 Legislative Session, new accountability and transparency measures were added for those receiving this funding to include:

- A cap on the annual award of 15% for administrative expenses.
- A requirement for the cancer center to submit quarterly reports of all expenditures made by the cancer center with funds received through the Casey DeSantis Cancer Research Program.
- A provision to allow the Florida Department of Health and other state auditing bodies to audit all financial records, supporting documents, statistical records, and any other document pertinent to the allocation agreement.
- A provision requiring the annual reporting of outcome data and protocols used in achieving these outcomes.

Since 2014, Florida's investment in these centers has grown substantially, reflecting the state's commitment to supporting world-class cancer care and research. The \$127.5 million allocated for FY 2024-2025 represents a 27.5% increase from the \$100 million appropriated during the program's significant funding expansion in 2022.

Despite this substantial investment, these four centers are the only entities eligible for this funding stream. While their NCI designations highlight their exceptional capabilities, this exclusivity limits funding accessibility for other cancer facilities and research institutions across Florida, including those in rural or underserved areas.

#### **Expanding Eligibility**

Currently, the four NCI-designated centers serve only 10% of cancer patients, with the remaining 90% of cancer care being delivered by other facilities. These include Florida's two Cancer Centers of Excellence (CCEs) that are not NCI's (Memorial Cancer Institute and

Cleveland Clinic), numerous Commission on Cancer (CoC)-accredited centers, pediatric cancer hospitals, and community-based cancer centers, all of which play essential roles in delivering high-quality care but are ineligible for certain state funding streams.

Prominent hospitals like Tampa General Hospital, AdventHealth Orlando, and Miami Cancer Institute at Baptist Hospital, ranked among the best cancer care providers in Florida by U.S. News Best Hospitals 2024-2025<sup>8</sup>, also remain excluded from funding through the Casey DeSantis Cancer Research Program. Large networks such as AdventHealth, Baptist Health, and Orlando Health provide comprehensive cancer programs statewide, including advanced treatments like surgical oncology, radiation, and chemotherapy. Similarly, community-focused providers like Lee Health Regional Cancer Center and Florida Cancer Specialists and Research Institute ensure accessible care in both urban and rural settings.

Expanding funding eligibility under the Casey DeSantis Cancer Research Program to include these facilities would reflect the diversity and reach of cancer care across Florida. Collaboration should remain a cornerstone of any eligibility expansion, with potential carve-outs for pediatric and community-based cancer centers to address unmet needs and enhance access to care. Table 1 provides a summary of key cancer center designations and the number of facilities in Florida that could benefit from such an approach.

Designation	Designating Entity	Number of Florida-based facilities
NCIs	National Cancer Institute	4
Cancer Centers of Excellence (CCE)	State of Florida, administered by the Florida Department of Health, includes the four NCIs.	6
Commission on Cancer (COC)	American College of Surgeons, Commission on Cancer	62

**Table 1: Florida Cancer Centers by Type of Designation** 

## Implications of Exclusive Facility-Based Funding

The exclusive allocation of funds to only the four NCI-designated cancer centers creates a funding bottleneck that may unintentionally limit innovation and expanded access in cancer care. Expanding eligibility could foster broader collaboration and ensure that patients in every corner of Florida have access to cutting-edge treatments. Rural areas, which often lack proximity to NCI-designated cancer centers, could particularly benefit from this expansion, allowing for a more inclusive and statewide approach to cancer research and treatment.

Currently, two-thirds (68%) of Florida's cancer research funding, allocated through the Casey DeSantis Cancer Research Program, goes to the four NCI-designated institutions (this does not include funding that these facilities received via applications to the Cancer Innovation Fund during FY 2023-2024 or any direct NCI funding they receive). By exploring ways to broaden eligibility, such as pooling funding under one single statewide entity and amending section 381.915, Florida Statutes, Florida can build on the success of its NCI-designated cancer centers while enhancing access to state funding for other deserving institutions.

<sup>&</sup>lt;sup>8</sup> Top 7 Hospitals in Florida for Cancer in 2024-2025 | U.S. News

#### **Cancer Innovation Fund**

For FY 2023-2024, the Florida Legislature authorized \$20 million for the new Cancer Innovation Fund. In its inaugural year, the Florida Department of Health accepted applications beginning October 4, 2023, and distributed those funds across the state for pilot projects in cancer research and innovation. There were 147 applications submitted to the Cancer Innovation Fund for FY 2023-2024. The final 30 awardees represented 15 Florida-based institutions, including one private company, and demonstrated a wide geographical spread across the state, spanning from the Panhandle to Miami. Awardees included innovative cancer research across a broad range of types including breast, colorectal, liver, brain, ovarian, skin, bladder, blood, pancreatic, lung, and esophageal cancers. Pediatric cancer research was also represented, and two applications received an award for projects focused on brain and blood (leukemia) cancers.

The Cancer Innovation Fund focuses on three areas to bring a revolutionary new approach to treating cancer in Florida:

- Innovation is about cutting the red tape and fully unleashing the power of innovation in
  the battle against cancer. Advancements in technology improve at an exponential rate,
  yet clinical application has historically lagged. Research should identify the reasons that
  technology gets delayed whether it be special interests, over-litigiousness, or
  bureaucratic red tape and recommend ways to eliminate these barriers.
- Data and statistics on cancer prevalence and treatment must be timely and readily
  accessible. Research efforts should focus on identifying the factors that delay or hinder
  access to this data and work to eliminate those obstacles.
- Best practices should not be proprietary when it comes to treating cancer. Research should seek to streamline, encourage, and incentivize the sharing of treatment best practices among public and private entities so that everyone is treated with the most effective treatment possible.

Funding for the Cancer Innovation Fund increased to \$60 million in FY 2024-2025.

## **Additional Biomedical Research Cancer Programs**

The Live Like Bella Pediatric Cancer Research Initiative

(Bella Initiative).

Along with the two funding streams within the Casey DeSantis Cancer Research Program, Florida also administers three smaller cancer research initiatives, authorized by the Florida Legislature, to support researchers in their work to improve cancer prevention, diagnosis, and treatment. Table 2 details the funding allocated by each of these programs for FY 2024-2025 for the three cancer research programs.

Cancer Research Program	Funding Amount (FY 2024-
William G. "Bill" Bankhead, Jr., and David Coley Cancer Research Program (Bankhead-Coley Program).	\$10,000,000
The James and Esther King Biomedical Research Program (King Program).	\$7,850,000

Table 2: Additional State-Funding Allocated to Cancer Research

\$3,000,000

\$20,850,000

25)

A broader array of applicants can seek funding under these programs. Specifically, an eligible institution is defined as any university, research hospital, Florida-based Veteran's Administration hospital, or established research institute in Florida. An established research institute is further defined as an organization that is any Florida nonprofit covered under Chapter 617, Florida Statutes, with a physical location in Florida, whose stated purpose and powers are scientific, biomedical, or biotechnological research and/or development and is legally registered with the Florida Department of State, Division of Corporations.

## **Opportunities for Focus Area and Entity Expansion**

The success of the inaugural Cancer Innovation Fund grant cycle is evident. In FY 2024-2025, the Cancer Innovation Fund will continue to encourage groundbreaking research by breaking down traditional silos among researchers, facilities, and providers. Additional funding would allow more projects and entity types to receive funding.

This funding prioritizes:

- Pediatric cancer
- Mitigation of cancer risk factors

### **Pediatric Cancer Hospitals**

Pediatric cancer hospitals represent a key group that could benefit from the expansion of Cancer Innovation Funding and expansion of the NCI-earmarked funding. Access to this funding would enhance their research capacity and elevate the reputation of these institutions.

Florida, home to the third-largest child population in the U.S., accounts for approximately 6% of all new pediatric cancer cases nationwide. <sup>9</sup> Despite this, in FY 2023-24, only 2.6% of Florida's \$208,350,000 cancer research funding, or \$5,427,284, is allocated to pediatric research.

Florida's pediatric cancer care is supported by respected institutions with specialized programs for treating children with cancer. Many of these centers participate in clinical trials and research studies, providing access to cutting-edge treatments. These hospitals typically offer multidisciplinary teams of pediatric oncologists, surgeons, nurses, and support staff, addressing not just medical care but also psychological support and family counseling. However, despite these strengths, Florida has only one hospital ranked in U.S. News & World Report's Top 50 Children's Hospitals for Cancer, and none are in the top 25. Expanding funding for pediatric cancer research could help improve both the quality and reach of these vital services.

## Other State Funding Models to Support Cancer Research and Innovation

Apart from Cancer Innovation Fund dollars, Florida's model for funding cancer research and innovation is primarily facility-based. Florida's four NCI-designated cancer centers share \$127.5 million in current funding. Over the past decade, general revenue funding from FY 2014-2015 through FY 2024-2025 for Florida's NCI-designated facilities totaled \$847.1 million. Models from other states such as California, Massachusetts, New Jersey, and Texas prioritize research and grant funding rather than funding for specific facilities.

<sup>9</sup> http://wonder.cdc.gov/cancer-v2020.html

### **State-Funded Cancer Research Programs**

State cancer research funding varies significantly across different states and can come from a mix of state budgets, obligation bonds, grants, and partnerships with universities and private organizations. Many states have established dedicated cancer research programs, often focusing on specific types of cancer or certain research initiatives.

### **Sources of Funding**

- State Budgets: Many states allocate a portion of their general funds specifically for cancer research or use obligation bonds. This funding often supports state health departments, cancer registries, and various initiatives aimed at prevention and treatment.
- Grants: States may receive federal grants, such as those from the National Institutes of Health (NIH) or the Centers for Disease Control and Prevention (CDC), to support cancer research projects. Additionally, private foundations and nonprofit organizations often offer grants that states can apply for to fund specific research initiatives.
- Partnerships: Collaborations between state governments and universities or research institutions are common. These partnerships can lead to joint funding opportunities and shared resources, enhancing the overall capacity for cancer research within the state.
- **Private Industry:** Some states work with pharmaceutical manufacturers and biotechnology companies that invest in research to develop new treatments and diagnostics. Some of these public-private partnerships are in the form of matching grants, thereby serving as a force multiplier in cancer research.

## **Dedicated Cancer Research Programs**

Many states have established specialized cancer research programs that focus on:

- Targeted Research Initiatives: States may prioritize certain types of cancer that are
  more prevalent or pose a significant public health challenge. For example, lung cancer
  research might receive more funding in states with high smoking rates.
- Prevention and Screening: Some programs focus on improving prevention strategies and increasing screening rates among at-risk populations. This includes funding for public awareness campaigns and community outreach programs.
- **Clinical Trials:** States often support clinical trials to evaluate new treatments and therapies. This not only advances research but also provides local patients access to cutting-edge care.
- **Dissemination and Implementation:** Some programs fund research that aims to bridge the gap between scientific discovery and real-world impact by studying how best to spread and integrate evidence-based best practices. Dissemination focuses on distributing knowledge and tools to health care providers, policy makers, and communities, such as rural areas. Implementation examines how to effectively adopt best practices in health care systems and communities. Florida Cancer Control and Research Advisory Council (CCRAB) successfully piloted an implementation grant for the Florida Cancer Plan that involved the regional cancer collaboratives.

Several states, e.g., Texas, California, New York, New Jersey, and Massachusetts, have launched state-funded cancer research programs that encompass a broad spectrum of activities, including research, education, training, prevention, diagnosis, treatment, and survivorship.

Investing in cancer research is both a health and economic strategy with significant returns. Research funding yields substantial returns on investment (ROI) by enabling early detection, prevention, and cost savings through reduced treatment needs. It also creates jobs in research and health care while fostering innovative treatments that improve survival and quality of life. Additionally, research enhances public health knowledge, engages communities in prevention, and informs effective health policies.

Although measuring ROI can be complex due to time lags and the challenges of isolating research impacts, studies indicate that every dollar invested can yield multiple dollars in health savings and productivity gains, highlighting the critical importance of investing in cancer research. In fact, Texas reports that for every \$1 invested in a cancer grant program like the Cancer Prevention and Research Institute of Texas (CPRIT), especially for screening and prevention and detection, there is a potential economic return of \$29.08, driven by job creation, health care cost savings, commercialization of new therapies, and long-term public health improvements.<sup>10</sup>

## 5. Cancer Funding Transformation

Transforming Florida's approach to cancer prevention, treatment, and research will provide funding for a broader range of cancer facilities, improve cancer care, and further drive innovative research. By expanding access to cancer funding to a broader range of cancer facilities, this transformative process offers the possibility of creating a stronger, broader cancer care network with access for people in rural areas and one that includes pediatric cancer facilities.

Funding transformation along with the creation of the Florida Cancer Research Network will address these three components:

- 1. Expanding the field of recipients of state investments to help fight cancer.
- 2. Increasing access to high quality care and research in rural communities.
- 3. Increasing access to high quality care and research for children and adolescents.

## Creation of a Statewide Florida Cancer Innovation Program

Transformation of the Casey DeSantis Cancer Research Program funding model will include the creation of a statewide entity and program – the Florida Cancer Research Network – housed within, and administered by, the Florida Department of Health under the direction of the Cancer Connect Collaborative.

This new innovative, comprehensive, and strategic program will position the Florida Department of Health and the Cancer Connect Collaborative as central drivers in transforming cancer research, treatment, and care in the state. Rooted in the Casey DeSantis Cancer Research Program, this initiative will unify statewide efforts, promote groundbreaking innovation, and elevate Florida as a leader in the fight against cancer.

<sup>&</sup>lt;sup>10</sup> Cancer Prevention & Research Institute of Texas

With a focus on collaboration, accountability, and measurable impact, the Florida Cancer Research Network will advance cutting-edge research, improve patient outcomes, and increase access to cancer care across all corners of the state. It will serve as a beacon of excellence, fostering a robust ecosystem of innovation that aligns public and private stakeholders in the shared mission of eradicating cancer.

To bring this vision to life, the Florida Department of Health will integrate the Florida Cancer Research Network within its existing organizational framework, aligning its functions with related initiatives like the Health Care Innovation Council (381.4015, Florida Statutes) and the Cancer Connect Collaborative Council (381.915, Florida Statutes). This centralized structure will streamline coordination, amplify synergies, and enable strategic oversight. The program will be supported by dedicated staff and resources at the Florida Department of Health.

## **Key Components of Implementation**

### 1) Establishing Infrastructure

This program will be housed within the Florida Department of Health and supported by dedicated staff and resources. Under the direction of the Cancer Connect Collaborative, a multidisciplinary oversight committee (Appendix 10 provides more details on a proposed oversight framework) will be created to ensure transparency and alignment with strategic goals, including representation and inclusion from the CCRAB, BRAC, and other key stakeholders. Robust data-tracking tools to monitor patient outcomes, provider metrics, and project expenditures will be developed to recognize the ROI of state dollars.

## 2) Competitive Funding Program

By creating a competitive model for existing funding streams, the program will launch a diverse funding portfolio to support innovative cancer research, prevention, and treatment projects, and prioritize projects with the potential for high impact, including translational research, underserved populations (e.g., pediatrics and rural communities), and emerging areas in oncology. The \$127.5 million funding dedicated exclusively to NCI-designated facilities along with the \$60 million from the Cancer Innovation Fund would provide opportunities for facilities across Florida to seek funding.

#### 3) Capacity Building and Collaboration

The program will facilitate partnerships between academic institutions, health care providers, and private sector entities to amplify research impact. It will also offer funding for oncology workforce development, including post-doctoral researchers, clinical oncologists, and eminent scholar recruitment.

## 4) Knowledge Sharing and Dissemination

The program will create an online knowledge-sharing platform to serve as a repository of best practices, research findings, and success stories. Under this program, the Florida Department of Health will host workshops, focus groups, and webinars to foster a deeper collaboration among researchers, clinicians, and policymakers.

#### 5) Metrics and Accountability

Under the direction and advisement of the Cancer Connect Collaborative, the program will establish clear guidelines for evaluating grant proposals based on feasibility, impact, and alignment with the program's goals. The program will regularly collect and report on metrics such as patient outcomes, project milestones, and financial performance. Further, the program will use data-driven insights to refine funding priorities and inform strategic decision-making under the direction of the Cancer Connect Collaborative.

### 6) Strategic Partnerships

The program will actively engage with other councils, organizations, and external stakeholders, fostering a statewide network that leverages the strengths of Florida's biomedical research ecosystem. It will also align with national and global initiatives to ensure that Florida remains at the forefront of cancer innovation.

### **Expected Outcomes**

By focusing on cutting-edge research, comprehensive care, and state-wide access, the program will lead to:

- Accelerated scientific discoveries.
- Improved patient care and access for underserved communities.
- Enhanced capacity for Florida to attract and retain top oncology talent.
- A data-driven approach to combating cancer and improving statewide health outcomes.

This transformative initiative will reflect the Casey DeSantis Cancer Research Program's commitment to combating cancer through innovation, collaboration, and accountability, solidifying its role as a national leader in cancer research and care.

## Florida Cancer Research Network Priority Areas

The Florida Cancer Research Network will be responsible for operationalizing four broad areas of responsibility aimed at improving Florida's fight against cancer, (1) Research, (2) Recruitment, (3) Infrastructure and Technology, and (4) Program Development. These interconnected areas will promote collaboration, innovation, and measurable impact statewide.

**Research** will focus on establishing rigorous funding criteria based on measurable indicators like reportable cancer cases. The program will manage competitive grant programs for academic research, product development, and prevention initiatives, prioritizing collaborative projects with Florida-based community cancer centers and commercial partners. By funding diverse research, from translational studies to projects addressing underserved populations, the program will accelerate breakthroughs in prevention, treatment, and patient outcomes.

**Recruitment** will enhance Florida's oncology workforce by creating relocation and recruitment packages to attract eminent scholars and clinicians. Fellowship and endowed chair programs will be established to support cutting-edge research and clinical expertise. Collaboration with state programs like the Florida Reimbursement Assistance for Medical Education (FRAME) and Medicaid will expand loan repayment and rural residency opportunities, addressing health care professional shortages.

**Infrastructure and Technology** will modernize the FCDS to include critical data on cancer recurrence, survivorship, and treatment outcomes. The program will leverage innovative health data tools, such as the Florida Health Information Exchange (HIE), to enhance data quality and coordination of care. Investments in advanced technologies like proton therapy and liquid biopsy systems, with shared-use agreements, will expand access for smaller institutions. Matching

grants and private partnerships will enable strategic infrastructure improvements, maximizing state funding while advancing treatment capabilities.

**Program Development** will foster a robust cancer care network across Florida by facilitating partnerships, connecting stakeholders, and creating funding opportunities. The program will support collaborative efforts to improve access to pediatric and rural care through hub-and-spoke models and satellite clinics. It will integrate with advisory councils like CCRAB and BRAC to guide activities and funding decisions. By sharing resources, funding innovative projects, and leveraging programs like the Mary Brogan Cancer Early Detection Program, the program will reduce lack of access to care and ensure that innovative solutions benefit all Floridians.

## **Proposed Funding Options**

Funding options for cancer innovation depend on legislative direction. Table 3 provides different configurations for funding the Florida Cancer Research Network.

Table 3: Florida Cancer Research Network and Grant Activities Based on Different Funding Levels

Number	Description	Funding Option
1.	Creates the Florida Cancer Research Network under the Casey DeSantis Cancer Research Program and considers all current state funding linking to other statutory requirements.  The Florida Cancer Research Network will broaden the scope of cancer grants and activities in the state.	Oversees all state-funded cancer research operated by one statewide funding body. For example, the Cancer Innovation Fund grants (\$60 million), the \$127.5 million Casey DeSantis Cancer Research Program funding (currently allocated solely to the NCI-designated centers), and the other three cancerrelated biomedical research funds (\$20.85 million), to create a single fund distributor for cancer research, recruitment, infrastructure and technology and program development.
2.	Creates the Florida Cancer Research Network under the Casey DeSantis Cancer Research Program and Considers Current Funding levels.  The Florida Cancer Research Network will broaden the scope of cancer grants and activities in the state. Includes pediatric cancer carve out from current funds.	Oversees all state-funded cancer research operated by one statewide funding body. For example, the Cancer Innovation Fund grants (\$60 million), the \$127.5 million Casey DeSantis Cancer Research Program funding (currently allocated solely to the NCI-designated centers), and the other three cancerrelated biomedical research funds (\$20.85 million), to create a single fund distributor for cancer research, recruitment, infrastructure, technology, and program development. Includes a carve out specifically for pediatric cancer research and treatment, with 6% of funds targeted toward pediatric cancer research and related activities based on current national burden in Florida.

## 6. Evaluation of Patient Outcomes, Quality of Care, and Efficacy of Treatment

The second required component for this long-range plan is the evaluation of metrics that focus on patient outcomes, quality of care, and efficacy of treatment. The importance of having meaningful metrics is discussed below along with a description of current reporting requirements. Proposed metrics are also considered as well as a methodology for collecting, reporting, and using research findings.

## **Current Population Based Data Collection**

## Florida Cancer Registry

The Florida Cancer Data System (FCDS) is the statewide cancer registry program established in statute (section 385.202, Florida Statutes) to ensure that cancer reports are maintained and available for use during any study to reduce morbidity and mortality. More than 200 facilities, including laboratories and other organizations licensed under Chapters 395 and 483, and section 408.07(20), Florida Statutes, and practitioners licensed under Chapters 458, 459, 464, Florida Statutes, are required to report cancer incidence information to the Florida Department of Health (through FCDS), as specified by Rule 64D-3.034, Florida Administrative Code.

As previously mentioned, more than 130,000 new cancer cases are diagnosed and reported each year to the FCDS, which serves as the statewide cancer registry. FCDS receives information from 254 hospitals, 108 radiation therapy centers, 515 surgery centers, and 5,688 physician offices, which report over 239,000 cases annually.

At present, facilities must report patient information to FCDS including:

- Cancer diagnosis
- Method of diagnosis
- Stage at diagnosis
- Patient demographics
- Medical history
- Laboratory data
- Tissue diagnosis
- · Method of treatment (first course)

#### **Annual Report**

As required by section 381.915, Florida Statutes, starting July 1, 2025, and annually thereafter, the Florida Department of Health, in collaboration with participating cancer centers, will be required to submit a report to the CCRAB detailing key metrics related to cancer mortality and external funding for cancer research in the state. The report will include:

 Analysis of Age-Adjusted Cancer Mortality Trends: A comprehensive analysis of age-adjusted cancer mortality rates in the state, including, at a minimum, overall ageadjusted mortality rates for cancer statewide, as well as breakdowns by age group, geographic region, and cancer type. This must include the following cancers: lung,

<sup>&</sup>lt;sup>11</sup> Florida Statewide Cancer Registry, Florida Cancer Data System, *Annual Cancer Reports: 2016–2020.* Florida Department of Health. <a href="https://fcds.med.miami.edu/inc/publications.shtml">https://fcds.med.miami.edu/inc/publications.shtml</a>

- pancreatic, sarcoma, melanoma, leukemia and myelodysplastic syndromes, brain, and breast cancer.
- Trends in Federal Research Funding: An overview of trends in federal funding for cancer-related research in the state, with detailed breakdowns by institutional source.
- Collaborative Grants and Inter-Institutional Partnerships: A detailed list and
  narrative description of collaborative grants and inter-institutional collaborations among
  participating cancer centers. This section should also include a comparison of the
  proportion of collaborative grants relative to total grant funding for each cancer center, a
  catalog of retreats and seed grants funded by state resources, as well as future
  collaboration targets and progress updates on achieving these targets where applicable.

## Importance of Metrics in Cancer Research and Current Reporting

Metrics play a critical role in evaluating the quality of cancer care, driving efforts to improve clinical outcomes, boost patient satisfaction, and optimize the health care experience for both cancer patients and survivors. This evidence-based approach not only improves patient outcomes but also enhances the overall quality of care.<sup>12,13,14, 15</sup>

- Evidence-based decision-making: Patient outcome data can provide evidence of the effectiveness of cancer treatments, which can help researchers make informed decisions about which treatments to fund and which to discontinue.
- **Identification of areas for improvement:** Patient outcome data aids researchers in identifying opportunities for refining cancer treatments, such as reducing side effects or improving quality of life for patients.
- Patient-centered research: Patient outcome data can help researchers focus on patient-centered research and incorporating the patient's perspective and experience of cancer treatment.
- **Improved quality of care:** Patient outcome data can help elevate the quality of care for cancer patients by identifying best practices and areas for improvement.
- Increased funding access: Patient outcome data can significantly bolster funding prospects for cancer research by demonstrating the tangible impact of the research on patient outcomes.

## **Proposed Metrics for Evaluation**

There are several patient outcomes, treatment efficacy, and quality of life measures that can be reported by cancer centers. Examples include the following:

• Patient-Reported Outcome Measures (PROMs): PROMs are questionnaires that patients complete to report their symptoms, quality of life, and other outcomes related to

<sup>&</sup>lt;sup>12</sup> 314e. (2022). The Role and Importance of Data Collection in Healthcare. <u>The Role and Importance of Data Collection in Healthcare</u> - 314e

<sup>&</sup>lt;sup>13</sup> 314e. (2022). The Role and Importance of Data Collection in Healthcare. <u>The Role and Importance of Data Collection in Healthcare</u> - 314e

<sup>&</sup>lt;sup>14</sup> National Cancer Institute. Division of Cancer Control & Population Statistics. Healthcare Delivery Research Program, About the Outcomes Research Branch. <a href="https://healthcaredelivery.cancer.gov/about/orb/">https://healthcaredelivery.cancer.gov/about/orb/</a>

<sup>&</sup>lt;sup>15</sup> Silveira, A, et al. (2022). Patient reported outcomes in oncology: changing perspective—a systematic review. *Health and Quality of Life Outcomes*, 20(82):1–15. https://hglo.biomedcentral.com/articles/10.1186/s12955-022-01987-x

- their cancer treatment. PROMs can be used to assess the effectiveness of treatments, identify areas where quality of care can be improved, and involve patients in research.<sup>16</sup>
- Key Performance Indicators (KPIs): KPIs are metrics used to measure and evaluate the
  effectiveness, quality, and efficiency of care provided to cancer patients. These indicators
  help health care facilities monitor performance, improve care, and ensure that patient
  needs are met.
- Core Outcome Sets (COS): COS represent agreed-upon recommendations regarding
  what outcomes should be measured as a minimum in studies of a health condition. COS
  can be used to standardize outcome measures in cancer research and ensure that
  research is focused on patient outcomes.<sup>17</sup>
- Objective Measures: Objective measures can include laboratory tests, imaging studies, and other tests that provide objective data on a patient's cancer treatment. These measures can be used to assess the effectiveness of treatments and to identify areas where quality of care can be improved.<sup>18</sup>
- **Survival Statistics:** Survival statistics are of great interest to patients, clinicians, researchers, and policy makers. A variety of survival statistics exist, each possessing their own statistical methods developed to answer different questions. Some survival statistics which exist to provide insight into patient outcomes and efficacy of treatment include overall survival, relative survival, and cause-specific survival.<sup>19</sup>

These performance measures are key to evaluating the effectiveness of cancer treatments, guiding treatment decisions, and improving patient outcomes and quality of life. It is important for health care providers and researchers to use a combination of these measures to comprehensively assess the efficacy of different cancer treatments. An expert panel (e.g., CCRAB) could be tasked with reviewing and vetting measures to satisfy the requirement.

## Proposed Methods for Cancer Data Collection

- **Surveys and Questionnaires** Designing a robust methodology for collecting data from cancer care surveys and questionnaires involves several key steps to ensure that the data is reliable, valid, and actionable.
- **Focus Groups** Focus groups also support the development of health policies, address disparities, and ensure that treatment is tailored to diverse cultural and socioeconomic factors. Overall, they offer valuable context that improves cancer research, patient outcomes, and health care practices.
- **Dissemination and Implementation Projects** Dissemination and implementation projects aim to bridge the gap between research and real-world practice by effectively spreading evidence-based findings and integrating them into health care settings.
- Clinical Data Analysis Clinical data analysis involves collecting data from sources like
  electronic health records (EHRs), clinical trials, and patient registries, covering both
  structured data (e.g., lab results) and unstructured data (e.g., clinician notes). After
  cleaning and preparing the data for accuracy, statistical analysis is used to identify trends,

DiMaio, M, Basch, E, Denis, F, et al. The role of patient-reported outcome measures in the continuum of cancer clinical care:
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<sup>&</sup>lt;sup>17</sup> Ramsey, I, et al. (2020). Core outcome sets in cancer and their approaches to identifying and selecting patient-reported outcome measures: a systematic review. *Journal of Patient-Reported Outcomes, 4*(77) <a href="https://ipro.springeropen.com/articles/10.1186/s41687-020-00244-3">https://ipro.springeropen.com/articles/10.1186/s41687-020-00244-3</a>

<sup>&</sup>lt;sup>18</sup> Maldonado, E, et al. (2021). Outcome Measures in Cancer Rehabilitation: Pain, Function, and Symptom Assessment. *Frontiers in Pain Research*, 2(692237). https://www.frontiersin.org/articles/10.3389/fpain.2021.692237/full

<sup>&</sup>lt;sup>19</sup> Mariotto, AB, et al. (2014). Cancer Survival: An Overview of Measures, Uses, and Interpretation. *Journal of the National Cancer Institute. Monographs 2014, 49*:145–186. https://pubmed.ncbi.nlm.nih.gov/25417231/

- correlations, and insights that inform clinical decision-making, population health management, and predictive analytics for future outcomes.
- Comparative Analysis This method begins by defining objectives, selecting subjects for comparison, and establishing relevant metrics, both qualitative (e.g., patient satisfaction) and quantitative (e.g., financial performance). The results are interpreted, visualized, and accompanied by actionable recommendations.

## Reporting and Utilization of Findings

#### Florida Cancer Research Network

The Florida Cancer Research Network will serve as a central resource for best practices in cancer care, sharing successful interventions and findings with health care providers and stakeholders nationwide. Through workshops, publications, focus groups, surveys, and an online platform (such as the Cancer Connect website), the Network will foster the exchange of evidence-based practices across multidisciplinary teams, enabling researchers and health care providers to collaborate, learn from each other, and implement effective solutions.

## Florida Health Information Exchange

The Florida Health Information Exchange (HIE) facilitates the secure exchange of health information between health care providers, hospital systems, and payers. The Florida Agency for Health Care Administration governs the Florida HIE by setting policy, convening stakeholders, providing oversight, engaging federal partners, and promoting the benefits of health information technology. These efforts can be augmented with shared agency list servs and information stored in data lake-houses. Continued evaluation of the success of these collaborations and celebrating achievements together helps strengthen relationships for future initiatives, ultimately creating a more significant and lasting impact in the community.

#### **Dynamic Improvement Process: Training and Education**

Dynamic Improvement training and education is vital to ensure that individuals and organizations can continuously adapt to changing environments and emerging challenges. By integrating a Dynamic Improvement process into cancer care, health care providers can ensure that they deliver the most up-to-date, effective, and compassionate care, ultimately enhancing patient outcomes and experiences. Dynamic Improvement includes a focus on the following components:

- Rapid Advancements: Cancer treatment and research are continually evolving, with new therapies, technologies, and techniques emerging regularly. A Dynamic Improvement approach ensures that health care professionals stay current with the latest advancements and integrate them into patient care.
- **Personalized Medicine**: Cancer care increasingly focuses on personalized treatment plans tailored to individual patients. Continuous training helps health care providers understand and apply the latest methods for genetic profiling and personalized therapies, improving patient outcomes.
- Quality of Care: Regularly updating knowledge and skills enhances the quality of care
  provided to cancer patients, leading to better management of symptoms, side effects,
  and overall treatment efficacy.

- Evidence-Based Practice: Ongoing education ensures that cancer care practices are based on the latest research and evidence, improving the effectiveness of treatments and interventions.
- Interdisciplinary Collaboration: Cancer care often involves a multidisciplinary team, including oncologists, nurses, radiologists, and support staff. Dynamic training fosters better collaboration and communication among team members, leading to more comprehensive and cohesive care.
- Patient Support and Education: Training in the latest supportive care techniques helps health care professionals provide better psychosocial support and education to patients and their families, addressing their needs throughout the cancer journey.
- Adaptation to Challenges: The cancer care field faces unique challenges such as managing complex cases and navigating the side effects of aggressive treatments. A dynamic improvement process helps health care providers adapt strategies to overcome these challenges effectively.

## 7. Compilation of Best Practices in Cancer Research and Treatment

The third and final component of this long-range plan focuses on best practices in cancer research, prevention, treatment, and care. Section 7 explains what best practices are, identifies different sources of best practices, categories of best practices, and offers potential strategy recommendations regarding best practices.

Standardizing cancer research practices presents challenges due to factors like varying patient populations, resources, institutional priorities, and research focuses. The fast pace of advancements, differences in clinical trial protocols, and regulatory environments add complexity. Institutional cultures and the challenges of interdisciplinary collaboration also provide obstacles for consistency. To achieve best practices, ongoing collaboration, flexible protocols, and regular updates are essential.

Key strategies for collecting and sharing best practices include creating evidence-based guidelines, fostering national and international collaboration, and providing centralized training programs. Using technology for data sharing, promoting quality improvement, and supporting multidisciplinary care teams are also important. While standardization is needed, practices must also be adaptable to local needs, with ongoing monitoring to improve cancer care and research outcomes.

## **Definition and Sources of Best Practices**

Best practices in cancer treatment and care focus on delivering the highest quality, most personalized care possible. This approach ensures that treatments are based on the latest evidence-based guidelines, reflecting the most current research. Each care plan is tailored to the individual needs and conditions of the patient, with a team of specialists working together to provide comprehensive, patient-centered care. Decisions are made with the patient's preferences and values in mind, while safety and quality are maintained through strict protocols. In addition to medical care, patients receive support in areas such as pain management,

nutrition, and emotional well-being. Clear and open communication keeps patients informed and actively involved in their treatment, while regular monitoring and follow-ups allow for adjustments as needed to ensure effective care. Compassion and respect are emphasized, especially when addressing end-of-life concerns, and the integration of new technologies and innovations helps to continuously improve treatment outcomes and enhance the patient experience.

Research institutions, including universities and cancer centers, play a crucial role in publishing studies that highlight effective treatment strategies and innovations in care. Professional associations support health care providers by offering crucial guidelines and resources, while government agencies establish relevant standards and fund vital research initiatives. In addition, medical journals and publications provide valuable insights into the latest research and treatment protocols, ensuring that practitioners are well-informed and up-to-date in the rapidly evolving field of cancer care. Ultimately, these various sources create a robust framework for identifying and implementing best practices in cancer care and treatment.

Comprehensive cancer centers engage in a multidisciplinary approach that fosters collaboration among specialists to create personalized treatment plans. An example of the multidisciplinary approach to best practices can be seen at MD Anderson Cancer Center, the largest comprehensive cancer center in the world. MD Anderson Cancer Center has created an invaluable resource for care delivery to assist in cancer screening, diagnostic evaluation, management of clinical symptoms, and transition to survivorship. Under each of these major categories are extensive process map algorithms outlining best practices for care delivery from clinical presentation to treatment and follow-up.

Key professional oncology associations and societies, such as the American Society of Clinical Oncology, American Association for Cancer Research, and European Society for Medical Oncology, play vital roles in advancing cancer research, education, and care. They organize annual meetings, publish influential journals, and develop clinical practice guidelines to standardize treatment. Other notable groups include the National Comprehensive Cancer Network, which focuses on quality cancer care; the Society of Surgical Oncology, and American Society for Radiation Oncology, which cater to specific treatment modalities; and organizations like Cancer Research UK and the International Agency for Research on Cancer, which prioritize research and awareness. Collectively, these organizations foster collaboration, provide valuable resources, and advocate for policies to improve cancer care and research outcomes.

Case studies in cancer care and treatment best practices provide real-world evidence of how specific strategies perform in clinical settings. By showcasing both successes and challenges, they enable health care professionals to learn from the experiences of others, thereby informing decision-making and guiding the adoption of effective practices. These detailed accounts highlight innovative approaches, emphasize the importance of patient-centered care, and illustrate the benefits of multidisciplinary collaboration. Case studies can identify areas for quality improvement, optimize resource allocation, and serve as a foundation for further research. Ultimately, they play a vital role in enhancing the quality of care and improving patient outcomes in the evolving landscape of cancer treatment.

## **Categories of Best Practices**

Best practices in cancer prevention, treatment, and care can be organized in many ways. The best practices framework used for this report organizes best practices into four categories: 1) screening and risk reduction, 2) clinical management, 3) clinical trials, and 4) survivorship.

## **Screening and Risk Reduction**

Adhering to established screening guidelines based on individual risk factors, providing thorough patient education, and promoting healthy lifestyle choices are essential for improving cancer detection and outcomes. Ensuring access to screening services, particularly for underserved populations, and implementing reminder systems for follow-ups are crucial steps in maintaining consistent care. Leveraging technology to streamline processes and targeting highrisk groups with specialized options further enhances effectiveness. Engaging multidisciplinary teams in the screening process also helps ensure comprehensive care. In addition, continuously evaluating screening programs through data analysis and patient feedback allows for necessary adjustments. By adopting these practices, health care providers can improve early detection, treatment outcomes, and reduce cancer incidence and mortality.

Currently, the Florida Department of Health provides cancer screening programs for breast, cervical, and colorectal cancer. These include The Florida Breast and Cervical Cancer Early Detection Program (FBCC), which is designed to promote access to breast and cervical cancer screenings recommended by doctors. These screenings are free or low cost if the individual meets program eligibility requirements. Screening resources for colorectal cancer can also be found in some of Florida's county health departments. The Florida Department of Health's website on cancer provides other resources for colorectal cancer screening, which include:

- The Center for Change
- o The National Center for Farm Workers Health
- CancerCare

#### **Clinical Management**

Best practices in clinical management prioritize high-quality, patient-centered care, emphasizing active patient engagement, open communication, and evidence-based guidelines, while continuous education for health care professionals ensures care remains aligned with the latest research. Data-driven decision-making through health information technology (HIT) enhances care by enabling real-time monitoring of patient outcomes and trends. Electronic health records (EHRs) and analytics help identify areas for improvement, track treatment effectiveness, and facilitate timely adjustments to care plans, particularly for underrepresented populations. Together, collaboration and data-driven insights form the foundation for delivering optimal patient care.

#### **Clinical Trials**

Clinical trials in cancer assess new treatments, drugs, and therapies for safety and effectiveness. They are conducted in phases: Phase I focuses on safety and dosage with a small group, Phase II evaluates efficacy on a larger scale, Phase III compares new treatments to standard options in an even larger population, and Phase IV monitors long-term effects post-approval. Trials can be interventional, observational, or aimed at prevention, screening, or quality of life. Key design elements include randomization, blinding, and defined endpoints, while strict eligibility criteria determine participant inclusion. Clinical trials advance treatment options, facilitate personalized medicine, and provide patients access to innovative therapies, ultimately enhancing cancer care and outcomes.

#### **Survivorship**

Survivorship as it pertains to cancer care is essential for supporting individuals after treatment and addressing the various challenges they may face. Comprehensive survivorship care plans should be developed for each survivor, outlining personalized follow-up care, health screenings, and management strategies for potential late effects of treatment.

## Sharing Results with Stakeholders and Public

Effectively sharing results with stakeholders is crucial for transparency, trust, and informed decision-making in cancer care. Tailored communication with health care providers, patients, advocacy groups, and policymakers ensures data is accessible and clear. Community forums and webinars foster direct interaction, allowing for questions and discussion. Regular updates and open communication promote accountability and encourage participation, empowering patients, and communities to make informed health decisions and enhancing the effectiveness of cancer care.

### Florida Cancer Research Network – Resource and Knowledge Sharing Platform

The Florida Cancer Connect website represents a centralized resource center for cancer patients, caregivers, and survivors impacted by cancer. The site maintains trusted information from local medical practitioners to help patients and families make informed decisions on treatment and care. Currently, the site provides the following resources:

- Locating a cancer care provider
- How to navigate insurance coverage
- Survivor Stories
- Resources and Support for Cancer Caregivers
- Cancer Screening and Prevention Resources
- o Cancer Connect Collaborative
- Florida Cancer Innovation Fund

Expansion of the Florida Cancer Connect website can include the addition of best practices for cancer treatment and care developed by Florida-based institutions, including a requirement by any institution that is funded under the Casey DeSantis Cancer Research Program to provide any current best practices to be added to the website. Furthermore, any researcher that receives funding through the Cancer Innovation Fund where the grant funds lead to the development or improvement of an existing best practice, will be required to provide the information to the Florida Cancer Connect website.

The Florida Cancer Research Network, with its commitment to innovation, accountability, and data-sharing, will establish Florida as a front-runner in cancer research and patient care. This initiative is expected to catalyze significant advancements in cancer care, ultimately positioning the state as a model for cancer research and treatment excellence.

## 8. Recommendations and Strategies

## 1. Expand funding opportunities.

The Florida Cancer Research Network will expand funding for high-impact cancer research, prioritizing areas such as pediatric oncology and improving health care access. Grants will support pilot studies, translational research, and workforce development, with projects aligned to the goals of the Casey DeSantis Cancer Research Program to drive progress in cancer care across Florida.

## 1. Merit-based Funding

The Florida Cancer Research Network will implement a merit-based grant program to fund transformative cancer research initiatives, focusing on high-quality, impactful projects. Grants will be awarded based on rigorous evaluation criteria, prioritizing research excellence and innovation in areas such as pilot studies, translational and implementation research, and post-doctoral and workforce fellowships. Special emphasis will be placed on addressing underserved areas, including pediatric oncology and minority health. This merit-driven approach seeks to accelerate scientific breakthroughs, enhance patient care, and expand equitable access to cutting-edge cancer research and treatments across Florida. Expansion would be supported using current funding under the Casey DeSantis Cancer Research Program by removing the tiered structure and allocation methodology in section 381.915, Florida Statutes, to allow access to the \$127.5 million for other entities based on merit, return on investment, and patient care needs.

## 2. Oversight by the Cancer Connect Collaborative

Partnering with the Cancer Connect Collaborative, the Florida Cancer Research Network will establish clear evaluation criteria for all projects, ensuring alignment with the overarching goals of the Casey DeSantis Cancer Research Program. This collaboration will enable effective resource management, ensuring funded projects have the highest potential for success and impact on Florida's cancer care landscape.

# 2. Create a statewide entity with the purpose of issuing cancer research funding and providing oversight and transparency of data, best practices, and patient care in Florida.

The following strategies may transform Florida's approach to cancer prevention, treatment, and research by providing funding for a broader range of facilities to improve cancer care and further drive innovative research.

#### 1. Centralized Florida Cancer Research Network Creation

Establishing the Florida Cancer Research Network as a central framework for managing Florida's cancer research and treatment funding, positioned under the Florida Department of Health in partnership with the Cancer Connect Collaborative, will streamline efforts to advance cancer research, prevention, and treatment by providing targeted grants and acting as a central resource for innovation and best practices.

## 2. Strategic, Competitive Funding

The Florida Cancer Research Network will allocate competitive grants for cancer research

initiatives, emphasizing high-impact projects. Funding will prioritize a variety of research types, including pilot studies, translational and implementation research, and post-doctoral and workforce fellowships, with a focus on addressing underserved areas such as pediatric oncology and minority health. This approach aims to accelerate scientific progress, improve patient care, and expand access across Florida.

### 3. Oversight by the Cancer Connect Collaborative

Partnering with the Cancer Connect Collaborative, the Florida Cancer Research Network will establish clear evaluation criteria for all projects, ensuring alignment with the overarching goals of the Casey DeSantis Cancer Research Program. This collaboration will enable effective resource management, ensuring funded projects have the highest potential for success and impact on Florida's cancer care landscape.

## 4. Resource and Knowledge-Sharing Platform

As a central repository for best practices and successful interventions in cancer care, the Florida Cancer Research Network will facilitate the dissemination of evidence-based practices throughout Florida and beyond. Through a variety of outreach efforts, including workshops, publications, surveys, and an online knowledge-sharing platform, the Florida Cancer Research Network will foster collaboration among health care providers, researchers, and stakeholders.

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## 9. Appendix

## Proposed Framework for an Oversight Committee for the Florida Cancer Research Network

## **Purpose and Responsibilities**

Using the existing structure of the Cancer Connect Collaborative, this appointed group would become the Oversight Committee for the Florida Cancer Research Network, ensuring strategic leadership, governance, and accountability for the Florida Cancer Research Network's activities.

The Cancer Connect Collaborative will:

- Ensure alignment of the Florida Cancer Research Network's goals with the Casey DeSantis Cancer Research Program's mission and priorities.
- Establish fair and transparent processes for grant funding decisions and program evaluation by creating guidelines for conflicts of interest.
- Monitor performance metrics, outcomes, and financial stewardship and assess annually the return on investment for state dollars.
- Facilitate collaboration among stakeholders, including researchers, health care providers, policymakers, and community representatives.

Benefits to an oversight committee will ensure enhanced governance of state cancer research and treatment and will promote accountability and transparency in funding and operations. The Cancer Connect Collaborative will leverage specialized knowledge through subcommittees and advisory bodies. With a community-centered approach, the Cancer Connect Collaborative and the Florida Cancer Research Network will align research and care initiatives with the needs and priorities of Florida's diverse populations and encourages a unified effort in advancing cancer research and improving patient care statewide.

The Cancer Connect Collaborative will submit an annual report to the Governor, Speaker of the House of Representatives, and President of the Senate, detailing funded projects, outcomes, and recommendations for future initiatives.

#### **Proposed Oversight Committee Structure**

The Cancer Connect Collaborative may have an appointed chairperson and vice-chairperson. These appointed leaders will be responsible for facilitating meetings, driving agendas, and representing the committee. Other members of the committee would be from a diverse group comprised of experts in oncology, public health, research, patient advocacy, and community health. For the purposes of overseeing grant funding, membership will also include representatives from other already established key advisory bodies and councils, such as Florida Cancer Control and Research Advisory Council (CCRAB), Biomedical Research Advisory Council (BRAC), and the current members of the Cancer Connect Collaborative. Integration with advisory committees and councils will foster seamless integration and coordination.

### **Subcommittee Integration**

To promote efficiency and specialized oversight, the following subcommittees may support the Cancer Connect Collaborative:

## **Research Funding Subcommittee**

- Reviews and evaluates grant proposals, ensuring funding decisions are based on feasibility, innovation, and potential impact.
- Develops and enforces funding guidelines and criteria in collaboration with other councils.

## **Community Needs and Access Subcommittee**

- Collaborates with CCRAB and other advisory councils to assess and address community needs, focusing on equitable access to cancer care and clinical trials.
- Ensures initiatives prioritize underserved populations and regions.

#### **Metrics and Outcomes Subcommittee**

- Tracks the progress of funded projects, collecting data on patient outcomes, research advancements, and program impact.
- Prepares regular performance reports for stakeholders and public dissemination.

#### **Collaboration and Knowledge-Sharing Subcommittee**

• Provides direction on the identification and sharing of best practices and enhancing the knowledge sharing platform, its use and engagement of stakeholders across the state.

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