

Casey DeSantis Cancer Research Program Long-Range Plan

January 1, 2024



Ron DeSantis

Governor

Joseph A. Ladapo, MD, PhD

State Surgeon General

Table of Contents

1. Acknowledgements	1
2. Executive Summary	2
3. Introduction	3
3.1 Casey DeSantis Cancer Research Program	3
3.2 Purpose	4
3.3 Florida-Based Cancer Research Organizations	4
4. Analysis and Assessment for Change	6
4.1 Current Eligibility and Tier Structure	6
4.2 Current Allocation Methodology	7
4.3 Collaborative Efforts in Cancer Research	12
4.4 Data Collection and Reporting	15
5. Recommendations	17
5.1 Tier Structure	17
5.2 Allocation Methodology	18
5.3 Collaborative Efforts in Cancer Research	18
5.4 Data Collection and Reporting	20
6. Next Steps	25
6.1 Goals and Objectives	25
7. Conclusion	26
8. Appendix	28
8.1 Other State Funding Available for Cancer Research	28
8.2 Survey Data Collection Strategy	29
8.3 Funding for Cancer Research and Research Achievements	29
8.4 National Cancer Institute	32
8.5 Federal Funding Available for Cancer Research	33
8.6 COC-Accredited Cancer Centers	34
8.7 Collaboration in Cancer	36
8.8 Acronyms	38
8.9 Glossary	39
8.10 References	41

Table of Figures

Figure 1: Florida Cancer Centers of Excellence	5
Figure 2: Number of Reported Cases Enrolled vs. Not Enrolled in Interventional Trials by Institution and Fiscal Year	10
Figure 3: Number of Biomedical Education Trainees by Institution and Fiscal Year	11
Figure 4: Ways to Strengthen Academic and Research Collaboration with Medical Providers	14
Figure 5: Sister Facility by Type.....	14
Figure 6: Elements and Strategies to Improve Data Collection	16
Figure 7: Survey Respondents’ Membership on Florida-Based Cancer Collaboratives	20
Figure 8: Survey Respondents’ Primary Funding Sources for Cancer Research Programs.....	30
Figure 9: Primary Areas of Cancer Research Reported by Survey Respondents.....	31
Figure 10: Cancer Types Treated by Survey Respondent Facilities	32
Figure 11: NIH Funding, Florida, 2012–2022.....	33
Figure 12: Florida Academic Cancer Center Alliance (FACCA) Catchment Areas	37

Table of Tables

Table 1: Florida-Based NCI-Designated Institutions with Casey DeSantis Program Eligibility	7
Table 2: Facilities Reporting ≥ 3,000 Cancer Cases Annually, 2017–2021	8
Table 3: Stakeholders Expressed Support for Research-Driven and Public-Private Partnerships	13
Table 4: Examples of Quality of Cancer Care Performance Measures	23
Table 5: Examples of Efficacy of Cancer Treatment Performance Measures	24
Table 6: FY 2022-23 Recipients for the King Program, Bankhead-Coley Program, and Bella Initiative	28
Table 7: NCI-Designated Cancer Centers by Tier Designation, Type of Institution, and Number of NIH Projects, FY 2020–2022.....	33
Table 8: Florida-based Organizations with NIH-Funded Cancer Projects, FY 2020–2022	34
Table 9: COC-Accredited Cancer Centers.....	34
Table 10: FACCA Pilot Project Collaborations and Results, 2020–2022	37

Table of Equations

Equation 1: Current Tier-Weighted Allocation Fraction Formula	7
Equation 2: Proposed Tier-Weighted Allocation Fraction Formula.....	18

1. Acknowledgements

This Long-Range Plan was developed based on input from 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 those individuals, organizations, and institutions who participated in completing the survey, attended the stakeholder meetings, and provided input for the Casey DeSantis Cancer Research Program's Long-Range Plan.

2. Executive Summary

The 2023 Legislature directed the Florida Department of Health (Department) to develop a Long-Range Plan (Plan) for the Casey DeSantis Cancer Research Program (Casey DeSantis Program). As described in the Chapter 2023–239, Laws of Florida, the Plan will include the following components:

1. Expanded eligibility of the Casey DeSantis Program to include a broader pool of Florida-based cancer centers, research institutions, biomedical education institutions, hospitals, and medical providers to receive funding through the program.
2. Development of an academic collaborative that integrates research institutions and medical schools into the Casey DeSantis Program to expand geographic reach into underserved areas of the state.
3. Revision of the tiers established in section 381.915(4), Florida Statutes, to be replaced by a fund weighting methodology that focuses on quality of care, efficacy of treatment, and patient outcomes and includes consideration for philanthropic sources of fund generation by applicant cancer research centers.

Under current state law, the Casey DeSantis Program allocates funding exclusively to Florida-based institutions that hold National Cancer Institute (NCI) designation as comprehensive cancer centers, NCI-designated cancer centers, or cancer centers actively striving to attain NCI recognition.

The Casey DeSantis Program, with state funding of more than \$100 million, can fund eligible institutions and leverage collaborative opportunities to strengthen cancer research in Florida, and ultimately improve the lives of those impacted by cancer in the state.

Recommendations

The Plan proposes recommendations in the following areas:

Expanded Eligibility. Expand eligibility to allow additional cancer institutions access to the Casey DeSantis Program. The proposed expanded eligibility results in three revised tiers as follows.

- Tier 1: Florida-based NCI-designated institutions.
- Tier 2: Florida-based cancer centers designated Cancer Centers of Excellence (section 381.925, Florida Statutes).
- Tier 3: Florida-based institutions which report at least 3,000 reportable cancer cases annually.

Allocation Methodology. The Casey DeSantis Program's eligibility tiers are closely linked to the allocation methodology. Changes to statute are recommended to revise and clarify the allocation formula components (e.g., clinical trial enrollment, verification of reportable cases, and new quality improvement requirements for the allocation methodology).

Academic Collaboration. A revision of the tiers is recommended to support the activities and projects associated with an academic collaborative. This revision could also support the development of a formal consortium that integrates research institutions and medical schools into the program to expand the program's geographic reach into underserved areas of the state.

Data Collection and Reporting. To capture new data elements that address quality of care, efficacy of treatment, and patient outcomes, per Chapter 2023–239, Laws of Florida, the

recommendation is to establish a facility-based cancer quality improvement report card under the Florida Cancer Control and Research Advisory Council (CCRAB) to support the quality improvement efforts within the tier-weighted allocation fraction formula.

This Plan is provided by the Department in fulfillment of its 2023 legislative directive.

3. Introduction

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).¹

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 (U.S.).² In Florida, cancer is the second leading cause of death, after heart disease.³ Florida also has the second highest cancer burden in the nation, despite having the country's third largest population.⁴ In addition to the higher per-capita occurrence of cancer across the state, more than 120,000 new cancer cases are diagnosed and reported each year to the statewide cancer registry, the Florida Cancer Data System (FCDS).⁵

3.1 Casey DeSantis Cancer Research Program

In 2014, the Florida Legislature created the Florida Consortium of NCI Centers Program and later renamed it the Casey DeSantis Cancer Research Program (Casey DeSantis Program). Throughout this document the Casey DeSantis Program name will be used even for years prior to the 2022 name change. The program was established to:

- Enhance the quality and competitiveness of cancer care in Florida.
- Further a statewide biomedical research strategy directly responsive to the health needs of Florida's citizens.
- Capitalize on potential educational opportunities available to students.

In recent years, the Florida's Governor and Legislature's commitment to cancer research, treatment, and funding has increased significantly. During Florida's 2022 Legislative Session, the Legislature appropriated a historic \$100 million to the Casey DeSantis Program; total funding was increased for the Casey DeSantis Program in fiscal year (FY) 2023–24 to \$111 million. Although not included in this Plan, it is important to note that an additional \$20 million for the Casey DeSantis Cancer Innovation Research Program was also provided in FY 2023–24 but this funding is not the focus of this Plan. For further information on other state-funded cancer research programs, see Appendix 8.1.

¹ National Cancer Institute. Understanding Cancer > What is Cancer? <https://www.cancer.gov/about-cancer/understanding/what-is-cancer>

² 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>

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

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

⁵ Florida Statewide Cancer Registry, Florida Cancer Data System, *Annual Cancer Reports: 2016–2020*. Florida Department of Health. <https://fcds.med.miami.edu/inc/publications.shtml>

3.2 Purpose

The 2023 Legislature directed the Florida Department of Health (Department) to develop a Long-Range Plan (Plan) for the Casey DeSantis Program. As described in the Chapter 2023-239, Laws of Florida, the Plan will include the below components:

1. Expanded eligibility of the Casey DeSantis Program to include a broader pool of Florida-based cancer centers, research institutions, biomedical education institutions, hospitals, and medical providers to receive funding through the program.
2. Development of an academic collaborative that integrates research institutions and medical schools into the Casey DeSantis Program to expand geographic reach into underserved areas of the state.
3. Revision of the tiers established in section 381.915(4), Florida Statutes, to be replaced by a fund weighting methodology that focuses on quality of care, efficacy of treatment, and patient outcomes and includes consideration for philanthropic sources of fund generation by applicant cancer research centers.

The Legislature also provided funding for the Department to engage a vendor to assess the current state of cancer research in Florida and gather information to inform the Legislature's charge. Development of the Plan included a review of literature, documents, and available data; a stakeholder survey; a series of three stakeholder meetings, and a review of cancer centers, research institutions, biomedical education facilities, hospitals, and medical providers. For more information about the survey, see Appendix 8.2.

Across the board, cancer research stakeholders advocated for additional cancer research funding, whether for underfunded cancer types or specific populations. For more information, see Appendix 8.3.

3.3 Florida-Based Cancer Research Organizations

The distinctions and criteria for understanding cancer centers, along with other accreditations or designations, may be useful when considering options to expand eligibility for Casey DeSantis Program funding. Florida maintains a spectrum of different cancer treatment facilities and centers, each with varying levels of patient care and access. The fluid nature of the term cancer centers makes specific structures for recognizing cancer organizations important.

National Cancer Institutes

The National Cancer Institute (NCI) Program 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. The NCI recognizes a total of 72 institutions nationally, with four having Florida-based campuses (see Appendix 8.4). NCI-designated cancer centers integrate research activities across three major areas: laboratory research, clinical research, and population-based research. Federal funding is available to support these activities (see Appendix 8.5).

Many of these centers also provide care and services for cancer patients. These efforts can be expanded to include extensive community outreach and education programs, designating these facilities as comprehensive cancer centers. Specific NCI-designations are as follows:

- NCI Cancer Center: A center which meets NCI standards for cancer prevention, clinical services, and/or research.

- NCI Comprehensive Cancer Center: A center which meets NCI standards for all three categories (i.e., cancer prevention, clinical services, and research) and conducts outreach and education.
- NCI Basic Laboratory Cancer Center: A center which only conducts laboratory research and does not provide patient treatment.

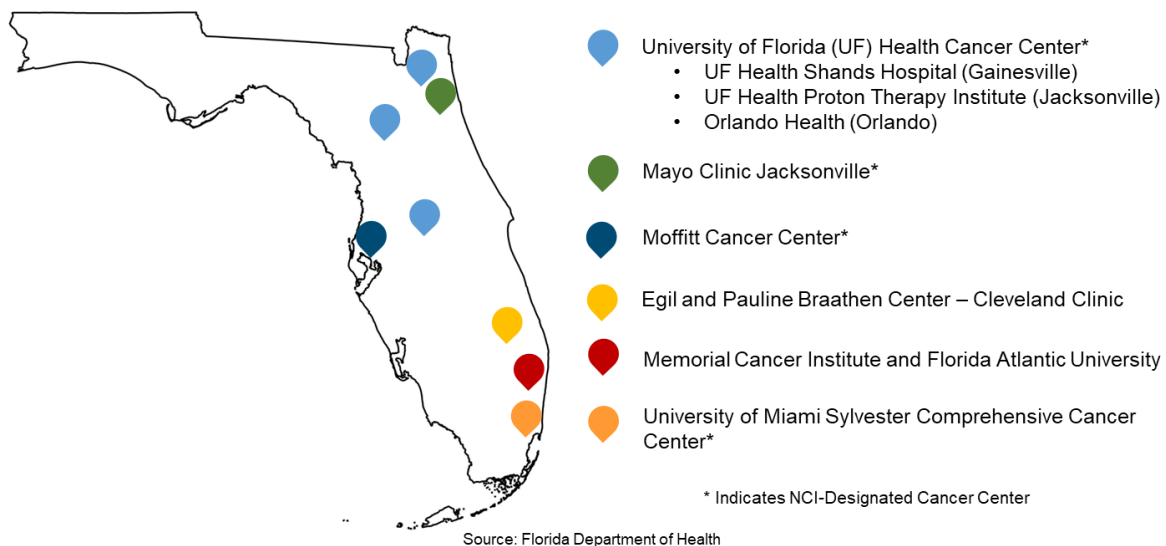
Florida Cancer Centers of Excellence

Florida also has a state designation for Cancer Centers of Excellence (CCE) that is used to recognize organizations that demonstrate excellence in patient-centered coordinated care for persons undergoing cancer treatment and therapy in Florida. The goal of the CCE program is to encourage excellence in cancer care in Florida and attract and retain the best cancer care professionals to the state.

The CCE designation is based on a systems approach to improving the quality of cancer care in Florida. The designation comprises three areas: the health care organization, health care team members, and patients and family members. Each of these three components contributes to the success of the system and has defined outcomes and rigorous performance measures. If an eligible organization meets all performance measures it may be designated as a CCE. The standards in each area are performance-based, using objective criteria and measurable outcomes to evaluate whether a standard is met.

Figure 1 shows Florida’s six CCEs and their locations.

Figure 1: Florida Cancer Centers of Excellence



These six centers, as evidenced by their CCE status, have each met the state’s high standards for excellence in cancer care. The two CCEs that are not currently NCI designated, along with other cancer centers in the state, have the ability to seek NCI designation and could be considered for future Casey DeSantis Program eligibility (in the highest tier). As demonstrated on the map, there is a lack of CCEs in the Florida Panhandle as well as southwest Florida. This indicates a potential opportunity for improved patient care and access to treatment in that area.

Being close to an NCI-designated institution or CCE or NCI-designated center offers numerous benefits for individuals facing cancer diagnosis. These specialized centers typically house a

multidisciplinary team of highly skilled health care professionals, including oncologists, surgeons, radiologists, and support staff, all with expertise in cancer care. Patients can benefit from state-of-the-art diagnostic and treatment options, including the latest advancements in cancer therapies and clinical trials. Additionally, proximity to a CCE can reduce travel time and costs, making it easier for patients to access regular treatments, consultations, support services, and have family support nearby.

Commission on Cancer (COC) Accreditation

Cancer centers can also be accredited by the American College of Surgeons' (ACS) Commission on Cancer (COC). The COC is a consortium of professional organizations dedicated to improving survival and quality of life for patients with cancer by setting and raising standards. In Florida, there are 62 COC centers. For more information on Florida's COC centers, see Appendix 8.6.

4. Analysis and Assessment for Change

The majority of Florida's cancer research funding, allocated through the Casey DeSantis Cancer Research Program, goes to four NCI-designated institutions.

4.1 Current Eligibility and Tier Structure

Currently, funding opportunities through the Casey DeSantis Program, except for \$20 million in funding for cancer innovation provided by the 2023 Legislature, are limited to a narrow range of cancer research organizations. Section 381.915, Florida Statutes, sets eligibility parameters for the Casey DeSantis Program based on an institution's recognition or status through the NCI. Based on NCI designation, the Casey DeSantis Program provides funding eligibility according to three tiers.

- Tier 1: Florida-based NCI-designated comprehensive cancer centers.
- Tier 2: Florida-based NCI-designated cancer centers.
- Tier 3: Florida-based cancer centers seeking NCI-designation as well as meeting additional criteria related to their research and biomedical education.

Based on the eligibility tiers, only four institutions are eligible to receive 2023 Casey DeSantis Program funding. Until recently, the University of Florida (UF) Health Cancer Center held Tier 3 status, which changed when they received their NCI designation in June 2023. Mayo Clinic Jacksonville⁶ became eligible to receive funding under the program in FY 2023–24 when legislation for the Casey DeSantis Program was changed to include institutions headquartered in a state other than Florida that have a Florida-based site.

FY 2023–24 is the first year that Casey DeSantis Program funding is allocated to Mayo Clinic Jacksonville. Table 1, on the following page, shows total Casey DeSantis Program funds allocated to recipient institutions from FY 2015–16 through FY 2022–23.

⁶ Mayo Clinic Jacksonville was established in Florida in 1986. Mayo Clinic originated in Rochester, Minnesota (est. 1914), and has an additional site in Scottsdale, Arizona (est. 1987).

Table 1: Florida-Based NCI-Designated Institutions with Casey DeSantis Program Eligibility

Institution	NCI-Designation	Tier	Location	Total Funds Allocation FY 2015–16 through FY 2022–23
H. Lee Moffitt (Moffitt) Cancer Center	Comprehensive Cancer Center	1	Tampa, FL	\$214,438,350
Mayo Clinic Jacksonville	Comprehensive Cancer Center	1	Jacksonville, FL	\$0 (eligible for FY 2023–24)
University of Florida (UF) Health Cancer Center	Cancer Center	2*	Gainesville, FL	\$171,041,383
University of Miami (UM) Sylvester Cancer Center	Cancer Center	2	Miami, FL	\$145,663,980

Source: National Cancer Institute and Florida Department of Health

*Current tier in FY 2023–24, previously Tier 3.

4.2 Current Allocation Methodology

The statutory tiers for the Casey DeSantis Program identify who is eligible for funding. The tiers also include a weighting mechanism that is used in the final allocation of funds. Separately, section 381.915, Florida Statutes, specifies a funding allocation methodology based on additional factors that must be considered. Accordingly, the following formula is used to calculate a participating cancer center’s allocation fraction:

Equation 1: Current Tier-Weighted Allocation Fraction Formula

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

Where:

CAF = A cancer center’s allocation fraction.

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.

Additional statutory criteria for the allocation methodology are as follows:

- If the [allocation methodology] 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.
- All cancer centers receiving funding under the Casey DeSantis Program shall submit to the Florida Cancer Data System, on a quarterly bases beginning September 30, 2023, data on new cancer diagnoses, cancer recurrence, data on patient outcomes by cancer type, mortality, and survival rates.

The components in the allocation formula include number of reportable cases, peer-review costs, and biomedical education and training. Understanding each of these components is vital to understanding the allocation formula and each is discussed separately. However, of the state elements used in the current allocation formula, only one data element (reportable cancer cases) is currently collected and reported by facilities that report to the state’s cancer registry, FCDS. It is also important to note that statute does not define the reporting period for reporting cases.

Reportable Cases

Within the program’s statutory authority, reportable cases are defined as: incidences of cancer in which a cancer center is involved in the diagnosis, evaluation of the diagnosis, evaluation of the extent of cancer spread at the time of diagnosis, or administration of all or any part of the first course of therapy for the most recent annual reporting period available. Additionally, cases relating to patients enrolled in institutional or investigator-initiated interventional clinical trials are weighted at 1.2 relative to other cases weighted at 1.0. Determination of institutional or investigator-initiated interventional clinical trials must be consistent with reporting guidelines provided by the NCI. FCDS data were analyzed to examine which facilities are reporting the highest numbers of cancer cases. Table 2 displays facilities and the number of cancer cases reported over a 5-year period (2017–2021).

Table 2: Facilities Reporting ≥ 3,000 Cancer Cases Annually, 2017–2021

	Facilities ¹	2017	2018	2019	2020	2021	5-Year Avg
1	Moffitt Cancer Center ^{2,3}	14,639	15,264	15,496	15,308	16,933	15,528
2	University of Miami Hospital Clinics ^{2,3}	7,177	8,090	8,567	7,140	9,170	8,029
3	AdventHealth Orlando – South ²	5,594	5,589	6,475	5,690	5,491	5,768
4	Mayo Clinic Hospital ^{2,3}	5,552	5,298	5,274	4,760	5,314	5,240
5	Orlando Health Cancer Institute ^{2,3}	5,244	5,723	6,035	5,726	5,203	5,586
6	Baptist Hospital Miami ³	4,916	5,024	5,450	4,356	5,424	5,034
7	University of Florida Shands Hospital ^{2,3}	4,483	4,428	4,520	4,323	4,672	4,485
8	Boca Raton Regional Hospital ³	4,111	4,147	4,202	4,098	4,374	4,186
9	Tampa General Hospital	3,850	4,339	4,956	4,819	6,166	4,826
10	Sarasota Memorial Hospital ²	3,654	3,816	4,060	4,063	4,214	3,961
11	Baptist Medical Center Jacksonville	3,316	3,832	4,495	4,319	4,837	4,160
12	Mount Sinai Medical Center ²	3,388	3,379	3,406	2,598	3,227	3,200
13	Morton Plant Hospital	2,885	3,174	3,381	3,076	3,222	3,148
14	Lee Memorial Health System	2,677	3,077	3,150	3,101	3,115	3,024
15	AdventHealth Celebration	2,507	2,738	3,222	2,939	3,105	2,902
16	AdventHealth Altamonte Springs	2,595	2,635	3,064	2,594	2,868	2,751
17	Regional Cancer Center Gulf Coast Hospital	2,207	2,401	2,475	2,994	4,022	2,820
	Physician Offices (N=5,688)	39,096	38,751	38,099	39,708	46,442	40,419
	Freestanding Radiation Therapy Centers (N=121)	9,709	11,692	7,683	7,804	6,969	8,771

¹ Highlighted facilities receive funding through the Casey DeSantis Program.

² Facility receives federal cancer research funding.

³ Facility receives state cancer research funding through the Bankhead-Coley Program, King Program, or Bella Initiative. Source: Florida Department of Health

Institutions which report 3,000 or more cancer cases annually indicate that they have a higher capacity to treat a larger patient population. Eleven facilities (see 1–11 in Table 2) consistently reported 3,000 or more cancer cases annually, of which four are NCI-designated institutions. Seven of these facilities have received federal funding for cancer research from the NIH and seven received state funding through one of the four cancer research programs. Six facilities reported 3,000 or more cancer cases at least once during the 5-year period, of which one facility receives federal funding through the NIH.

Clinical Trials

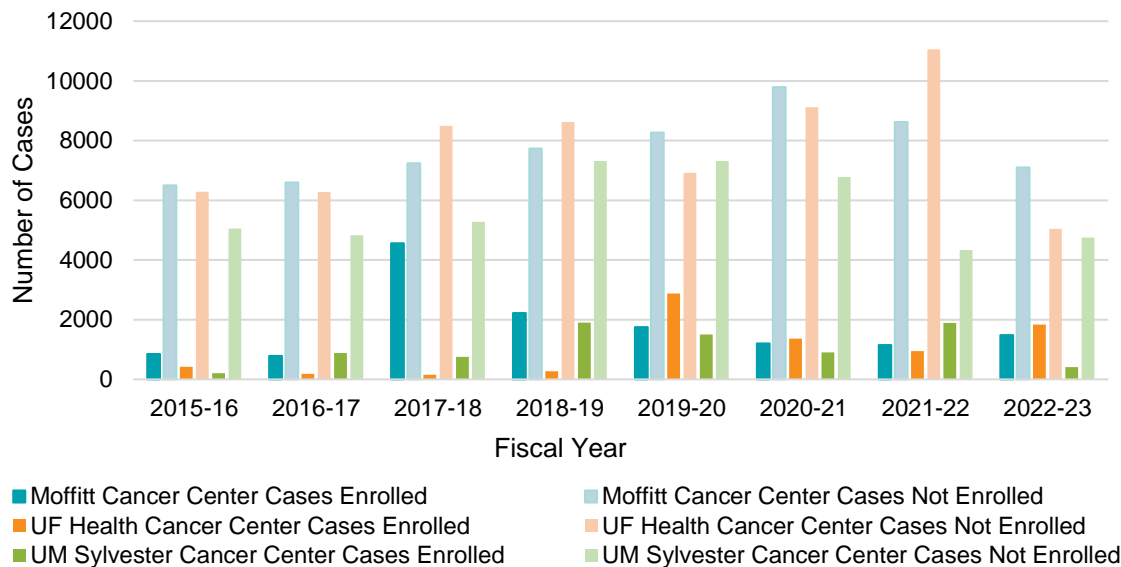
The reportable cases statutory component includes cancer cases in clinical trials. For cancer centers, clinical trials serve as the primary method for testing novel advancements in cancer care and developing cutting-edge cancer treatments. Because of their methodical nature, clinical trials also offer patients a structured path to receive meticulous cancer treatment and potentially improve patient outcomes. It is important to note that the clinical trials component, as part of the broader reportable cases indicator, does not specify a timeframe for clinical trials (e.g., within the last complete fiscal year). Further, the statute stipulates for the allocation of cases in a clinical trial as relating to patients enrolled in institutional or investigator-initiated interventional clinical trials are weighted at 1.2 relative to other cases weighted at 1.0. Thus, clarification on the type of trial (cancer treatment or cancer prevention) is required to ensure that the number of cases included in the allocation methodology is reported correctly and is not under or over estimated.

Florida cancer centers, supported through the Casey DeSantis Program, are powerful drivers of research activity and clinical trials, developing and translating scientific knowledge from promising laboratory discoveries into new treatments for cancer patients.⁷ NCI-designated cancer centers are expected to maintain a large portfolio of clinical trials.

Figure 2 shows the number of reportable cancer cases enrolled versus not enrolled in interventional clinical trials at three of Florida's four NCI-designated institutions – Moffitt Cancer Center, UF Health Cancer Center, and UM Sylvester Cancer Center from FY 2015–16 through FY 2022–23. When examining the interventional trial enrollment averages of the past three years (FY 2020–21 to FY 2022–23), Moffitt Cancer Center had an 8% decrease in the average number of reported cases enrolled versus not enrolled. In contrast, UF Health Cancer Center and UM Sylvester Cancer Center both experienced increases in the average number of reported cases enrolled in interventional trials, with UF Health Cancer Center experiencing a 5% increase and UM Sylvester Cancer Center a 3% increase. This indicates that the majority of Florida-based NCI-designated institutions have made progress in increasing the number of individuals enrolled into interventional trials and subsequently increased the number of individuals who have access to new or novel treatments.

⁷ National Cancer Institute. *NCI-Designated Cancer Centers*, available at: <https://www.cancer.gov/research/infrastructure/cancer-centers>

Figure 2: Number of Reported Cases Enrolled vs. Not Enrolled in Interventional Trials by Institution and Fiscal Year



Source: Florida Department of Health

When asked about the total number of individuals enrolled in clinical trials at their facility for the most recent fiscal year, 17 survey respondents reported figures ranging from two to more than 5,000. More than half of respondents (N=10) reported 90 or fewer patients enrolled. Three institutions reported more than 1,000 patients enrolled in clinical trials within the last fiscal year.

Stakeholder survey respondents were also asked whether their institution hosts or conducts cancer-related interventional clinical trials which are registered with the NCI’s Clinical Trials Reporting Program (CTRP).⁸ Of the 28 facilities which responded to this question, 85% (N=24) indicated they conduct clinical trials registered with the NCI CTRP.

A total of 40 facilities responded to the survey question inquiring whether any clinical trials or experimental treatments are currently being conducted at their facility, of which more than half (N=23) reported that they have active clinical trials. Survey respondents were also asked to describe their active clinical trials and descriptions provided included various types of clinical trials (e.g., interventional, supportive care, prevention, observational), registry trials, government-sponsored trials, physician-initiated investigator trials, Children’s Oncology Group trials, Pediatric Neuro-Oncology Consortium trials, vaccine trials, and phase II and III pharmaceutical-funded trials.

Peer-Review Costs

Per statute, peer-review costs are defined as total annual direct costs for peer-reviewed cancer-related research projects, consistent with reporting guidelines provided by the NCI, for the most recent annual reporting period available. Peer-review funding represents an essential financial support source for NCI-designated institutions and is another data element used to calculate funding allocations for Casey DeSantis Program eligible applicants. When surveyed about the

⁸ NCI Clinical Trials Reporting Program (CTRP) maintains a comprehensive database of information on all interventional clinical trials directly and indirectly funded by NCI, open to accrual as of January 1, 2009, as well as observational studies open to accrual as of January 1, 2020. This database helps identify gaps and duplicate studies in clinical research, facilitates clinical trial prioritization, and standardizes trial data capture and sharing.

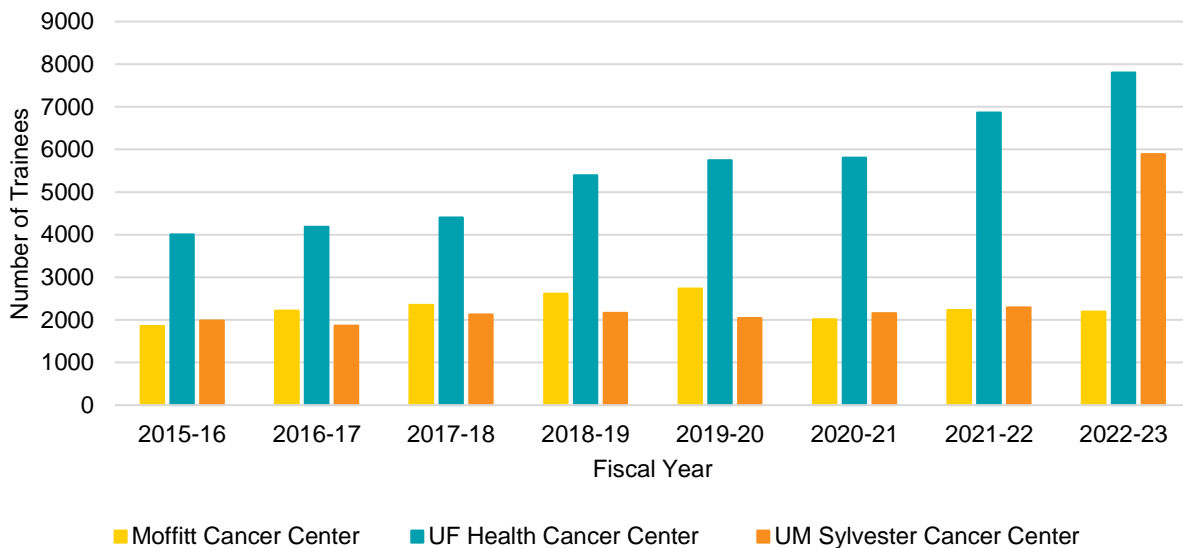
total peer-review costs at their facility for the most recent fiscal year, seven respondents provided cost information, which ranged from \$20,000 to more than \$55 million. The average peer-review costs based on responses was approximately \$23.6 million.

Biomedical Education and Training

The third component in the allocation formula captures biomedical education and training by each facility. As defined, biomedical instruction is offered to a student who is enrolled in a biomedical research program at an affiliated university as a medical student or a student in a master’s or doctoral degree program, or who is a resident physician trainee or postdoctoral trainee in such program. An affiliated university biomedical research program must be accredited or approved by a nationally recognized agency and offered through an institution accredited by an accrediting agency or association recognized by the database created and maintained by the U.S. Department of Education. Full-time equivalency for trainees shall be prorated for training received in oncologic sciences and oncologic medicine.

The notable investment made by Florida’s NCI-designated institutions in biomedical education and training is evident from the substantial surge in the involvement of trainees in these programs over recent years. Figure 3 shows the number of trainees engaged in biomedical education at each of the three NCI-designated institutions from FY 2015–16 through FY 2022–23. During this period, all three institutions experienced growth in the number of biomedical education trainees, with UM Sylvester Cancer Center having the most significant increase at 197%. UF Health Cancer Center experienced a 95% increase in the number of biomedical education trainees, followed by Moffitt at 18%. The increasing number of trainees signifies the institutions’ advancements in developing future cancer researchers and their success in meeting NCI and Casey DeSantis Program goals related to biomedical education and training.

Figure 3: Number of Biomedical Education Trainees by Institution and Fiscal Year



Source: Florida Department of Health

Allocation Weights

Current tier designations and corresponding weights within the Casey DeSantis Program are as follows:

- Tier 1: NCI-designated comprehensive cancer centers, which shall be weighted at 1.5.
- Tier 2: NCI-designated cancer centers, which shall be weighted at 1.25.
- Tier 3: Cancer centers seeking designation as either an NCI-designated cancer center or NCI-designated comprehensive cancer center, which shall be weighted at 1.0.

An important consideration regarding the current tier structure is that as of FY 2023–24 there are no facilities that can be considered for Tier 3. Per statute, a cancer center’s participation in Tier 3 may not extend beyond June 30, 2024; therefore, this tier will be obsolete. Per statute, a cancer center’s participation in Tier 3 may not extend beyond June 30, 2024;⁹ therefore, this tier will be obsolete.

Although the current allocation methodology relies on specific data elements – the number of reportable cancer cases, peer-review funding, and biomedical education and training – to calculate allocations for eligible applicants, these measures do not fully encompass how a cancer center performs, nor do they address patient outcomes, efficacy of treatment, and quality of care. The current data elements are also not indicative of whether the significant investment by the Casey DeSantis Program is ultimately helping to improve patient outcomes.

4.3 Collaborative Efforts in Cancer Research

Collaborative cancer research efforts provide one path to expanding the state’s cancer research infrastructure. Florida’s NCI-designated institutions are predominantly located in urban and suburban areas, which can leave individuals living in rural communities without direct access to state-of-the-art cancer facilities and treatments.

Integrating academic and community cancer care and research through multidisciplinary oncology pathways can facilitate comprehensive care plans for each cancer patient throughout their cancer journey and across different health care settings, including those in rural areas. This approach ensures that patients receive the best possible care and treatment, regardless of location. Collaboration can also enable the integration of multiple data streams into a single platform that can be accessed simultaneously by clinicians, patients, and multidisciplinary teams from tertiary and regional hospitals.¹⁰ Further, through the NCI, consortiums can be formally formed when an NCI-designated center and a non-designated partner collaborate.

Florida is home to 10 medical schools, three of which are associated with NCI-designated cancer centers. Medical schools associated with NCI-designated institutions, and the Florida Academic

⁹ Additional criteria for Tier 3 include: Conducting cancer-related basic scientific research and cancer-related population scientific research. Offering and providing the full range of diagnostic and treatment services on site, as determined by the Commission on Cancer of the American College of Surgeons. Hosting or conducting cancer-related interventional clinical trials that are registered with the NCI’s Clinical Trials Reporting Program. Offering degree-granting programs or affiliating with universities through degree-granting programs accredited or approved by a nationally recognized agency and offered through the center or through the center in conjunction with another institution accredited by an accrediting agency or association recognized by the database created and maintained by the United States Department of Education. Providing training to clinical trainees, medical trainees accredited by the Accreditation Council for Graduate Medical Education or the American Osteopathic Association, and postdoctoral fellows recently awarded a doctorate degree. Having more than \$5 million in annual direct costs associated with their total NCI peer-reviewed grant funding. The General Appropriations Act or accompanying legislation may limit the number of cancer centers which shall receive Tier 3 designations or provide additional criteria for such designation. A cancer center that qualifies as a designated Tier 3 center under the criteria provided in subparagraph 1, by July 1, 2014, is authorized to pursue NCI designation as a cancer center or a comprehensive cancer center until June 30, 2024.

¹⁰ University of Cambridge. (2021). Collaboration could enable cancer patients to get faster and more personalized treatment. <https://www.cam.ac.uk/research/news/collaboration-could-enable-cancer-patients-to-get-faster-and-more-personalised-treatment>

Cancer Center Alliance (FACCA), include the UF College of Medicine (UF Health Cancer Center) in Gainesville; UM Miller School of Medicine (UM Sylvester Cancer Center) in Miami; the University of South Florida Morsani School of Medicine (Moffitt Cancer Center) in Tampa; and the Mayo Clinic College of Medicine and Science (Mayo Clinic Jacksonville) in Jacksonville.

Other examples of current statewide and regional cancer collaboratives and councils include:

- The Biomedical Research Advisory Council (BRAC).
- The Cancer Connect Collaborative.
- The Florida Academic Cancer Center Alliance (FACCA).
- The Florida Cancer Control and Research Advisory Council (CCRAB).
- The Florida Prostate Cancer Advisory Council.
- The six Regional Cancer Control Collaboratives.

Academic collaboratives are essential for driving cancer research and promoting positive patient outcomes by facilitating collaboration, multidisciplinary care, data integration, population-based research, and patient advocacy. As shown in Table 3, 46% of stakeholder survey respondents emphasized research-driven partnerships as mechanisms that can drive access to cancer care. FACCA is the only academic collaborative whose purpose is fostering trans-state research collaborations. For additional information about FACCA activities, see Appendix 8.7.

Table 3: Stakeholders Expressed Support for Research-Driven and Public-Private Partnerships

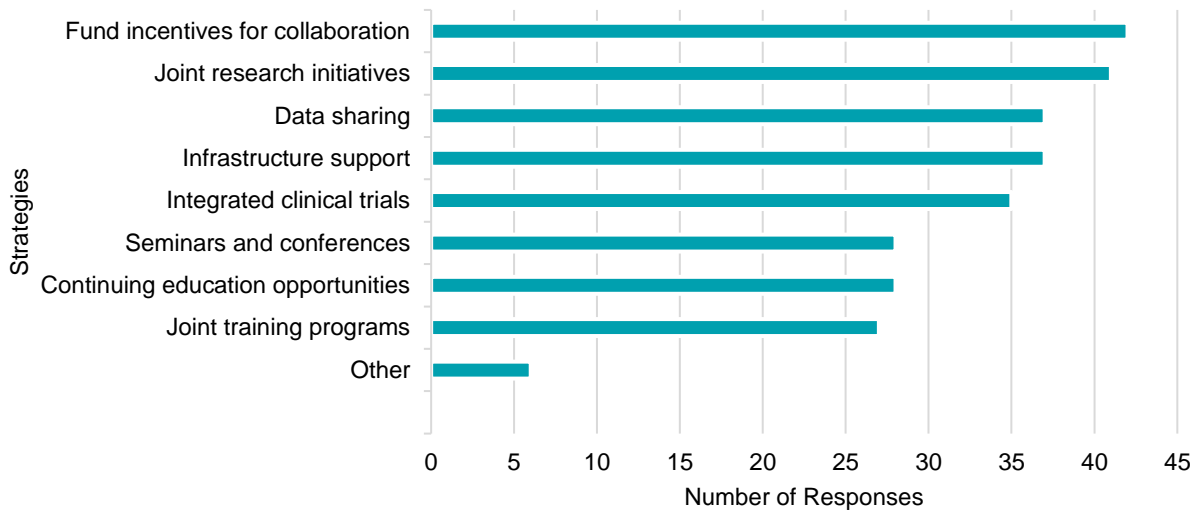
Are there innovative funding models or mechanisms that can drive improvements in cancer care accessibility? If so, select all that apply.	26 responses
Research-driven partnerships	46%
Public-private partnerships	35%
Philanthropic consortia	11%
Impact investing	7%
Value-based payments	1%

Source: Florida Department of Health

When asked about the total number of patients who were provided clinical consultations outside of a given facility’s service area, 16 respondents provided consultation numbers, which ranged from three to more than 14,000. The median number of reported clinical consultations for the last fiscal year was 150. Facilities reporting more than 2,000 clinical consultations outside their service areas consisted of three NCI-designated institutions.

When surveyed about ways Florida can strengthen academic and research collaboration with medical treatment providers to expand the reach of cancer research and treatment across the state, the top three responses were: fund incentives for collaboration (N=42), joint research initiatives (N=41), and data sharing (N=37). Figure 4 shows all responses and the number of times they were selected. Other responses submitted included fund community oncology programs; match philanthropic dollars for cancer research and care; fund dissemination and implementation projects; fund regional cancer collaboratives; fund FCDS to collect genetic and biomarker data; use artificial intelligence (AI) technology to create chatbots that define the National Comprehensive Cancer Network proven workflow; and fund the Children’s Oncology Group.

Figure 4: Ways to Strengthen Academic and Research Collaboration with Medical Providers



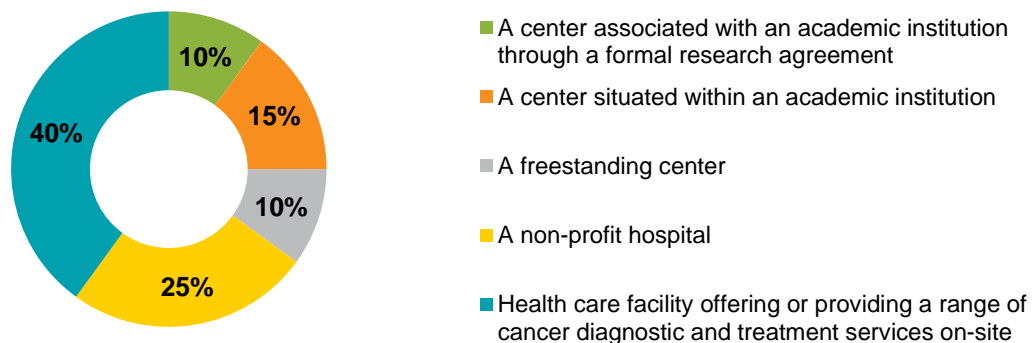
Source: Florida Department of Health, Environmental Scan Survey

Sister Sites and Mentorships

Formal relationships, such as mentorship agreements and sister facilities, provide an avenue for formal collaboration. More than three-quarters of responding facilities indicated they collaborate with other health care facilities to provide a continuum of care for cancer patients. However, only eight survey respondents indicated they have a formal mentorship agreement with one or more treatment facilities.

For those survey respondents reporting they have a sister facility (N=20), 12 reported their sister facility’s location as between 0 and 59 miles away from their organization and five reported their sister facility being greater than 150 miles away. Additionally, eight respondents described their sister facility as a health care facility offering or providing a range of cancer diagnostic and treatment services on-site. Of those facilities reporting a sister facility relationship, 12 reported conducting research in conjunction with a sister facility. Figure 5 provides a breakdown of sister facility descriptions provided by survey respondents.

Figure 5: Sister Facility by Type



Source: Florida Department of Health, Environmental Scan Survey

4.4 Data Collection and Reporting

Data collection plays a prominent part in all decision-making processes. According to research, health care providers can identify patterns and trends by collecting and analyzing patient demographics, medical history, and treatment outcomes to help develop more effective treatment plans. This can lead to improved patient outcomes and a better overall quality of care.¹¹ These metrics are crucial for assessing the quality of cancer care and guiding efforts to improve outcomes, enhance patient satisfaction, and optimize the overall health care experience for cancer patients and survivors.

Florida's statewide cancer registry program, FCDS, was 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, and 464, Florida Statutes, are required to report cancer incidence information to the Department through FCDS, as specified by Rule 64D-3.034, Florida Administrative Code.

Information required to be reported into FCDS includes:

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

Subject to appropriation by the Legislature (beginning July 1, 2017, and every three years thereafter), the Department, in conjunction with participating cancer centers, must submit a report to the CCRAB on specific metrics relating to cancer mortality and external funding for cancer-related research in the state. If a cancer center does not endorse this report or produce an equivalent independent report, the cancer center shall be suspended from the program for one year. Per statute, the report must include:

- (a) An analysis of trending age-adjusted cancer mortality rates in the state, which must include, at a minimum, overall age-adjusted mortality rates for cancer statewide and age-adjusted mortality rates by age group, geographic region, and type of cancer, which must include, at a minimum: lung cancer; pancreatic cancer; sarcoma; melanoma; leukemia and myelodysplastic syndromes; brain cancer; and breast cancer.
- (b) Identification of trends in overall federal funding, broken down by institutional source, for cancer-related research in the state.
- (c) A list and narrative description of collaborative grants and interinstitutional collaboration among participating cancer centers, a comparison of collaborative grants in proportion to the grant totals for each cancer center, a catalog of retreats and progress seed grants using state

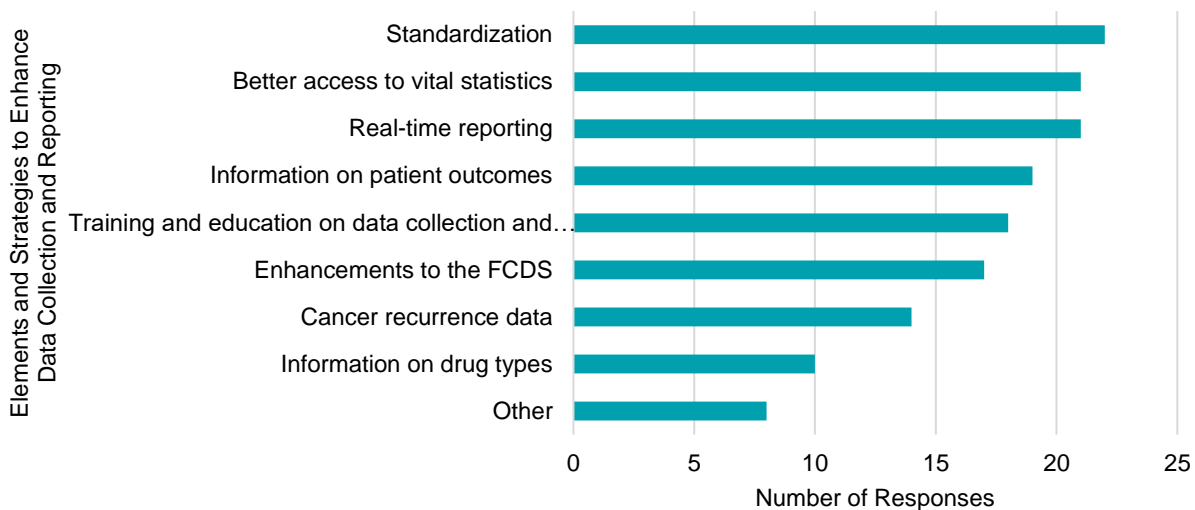
¹¹ 314e. (2022). The Role and Importance of Data Collection in Healthcare. [The Role and Importance of Data Collection in Healthcare - 314e](#)

funds, and targets for collaboration in the future and reports on progress regarding such targets where appropriate.

A total of 39 facilities responded to a survey question about elements or strategies that could enhance or improve data collection and reporting related to cancer research and treatment programs. The top responses included data standardization (N=22), better access to vital statistics (N=21), real-time reporting (N=21), and information on patient outcomes (N=19).

Figure 6 shows the distribution of all responses. Other responses submitted by facilities included expanding the collection of population-based data related to molecular testing, cancer screening, and social determinants of health; an all-claims medical claims database that is linkable to FCDS; information on radiation treatments, surgery, and next generation genetics; and more support for FCDS to automate data collection.

Figure 6: Elements and Strategies to Improve Data Collection



Source: Florida Department of Health, Environmental Scan Survey

Cancer recurrence data was recently added to the list of required reporting elements and marks a significant advancement for the state’s cancer registry; however, there is currently a lack of standardization in the way facilities submit recurrence data. Moreover, the required FCDS data elements do not include metrics to help determine quality of care, efficacy of treatment, and patient outcomes. The collection of metrics to derive those answers would help to assess health care system performance. Collecting these metrics may also help identify areas for enhancement, ensure patients receive effective and safe care, and ultimately drive continuous quality improvement to enhance overall cancer care and treatment delivery.

A total of 39 facilities responded to the survey question about whether their institution currently collects cancer recurrence data, of which more than half (N=22) indicated they do. When asked to consider the most important data elements and information the state needs to collect to advance cancer research and treatment efforts, a total of 39 facilities responded and indicated the top four data elements are:

- Patient outcomes (N=34).
- Mortality and survival rates for treated patients (N=28).

- Cancer recurrence (N=27).
- Survivorship and quality of life (N=26).

Other important data elements submitted by respondents included cancer genetics and biomarker data; community engagement and education; molecular test results; and treatment beyond the first course of treatment.

When surveyed about whether their institution/organization maintains a registry like that found in hospitals, a total of 35 institutions responded, of which more than half (N=23) indicated they do have a registry. For those with registries, several descriptions included that they have a tumor registry or hospital-based registry.

When surveyed about current cancer recurrence, survival, and progression-free survival rates for patients receiving treatment at their facilities, fewer than 10 facilities reported that they collect or track these figures, but three or less facilities provided rates. Several facilities responded that these rates are typically tracked by cancer type and others stated they calculate 1- and 5-year relative survival rates, making it difficult to provide a general/overall rate of recurrence, survival, or progression-free survival.

The survey also asked if there are additional components or data elements that would increase the value or usefulness of a new report which will be required for the Casey DeSantis Program beginning on January 1, 2024. Eleven facilities indicated a need for additional data elements, including: community education efforts; survival outcomes; data on patients versus protocol; patient outcomes; data on disparities; data on screening programs; outreach and prevention efforts; treatment toxicities per visit; quality of life; biomarkers; and patient survival outcomes.

5. Recommendations

5.1 Tier Structure

Recommendation: Revise the tier structure to consolidate Tiers 1 and 2, encompassing all NCI-designated institutions, and establish two new tiers – one tier comprising Florida-based cancer centers designated as CCEs and another tier for Florida-based institutions that are reporting at least 3,000 cancer cases annually. These changes would result in three tiers as proposed below.

- Tier 1: Florida-based NCI-designated institutions.
- Tier 2: Florida-based cancer centers designated Cancer Center of Excellence.
- Tier 3: Florida-based institutions which report at least 3,000 reportable cancer cases annually.

Based on these proposed tiers, the four current NCIs would fall in Tier 1. For Tier 2, there are six facilities designated as a Cancer Center of Excellence.¹² However, four of these six are NCIs which would leave two facilities for tier 2 status. As shown in table 2, in addition to the four NCIs, there are 10 facilities that reported an average of 3,000 or more reportable cancer cases over the five-year period beginning in 2017. However, it is unknown whether any of these facilities would meet the criteria for Tier 3 status including various allocation criteria (e.g., biomedical research training, clinical trial participation, other reporting requirements).

¹² Memorial Cancer Institute and Florida Atlantic University and Cleveland Clinic Florida Maroon Cancer Center along with the four NCIs comprise the six facilities designated as a Cancer Center of Excellence.

5.2 Allocation Methodology

Recommendation: Revise and clarify the allocation formula components (e.g., clinical trial enrollment, verification of reportable cases through FCDS, and new quality improvement requirements for the allocation methodology).

A designated timeframe for reporting clinical trial participants and reportable cases to the Department before funding allocation takes place is needed and is not currently listed or clarified in statute. Providing a dedicated timeframe will ensure that there is no under or overestimating of reportable cases to be included in the allocation methodology. Additionally, it is recommended that there is specific clarification of the types of clinical trials (e.g., cancer treatment, cancer prevention, or others) and if patients or cases are required to have a cancer diagnosis to be included in the definition and align with the reportable cases definition.

The current allocation methodology, as displayed in Equation 1 (see Section 4.2), does not currently consider quality of care, patient care outcomes, or treatment efficacy that are specifically required per Chapter 2023–239, Laws of Florida. These measures are vast and vary across cancer types. As a result, identifying one measure to capture these components that will be included in the equation is not feasible.

An example of a more realistic approach would be to request the Legislature to direct CCRAB to establish a facility quality improvement report card that assesses patient outcomes, quality of care, and efficacy of treatment. Such a report card score could potentially use quality improvement measures, like those established by the ACS, which assist in documenting efforts to improve specific metrics or processes (e.g., patient outcomes).¹³ Structured quality improvement initiatives are useful as they foster data-driven strategies to readily identify and address problems, outcomes improvement, and ensure patient safety within the cancer program. COC-accredited institutions are required to report on QI initiatives annually.

A proposed tier-weighted allocation fraction formula which incorporates a quality improvement measure to be reported through the reporting period is shown below in Equation 2.

Equation 2: Proposed Tier-Weighted Allocation Fraction Formula

The modified funding equation for the Casey DeSantis Cancer Research Program incorporates a patient quality experience score (PQES). This score will be based on work begun and completed by the CCRAB. CCRAB members possess the expertise to develop the PQES using a minimum of 10 indicators as described below.

$$\text{CAF} = [0.25(\text{CRC} \div \text{TCRC})] + [0.30(\text{CT} \div \text{TCT})] + [0.15(\text{CPC} \div \text{TCPC})] + [0.15(\text{CBE} \div \text{TCBE})] + [0.10(\text{PQES})] + [0.05(\text{TRS})]$$

Where:

CAF = A cancer center's allocation fraction.

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

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

¹³ American College of Surgeons. Commission on Cancer. *Optimal Resources for Cancer Care. 2020 Standards* (Updated June 2023). https://accreditation.facs.org/accreditationdocuments/CoC/Standards/Optimal_Resources_for_Cancer_Care_Feb_2023.pdf

CT = A cancer center's tier-weighted number of individuals enrolled in cancer prevention and treatment clinical trials during specified reporting period.

TCT = The total tier-weighted clinical trials for all cancer centers during specified time.

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

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

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

TCBE = The total tier-weighted biomedical education and training for all cancer centers during specified time

PQES = Patient Quality Experience Score. Tier-weighted score derived from CCRAB cancer scorecard that assesses facility cancer patient treatment outcomes, efficacy of treatment, and quality of care indicators.¹⁴

TRS = Timely Reporting Score. Tier-weighted score derived from facility's timely reporting of data to the FCDS as follows: 1) data on new cancer diagnoses reported within 3 months, 2) data on cancer recurrence reported within 3 months, 3) data on mortality and survival rates for patients treated at funded cancer entities reported every 6 months. Facilities that score less than 50% for timely reporting will have their allocation weight reduced to the next level (e.g., tier 1 facilities will be weighted as a tier 2 facility if reporting is not timely).

5.3 Collaborative Efforts in Cancer Research

Recommendation: A revision of the tiers is recommended to support the activities and projects associated with an academic collaborative. This revision could also support the development of a formal consortium that integrates research institutions and medical schools into the program to expand the program's geographic reach into underserved areas of the state.

Funding priority could be given to collaborative applications which include or address the following:

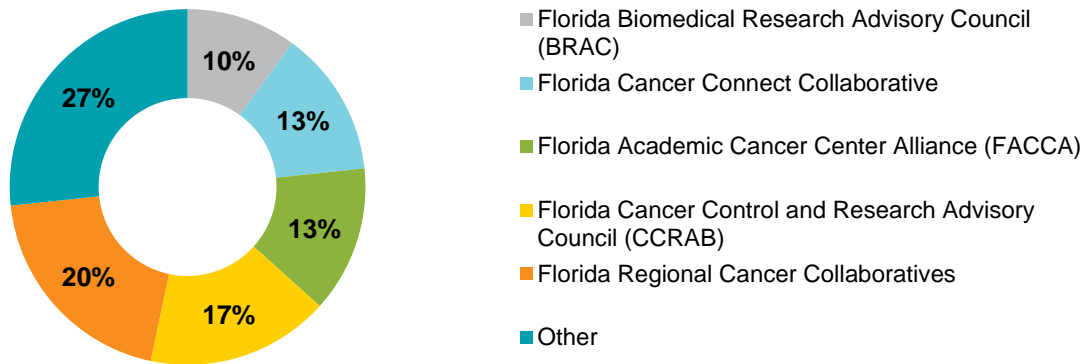
- Expanding research and treatment innovations and services into underserved areas of the state (e.g., Florida Panhandle).
- Building collaborations through sister facilities, formal agreements, or through satellite locations.
- Providing training and education that reaches a wide audience of cancer stakeholders, especially stakeholders from geographically underserved areas and early-career researchers.

Collaboration and knowledge sharing among different cancer research and treatment programs in Florida was perceived as good or fair by nearly two-thirds (N=37) of stakeholder survey respondents (N=59). Less than one-quarter (N=14) of respondents perceived collaboration and knowledge sharing as poor, and one-tenth (N=6) of respondents reported that collaboration is exceptional.

¹⁴ CCRAB will use a minimum of 10 (total) outcome, efficacy, and quality of care indicators to develop the PQE Score to be implemented in FY 2025-26.

More than one-quarter (N=17) of survey respondents (N=59) indicated they were a part of any Florida-based collaboratives and Figure 7 displays which collaborative groups were referenced in survey responses. Respondents submitting responses other than those listed included: Florida Association of Pediatric Tumor Programs; Florida Cancer Registry; OneFlorida/Patient-Centered Outcomes Research Institute and the Sunshine Project. It was also noted that there are no Florida-based children’s cancer initiatives.

Figure 7: Survey Respondents’ Membership on Florida-Based Cancer Collaboratives



Source: Florida Department of Health, Environmental Scan Survey

5.4 Data Collection and Reporting

Recommendation: Require standardized collection and reporting of new and existing data elements that address quality of care, efficacy of treatment, and patient outcomes.

The 2023–24 allocation period for the Casey DeSantis Program highlighted the potential for statutory changes to address reporting periods and clinical trial patient enrollment. For the first time since the inauguration of the Casey DeSantis Program, two NCI-designated facilities reported clinical trials with patient totals exceeding the annual total reportable cases for the reporting period. These events reveal a need to address the language in statute to eliminate the possibility of duplicating patients, which would consequently create calculation errors within the original allocation formula. The following recommendations outline potential statutory considerations:

- Create a structured reporting timeframe for reportable cases.
- Create a structured reporting timeframe and definition for clinical trial participants.

Although the Casey DeSantis Program relies on specific data elements – the number of reportable cancer cases, peer-review funding, and training – to calculate allocations for eligible applicants, these measures do not fully encompass how a cancer center performs and does not address patient outcomes, efficacy of treatment, and quality of care. The current data elements also do not provide enough information to accurately assess improvements in patient outcomes as a result of the investment by the Casey DeSantis Program.

The recent addition of cancer recurrence data to the state’s cancer registry may offer insights into patient outcomes; however, this measure is yet to be collected uniformly across reporting facilities. Due to the absence of review for research proposed by Casey DeSantis Program applicants, it is critical to gain an understanding of each institution’s performance by using metrics

tied to outcomes of patients receiving treatment at their site and the quality and success of those treatments.

Data Quality and Improvement Measures

The revision of the current Casey DeSantis Program allocation methodology which focuses on quality of care, efficacy of treatment, and patient outcomes aligns with one of the goals of the Florida Cancer Plan, 2020–2025, which is to ensure the collection of comprehensive and high-quality cancer-related data from all Florida cancer patients to inform cancer prevention and control programs.¹⁵

Research demonstrates that patient outcome metrics are essential for cancer research funding, providing critical evidence of treatment effectiveness and offering valuable insights into areas in need of improvement. Patient outcome data is vital to cancer research funding for several key reasons:^{16,17, 18}

- **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, 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.

Research indicates 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 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.¹⁹
- **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.²⁰

¹⁵ Florida Cancer Control and Research Advisory Council. [2020-2025 Florida Cancer Plan](#).

¹⁶ 314e. (2022). The Role and Importance of Data Collection in Healthcare. [The Role and Importance of Data Collection in Healthcare - 314e](#)

¹⁷ National Cancer Institute. Division of Cancer Control & Population Statistics. Healthcare Delivery Research Program, About the Outcomes Research Branch. <https://healthcaredelivery.cancer.gov/about/orb/>

¹⁸ 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>

¹⁹ DiMaio, M, Basch, E, Denis, F, et al. The role of patient-reported outcome measures in the continuum of cancer clinical care: European Society of Medical Oncology (ESMO) Clinical Practice Guideline. *Annals of Oncology*, 33(9):878–892. [https://www.annalsofoncology.org/article/S0923-7534\(22\)00691-3/pdf](https://www.annalsofoncology.org/article/S0923-7534(22)00691-3/pdf)

²⁰ 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) <https://jpro.springeropen.com/articles/10.1186/s41687-020-00244-3>

- **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.²¹
- **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.²²

These performance measures are essential for 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.

Additional potential measures referenced in the literature that may satisfy this requirement are listed in Tables 4 and 5 on the following pages; however, an expert panel (e.g., CCRAB) could be tasked with reviewing and vetting measures to satisfy the requirement.

²¹ 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>

²² 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/>

Table 4: Examples of Quality of Cancer Care Performance Measures

Indicator	Performance Measure
Cancer Screening Rates	<ul style="list-style-type: none"> Percentage of eligible individuals screened for common cancers (e.g., breast, colorectal, cervical) within recommended timeframes.
Timeliness of Diagnosis and Treatment	<ul style="list-style-type: none"> Time interval between abnormal cancer screening results and diagnostic resolution. Time from cancer diagnosis to initiation of treatment.
Clinical Guidelines Adherence	<ul style="list-style-type: none"> Percentage of patients receiving cancer treatments according to established clinical guidelines. Adherence to recommended follow-up screenings and tests after cancer treatment.
Survival Rates	<ul style="list-style-type: none"> Cancer-specific survival rates at specific time points (e.g., 1-year, 5-year) after diagnosis. Overall survival rates for cancer patients.
Patient Experience and Satisfaction	<ul style="list-style-type: none"> Patient-reported experience measures (PREMs) related to communication with health care providers, emotional support, and involvement in treatment decisions. Patient satisfaction surveys assessing the overall experience with cancer care services.
Complication Rates	<ul style="list-style-type: none"> Rates of treatment-related complications or adverse events. Hospital readmission rates for cancer patients within a specific timeframe after discharge.
Palliative and Supportive Care	<ul style="list-style-type: none"> Percentage of eligible cancer patients receiving palliative care services. Availability and utilization of supportive care services (e.g., pain management, psychosocial support) for cancer patients.
Health-Related Quality of Life (HRQoL)	<ul style="list-style-type: none"> Assessment of cancer patients' quality of life, including physical, emotional, social, and functional well-being during and after treatment.
Follow-up and Survivorship Care	<ul style="list-style-type: none"> Percentage of cancer survivors receiving survivorship care plans outlining recommended follow-up care and potential late effects of treatment. Monitoring of long-term outcomes and quality of life for cancer survivors.
Provider Volume and Expertise	<ul style="list-style-type: none"> Relationship between provider volume and patient outcomes (higher volume providers often have better outcomes for certain cancer surgeries or procedures). Board certifications and expertise of health care providers involved in cancer care.
Coordination of Care	<ul style="list-style-type: none"> Measures related to care coordination among different health care providers and specialties involved in cancer treatment (e.g., oncologists, surgeons, radiologists, primary care physicians).

Table 5: Examples of Efficacy of Cancer Treatment Performance Measures

Indicator	Performance Measure
Tumor Response Rates	<ul style="list-style-type: none"> • Percentage of patients whose tumors shrink (partial response) or disappear (complete response) after treatment. • Response rates are often categorized based on established criteria such as RECIST (Response Evaluation Criteria in Solid Tumors).
Progression-Free Survival (PFS)	<ul style="list-style-type: none"> • Length of time during and after the treatment of cancer that a patient lives with the disease without it getting worse. • Indicates the duration of time before the cancer progresses or the patient experiences a recurrence.
Overall Survival (OS)	<ul style="list-style-type: none"> • Percentage of patients who are still alive at a specific time point after diagnosis or treatment. • Commonly reported at 1-year, 3-year, and 5-year intervals after treatment initiation.
Disease-Free Survival (DFS)	<ul style="list-style-type: none"> • Length of time after primary treatment for a cancer ends that the patient survives without any signs or symptoms of the cancer. • Often used in cancer types where complete surgical removal of the tumor is possible.
Time to Progression (TTP)	<ul style="list-style-type: none"> • Time from the start of treatment to the time when the cancer starts to grow again. • Particularly relevant for chronic diseases and cancers that have a slower growth rate.
Quality of Life (QoL) Assessments	<ul style="list-style-type: none"> • Patient-reported outcomes related to physical, emotional, social, and functional well-being during and after cancer treatment. • Assessments can include validated questionnaires and interviews to measure the impact of treatment on patients' daily lives.
Adverse Event Monitoring	<ul style="list-style-type: none"> • Frequency and severity of treatment-related side effects and adverse events. • Monitoring and managing adverse events are crucial to ensuring that the benefits of treatment outweigh the risks.
Patient-Reported Outcome Measures (PROMs)	<ul style="list-style-type: none"> • Patient-reported data on symptoms, side effects, and overall well-being during and after treatment. • PROMs provide insights into the patient's perspective on the efficacy and tolerability of the treatment.
Treatment Compliance and Persistence	<ul style="list-style-type: none"> • Percentage of patients who adhere to the prescribed treatment plan and complete the recommended course of therapy. • Duration of time patients continue treatment without interruptions or discontinuations.
Biomarker Response	<ul style="list-style-type: none"> • Changes in specific biomarkers (e.g., tumor markers, genetic mutations) that indicate the response of the cancer to treatment. • Biomarker responses can be used to assess targeted therapies and personalized medicine approaches.
Long-term Outcomes and Survivorship	<ul style="list-style-type: none"> • Monitoring cancer survivors for late effects of treatment, secondary cancers, and overall health status. • Assessing the quality of life and psychosocial well-being of cancer survivors in the years following treatment.

6. Next Steps

6.1 Goals and Objectives

Goal 1: Expand eligibility for the Casey DeSantis Program to a wider array of Florida-based institutions.

Objectives:

- Amend section 381.915, Florida Statutes, to revise the current tier structure to expand eligibility.
- Amend section 381.915, Florida Statutes, to establish a structured timeframe for reporting reportable cases and define and clarify clinical trial participants to the Department.
- Develop an implementation plan, including timelines, responsibilities, and a process for applying the new tier structure.
- Develop a communication plan to inform the academic and research community about the new tier structure and its significance in advancing Florida's cancer research efforts.

Goal 2: Develop an allocation methodology which incorporates a metric that focuses on patient outcomes, quality of care, and efficacy of treatment.

Objectives:

- Amend section 381.915, Florida Statutes, to revise the allocation formula to include a weighted quality improvement metric.
- Amend section 381.915, Florida Statutes, to establish a structured timeframe for reporting reportable cases and define and clarify clinical trial participants to the Department.
- Reassess the impact of the annual allocation floor amount (\$16 million) should the pool of eligible applicants be expanded.

Goal 3: Revise data reporting requirements for cancer centers reporting into the state's cancer registry, FCDS.

Objectives:

- Amend section 385.202, Florida Statutes, and, Rule 64D-3.034, Florida Administrative Code to establish the new metrics to be reported.
- Engage CCRAB to provide their collective expertise in reviewing and identifying new metrics to be reported into FCDS.
- Implement a pilot testing phase in which a select group of institutions are asked to report the newly added identified metrics.

Goal 4: Create an academic collaborative to expand the geographic reach of the Casey DeSantis Program.

Objectives:

- Amend section 381.915, Florida Statutes, to include the Tier 2 where CCEs are required to enter a research partnership with at least one other organization.

7. Conclusion

Statutory and other modifications are needed to fully realize changes to the Casey DeSantis Program, as directed by the Legislature.

This Plan recommends potential statutory changes in the Casey DeSantis Program. Recommended changes to be considered include changing the current tier structure to expand eligibility and allow other cancer centers in Florida to participate in the program.

Additionally, the Plan recommends defining reporting periods for all required elements of the allocation methodology to the Department, further definition, and clarification of clinical trial patient enrollment, to account for potential for duplications or underestimations in patient counts in the existing allocation methodology.

Moreover, the Plan highlights the need for the allocation methodology to consider for crucial factors mandated by Chapter 2023–239, Laws of Florida, such as quality of care, patient outcomes, and treatment efficacy. Given the vast and varied nature of these measures across cancer types, a realistic approach proposes the establishment of a facility quality improvement report card by directing CCRAB, supported also by a tier-weighted quality improvement allocation fraction formula. This formula, integrating a quality improvement measure, aligns with the need to capture the multifaceted components essential for assessing cancer center performance.

In alignment with the Florida Cancer Plan, 2020–2025, the suggested revision of the Casey DeSantis Program's allocation methodology prioritizes comprehensive and high-quality cancer-related data collection. This shift toward patient outcome metrics meets program goals and aligns with research practices that emphasize the importance of such metrics for adequate cancer research funding and program improvement.

This Plan also emphasizes the importance of requiring standardized collection and reporting of data elements related to quality of care, efficacy of treatment, and patient outcomes. It points out the limitations of the current data elements used for Casey DeSantis Program allocations, highlighting the necessity of metrics tied to patient outcomes and treatment quality to truly evaluate the program's impact.

Furthermore, this review advocates for collaboration and knowledge sharing among different Florida cancer research and treatment programs through the revised tier structure, allowing for cancer centers to participate in the funding through formal partnerships and consortium with a designated NCI center.

This Plan and its recommendations provide the guidance needed to navigate dynamic landscapes, ensuring that overarching goals and objectives are achieved. These steps establish priorities, anticipate resource allocation, and establish clear pathways for progress. With this approach, the Plan is adaptive, relevant, and forward-looking, allowing implementors to respond effectively to evolving challenges and opportunities.

Report Appendices and References

8. Appendix

8.1 Other State Funding Available for Cancer Research

In addition to the Casey DeSantis Program, Florida administers three smaller cancer research initiatives, authorized by the Legislature, which support researchers in their work to improve cancer prevention, diagnosis, and treatment.

- The William G. "Bill" Bankhead, Jr., and David Coley Cancer Research Program (Bankhead-Coley Program).
- The James and Esther King Biomedical Research Program (King Program).
- The Live Like Bella Pediatric Cancer Research Initiative (Bella Initiative).

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, 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. The Bankhead-Coley Program, King Program, and Bella Initiative are peer-reviewed funding instruments, unlike the Casey DeSantis Program. Table 6 presents funding allocated by each of the programs for FY 2022–23 and funds ranged from \$3 million for the Bella Initiative to \$8.7 million for the Bankhead-Coley Program. Funding opportunities through these programs for FY 2022–23 totaled \$18.6 million.

Table 6: FY 2022-23 Recipients for the King Program, Bankhead-Coley Program, and Bella Initiative

Recipient	King Program	Bankhead-Coley Program	Bella Initiative
Florida Atlantic University	NA	\$588,600	\$248,050
Florida State University	NA	NA	\$124,025
Moffitt Cancer Center	\$1,996,841	\$3,873,208	\$668,392
Mayo Clinic of Jacksonville	\$569,400	NA	NA
University of Central Florida	NA	\$1,177,200	\$248,050
University of Florida	\$2,842,188	\$1,081,397	\$1,165,773
University of Miami	\$1,423,500	\$2,060,100	\$545,710
Total	\$6,831,929	\$8,780,505	\$3,000,000

Source: Florida Department of Health

Florida Cancer Innovation Fund

For FY 2023–24, the Legislature authorized \$20 million for a Casey DeSantis Program innovation funding opportunity. The Department accepted applications beginning October 4, 2023, for pilot projects in cancer research and innovation. The purpose of this effort is to energize collaborations between oncologists, cutting-edge researchers, and cancer facilities and to provide a plausible route for expedited funding to bolster competitiveness for extramural cancer research funding. Innovation fund applicants included but were not limited to researchers working on cutting edge cancer treatments; post-doctoral/graduate student fellows; non-profit organizations; medical providers; oncology practices; and Florida Cancer Centers of Excellence.

Innovation funding proposal topics were focused on innovative cancer research and had to adhere to the main goals of the funding opportunity announcement as follows:

- **Data** – Improve data timeliness and accessibility.
- **Best Practices** – Streamline, encourage, and incentivize the sharing of treatment best practices among public and private entities.
- **Innovation** – Advancements in cutting-edge technology and clinical treatments.

8.2 Survey Data Collection Strategy

This review was based on an extensive examination of literature, documentation, and data. The assessment incorporated peer-reviewed publications, annual reports from state-funded programs, and state and federal data sets (programmatic and fiscal).

In addition, an environmental scan survey was conducted to gather valuable insights into overall cancer research and treatment efforts in Florida. A survey tool was distributed to a recipient list comprising 123 unique facilities. It included hospital administrators statewide, facilities reporting to FCDS, and members of CCRAB, the Casey DeSantis Program, and the Florida Cancer Plan. Additionally, a random sample of 1,359 oncology private physicians/practices received the survey.²³ A total of 71 individual survey responses were received, with several institutions responding multiple times. Multiple responses from the same institution were combined, resulting in responses from 59 unique institutions, organizations, or physician practices. Out of the 123 unique facilities that the survey was sent to, responses were received from 39 facilities upon removal of private physicians/oncology practices from the responding facilities, resulting in a response rate of 31%.

As part of the analysis, three stakeholder meetings were held to gather diverse participants and organizations. The meetings were organized around cancer research, research funding, and access to care and treatment. Stakeholders attending the meetings included clinicians, researchers, administrators, and tumor registrars from cancer centers, research institutions, biomedical education institutions, hospitals, and clinics across Florida. This diverse group of stakeholders brought a variety of perspectives, creative ideas, and a balanced approach to addressing the challenges in cancer research and care.

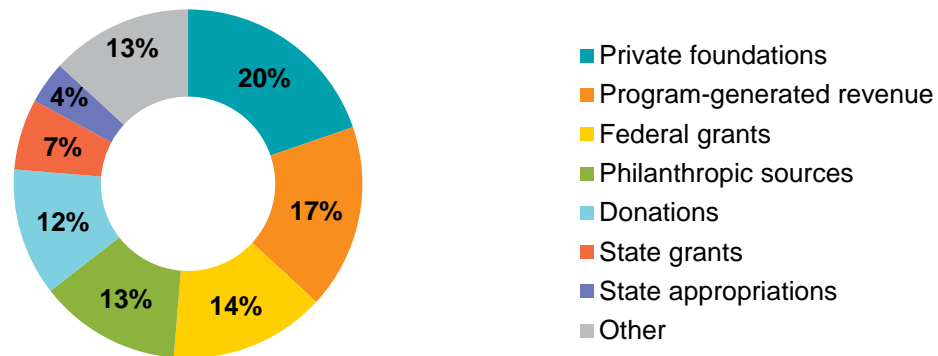
8.3 Funding for Cancer Research and Research Achievements

In response to survey questions about cancer research funding in Florida, a total of 32 respondents provided responses about the primary source of funding for cancer research programs. As shown in Figure 8, the most frequently cited funding source was private foundations (N=15), followed by program-generated revenue (N=13), federal grants (N=11), and philanthropic sources (N=10). State grants (N=5) and state appropriations (N=3) made up the smallest portions of research funding sources reported by survey respondents. Other primary funding sources for

²³ The survey tool was distributed to 162 hospital administrators statewide (excluding rehabilitation and mental health facilities); 119 facilities reporting into the state's cancer registry, FCDS; 87 points of contact including members of CCRAB, Casey DeSantis Program, and Florida Cancer Plan. However, facilities with multiple or satellite locations were counted as a single entity in this Plan. In addition, it is important to note that the points of contact for the hospital administrators, FCDS facilities, and the members of CCRAB, Casey DeSantis Program, and/or Florida Cancer Plan are not mutually exclusive. The same points of contact are represented on multiple lists.

research submitted by respondents include industry-private partnerships, industry-sponsored trials funding, and pharmaceutical-funded clinical trials.

Figure 8: Survey Respondents' Primary Funding Sources for Cancer Research Programs



Source: Florida Department of Health, Environmental Scan Survey

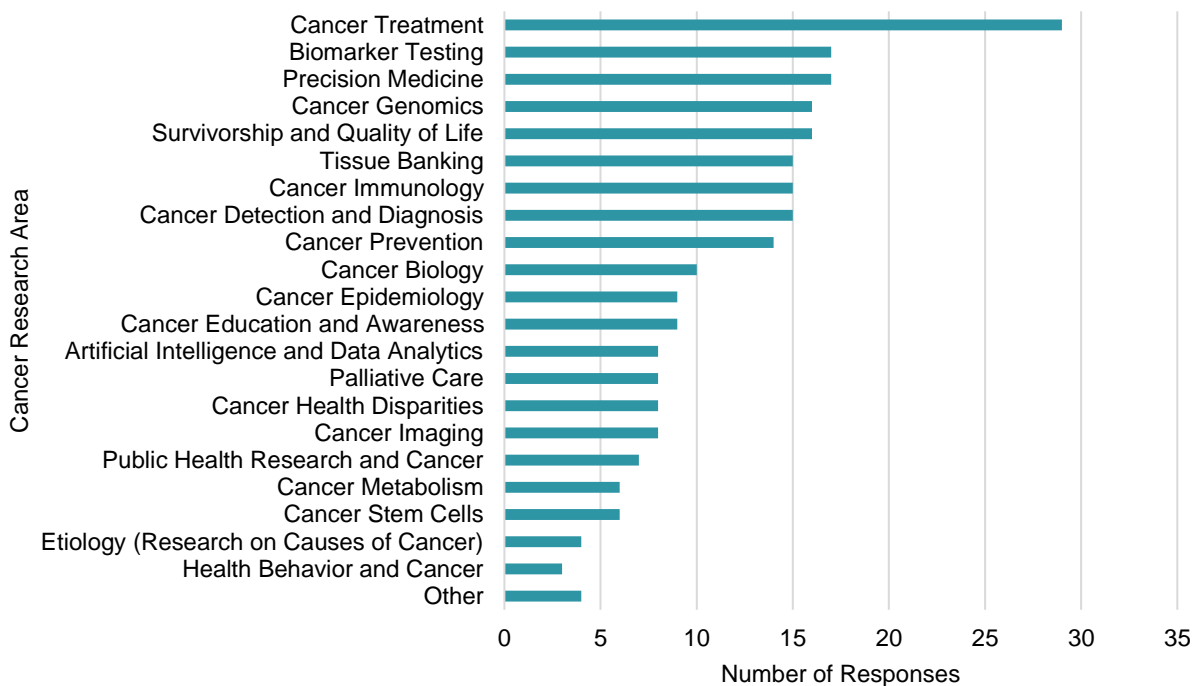
Across the board, survey respondents suggested that more funding was needed to support cancer research and innovation in Florida. They also shared some of their key achievements and research breakthroughs made by their institution/program in the last three years.

- National Cancer Data Base retrospective research and publications.
- Use of AI in the identification of breast cancer during mammography studies.
- Changes in the standard of care for pediatric cancer treatment.
- U.S. Food and Drug Administration approval of Pirtobrutinib.
- CAR T-cell therapy; development and translation of chimeric antigen receptor T-cell therapy and tumor infiltrating lymphocyte (TIL) therapy.
- Next Generation Sequencing of pediatric leukemias.
- Expanded Access Program for metastatic melanoma treated with TIL therapy—first globally to open.
- Mechanisms of resistance to tyrosine kinase inhibitors; work on IDH1, IDH2, and LSD1 inhibitors in cancer.
- Identification of novel biomarkers for uterine cancer; initiation of CAR T-cell therapies for gynecologic malignancies.
- Total neoadjuvant therapy for rectal cancer being extended to all newly diagnosed patients with stage 2 and 3 rectal cancers: laser interstitial thermal therapy plus immunotherapy for brain cancer.

More than half of (N=32) survey respondents (N=59) indicated their institution/organization conducts research and nearly half (N=29) conduct clinical trials. Regarding perceptions about how well cancer research findings and innovations are being applied to clinical practice (i.e., translation), a total of 32 facilities responded, of which more than two-thirds (N=21) felt that research findings are being applied to clinical practice either well (N=14), very well (N=8), or extremely well (N=1) in their region or service area; and more than one-quarter (N=9) felt that the application of research findings to clinical practice was being done poorly (N=8) or very poorly (N=1).

Twenty-nine (N=29) survey respondents indicated one of their institution’s primary areas of research was cancer treatment. The next top three areas of cancer research reported by respondents were biomarker testing (N=17), precision medicine (N=17), and cancer genomics (N=16). Other areas of research not represented on the list of options but reported by respondents include blood and marrow transplant; cancer communication; cancer drug and device development; cancer health services research; molecular medicine; mathematical oncology; cancer bioengineering; drug discovery; cellular immunotherapy; cancer vaccines; solid tumors; and registry studies. Figure 9 displays all cancer research areas and the number of survey responses.

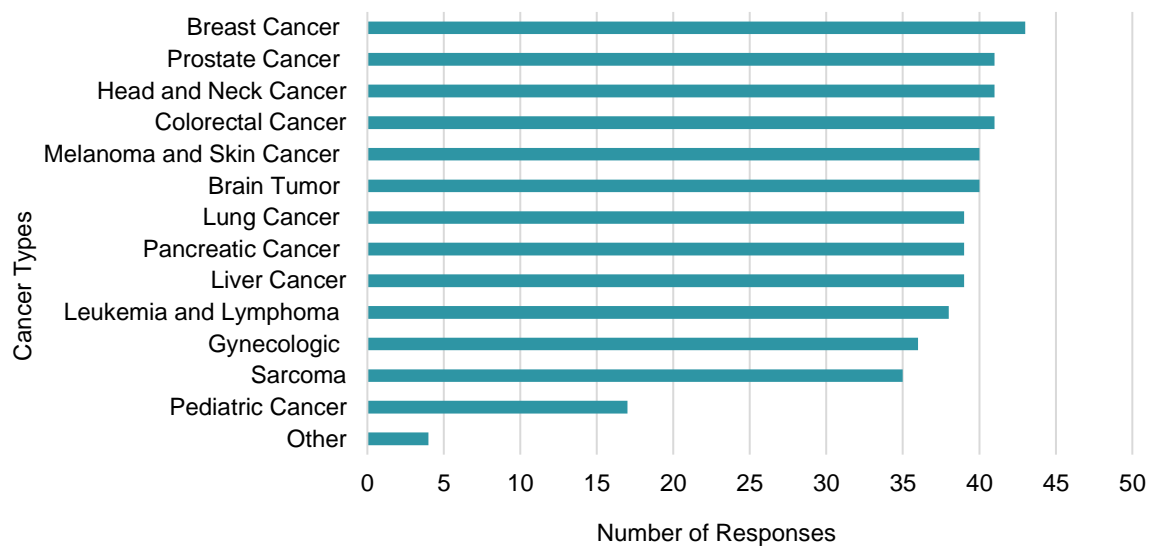
Figure 9: Primary Areas of Cancer Research Reported by Survey Respondents



Source: Florida Department of Health, Environmental Scan Survey

In terms of the cancer types treated by facilities responding to the survey (N=59), the four cancers cited most frequently include breast (N=43), prostate (N=41), head and neck (N=41), and colorectal (N=41). Other cancers treated by respondent facilities include gastrointestinal, musculoskeletal, genitourinary (e.g., bladder, kidney), geriatric cancers, multiple myeloma, thyroid, and adrenal. Figure 10 shows all cancer types and the number of responses received for each.

Figure 10: Cancer Types Treated by Survey Respondent Facilities



Source: Florida Department of Health, Environmental Scan Survey

8.4 National Cancer Institute

The NCI Cancer Centers Program nationally 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. The NCI recognizes a total of 72 institutions nationwide that are one of three types.

- Nine cancer centers are recognized for their scientific leadership, resources, and the depth and breadth of their research in basic, clinical, and/or prevention, cancer control, and population science.
- Fifty-six comprehensive cancer centers are recognized for their leadership and resources, in addition to demonstrating an added depth and breadth of research, as well as substantial transdisciplinary research that bridges these scientific areas.
- Seven basic laboratory cancer centers primarily focus on laboratory research and often conduct preclinical translation while working collaboratively with other institutions to apply these laboratory findings to new and better treatments.

There are subtle distinctions between NCI cancer center designations. In Florida, NCI-designated comprehensive cancer centers and NCI-designated cancer centers significantly contribute to cancer research. NCI cancer centers sometimes engage in more research projects than NCI comprehensive cancer centers, as shown in Table 7. For example, both Tier 2 designated organizations in Florida have engaged in more than double the number of NIH-funded research projects than a Tier 1 designated institution in Florida. Moreover, Florida has recognized all NCI-designated institutions as CCEs, underlining their comprehensive research and treatment portfolios and collective commitment to fighting cancer and advancing research.

Table 7: NCI-Designated Cancer Centers by Tier Designation, Type of Institution, and Number of NIH Projects, FY 2020–2022

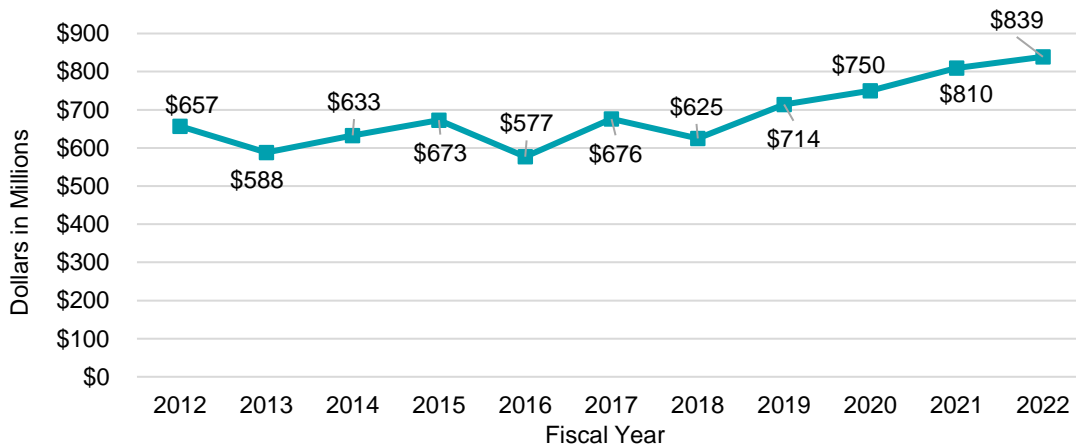
Organization	Tier	Type of Institution	Number of Projects
Moffitt Cancer Center	Tier 1	NCI Comprehensive Cancer Center	254
Mayo Clinic Jacksonville	Tier 1	NCI Comprehensive Cancer Center	51
UF Health Cancer Center	Tier 2	NCI Cancer Center	124
University of Miami Sylvester Cancer Center	Tier 2	NCI Cancer Center	135

Source: Florida Department of Health and National Institutes of Health

8.5 Federal Funding Available for Cancer Research

While Florida’s investment in state cancer research funding is significant, federal funding remains an essential funding stream for cancer institutions. Federal funding supplements state funding and supports the research efforts of NCI-designated and non-NCI-designated institutions. Over the past 10 years, NIH cancer-specific funding in the United States has increased 63.5%, from an estimated \$8.021 billion in 2012 to \$13.119 billion in 2022.²⁴ NIH funding in Florida has also increased over the past 10 years. As shown in Figure 11, NIH funding awarded to Florida researchers has increased by nearly 28%, to more than \$839 million in 2022.²⁵ Notably, Florida-based cancer researchers and institutions have consistently ranked among the top 15 states in NIH funding since 2015. Florida ranks 13th in funding with a total of \$839,642,634 for 2022.

Figure 11: NIH Funding, Florida, 2012–2022



Source: National Institutes of Health

Table 8 presents NIH funding for Florida cancer research projects from 2020 through 2022. The recipients of this funding are a diverse group and include NCI-designated institutions which are also accredited by the ACS COC and designated as CCEs by the state; multiple academic institutions; medical schools; independent research institutions; therapeutics research organizations; and hospitals. Florida’s designation of CCEs acknowledges the exceptional standards set by providers, highlighting their distinction in offering high-quality, patient-centered, and comprehensive care.

²⁴ NIH RePORT, Categorical Spending, available at: <https://report.nih.gov/funding/categorical-spending/>

²⁵ NIH RePORT, NIH Funding by State, available at: https://reporter.nih.gov/search/bBt_LoVQqEWDOhmTY2c5Dg/projects/charts

Table 8: Florida-based Organizations with NIH-Funded Cancer Projects, FY 2020–2022²⁶

Organization	Type of Institution	Number of Projects	Total Funding
Moffitt Cancer Center	NCI-Designated	254	\$101,010,441
UM Sylvester Cancer Center	NCI-Designated	135	\$41,772,125
UF Health Cancer Center	NCI-Designated	124	\$42,210,599
Mayo Clinic Jacksonville	NCI-Designated	51	\$20,127,235
University of South Florida	Academic Institution	26	\$8,959,624
Scripps Florida	Research Institution	20	\$8,084,124
UM Coral Gables	Academic Institution	13	\$5,401,978
Florida International University	Academic Institution	10	\$4,613,800
University of Central Florida	Academic Institution	9	\$2,084,607
Alchem Laboratories Corporation	Therapeutics Research Company	8	\$3,527,992
Stemsynergy Therapeutics, Inc.	Therapeutics Research Company	5	\$3,397,991
Sarasota County Public Hospital District	Hospital	4	\$159,461
Inspirata, Inc.	Health Technology Company	3	\$2,616,901
Florida Association of Pediatric Tumor Programs	Research Institution	3	\$2,025,089
Florida Atlantic University	Academic Institution	3	\$380,152
Florida Agricultural and Mechanical University	Academic Institution	3	\$2,722,119
Stinginn, LLC	Therapeutics Research Company	2	\$1,245,284
Integrated Sensors, LLC	Therapeutics Research Company	2	\$1,198,774
Florida State University	Academic Institution	2	\$615,942
Foundation for Applied Molecular Evolution	Research Institution	2	\$341,196
South Florida VA Foundation for Research and Education	Research Institution	2	\$127,200
Carevive Systems, Inc.	Health Technology Company	1	\$1,500,000
Decimal, Inc.	Medical Equipment Manufacturer	1	\$1,059,095
Lacerta Therapeutics, Inc.	Therapeutics Research Company	1	\$999,999
Nova Southeastern University	Academic Institution	1	\$453,399
Morphogenesis, Inc.	Therapeutics Research Company	1	\$400,000
Vanquish Bio, LLC	Therapeutics Research Company	1	\$399,580
Infotech Soft, Inc.	Health Technology Company	1	\$398,604
Avantyx, LLC	Therapeutics Research Company	1	\$355,723
Total		689	\$258,189,034

Source: National Institutes of Health

8.6 COC-Accredited Cancer Centers

Table 9: COC-Accredited Cancer Centers

Institution	City	County
AdventHealth Daytona Beach	Daytona Beach	Volusia
AdventHealth DeLand	DeLand	Volusia
AdventHealth Fish Memorial	Orange City	Volusia
AdventHealth Orlando	Orlando	Orange
AdventHealth Palm Coast	Palm Coast	Flagler
AdventHealth Tampa	Tampa	Hillsborough
AdventHealth Waterman	Tavares	Lake
Ascension Sacred Heart	Pensacola	Escambia
Ascension St. Vincent's Riverside	Jacksonville	Duval
Baptist Health Boca Raton Regional Hospital	Boca Raton	Palm Beach

²⁶ NIH Awards by Location and Organization - NIH Research Portfolio Online Reporting Tools (RePORT) available at: <https://reporter.nih.gov/>

Institution	City	County
Baptist Hospital	Pensacola	Escambia
Baptist MD Anderson at Baptist Health	Jacksonville	Duval
Bay Pines VA Healthcare System	Bay Pines	Pinellas
Broward Health Medical Center	Fort Lauderdale	Broward
Central Florida Health	Leesburg	Lake
Cleveland Clinic Hospital	Weston	Broward
Cleveland Clinic Martin North Hospital	Stuart	Martin
Delray Medical Center	Delray Beach	Palm Beach
Flagler Hospital	St. Augustine	St. Johns
Good Samaritan Medical Center	West Palm Beach	Palm Beach
Moffitt Cancer Center	Tampa	Hillsborough
HCA Florida Aventura Hospital	Aventura	Miami-Dade
HCA Florida Blake Hospital	Bradenton	Manatee
HCA Florida Capital Hospital	Tallahassee	Leon
HCA Florida Fawcett Hospital	Port Charlotte	Charlotte
HCA Florida Fort Walton-Destin Hospital	Fort Walton Beach	Okaloosa
HCA Florida Gulf Coast Hospital	Panama City	Bay
HCA Florida JFK Hospital	West Palm Beach	Palm Beach
HCA Florida Largo Hospital	Largo	Pinellas
HCA Florida Memorial Hospital	Jacksonville	Duval
HCA Florida Mercy Hospital	Miami	Miami-Dade
HCA Florida North Florida Hospital	Gainesville	Alachua
HCA Florida Ocala Hospital	Ocala	Marion
HCA Florida Orange Park Hospital	Orange Park	Clay
HCA Florida Osceola Hospital	Kissimmee	Osceola
HCA Florida St. Petersburg Hospital	St. Petersburg	Pinellas
HCA Florida Trinity Hospital	Trinity	Pasco
HCA Florida West Hospital	Pensacola	Escambia
Holy Cross Hospital	Fort Lauderdale	Broward
Indian River Memorial Hospital	Vero Beach	Indian River
Jupiter Medical Center	Jupiter	Palm Beach
Kendall Regional Medical Center	Miami	Miami-Dade
Lakeland Regional Health	Lakeland	Polk
Lee Memorial Health System	Fort Myers	Lee
Manatee Memorial Hospital	Bradenton	Manatee
Mayo Clinic Cancer Center-Jacksonville	Jacksonville	Duval
Memorial Healthcare System	Hollywood	Broward
Miami Cancer Institute	Miami	Miami-Dade
Morton Plant Mease Health Care	Clearwater	Pinellas
Mount Sinai Medical Center	Miami Beach	Miami-Dade
Nicklaus Children's Hospital	Miami	Miami-Dade

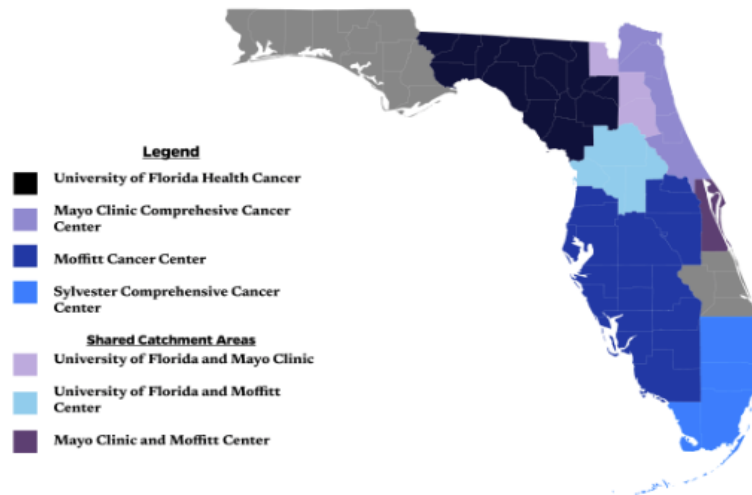
Institution	City	County
Orlando Health Cancer Institute	Orlando	Orange
Parrish Medical Center	Titusville	Brevard
Sarasota Memorial Hospital	Sarasota	Sarasota
St. Anthony's Hospital	St. Petersburg	Pinellas
St. Joseph's Hospitals	Tampa	Hillsborough
Tallahassee Memorial Cancer Center	Tallahassee	Leon
Tampa General Hospital	Tampa	Hillsborough
Trustees of Mease Hospital	Safety Harbor	Pinellas
UF Health Cancer Center	Gainesville	Alachua
UF Health Jacksonville (Shands Medical Center)	Jacksonville	Duval
UM Sylvester Comprehensive Cancer Center	Miami	Miami-Dade

8.7 Collaboration in Cancer

FACCA is the only academic collaborative whose purpose is fostering trans-state research collaborations. In contrast, CCRAB serves the state in an advisory capacity and the six regional cancer control collaboratives were established to develop local strategic cancer plans to address the Florida Cancer Plan's goals at the local level.

As shown in Figure 12, the FACCA collaborative divides the state into geographic catchment areas which are set along county lines and based on the area that each cancer center serves. There are gaps in coverage with FACCA's current catchment areas, leaving the western Florida Panhandle (from Tallahassee westward) and a four-county area just north of Palm Beach County (Martin, St. Lucie, Indian River, and Okeechobee counties) without access to research engagement that the collaborative can provide. The seven other medical schools in Florida are located primarily in central and south Florida, except for one – Florida State University College of Medicine, which is located centrally in the Florida Panhandle. Although the FACCA collaborative currently touches on rural areas within the state, it does not specifically focus its work within these areas, leaving rural areas of the state underrepresented.

Figure 12: Florida Academic Cancer Center Alliance (FACCA) Catchment Areas



Source: Florida Academic Cancer Center Alliance (FACCA)

The FACCA also provides a recent example of how an innovative academic collaborative brings together Florida’s NCI-designated institutions to share knowledge and resources through annual meetings and regular retreats. The FACCA has developed a pilot grant program whereby funds from the institutions are used to support early-career researchers in carrying out research projects which helps to grow future cancer scientists and generate additional extramural funding.

Since initiating the FACCA Pilot Program in 2015, the NCI-designated institutions funded under the Casey DeSantis Program have cumulatively invested \$2.75 million in the program, awarding 23 collaborative pilot (or seed) grants to 60 researchers across the three cancer centers. The awarded investigators were highly successful and returned \$45 million in extramural funding with 79% of awards coming from peer-review sponsors.²⁷ The collaborative’s investment in pilot projects, coupled with the subsequent extramural funding gains, not only demonstrates the unified commitment of these institutions to nurture early-career researchers, but provides a best practice model for how a collaborative can combine funding to support early-career research grants. Table 10 shows the most recent investments in the FACCA pilot.

Table 10: FACCA Pilot Project Collaborations and Results, 2020–2022

Institution	Dollars Invested	Number of Pilot Awards	Number of Investigators	Extramural Funding Return	Extramural Funding Received as Prime	Extramural Funding ROI
Moffitt Cancer Center	\$850,000	17	20	\$29,800,000	\$18,200,000	20:1
UM Sylvester Cancer Center	\$1,050,000	21	23	\$43,700,000	\$7,700,000	6:1
UF Health Cancer Center	\$850,000	17	17	\$43,500,000	\$18,800,000	21:1

²⁷ Florida Department of Health. *Casey DeSantis Cancer Research Program: Three-Year Report to the Cancer Control and Research Advisory Council*. July 1, 2023.

8.8 Acronyms

AI	Artificial Intelligence
ACS	American College of Surgeons
BRAC	Biomedical Research Advisory Council
CAR T-Cell	Chimeric Antigen Receptor T-Cell
CCE	Cancer Center of Excellence
CCRAB	Florida Cancer Control and Research Advisory Council
Casey DeSantis Program	Casey DeSantis Cancer Research Program
COC	Commission on Cancer
COS	Core Outcome Sets
CTRP	NCI Clinical Trials Reporting Program
DFS	Disease-Free Survival
FACCA	Florida Academic Cancer Center Alliance
FCDS	Florida Cancer Data System
F.S.	Florida Statute
FY	Fiscal Year
HRQoL	Health-Related Quality of Life
NCI	National Cancer Institute
NIH	National Institutes of Health
OS	Overall Survival
PFS	Progression-Free Survival
PROM	Patient-Reported Outcome Measure
QI	Quality Improvement
QoL	Quality of Life
TIL	Tumor Infiltrating Lymphocyte
TTP	Time to Progression
UF	University of Florida
UM	University of Miami
U.S.	United States

8.9 Glossary

American College of Surgeons (ACS): The American College of Surgeons is a professional medical association for surgeons and surgical team members, founded in 1913.

Biomedical Education and Training: Instruction that is offered to a student who is enrolled in a biomedical research program at an affiliated university as a medical student or a student in a master's or doctoral degree program, or who is a resident physician trainee or postdoctoral trainee in such program.

Biomedical Research Advisory Council (BRAC): Established through state statute, this 11-member council advises the State Surgeon General on the direction and scope of the Bankhead-Coley, King, and Bella cancer research initiatives. Four of the BRAC members are appointed by the Governor.

Casey DeSantis Cancer Research Program: A program created by the Florida Legislature in 2014 as the Florida Consortium of National Cancer Institute (NCI) Centers Program and renamed the Casey DeSantis Cancer Research Program in 2022. This program was established to enhance the quality and competitiveness of cancer care in Florida; further a statewide biomedical research strategy directly responsive to the health needs of Florida's citizens; and capitalize on potential educational opportunities available to students.

Cancer Connect Collaborative: An expansion of Florida Cancer Connect and established by First Lady Casey DeSantis, this collaborative was assembled to analyze and rethink Florida's approach to combatting cancer.

Commission on Cancer (COC): Established by the American College of Surgeons in 1922, the Commission on Cancer is a consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through standard-setting, prevention, research, education, and the monitoring of comprehensive quality of care.

Florida Academic Cancer Center Alliance (FACCA): A collaborative comprising Florida's NCI-designated cancer centers (Moffitt, UM Sylvester, UF Health, and Mayo Clinic Jacksonville) with the purpose of fostering trans-state research collaborations to promote excellence in cancer research for Florida's residents.

Florida Cancer Control and Research Advisory Council (CCRAB): The council, which consists of 15 appointed members, was founded by state statute in 1979 to advise the Legislature, Governor, and State Surgeon General on ways to reduce Florida's cancer burden.

Florida Cancer Data System (FCDS): The Florida Cancer Data System is Florida Statewide Cancer Registry. In 1978, the Florida Department of Health contracted with the Sylvester Comprehensive Cancer Center (SCCC) at the University of Miami School of Medicine to design and implement the registry. FCDS has been collecting incidence data since 1981.

National Cancer Institute (NCI): The National Cancer Institute coordinates the United States National Cancer Program and is part of the National Institutes of Health, which is one of eleven agencies that are part of the U.S. Department of Health and Human Services.

National Cancer Centers Program: The NCI Cancer Centers Program was created as part of the National Cancer Act of 1971 and is one of the anchors of the nation's cancer research effort. Through this program, NCI recognizes centers around the country that meet rigorous standards for transdisciplinary, state-of-the-art research focused on developing new and better approaches to preventing, diagnosing, and treating cancer.

National Cancer Institute (NCI) Designations: The NCI-Designated Cancer Centers are recognized for their scientific leadership in laboratory and clinical research. This research aligns with the goals of the National Cancer Plan. Three designations are recognized: Comprehensive Cancer Centers, Clinical Cancer Centers, and Basic Laboratory Cancer Centers.

National Cancer Institute (NCI) Clinical Trials Reporting Program: A comprehensive database of information on all interventional clinical trials directly and indirectly funded by NCI, open to accrual as of January 1, 2009, as well as observational studies open to accrual as of January 1, 2020.

Peer-Review Costs: The total annual direct costs for peer-reviewed cancer-related research projects, consistent with reporting guidelines provided by the NCI, for the most recent reporting period available.

Reportable Cases: Cases of cancer in which a cancer center is involved in the diagnosis, evaluation of the diagnosis, evaluation of the extend of cancer spread at the time of diagnosis, or administration of all or any part of the first course of therapy for the most recent annual reporting period available.

8.10 References

1. 314e. (2022). The Role and Importance of Data Collection in Healthcare. <https://www.314e.com/blog/the-role-and-importance-of-data-collection-in-healthcare/>
2. American College of Surgeons. Commission on Cancer. *Optimal Resources for Cancer Care. 2020 Standards* (Updated June 2023). https://accreditation.facs.org/accreditationdocuments/CoC/Standards/Optimal_Resources_for_Cancer_Care_Feb_2023.pdf
3. American Society of Clinical Oncology. Cancer.net. NCI-Designated Cancer Centers and Cooperative Groups. <https://www.cancer.net/navigating-cancer-care/cancer-basics/cancer-care-team/find-nci-designated-cancer-center>
4. Centers for Disease Control and Prevention (CDC) Foundation. *What is Public Health*. Atlanta, GA. <https://www.cdcfoundation.org/what-public-health>
5. Centers for Disease Control and Prevention. United States Cancer Statistics: Data Visualizations. *Cancer Statistics At a Glance*. <https://gis.cdc.gov/Cancer/USCS/#/AtAGlance/>
6. DiMaio, M, Basch, E, Denis, F, et al. The role of patient-reported outcome measures in the continuum of cancer clinical care: European Society of Medical Oncology (ESMO) Clinical Practice Guideline. *Annals of Oncology*, 33(9):878–892. [https://www.annalsofoncology.org/article/S0923-7534\(22\)00691-3/pdf](https://www.annalsofoncology.org/article/S0923-7534(22)00691-3/pdf)
7. Florida Department of Health, FLHealthCHARTS. *Leading Causes of Death Profile*. <https://www.flhealthcharts.gov/ChartsReports/rdPage.aspx?rdReport=ChartsProfiles.LeadngCausesOfDeathProfile>
8. Florida Department of Health. *Casey DeSantis Cancer Research Program: Three-Year Report to the Cancer Control and Research Advisory Council*. July 1, 2023.
9. Florida Statewide Cancer Registry, Florida Cancer Data System, *Annual Cancer Reports: 2016–2020*. Florida Department of Health. <https://fcds.med.miami.edu/inc/publications.shtml>
10. 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>
11. 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/>
12. 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>
13. National Cancer Institute. Division of Cancer Control & Population Statistics. Healthcare Delivery Research Program, About the Outcomes Research Branch. <https://healthcaredelivery.cancer.gov/about/orb/>
14. National Cancer Institute. NCI-Designated Cancer Centers. <https://www.cancer.gov/research/infrastructure/cancer-centers>
15. National Cancer Institute. Understanding Cancer > What is Cancer? <https://www.cancer.gov/about-cancer/understanding/what-is-cancer>
16. NIH Awards by Location and Organization - NIH Research Portfolio Online Reporting Tools (RePORT). <https://reporter.nih.gov/>

17. NIH RePORT, Categorical Spending. <https://report.nih.gov/funding/categorical-spending/>
18. NIH RePORT, NIH Funding by State. https://reporter.nih.gov/search/bBt_LoVQqEWDOhmTY2c5Dg/projects/charts
19. 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) <https://jpro.springeropen.com/articles/10.1186/s41687-020-00244-3>
20. 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://hqlo.biomedcentral.com/articles/10.1186/s12955-022-01987-x>
21. Simone, JV. (2002). Understanding Cancer Centers. *Journal of Clinical Oncology*, 20(23):4503-4507. <https://ascopubs.org/doi/10.1200/JCO.2002.07.574>
22. University of Cambridge. (2021). *Collaboration could enable cancer patients to get faster and more personalized treatment*. <https://www.cam.ac.uk/research/news/collaboration-could-enable-cancer-patients-to-get-faster-and-more-personalised-treatment>

