

2023 NPCR FLORIDA SUCCESS STORY

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New Frontiers – Collecting Cancer Recurrence in Florida

National Program of Cancer Registries SUCCESS STORY

SUMMARY

The Florida Department of Health has pursued a new initiative to collect cancer recurrence data across the state's National Cancer Institute Cancer Centers, with the Florida Cancer Data System (FCDS) serving as the central repository. The reporting of cancer recurrence and infrastructure development is underway using existing standards and collaborative efforts.

The FCDS is a statewide population-based incidence-only central registry and has been in operation since 1981. The FCDS is operated by the University of Miami under contract by the Florida Department of Health and is part of the National Program of Cancer Registries at the Centers for Disease Control and Prevention. In 2022, under the direction of the First Lady of Florida, Casey DeSantis, the collection of cancer recurrence data was legislatively mandated (Florida Senate SB 2500, line 464. 2023) starting with the four NCI-designated cancer centers in the state.

This effort addressed the knowledge gap in cancer outcomes for cancer recurrence at the population level. Mandating all NCI-designated cancer centers to report cancer recurrence was meant to pave the way toward building the required infrastructure to collect, receive, link, and analyze essential cancer outcomes for the state. This ongoing work is being undertaken in partnership with the Florida Department of Health and the Florida Agency for Health Care Administration.

As a Gold Certified central cancer registry and a Registry of Excellence, the Florida Cancer Data System was the obvious mechanism by which cancer recurrence would be reported, stored, linked, and analyzed. The FCDS already receives over 100,000 cases of cancer incidence records annually and has established relationships with facilities over decades. Leveraging the existing standard 6.5 published by the Commission on Cancer (COC, ACS 2020), the FCDS worked with Florida Department of Health leadership and each of the four NCI-designated cancer centers on understanding, planning, troubleshooting, and developing best practices for reporting cancer recurrence.

While the COC standards require each COC-accredited cancer center to follow the 6.5 standard for collecting cancer recurrence, the practical challenges of following cancer patients produce various levels of completeness, and the FCDS had never attempted to collect these data. Nevertheless, each of the four cancer centers has successfully submitted the first set of cancer recurrence data to the FCDS. Through funding supported by the state, the FCDS will develop the required infrastructure and hire the appropriate staff. While this is only year one of the new state initiative, the expectations are to maintain ongoing reporting by the four NCI cancer centers and expand the program to additional COC hospitals.

CHALLENGE

- Until recently, Florida statute did not require reporting of cancer recurrence data.
- Existing standards for reporting cancer recurrence are mainly used by hospitals accredited by the American College of Surgeons, Commission on Cancer.
- Central cancer registries across North America have minimal experience collecting cancer recurrence data at the population level.
- Even with the standard published by the Commission on Cancer under 6.5, the methods for tracking cancer patients vary across facilities.

SOLUTION

- Florida statute has been modified to require NCI-designated cancer centers to report cancer recurrence to the FCDS.
- Data standards for reporting recurrence data leverage standards published by the COC under section 6.5.
- Engaging the NCI cancer centers to collaborate with the FCDS and Florida Department of Health provided important insight on best practices, methodologies, and areas of concern.

RESULTS

- In September of 2023, all four NCI-designated cancer centers in Florida submitted data on cancer recurrence.
- Over 40,000 records on recurrence have been received by the FCDS.
- Best practices for collecting cancer recurrence have been identified and promoted across cancer centers.
- State funding has been awarded to the FCDS to develop the infrastructure and methodology for collecting cancer recurrence over the next two years.

SUSTAINING SUCCESS

The next steps are to:

- Expand to additional CoC hospitals.
- Obtain ongoing state funding to support the collection of cancer recurrence.
- Promote best practices.
- Investigate other methodologies to collect recurrence data at a population-based level.

STORY QUOTE

“Collecting the recurrence of cancer is essential to understanding the proportion of recurrence in Florida and working toward ways to reduce the burden.”
– Gary Levin, Project Director, FCDS

REGISTRY CONTACT

<https://fcds.med.miami.edu/inc/welcome.shtml>

REFERENCES

American College of Surgeons, Commission on Cancer. Optimal Resources for Cancer Care, 2020 Standards. [facs.org/cancer](https://www.facs.org/cancer)
S.B. 2500, Appropriations, 2023 Reg. Sess. (FL 2023). <https://www.flsenate.gov/Session/Bill/2023/2500>



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