

Empowering Research: ODS Support for Data Requestors in Florida Pilot Project Drives Success

AUTHORS: Monique N. Hernandez, PhD; Gary Levin, BA, ODS; David J. Lee, PhD; Heather Lake-Burger, MS, MPH, CHES; Brad Wohler, BS

SUMMARY

The Florida Cancer Data System (FCDS) is a statewide, population-based registry that has been tracking cancer incidence since 1981. Managed by the University of Miami under the Florida Department of Health, FCDS is a key component of CDC's National Program of Cancer Registries.

As part of the Florida Cancer Plan Objective 2.6, which focuses on improving data access and use, FCDS initiated a working group to streamline data request processes. In 2024, this group launched the Oncology Data Specialists (ODS) Support Pilot Program to connect data requestors with certified ODS professionals. The program was designed to ensure accurate data selection and reduce delays between requestors and FCDS staff.

CHALLENGES

- Difficulty in selecting appropriate cancer registry data items for research topics.
- Challenges in defining inclusion and exclusion criteria for the data request.
- Lack of understanding of cancer data standards, leading to inaccuracies.
- Delays in the application process due to improper data requests.

- Increased back-and-forth communication between requestors and FCDS staff.
- Datasets that do not align with the data requestor's research objectives.

SOLUTION

In 2024, the Data Access and Utilization Working Group began the first phase of the pilot program to assist FCDS data requestors by connecting them with qualified oncology data specialists (ODS). The first step required requestors to begin a data request application, after which an FCDS staff member identified applicants who required additional support. The researchers were paired with an ODS professional to ensure that the data selected aligned with their research objectives. Meetings were held remotely through Zoom, and the applications were shared with ODS staff prior to these meetings.

RESULTS

In the first phase of the pilot, three ODS staff from the Moffitt Cancer Center met with five data requestors across Florida. These data requestors were identified either by their data request application or by email communications between researchers and FCDS staff. The ODS staff then reached out to the researchers, set up the initial Zoom meeting, and reviewed the applications together virtually. Post-meeting summaries were provided back to the working group to identify lessons learned and enhancements to the pilot program. The feedback from researchers who participated was overwhelmingly positive and helped define the pilot program's next steps.

Steps taken:

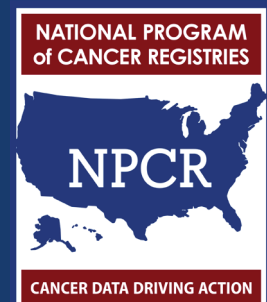
- **Initiation:** The Data Access and Utilization Working Group launched the pilot program in 2024, connecting data requestors with certified ODS professionals after their initial data request submission.
- **Continuing education credits:** To encourage the participation of ODS volunteers, the workgroup received approval for continuing education credits from the National Cancer Registrars Association for hours performed on this project. This will also be offered to future ODS participants.

- **Matching process:** FCDS staff reviewed the research objectives and matched requestors with qualified ODSs who helped select appropriate data items.
- **Support and guidance:** The ODSs provided guidance on cancer data standards and inclusion/exclusion criteria and ensured that the dataset met the research objectives.
- **Feedback:** The ODSs wrote suggested enhancements to the program.

Several lessons were learned during the pilot. Continuous education on cancer data standards and the request process is essential for researchers and data requestors. The program also highlighted the need for expert guidance in selecting data items that align with research goals. It became clear that the time spent with ODS staff should be limited to no more than 3 hours, including initial communications, Zoom meetings, and follow-up. Additionally, to improve efficiency and minimize back-and-forth communication, FCDS recognized the need to integrate the selection, communication, and matching process directly into the data request system.

CONCLUDING REMARKS

Overall, the program demonstrated the value of expert support in ensuring efficient and accurate data requests and reduced the back-and-forth communications with FCDS staff. Moving forward, the program will focus on enhancing the data request system, recruiting additional ODS staff, and promoting the program to more data requestors. Tracking the time from submission to completion of data requests will also be a key part of evaluating the program's success.



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention