

Veterans' Data Submissions Improve High-Quality Cancer Data in Maine and Address Historic Gaps

AUTHORS: Kathy Boris, Jackie Neas, Carolyn Bancroft, Kim Haggan

SUMMARY

In September 2024, after 2 years of dialogue between the Maine Cancer Registry (MCR) and the Veterans Administration (VA), MCR received a data submission from the VA National Oncology Program for the first time in more than 20 years. Data submissions included diagnosis years 2007 through 2022. A total of 2,667 records were submitted to Maine. As a result of the data submissions, more than 700 new tumor records were added and 144 death certificate only (DCO) cases were updated in the MCR database.

CHALLENGE

Prior to 2024, MCR had not received data from Togus (our local VA facility) since 2006. While MCR and the VA had established a standing order in 2022, efforts to finalize a data sharing agreement stalled between 2022 and 2023, and no data were transferred. Based on historic data submissions from Togus, MCR estimated that 400 to 500 cases per year were missed due to lack of VA data.

SOLUTION

After establishing a standing order in 2022, the MCR director met with members of the VA National Oncology Program at North American Association of Central Cancer Registries (NAACCR) summer forums 2023 and 2024 to discuss efforts to resume receiving VA data submissions. These efforts were supported by federal legislation passed in 2024 that required the VA to begin working with central cancer registries to report VA data.

In the fall of 2024, MCR followed up with leadership at the VA National Oncology Program. While they were unable to access the database at Togus, they were able to transfer data for Maine residents from the VA's national central cancer registry.

RESULTS

MCR received 2,667 cases for diagnosis years 2007 to 2022 from the central VA. Although the data are likely incomplete due to lack of certified oncology data specialist (ODS-C) staff in the Togus cancer registry, this transfer is more data than we have received from the VA in nearly 20 years. As a result of the data submission, we updated 144 DCO cases and added 704 new tumor records to our database prior to our 2024 NPCR data submission (see Figure 1). More than 1,200 cases remain for consolidation that may or may not update treatment information in our database. The VA submissions make our data more complete and higher quality than they have been in over a decade, especially for veterans.

CONCLUDING REMARKS

We will continue to partner with the VA to ensure that data transfers occur—and hopefully increase—to address any backlog and delays in cancer reporting due to staffing shortages. MCR still has not established contact with Togus and will continue working with national VA partners to ensure that cancer data for veterans in Maine are shared. We are also exploring ways to share data from MCR with the VA National Oncology Program.



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