

## 2018 NPCR CANCER REGISTRY SUCCESS STORY

**CANCER REGISTRY NAME:** South Dakota Cancer Registry

**STORY TOPIC/FOCUS:** Clinical Trial Collaborative Project

**STORY TITLE:** Collaboration to Improve Clinical Trial Participation in South Dakota

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### **SUMMARY:**

The South Dakota Cancer Coalition developed the South Dakota Comprehensive Cancer Control State Plan 2015-2020 in an effort to establish an actionable framework to reduce the burden of cancer in South Dakota. One of the established priorities of the plan was to increase participation in cancer clinical trials and a workgroup was formed to develop strategies. The workgroup needed to establish the current clinical trial accrual rates within South Dakota to establish a baseline for measurement.

The South Dakota Cancer Coalition approached the South Dakota Cancer Registry (SDCR) and asked if it would be willing to form a partnership to work collaboratively to obtain South Dakota clinical trial data from the hospital-based cancer centers. The SDCR agreed to request the data from the hospital-based cancer registries with the knowledge that this reporting would be voluntary. The SDCR assured the hospital-based cancer registries that the individual hospital-based data would be held in confidence and only aggregate data would be shared.

In 2015, the clinical trial data collection began with 100% of the South Dakota hospital-based cancer registries reporting data for two consecutive years, 2013 and 2014. This 100% response rate continued in 2016 and 2017 with data being reported for years 2015 and 2016 respectively. With four years of data, analysis was completed to examine the South Dakota clinical trial data trends and barriers to participation. With identification of the challenges regarding clinical trial participation, a better understanding will help to develop strategies that will promote clinical trials at the South Dakota hospital-based cancer centers. A presentation was developed and shared with stakeholders in South Dakota to promote clinical trial awareness. Going forward, measurement of the clinical trial accrual rates continue to be reported to the SDCR and the 2017 data was received in 2018.

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## CHALLENGE:

One of the priorities of the South Dakota Cancer Coalition in the South Dakota Comprehensive Cancer Control State Plan 2015-2020 was to increase participation in cancer clinical trials at the South Dakota cancer centers. A workgroup was established to develop strategies. The challenge was to collect statewide clinical trial data to establish a baseline for measurement as well as collect this data annually to measure progress and impact.

## SOLUTION:

The South Dakota Cancer Registry (SDCR) was asked to collect the clinical trial data from the South Dakota hospital-based cancer centers. The SDCR was the natural choice since it is a trusted entity in South Dakota and the framework already existed for confidential reporting. The SDCR assured that the reported clinical trial data would be secure, confidential, and only shared in aggregate. The coalition workgroup developed a reporting collection template that aligned with the Commission on Cancer Standard 1.9 to streamline reporting efforts, which the SDCR utilized to collect the data.

## RESULTS:

The South Dakota cancer centers participated in the voluntary reporting of clinical trial data at 100% for data years 2013 – 2016. Data analysis on the four years of data was completed to better understand the South Dakota clinical trial data trends and barriers to participation. A presentation was developed and shared with stakeholders in South Dakota to promote clinical trial awareness. A publication featuring the data analysis and recommendations is currently under development.

## SUSTAINING SUCCESS:

The inclusion of this priority within the South Dakota Cancer Plan helps ensure cancer clinical trial participation remains a focus in South Dakota. The objective to collect the clinical trial data at the SDCR continues with the voluntary reporting of the 2017 data in 2018 from the hospital-based cancer centers.

## REGISTRY CONTACT INFORMATION:

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South Dakota Cancer Registry website - <http://getscreened.sd.gov/registry/data/>

South Dakota Cancer Coalition website - <https://www.cancersd.com/>