

# 2020 NPCR ALASKA CANCER REGISTRY SUCCESS STORY

STORY TOPIC: Collaborative Partnerships/Projects

STORY CATEGORY: Public Health Impact

STORY TITLE: Using Cancer Registry Data as Part of a Collaborative Partnership to Conduct a Cancer Survivor Needs Assessment

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## SUMMARY

In the Fall of 2019, the Alaska Cancer Registry (ACR) collaborated with the Alaska Cancer Partnership so that the Partnership could conduct a survey among cancer survivors in Alaska, to improve efforts to support cancer survivors. The study's objectives were to identify unmet needs, opportunities for improvement, and recommendations for action. Cancer survivors were identified using the ACR database. There were 344 survivors diagnosed between 2004-2016 who completed the mailed survey in fall 2019. Among survivors who completed all questions about need, 29% had no unmet needs. Young adults (ages 18-44 at diagnosis), Alaska Native, and survivors still or recently receiving care had the most unmet needs.

## CHALLENGE

The Alaska Cancer Partnership needed to identify a pool of cancer survivors to take a survey for its study. The study's objectives were as follows:

- Identify the unmet needs of Alaska's cancer survivors
- Increase awareness of unmet needs
- Identify opportunities for improvement
- Develop recommendations for individuals, public health and community organizations, and health care providers

Note that the project was reviewed by two Institutional Review Boards (IRBs) prior to approval and was determined to be "Not Research."

The ACR database was used as the source of the pool of cancer survivors. A sample of 2,600 cancer survivors was drawn from ACR database stratified by diagnosis years 2004-2016 (200 sampled per calendar year). If a survivor had more than one record in the ACR database, only the earliest record in that period was chosen. Eligibility criteria for the pool included the following:

Alaska resident as identified in the ACR database: While cancer cases are identified as Alaska residents at the time of their diagnosis, the ACR database does not have information about current residency status. This was the biggest challenge of the project.

- Diagnosed between 2004-2016: This information was readily available.
- Age 18 or older at time of diagnosis: This information was readily available.

- Not deceased: ACR has current cancer case vital status as of the last time linkages were performed on the state mortality database, Social Security Death Index, and National Death Index. However, those linkages are only performed for the death year of the most complete year of cancer data and not for the current calendar year. Therefore, there would most likely be some decedents in the cancer survivor pool.

## SOLUTION

The ACR data analyst developed an MS Access database that connected to the ACR SQL database. Using the criteria required by the Alaska Cancer Partnership to build its survivorship pool, the data analyst used Access queries to compile a list of 2,600 cancer survivors that spanned diagnosis years 2004 to 2016 with their cancer diagnosis information and their addresses at the time they were diagnosed. While the ACR database also has a “current address” field, it is often not complete and does not undergo quality control review.

The ACR database includes the most recent address for each cancer patient. However, it is unknown whether the cancer patient still resides at that address. To obtain the most current address, the ACR data analyst used MS Access to link the cancer survivor pool with the 2018 Alaska Permanent Fund (PFD) Applicant Database, which at the time was the most recent data available. The PFD database is used to track people who apply for the annual state government dividend from oil royalties paid out by the petroleum industry. The dividend program is open to all Alaska residents and must be applied for annually, thus the database represents an annual address history of about 93% of Alaska residents. If the ACR record matched to a corresponding record in the PFD database, then it was used for the survey mailing address. If there was no match, then the ACR’s “address at diagnosis” was used.

The ACR data analyst compiled this information into a final mailing list. This mailing list was provided to the Alaska Cancer Partnership’s contractor, who then mailed out the letters, opt-out cards, and surveys.

## RESULTS

The project contractor mailed invitations to the cancer survivorship pool during September-November 2019. Participation was strictly voluntary; no incentive was offered.

- 1st mailing 9/9/2019: Study notification letter and opt-out postcard
- 2nd mailing 9/23/2019: If they did not return the opt-out postcard, respondents were mailed the survey and study information
- 3rd mailing 10/7/2019: People who had not responded were mailed a reminder letter and new copy of the survey

From the original pool of 2,600 cancer survivors to whom surveys were mailed, there was a 13.4% response rate, after adjusting for ineligible respondents:

- 344 total survey responses were received
  - 321 original responses
  - 23 late responses
- 240 opt-out cards received
  - 13 opted out specifically because they said they had not had cancer (ineligible)

- 12 were deceased (ineligible)
- 7 were undeliverable
- 1,997 did not respond

The respondents who said they did not have cancer required further research. The names of these patients were provided to the ACR data analyst, who queried them in the ACR database. It was determined that these patients were diagnosed with benign brain tumors. Although these are reportable cases, they are not considered a cancer diagnosis and should have been excluded from the original survivorship pool.

Breast and prostate cancer survivors made up the largest share of survey participants (34% and 18%, respectively). This is not surprising as these 2 cancers are the top ranked cancers in the survey period. The remaining participants had been diagnosed with cancers from a wide variety of sites. In addition, participation was relatively better among people diagnosed with breast or prostate cancer in comparison to other types of cancers. Participation was also relatively greater among females than males, and among White survivors compared to Alaska Native or survivors from other races.

The average current age of respondents was 65.6 years, and the average (self-reported) age at diagnosis was 56.4 years. Average time since diagnosis was 8.8 years. More than half (60%) of respondents were female, and most were White (81%) or Alaska Native (12%).

The project included a quality check, based on concerns about whether surveys had reached the right people. Three demographic characteristics in the survey responses were compared with the same demographics in the ACR database for each respondent (if data available):

- Gender matched well (97.4%)
- Alaska Native race matched relatively well (88.1%)
- There was poor exact match for age of diagnosis, which may be related to recall bias rather than identifying an incorrect survey respondent.

According to the survey, the following are “top 10” rankings for cancer survivorship unmet needs.

#### Most highly ranked Unmet needs

Rank	Indicator: <i>In the last month I need...</i>	% Need
1	I need help to reduce stress in my life	27.3%
2	I need to know that all my doctors talk to each other to coordinate my care	26.4%
3	I need help to manage concerns about the cancer coming back	24.9%
4	I need help to find out about financial support and/or government benefits to which I am entitled	21.3%
5	I need access to complementary and/or alternative therapy services	21.0%
6	I need an ongoing case manager to whom I can go to find out about services whenever they are needed	20.4%
7	I need help to address problems with my/our sex life	20.1%
8	I need help to adjust to changes to the way I feel about my body	19.9%
9	I need to feel like I am managing my health together with the medical team	19.2%
10	I need help to manage ongoing side effects and/or complications of treatment	19.2%

#### SUSTAINING SUCCESS

This project is a prime example of how a comprehensive cancer control and prevention program can collaborate with the Alaska Cancer Registry to have positive outcomes in their community efforts. This study’s objectives included identifying the unmet needs of Alaska’s cancer survivors, increasing awareness of unmet needs, and identifying opportunities for improvement. This study’s finding can be implemented by community organizations and health programs around the state.

#### REGISTRY CONTACT INFORMATION

Phone: 907-269-0995

Website: <http://dhss.alaska.gov/dph/Chronic/Pages/Cancer/registry.aspx>