

# 2021 NPCR WEST VIRGINIA SUCCESS STORY

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*Expanding Research Access to West Virginia Cancer Registry Data*

## National Program of Cancer Registries SUCCESS STORY

### SUMMARY

State privacy laws prohibit the West Virginia Cancer Registry (WVCR) from sharing identifiable information from cancer patients with researchers without the patient's written consent, severely limiting researcher's access to this potentially valuable pool of respondents. We developed procedures for "blind contact" of cancer patients, allowing researchers access to patients in the registry while maintaining patient confidentiality.

### CHALLENGE

Laws that protect the privacy of cancer patients in West Virginia are one barrier that limits researchers' ability to access and fully utilize data collected by the WVCR. Signed consent from each patient is required before any information can be released. We sought to develop procedures that would allow researchers to access our database of cancer patients without violating patient confidentiality.

### SOLUTION

Our solution to this problem was to develop procedures for "blind contact" of patients. The researchers specify the details of the sample they wish to contact and provide WVCR with all the contact materials. The registry then selects the sample of patients meeting those criteria from our database and mails out the research packets directly without releasing any personal information to the researchers. The research materials are returned directly to the researchers by the patients, effectively having each patient provide their own consent by contacting the researchers themselves. Using this method, we can contact individuals in our cancer database without releasing personal information to the researcher.

### RESULTS

We collaborated with West Virginia University (WVU) Cancer Institute for our first survey project. The survey was sent to individuals diagnosed with cervical cancer between 2000-2020 and had a West Virginia address at the time of diagnosis. The purpose of the survey was to determine if adverse childhood experiences (ACEs) were associated with provider relationships and how that may influence cervical cancer diagnosis and health care. Before we began mailing, we compiled a list of cervical cancer survivors in the state that were alive around the time of mailing to avoid sending mail to deceased individuals and their families. This required comparing cancer records to the state's Vital Records and the Social Security Death Index (SSDI). Next, we printed, collated, sealed, and addressed the envelopes. The first set of letters were mailed on July 23rd, followed by the reminder letters three weeks later. WVU Cancer Institute ultimately had an 8.0% response rate, with no negative feedback from survey takers. These procedures allowed the researchers to collect information from a specific cohort of interest that would have been very difficult to recruit by any other means.

### SUSTAINING SUCCESS

After the success of our first survey project, we discovered that there were facets of the project that worked very well, while others needed adjusting. For instance, having the WVCR handling the address labels and mailing was seamless; the researcher was able to receive survey responses without ever realizing the identities of the survey takers. However, the manual labor that went into printing, collating, and sealing almost 1,200 surveys proved to be very tedious and time-consuming. For future surveys, we plan to continue with printing and affixing mailing labels, but we would highly encourage the researcher to collate and seal the envelopes themselves or through a printing company. Additionally, we found that the reminder letter did not significantly increase the response rate, so we do not plan on using follow-up letters for future projects. Finally, we found it useful to complete a linkage between our mailing list and SSDI/Vital Statistics to avoid sending surveys to deceased individuals. Ultimately, we found that this survey methodology can be expanded to any research requiring patient contact. We provide the patient with the researchers' contact information, and the patient then initiates contact with the researcher. This will allow additional opportunities to utilize our local cancer data to improve the health and well-being of West Virginians.

### REGISTRY CONTACT INFORMATION

304-558-4463

<https://dhhr.wv.gov/oeps/cancer/Pages/default.aspx>



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