



Virtual Pooled Registry (VPR) Project

Instructions For Creating the Annual VPR-CLS Linkage File

In 2019, NAACCR will launch the Virtual Pooled Registry Cancer Linkage System (VPR-CLS) which will facilitate streamlined linkages between research cohorts and multiple cancer registries. Linkages with cohort files will occur behind each individual registry's firewall.

Our goal is for registries to create a single, standardized file once a year. This file will be used for all linkages that occur during a calendar year and serve as a static file from which researcher-requested data items will be selected. Generating the VPR-CLS file is voluntary; however, we are optimistic that all registries will create this file for potential linkages in 2019. VPR-CLS file specifications and steps for creating the file are included below.

Timeframe for File Creation: Registries will prepare the VPR-CLS linkage file as part of the annual NAACCR Call for Data process during the time period from December 1, 2018 to January 31, 2019, after 12-month data (cases diagnosed in 2017) have been submitted to NAACCR, NPCR and/or SEER. Producing the VPR-CLS file at this time, immediately following the Call for Data, ensures that all registry files contain comparable timeframes for follow-up and the most complete, high quality, edited data for linkage and data release. **The VPR-CLS file will remain at the cancer registry.**

Case Selection Criteria: Cancer registries will extract NAACCR Version 16 Type C records to include state resident cases, regardless of diagnosis year. *At a minimum*, include cases from inception year to 2017. Registries are encouraged to include data from as far back as possible. The extract should include all reportable cases (including VA, DCOs, and cases received through inter-state data exchange) routinely submitted in the NAACCR data submission (e.g., in situ, invasive, and benign brain/CNS-prior to 2004 if collected). The file must have the extension .txt.

Non-releasable cases: Some of the above noted cases, particularly VA cases, may need to be removed prior to releasing individual-level data to the study investigators. It is important that registries be able to identify and provide investigators the number of cases that are unable to be released.

NAACCR Prep: A utility that includes a VPR-CLS option that runs NHAPIIA algorithm and generates associated fields without deleting the first/last/middle name. NAACCR Prep calculates additional data items of interest, and also allows registries to exclude specific data items that they would not want to release.

Link*Prep: A utility that standardizes and edits key linkage data items (including street address) and creates a recoded patient ID. The recoded patient ID is inserted into the beginning of the state requestor items section and the existing data within the field is shifted to the right. Link*Prep should be run on all VPR-CLS files to ensure the best linkage results.

Note: If a registry calculates their own recoded (alias) patient ID, it should be placed in the field for Patient ID Number [NAACCR Item #20] and a separate crosswalk should be maintained.

Steps for creating the VPR-CLS linkage file:

1. Create a fully populated Type C NAACCR layout file using the Case Selection Criteria listed above.
2. Download NAACCR Prep and Link*Prep from NAACCR Call for Data page.
3. Open NAACCR Prep and browse to the Type C file created in Step 1.
4. Specify the name and location of the file to be created.
5. Select “VPR-CLS 1995-2017” as the purpose for creating the data file.
 - a. If the registry file includes data prior to 1995, click the “Customize” box and select the diagnosis date range that matches the Type C file.
 - b. If certain items need to be excluded from the output file, click the “Customize” box and uncheck those fields in the section on “Data to be Retained”.
6. Click “Export Data”.
7. Open Link*Prep and browse to the file created in Step 6 (see screenshot below).
8. Specify the location for the standardized output file and use the following naming convention to identify your state, diagnosis years (dates may vary by registry) and fact of standardization: ‘XX(state)19952017_standardized.txt’.
9. Specify the location and file name for the edit error log file and .csv file. The resulting edit errors will be based on the original file prior to standardization (see Note below).
10. Click “Run”.
11. Keep a copy of the standardized file created in Step 10 for use in future VPR-CLS linkages and data release activities.

NOTE: When Link*Prep standardizes the file, it may eliminate some of the initial edits identified in the error log (Step 9). If your registry would like to see the post-standardization edit report, you will need to rerun Link*Prep on the standardized file created in Step 10 and save a copy of the new edit log, which includes a summary of edits at the end. There is no need to standardize the file a second time, so when prompted to “Specify where you would like to write the standardized output file (recommended)”, leave the field blank. **Edits do not need to be resolved.**

