VPR-CLS Registry Profile: Instructions for Completing and Modifying

(Updated September 24, 2025)

**General Information:** The Registry Profile captures essential information on the required forms, agreements, and various other aspects associated with your registry application process. This information is used to drive the Phase II VPR-CLS workflow and is also used to populate tables displayed in the VPR-CLS (see Example 1). Any questions can be sent to Castine Clerkin (cclerkin@naaccr.org ).

**Profile Updates:** In September 2025, the following new sections were added to the Registry Profile page:

- Security Protections Documents: This online form captures the security protections in place at each registry. This information will be compiled and shared with researchers. Registries initially filled out these forms when they joined the VPR and now need to complete this new online form to reflect the latest security protections.
- Amendment Requirements: This section is designed to gather information on amendment requirements for each registry and affiliated IRB, if applicable. This information will inform development of the VPR approach to amendments and drive future workflows.

**Timing for Completion:** In October 2025, VPR Liaisons will complete the two new sections of the profile, make updates to the old content, and attest that the information is accurate. Every November, starting in 2026, registries will be required to perform an annual review and attestation that the profile information is accurate. During the annual updates, registries will have 30 days to update/attest and will receive reminders until the update/attestation is completed. Between annual updates, VPR Liaisons can make ad hoc updates to their Registry Profile if requirements or contact people change.

**Instructions for Completing and Updating the Registry Profile:**

1. The VPR Liaison(s) in your registry will review and update the Registry Profile.
2. Log into the VPR-CLS site: https://apps.naaccr.org/vpr-cls/
3. Click "You are not logged in" in the top right corner and enter your login credentials.
4. Click the arrow beside your name in the upper right corner and select "Edit Registry Profile".
5. Registry Application Group and Associated Questions: Based on previous communication with NAACCR, each registry has been assigned a Registry Application Group. The Application Group categories reflect the type of review (Registry, IRB, Central IRB or a combination thereof) and whether the Templated IRB/Registry Application (TIRA) can be used by the reviewing body (see Table 1 below). Please note that the CIRB always uses TIRA for their review. The Application Group guides the VPR system workflow. Depending on the Registry Application Group, one or two associated questions will need to be completed.
    a. **PLEASE NOTE:** Reference to the "registry" forms or review process is a general term that describes any **non-IRB** reviewing body(ies), such as an advisory/research committee, data release committee, etc. from which review and approval must be tracked in the VPR.
    b. If there are any questions about or changes to your Registry Application Group, please contact Castine Clerkin (cclerkin@naaccr.org).

6. Required Signed Agreements: If a registry requires signed agreements for release of data, the details should be entered in this section. The list of agreements is then presented to the study requestors within the VPR-CLS (see Example 1). If a registry has adopted the VPR Templated DUA, it will be reflected in this section. For each agreement, please complete the following fields:

a. **Document Type:** Select the appropriate name for the agreement from the drop-down list or select "Other" and enter the name. If a registry has adopted the VPR Templated DUA, enter this as the document type.
b. **Link/URL:** Enter the URL for the agreement, if available. If there is no URL, leave the field blank. If a registry has adopted the VPR Templated DUA, the URL should be left blank because the VPR-CLS will provide the researcher with a standard link to the document.
c. **Submission Time Frame:** Indicate when the signed agreement must be submitted, either pre-review with the submission packet or post-approval prior to data release.
d. **Reviewing Body:** When there is more than one reviewing body, this field identifies which reviewing body should receive the required signed agreement.
    a. **PLEASE NOTE:** If a registry IRB has agreed to cede review to the Central IRB, local IRB review will no longer be required/tracked, and the reviewing body should be the Registry rather than the IRB.
e. **Description/Instructions:** Enter a description of the document (if not self-explanatory) or pertinent instructions for the researcher. If the "Link/URL" field was left blank, provide information on how to retrieve the document (e.g. Request document from the contact provided). A link to the VPR Templated DUA is automatically provided to researchers within the VPR-CLS, so there is no need to enter instructions on how to retrieve the document. Also, indicate who from the researcher's institution is required to sign the agreement (e.g. principle investigator, authorized representative for the organization, all individuals handling the data, etc.). Text in the "Description/Instructions" should be kept simple and succinct.
f. **Recipient Name and Email:** Individual at the registry or IRB that researcher should contact to request/submit forms.

**IMPORTANT NOTE:** If more than one signed agreement is required, simply click on the option to "Add Signed Agreements" (below the initial entry form) and complete all associated fields.

7. State-Specific Forms: For registries where the Templated IRB/Registry Application (TIRA) is unable to be used, the VPR-CLS will provide the requestor with a list, and associated URLs, of registry/IRB forms that must be completed and submitted according to normal practices, outside of the VPR-CLS (see Example 1). URLs for these applications are automatically pulled from NAACCR's CaRI Database, which is completed/reviewed during the NAACCR Call for Data (CFD) process. Please check the URL and, if incorrect, make updates within the CaRI Database as needed. Instructions for updating the CaRI Database are included in the General Instructions for the NAACCR CFD.

8. Additional Documents: **This section is ONLY completed by registries and/or IRBs that use the Templated IRB/Registry Application (TIRA)**. This section captures any additional documents required by the TIRA reviewing body, **ABOVE AND BEYOND** the required agreements (from #6 above) and the following documents that are submitted in the TIRA packet:
    - Study related: The TIRA, study protocol, current letter of determination from researcher's institutional IRB, Central IRB determination letter (for registries that have adopted it), consent form or documentation of waiver of informed consent, and requested data items
    - Personnel related: Curriculum vitae/biosketch and copy of certificate of human subjects training for PI/Co-PI and all persons handling the data

The VPR-CLS will provide the requestor with a list of additional documents that must be submitted outside of the VPR-CLS (see Example 1). For each document, please complete the following fields:

a. **Link/URL:** Enter URL for the document. If there is no URL, leave the field blank.
b. **Document Type:** Enter the appropriate name for the additional document.
c. **Reviewing Body:** When there is more than one reviewing body, this field identifies which reviewing body should receive the additional document.
    i. **PLEASE NOTE:** If a registry IRB has agreed to cede review to the Central IRB, the reviewing body should be the Registry rather than the IRB.
d. **Submission Time Frame:** Indicate when the additional document must be submitted, either pre-review with the submission packet or post-approval prior to data release.
e. **Description/Instructions:** Enter a description of the document (if not self-explanatory) or pertinent instructions for the researcher. If the "Link/URL" field was left blank, provide information on how to retrieve the document (e.g. Request document from the contact provided). Text in the "Description/Instructions" should be kept simple and succinct.
f. **Recipient Name and Email:** Individual at the registry or IRB that researcher should contact to request/submit forms.

**IMPORTANT NOTE**: If more than one additional document is required, simply click on the option to "Add Additional Documents" (below the initial entry form) and complete all associated fields.

9. Security Protections Documents: This section captures the security protection that each registry has in place. To update the document, please do the following:
    a. Click on the hyperlink to "Update Security Document".
    b. Click on the blue button to "Update Security Document" and review the content displayed in the static form. The list of VPR Liaisons that have a VPR-CLS account will be automatically populated in Question #1.
        i. If no changes to the security document are needed, click the button to "Attest That No Changes Are Needed".
        ii. If the content of the security document needs to be completed or modified, click the blue button to "Update Security Document" to access the fillable form. If any of the boxes (excluding #2) cannot be checked, be sure to enter the item # and description of why it cannot be checked, in the final text box in the form. You can then either "Save for Later" or "Save and Attest".

10. Amendment Requirements: This section is currently being used to gather information on amendment requirements for each registry and their IRB, if applicable. For each question, please select all amendment types that are applicable. If there are additional forms that the researcher must submit with their amendment, please enter the following information:
    a. **Document Type**: Enter the appropriate name for the additional document.
    b. **Description/Instructions**: Enter a description of the document (if not self-explanatory) or pertinent instructions for the researcher. If the "Link/URL" field was left blank, provide information on how to retrieve the document (e.g. Request document from the contact provided). Text in the "Description/Instructions" should be kept simple and succinct.
    c. **Link/URL**: Enter URL for the document. If there is no URL, leave the field blank.
    d. **Recipient Name and Email**: Individual at the registry or IRB that researcher should contact to request/submit forms.

e. **Amendment Type**: Select the Amendment Types for which this document is applicable.

**IMPORTANT NOTE**: If more than one additional form is required for amendments, simply click on the option to "Add" additional amendment documents" (below the entry form) and complete all associated fields.

11. Submit/Confirm Information: Once you have reviewed, edited, and entered all the necessary information, please click on the "Submit/Confirm" button. If updates are made during the annual review, you will click on the "Attest that the Profile has been fully reviewed/updated and is accurate" button.

If questions arise, please contact Castine Clerkin (cclerkin@naaccr.org ).

Example 1: Screenshot of additional applications and state-specific forms presented to the Requestor

☐ Exclude Post Approval Forms
☐ Exclude Completed Forms

☐ Only Show State-Specific Documents
☐ Only Show DUAs and Other Agreements

| Registry | AG | Estimated Processing Time | HQ# | Form Type | Form Name(URL as Available) | Description | Send To | All Forms Submitted? |
|---|---|---|---|---|---|---|---|---|
| **Alaska** | A3 | 1 - 3 months | 2 | Post Approval | VPR DUA April 2023 | | | Submitted: 11/01/2024 |
| **Arizona** | A5 | 1 - 3 months | 41 | IRB | Confidentiality Agreement | Confidentiality Statement which describes confidentiality requirements. | | CONFIRM FORM(S) |
| | | | | | Security Considerations Checklist | Checklist to address security considerations in your research protocol or request for Arizona Department of Health Services-maintained data. | | |
| **California Regional (GBACR)** | B1 | 1 - 3 months | 197 | Registry | Confidentiality Agreement | Appendix 3 (CCR Confidentiality Agreement): signed by the researcher and institution's representative. | | CONFIRM FORM(S) |
| | | | | | IRB Approval Letter | The approval letter from the California Committee for the Protection of Human Subjects (CPHS) must be submitted to initiate the registry review process. | | |
| | | | | | Vital Statistics Approval (if applicable) | Researchers that request death related items (e.g. vital status, date of death, COD, survival time, etc.) will need to obtain and submit approval from Vital Statistics. Contact for appropriate forms. | | |
| | | | | IRB | Letter of Support | Before applying to the IRB, researcher must obtain a Letter of Support from the California Cancer Registry by submitting a study abstract, with the study title and PI's name/address, to the following email: . Once the LOS is received, please follow the IRB submission details available online. | | CONFIRM FORM(S) |
| | | | | | IRB Form(s) | Submission details available online. | | |
| **Colorado** | A3 | 1 - 3 months | 20 | Registry | Confidentiality Agreement | Request document from the contact provided. | | CONFIRM FORM(S) |
| | | | | | VPR DUA April 2023 | | | |
| **Connecticut** | A4 | 1 - 3 months | 12 | Post Approval | Investigator Agreement | Only submit post-approval documents after approval. | | CONFIRM FORM(S) |
| | | | | IRB | Confidentiality Agreement | Signed Confidentiality Pledge required for all study personnel. | | CONFIRM FORM(S) |
| | | | | | Assurances Form | Email for copy of Assurances Form, which must be signed by the PI. | | |
| **Georgia** | A1 | 1 - 3 months | 14 | Post Approval | Data Use Agreement | Log into the PHIP https://dph.georgia.gov/phip-data-request , complete required fields, and attach the GA DPH IRB or BRANY central IRB approval letter. The PHIP includes the DUA and is where data will be posted when released to researchers . | | CONFIRM FORM(S) |
| **Hawaii** | A2 | 1 - 3 months | 4 | Post Approval | VPR DUA April 2023 | | | Submitted: 10/24/2024 |
| **Idaho** | A3 | 1 - 3 months | 1 | Registry | Vital Statistics Approval (if applicable) | If cause of death is requested, researcher needs approval from state vital statistics. Please contact Idaho VPR liaison for appropriate forms. | | |
| | | | | Post Approval | VPR DUA April 2023 | Only submit post-approval documents after approval. | | CONFIRM FORM(S) |
| **Indiana** | A3 | 1 - 3 months | 27 | Registry | Confidentiality Agreement | Retrieve State Form 52104 | | CONFIRM FORM(S) |
| **Iowa** | A3 | 1 - 3 months | 11 | Post Approval | VPR DUA April 2023 | | | Submitted: 10/24/2024 |
| **Kentucky** | A3 | Less than 1 month | 10 | Registry | VPR DUA April 2023 | | | Submitted: 10/24/2024 |

Table 1: Registry Application Groups

| Group A: Templated IRB/Registry Application used by all reviewing bodies | |
|---|---|
| | A1: CIRB Only |
| | A2: CIRB and TIRA for Registry |
| | A3: TIRA for Registry |
| | A4: TIRA for IRB |
| | A5: TIRA for both IRB and Registry |
| Group B: Combination of TIRA and state-specific application | |
| | B1: State-specific IRB Form and TIRA for Registry |
| | B2: State-specific Registry Form and TIRA for IRB |
| Group C: State-specific applications only | |
| | C1: State-specific Registry Form |
| | C2: State-specific IRB Forms |
| | C3: State-specific IRB and Registry Forms |