

VPR-CLS Registry Profile: Instructions for Completing and Modifying

(Updated December 9, 2024)

The Registry Profile captures information on your registry that is essential for the Phase II VPR-CLS workflow. This information is also used to populate tables displayed in the VPR-CLS (see Example 1). The Registry Profile should be updated by the VPR Liaison when requirements or contact person changes. Please review and update your Registry Profile using the instructions below. Any questions can be sent to Castine Clerkin (cclerkin@naaccr.org).

1. The Registry Profile can be completed by the VPR Liaison(s) in your registry.
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. The VPR-CLS has a multi-factor login, so you will have a second login verification step.
4. Click the arrow beside your name 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) is able to be used by the reviewing body (see Table 1 below). Please note that the CIRB always uses the 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:** This section captures the various types of signed agreements (e.g. confidentiality agreement, research agreement, investigator agreement, or data use agreement) in a single location and provides this information to 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. Text in the “Description/Instructions” should be kept simple and succinct.
- f. **Recipient Name and Email:** Individual that researcher contacts 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 the normal practices, outside of the VPR-CLS (see Example 1). This information is automatically pulled from NAACCR’s CaRI Database, which is completed/reviewed during the NAACCR Call for Data process. Please check the URL and, if incorrect, make updates within the CaRI Database as needed.
- 8. **Additional Documents:** **ONLY complete this section for 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. **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.
- d. **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.
- 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 that researcher contacts 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. **Submit/Confirm Information:** Once you have reviewed, edited, and entered all the necessary information, please click on the “Submit/Confirm” 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.		CONFIRM FORM(S)
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.		CONFIRM FORM(S)
					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 [redacted] 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: [redacted]. 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)
					Confidentiality Agreement	Signed Confidentiality Pledge required for all study personnel.		CONFIRM FORM(S)
				IRB	Assurances Form	Email [redacted] for copy of Assurances Form, which must be signed by the PI.		CONFIRM FORM(S)
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.	
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 – with number of registries shown in (#)

Group A: Templated IRB/Registry Application used by all reviewing bodies	
	A1: CIRB Only (9)
	A2: CIRB and TIRA for Registry (7)
	A3: TIRA for Registry (16)
	A4: TIRA for IRB (4)
	A5: TIRA for both IRB and Registry (3)
Group B: Combination of TIRA and state-specific application	
	B1: State-specific IRB Form and TIRA for Registry (2)
	B2: State-specific Registry Form and TIRA for IRB (0)
Group C: State-specific applications only	
	C1: State-specific Registry Form (2)
	C2: State-specific IRB Forms (1)
	C3: State-specific IRB and Registry Forms (0)