

The RoPR data collection system will be a web based collection mechanism. The screenshots included in this section are from the prototype system used with stakeholders to complete usability testing. The form has 6 sections.

1)

### Registry Description

**Registry Version** *Registry version identifier.* \* Required Field

**Registry Geography \*** *Identify geographic area of Registry providers.* Registry Geography is a required field.

-- Select --

**Location** *Add Location information if Registry Geography is identified*

**Registry Title \*** *Registry title intended for the lay public.* Registry Title is a required field.

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2)

### Registry Classification and Purpose

**Registry Classification \*** *Select all that apply. Enter Other if none or additional Classifications apply.* \* Required Field

Registry Classification is a required field.

|   |  |                                     |
|---|--|-------------------------------------|
| <input type="checkbox"/> Disease/Disorder/Condition | <input type="checkbox"/> Product, Drug     | <input type="checkbox"/> Vaccine    |
| <input type="checkbox"/> Service, Procedure         | <input type="checkbox"/> Product, Device   | <input type="checkbox"/> Transplant |
| <input type="checkbox"/> Service, Encounter         | <input type="checkbox"/> Product, Biologic | <input type="checkbox"/> Tumor      |
| <input type="checkbox"/> Service, Hospitalization   | <input type="checkbox"/> Pregnancy         |                                     |
| <input type="checkbox"/> Other                      | <input type="text"/>                       |                                     |

**Registry Purpose \*** *Select all that apply. Enter Other if none or additional Purposes apply.* Registry Purpose is a required field.

|   |   |  |
|---|---|--|
| <input type="checkbox"/> Natural History of Disease | <input type="checkbox"/> Quality Improvement          | <input type="checkbox"/> Payment/Certification     |
| <input type="checkbox"/> Effectiveness              | <input type="checkbox"/> Clinical Practice Assessment | <input type="checkbox"/> Post Marketing Commitment |
| <input type="checkbox"/> Safety or Harm             | <input type="checkbox"/> Public Health Surveillance   |  |
| <input type="checkbox"/> Other                      | <input type="text"/>                                  |  |

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3)

Public reporting burden for this collection of information is estimated to average 45 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

## Contact and Conditions of Access

\* Required Field

**Interest in Being Contacted \***

Identify if the sponsor is interested in being contacted for reasons listed below.

Yes  No

**Reasons for Being Contacted**

Select all that apply. Enter Other if none or additional Reasons apply..

- Data Access  Participation - Investigator  
 More Information  Participation - Participant  
 Collaboration  
 Other

**Organization**

The primary contact organization.

**First Name**

The primary contact individual's first name.

**Last Name**

The primary contact individual's last name.

**Title**

The primary contact individual's title.

**E-Mail**

The primary contact e-mail address.

*It is recommended that this e-mail be a department or distribution list so that if the contact person leaves the organization, the e-mail will still be delivered to a person within the department that can respond to the inquiry.*

**Phone**

The primary contact phone number.

Ext.

**Link to Organization or Registry Site**

The URL for the organization or registry.

**Link to Conditions of Access**

The primary contact's URL for the organization or registry.

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4)

## Progress Report

**ADD PROGRESS REPORT** \* Required Field

### New Progress Report

|   |   |
|---|---|
| <b>Progress Report Summary *</b>            | <i>Summary of all relevant progress report information. May include summary of interim reports, annual reports, and/or other related Registry progress reports.</i> |
| <b>Link to Progress Report</b>              | <i>A complete URL, to the progress report.</i>  |
| <b>Number of Participants in Registry *</b> | <i>Progress data identifying the current number of participants in the Registry.</i>  |
| <b>Length of Follow-up *</b>                | <i>Progress data identifying the length of follow-up data currently available within the Registry.</i>  |

**SAVE** **CANCEL**

**PREVIOUS** **NEXT**

5)

## Related Information

**ADD RELATED LINK** \* Required Field

### New Related Link

|                      |   |
|----------------------|---|
| <b>Link *</b>        | <i>A link to relevant registry information.</i>         |
| <b>Description *</b> | <i>A title of brief discription of the linked page.</i> |

**SAVE** **CANCEL**

**PREVIOUS** **NEXT**

6)

## Condition or Service of Interest for Registry

Condition

### Outcome Measures and Common Data Elements - Condition or Service of Interest **\* At least one Condition is Required**

Select all that apply.

- |  |   |
|--|---|
| <input type="checkbox"/> Bacterial and Fungal Diseases                     | <input type="checkbox"/> Immune System Diseases                                 |
| <input type="checkbox"/> Behaviors and Mental Disorders                    | <input type="checkbox"/> Mouth and Tooth Diseases                               |
| <input type="checkbox"/> Blood and Lymph Conditions                        | <input type="checkbox"/> Muscle, Bone, and Cartilage Diseases                   |
| <input type="checkbox"/> Cancers and other Neoplasms                       | <input type="checkbox"/> Nervous System Diseases                                |
| <input type="checkbox"/> Cardiovascular Diseases                           | <input type="checkbox"/> Nutritional and Metabolic Diseases                     |
| <input type="checkbox"/> Diseases or Abnormalities at or before Birth      | <input type="checkbox"/> Parasitic Diseases                                     |
| <input type="checkbox"/> Digestive System Diseases                         | <input type="checkbox"/> Symptoms and General Pathology                         |
| <input type="checkbox"/> Ear, Nose, and Throat Diseases                    | <input type="checkbox"/> Respiratory Tract (Lung and Bronchial) Diseases        |
| <input type="checkbox"/> Eye Diseases                                      | <input type="checkbox"/> Skin and Connective Tissue Diseases                    |
| <input type="checkbox"/> Gland and Hormone Related Diseases                | <input type="checkbox"/> Urinary Tract, Sexual Organs, and Pregnancy Conditions |
| <input type="checkbox"/> Injuries, Poisonings, and Occupational Conditions | <input type="checkbox"/> Viral Diseases   |
| <input type="checkbox"/> Other   |   |

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## Category of Interest for Registry

Condition

Category

### Outcome Measures and Common Data Elements - Category

Select all that apply. Enter Other if additional Categories apply.

**\* At least one Category is required**

- |   |   |
|---|---|
| <input type="checkbox"/> Clinical Assessments | <input type="checkbox"/> Health System Utilization    |
| <input type="checkbox"/> Demographics         | <input type="checkbox"/> Medications                  |
| <input type="checkbox"/> Devices              | <input type="checkbox"/> Patient-Reported Outcomes    |
| <input type="checkbox"/> Diagnosis            | <input type="checkbox"/> Risk Factors/Staging Systems |
| <input type="checkbox"/> Disease Response     | <input type="checkbox"/> Survival Outcomes            |
| <input type="checkbox"/> Events of Interest   | <input type="checkbox"/> Treatments                   |
| <input type="checkbox"/> Genetic Information  |   |
| <input type="checkbox"/> Other                |   |

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