

Attachment B: Questionnaires/Data Collection Instruments

Form Approved  
OMB No. 0935-XXXX  
Exp. Date XX/XX/20XX

The RoPR data collection system is a web based collection mechanism. The screenshots included in this section are from the live RoPR system. The online form has 9 sections.

1)

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Completion Status: 0 of 6 Sections 0% 0 % Completed

### ROPR | REGISTRY of PATIENT REGISTRIES

#### Welcome to RoPR - Registry Profile Overview

E-Mail:  **SAVE E-MAIL** E-mail is required.

Confirm:  Confirm is required.

*This email will only be used by RoPR and will not be distributed.*

Registry Description	INCOMPLETE
Registry Classification and Purpose	INCOMPLETE
Contact and Conditions of Access	INCOMPLETE
Progress Report	INCOMPLETE
Related Information	INCOMPLETE
Outcome Measures and Common Data Elements	INCOMPLETE

**UPLOAD REGISTRY RECORD**

Import and upload XML file

Browse...

[XML Upload Template](#)

[Registry Profile Schema](#)

**UPLOAD**

**ROPR HELP**

- [Frequently Asked Questions](#)
- [Upload of Registry Profile Help](#)
- [Policies and Procedures Documentation](#)
- [E-mail Contact for RoPR Administrators](#)

Public reporting burden for this collection of information is estimated to 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/ CFACT Attn: Reports Clearance Officer, Paperwork Reduction Project (0935-XXXX), 5600 Fishers Lane, Mail Stop Number 07W41A; Rockville, MD 20857

2)

Completion Status: 0 of 6 Sections  0% 0 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

OVERVIEW

- Registry Description
- Registry Classification and Purpose
- Contact and Conditions of Access
- Progress Report
- Related Information
- Outcome Measures and Common Data Elements

PREVIEW

- SAVE/RELEASE REGISTRY PROFILE

### Registry Description \* Required Field

**Registry Version** Registry version identifier.

**Registry Geography \*** Identify geographic scope of data collection for the registry.  
 Registry Geography is required.

**Registry Location** Provide additional location information to clarify Registry Geography as selected.

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

**Brief Description**  

This content is not yet available from ClinicalTrials.gov.

**Long Description**  

This content is not yet available from ClinicalTrials.gov.

4)

Completion Status: 0 of 6 Sections  0% 0 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

OVERVIEW

- Registry Description
- Registry Classification and Purpose
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PREVIEW

- SAVE/RELEASE REGISTRY PROFILE

### Registry Classification and Purpose \* Required Field

**Registry Classification \*** Select all that apply. Enter Other if additional classifications apply.

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

Other

**Registry Purpose \*** Select all that apply. Enter Other if additional purposes apply.

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

Other

5)

Completion Status: 0 of 6 Sections  0% 0 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

### Contact and Conditions of Access \* Required Field

OVERVIEW

- Registry Description
- Registry Classification and Purpose
- Contact and Conditions of Access
- Progress Report
- Related Information
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PREVIEW

SAVE/RELEASE REGISTRY PROFILE

**Interest in Being Contacted? \*** Identify if the sponsor is interested in being contacted for reasons listed below.  
 Yes  No

**Reasons for Being Contacted \*** Identify sponsor's reasons for being contacted. Enter Other if additional reasons apply.

Collaboration  Participation - Investigator  
 Data Access  Participation - Participant  
 More Information  
 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 email.  
  
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** A link to the the organization or registry's Web site (including http:// or https://).

**Link to Conditions of Access** A link to a Web site or document describing conditions of access required by sponsor (including http:// or https://).

**Reasons for Being Contacted is required.**

**Organization is required.**

**Either Contact E-mail or Contact Phone is required.**

**Either Contact E-mail or Contact Phone is required.**

PREVIOUS NEXT

6)

Completion Status: 0 of 6 Sections  0% 0 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

OVERVIEW

- Registry Description
- Registry Classification and Purpose
- Contact and Conditions of Access
- Progress Report
- Related Information**
- Outcome Measures and Common Data Elements

PREVIEW

SAVE/RELEASE REGISTRY PROFILE

### Related Information

**Are Related Links Available? \*** \* Required Field

Yes  No You must add at least one Related Link.

#### New Related Link

**Link \*** A link to a Web site for relevant registry information (including http:// or https://). Link is required.

  

**Description \*** A title or brief description of the linked page. Link Description is required.

7)

Completion Status: 4 of 6 Sections  67% 67 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

OVERVIEW

- Registry Description
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- Outcome Measures and Common Data Elements**

PREVIEW

SAVE/RELEASE REGISTRY PROFILE

### Condition or Service of Interest for Registry

**Condition** **Category**

**Outcome Measures and Common Data Elements - Condition or Service of Interest \*** \* Required Field

Primary disease, condition or service being studied. Use the National Library of Medicine's Medical Subject Headings (MeSH). Select all that apply. Enter Other if additional Conditions apply.

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

8)

Completion Status: 0 of 6 Sections  0% 0 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

OVERVIEW

Registry Description

Registry Classification and Purpose

Contact and Conditions of Access

Progress Report

Related Information

Outcome Measures and Common Data Elements

PREVIEW

SAVE/RELEASE REGISTRY PROFILE

### Category of Interest for Registry

Condition Category

**Outcome Measures and Common Data Elements - Categories \*** \* Required Field

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

<input type="checkbox"/> Clinical Assessments	<input type="checkbox"/> Patient Reported Outcomes
<input type="checkbox"/> Demographics	<input type="checkbox"/> Procedures
<input type="checkbox"/> Devices	<input type="checkbox"/> Risk Factors
<input type="checkbox"/> Diagnosis	<input type="checkbox"/> 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"/> Vitals
<input type="checkbox"/> Medications	
<input type="checkbox"/> Other <input style="width: 150px;" type="text"/>	

At least one Category is required.

PREVIOUS
NEXT

9)

Completion Status: 6 of 6 Sections  100% 100 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

OVERVIEW

Registry Description

Registry Classification and Purpose

Contact and Conditions of Access

Progress Report

Related Information

Outcome Measures and Common Data Elements

PREVIEW

SAVE/RELEASE REGISTRY PROFILE

### Registry Profile Preview

**Knee Arthroplasty Registry**  
RoPR ID: 493  
NCT ID - Pending Release to ClinicalTrials.gov  
(Click the NCT ID to view the ClinicalTrials.gov details for this record)

Use the Edit Icon to navigate to the specific section.

**REGISTRY DESCRIPTION**

Registry Title	Knee Arthroplasty Registry
Version	
Last Updated On	December 2, 2014
First Received On	November 26, 2014
Brief Description	
Long Description	
Geography and Location	National

**REGISTRY CLASSIFICATION AND PURPOSE**

Registry Classification	Disease/Disorder/Condition Service, Encounter Service, Hospitalization
Registry Purpose	Clinical Practice Assessment Effectiveness Quality Improvement

**CONTACT AND CONDITIONS OF ACCESS**

Interested in Being	No
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10)

Completion Status: 6 of 6 Sections 100% 100 % Completed

## ROPR | REGISTRY of PATIENT REGISTRIES

### Save/Release RoPR Registry Profile

*Last updated: December 2, 2014*

I confirm that the RoPR Registry Profile Record is accurate to the best of my knowledge.

I Agree

*All Sections must be Complete in order to release the Registry Profile*

RoPR Registry Profiles are made available to the public search site <https://patientregistry.ahrq.gov> within 1 day of release, following system validation.

Please complete the corresponding ClinicalTrials.gov record upon exiting the RoPR. Previous versions of the RoPR Registry Profile will be available to the public, though the default view will be the most recent version.

**SAVE AND EXIT**

Click to save your Registry Profile without releasing to the RoPR public search site

**RELEASE AND EXIT**

Click to release your Registry Profile to the RoPR public search site

Registry Description	COMPLETE
Registry Classification and Purpose	COMPLETE
Contact and Conditions of Access	COMPLETE
Progress Report	COMPLETE
Related Information	COMPLETE
Outcome Measures and Common Data Elements	COMPLETE