

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

Registry Version Registry version identifier. * Required Field

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

--Select--

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

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

Disease/Disorder/Condition Product, Drug Transplant

Pregnancy Service, Encounter Tumor

Product, Biologic Service, Hospitalization Vaccine

Product, Device Service, Procedure

Other

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

Clinical Practice Assessment Payment / Certification Quality Improvement

Effectiveness Post Marketing Commitment Safety or Harm

Natural History of Disease 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
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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://).

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	At least one Category is required.
<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"/>		

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