RareKids CAN

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RareKids-CAN Rare Disease Registry Resource Environmental Scan Data Dictionaries

Toward improved quality of rare disease registries, many initiatives and organizations in Canada and internationally have developed resources to support developers, holders, and users of patient registries. The purpose of this environmental scan is to catalogue key resources to provide general and tailored guidance to rare disease registry knowledge users, particularly those based in Canada. Specifically, we aim to support these knowledge users to develop, maintain, and use high-quality patient registries toward generating fit-for-purpose real-world evidence to support decision-making about treatments for rare diseases.

To be included, a source (e.g., an initiative or organization) had to be broader than a single rare disease registry or research project and relate to one of the following categories: registry guidance, registry platforms, common data elements, data quality/management, interoperability beyond core data elements, or registry inventory. To read the RareKids-CAN Rare Disease Registry Resource Environmental Scan protocol, click here.

The RareKids-CAN Rare Disease Registry Resource Environmental Scan is hosted on the Research Electronic Data Capture (REDCap) software across two separate projects: one for initiatives and organizations, and another for documents and articles. Each record contains information regarding the purpose and scope of a unique initiative/organization or document/article. The data dictionaries in Table 1, 2, and 3 below provide a detailed overview of the fields extracted for each record.

Table 1. RareKids-CAN Rare Disease Registry Resource Environmental Scan Data Dictionary – Document and Articles

Field Label	Variable Name	Field Type	Description	Categories
Record ID	record_id	Text Box	ID number assigned to record in sequential order.	Not applicable
Title	title	Text Box	Title of the document or article.	Not applicable
First Author	author	Text Box	Last name of first author of the article or document.	Not applicable
Year of Publication	year	Text Box	The year the document or article was published.	Not applicable
Journal	journal	Text Box	The journal in which the document or article was published.	Not applicable

Digital Object Identifier	doi	Text Box	Unique digital object identifier for the document or article.	Not applicable
PubMed ID	pmid	Text Box	Unique identifier assigned to documents or articles in the PubMed database.	Not applicable
Document/Article Category	category	Checkboxes	Category assigned to the initiative or organization (see protocol for definitions)	1, Registry guidance 2, Registry platform 3, Common data elements 4, Data quality/management 5, Interoperability beyond core data elements
Description	purpose	Notes Box	Verbatim description of document or article from source or adapted for clarity.	Not applicable
Type of Resource	type_of_resource	Checkboxes	Identifies whether the resource is specific to rare diseases, registries, or is a generic resource that applies to a broader area.	1, Rare disease specific 2, Registry specific 3, Generic
Audience	audience	Checkboxes	Audience the resource is intended to support.	1, Registry developers/holders 2, Registry users
Hyperlinks	hyperlinks	Text Box	Websites for documents or articles.	Not applicable

Table 2. RareKids-CAN Rare Disease Registry Resource Environmental Scan Data Dictionary – Initiatives and Organizations

Field Label	Variable Name	Field Type	Description	Categories
Record ID	record_id	Text Box	ID number assigned to record in sequential order.	Not applicable

Initiative/Organization Name	name	Text Box	Name of the initiative or organization.	Not applicable
Initiative/Organization Category	category	Checkboxes	Category assigned to the initiative or organization (see protocol for definitions). See Table 3 below for conditional fields based on the Initiative/Organization category.	1, Registry guidance 2, Registry platform 3, Common data elements 4, Data quality/management 5, Interoperability beyond core data elements 6, Registry inventory
Canada's Drug Agency (CDA) ***Best Practices and Standards to Enhance the Quality of Rare Disease Registries in Canada*** Tag	cda_tag	Checkboxes	Identifies which of CDA's ***Best Practices and Standards to Enhance the Quality of Rare Disease Registries in Canada*** domain the initiative or organization addresses.	1, Governance Best Practices and Standards 2, Data Best Practices and Standards 3, Information Technology Infrastructure Best Practices and Standards 4, Not applicable
Description	purpose	Notes Box	Verbatim description of initiative or organization from source website or adapted for clarity.	Not applicable
Type of Resource	type_of_resource	Checkboxes	Identifies whether the resource is specific to rare diseases, registries, or is a generic resource that applies to a broader area.	1, Rare disease specific 2, Registry specific 3, Generic
Year of Initiative/Organization Establishment	year	Text Box	The year the initiative or organization was developed.	Not applicable
Audience	audience	Checkboxes	Audience the resource is intended to support.	1, Registry developers/holders 2, Registry users

Geographical Origin/Host (Note: we have specifically searched on Canadian, American, and European initiatives)	geographical_origin	Checkboxes	Geographical origin of the resource.	1, Canada 2, United States 3, Europe 4, International 5, Other (origin_other (Text Box): Other Geographical Origin))
Current Status (as of January 2026)	current_status	Checkboxes	Reports whether the initiative or organization is still active as of January 2025. **Active**: Initiative or organization is not retired. **Time-limited:** Initiative or organization is not active, and resources are still publicly available. **Retired**: Initiative or organization is retired, and resources are no longer publicly available.	1, Active 2, Time-limited 3, Retired
Hyperlinks	hyperlinks	Notes Box	Websites with information on the resource.	Not applicable
Files	files	File Upload	Files with information on the resource.	Not applicable

Table 3. RareKids-CAN Rare Disease Registry Resource Environmental Scan Data Dictionary – Initiatives and Organizations: Conditional Fields for Initiative/Organization Category.

Registry guidance category (category=1)				
Field Label	**Variable Name**	**Field Type**	**Description**	**Categories**
Patient and Family Partners or Patient Organizations involved	guidance_partnership	Multiple Choice	Reports whether patient and family partners or patient organizations were involved in the guidance development	1, Yes 2, No 3, Not available

in guidance development				
Registry platform category (category=2)				
Field Label	**Variable Name**	**Field Type**	**Description**	**Categories**
Number of registries hosted on the platform	platform_numberreg	Text Box	Records how many registries are hosted on the platform	Not applicable
Number of rare disease registries hosted on the platform	platform_numberrarereg	Text Box	Records how many rare disease registries are hosted on the platform	Not applicable
Multilingual platform	multilingual_yes	Multiple Choice	Records whether the platform has the ability to be multilingual	1, Yes 2, No 3, Not available
Canadian-led platform	platform_canadian	Multiple Choice	Records if the platform was developed in Canada	1, Yes 2, No 3, Not available
Types of data supported on the platform	platform_data	Checkboxes	Records the types of data supported on the platform	1, Patient/caregiver-reported surveys 2, Clinical/laboratory data entered by providers 3, Electronic medical record or lab data automatically entered 4, Genomic data 5, Imaging data 6, Not available 7, Other
Data security described on the platform's public website	platform_datasecurity	Multiple Choice	Records if data security described on the platform's public website	1, Yes 2, No 3, Not available
Common data elements category (category=3)				
Field Label	**Variable Name**	**Field Type**	**Description**	**Categories**

Scope of common data elements initiative	cde_scope	Multiple Choice	Describes the scope of the common data elements initiative	1, All rare diseases 2, Group of rare disorders (based on Orphanet) 3, Single rare disorder (based on Orphanet) 4, Other 5, Not available
Patient and Family Partners or Patient Organizations involved in common data elements development	cde_partnership	Multiple Choice	Reports whether patient and family partners or patient organizations were involved in the common data elements development	1, Yes 2, No 3, Not available
Measurement tools described for common data elements	cde_measurement	Multiple Choice	Reports whether there are measurement tools described for the common data elements	1, Yes 2, No 3, Not available
Registry inventory category (category=6)				
Field Label	**Variable Name**	**Field Type**	**Description**	**Categories**
Inventory updated in the last two years	inventory_updated	Multiple Choice	Records whether the inventory has been updated in the last two years	1, Yes 2, No 3, Not available
Inventory geographical reach (Note: we have specifically searched on Canadian, American, and European initiatives)	registry_geograph	Checkboxes	Records the inventory's geographical reach	1, Canada 2, United States 3, Europe 4, International 5, Not available 6, Other
Inventory publicly available	inventory_public	Multiple Choice	Records whether the inventory is publicly available	1, Yes 2, No 3, Not available
Inventory self-enrollment available	inventory_enrol	Multiple Choice	Records if registry developers can self-enrol	1, Yes 2, No 3, Not available