

Variable / Field Name	Field Label <i>Field Note</i>	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)																																	
[registry_name]	Name of the registry	text, Required Field Annotation: C1.2																																	
[registry_acronym]	Registry acronym	text Field Annotation: C1.3																																	
[clinicaltrial_id]	ClinicalTrials.gov ID	text																																	
[registry_type]	Type of registry	radio <table><tr><td>1</td><td>Contact registry</td></tr><tr><td>2</td><td>Disease registry</td></tr></table> Custom alignment: LV	1	Contact registry	2	Disease registry																													
1	Contact registry																																		
2	Disease registry																																		
[registry_biobank] Show the field ONLY if: [registry_type] = '2'	Does the registry have a biobank?	yesno <table><tr><td>1</td><td>Yes</td></tr><tr><td>0</td><td>No</td></tr></table> Custom alignment: RH	1	Yes	0	No																													
1	Yes																																		
0	No																																		
[y_creation]	Year registry established (YYYY)	text Field Annotation: C4.5																																	
[recruitment_status]	Recruitment Status	dropdown <table><tr><td>1</td><td>Active</td></tr><tr><td>2</td><td>Inactive</td></tr><tr><td>3</td><td>Temporarily inactive</td></tr></table>	1	Active	2	Inactive	3	Temporarily inactive																											
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2	Inactive																																		
3	Temporarily inactive																																		
[y_recruitment]	Registry time span YYYY <i>First collection</i> -YYYY <i>Last collection</i>	text Field Annotation: C1.12, C1.13																																	
[rd_rds_table]		descriptive Field Annotation: @INSTANCETABLE-HIDEINSTANCECOL @INSTANCETABLE-HIDEFORMSTATUS @INSTANCETABLE-HIDEFORMMINMENU @INSTANCETABLE-HIDEADD @INSTANCETABLE=rare_diseases @INSTANCETABLE-VARLIST=rdn11_b5170f																																	
[rd_classification]	RareKids-CAN Rare Disease Classification (For all rare diseases listed in the registry)	checkbox, Required <table><tr><td>1</td><td>rd_classification__1</td><td>Allergic Diseases</td></tr><tr><td>2</td><td>rd_classification__2</td><td>Bone and Musculoskeletal Diseases</td></tr><tr><td>3</td><td>rd_classification__3</td><td>Cardiovascular Diseases</td></tr><tr><td>4</td><td>rd_classification__4</td><td>Developmental anomalies during embryogenesis</td></tr><tr><td>5</td><td>rd_classification__5</td><td>Endocrine Diseases</td></tr><tr><td>6</td><td>rd_classification__6</td><td>Gastroenterological Diseases</td></tr><tr><td>7</td><td>rd_classification__7</td><td>Genetic Diseases</td></tr><tr><td>8</td><td>rd_classification__8</td><td>Hematological Diseases</td></tr><tr><td>9</td><td>rd_classification__9</td><td>Inherited Metabolic Disorders</td></tr><tr><td>10</td><td>rd_classification__10</td><td>Infectious Diseases</td></tr><tr><td>11</td><td>rd_classification__11</td><td>Neurological and Psychiatric Diseases</td></tr></table>	1	rd_classification__1	Allergic Diseases	2	rd_classification__2	Bone and Musculoskeletal Diseases	3	rd_classification__3	Cardiovascular Diseases	4	rd_classification__4	Developmental anomalies during embryogenesis	5	rd_classification__5	Endocrine Diseases	6	rd_classification__6	Gastroenterological Diseases	7	rd_classification__7	Genetic Diseases	8	rd_classification__8	Hematological Diseases	9	rd_classification__9	Inherited Metabolic Disorders	10	rd_classification__10	Infectious Diseases	11	rd_classification__11	Neurological and Psychiatric Diseases
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[type_enrollment]	Type of enrollment	checkbox <table> <tr><td>1</td><td>type_enrollment__1</td><td>Identified through electronic medical records</td></tr> <tr><td>2</td><td>type_enrollment__2</td><td>Self-registration Online (e.g., online form)</td></tr> <tr><td>7</td><td>type_enrollment__7</td><td>Self-registration via direct contact (e.g., email)</td></tr> <tr><td>3</td><td>type_enrollment__3</td><td>Patient organization(s) or patient advocacy group(s)</td></tr> <tr><td>4</td><td>type_enrollment__4</td><td>Referral from healthcare provide(s)</td></tr> <tr><td>5</td><td>type_enrollment__5</td><td>Through participation in existing research studies or clinical trials</td></tr> <tr><td>6</td><td>type_enrollment__6</td><td>Other</td></tr> <tr><td>99</td><td>type_enrollment__99</td><td>Unknown</td></tr> </table> Custom alignment: LV	1	type_enrollment__1	Identified through electronic medical records	2	type_enrollment__2	Self-registration Online (e.g., online form)	7	type_enrollment__7	Self-registration via direct contact (e.g., email)	3	type_enrollment__3	Patient organization(s) or patient advocacy group(s)	4	type_enrollment__4	Referral from healthcare provide(s)	5	type_enrollment__5	Through participation in existing research studies or clinical trials	6	type_enrollment__6	Other	99	type_enrollment__99	Unknown			
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99	type_enrollment__99	Unknown																											
[other_enrollment] Show the field ONLY if: [type_enrollment(6)] = '1'	Please specify other type of enrollment	text																											
[group_age]	Age groups included	checkbox <table> <tr><td>1</td><td>group_age__1</td><td>Children</td></tr> <tr><td>2</td><td>group_age__2</td><td>Adolescents</td></tr> <tr><td>3</td><td>group_age__3</td><td>Adults</td></tr> <tr><td>99</td><td>group_age__99</td><td>Unknown</td></tr> </table> Custom alignment: LH Field Annotation: C1.8	1	group_age__1	Children	2	group_age__2	Adolescents	3	group_age__3	Adults	99	group_age__99	Unknown															
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[registry_pop_size]	Population size (Total number of unique individuals)	text Field Annotation: C7.1																											
[type_data]	Type of data collected in the registry	checkbox <table> <tr><td>1</td><td>type_data__1</td><td>Caregiver data (e.g., Family history)</td></tr> <tr><td>2</td><td>type_data__2</td><td>Clinical data (e.g., disease severity, medical history, medication history, diagnosis data, Clinical measurement etc.)</td></tr> </table>	1	type_data__1	Caregiver data (e.g., Family history)	2	type_data__2	Clinical data (e.g., disease severity, medical history, medication history, diagnosis data, Clinical measurement etc.)																					
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[registry_reg]	Geographical Accessibility	radio <table><tr><td>1</td><td>International</td></tr><tr><td>2</td><td>National</td></tr><tr><td>3</td><td>Regional</td></tr><tr><td>4</td><td>Local</td></tr></table> Custom alignment: LH	1	International	2	National	3	Regional	4	Local																						
1	International																															
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4	Local																															
[nb_countries] Show the field ONLY if: [registry_reg] = '1'	Number of participating countries	text																														
[french_language]	Available in French	yesno <table><tr><td>1</td><td>Yes</td></tr><tr><td>0</td><td>No</td></tr></table> Custom alignment: RH	1	Yes	0	No																										
1	Yes																															
0	No																															
[coverage_canada]	Registry regions in Canada with enrolled participants	checkbox <table><tr><td>AB</td><td>coverage_canada___ab</td><td>Alberta</td></tr><tr><td>BC</td><td>coverage_canada___bc</td><td>British Columbia</td></tr><tr><td>MB</td><td>coverage_canada___mb</td><td>Manitoba</td></tr><tr><td>NB</td><td>coverage_canada___nb</td><td>New Brunswick</td></tr><tr><td>NL</td><td>coverage_canada___nl</td><td>Newfoundland and Labrador</td></tr><tr><td>NT</td><td>coverage_canada___nt</td><td>Northwest Territories</td></tr></table>	AB	coverage_canada___ab	Alberta	BC	coverage_canada___bc	British Columbia	MB	coverage_canada___mb	Manitoba	NB	coverage_canada___nb	New Brunswick	NL	coverage_canada___nl	Newfoundland and Labrador	NT	coverage_canada___nt	Northwest Territories												
AB	coverage_canada___ab	Alberta																														
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		<table><tr><td>NS</td><td>coverage_canada___ns</td><td>Nova Scotia</td></tr><tr><td>NU</td><td>coverage_canada___nu</td><td>Nunavut</td></tr><tr><td>ON</td><td>coverage_canada___on</td><td>Ontario</td></tr><tr><td>PE</td><td>coverage_canada___pe</td><td>Prince Edward Island</td></tr><tr><td>QC</td><td>coverage_canada___qc</td><td>Quebec</td></tr><tr><td>SK</td><td>coverage_canada___sk</td><td>Saskatchewan</td></tr><tr><td>YT</td><td>coverage_canada___yt</td><td>Yukon</td></tr><tr><td>UNK</td><td>coverage_canada___unk</td><td>Unknown</td></tr></table> Custom alignment: LV Field Annotation: C1.5.1	NS	coverage_canada___ns	Nova Scotia	NU	coverage_canada___nu	Nunavut	ON	coverage_canada___on	Ontario	PE	coverage_canada___pe	Prince Edward Island	QC	coverage_canada___qc	Quebec	SK	coverage_canada___sk	Saskatchewan	YT	coverage_canada___yt	Yukon	UNK	coverage_canada___unk	Unknown
NS	coverage_canada___ns	Nova Scotia																								
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SK	coverage_canada___sk	Saskatchewan																								
YT	coverage_canada___yt	Yukon																								
UNK	coverage_canada___unk	Unknown																								
[organization]	Lead organization(s)	text																								
[lead_local]	Lead organization(s) localization (City, State, Country)	text																								
[contact_email]	Registry contact for enrollment	text Field Annotation: M1.3, M1.6																								
[data_access]	Is data access possible?	dropdown <table><tr><td>0</td><td>No</td></tr><tr><td>1</td><td>Yes</td></tr><tr><td>99</td><td>Unknown</td></tr></table> Custom alignment: RH	0	No	1	Yes	99	Unknown																		
0	No																									
1	Yes																									
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[alternativecontact_email]] Show the field ONLY if: [data_access] = '1' or [data_access] = '99'	Registry contact or link for data access	text Field Annotation: M1.3, M1.6																								
[registry_web]	Registry website	text Field Annotation: C11.1																								