CRRD Data Collection Definition

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Label of the variable	CSV column name	Mandatory?	Definition of the variable	Possible values EN	Possible values FR	Possible values NL	Extra information	Type of variable	Validation rules in HD4DP (blocking error in HD4DP)	Validation rules performed by CRRD team after submission	Changes of V2.0 compared to V1.0
UNIQUE NIHDI-CODE OF THE REGISTERING CENTRE	unique_nihdicode_of_the_registering_centre	yes	Unique NIHDI-code of the registering centre.	81199094996 82499092996 82699032996 82899069996 82999039996 84499074996 85299028996 86299019996			81199094996 - UZA 82499092996 - UZ Leuven 82699032996 - St-Luc 82899069996 - Erasme 82999039996 - UZ Brussel 84499074996 - UZ Gent 85299028996 - IPG 86299019996 - CHU Liège	*Identifier* • Quality control • Feedback reporting • Descriptive analyses by centre • Inform centres about probably eligible patients for relevant (clinical) research	This field consists of 11 digits: no punctuation, just numbers. It must be one of the given codes.		
NIHDI-CODE OF THE SPECIALIST	nihdicode_of_the_specialist	yes	The NIHDI code of the physician who saw the patient in consultation.	NIHDI code			Encoded by eHealth to ensure the privacy of the specialist	*Identifier* • Quality control • Feedback reporting • Inform centres about possibly eligible patients for relevant (clinical) research and the physicians these patients consulted in the centre	This field consists of 11 digits: no punctuation, just numbers.		
NATIONAL REGISTRY ID OF THE PATIENT	patient_id	yes	Unique identification number for the patient. If the patient resides in Belgium it is mandatory to use a NR number or SSIN number.	National Register Number (NR-number) or Social Security Identification Number (SSIN) Empty if none of these numbers is available.			The software will automaticaly generate a unique identifier based on the name, birth date and sex of the patient only if this field is empty and if the variable patient_id|generated is set to "TRUE" in the CSV or if the check-box is checked in the form. No other patient identifiers should be entered in here. Encoded by eHealth to ensure the privacy of the patient	*Identifier* • Unambiguous patient coding to ensure correct statistics • Longitudinal follow-up of patients / throughout health care system • Ensure interoperability, f.e. with the National Register • Quality control • Facilitation of recruitment of eligible patients for (clinical) research • Pooling of data at European level	Length of field = 11 characters. The validity of the national registry number is checked with the mod97 control		
GENERATED	patient_id|generated	no	The patient_id|generated column in the CSV can be set to 'TRUE' to automatically generate a patient_id if none was provided.	TRUE FALSE			**When using CSV upload** this variable must be put on "TRUE". If "TRUE" is entered by default and the NISS number is not missing, no patient ID will be generated nor overwritten. In case the NISS number is missing, the patient ID will be generated. If this case is left empty or 'FALSE", you can still generate a patient ID (code path) after CSV upload by opening the form and check the box. This action must be performed case by case. This also applies if you don't use CSV upload but directly enter the data in the webform.	*Identifier*			This variable has been added
NAME	patient_id|name	no	The family name of the patient.	The family name of the patient.			This field is a free text field. The information for this variable will stay locally and will not be sent to the WIV-ISP or anywhere else outside the hospital.	*Identifier* • Generation of a patient identifier in case no NISS number is available • Facilitation of data management in the software (e.g. for quality control)	Maximum length of field = 50 characters.		
FIRST NAME	patient_id|first_name	no	The first name of the patient.	The first name of the patient.			This field is a free text field. The information for this variable will stay locally and will not be sent to the WIV-ISP or anywhere else outside the hospital.	*Identifier* • Generation of a patient identifier in case no NISS number is available • Facilitation of data management in the software (e.g. for quality control)	Maximum length of field = 50 characters.		
DATE OF BIRTH	patient_id|date_of_birth	yes	Date of birth of the patient.	Date of birth of the patient.				*Identifier* • Generation of a patient identifier in case no NISS number is available *Demographic variable/patient profile* • Age at diagnosis, death • Analyses by age	This field contains a date entered in the form DD/MM/YYYY. Date of birth cannot be after the Date of death Date of birth cannot be in the future	Date of first consultation in the registering centre cannot be before the Date of birth Time of first symptoms cannot be before the Date of birth Time of current diagnosis cannot be before the Date of birth The Date of current consultation cannot be before the Date of birth	Validation rules have moved from HD4DP to validations after submission.
SEX	patient_id|sex	yes	Sex of the patient as it appears in the National Register or on the patient's passport or birth certificate.	M F			M - Male F - Female	*Identifier* *Demographic variable/patient profile* • Sex-related differences in e.g. epidemiology	Maximum length of field = minimum length = 1 character. Only M or F are accepted		
DECEASED: DATE OF DEATH	1: patient_id|deceased 2: patient_id|date_of_death	1: no 2: no	The indication whether the patient is deceased or not and the date of death (if applicable and known).	For 1: TRUE FALSE For 2: Date of death			TRUE if patient is deceased	*Identifier* *Demographic variable/health status* • Prevalence • Mortality/survival	Date of death: this field contains a date entered in the form DD/MM/YYYY. Date of birth cannot be after the Date of death The Date of death cannot be in the future.		
PLACE OF RESIDENCE	patient_id|place_of_residence	yes	The postal code of the main place of residence of the patient.	4-digit postal code for patients who have their main residence in Belgium. Free format postal code or city name for patients having their main residence abroad.				*Identifier* *Demographic variable/patient profile* • Geographic variation in incidence, prevalence, mortality... • Mobility/Territorial accessibility (incl. crossborder aspect)	4-digit numeric code when the country of residence is Belgium. Free text field when country of residence is not Belgium.		
COUNTRY OF RESIDENCE	country_of_residence	yes	The country of the main place of residence of the patient.	Preferably 2 letter country code: ISO 3166-1 alpha-2 standard. For patients who have their main residence in Belgium, mention BE. For patients having their main residence abroad, indicate the country.				*Demographic variable/patient profile* • Incidence & prevalence: attribution to geographical area • Mobility/Territorial accessibility (incl. crossborder aspect)	This field is a free text field. Preferably, the 2 letter country codes are used (ISO 3166-1 alpha-2 standard). Maximum field length = 50 characters.		
INTERNAL PATIENT ID	patient_id|internal_patient_id	no	Internal patient ID or reference number.	This is a free text field.			This field can be used to enter an internal ID or reference number. If there is an integration between HD4DP and your organisation's patient administration system, additional patient identification information such as date of birth, sex and NR-number can be automatically enriched based on this internal patient ID. Please do not encode the NR-number in this field as it must be encoded in the patient ID field. The information for this variable will stay locally and will not be sent to the WIV-ISP or anywhere else outside the hospital.	Several dataproviders asked to include this information. It can be used to track a patient in your system if extra information or corrections are necessary.			Non-mandatory variable added after request by data providers. Intended for internal use only.
REFERRED BY	referred_by	yes	The physician or entity who referred the patient to the registering centre.	By preference use the code (number between parantheses) general_physician (1) specialist (2) patient_own_initiative (3) geneticist (4) other_health_care_professional (5) second_opinion (6) family_history (7)	De préférence utiliser le code entre parenthèses medecin_generaliste (1) specialiste (2) initiative_propre (3) geneticien (4) autre_fournisseur_de_soins_de_sante (5) deuxieme_avis (6) histoire_familiale (7)	Bij voorkeur de code die tussen haakjes opgegeven is gebruiken huisarts (1) specialist (2) eigen_initiatief (3) geneticus (4) andere_zorgverlener (5) tweede_opinie (6) familiegeschiedenis (7)	Geneticist= family members invited by geneticist for segregation analysis or testing for de novo analysis, or referred by other geneticist for diagnostic work-up or follow-up many years after initial visit Family history = known familial disease and informed by family member For transition of V1 to V2 empty fields can be completed with "value_missing"	*Descriptive parameter care pathway* • Path to diagnosis • Referral patterns & trends**	Maximum length of field = 200 characters.	Only data values from the list are accepted.	Addition of list with data values after approval of the College of Genetics. This field is now mandatory. Instead of text, a code can be used.
COUNTRY OF REFERRAL	country_of_referral	yes	The country of the physician/entity who referred the patient to the registering centre.	Indicate the country code (ISO 3166-1 alpha-2 standard). This is BE for Belgium.			For patients referred from within Belgium, mention BE. For patients referred from abroad, indicate the country.	*Descriptive parameter care pathway* • Referral patterns (cross-border aspect) & trends**	This field is a free text field. Preferably, the 2 letter country codes are used (ISO 3166-1 alpha-2 standard). Maximum field length = 50 characters.		This field is now mandatory

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TYPE OF SERVICE REQUESTED	type_of_service_requested	yes	The type of service requested from the registering centre.	By preference use the code (number between parantheses) diagnostic_setting_postnatal (1) predictive_testing (2) carrier_testing (3) prenatal_counseling (4) preconceptional_counseling (5) follow_up (6) or code (number between parantheses)	De préférence utiliser le code entre parenthèses diagnostique_postnatal (1) test_predictif (2) test_de_porteur (3) conseil_prenatal (4) conseil_preconceptionel (5) suivi (6)	Bij voorkeur de code die tussen haakjes opgegeven is gebruiken postnataal_diagnostiek (1) predictieve_test (2) dragerschap (3) prenatale_counseling (4) preconceptuele_counseling (5) follow_up (6)	Carrier testing for autosomal recessif or X-linked disease Preconceptional counseling includes PGD testing For transition of V1 to V2 empty fields can be completed with "value_missing"	*Descriptive parameter care pathway* • Quantification of (specific types of) health service delivery • Referral patterns and trends**	Maximum length of field = 200 characters.	Only data values from the list are accepted.	Addition of list with data values after approval of the College of Genetics. This field is now mandatory. Instead of text, a code can be used.
DATE OF FIRST CONSULTATION IN THE REGISTERING CENTRE	date_of_first_consultation_in_the_registering_centre	yes	The date on which the patient consulted for the first time a physician in the registering centre.	The date on which the patient consulted for the first time a physician in the registering centre.				*Descriptive parameter care pathway* • Path to diagnosis	This field contains a date, recorded as DD/MM/YYYY. Date of first consultation in the registering centre cannot be in the future	Date of first consultation in the registering centre cannot be before the date of birth Date of first consultation in the registering centre cannot be after the date of current consultation	Validation rules have moved from HD4DP to validations after submission.
TIME OF CURRENT DIAGNOSIS	1. time_of_current_diagnosis 2. time_of_current_diagnosis_specify	1: no 2: yes	The answer given is the date, or best estimate thereof, when the diagnosis (or the change of diagnosis) was communicated to the patient by a physician.	1. This column can be ommited if the format in column 2 is one of the validated formats. According to the accuracy of the obtained data, different answering possibilities are possible: • full date • month and year • year • age range • gestational age • unknown 2. See column validation rules in HD4DP			Age range categories corresponding to those in Orphanet can be used either the age range and/or the category name - 0 - 4 weeks : Neonatal - Neonataal - Néonatal - 4w – 2 year : Infancy - Zuigeling - Nourisson - 2 – 11 year : Childhood - Kindertijd - Enfance - 12 – 18 year : Adolescence - Adolescentie - Adolescence - 19 – 40 year : Young Adulthood - Jong volwassen - Jeune adulte - 41 – 60 year : Adulthood - Volwassen - Adulte - >60 year : Elderly - Ouderen- Personnes âgées Prenatal diagnosis must be expressed in gestational age	*Descriptive parameter diagnosis/care* • Path to diagnosis • Time till diagnosis • Age at diagnosis The time it takes to obtain a diagnosis is an established performance indicator for the national plan for rare diseases as well as an EUROPLAN indicator. It concerns the total health care system, not the individual centres.	• for "full_date" --> DD/MM/YYYY (date) • for "month_and_year" --> MM/YYYY (date) • for "year" --> YYYY (date) • for "age_range" --> x-y (symbol"-" present) or Orphanet category • for "gestational_age" --> x weeks ("weeks", "semaines", "weken" or any abbreviation of these must be present) • for "unknown" --> "unknown" Time of current diagnosis cannot be in the future	Time of current diagnosis cannot be before the Date of birth	Validation rules have moved from HD4DP to validations after submission. Orphanet age range categories are accepted as "age range"
DATE OF CURRENT CONSULTATION	date_of_current_consultation	yes	The date of the current consultation in the registering centre.	The date of the current consultation in the registering centre.				*Descriptive parameter care pathway* • Quantification of (specific types of) health service delivery	This field contains a date, recorded as DD/MM/YYYY. The Date of current consultation cannot be in the future	The Date of current consultation cannot be before the Date of birth The Date of current consultation cannot before the Date of first consultation in the registering centre	Validation rules have moved from HD4DP to validations after submission.
COUNTRY OF CURRENT CONSULTATION	country_of_current_consultation	yes	The country code of the place of the current consultation.	Indicate the country code (ISO 3166-1 alpha-2 standard). This is BE for Belgium.				*Descriptive parameter care pathway* • Mobility/Territorial accessibility (incl. crossborder aspect) • Geographical quantification of (types of) health service delivery	This field contains the 2 letter country code: ISO 3166-1 alpha-2 standard. Maximum length of field = minimum length = 2 characters.		
CITY OF CURRENT CONSULTATION	city_of_current_consultation	yes	The postal code of the place of the current consultation.	4-digit postal code for consultation in Belgium. Free format postal code or city name for consultation abroad.				*Descriptive parameter care pathway* • Mobility/Territorial accessibility (incl. crossborder aspect)	This field is a free text field. Preferably, the 4 digit postal code for consultations in Belgium. Free format for consultations abroad Maximum field length = 50 characters.		
TIME OF FIRST SYMPTOMS (FIRST CONSULTATION)	1. time_of_first_symptoms_first_consultation 2. time_of_first_symptoms_first_consultation_specify	1: no 2: yes	The time of first symptoms is the date, or best estimate thereof, when the patient went for the first time to see **any** physician for symptoms of his rare disease. Or, in the case of occasional findings or prenatal symptoms, it is the date when the disease manifestations (either subjective symptoms or objective signs) first came to the attention of a physician.	1.This column can be ommited if the format in column 2 is one of the validated formats. According to the accuracy of the obtained data, different answering possibilities are possible: • full_date • month_and_year • only_only_year • age_range • gestational_age • unknown • no_symptoms 2. See column validation rules in HD4DP			Age range categories corresponding to those in Orphanet can be used either the age range and/or the category name - 0 - 4 weeks : Neonatal - Neonataal - Néonatal - 4w – 2 year : Infancy - Zuigeling - Nourisson - 2 – 11 year : Childhood - Kindertijd - Enfance - 12 – 18 year : Adolescence - Adolescentie - Adolescence - 19 – 40 year : Young Adulthood - Jong volwassen - Jeune adulte - 41 – 60 year : Adulthood - Volwassen - Adulte - >60 year : Elderly - Ouderen- Personnes âgées Abnormal findings detected during prenatal diagnosis must be expressed in gestational age	*Indicator Health status/Descriptive parameter diagnosis* • Path to diagnosis • Time till diagnosis** The time it takes to obtain a diagnosis is an established performance indicator for the national plan for rare diseases as well as an EUROPLAN indicator. It concerns the total health care system, not the individual centres.	• for "full_date" --> DD/MM/YYYY (date) • for "month_and_year" --> MM/YYYY (date) • for "year" --> YYYY (date) • for "age_range" --> x-y (symbol"-" present) or Orphanet category • for "gestational_age" --> x weeks ("weeks", "semaines", "weken" or any abbreviation of these must be present) • for "unknown" --> "unknown" • for "no_symptoms" --> "no symptoms" Time of first symptoms cannot be in the future	Time of first symptoms cannot be before the Date of birth	1 validation rule moved from HD4DP to validations after submission. Orphanet age range categories are accepted as "age range"
STATUS DIAGNOSIS	status_diagnosis	yes	The indication whether the status of the current diagnosis is provisional or definitive.	provisional definitive			"Working diagnosis" should be registered as provisional diagnosis if this diagnosis has been communicated to the patient. If no diagnostic test is available for a disease, the patient should be registered with a definitive diagnosis based only on clinical signs. Undetermined diagnosis can be registered using an ORPHA code for a group of diseases or for a category (higher level in the classification).	*Descriptive parameter diagnosis/care* • Path to diagnosis • Trends in diagnostics	Maximum length of field = 11, minimum length = 10 characters. Accepts only the data values "definitive" and "provisional"		
BASE OF DIAGNOSIS	1. base_of_diagnosis 2. base_of_diagnosis|specify	yes	The different elements on which the current diagnosis is based.	1.:clinical_signs family_history genetic_test other 2: Free text			All sources that were used to establish the current diagnosis must be included. More than one answer are allowed.	*Descriptive parameter diagnosis/care* • Path to diagnosis • Trends in diagnostics	1.Accepts only the data values or combination of these Multiple choices are possible. Separator = "|" 2. If Base of diagnosis = other: please specify --> free text field (maximum length = 250 characters)		No capital letters in the data values
REMARK ON DISEASE CODES							A disease can be described by using different coding systems. Preference is given to the use of the Orphanet classification because it is the most complete and accurate classification system for rare diseases. If multiple coding systems are used to describe the disease, different codes can be inserted in the respective fields. It is mandatory to fill in at least one of these fields. If several codes of a classification are used to describe the same diagnosis, they can be provided in one fields separated with an "|". **If a patient suffers from several diseases, several lines in the CSV file or several forms in the HD4DP software need to be completed for this patient.** In this way, it is possible to distinguish all the associated variables that are disease specific.	*Identifiers diagnosis/test result* For all codes: • Mapping between the different coding systems • Internal validation of data • External validation of data, e.g. assess completeness where possible • Path to diagnosis Specific for ORPHA CODES • Statistical analyses by rare disease (group) • International data exchange / pooling data for rare diseases	Minimum one of the following fields is mandatory	If no ORPHA-code was provided, we'll perform a mapping to obtain an ORPHA-code. It may be possible that we have a question concerning this mapping or we may make a suggestion to change the given code if this doesn't match the disease name. In both situations we'll send the record back with a comment to the data provider.	
DIAGNOSIS: ORPHA-CODE	disease_code|diagnosis_orphacode		Provisional or definitive diagnosis described using the code assigned to the disease in the Orphanet classification.	The code assigned to the disease in the Orphanet classification.			**Preference is given to the use of the Orphanet classification.** In the future the ORPHA code will become mandatory.	*Identifier diagnosis*	Maximum length of field = 35 characters. The word ORPHA is omitted. Several codes (to describe 1 disease) can be separated by an "|".		
DIAGNOSIS: ICD-10-CODE	disease_code|diagnosis_icd10code		Provisional or definitive diagnosis described using the code assigned to the disease in the ICD-10 classification.	The code assigned to the disease in the ICD-10 classification.				*Identifier diagnosis*	Maximum length of field = 35 characters. Separator = "|"		
DIAGNOSIS: SNOMED-CT-CODE	disease_code|diagnosis_snomedctcode		Provisional or definitive diagnosis described using the code assigned to the disease in the SNOMED-CT nomenclature.	The code assigned to the disease in the SNOMED-CT nomenclature.				*Identifier diagnosis*	Maximum length of field = 35 characters. Separator = "|"		
DIAGNOSIS: ICD-O-CODE	disease_code|diagnosis_icdocode		Provisional or definitive diagnosis described using the code assigned to the disease in the ICD-O classification.	The code assigned to the disease in the ICD-O classification.				*Identifier diagnosis*	Maximum length of field = 35 characters. Separator = "|"		
DIAGNOSIS: HPO-CODE	disease_code|diagnosis_hpocode		Provisional or definitive diagnosis described using the HPO code assigned to the disease.	The HPO code assigned to the disease.				*Identifier diagnosis*	Maximum length of field = 35 characters. Separator = "|"		

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DIAGNOSIS: OMIM-CODE	disease_code|diagnosis_omimcode		Provisional or definitive diagnosis described using an OMIM code assigned to the disease.	The OMIM code assigned to the disease.				*Identifier diagnosis*	Maximum length of field = 35 characters. Separator = "|"		
DIAGNOSIS: ISCN-CODE	disease_code|diagnosis_iscncode		Provisional or definitive diagnosis described using the code assigned to the genotype in the ISCN nomenclature.	The code assigned to the genotype in the ISCN nomenclature.				*Identifier genotype*	Maximum length of field = 200 characters.		
DIAGNOSIS: LOINC-CODE	disease_code|diagnosis_loinccode	no	Provisional or definitive diagnosis additionally described using the code assigned to a test and test result in the LOINC nomenclature.	The code assigned to a test and test result in the LOINC nomenclature.			This code describes a test and test result and not the disease. Therefore it can not be used alone and should always be combined with at least one other code.	*Identifier test and test result*	This code is supplementary to the mandatory codes as described before. Maximum length of field = 200 characters. Separator = "|"		
DIAGNOSIS: DISEASE NAME	disease_code|diagnosis_disease_name	yes	The diagnosis described in words using the name, acronym or synonym of the disease in EN, FR or NL.	The diagnosis described in words using the name, acronym or synonym of the disease in EN, FR or NL.				• Quality control • Facilitation of mapping between the different coding systems	Free text field. Maximum field length = 200 characters.	The disease name must correspond to the disease code.	
REFERRED TO	referred_to	yes	The health service or physician the patient is referred to.	By preference use the code (number between parantheses) general_physician (1) specialist (2) geneticist (3) specific_multidisciplinary_outpatient_consultation (4) foreign_expert (5) no_referral (6)	De préfénce utiliser le code entre parenthèses medecin_generaliste (1) specialiste (2) geneticien (3) consultation_multidisciplinaire (4) expert_etranger (5) pas_de_renvoi (6)	Bij voorkeur de code die tussen haakjes opgegeven is gebruiken huisarts (1) specialist (2) geneticus 3() multidisciplinair_consultatie (4) buitenlandse_expert (5) geen_doorverwijzing (6)		*Descriptive parameter care pathway* • Referral patterns & trends • Path to diagnosis • Cross-border care	Maximum length of field = 200 characters.	Only data values from the list are accepted.	Addition of list with data values after approval of the College of Genetics This field is now mandatory Instead of text, a code can be used
CONSENT OF PATIENT FOR FACILITATION OF RECRUITMENT	consent_of_patient_for_facilitation_of_recruitment	no	The consent of the patient for facilitation of recruitment for clinical trials/research.	TRUE FALSE			*This variable is not mandatory after authorisation granted in deliberations no.13/105 of 22/10/2013 and modification of 16/06/2015 of the Sectoral Committee of Health and the information is not collected anymore after the modification. This column can be omitted in the CSV upload file.* We kindly remind you that information of the patient remains obligatory. This can be performed by providing the CRRD flyer to the patient. Flyers inEN, FR and NL can be obtained on request by sending an e- mail to CRRD@wiv-isp.be	*Regulatory* • Facilitation of recruitment for (clinical) research One of the goals of the registry is to facilitate the recruitment for clinical studies of patients matching specific criteria. In this context, the registry will play a facilitating role but the patient will always be contacted through a treating clinician.			The answer must be written in capital letters
COMMENTS	comments	no	In this free text field comments can be given that applies to the patient	This field is a free text field.			Please do not insert identification data of the patient in this field because the contect of the field will be send and visible to the CRRD team members.		Maximum field length = 500 characters.		