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Common Data Elements & Coding systems in the CPMS

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2 Introduction

This document summarizes the data-set and the coding systems used in the CPMS to build the consultation form. All the fields listed are intended as generic in order to enable you to customize as per the condition specificities.

3 Data-set v4.3 Generic CDE

Form Group/Section	Field Origin Ref.	Field Name	Fields Type	Control
Patient enrolment	ERN.3	Patient ID	Auto generated / Matched existing	
	ERN.5	Date enrolled	Day/Month/Year	Calendar
	ERN.81	Have you sought advice on this patient at a national healthcare provider organisation?	Radio	Yes/No
	ERN.82	Please specify	Alphanumeric (max char.)	Free text
Consent	RD3a	Consent for Care	Radio	Boolean
	ERN.80	Date of consent	Calendar	Day/Month/Year
	RD3b	Consent for ERN databases/Registries	Radio	Boolean
	ERN.80b	Date of consent	Calendar	Day/Month/Year
	ERN.6	Please specify (e.g. Registry name)	Text	Text box
	RD3c	Consent to be contacted for research	Radio	Boolean
	ERN.80c	Date of consent	Calendar	Day/Month/Year
Identifying data	ERN.6	Please specify (e.g. specific purpose of research)	Alphanumeric (max char.)	Free text
	ERN.83	First name	Alphanumeric (50 char.)	Free text
	ERN.84	Last name	Alphanumeric (50 char.)	Free text
	ERN.85	Gender	Drop-down	Male/Female/Undifferentiated/Unknown
	PS1.3	Date of birth	Day/Month/Year loose	Calendar
ERN.86	Record Label	Auto-generate		
Consultation Request	ERN.4	Nickname	Alphanumeric (50 char.)	Free text
	ERN.4a	Is urgency required for this panel?	Checkbox	Boolean
	ERN.2	Is this a repeat of a previous panel for the same patient but a different episode?	Radio	Yes/No/Don't know
	ERN.12	Consultation Request Description Short	Alphanumeric (100 char.)	Free text

	ERN.13	Consultation Request Reason	Radio	Diagnosis/Treatment/Other
	ERN.87	Please specify	Alphanumeric (100 char.)	Free text
	ERN.14	Consultation Request Description	Alphanumeric (max char.)	Free text
	ERN.9	Healthcare Provider (HCP)	Auto-populate (user info)	Automatic
	ERN.9a	Point of care specialist	Alphanumeric (100 char.)	Free text
	ERN.7	ERN	Radio	Boolean
	ERN.88	Panel Lead	Drop-down	List of HPs (health professionals) available
	ERN.8b	Panel Manager	Drop-down	List of Panel Managers available
	ERN.8	Primary Thematic Area	Radio	Boolean
	ERN.8a	Secondary Thematic Areas	Multi-select checkboxes	List of remaining thematic areas (excluding that selected as primary at ERN.8)
Patient Information	ERN.1	Panel ID	Auto-generate	
	ERN.54	Birth complications	Multi-select checkboxes	LOINC, MedDRA, free text
	ERN.54a	ICD-10	Auto-complete	ICD-10
	ERN.54b	MedDRA	Auto-complete	MedDRA
	ERN.54c	Text	Alphanumeric (max char.)	Free text
	PS1.3a	Age when panel opened	Auto-complete (editable)	Text based on date of birth – panel opened interval
	PS1.2	Gender	Auto-complete (removable)	Male/Female/Undifferentiated/Unknown
	ERN.75	Pregnancy	Radio	Yes/No
	PS1.5.6	Country of Residence	Drop-down	ISO 3166-1 Country codes
	EPI.1	Country of Birth	Auto-complete	ISO 3166-1 Country codes
	RD4	Education Level	Drop-down	ISCED 0: Early childhood education ('less than primary' for educational attainment) ISCED 1: Primary education ISCED 2: Lower secondary education ISCED 3: Upper secondary education ISCED 4: Post-secondary non-

				tertiary education ISCED 5: Short-cycle tertiary education ISCED 6: Bachelor's or equivalent level ISCED 7: Master's or equivalent level ISCED 8: Doctoral or equivalent level
	RD5	Occupation	Drop-down	Eurostar classification for self-defined current economic status (http://ec.europa.eu/eurostat/statistics-explained/index.php/EU_statistics_on_income_and_living_conditions_(EU-SILC)_methodology_-_definition_of_dimensions#Self-defined_current_economic_status)
	PS14	Functional Status and or Disability	Multi-select checkboxes	LOINC for observation MedDRA freetext
	PS14a	ICD-10	Auto-complete	ICD-10
	PS14b	MedDRA	Auto-complete	MedDRA
	PS14c	Text	Alphanumeric (max char.)	Free text
	PS14d	WHODAS 2.0 Score	Numeric (%)	Integer, 0-100
	ERN.74	Other relevant information	Alphanumeric (max char.)	Free text
Episode Description History	ERN.15	History	Alphanumeric (max. char) + poss attachment	Free text Attachment
Episode Description Main symptom	ERN.16	Main Symptoms	Multi-select Checkboxes	LOINC MedDRA ICD-10 Free-text Alphanumeric (max. char) + poss attachment
	ERN.16a	LOINC	Auto-complete	LOINC
	ERN.16b	MedDRA	Auto-complete	MedDRA

	ERN.16c	ICD-10	Auto-complete	ICD-10
	ERN.16d	Text	Alphanumeric (max char.)	Free text
Episode Description Current Treatment	ERN.17	Current Treatment	Auto-complete Alphanumeric (max char.) + poss attachment	ATC Free text Attachment
	ERN.17e	ATC	Auto-complete	ATC
	ERN.17d	Text	Alphanumeric (max char.)	Free text
Episode Description Exam Findings	ERN.18	Exam Findings	Multi-select Checkboxes	LOINC MedDRA ICD-10 Free text Attachment
	ERN.18a	LOINC	Auto-complete	LOINC
	ERN.18b	MedDRA	Auto-complete	MedDRA
	ERN.18c	ICD-10	Auto-complete	ICD-10
	ERN.18d	Text	Alphanumeric (max char.)	Free text
	ERN.76	Notes on the exam finding (obs values/dates, etc.)	Alphanumeric (max char.)	Free text
Episode Description Laboratory Findings	ERN.19	Laboratory Findings	Multi-select Checkboxes	LOINC MedDRA Free text Attachment
	ERN.19a	LOINC	Auto-complete	LOINC
	ERN.19b	MedDRA	Auto-complete	MedDRA
	ERN.19d	Text	Alphanumeric (max char.)	Free text
	ERN.77	Notes on the lab finding (obs values/dates, etc.)	Alphanumeric (max char.)	Free text
Episode Description Imaging Findings	ERN.20	Imaging Findings	Multi-select Checkboxes	ICD-10-PCS Free text Attachment
	ERN.20a1	ICD-10-PCS	Auto-complete	ICD-10-PCS
	ERN.20d	Text	Alphanumeric (max char.)	Free text
	ERN.78	Notes on the imaging finding (obs values/dates, etc.)	Alphanumeric (max char.)	Free text

Episode Description Other Findings	ERN.21	Other Findings	Alphanumeric (max. char.) + poss attachment	Free text
	ERN.79	Notes on the other finding (obs values/dates, etc.)	Alphanumeric (max char.)	Free text
	ERN.22d	Text	Alphanumeric (max char.)	Free text
Episode Description Clinical Trial Participation	ERN.56	Previous clinical trial participation	Alphanumeric (max char.)	Free text
Episode Description Other Information	ERN.22	Other Information	Multi-select Checkboxes	LOINC Free text Attachment
	ERN.22e	LOINC	Auto-complete	LOINC
	ERN.22d	Text	Alphanumeric (max char.)	Free text
Rare Disease Diagnosis	RD8.2	Search All Coding Systems	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers, based on ICD-O-3) Other	Autopopulated based on code selected, dropdown + free text
	RD8.2	Diagnostic Coding System	Multi-select checkboxes	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers) Other - free text description below
	RD8.2a	ICD-10 classification	Auto-complete	ICD-10
	RD8.2b	ICCC-3 Diagnostic Group	Auto-complete	ICCC-3
	RD8.2bi	ICCC-3 Histology/Morphology	Auto-complete	ICCC-3
	RD8.2bii	ICCC-3 Topography	Auto-complete	ICCC-3
	RD8.2c	Orphanet nomenclature	Auto-complete	ORDO
	RD8.1d	Other	Alphanumeric (max. char.)	Free text
	RD8.4	Date of first symptoms onset	Day/Month/Year Loose	Calendar
	RD8.4a	Age at first symptoms onset	Auto calculated [RD8.4 Date of first symptoms onset] - [PS1.3 Date of Birth] (editable)	Prenatal; XX years, XX months
	RD8.6	Date of current diagnosis	Day/Month/Year Loose	Calendar
	PO2.4	Age at diagnosis	Auto calculated [RD8.6 Date of current diagnosis] - [PS1.3 Date of Birth]	Prenatal; XX years, XX months

			(editable)	
	RD8.7	Status of current diagnosis	Drop-down	Active/In Remission / Resolved / Relapsed / Other
	RD8.7a	Other	Alphanumeric (max.char.)	Free Text
	RD8.9.1	Diagnosis Provider	Radio	ERN member; Affiliated; Non-ERN member
	RD8.9.1a	ERN member healthcare provider	Auto-complete	List of ERN HCPs
	RD8.9.1b	Affiliated healthcare provider	Auto-complete	List of Affiliated HCPs. If none exist, free text
	RD8.9.1c	Non-ERN member healthcare provider	Alphanumeric	Free text
	RD8.9.3	Country of diagnosing Healthcare Provider	Autocomplete	ISO 3166 country codes or auto-populate based on answer to RD8.9.1a or RD8.9.1b
	RD8.9.2	Treatment Healthcare Provider	Drop-down	ERN member; Affiliated; Non-ERN member
	RD8.9.2a	ERN member healthcare provider	Auto-complete	List of ERN HCPs
	RD8.9.2b	Affiliated healthcare provider	Auto-complete	List of Affiliated HCPs
	RD8.9.2c	Non-ERN member healthcare provider	Alphanumeric (max. char. 500)	Free text
	PS18.1	Diagnostic Test	Multi-select checkboxes	LOINC Free text
	PS18.1a	LOINC	Auto-complete	LOINC
	PS18.1d	Text	Alphanumeric (max. char.)	Free text
	PS18.2	Date of observation	Day/Month/Year Loose	Calendar
	ERN.24	Result	Attachment	
Rare Disease Diagnosis Working Diagnosis	RD8.22	Search All Coding Systems	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers, based on ICD-O-3) Other	Autopopulated based on code selected, dropdown + free text
	RD8.22	Diagnosis coding system	Multi-select Checkboxes	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers) Other - free text description below
	RD8.22a	ICD-10 Classification	Auto-complete	ICD-10

	RD8.22b	ICCC-3 Diagnostic Group	Auto-complete	ICCC-3
	RD8.22bi	ICCC-3 Histology/Morphology	Auto-complete	ICCC-3
	RD8.22bii	ICCC-3 topography	Auto-complete	ICCC-3
	RD8.22c	Orphanet nomenclature	Auto-complete	ORDO
	RD8.12d	Other	Alphanumeric (max.char.)	Free Text
	RD8.42	Date of working diagnosis	Day/Month/Year/Loose	Calendar
	ERN.242	Result	Attachment	
Rare Disease Diagnosis Differential Diagnosis (Repeatable section nested within Working Diagnosis)	RD8.23	Search All Coding Systems	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers, based on ICD-O-3) Other	Autopopulated based on code selected, dropdown + free text
	RD8.23	Diagnosis coding system	Multi-select Checkboxes	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers) Other - free text description below
	RD8.23a	ICD-10 Classification	Auto-complete	ICD-10
	RD8.23b	ICCC-3 Diagnostic Group	Auto-complete	ICCC-3
	RD8.23bi	ICCC-3 Histology/Morphology	Auto-complete	ICCC-3
	RD8.23bii	ICCC-3 topography	Auto-complete	ICCC-3
	RD8.23c	Orphanet nomenclature	Auto-complete	ORDO
	RD8.13d	Other	Alphanumeric (max.char.)	Free Text
	RD8.43	Date of differential diagnosis	Day/Month/Year/Loose	Calendar
	RD8.44	Elimination Process	Alphanumeric (max.char)	Free Text
	ERN.243	Result	Attachment	
Comorbidities (repeatable section)	RD8.4	Search All Coding Systems	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers, based on ICD-O-3) Other	Autopopulated based on code selected, dropdown + free text
	PS11.4	Diagnosis coding system	Multi-select Checkboxes	Orphanet List of rare diseases ICD10 List of diseases ICCC-3 (childhood cancers) Other - free text description below

	RD8.24a	ICD-10 classification	Auto-complete	ICD-10
	RD8.24b	ICCC-3 Diagnostic Group	Auto-complete	ICCC-3
	RD8.24bi	ICCC-3 Histology/Morphology	Auto-complete	ICCC-3
	RD8.24bii	ICCC-3 Topography	Auto-complete	ICCC-3
	RD8.24c	Orphanet nomenclature	Auto-complete	LOINC
	RD8.14d	Other	Alphanumeric (max. char.)	Free-text
	RD8.64	Date of Diagnosis	Day/Month/Year Loose	Calendar
	RD8.74	Status of diagnosis	Multi-Select Checkboxes	Active/In Remission / Resolved / Relapsed / Other
	RD8.74a	Other	Alphanumeric (max. char.)	Free-text
Phenotype and Genetic Features and Biobanks (repeatable section)	ERN.65	Genetic study performed	LOINC Alphanumeric	Auto-complete Free text
	ERN.65a	LOINC	Auto-complete	LOINC
	ERN.65d	Text	Alphanumeric (max. char.)	Free text
	RD10.1	Gene affected	Multi-Select Checkboxes	OMIM HGNC symbols Free text
	RD10.1a	HGNC symbols	Auto-complete	HGNC
	RD10.1d	Text	Alphanumeric (max. char.)	Free text
	ERN.58	DNA variant	Drop-down	Substitution Deletion Duplication Insertion Inversion Conversion Deletion-insertion Alleles Repeated sequences Complex (hgvs/iscn)
	RD10.4	DNA Nucleotide reference sequence (RefSeq id/LRG id)	Auto-complete	Coded element: NCBI genomic nucleotide RefSeq Id/LRG Id
	RD10.5	DNA Nucleotide variant description	Alphanumeric (max. char.)	Free text
	ERN.66	RNA Variant	Drop-down	Substitution Deletion

				Duplication Insertion Inversion Conversion Deletion-insertion Alleles Repeated sequences Splicing
ERN.68	RNA Nucleotide reference sequence (LRG id)	Auto-complete	Coded element: NCBI genomic nucleotide RefSeq Id/LRG Id	
ERN.67	RNA Nucleotide variant description	Alphanumeric (max. char.)	Free text	
ERN.59	Protein Variant	Drop-down	Substitution Deletion Duplication Insertion Deletion-Insertion Alleles Repeated sequences Frame shift Extension	
ERN.70	Protein sequence (RefSeq id/LRG id)	Auto-complete	Coded element: NCBI genomic nucleotide RefSeq Id/LRG Id	
ERN.69	Protein variant description	Alphanumeric (max. char.)	Free text	
ECRF.6	Phenotypic Abnormality (HPO)	Auto-complete	Human Phenotype Ontology vocabulary (HPO)	
ERN.71	Other changes: e.g. DNA methylation	Alphanumeric (max. char.)	Free text	
ERN.57	Allelic State	Drop-down	LOINC "preferred answer list" for the allelic state: Heteroplasmic; Homoplasmic; Homozygous; Heterozygous; Hemizygous	
ERN.73	Somatic Mutation as included in COSMIC	Alphanumeric (max. char.)	Free text	
ERN.60	Specimens stored at biobank	Alphanumeric (max. char.)	Free text	
ERN.72	Biobank details	Alphanumeric (max. char.)	Free text	

Family History	EPI.2	Consanguineous Parents?	Radio	Yes/No/Unkown
	RD9.3	Healthy carriers in the family?	Radio	Yes/No/Unkown
	EPI.3	If Yes – kinship of Carrier	Drop-down	Do not know None Brother Daughter Father Granddaughter Grandson Half Brother Half Sister Maternal Aunt Maternal Cousin Maternal Grandfather Maternal Grandmother Maternal Uncle Nephew Niece Paternal Aunt Paternal Cousin Paternal Grandfather Paternal Grandmother Paternal Uncle Sister Son
	RD9.1	Other cases in the family?	Radio	Yes/No/Unkown
	EPI.4	If Yes – kinship of Carrier	Drop-down	Do not know None Brother Daughter Father Granddaughter Grandson Half Brother Half Sister Maternal Aunt Maternal Cousin Maternal Grandfather

				Maternal Grandmother Maternal Uncle Nephew Niece Paternal Aunt Paternal Cousin Paternal Grandfather Paternal Grandmother Paternal Uncle Sister Son
Health Behaviours	PS15.1a	Tobacco or nicotine	Radio	Current/ Former/ Exposure (environmental, occupational)/ Never
	ERN.25a	Frequency	Radio	Daily; Occasionally
	ERN.25	Please specify	Alphanumeric (500 char)	Free-text
	PS 15.1b	Drug use	Radio	Yes/No
	ERN.26	Please specify	Alphanumeric (500 char)	Free text
	PS 15.1c	Alcohol use	Radio	Yes/No
	ERN.27	Please specify	Drop-down	Daily; Weekly; Less than Monthly; Monthly; No longer
Allergies and Other Adverse Reactions (repeatable section)	ECRF.2	Category	Drop-down	Environment/ Food/ Medication/ Other
	PS5.1	Allergy Display Name	Auto-complete and Alphanumeric (max char)	ATC Free text
	PS5.1a	If not ATC	Alphanumeric (500 char)	Free-text
	ECRF.3	Please Specify	Alphanumeric (500 char)	Free-text
	ECRF.1	Status	Radio	Active; Inactive; Resolved; Confirmed; Unconfirmed
	PS5.3	Date of Allergy Onset	Day/Month/Year Loose	Calendar
	ECRF.4	Date of Last Occurrence	Day/Month/Year Loose	Calendar
	RE12.2.9.2	Adverse effects	Auto-complete	MedDRA
	ECRF.5	Manifestation	Alphanumeric (max char)	Free text
	PS7.2	Past illness and disorder (ICD-10)	Auto-complete	ICD-10
	PS7.1	Description	Alphanumeric (max char)	Free text

History of Past Illness and Disorders (repeatable section)	PS7.3	Date of Onset	Day/Month/Year Loose	Calendar
	PS7.4	End date	Day/Month/Year Loose	Calendar
Special Treatment and Intervention (e.g. Diet; Blood Transfusions, etc.) (repeatable section)	ERN.61	Special Treatment	Radiation therapy; Chemotherapy; Immunotherapy; Targeted Therapy; Hormone Therapy; Stem Cell Transplant; Precision Medicine; Diet; Blood transfusions; Other	Dropdown
	ERN.62	Special Treatment - Other	Alphanumeric (max char)	Free text
	ERN.63	Comments/Notes	Alphanumeric (max. char.) + possible attachment	Free text Attachment
Surgical Procedures (repeatable section)	PS9.1	Surgical Procedure Description	Alphanumeric (max. char.)	Free text
	PS9.3	Date of surgical procedure	Day/Month/Year Loose	Calendar
Transplantation History (repeatable section)	RD16.3	Transplant Material	Alphanumeric (max. char.)	Free text
	ERN.28	Transplant Material Description	Alphanumeric (max. char.)	Free text
	RD16.2	Date of transplant	Day/Month/Year Loose	Calendar
Medication (repeatable section)	RD13	Is the patient receiving medication for his/her rare disease?	Radio	Yes/No
	ERN.29	Medication for Rare Disease Description	Text Box	Text box
	PS19.2	Active Ingredient (ATC)	Auto-complete	ATC
	PS19.2a	If not ATC	Alphanumeric (500 char)	Free-text
	PS19.3	Strength	Alphanumeric (500 char)	Free-text
	PS19.4	Type of unit	Drop-down	UCUM code system
	PS19.5	Frequency of intake	Alphanumeric (max. char. 500)	Free text
	PS19.6a	Start Date	Day/Month/Year/Loose	Calendar
	PS19.6b	End Date	Day/Month/Year/Loose	Calendar
	PS19.6	Duration of treatment	Alphanumeric (max. char. 500)	Free text
PS19.8	Pharmaceutical Dose Form	Drop-down	EDQM	

	ERN.43	Medication compliance	Radio	Compromised execution (patients who are actively engaged in therapy, but use medication inconsistent with provider instructions, i.e. skipping dosages and splitting pills); Discontinuation (occurs when a patient stops taking a prescription too early); Primary non-adherence (occurs when patient does not obtain prescribed medication)
	RD132	Is the patient following any other medication?	Radio	Yes/no
	PS19.22	Active Ingredient (ATC)	Auto-complete	ATC
	PS19.22a	If not ATC	Alphanumeric (500 char)	Free-text
	PS19.32	Strength	Alphanumeric (500 char)	Free-text
	PS19.42	Type of unit	Drop-down	UCUM code system
	PS19.52	Frequency of intake	Alphanumeric (max. char. 500)	Free text
	PS19.62a	Start Date	Day/Month/Year/Loose	Calendar
	PS19.62b	End Date	Day/Month/Year/Loose	Calendar
	PS19.62	Duration of treatment	Alphanumeric (max. char. 500)	Free text
	PS19.82	Pharmaceutical Dose Form	Drop-down	EDQM
	ERN.432	Medication compliance	Radio	Compromised execution (patients who are actively engaged in therapy, but use medication inconsistent with provider instructions, i.e. skipping dosages and splitting pills); Discontinuation (occurs when a patient stops taking a prescription too early);

				Primary non-adherence (occurs when patient does not obtain prescribed medication)
Others (general comment)	ERN.89	Comment	Alphanumeric (max.char.)	Free-text

4 Data Collection & Coding Systems v.6

The data model running onto the CPMS conforms to European standards, nomenclatures and strategies to share health data syntactically and semantically in the eHealth sector, in particular the eHealth Action Plan and international standards.

All ERNs will be using one generic data set known as the Common Data Elements in the CPMS. Then, further in the development process of the CPMS, a dataset will be developed based on the customised need of each ERN. It highly expected that each ERN will have unique requirements for each single condition or specific thematic disease area. Notably, the Common Data Elements allow users to add attachments and view images in a DICOM viewer. The table below lists all the coding systems and terminology classification used to build the consultation form in the CPMS.

Code system	SDO/Maintenance organisation	Scope	Release format	Conditions of use/ downloadable at	Frequency of updates	Version used in CPMS
ATC Classification System	WHO	Classifies active substances into different groups according to the organ or system on which they act and their therapeutic, pharmacological, and chemical properties	Excel, XML, and ASCII format	ATC classification index with DDD in electronic format: https://www.whocc.no/atc_ddd_index/	Annually (January)	January 2017
EDQM Standard Terms	European Directorate for the Quality of Medicines and Healthcare (EDQM) – Council of Europe	Controlled vocabularies for pharmaceutical dose forms; routes or methods of administration; and containers, closures, and delivery devices	As of March 2016, APIs have been introduced to allow authorised users to access and download Standard Terms	EDQM Standard Terms Database is reproduced with the permission of the European Directorate for the Quality of Medicines & Healthcare, Council of Europe (EDQM). The EDQM Standard Terms database is not a static list and content can change over time: https://stand-ardterms.edqm.eu/user/login?_next=#	As requested from regulators, EMA and EC	Version 1.0.0 – 2014-11-14
Eurostat classification for self-defined current economic status	Eurostat	Classification for self-defined current economic status. The most frequent activity status is the status that individuals declare themselves to have occupied for more than half the total number of months for which information on any status is available	TXT	http://ec.europa.eu/eurostat/statistics-explained/index.php/EU_statistics_on_income_and_living_conditions_(EU-SILC)_methodology_-_definition_of_dimensions#Self-defined_current_economic_status	-	Accessed August 2017
HGNC	HUGO Gene Nomenclature Committee	HGNC database includes unique symbols and names for human loci, including protein coding genes, ncRNA genes and pseudogenes, to allow unambiguous scientific communication	TXT and JSON format available	Terms of Use reflect EMBL-EBI's commitment to OpenScience through its mission to provide freely available online services, databases and software relating to data contributed from life science experiments to the largest possible community. They impose no additional constraints on the use of the contributed data than those provided by the data owner. https://www.genenames.org/cgi-bin/statistics	Daily	Accessed 2018-07-17
HPO	Charité Berlin and the Monach Institute	The Human Phenotype Ontology (HPO) aims to provide a standardized vocabulary of phenotypic abnormalities encountered in human disease	OWL and OBO	http://purl.obolibrary.org/obo/hp.owl http://purl.obolibrary.org/obo/hp.obo	Approx. two monthly. http://www.humanphenotypeontology.org	Version: 2018-06-13
ICCC-3 based on ICD-O-3	WHO	The classification of childhood cancer is based on tumour morphology and primary site with an emphasis on morphology rather than the emphasis on primary site for adults	CSV	Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, Third Edition. <i>Cancer</i> 2005; 103: 1457-67	Infrequent: last update 2011	ICCC-3, Main classification 2011
ICD-10	WHO IARC	International Statistical Classification of Diseases and Related Health Problems (10 th revision)	ClaML	Licence FAQ: http://www.who.int/about/licensing/Intetext_FAQ.pdf . Available upon registration at: http://apps.who.int/classifications/apps/icd/Classifi	Annually (January)	ICD-10

Code system	SDO/Maintenance organisation	Scope	Release format	Conditions of use/ downloadable at	Frequency of updates	Version used in CPMS
				cationDownloadNR/login.aspx?ReturnUrl=%2fclassifications%2fapps%2fid%2fClassificationDownload%2fdefault.aspx		
ICD-10-PCS	Centers for Medicare & Medicaid Services (CMS)	A procedure classification published by the US for classifying procedures performed in hospital inpatient healthcare settings	XML	https://www.cms.gov/Medicare/Coding/ICD10/2019-ICD-10-PCS.html	Annually (October)	2019
ISCED	Eurostat	ISCED is the reference international classification for organising education programmes and related qualifications by levels and fields	TXT	http://ec.europa.eu/eurostat/statistics-explained/index.php?title=Glossary:International_standard_classification_of_education_(ISCED)	-	ISCED 2011
ISCO	International Labour Organization (ILO)	International Standard Classification of Occupations (member of the International Family of Economic and Social Classifications)	XLSX	ISCO -08 structure and definitions available for download at: http://www.ilo.org/public/english/bureau/stat/isco/isco08/index.htm	-	ISCO-08, adopted December 2007
ISO 3166-1	ISO 3166 Maintenance Agency	International Standard for country codes and their dependent territories, and special areas of geographical interest	XML, CSV, XLS	https://www.iso.org/iso-3166-country-codes.html	Maximum 5-yearly updates	Accessed August 2017
LOINC	Regenstrief Institute, Inc.	Provides a set of universal names and codes for identifying laboratory and clinical test results, facilitating the exchange and pooling of results (e.g., blood haemoglobin, serum potassium), or vital signs, for clinical care, outcome management, and research	CSV / Microsoft Access	LOINC Codes, LOINC Table (regardless of format), LOINC Release Notes, LOINC Changes File, and LOINC User's Guide are copyright (c) 1995-2018 of the Regenstrief Institute, Inc. and the Logical Observation Identifiers Names and Codes (LOINC) Committee. The LOINC panels and forms file; LOINC document ontology file; and the LOINC hierarchies, LOINC linguistic variants files, LOINC/RSNA Radiology Playbook, and LOINC/IEEE Medical Device Code Mapping Table (all subject to the copyright above with respect to the LOINC Codes and LOINC Table) are copyright (c) 1995-2018 of the Regenstrief Institute Inc. All these Licensed Materials are granted permission in perpetuity to be used, copied, or distributed without payment of license fees or royalties, for any commercial or non-commercial purpose, subject to the terms and conditions specified in the Copyright Notice and License. First, using LOINC Codes and Table should not pursue the development or promulgation of a different standard that will dilute the purpose of LOINC, i.e. providing a definite standard for identifying clinical information in electronic reports. Users are also required to include a specific notice (see Section 9 of the LOINC Copyright Notice and License for the text). https://loinc.org/downloads/	Twice per year (June and December)	2.64, 2018-06-15
MedDRA	ICH MedDRA	A standardised international medical	ASCII	The CPMS avails from MedDRA free of charge as	Twice per year	21.0, March 2018.

Code system	SDO/Maintenance organisation	Scope	Release format	Conditions of use/ downloadable at	Frequency of updates	Version used in CPMS
	Maintenance and Support Services Organization (MSSO)	terminology which can be used for regulatory communication and evaluation of data pertaining to medicinal products for human use		it was provided though the EC as a regulatory authority eligible to receive MedDRA at no charge	(March and September)	
NCBI genomic nucleotide RefSeq Id/LRG Id	NCBI	A comprehensive, integrated, non-redundant, well-annotated set of reference sequences including genomic, transcript, and protein	TSV	ftp://ftp.ncbi.nlm.nih.gov/refseq/H_sapiens/RefSeqGene/LRG_RefSeqGene	Weekly	Accessed 2018-07-17
Orphanet Rare Disease Ontology (ORDO)	Orphanet	A structured vocabulary for rare diseases capturing relationships between diseases, genes and other relevant features	OWL and OBO format. Beta version of SPARQL Endpoint available	Creative Commons Attribution-NoDerivs Licence. Databases free to copy, distribute, display and make commercial use of in all legislations, provided credit is given. However, permission is required if it is intended to distribute a modified version. Orphadata: http://www.orphadata.org/cgi-bin/inc/ordo_orphanet.inc.php	Monthly	2.6, accessed 2018-07-17
UCUM	Regenstrief Institute, Inc./ BfArM	Code system intended to include all units of measure used in Science, Engineering and businesses	BfArM will provide UCUM codes, via an API, in the context of the ISO IDMP implementation	The UCUM Codes, UCUM table (regardless of format), and UCUM Specification are copyright (c) 1999-2009 of the Regenstrief Institute, Inc. and the Unified Codes for Units of Measures (UCUM) Organization. The use of those Licensed Materials is permitted in perpetuity, without any payment of license fees or royalties provided that the terms and conditions specified are followed. Users shall not use them with the aim of developing or promulgating a different standard for identifying the units of measure. Additionally, the Licensed Materials cannot be modified by the users neither can the users distribute modified versions of the UCUM Table or the UCUM Specifications: http://unitsof-measure.org/trac/wiki/TermsOfUse	New terms provided on demand via EMA (EU ISO IDMP implementation operating model) ¹	Version: 2.0.1, Revision: 438