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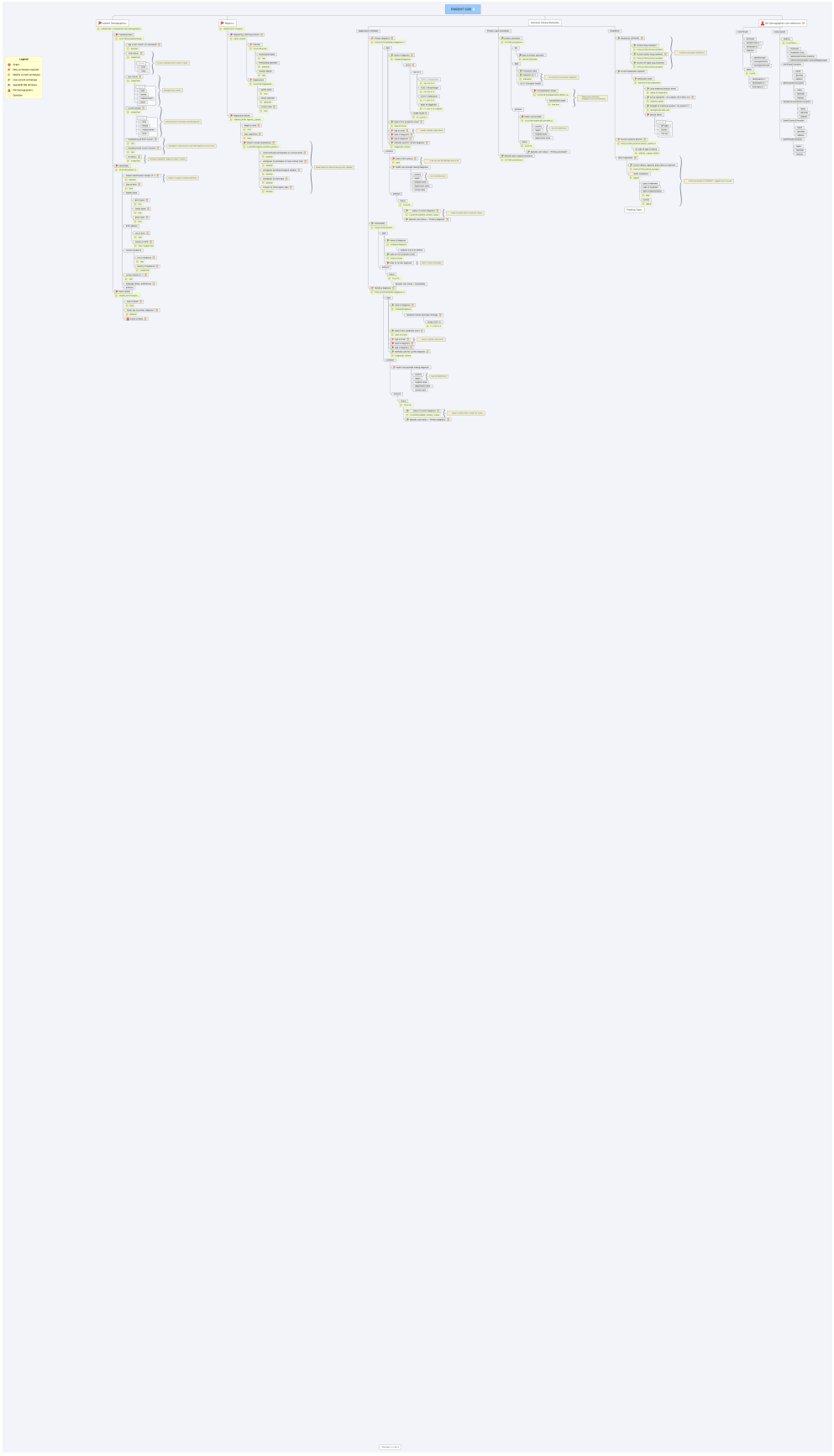
PARENT CODE
Legend
Start
Begin by collapse class list
Identify current workspace
Use current workflow
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Edit Demographics
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1. patient Demographics

1.1. Pseudonymised

1.1.1. Age at last contact (or calculated)

1.1.2. "Vital status"

Alive

Dead

1.1.3. Sex at birth

male

female

undetermined

other

1.1.4. Current Gender

male

female

undetermined

other

1.1.5. Pseudonmyised Birth location

1.1.6. Pseudonymised Current location

1.1.7. Is Foetus?

1.2. Identifiable

1.2.1. Patient identification number [0..*]

1.2.2. Date of birth

1.2.3. Patient name

Birth Name

Family Name

given name

1.2.4. Birth address

city of birth

country of birth

1.2.5. Current residence

city of residence

country of residence

1.2.6. contact details [0..*]

1.2.7. language needs / preferences

1.2.8. ethnicity

1.3. Death details

1.3.1. Date of death

1.3.2. Death due to primary diagnosis?

1.3.3. Cause of death

2. Registry

2.1. Registering /referring clinician

2.1.1. Clinician

Professional Name

Professional identifier

Contact details

2.1.2. Organisation

Centre name

Centre Identifier

Contact data

2.2. Registration details

2.2.1. Registry name

2.2.2. Date registered

2.2.3. Patient Consent preferences

curent and past participation in a clinical trials

willingness to parcitipate in future clinical trials

willingness donating biological samples

willingness to share data

Consent to store registry data

3. Common Clinical Elements

3.1. Diagnosis/co-morbidity

3.1.1. Primary diagnosis

data

name of diagnosis

ENCR

ICD-O-3

ICDO-3 Topography•

ICDO-3 Morphology•

ICD-O-3 Behaviour•

Basis of diagnosis•

Grade (ICDO-3)

Date of first symptoms onset

Age at onset

Date of diagnosis

Age at diagnosis

methods used for current diagnosis

protocol

Date of first contact

health care provider making diagnosis

country

region

hospital name

department name

contact data

protocol

status

status of current diagnosis

Episodic care status = "Primary diagnosis"

3.1.2. Comorbidity

data

name of diagnosis

codelist: ICD10 or ORPHA

Date of first symptoms onset

Date of current diagnosis

protocol

status

Episodic care status = Comorbidity

3.1.3. Tentative diagnosis

data

name of diagnosis

Orphanet Human phentype Ontology

Grade (ICDO-3)

Date of first symptoms onset

Age at onset

Date of diagnosis

Age at diagnosis

methods used for current diagnosis

protocol

health care provider making diagnosis

country

region

hospital name

department name

contact data

protocol

status

status of current diagnosis

Episodic care status = "Primary diagnosis"

3.2. Primary / past procedures

3.2.1. primary procedure

RM

date of primary operation

data

Procedure name

Indication [0..*]

SLOT: Procedure Details

Transplantation details

Transplanted organ

protocol

health care provider

country

region

hospital name

department name

status

Episodic care status = "Primary procedure"

3.2.2. Relevant past surgical procedure

RM

date of primary operation

data

Procedure name

Indication [0..*]

SLOT: Procedure Details

protocol

health care provider

country

region

hospital name

department name

status

3.3. Treatments

3.3.1. Medication (EPIRARE)

Current drug treatment

Current orphan drug treatment

Current off-label drug treatment

3.3.2. Current Medication (epSOS)

Medication order

Local medicinal product brand

Active ingredient :: DV_CODED_TEXT:WHO ATC

Strength of medicinal product:: DV_QUANTITY

Special Status

Off-label

Orphan

Trial use

3.3.3. Current assistive devices

ID code of type of device

3.3.4. Other treatments

Current dietary regimens prescribed as treatment

type of regimen

Other treatments

type of treatment

code of treatment

date of administration

current

4. ISA Demographics (for reference)

4.1. Core Person

4.1.1. BirthDate

4.1.2. GenderCode 0..*

4.1.3. DeathDate 0..*

4.1.4. Identifier

IdentifierType

IssuingAuthority

IssuingAuthorityID

4.1.5. Name

FamilyName 0..*

GivenName 0..*

BirthName 0..*

4.2. CoreLocation

4.2.1. Address

PostCode

PostName (City)

AdminUnitFirstline (Country)

AdminunitSecondline (county/Region/state)

4.2.2. BirthPlaceCvlocation

Name

Identifier

Address

4.2.3. BirthCountryCvLocation

Name

Identifier

Address

4.2.4. ResidenceJurisdiction (location)

Name

Identifier

Address

4.2.5. DeathCountryCvlocation

Name

Identifier

Address

4.2.6. DeathPlaceCvlocation

Name

Identifier

Address