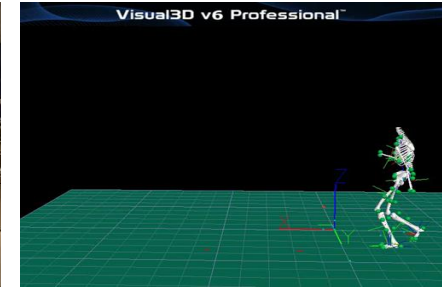


# How can RD-Code meet your needs?

Hospital Sant Joan de Déu de Barcelona

30 november 2021

[roser.francisco@sjd.es](mailto:roser.francisco@sjd.es)



# Many RD Reference Units

Benefits

Obligations



Periodic Data  
activity reports and  
Registry participation

Hospital RD  
Tranversal Task  
Force



## Our first Objective

### ✓ **SJD Rare Diseases Registry**

**Main Objective:** to know the number of patients diagnose of a RD attended at SJD.

#### Secondary Objectives:

- **Implement ORPHAcoding** into the local hospital information system
- **Facilitate the complementation of other mandatory notification registries** (CatSalut, MSCBS, CE, etc.)
- **Identify RD patients without a diagnosis with an orphan code** (“Syndromes Without A Name” or **SWAN**)
- **Define Common Data Elements (CDEs):** required to ensure that data is defined in the same way, uses the same standards and terminologies and we always use the same code equivalence tables.
- **Define monitoring indicators**



Catalog

# Catalog

## SJD RD Catalog

- ✓ Pediatric Diseases
- ✓ Only one way to name a RD (no synonyms, no different languages)
- ✓ “Custom” descriptions



Descriptive / Literal	Internal Code	Orpha number	ICD-10 CM code
Literally assigned by professionals and the registry Task Force TEAM	No visible	Orphadata	Assigned by the clinical documentation service with the help of the RD-CODE MF



It maintains  
interoperability  
with local and  
national  
administrations

## Where to start?

Thousands of RD



Groups of RD  
diseases



Nomenclature and  
Classification of RD

orphan<sup>data</sup>



## Where to start?

Nomenclature and  
Classification of RD

orphadata



By classifications, the  
list of RDs was  
reviewed by clinicians of  
each Unit/ Service





**Gemma Gelabert Colome**  
Disponible para las 8 horas siguientes  
CAP DOCUMENTACIO CLINICA, DOCUMENTACIO CLINICA I AR...  
Agregar ...



**Fernando Cid Samper**  
Disponible para las 8 horas siguientes  
TECNIC/A SUPERIOR, DIR. QUALITAT I EXPERIENCIA DEL P...  
Agregar ...

## Harmonized Criteria

- Decision making rules:
  - Only peadiatric RD
  - Only RD with patients in SJD
- No duplicates allowed
- When needed, description adaptation of the Orpha num. (SOP)



## Where to start?

Nomenclature and  
Classification of RD

orphadata



By classifications, the  
list of RDs was  
reviewed by clinicians of  
each Unit/ Service





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SJD RD Catalog



> 5000 RD

# Catalog

## SJD RD Catalog

- ✓ Pediatric Diseases
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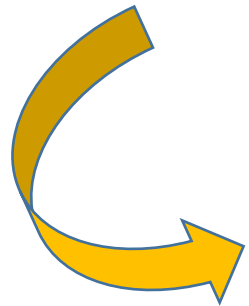
Descriptive / Literal	Internal Code	Orpha number	ICD-10 CM code
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It maintains interoperability with local and national administrations

# Catalog

- 27 lists
- > 45 clinicians
- Near 5.000 entities



**Duplication depuration  
SWAN Selection (SOP)**

LISTADO	ENTIDADES	ORPHA	CIM10-MC	SWAN
IDP	476	212	86	2
NEURO CUT	52	52	38	1
URO	36	36	35	1
NEFRO	116	112	83	4
AIS/AIF	119	118	91	11
ALER	4	4	6	1
HEMATO	143	142	90	10
NEUROMUS				
C	115	115	64	22
HEMATO_O				
NC	100	100	75	5
INFEC	150	140	152	6
MCC	364	325	59	4
ORL	125	125	86	8
OFT	289	282	185	21
GAST	270	255	185	4
CRANIO	147	138	78	5
RESP	103	95	91	5
OSS	181	181	111	2
END	303	300	165	26
ATA	184	180	54	16
NEUIMM	48	41	33	1
VASC	45	45	33	4
CARDIO	210	208	110	6
EPI	185	117		4
TUMOR	224	92		0
MALF	431	431		6
METAB	187	185		3
DERMA	468	454		24



New Functionality in our Electronic  
Health Record (EHR)



# EHR



Alertes

Història Clínica

Informe: 116369611  
Especialitats: REUMATOLOGIA  
Procedència: Servei HSJD  
Hospital: Hospital Sant Joan de Déu

Motiu de Consulta:

Antecedents:

Malalties familiars:

Antecedents personals:

Antecedents obstètrics i quirúrgics:

Antecedents perinatals: ☐ Apareix en l'informe  
Alimentació: ☐ Apareix en l'informe  
Desenvolupament Psicomotor: ☐ Apareix en l'informe

Al·lèrgies:  
Llista d'al·lèrgies: ☒ El pacient té al·lèrgies

Antecedents Patològics Prevalents

Enfermedades Previs

Antecedents perinatals  
D'interès per a programació quirúrgica  
Patologia CARDIOVASCULAR  
Patologia DERMATOLÒGICA  
Patologia DIGESTIVA  
Patologia ENDOCRINOLÒGICA  
Patologia GENÈTICA

Creación de un antecedente patológico

Dades de l'antecedent

Pacient: 1631821 PONCE CHILLIDA, SAILA

Contingut: Immunodeficiència combinada greu per deficiència de LC

Observacions:

Tipus: Enfermedades previas  
Importància: Major  
Estat: Actiu ☒ Inactiu ☐  
I. rellevant ☒  
Observacions informe ☒  
Data fi:

Tipus: Enfermedades previas  
Importància: Major  
Estat: Actiu ☒ Inactiu ☐  
I. rellevant ☒  
Observacions informe ☒  
Data fi:

Codificació: L20.89 Dermatitis atópica

Descripció

Enfermedades previas

Immunodeficiència combinada greu per deficiència de LC

Dermatitis atópica

Guardar Guardar y salir Netejar Salir

Guardar Guardar y salir Sortir Generar Informe

Qualsevol diagnòstic que correspongui a una malaltia minoritària quedarà marcat amb aquest símbol.

Després de guardar el registre, el diagnòstic apareixerà com a antecedent personal i al panell d'informació rellevant (si s'ha seleccionat)



The Pilot. November 2021

# Validation and implementation

Phase 1: PILOT *Novembre 2021*

4 Units/ Services

- First release
  - ✓ PIM
  - ✓ Kidney
  - ✓ Urology
  - ✓ Neurocutaneous diseases



# Catalog




680 different entities

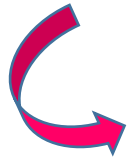


Unit/ Service	PID	KIDNEY	NECU	URO
N. Entities	476	116	52	36
Orpha	212	112	52	36
SWAN	2	4	2	2
ICD-10-MC	86	83	38	35

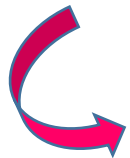


## Pilot results (4 weeks)

- 67/ 680 codes used
- The RD ICONE facilitates the identification of RD 
- > 20 users (clinicians)
- The 4 Units have participated and have value it very well



Improvement areas have been identify



RD Search in the application

## Phase 2

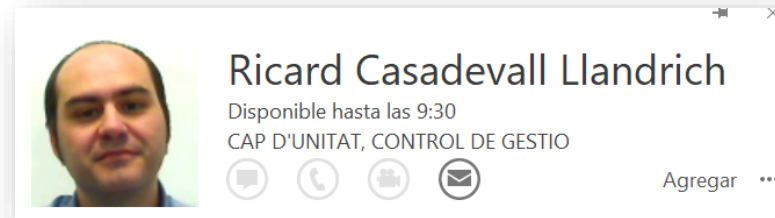
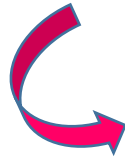
**Complete Catalog** *February 2022*

- User Manual (published in the hospital intranet)
- Communication plan (intranet, formative sessions, etc., videos, etc.)



## Next steps

- *Catalog maintenance*
- *DASHBOARD for case consultations*



- **Facilitate the complementation of other mandatory notification registries** (CatSalut, MSCBS, CE, etc.)
- **Define Common Data Elements of Records (CDEs):** required to ensure that data is defined in the same way, uses the same standards and terminologies and we always use the same code equivalence tables.
- **Define monitoring indicators**

Gràcies!!!