Update on JRC's recent health information activities in cancer and rare diseases

Commission's Expert Group on Health Indicators

Luxembourg, 06 December 2016
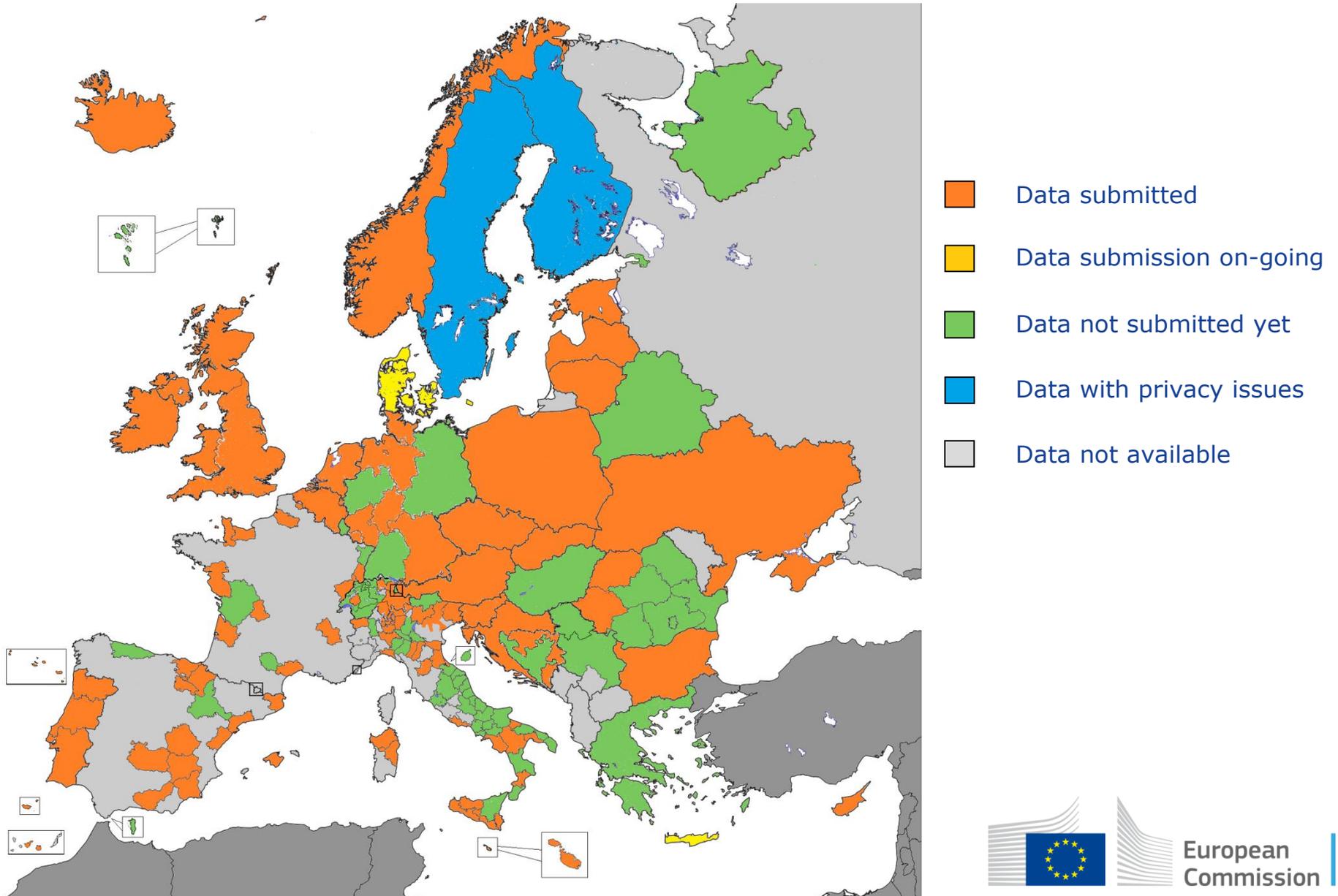
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Directorate for Health, Consumers and Reference Materials

Joint Research Centre

Cancer information - update

14 Jul Version 1.6.5 release of CR data-quality check software to European cancer registries (all cross-variable checks and multiple-primary rules)

28 Oct Involvement at EMA workshop on patient registries

20 Sep PANCREOS network working group meeting on data-collection protocol (collaboration between clinical and population-based registries)

5-7 Oct Organisation and hosting of the General Assembly of the European Network of Cancer Registries, including training seminar

13-14 Oct Presentation at International Association of Cancer Registries (IACR) of preliminary assessment on submitted CR data quality

11 Nov Dedicated workshop on ***The Role Of The JRC In Supporting and Harmonizing Cancer Data Collection*** within the EPH 2016 conference, Vienna

25 Nov Version 1.7.1 release of data-quality check software with bugs corrections following collected feedback

European Commission

Cancer Registries – update on status of 2016 data submission November 2016

Legend:
- Data submitted
- Data submission on-going
- Data not submitted yet
- Data with privacy issues
- Data not available

European Commission

The ENCR-JRC Project

**112 CRs
from 29
European countries**

Area	N. cancer registries	N. cases	%
Western Europe	30	7,962,316	34.0
Eastern Europe	5	3,662,454	15.6
Northern Europe	10	8,461,220	36.1
Southern Europe	33	3,345,138	14.3

**more than 23,500,000 records
so far in the database**

European Network for the Surveillance of Congenital Anomalies (EUROCAT)

Feb and Oct

2016 Data collection for newborns in 2014 and previous years updates at JRC-EUROCAT Central Registry

15-17 June

Organisation and hosting of:
- Annual Registries' Leader Meeting of EUROCAT, including training seminar on EDMP (EUROCAT Data Management Program)
- EUROCAT Symposium with publication of a special issue of **Birth Defects Research Part A** - Volume 106, Issue 6

Prevalence and perinatal mortality tables publication
(20/10/16 next update mid-December)
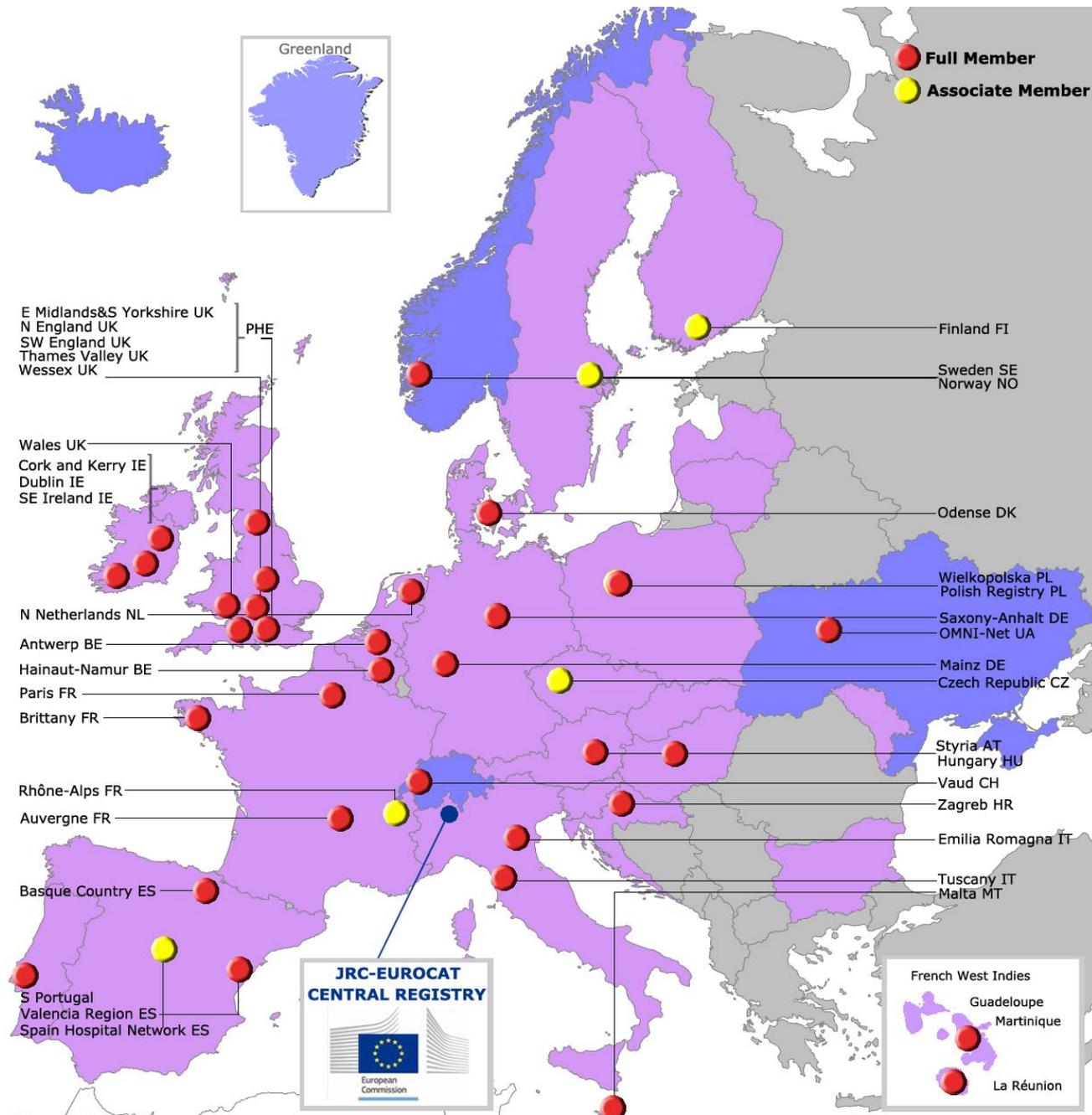
1. 26 Registries
2. 22,615 new cases 69,000 updated cases from PHE
3. About 650,000 newborns covered for 2014

Statistical monitoring on clusters and trends
ongoing

1. 16 Registries ,
2. Years covered 2010-2014 (C) 2005-2014 (T)
3. 92 anomalies subgroups investigated

New website with EC visual identity ➔ ongoing planned hosting mid-December

European Commission

EUROCAT Network

Greenland

● **Full Member**
● **Associate Member**

E Midlands&S Yorkshire UK
N England UK
SW England UK
Thames Valley UK
Wessex UK

PHE

Wales UK
Cork and Kerry IE
Dublin IE
SE Ireland IE

N Netherlands NL
Antwerp BE
Hainaut-Namur BE
Paris FR
Brittany FR
Rhône-Alps FR
Auvergne FR
Basque Country ES

S Portugal
Valencia Region ES
Spain Hospital Network ES

**JRC-EUROCAT
CENTRAL REGISTRY**

European Commission

Finland FI
Sweden SE
Norway NO
Odense DK
Wielkopolska PL
Polish Registry PL
Saxony-Anhalt DE
OMNI-Net UA
Mainz DE
Czech Republic CZ
Styria AT
Hungary HU
Vaud CH
Zagreb HR
Emilia Romagna IT
Tuscany IT
Malta MT

French West Indies
Guadeloupe
Martinique
La Réunion

FULL MEMBERS

- **32 registries in 18 countries**

- **population-based registries transmitting case data on all congenital anomaly (CA) cases in their region.**

ASSOCIATE MEMBERS

- **6 registries in 6 countries**

- **transmit an aggregate file containing the total number of cases in each congenital anomaly subgroup by type of birth.**

European Commission

European Network for the Surveillance of Cerebral Palsy (SCPE)

June - Sept

2016 Data collection for newborns in 2007 and previous years updates at JRC-SCPE Central Registry:
1. Submission from 13 Registries
2. 1,504 new cases
3. About 357.000 newborns covered for 2007

14-16 Oct

Organisation and hosting of the Annual Plenary Meeting of SCPE Registries

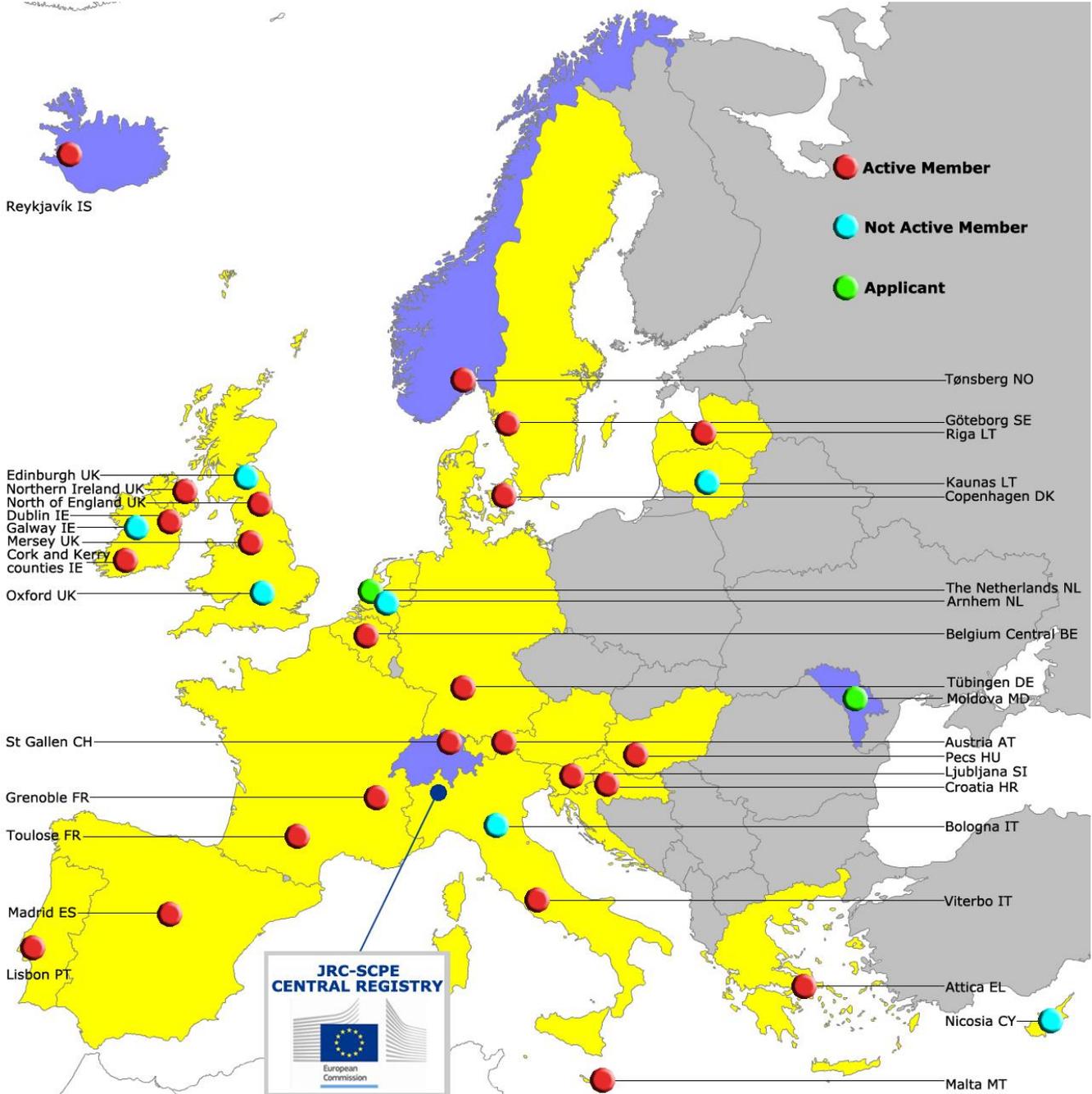**Validation of cases and feedback to the Registries**

➜ ongoing

New website with EC visual identity

➜ ongoing

Definition of Public health indicators to publish routinely on the website

➜ ongoing

European Commission

SCPE Network

Active Member

Not Active Member

Applicant

Reykjavík IS

Tønsberg NO

Göteborg SE
Riga LT

Kaunas LT
Copenhagen DK

Edinburgh UK
Northern Ireland UK
North of England UK
Dublin IE
Galway IE
Mersey UK
Cork and Kerry
counties IE

Oxford UK

The Netherlands NL
Arnhem NL

Belgium Central BE

Tübingen DE
Moldova MD

St Gallen CH

Austria AT
Pecs HU
Ljubljana SI
Croatia HR

Grenoble FR

Toulose FR

Bologna IT

Madrid ES

Viterbo IT

Lisbon PT

Attica EL

Nicosia CY

JRC-SCPE
CENTRAL REGISTRY
European Commission

Malta MT

THE SCPE NETWORK

31 registries in 23 countries

- **A network of population-based registries specialised in epidemiologic surveillance of cerebral palsies (CP)**

- **Active since 1998**

- **Active registries: 24**

- **Non-active registries: 7**

European Commission

Development of the European Platform for Rare Diseases Registration

7-8 April LUX

Organisation and hosting of **First Interoperability Workshop** together with experts, healthcare providers, patient representatives, decision makers and members of the Advisory Technical Group for the RD Platform **to define the most stringent measures and first steps to be addressed so as to ensure the interoperability of RD patient registries**. (23 participants outside the EC)

30 Nov LUX

Organisation and hosting of **Second Interoperability Workshop focused on the alignment of the European Platform on Rare Diseases** (RD) **Registration with** the European Reference Networks (**ERNs**) **IT Platform** and **other rare diseases-related IT platforms** being developed in the framework of European Commission supported projects. It will bring together ERNs Board of Member States, applicant ERN representatives, members of the Advisory Technical Group for the RD Platform, DG SANTE's relevant Units (B.3, B4, C1, A4), DG RTD (E.2), and the JRC (F.1).

European Commission

Joint Research Centre:

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Serving society.

https://ec.europa.eu/jrc/