Update on JRC's activities on cancer registries and rare diseases

Commission's Expert Group on Health Indicators

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Cancer Registries – update on activities in 2015

- Establishment of a single portal for the eventual handling of all data calls;

- Development of open-source data-quality-check software incorporating 3 levels of checks (data format, field values, inter-field checks);

- Launch of 2015 CR data call (August);

- Handling of data interface with the EUROCARE 6 project – underway since August/September;

- Handling of data interface with IARC (CI5 study) – discussions underway;

- Development of statistical and visualisation tools;

CRs – 2015 data call, current status

Country	EUROCARE	ENCR-JRC	IARC – CI5
AT - Austria		1	1
BA - Bosnia Herzegovina		1	
BE - Belgium	1	1	
BG - Bulgaria	1	1	1
CH - Switzerland	4	4	4
DE – Germany	7	6	7
EE – Estonia	1	1	
ES – Spain	3	2	2
FR – France	2	2	2
GR – Greece	1	1	1
HR – Croatia	1	1	1
IS – Iceland	1		1
IT – Italy	14	13	13
NL – the Netherlands	1	1	1
NO – Norway	1	1	
PL – Poland	3	2	2
PT – Portugal	2	4	2
RO – Romania	1	2	1
UK – United Kingdom	2	2	2
Total	**46**	**46**	**41**

Rare Diseases – update on activities in 2015

EUROCAT – Network of population-based registries for the epidemiological surveillance of congenital anomalies (CA) in Europe, established in 1979 1/3 of European births population – 1,7 million births/year and half a million cases of children with CA

Porting of data to JRC at end of 2014.

2015 data submission: between March and October.

SCPE - Network of population-based registries for the epidemiological surveillance of cerebral palsy(CP) in Europe (1998). 31 registries in 23 countries
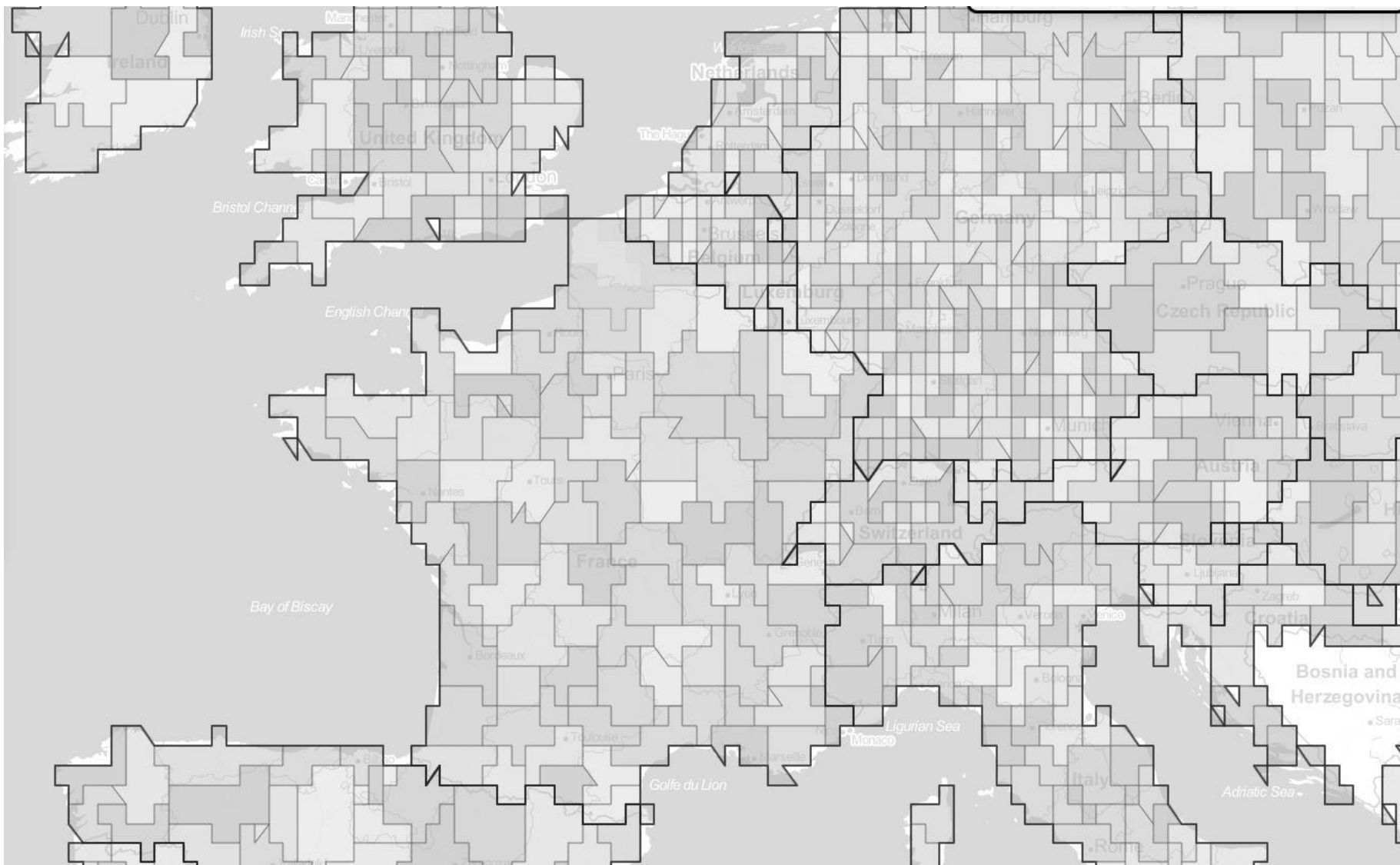
Re-development of data-submission portal.

Collaboration agreement being drawn up.

Wider RD community – 2016, Series of 4 Interoperability workshops.
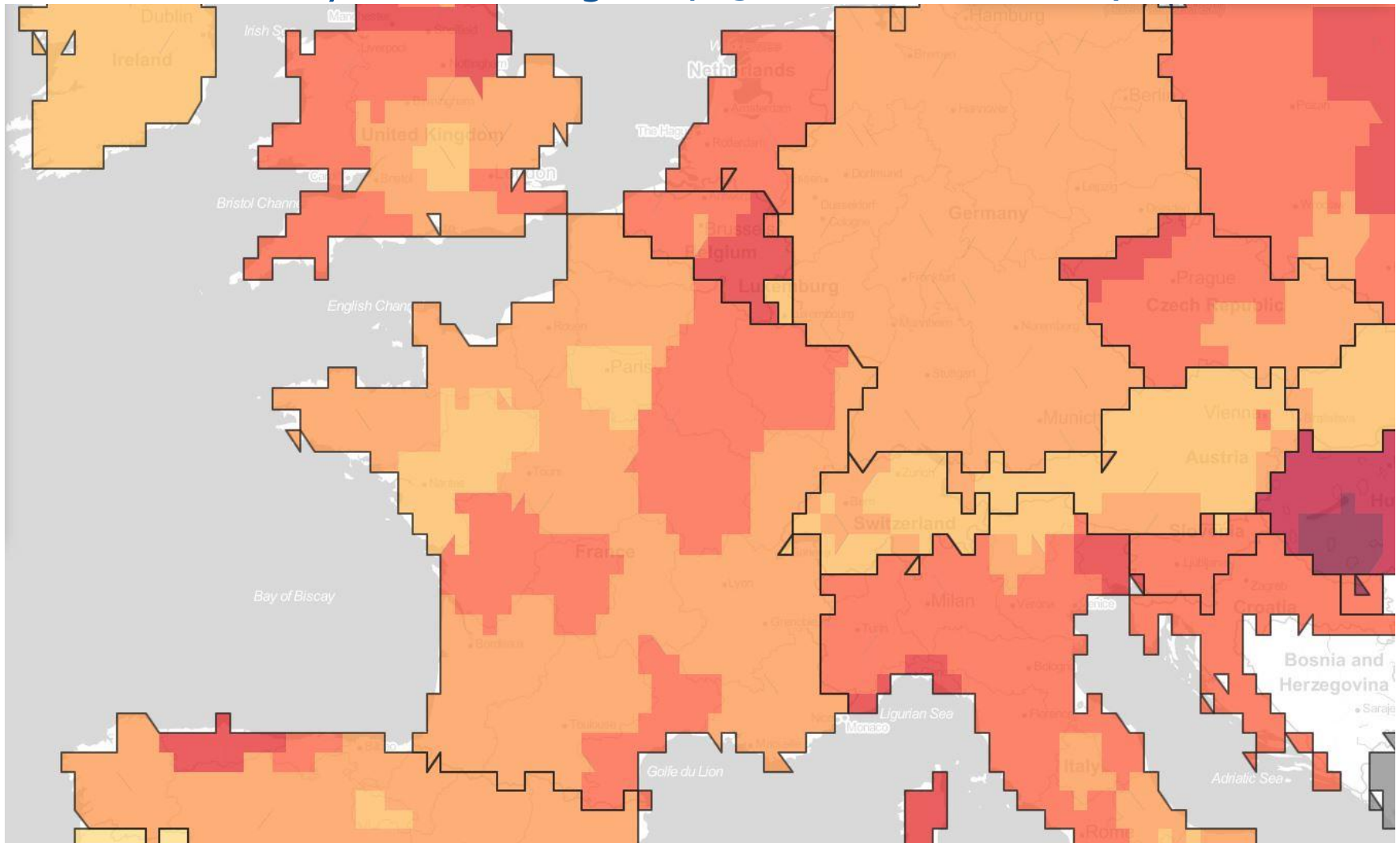
Steering and coordination activities

- Steering/coordination/management meetings: 2015 – EUROCAT (5), ENCR (4)

- Working groups/technical meetings (coding, classification, metadata, data quality) 2015: EUROCAT coding workshop; ENCR WG with stakeholders on ENCR-JRC portal; ENCR workshop on coding standards and training plan.

- Plenary meetings/scientific symposia:
    - 2014: Nov – **ENCR** general assembly, 160 participants from 33 countries;
    - 2015: June – **EUROCAT** June, 60 participants representing 36 registries, 21 countries; Nov – **SCPE**, 45 participants from 26 registries
    - 2016 - **EUROCAT** scientific symposium; **ENCR** general assembly

- Websites, newsletters, newsflashes
- Systems development
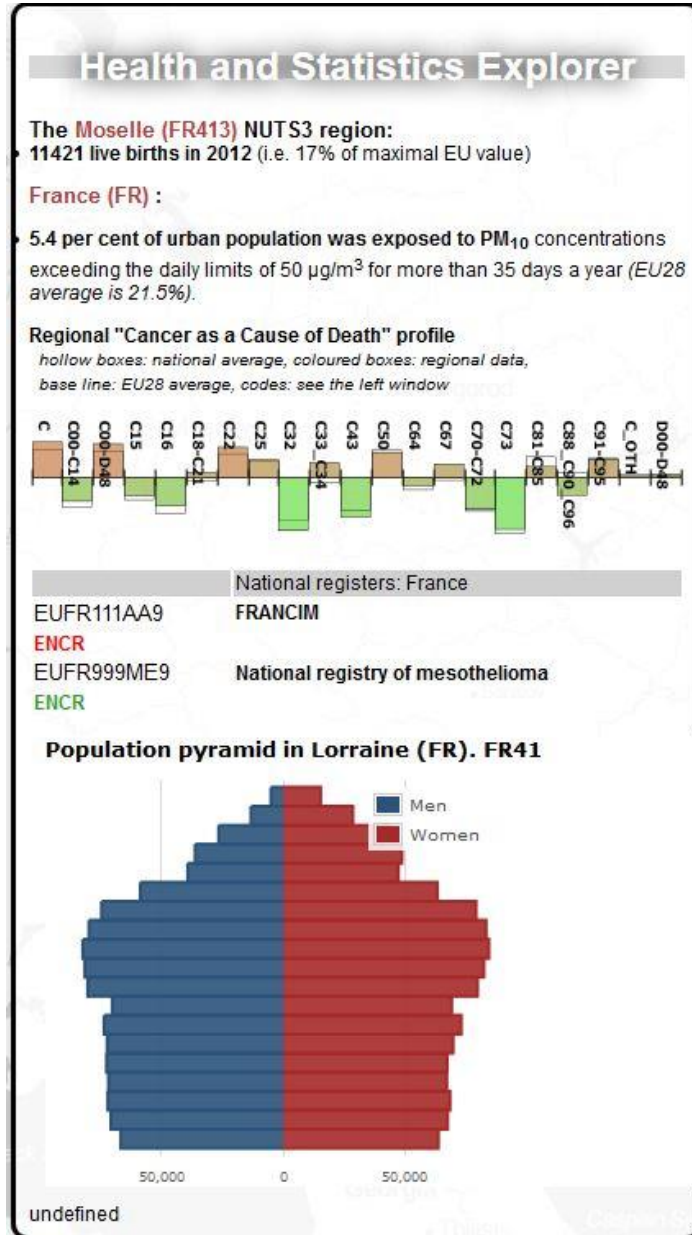- Factsheets, statistical/interactive data visualisation tools

European Commission

Europe NUTS 3 (polygon rendering)

Trachea, bronchus, and lung Ca deaths (crude rate) per 100,000 inhabitants (*3 yrs avg 2008-2010)* By NUTS 2 region *(Figures from Eurostat)*

European Commission

"Mouse-over" supplementary NUTS 3 information

Joint Research Centre:

Supporting legislation,
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