

Living donor registries in the European Union

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(on behalf of Accord Consortium)*

**FINAL RESULTS OF THE
ACCORD PROJECT**

2nd June, 2015



WP 4 'LIVING DONOR REGISTRIES'

A REPORT ON THE CURRENT EXPERIENCE WITH LIVING DONATION AND LIVING DONOR REGISTRIES



Accord

Achieving Comprehensive
Coordination in Organ Donation
throughout the European Union



Bulgaria: BEAT
Croatia: MOHSW
Cyprus: Ministry of Health
Czech Republic: KST
Estonia: TUH
France: ABM
Germany: DSO
Greece: HTO
Hungary: HNBTS
Ireland: HSE
Italy: ISS-CNT
Latvia: PSCUH
Lithuania: NTB
Malta: MHEC
Norway: HDIR
Poland: Poltransplant
Portugal: IPST
Romania: ANT
Slovenia: Slovenija Transplant
Slovak Republic: NTO
Spain: ONT
The Netherlands: DTF
United Kingdom: NHSBT

FIG. 1 ACCORD CONSORTIUM - ASSOCIATED PARTNER

ANNEX 2: WORK PACKAGE 4 PARTNERS

Associated partners:

- Croatia
- France
- Germany
- Ireland
- Italy
- Latvia
- Lithuania
- Netherlands – project leader
- Norway
- Poland
- Portugal
- Romania
- Spain
- Sweden
- United Kingdom

Collaborating partners:

- Hospital Clinic Universitari of Barcelona
- Eurotransplant
- Scandiarttransplant
- European Directorate for the Quality of Medicines and Healthcare (EDQM)
- World Health Organization (WHO)

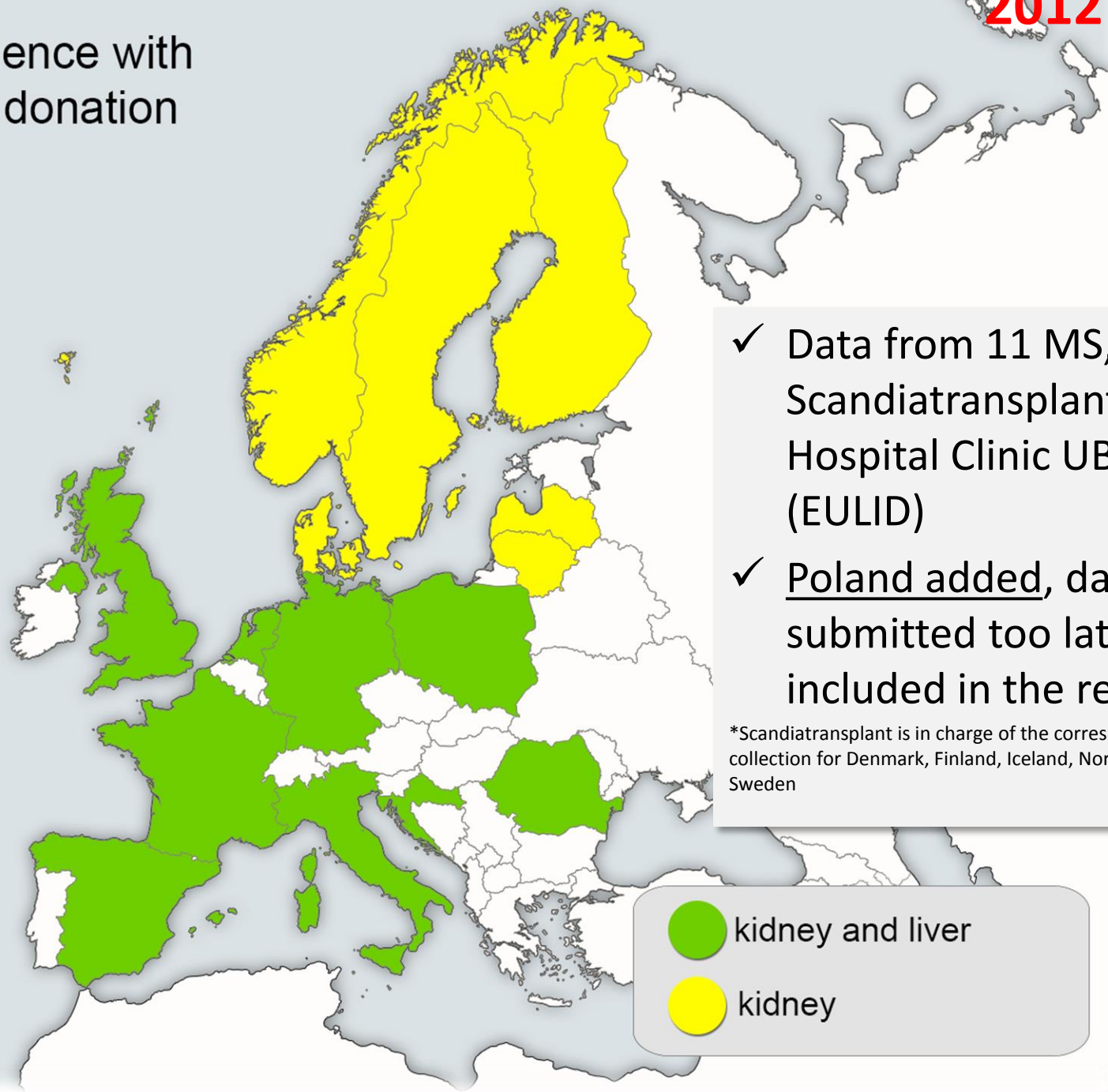
- July 2012, a questionnaire was sent to all associated and collaborative partners of WP4, to investigate the current status on existing living donor registries:
 - Variables, Follow-up frequency, Procedure for request for data from the registry, etc.
- November-December 2012, the outcome of the questionnaire is used to compose the first deliverable:
 - A report on state of the art of living donor registries

The questionnaire was divided into 5 focus areas:


- General information
- Current experience with living donation and current living donor follow-up
- Technical specification on the database
- Detailed specification on the content of the database
 - Data for evaluation of the donor
 - Data concerning the donation procedure
 - Data for follow-up of the donor
- Practical information about using the database


2012 data!

Experience with living donation



- ✓ Data from 11 MS, ScandiTransplant* and Hospital Clinic UB (EULID)
 - ✓ Poland added, data submitted too late to be included in the report
- *ScandiTransplant is in charge of the corresponding data collection for Denmark, Finland, Iceland, Norway and Sweden

 kidney and liver

 kidney

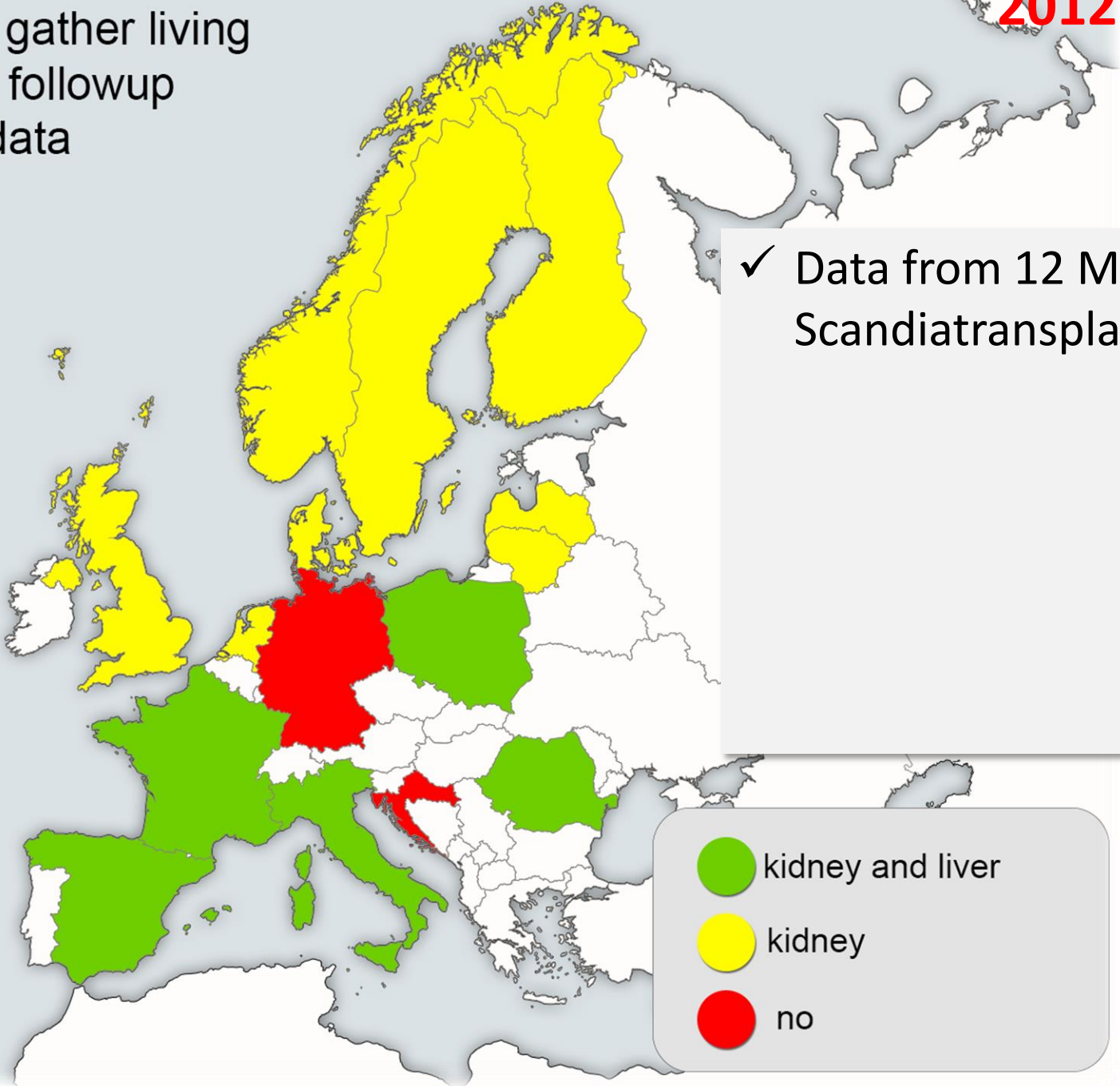
System to gather living donor followup data

2012 data!



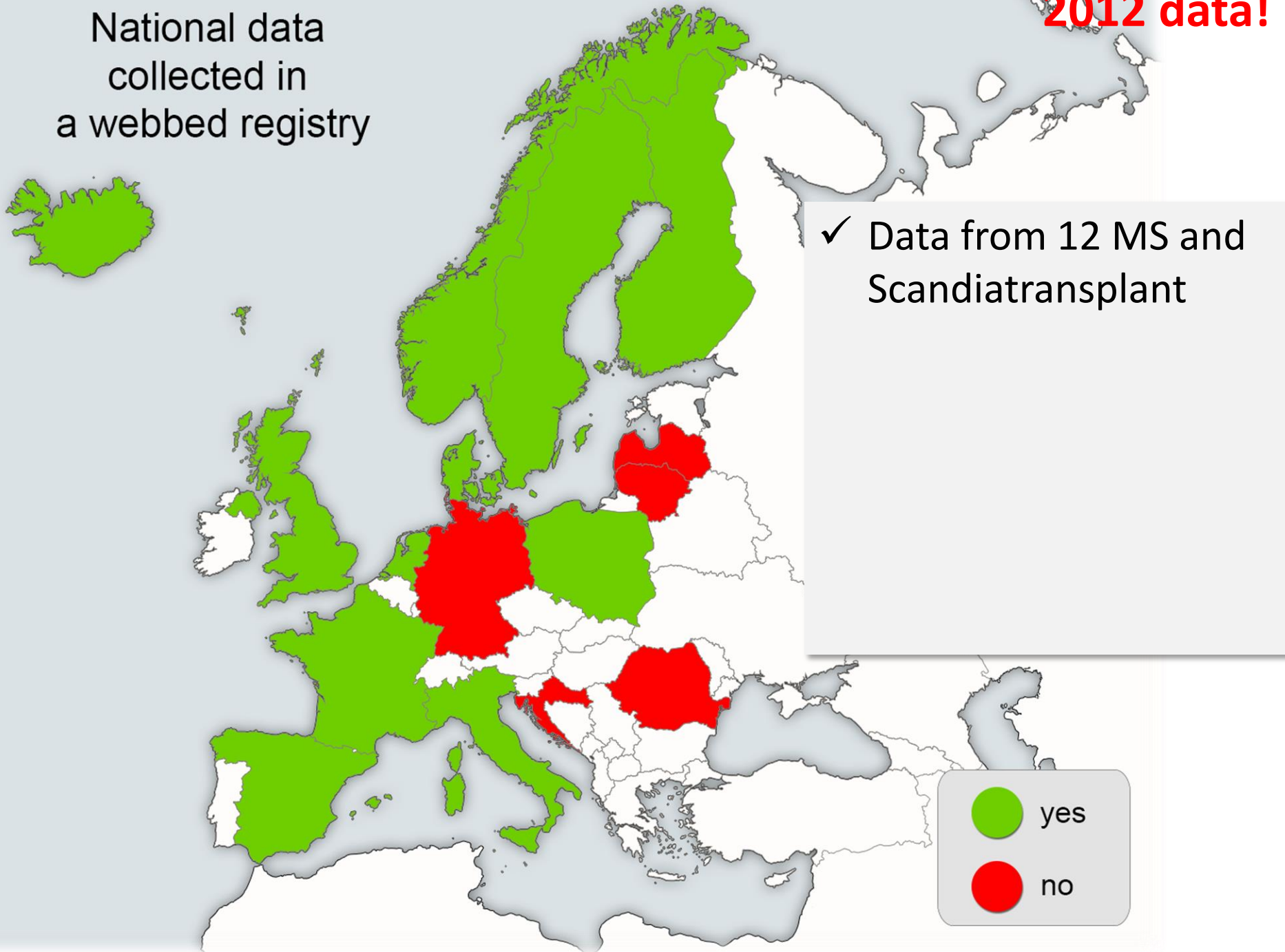
✓ Data from 12 MS and Scandiatriplant

- kidney and liver
- kidney
- no



2012 data!

National data
collected in
a webbed registry



✓ Data from 12 MS and
Scandiatransplant

● yes

● no

2012 data!

Starting date of living donor data collection



- Data collection:
- The Netherlands – **DTF**
 - Spain – **MSSSI**
 - **HCUB** (EULID, 2007-2009)
 - France – **ABM**
 - Italy – **Ministry of Health**
 - United Kingdom – **Directorate of Organ Donation and Transplantation**
 - Denmark, Iceland, Finland, Norway, Sweden – **ScandiTransplant**
 - Poland – **Poltransplant**

*ScandiTransplant

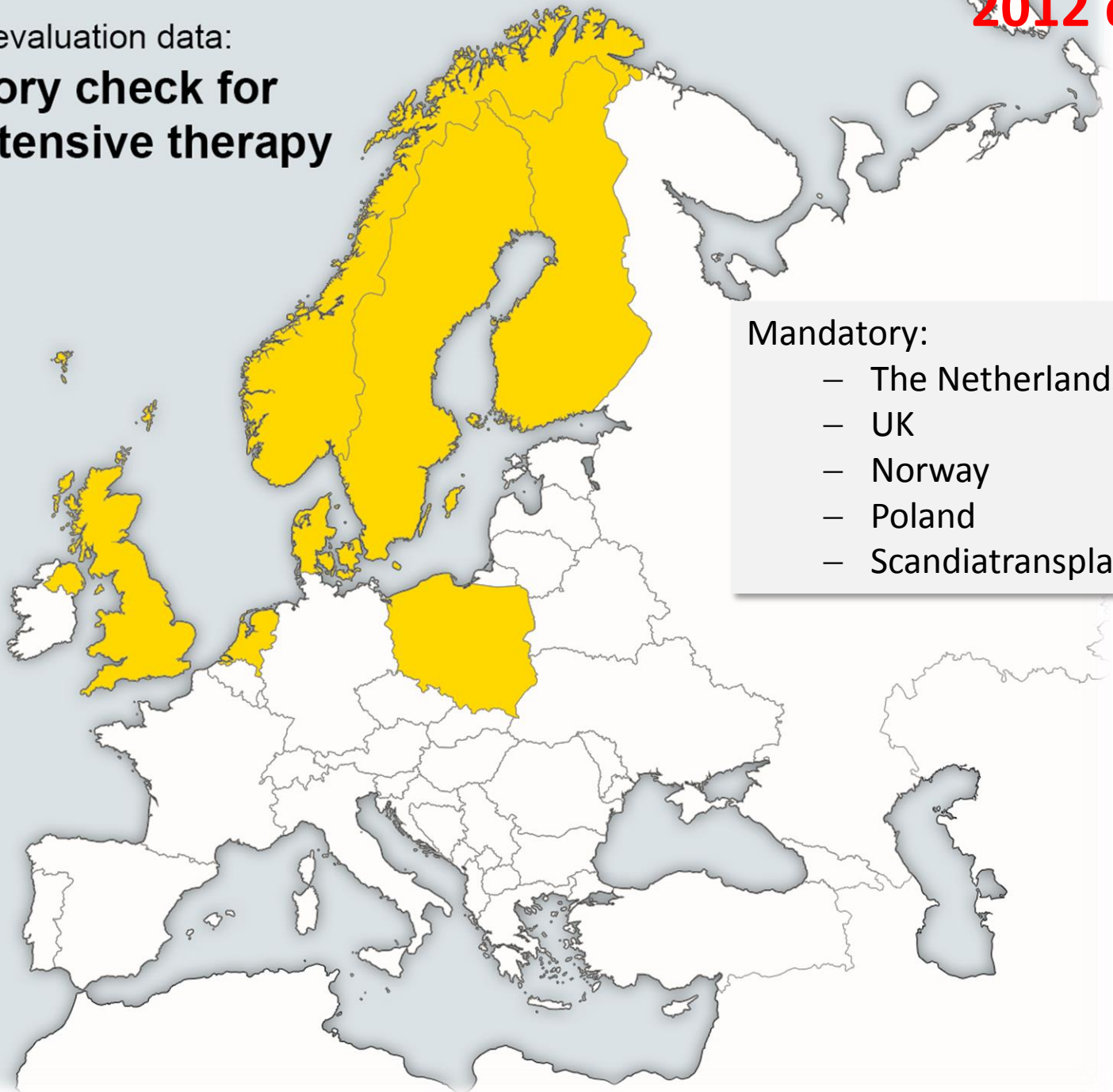
2012 data!

Data collected: data for evaluation of the donor

Item	Mandatory	Not mandatory or not collected
Age	13	0
Gender	13	0
Relation type	12	1
Weight	6	7
Lenght	6	7
Creatinine	10	3
Blood pressure	7	6
Anti-hypertensive drugs	5	8

2012 data!

Donor evaluation data:
**Mandatory check for
anti-hypertensive therapy**



Mandatory:

- The Netherlands
- UK
- Norway
- Poland
- ScandiTransplant

2012 data!

Data collected: data concerning the donation procedure

Item	Mandatory	Non mandatory or not collected
Operational technique	6	7
Left or right	7	6
Complications during operation	3	10
Blood group	10	3
HLA type	9	4
EBV	4	9
CMV	5	8
Hepatitis B, C	5	8

2012 data!

Data concerning the donation procedure:

Complications during operation



- Mandatory - 3
- Spain
 - Poland
 - Scandiatransplant

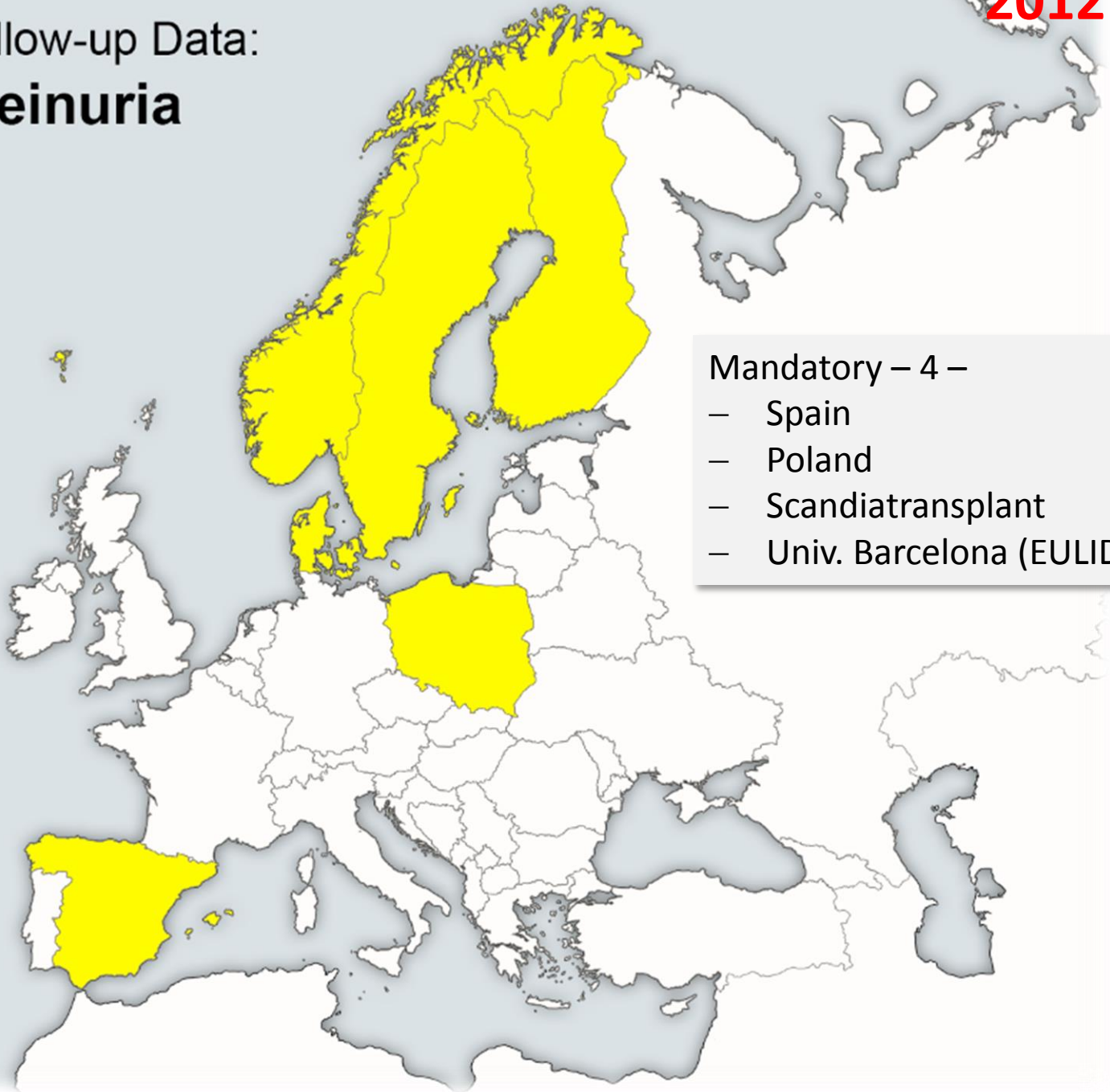
2012 data!

Data collected: data for follow-up of the donor

Item	Mandatory	Not mandatory or not collected
Creatinine	9	4
Proteinuria	4	9
Blood pressure	9	4
Anti-hypertensive drugs	7	6
Complications after operation	8	5

2012 data!

Donor Follow-up Data:
Proteinuria

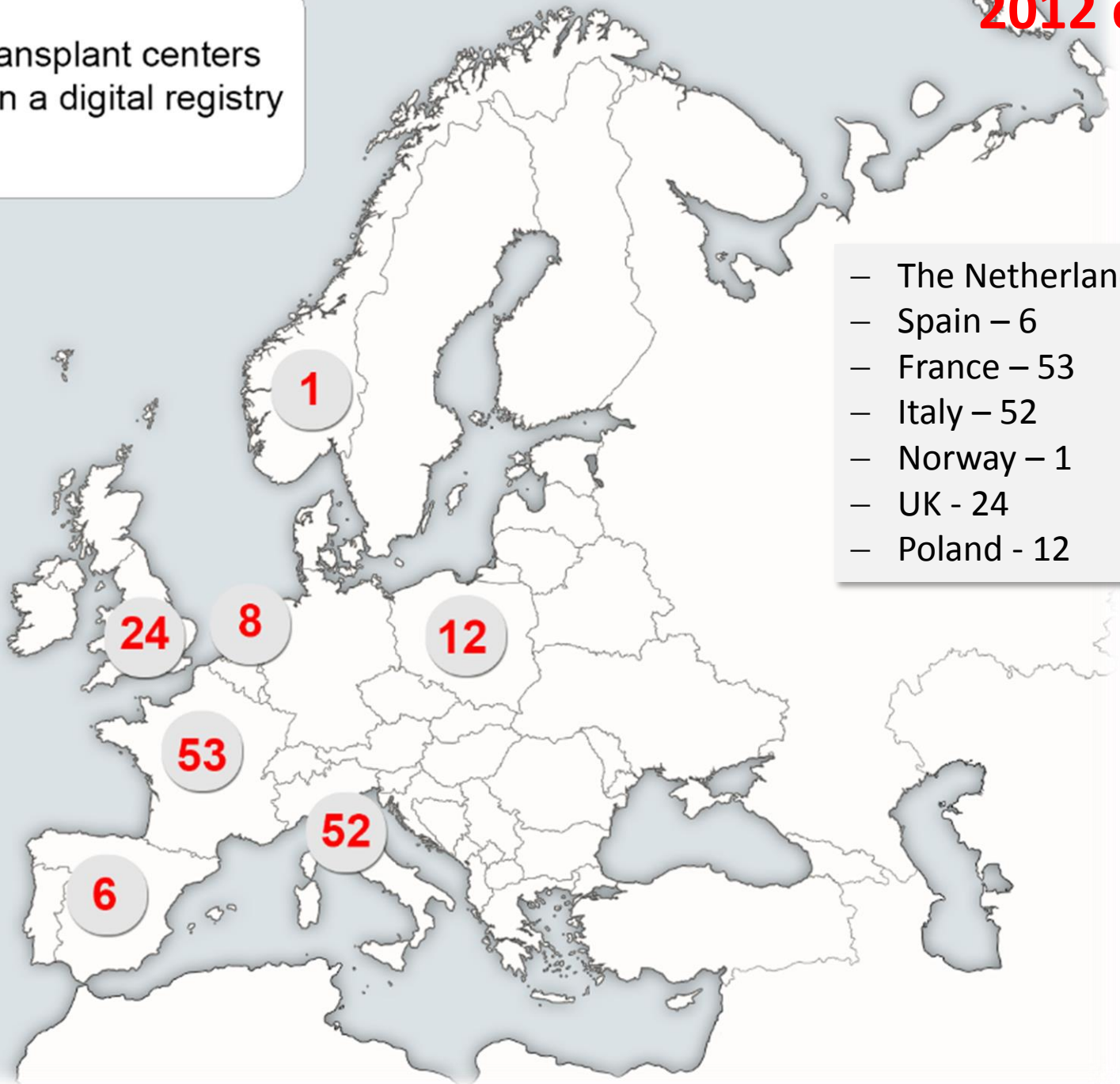


Mandatory – 4 –

- Spain
- Poland
- Scandi transplant
- Univ. Barcelona (EULID)

2012 data!

Number of transplant centers sharing data in a digital registry



- The Netherlands – 8
- Spain – 6
- France – 53
- Italy – 52
- Norway – 1
- UK - 24
- Poland - 12

The number of donors
included in registries
(national or local)

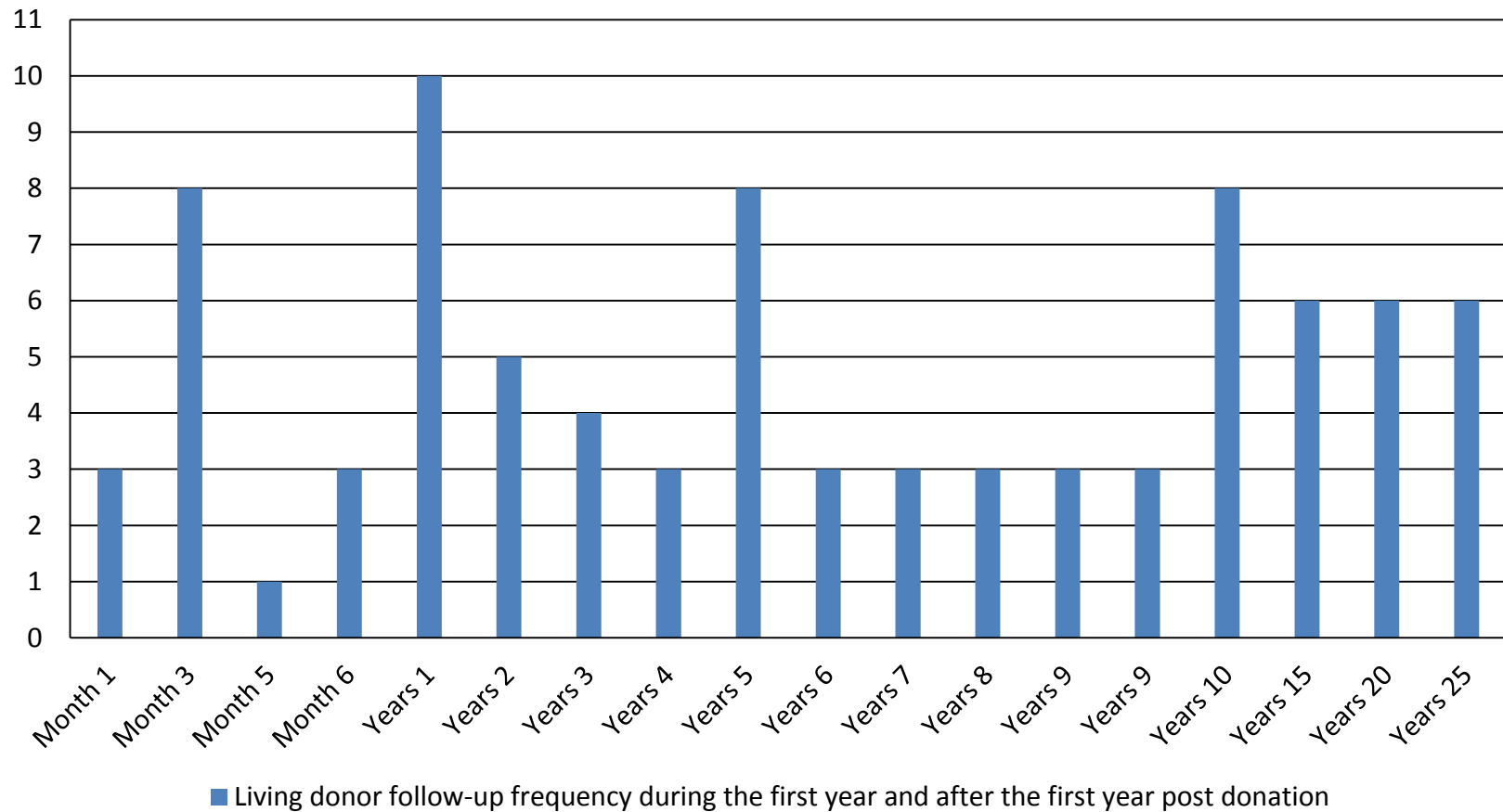
2012 data!



- The Netherlands – 5250
- Spain – 347
- France – 1839
- Italy – 1500
- Latvia – 22
- Lithuania – 153
- Norway – 1500
- Romania – 816
- UK – 11 761
- Poland – 582

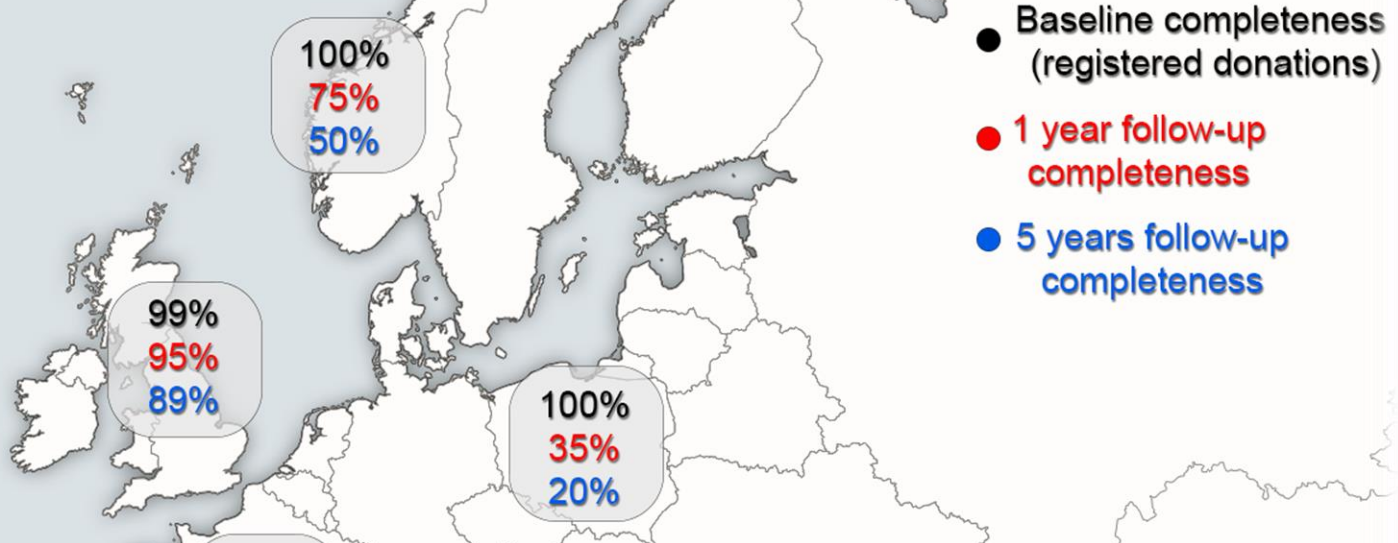
2012 data!

The follow-up frequency



2012 data!

Completeness of the Registries



	Baseline	1-year	5 years
Poland	100%	35%	20%
France		95%	
Italy		100%	
Norway	100%	75%	50%
UK	99%	95%	89%

Conclusions

- The registration of living donor follow-up information was not implemented in every MS in 2012.
- Not every hospital involved in live donation shares its data in registry
- Existing registries collect different donor data with different frequency of follow-up
- Accord faced many tasks