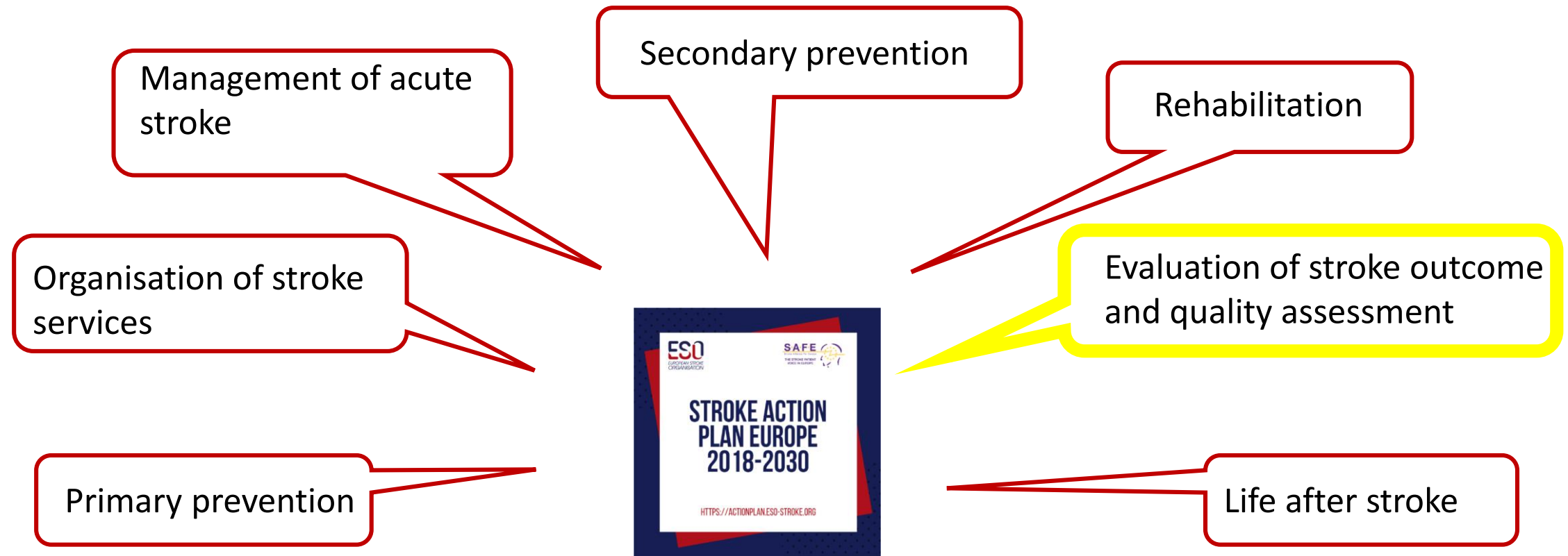


Urs Fischer
Diana Aguiar de Sousa
Hanne Christensen

SAP-E summary data reporting and presentation



The 7 domains in the chain of stroke care



Targets for 2030



Targets for 2030

1. Defining a Common European Framework of Reference for Stroke Care Quality that includes:
(a) development or update of European guidelines for management of acute stroke care, longer term rehabilitation and prevention; (b) definition of a common dataset covering core measures of stroke care quality to enable accurate international comparisons of care both in hospital and in the community (including structure, process, outcome measures and patient experience).
2. Assigning a named individual who is responsible for stroke quality improvement in each country or region.
3. Establishing national- and regional-level systems for assessing and accrediting stroke clinical services, providing peer support for quality improvement and making audit data routinely available to the general public.
4. Collecting patient-reported outcomes and longer term outcomes (e.g. six months and one year), covering both hospital and community care.

SAP-E summary data - Why?



Efforts to improve systems or processes must be driven by **reliable data**

What needs to be improved?
Are our efforts leading to improvement?

- Accurately **identify problems**
- **Prioritise** quality improvement initiatives
- Enables objective assessment of whether **change and improvement** have indeed occurred
- Influence **policy-makers and stakeholders**

Summary data



- Basics variables
- Key performance indicators
- No GDPR issues
 - Summary data only
 - No individual patient information

Summary data



- Basics variables
- Key performance indicators
- Comparison across countries
- Comparison over time

Basic variables

- Number of all strokes
- Number of ischemic strokes
- Number of hemorrhagic strokes
- Number of TIA
- Number of SAH
- Mortality
- Men and women %
- Mean/median age

Key performance indicators



- Admission to stroke unit
- Admission to stroke unit within 24 hours
- Provision of IVT
- Provision of EVT
- Access to stroke unit care

Key performance indicators

- Access to:
 - CT/MRI
 - vascular imaging
 - ECG
 - long-term ECG-monitoring
 - cardiac echo (TTE, TOE)
 - dysphagia screening
 - blood tests
- Access to early stroke unit rehabilitation (including early supported discharge)
- Plan for rehabilitation and support provided at discharge
- Follow-up at 3-6 months

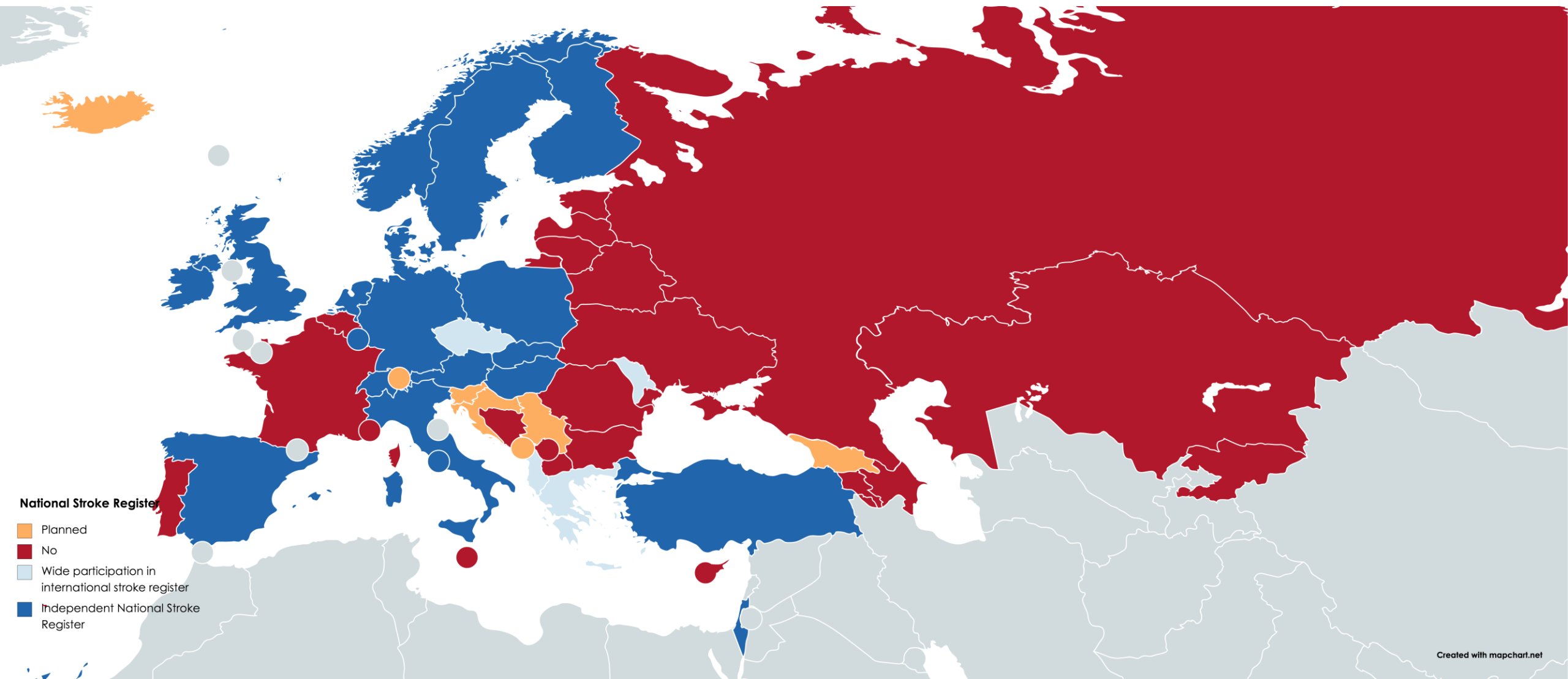
Stroke care mapping – The Route Map



Network/partnership approach

- Professional societies
- SSOs
- **MoH**
- **Stroke Registers**
- **Health authorities collecting surveillance data on stroke care**
- **Other European Societies – EAN, ESMINT**
- **Health organisations – WHO**
- **European Stakeholders – European Commission**

Data sources – Stroke registers



Data sources



- **Broad range of sources of information** on relevant indicators:
 - ✓ National and Regional Stroke Registers
 - ✓ International Stroke Registers
 - ✓ Public health surveillance data/DGR data (Ministries of Health, National authorities)
 - ✓ Collection of aggregated data across stroke units/comprehensive stroke centers

Compare performance indicators across Europe

Influence stakeholders and policymakers

- Ensure optimal care to all European stroke patients -

Monitoring progress in acute stroke care in Europe



2016

M Petrela, O Taka, E Enesi (Albania);
S Hiechl, M Brainin, F Fazekas (Austria)
P Konovalov (Belarus)
A Peeters, G Vanhooren, L Defreyne (Belgium)
H Haris, M Moranjkic (Bosnia and Herzegovina)
S Andonova, I Staikov (Bulgaria)
H Budincevic, D Ozretic, B Malojčić (Croatia)
A Tomek (Czech Republic)
H Iversen, SP Jonhsen (Denmark)
J Korv, R Vibo, V Malikov (Estonia)
T Sairanen, D Strbian, K Lappalainen (Finland)
S Timsit, E Touze, D Leys (France)
A Tsiskaridze, I Burduladze (Georgia)
M Dichgans, J Röther, J Fiehler (Germany)
G Tsivgoulis, G Ntaios, E Brountzos (Greece)
D Bereczki, C Óváry, I Szikora (Hungary)
B Thorarinsson, V Vilmarsson (Iceland)
J Harbison (Ireland)
N Bornstein, D Tanne, A Horev (Israel)
D Toni, S Mangiafico, V Caso (Italy)
A Murzaliev, I Lutsenko, A Artykbaev (Kyrgyzstan)
D Jatuzis, D Rastenyte, M Kurminas (Lithuania)
E Miglāne, K Krupcs, I Kikule (Latvia)
D Ulbricht (Luxembourg)

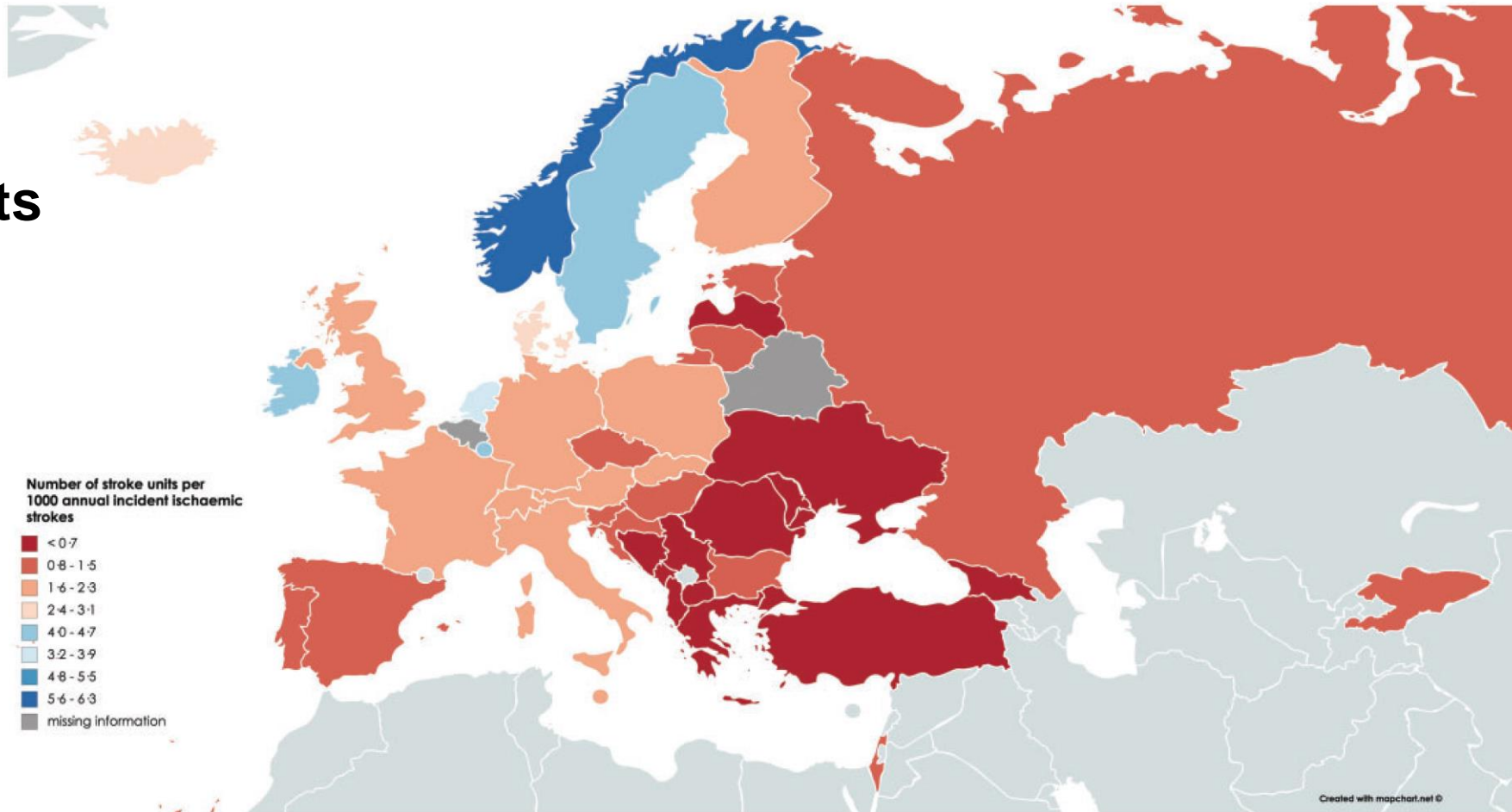
A Arsovska, M Smiceska, E Lickova (Macedonia)
M Mallia, R Grech, M Schembri (Malta)
V Lisnic, E Manole, E Zota (Moldova)
M Cukic (Montenegro)
D Dipplel, C Majoie, B Van der Worp (Netherlands)
S Akpinar (Northern Cyprus)
E Berge, Hanne Ellekjær (Norway)
A Czlonkowska, W Poncyljusz, A Kobayashi (Poland)
E Azevedo, V Tedim-Cruz, M Ribeiro (Portugal)
C Tiu (Romania)
T Kharitonova (Russia)
L Bumbasirevic (Serbia)
Z Gdovinova, I Vulev, P Turcani (Slovakia)
Z Bojana, V Svigelj, Z Milosevic (Slovenia)
J Gállego, M Rodríguez Yáñez, E Palacio-Portilla, A
Gonzalez Mandly, M Gallofré, S Abilleira, C Gimenez,
S Calleja-Puerta, J Marta-Moreno, M Óscar Ayo, A
Lago (Spain)
M Arnold (Switzerland)
M Mazya, T Moreira, A Kuntze-Soderqvist (Sweden)
N Uzuner, L Gungor, O Ozdemir (Turkey)
H Rodgers, J Dawson, P White (United Kingdom)
Y Flomin, D Shcheglov (Ukraine)

Monitoring progress in acute stroke care in Europe



Massive inequalities between European countries in 2016

Stroke Units



Stroke Units :
2222

Mean:
2.9

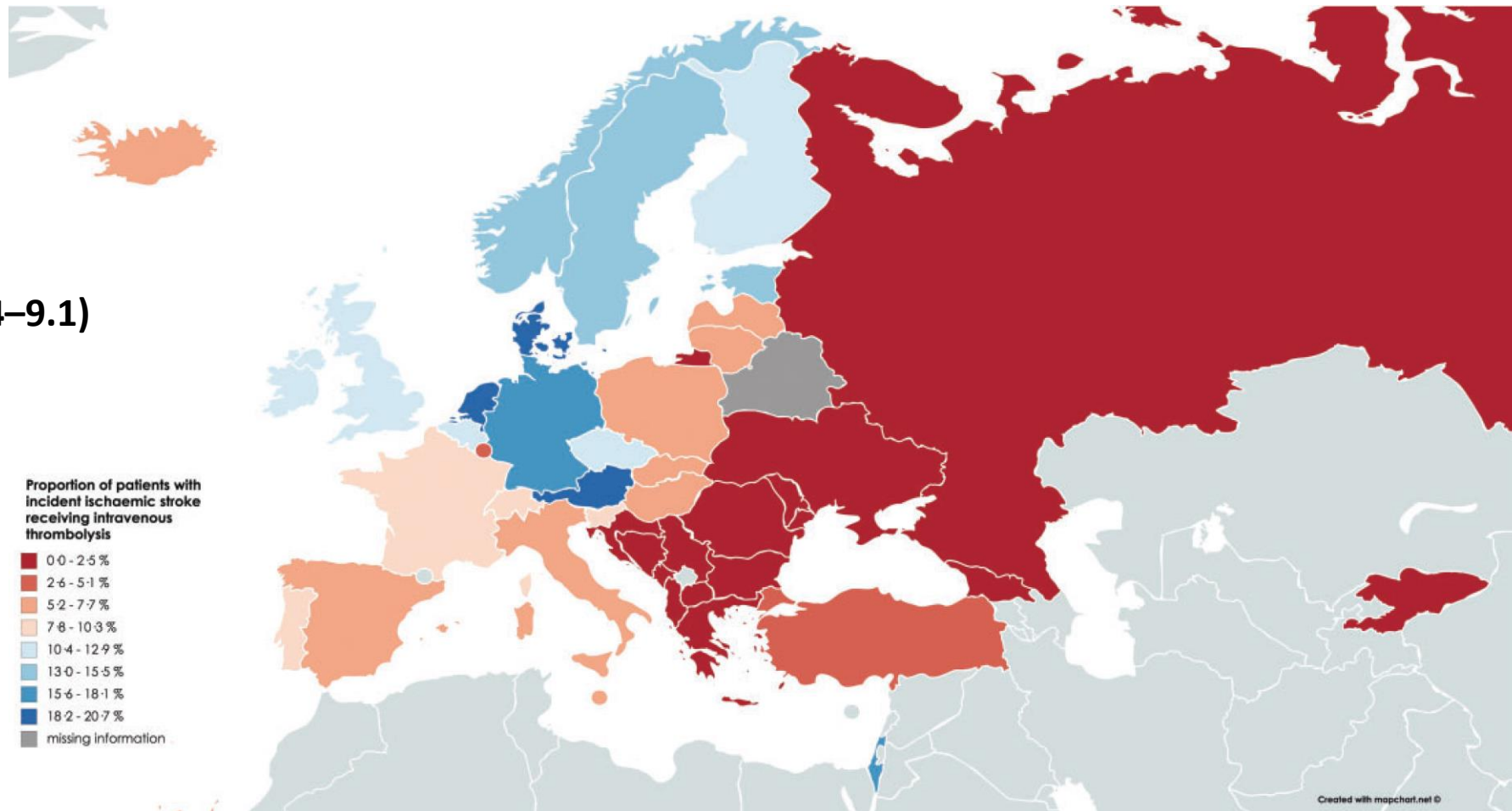
Best performing country:
9.2

Monitoring progress in acute stroke care in Europe

Massive inequalities between European countries in 2016

IVT rate

7.3% (95% CI; 5.4–9.1)

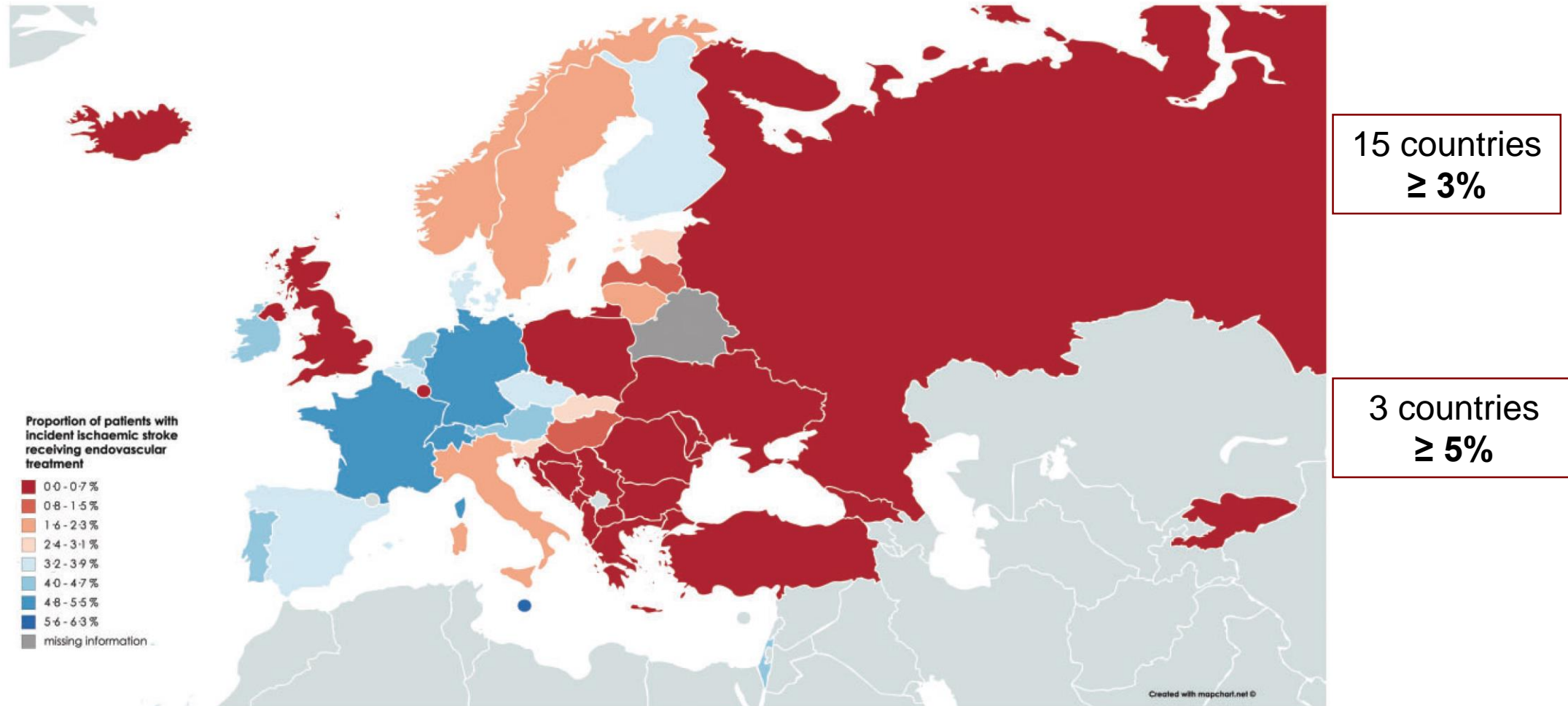


13 countries
IVT rates $\geq 10\%$

Monitoring progress in acute stroke care in Europe

Massive inequalities between European countries in 2016

EVT rate



Monitoring progress in acute stroke care in Europe



Data to be collected:

2019

2020

- ✓ **Number of Stroke Units and SU beds in the country**
- ✓ **Number of IVT during each year**
- ✓ **Number of EVT during each year**

Available national data:

- ✓ **Population**
 - United Nations World Population Prospects
- ✓ **Stroke incidence**
 - Global Burden of Disease

**Invitations to be
sent out soon**

Goal: Annual data upload – all KPIs



Web-based, user-friendly cross-sectional data integration platform for public health surveillance

- **Platform** for aggregated data in preparation
- Access through SAP-E website
- Password protected and logged country specific access
- Data upload by national coordinators
- Clear identification of **data sources**

Goal: Annual data upload – all KPIs



Why?

- Streamlined and more efficient information gathering
- Improved assessment/comparison of data quality/methodology
- Improved information access
- Accelerate comparisons across countries and over time
- Promotion of national and international joint cooperation
- Comparisons readily accessible to stakeholders
- Development of tailored strategies to improve the quality of stroke care

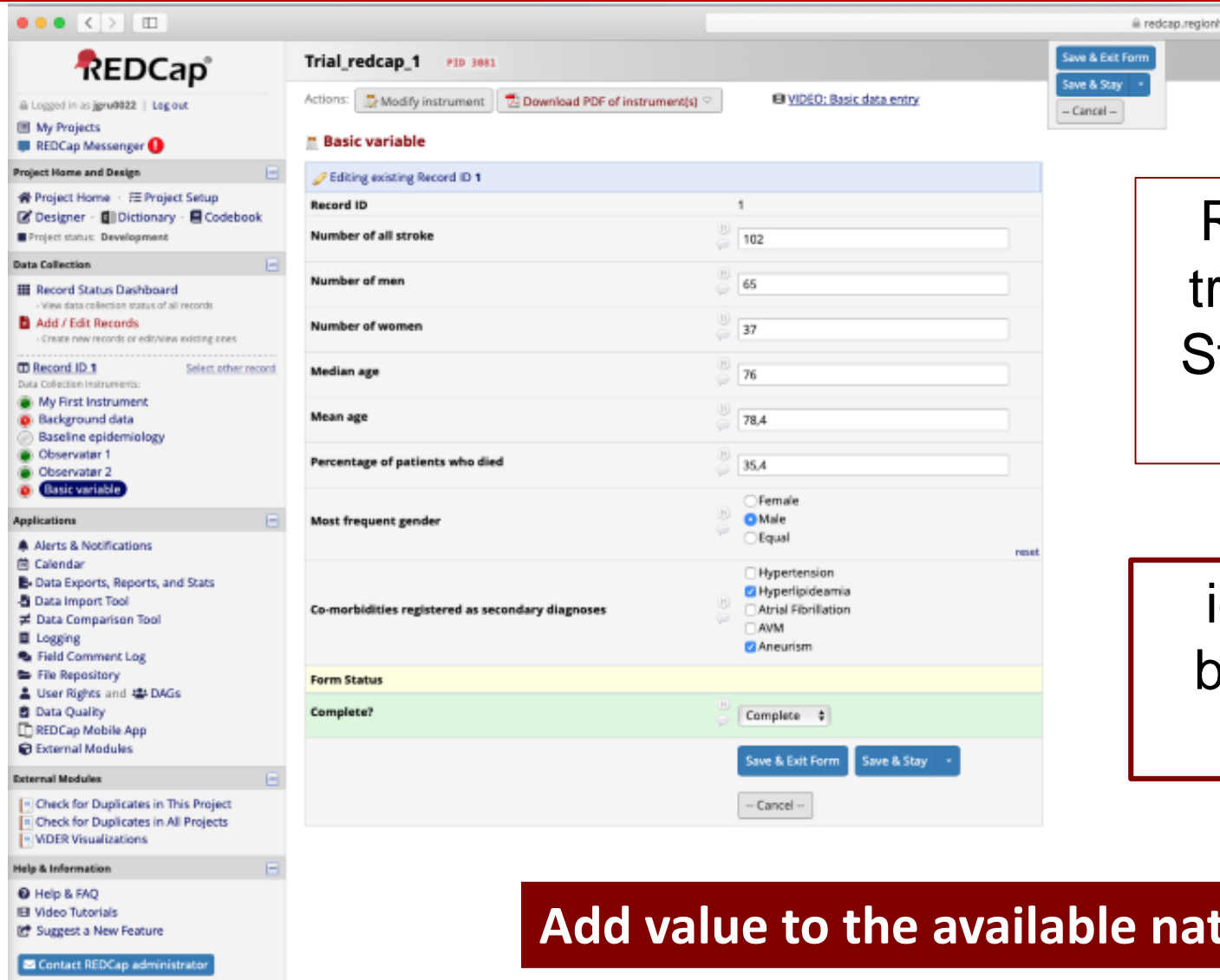
Goal: Annual data upload – all KPIs



Main Features

- **Flexible**
 - Countries include data on the available variables
 - Different data sources allowed
 - classification of data quality
- **Inclusive**
 - All countries included
 - Different levels of data quality

Upload interface



The screenshot shows the REDCap interface for a project named 'Trial_redcap_1' (PID 1001). The user is logged in as 'jgru9922'. The left sidebar contains navigation options: My Projects, REDCap Messenger, Project Home and Design, Data Collection, Applications, and External Modules. The main content area displays the 'Basic variable' form for 'Editing existing Record ID 1'. The form includes the following fields:

- Record ID: 1
- Number of all stroke: 102
- Number of men: 65
- Number of women: 37
- Median age: 76
- Mean age: 78.4
- Percentage of patients who died: 35.4
- Most frequent gender: Male (selected)
- Co-morbidities registered as secondary diagnoses: Hypertension, Hyperlipidaemia, Atrial Fibrillation, AVM, Aneurism (all selected)
- Form Status: Complete (selected)

Buttons at the bottom include 'Save & Exit Form', 'Save & Stay', and 'Cancel'. A 'VIDEO: Basic data entry' link is visible in the top right corner.

Review, analyze, map, and
trend aggregate data on the
Stroke KPIs at the European
level

identification of inequitably
burdened and undertreated
populations

Add value to the available national data resources

Annual data upload – all KPIs



Long-term goals

- More common **definitions of quality of care** indicators
- Availability of an **IT infrastructure for continuous online registration** of high quality and more harmonized national data
- **Real time feedback** supporting continuous improvement of care and outcomes in patients with stroke

Annual data upload – all KPIs



Way to get there

- Country consultations
- Catalogue of national surveillance information systems/sources
- Development
- Test, pilot
- Validation

Conclusions



Develop networks to promote **collaborative integration** of data on Stroke care in Europe

Support and empower people to work together to deliver **better care**

Closing gaps between **clinical guidelines and practice**

SAP-E is an improvement plan

Implement and deliver the key priorities set out in the SAP-E

Mapping stroke care

Critical **analysis**

Mapping **stroke care needs**

Taking **actions** and producing **recommendations**

THANK YOU

