

# **Haemophilia registries**

## **Patients' perspective - EHC**

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EHC Steering Committee member

# Who we are



- European non-profit patient organisation
- Brussels-based, patient-led
- Haemophilia, VWD, other RBDs
- Approx. 90,000 Europeans represented
- Founded in April 1989

# Our members



- National patient organisations
- 45 European countries
  - 27 EU Member States
  - Most Council of Europe countries
    - *Except Andorra, Liechtenstein, San Marino, Monaco*
  - And Kyrgyzstan

# Benefits of national registries



- Basic data greatly assist with planning of services:
  - number of people with haemophilia and other bleeding disorders
  - age distribution
  - severity
  - geographic distribution

## Benefits of national registries (2)

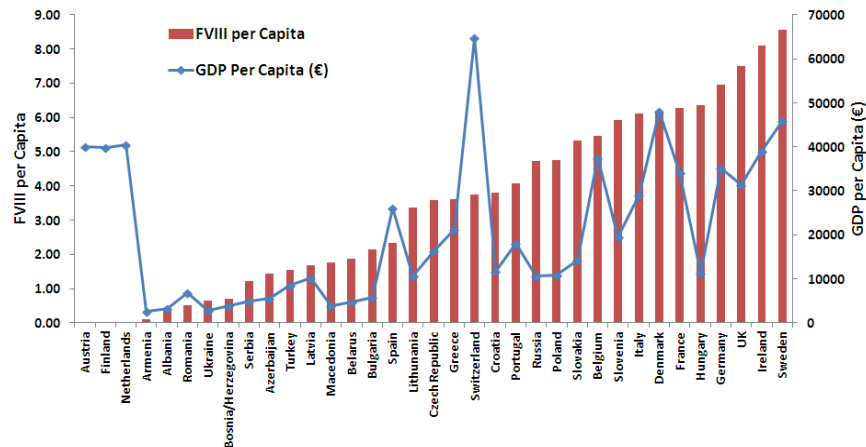


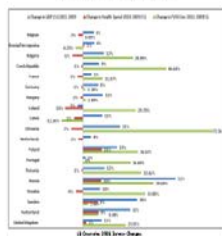
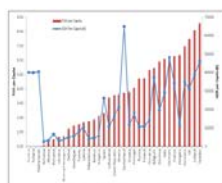
- Organisation of care nationally:
  - optimal location of comprehensive care and treatment centres
  - planning national tenders: predicting demand and supply required
  - distribution mechanism for CFCs

# Data collection



- Haemophilia care in 35 European countries
- European tenders and procurement survey



[illegible]

The studies of 171 people in 46 groups and with a wide range of life styles in individual countries. 2009. University was derived and made (redistribution) the subjects which the multiple choice of European countries (except all with the European principles) (the multiple choice) was conducted in a short (approximately 10 min) of

- The principles outlined were:
  - to set time and effort limits for multiple organisations to work closely with supporting bodies
  - to build new multiple partnerships
  - to develop of multi-agency competences to deal with social and complex reality, not multiple sources of services
  - to develop of new ideas, policies and projects in the domain of the multiple case
  - to set of realistic commitments to common treatment plans
  - to use evidence and ethics.

\*1. *Phyllanthus*  
 \*2. *Juniperus communis* var. *horizontalis* L.  
 \*3. *Salix repens* L.  
 \*4. *Scrophularia officinarum* L.  
 A total of 16 studies registered in the study, and the results were published in 2010 in the journal of *Stomatologia*. The study mentions significant variation in reaction to the application of hot vapors and a low probability of better outcomes in the long-term treatment analysis.

We reported the study last year (2012) and answered the question to a large extent. In particular, a total of 107 African countries were included in the IAC as potential. This was a result of requests and the IAC would like the country included in the countries for requesting. The information is provided here in more detail. The data has also been submitted to publication in the journal and might be a bit to present. Please let it also show the distribution in the IAC.

European Haemophilia Consortium

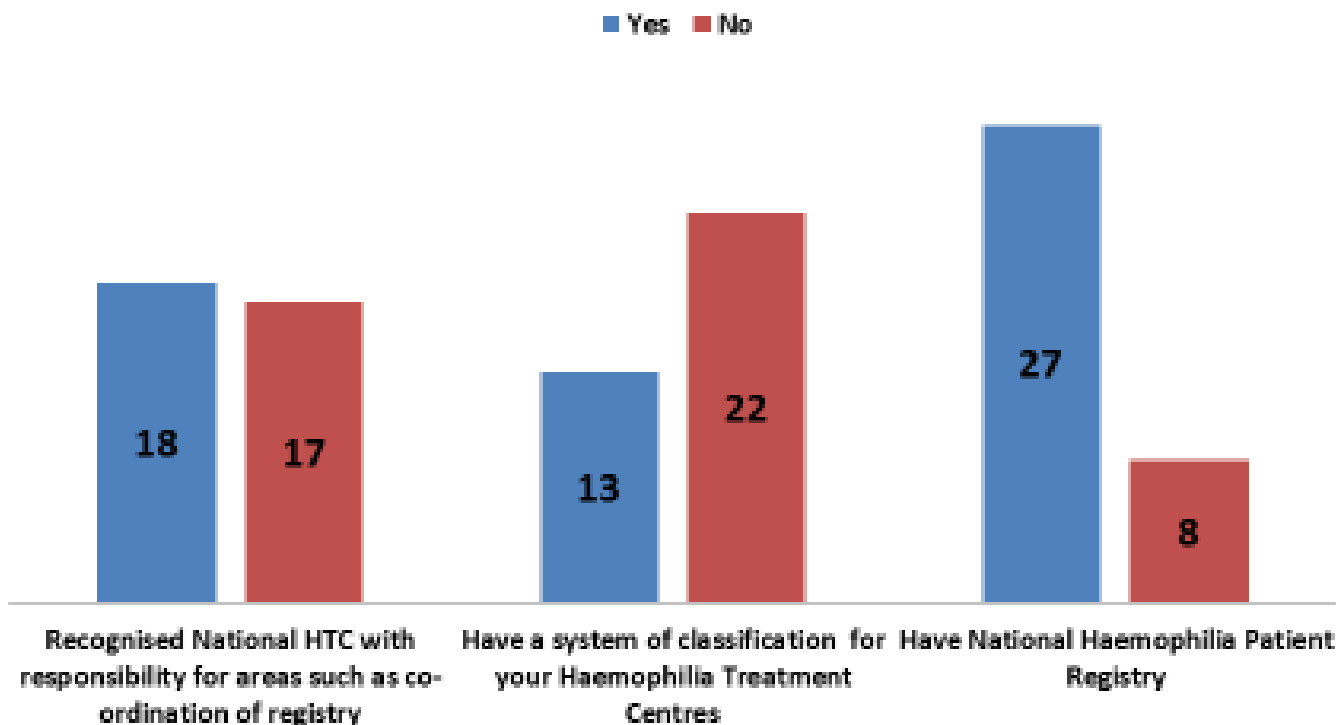
**President: Brian O'Mahony**



148 *Geographical Variation in the European Grasshopper*

Cronologia dos Regimes	
1930	Revolução
1934	Estado Novo
1936	Estado Novo
1938	Estado Novo
1940	Estado Novo
1942	Estado Novo
1944	Estado Novo
1946	Estado Novo
1948	Estado Novo
1950	Estado Novo
1952	Estado Novo
1954	Estado Novo
1956	Estado Novo
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2002	Estado Novo
2004	Estado Novo
2006	Estado Novo
2008	Estado Novo
2010	Estado Novo
2012	Estado Novo
2014	Estado Novo
2016	Estado Novo
2018	Estado Novo
2020	Estado Novo
2022	Estado Novo

# Survey of 35 countries (2)





# Survey of 35 countries (3)



- Involvement in management of the registry:
  - National Haemophilia Council or coordinating group: 6 countries
  - government: 4 countries
  - clinicians: 11 countries
  - academic organisation: 6 countries
  - national haemophilia patient org: 6 countries

# Survey of 35 countries (4)

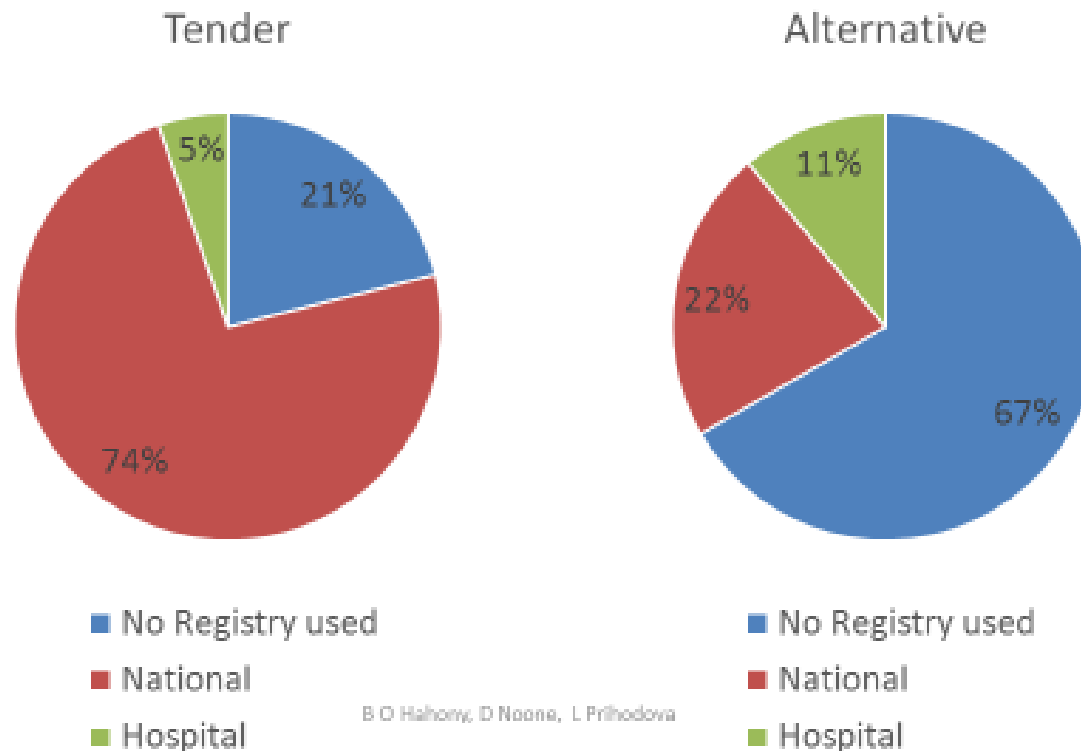


- 8 countries have more than one organisation involved
- In 18 countries there is a treatment centre which is designated as the national centre with responsibility for coordination, including the national registry

# Tenders and procurement survey



- Use of a registry to predict needed CFC volumes



# HTAs



- The Swedish HTA agency (TLV) as part of their assessment of prophylaxis in haemophilia mandated the creation of a national registry
- Employing new technologies in data collection not only may greatly improve collection of longitudinal data but also data of interest in HTAs

# Conclusions



- Each European country should have a national haemophilia registry maintained in a designated centre
- Too much rivalry may hinder development of national registries
- All patients in a country should be on national registry

## Conclusions (2)



- Ideally records should be continuously updated using a linked electronic patient record system utilised in all centres in a country
- Data from clinical studies should be made available and included in the established national and international databases and registries

## Conclusions (3)



- Who should have access to the data?
- Collaboration between clinicians and patient organisation
- Provides patients with an opportunity to contact/join national organisation
  - access to educational materials
  - planning of services by patient organisation

# Visit us



[www.ehc.eu](http://www.ehc.eu)

Facebook/EuropeanHaemophiliaConsortium

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Thank you!