

# 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

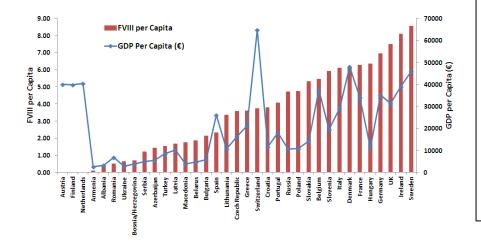
# Benefits of national registries (2)

- 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



### Haemophilia

The Official Journal of the Whole Federation of Hestophill Jumpeus Association for Hestophills and Afficial Hestophills and



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#### ORIGINAL ARTICLE

#### Haemophilia care in Europe - a survey of 35 countries

B. O'MAHONY, \* D. NOONE, \* P. L. F. GIANGRANDE? and L. PRIHODOVA?
\*bid: Ramophila Society, Debids, Indiand, Trafford Campothesian Hamophila Green, Oxford, UK; and 2Greekster
Schmid, Knitzer Institute for Society and Houlds, Medical Faculty, P.J. Edinki Unionesy, Knitze, Elmid, Espekhi

Summary. A quantisemain was circulated in 2012 to our kind barracybilla patient organizations in Benque affikantd to the European Hasmophilia Comortism (194C) and the World Endeation of Hemophilia (WFH) to setk information about the organization of hasmophilia care and transment available at a national level. The 33 responses received high-lighted major distribution in the availability of transmess and care. There was a wide senge in factor VIII commoppion with usage ranging from 0.20 fU per capita in Armenia to 0.56 fU per capita in Swedom (median) fU per capita). The docrease in health budgets in many commisse was not matched by docreases in use of PVIII per capita. In the 19 countries that repended to the previous norsey, them was a significant improvement in access to people-planic and being treatment.

Keywords Organisation, Specialist Care, Treatment

#### Introduction

A documere unclining the Bampeurs principles of harmosphila care, drafted by an interdisciplinary group of harmophila physicians with input from key patient opinion loaders and clinical name specialists, was published in 2006 [1]. This document was subsequently endorsed by both the European Harmophila Commission (ESPC) and the World Federation of Hermophila (WFFE) and was the misjort of an official lastech at the European Parliament in Brounds in January 2009.

The ten basic requirements contined in this article II are:

- Establishment of a control harmophilis organization in each country with supporting local group.
- National Haemophika patient ngintries.
   A network of multillaciplinary comprehensive care control and complementary haemophilia
- Partnership of health care professionals and patients in the delivery of homosphila care.
- Safe and effective concentrates at optimum treatment levels.
- 6. Home treatment and delivery.

DESIGNATION OF THE PARTY.

7. Peophylesis.

Correspondence B. O'Maluny, Irish Haermofellu Society, Cachedral Count, New Steet, Dubble E, Indoné. Tel. v 33: 33 437 9900; has v 33: 33 437 9900; a really belomble to the Society of the Society of

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- Specialis services and emergency care.
   Management of inhibitors.
- 10. Encouragement of education and newarch.

he 2010, a report on the Optimal Use of Blood and Blood products was published by the European division for the quality of medicine [2]. Assung the specific recommunications made in relation to treatment of Harmophilis was thus a mational level the minimum acceptable level of PVIII use should be at heart 2 EU per carits.

In 2009, we carried out a survey to determine the statest to which these enquirements of hasmophilis care already applied in the various countries within Rempe. [3]. A total of 19 countries empercisel. A further survey was carried out in 2012 and a total of 35 countries responded.

#### Methods

Bermsen February and July 2012, a questionnaire was developed and sent out to the 43 national hammophilia patiest organizations affiliated to the EDEC in all European countries. Responses were received from 35 countries. The national hammophilia organizations that expended were not asked to specify the sources of their dais, but typically they would have consulted clinicians and the national registry, whose one exists, in abilition to their own moords, it was not practical to sourcrain the precise concern of the information used by each national member organization in providing data for this survey, however, all information provided was provided with the box available knowledge

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# Survey of 35 countries

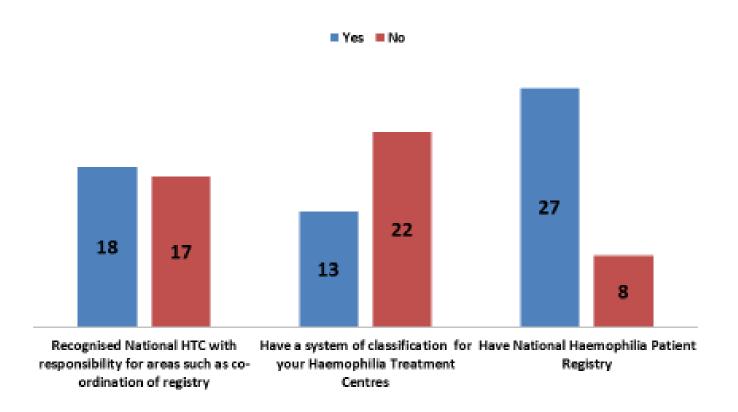


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# Survey of 35 countries (2)





# 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

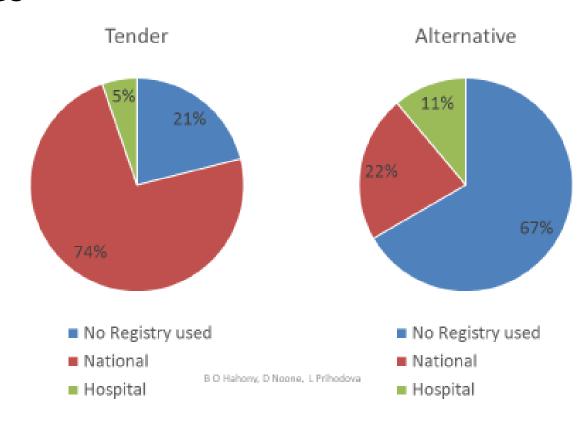
# Survey of 35 countries (4)



- 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



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Rue de l'Industrie 10, Brussels

Thank you!