Certification of Haemophilia Treatment Centres in Europe: The EHC View

HAEMOPHILIA CENTRE CERTIFICATION SYSTEMS ACROSS EUROPE

Rome, July 11, 2013

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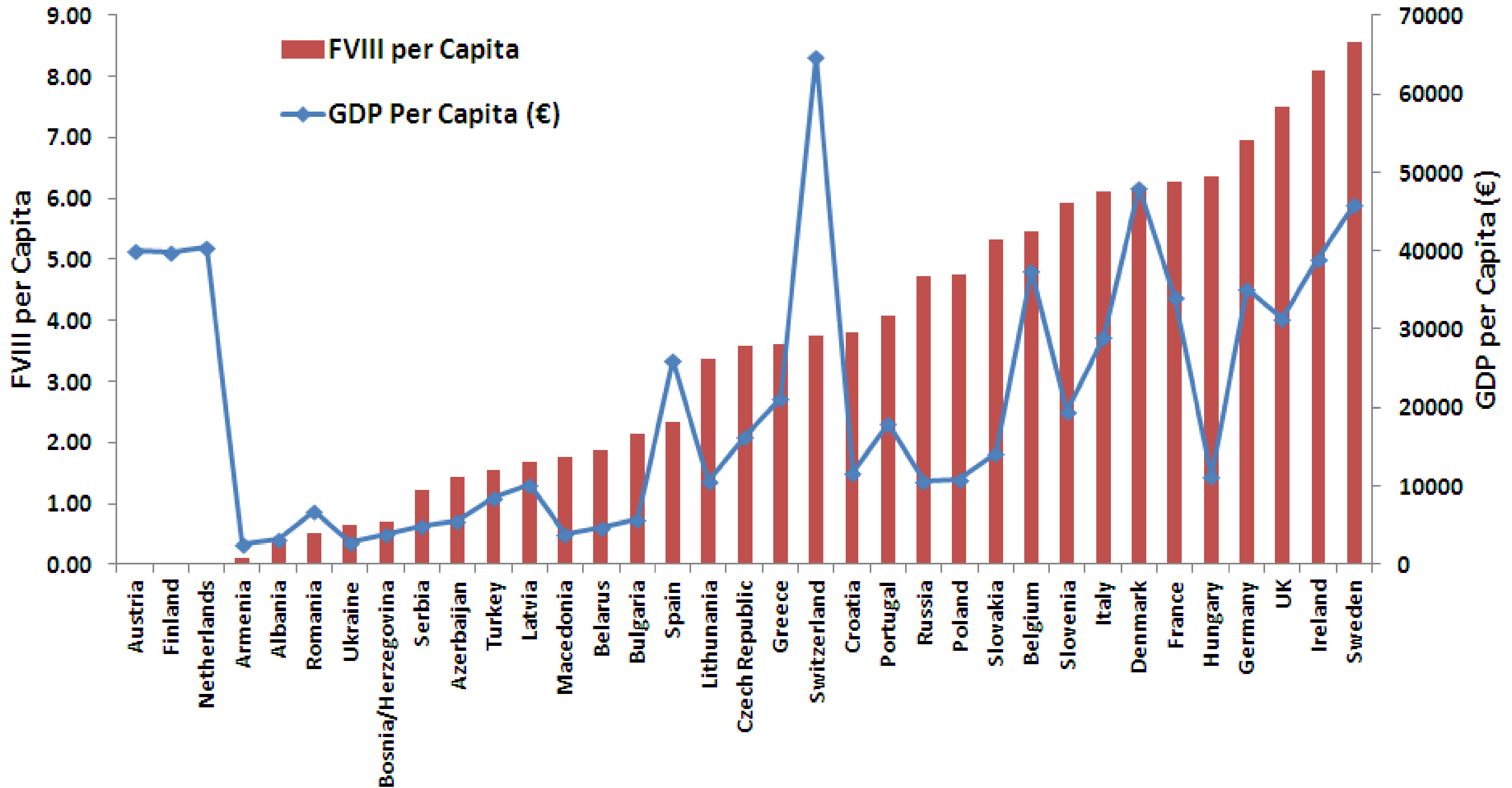
Requirement for Certification

- Great disparity in access to treatment in Europe
- Clear and identifiable gaps in access to comprehensive care
- Lack of clear definition of what constitutes a comprehensive care centre or a treatment centre
- Certification could lead to accreditation and peer reviewed external audit

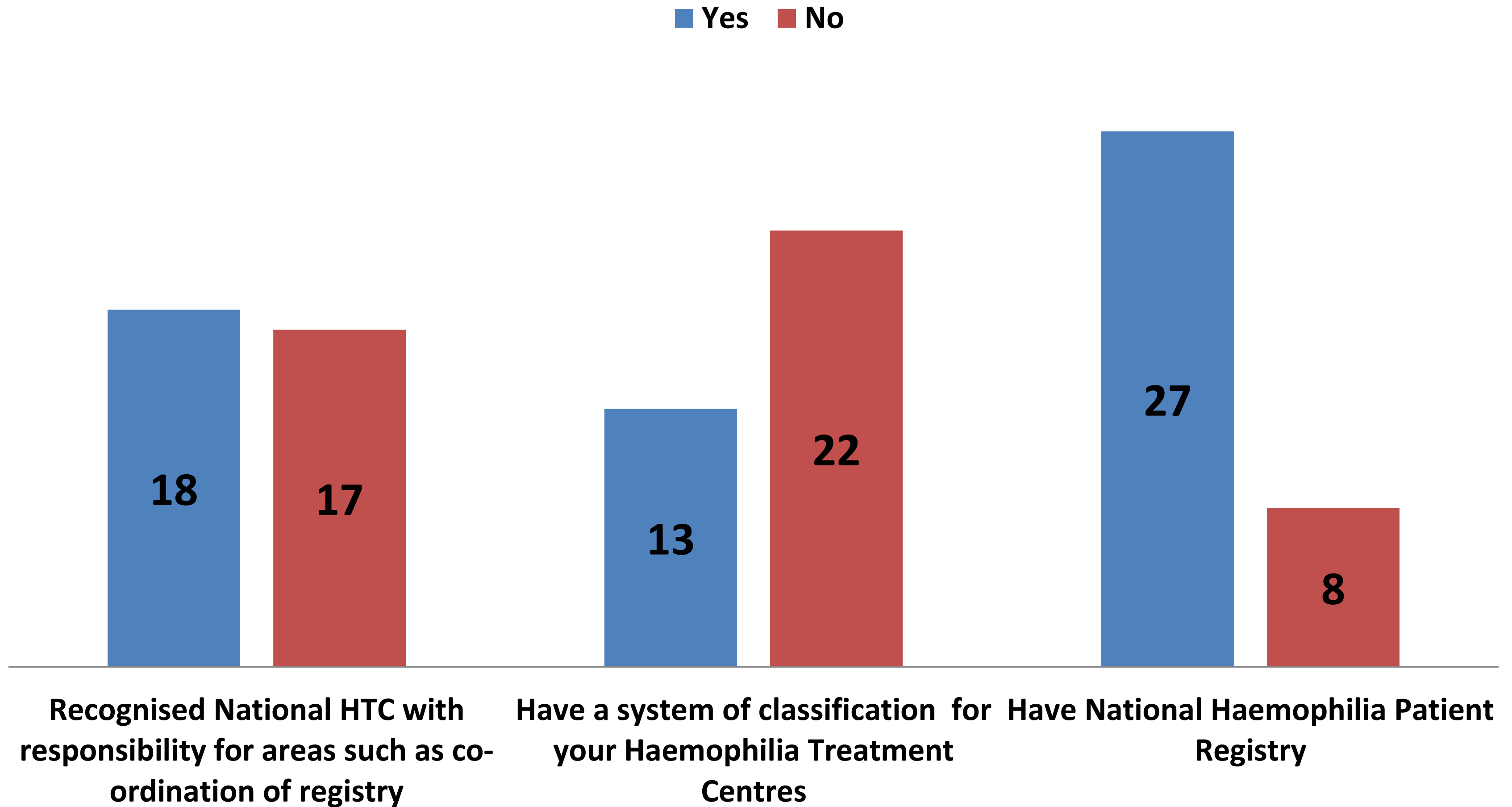
GDP per Capita (€) v FVIII per Capita



Organisation

- Optimum organisation on a national basis:
- National Treatment protocols
- National register
- Designated national centre
- Clearly designated comprehensive care and secondary centre's to meet demographic requirements of people with haemophilia

Co-Ordination and Registries



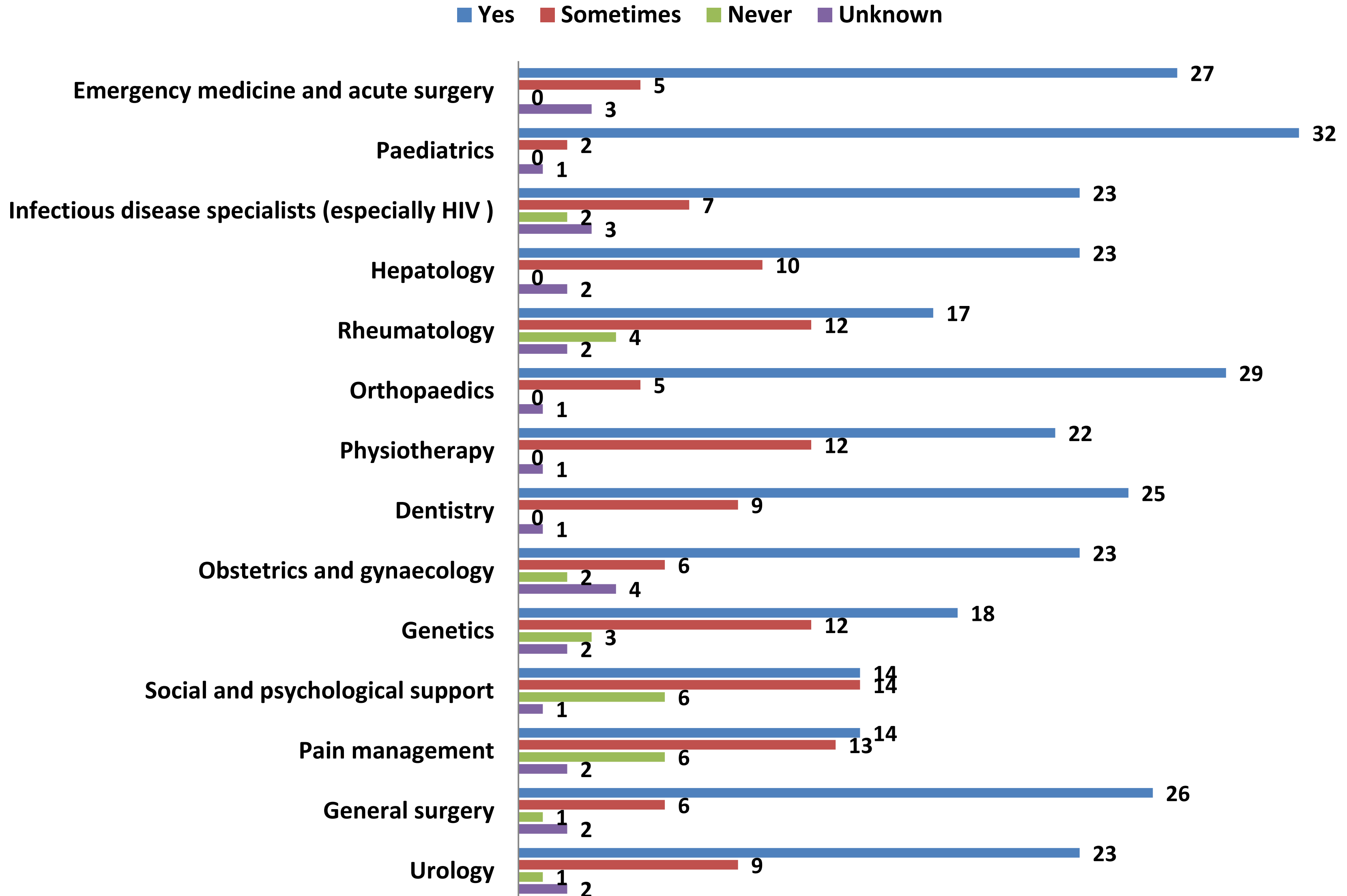
Organisation

- 22 of 35 Countries surveyed do not have a system for classification of their treatment centre's
- 17 of the 35 do not have a recognised national treatment centre

EAHAD Principles of care

1. Establishment of a central haemophilia organisation in each country with supporting local group
2. National Haemophilia patient registries
3. **A network of multidisciplinary comprehensive care centres and complementary haemophilia treatment centres**
4. Partnership of health care professionals and patients in the delivery of haemophilia care
5. Safe and effective concentrates at optimum treatment levels
6. Home treatment and delivery
7. Prophylaxis
8. Specialist services and emergency care
9. Management of inhibitors
10. Encouragement of education and research

Availability of Specialist Services



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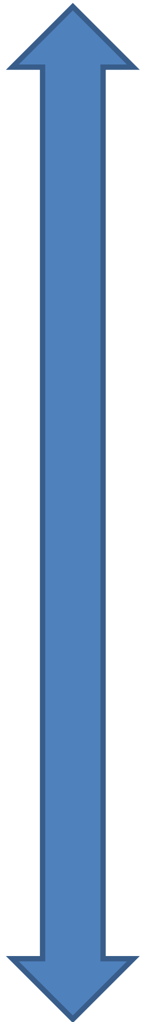

Least Availability

Social and psychological support
Pain management
Rheumatology
Genetics
Physiotherapy
Urology
Hepatology
Dentistry
Infectious disease specialists (especially HIV)
Obstetrics and gynaecology
General surgery
Emergency medicine and acute surgery
Orthopaedics
Paediatrics

Most Availability

	Yes	Sometimes	Never	Unknown
Emergency medicine and acute...	27	5	0	3
Paediatrics	32	2	0	1
Infectious disease specialists...	23	7	2	3
Hepatology	23	10	0	2
Rheumatology	17	12	4	2
Orthopaedics	29	5	0	1
Physiotherapy	22	12	0	1
Dentistry	25	9	0	1
Obstetrics and gynaecology	23	6	2	4
Genetics	18	12	3	2
Social and psychological support	14	14	6	1
Pain management	14	13	6	2
General surgery	26	6	1	2
Urology	23	9	1	2

Deficiencies in Comprehensive Care

Sometimes or Never available :

- Social and Psychological support- 20 countries
- Pain management – 19 countries
- Rheumatology – 16 countries
- Genetics – 15 countries
- Physiotherapy – 12 countries

Benefits of Certification

- Resources and expertise can be allocated based on level of centre and number of patients treated
- Designation of primary (Comprehensive) and secondary (Treatment) centres would allow for appropriate planned availability of specialist services

 - Example; orthopaedic surgery or genetics may only be available at comprehensive centre’s

Benefits of Certification

- Allows for development of accreditation system
- Allows for initiation of peer reviewed external audits
- Audits currently carried out in UK and Ireland

External Audits - Ireland

- Based on UKHCDO model
- Comprehensive centres (3) audited by team comprising Doctor, Nurse and Person with Haemophilia from abroad
- Treatment centres (3) audited by Doctor, Nurse and person with Haemophilia from Ireland

Advantages of audit

- Identification of deficiencies in service
- External nature of audit team increases probability of deficiencies being dealt with in a timely manner
  - Adverse outcome may generate media interest
- Learning experience for all staff
- Staff at Irish centres welcome the external audits

The state of haemophilia services

With an audit scheduled for later this month, Lloyd Mudiwa finds that moves to improve haemophilia services may be coming too late to impact the review

The Chief Executive of St James's Hospital, Dublin, promised auditors, during the last audit of the haemophilia service in the Hospital in November 2006, that an inpatient facility will be in place within two and a half years.

A patient asked to comment about the service at the Hospital in the same audit – a part of the peer-reviewed triennial audits of the three main comprehensive haemophilia care centres in Ireland – commented: "I am very grateful to the service we receive from all the carers, who are our friends as well as medical providers."

The promise and the patient's comment best sum up the state of haemophilia services in Ireland: Blessed with a hard-working and professional staff, but lacking in sufficient facilities and other resources including staff.

Apart from St James's Hospital, Our Lady's Hospital for Sick Children, Crumlin, Dublin, and Cork University Hospital (CUH)

"We have had constructive meetings with the Department of Health and the National Hospitals Office, and a lot of progress has been made in moving forward. I think there is a degree of understanding.

"One of the main advantages of having a Council in place, which we have pointed out to the Department of Health and the HSE, is that we set out clearly what we feel are the priorities for all the comprehensive centres.

"This gives them a very clear mandate, not just of clinicians, but also of the IHS, HSE and the Department of Health.

"The Department and the HSE have to recognise that rather than having 20 or so hospitals submitting their requirements, it is beneficial to have the Council shortlist the absolute priorities for three main centres, particularly given the recession. But then, you do expect to get movement if you are going to get competent services."

Mr O'Mahony explained that

of a formalised 24-hour on-call rota for specialised coagulation tests.

Although patients were admitted to the haematology/oncology ward, it is often difficult to find a bed and the ideal would be a new dedicated inpatient facility for haemophilia.

However, St James's Hospital will finally be going to tender shortly for the construction of a centralised inpatient unit for haemophilia and hepatology in the Hospital (*IMN 01/09/2008*), said Mr O'Mahony, who hoped it would be completed in 2009/2010.

The auditors also mentioned that as a national centre for specialised coagulation tests, the NCHCD should offer von Willebrand factor (vWf) multimers, platelet nucleotide and Factor VIII (FVIII) binding in-house, rather than sending these to the UK.

When patients were asked to comment on what was particularly good about the centre, the most common response was the staff.

St James's Hospital, Dublin

with bleeding episodes. Consequently, the outpatient reviews are carried out by another doctor who comes from St

ed the haemophilia centre, the audit report stresses.

However, Mr O'Mahony highlighted that a modular centre

es and storage of medical reports of patients with inherited bleeding disorders, which should be readily available on a 24-hour

External Peer Audits

- Crucial element in identification of deficiencies and improving care
- EQAS accepted for laboratories
  - Why not for haemophilia services
- Examine service through the prism of others experience

External Peer Audits

- Health service and Ministry attach more importance to external audits
- More interesting for Media
- An imminent audit focuses the staff and budget holders on correcting previously identified deficiencies

External Peer Audits

- Incomplete without Patient Representative
- Brings different perspective and experience to team
- Increases confidence of the Haemophilia Society in the process
- Advantages of Audits obvious to Health care workers, Haemophilia Society, NHC and Ministry of Health

Views of Treatment Centre Staff

- Audits viewed as positive and helpful
- Seen as assisting them in identification of deficiencies in service and in obtaining resources required
- Degree of apprehension before first audit- not seen with subsequent audits
- More preparatory work required for first audit

Views of Treatment Centre Staff

"Inclusion of a patient representative was great as he asked different and very relevant questions."

" I feel that the process gave me recognition for the work that I do."

" Will help me to improve how I do my job."