

Haemophilia Centres Certification in the Netherlands



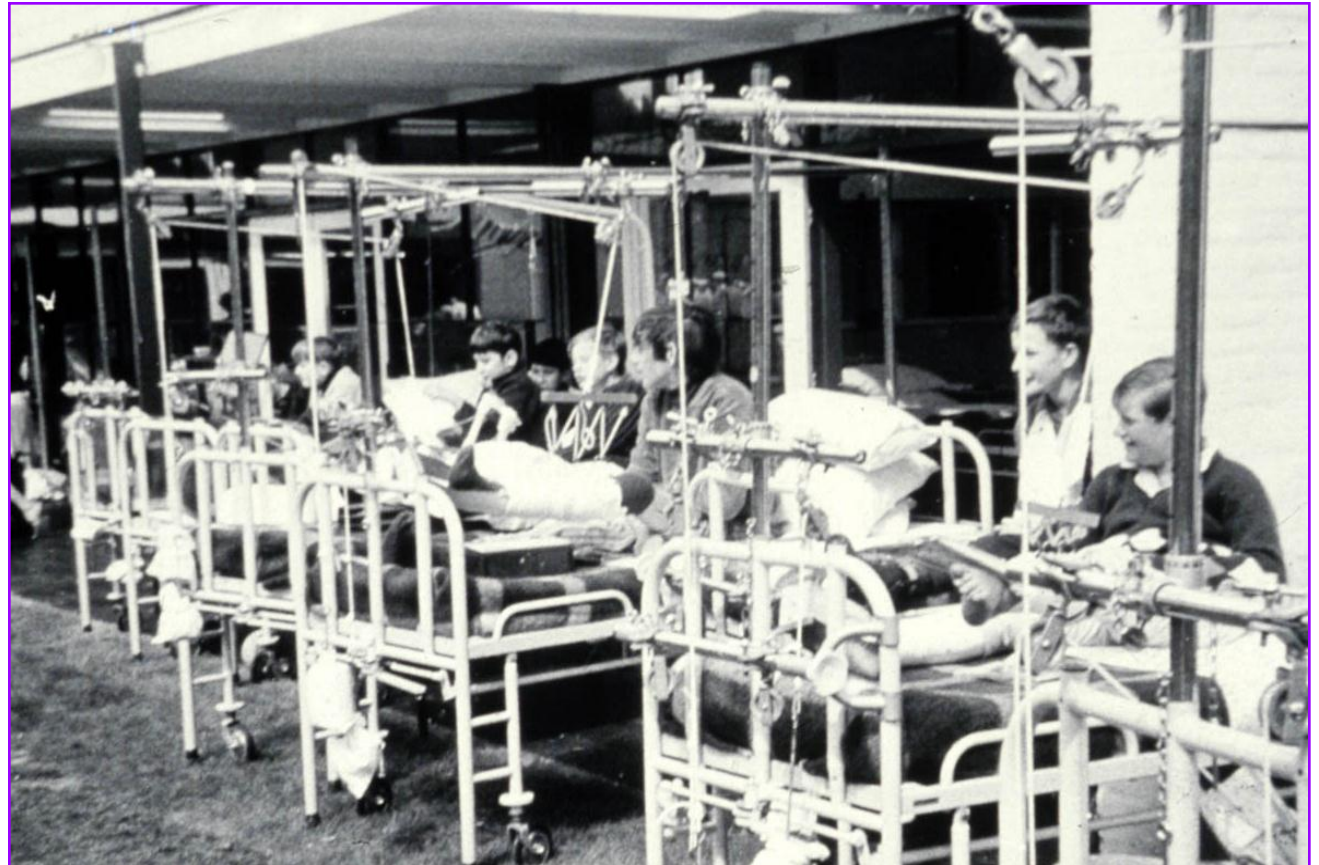
Kathelijn Fischer, MD PhD

Van Creveldkliniek, Dept of Haematology
UMCU, Utrecht, Netherlands

Haemophilia care in the Netherlands (I)

1964: founding of the Van Creveldkliniek

Comprehensive care including doctor, nurse, physiotherapist,
social worker, teacher





Haemophilia care in the Netherlands (II)

The Netherlands, 400x300 km, 16 Million inhabitants

- 1987: first consensus guideline on haemophilia treatment by Dutch Association of Haemophilia Treaters (NVHB)
- 1991: one national centre (Van Creveldkliniek)
8 regional centres
21 other treatment centres
- 2000: order of Minister of Health to concentrate care & clotting factor concentrates limited to HTC's
- 2002: still 13 HTC's



Haemophilia care in the Netherlands (III)

2008:

NVHB received funding from Minister of Health to improve quality of haemophilia care

Colvin et al: Principles of Haemophilia Care

(Haemophilia 2008;14:361)

Start of two projects

1. Defining national standards of care → certification
2. Designing and building a National Registry

Dutch standards of haemophilia care



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2009-2011

Project group Doctors (from large & smaller centres), Nurses, patient representative

Collaboration with institute for harmonization of quality standards in clinical care (HKZ)

1. Research: Study of available literature and visits to centres
2. Concept standards
3. Validation of concept standards in 2 centres
4. Discussion in the field: treaters, payers, patients, regulators
5. Final version of standards discussed and approved by Central body of Experts on quality standards in clinical care (CCvD-Z/W)

Dec 5th 2011- Quality Standards published



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Certificatieschema >

Hemofiliebehandelcentra

Versie 2011



Contents of quality standards

- I Practical conditions for optimum care
- II Execution of haemophilia care
- III CECK and ACT: evaluation and improvement



Contents: 'critical' standards (I)

1. Nr of patients :
 - Minimum 40 with severe haemophilia
 - Including 10 children
2. Multidisciplinary team including:
 - Physician for adults
 - Pediatrician
 - Haemophilia nurse
 - (Paediatric) physiotherapist
 - Social worker / (paediatric)psychologist



Contents: 'critical' standards (II)

3. Protocols for:

- Diagnostics
- Administration of clotting factor concentrates
- Treatment of bleeds
- Prophylaxis
- Peri-operative treatment
- Emergency department treatment
- Treatment of bleeds in inhibitor patients
- Immune tolerance induction
- Prevention and treatment of viral infections
- Management of pregnant carriers
- Teaching home treatment



Contents: 'critical' standards (III)

4. 24 hours' patient care available
5. Always haemophilia specialist on call
6. Each patient has individual treatment plan
7. Sufficient stock of concentrates
8. Use of National Registry (after institution)
9. Registration of side-effects in National System (KWARC)
10. Meetings: pediatric & adult physicians- every month
multidisciplinary grand round, 4x/yr
orthopedics, rehabilitation, physiotherapist, 6x/yr
gynaecologist, geneticist, 4x/yr

Certification

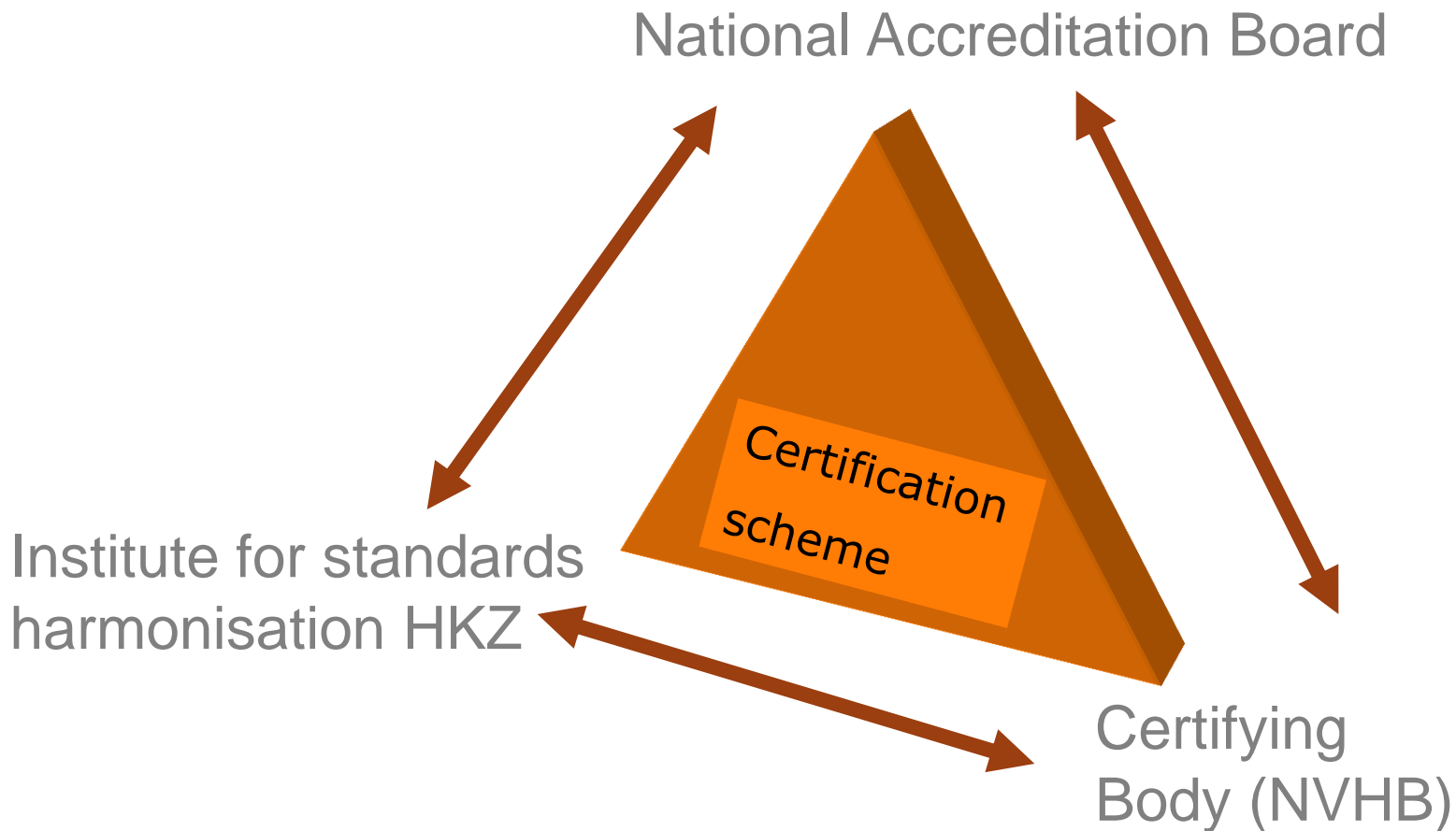


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- Accreditation of standards
 - Independent lead auditor
 - Use of experts
 - Certification-rules
- Quality certificate



Accreditation of Standards



Initial audit

Lead auditor, 2 experts (nurse & doctor)

- Phase I paperwork (protocols etc) & documentation
- Phase II practical implementation of standards

repeat every 3rd year

Annual surveillance

Lead auditor

(re) certification after 3 years



What if standards are not met?

- Minor shortcomings
 - Small deviations or non-critical standards
 - No immediate 'risk' for hospital
 - improvement within 3 months
 - Major shortcomings
 - Large deviations on critical standards
 - Immediate high risk for hospital
 - Or : non improvement of minor shortcoming
 - Issuing of label 'shortcoming' if one/more critical standards are not met
 - Improvement within 1 month
- No certification / withdrawal of certification**

- Training of 80% of expert auditors is completed
- Visits will start after summer 2013
- First round completed by summer 2014
- Registry:
 - working group of NVHB and patients' organisation
 - Application for additional funding

Thank you



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Table 1. The European principles of care according to Colvin *et al.* [6].

1. A central haemophilia organization with supporting local groups
 2. National haemophilia patient registries
 3. Comprehensive care centres (CCCs) and Haemophilia treatment centres (HTCs)
 4. Partnership in delivery of care
 5. Safe and effective concentrates at optimum treatment levels
 6. Home treatment and delivery
 7. Prophylactic (preventive) treatment
 8. Specialist services and emergency care
 9. Management of inhibitors
 10. Education and research
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Comprehensive
care centre (CCC)

Haemophilia
treatment centre (HTC)

Minimum of 40 patients with
severe haemophilia (FVIII/IX <1%)

24 h specialized care available

24 h lab service available

Provide multidisciplinary
comprehensive care teams,
including:

Employment of one full time
haematologist and/or

paediatrician

Dedicated nurse

Experienced physiotherapist

Social worker

Data management

Provide home treatment,
prophylaxis, inhibitor
treatment & ITI

Access to OBGYN,
orthopaedics, dental care,
genetics

Carry out clinical audits
(internal essential, external
desirable)

Adhere to consensus guidelines
and provide medical education

Perform and/or initiate research

No minimum number of patients
specified

24 h specialist cover

Lab services available (with delay)

Provide multidisciplinary
comprehensive care teams,
including:

Employment of one full time
haematologist and/or

paediatrician

Access to dedicated nurse

Access to experienced
physiotherapist

Access to social worker

Keep adequate records

In collaboration with CCC:
provide home treatment,
prophylaxis, inhibitor treatment
& ITI

In collaboration with CCC:
provide access to OBGYN,
orthopaedics, dental care, genetics

Carry out internal clinical audits

Adhere to consensus guidelines
and provide medical education

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Table 3. Adherence to principles 1, 2, 3 and 7 according to country.

Country	No. of centres	Principle 1 central organization	Principle 2 patient registry	Principle 3 all patients treated in CCC/HTC	No of CCC/HTC per million inhabitants
Belgium	1	No	No	No	0.83
France	1	Yes	Yes	Yes	0.71
Germany	2	Yes	Yes	No	0.89
Greece	1	Yes	Yes	Yes	0.37
Italy	3	Yes	Yes	Yes	0.81
Netherlands	2	Yes	No	Yes	0.78
Norway	1	Yes	No	Yes	0.40
Poland	1	Yes	No	No	0.84
Portugal	1	No	No	No	3.77
Slovakia	1	Yes	Yes	Yes	7.78
Spain	3	No	Yes	Yes	0.91
Sweden	1	Yes	No	Yes	0.32
Switzerland	1	Yes	Yes	No	1.27
United Kingdom	2	Yes	Yes	Yes	1.06
	Total 21	79% Yes	57% Yes	64% Yes	Median 0.84 IQR0.62–1.11