CROSS-BORDER ACCESS TO HEALTHCARE

INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

OVERVIEW

Primary health condition

- A medical issue leading to an impairment
- Not all PwD have it
- Arthritis, glaucoma, heart disease, CP

Secondary health condition

- Caused by the primary health condition
- Can be preventable
- Pressure ulcers, UTI, osteoporosis, pain

Co-morbid conditions

- Unrelated to the primary health condition
- Behavioural, socioeconomic, environmental factors
- Depression, obesity, high blood pressure

LIVING WITH SPINA BIFIDA (AND HYDROCEPHALUS)

IFSBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

DIRECTIVE 2011/24/EU OF PATIENTS' RIGHTS IN CROSS-BORDER HEALTHCARE

Aims:

- Facilitate the access to safe and high-quality ross-border healthcare
- Promote cooperation on healthcare between Member States

Scope:

- Provision of healthcare to patients, regardless of how it is organized, delivered and financed.

Exceptions:

- long-term care; organ transplantation; vaccination against infectious diseases within one territory
- HCP that are not part of the national social security system

IFSBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

DISABILITY-SPECIFIC PROVISIONS OF THE DIRECTIVE

- National contact points (NCPs) should be able to provide the information about the **accessibility of hospitals** to persons with disabilities (Art 4.2(a)
- Information provided by the NCPs should be made available by electronic means and in **formats accessible** to people with disabilities (Art 6.5)
- Member State may decided to reimburse **extra costs** which persons with disabilities might incur due to one or more disabilities when receiving cross-border healthcare (Art 7.4 3rd sentence)

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EUROPEAN REFERENCE NETWORKS

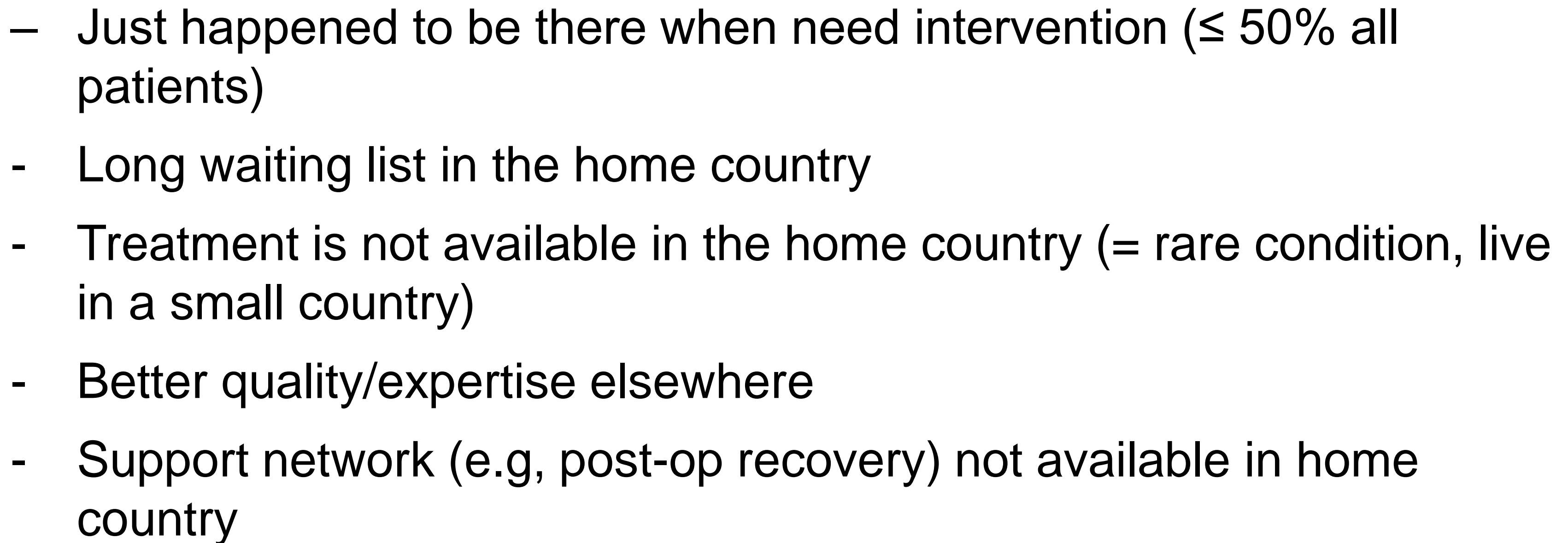
- Voluntary networks between healthcare providers and centres of expertise in the Member States in the area of rare diseases

- Foster European cooperation in highly specialized healthcare
- Improve diagnosis and delivery of high-quality care of rare conditions
- Maximise cost-effectiveness

- First 24 ERNs were designated in 2017
- Include a component of patient involvement

https://ec.europa.eu/health/ern/overview_en

WHY GO ABROAD FOR HEALTHCARE?



CRPD CONCLUDING OBSERVATIONS TO THE EU, 2015

- "notes the barriers faced by persons with disabilities in accessing health care in different member States"

- "recommends that the European Union (…) evaluate the impact of the (…) Directive 2011/24/EU on patients' rights in cross-border health care with regard to gaps in access for persons with disabilities, including **accessible information**, **reasonable accommodation** and **training of professionals**."

IF 2016 REPORT ON IMPACT OF CBHC ON PERSONS WITH DISABILITIES AND/OR CHRONIC CONDITIONS

- In collaboration with EPF and EDF
- Small-scale survey (<300 respondents)
- Complemented by IF’s own research and analysis
- Launched at EP in 2017

IF REPORT FINDINGS: LACK OF AWARENESS

77% respondents have never heard about the Directive

- Confirmed findings of the Special Barometer 425 (2015) – does not mention PwD
- 2015 Commission report on the operation of the Directive – does not mention PwD
- Commissioner Andriukaitis (24 October 2016) – does not mention PwD

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IF REPORT FINDINGS: NATIONAL CONTACT POINTS

86% have never heard of NCPs

- Most respondents prefer to access information online
- 12 out 24 NCPs do not provide info in accessible formats (notable exceptions: PL, SE)
- PL NCP receives four times more requests for information than any other MS (Commission, 2015)

https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/cbhc_ncp_en.pdf

IF REPORT FINDINGS: USE OF CBHC

Overall use of CBHC is low

- Not unexpected (people prefer to get care at home)
- Most respondents of the 2016 survey never used it

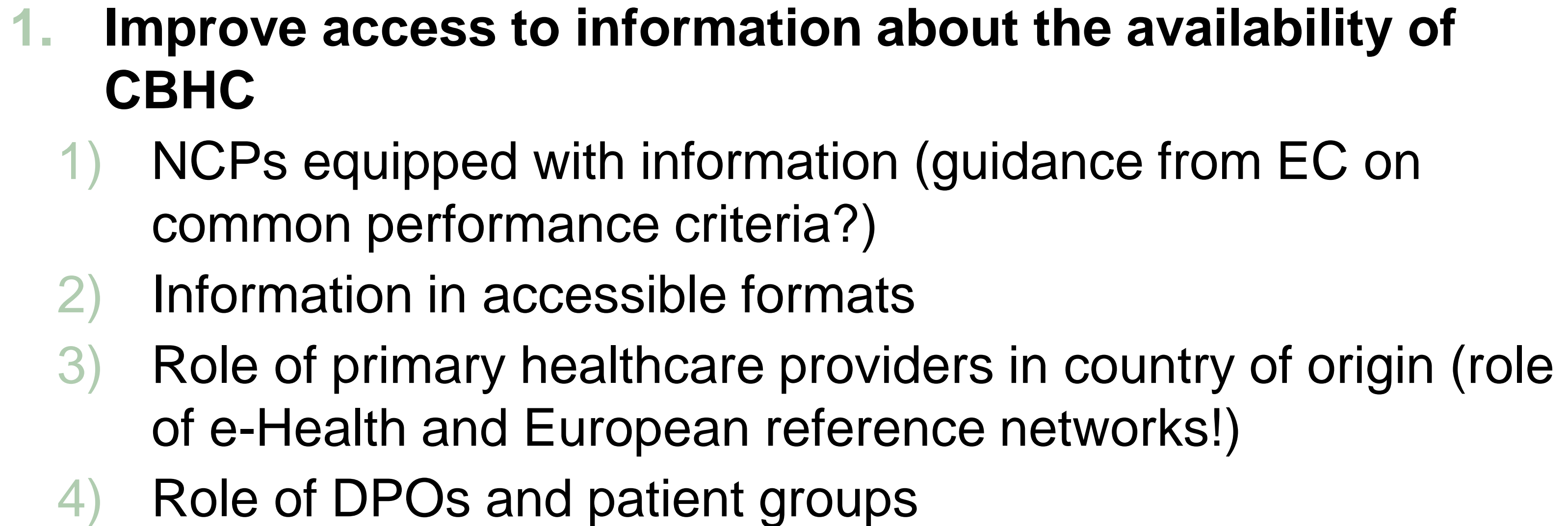
- Germany is the most important destination country for users of CBHC
  - Easiest to get reimbursement for care received in Germany
  - More requests for prior authorization of care in Germany granted

IF REPORT FINDINGS: REIMBURSEMENT

Reimbursement is low, unequal and uncertain

- Direct costs were reimbursed in only 23% cases
- 50% respondents did not receive any reimbursement (did not know how to seek; treatment was not reimbursable under national healthcare; prior authorization had not been sought)
- 76% respondents were not reimbursed for **additional costs** (personal assistant, reasonable accommodation, accessible transport or hotel)

CONCLUSIONS AND RECOMMENDATIONS I



1. **Improve access to information about the availability of CBHC**
    1) NCPs equipped with information (guidance from EC on common performance criteria?)
    2) Information in accessible formats
    3) Role of primary healthcare providers in country of origin (role of e-Health and European reference networks!)
    4) Role of DPOs and patient groups

CONCLUSIONS AND RECOMMENDATIONS II

2. **Improve reimbursement schemes**
   1) Prior authorization only in cases specified by the Directive
   2) Transparent information providing patients with certainty
   3) Reasonable reimbursement rates

3. National policies on (non-)reimbursement of additional costs must not be **indirect discrimination** against persons with disabilities (= same treatment, different effect)
   1) Clear reasonable accommodation policy in place supported by a fund to reimburse additional disability-related costs

Thank you!

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