

**EUCERD Joint Action / Work Package 4
EUROPLAN National Conference**

**Workshop Theme 2
DEFINITION, CODIFICATION,
INFORMATION & TRAINING**

Relevant extracts from the

COUNCIL RECOMMENDATION

on an action in the field of rare diseases

(2009/C 151/02)

8 June 2009

COUNCIL RECOMMENDATION

(The Council of the EU) “HEREBY RECOMMENDS that Member States:

II. Megfelelő definíció, RB-eg kodifikációjának helyzete:

- Use for the purposes of Community-level policy work a common definition of rare disease as a disease affecting no more than 5 per 10 000 persons.
 - **Ez a definíció elfogadott Magyarországon.**
- Aim to ensure that rare diseases are adequately coded and traceable in all health information systems, encouraging an adequate recognition of the disease in the national healthcare and reimbursement systems based on the ICD while respecting national procedures.
 - **Az cél elfogadott és komoly törekvések vannak ebbe az irányba.**

COUNCIL RECOMMENDATION

- Contribute actively to the development of the EU easily accessible and dynamic inventory of rare diseases based on the Orphanet network and other existing networks as referred to in the Commission Communication on rare diseases.
 - Ezek a honlapok Mo-on ismertek. A honlapok a graduális és postgraduális oktatás részét képezik. Egyre több hazai adat is szerepel ezekben.

COUNCIL RECOMMENDATION

- Consider supporting at all appropriate levels, including the Community level, on the one hand, specific disease information networks and, on the other hand, for epidemiological purposes, registries and databases, whilst being aware of an independent governance.”
 - Regiszterek és biobankok
 - Myocardialis inf., hepatitis, IBD regiszter
 - Országos Gyermektumor Reiszter
 - CF regiszter
 - Számos hazai betegség regiszter

INDIKÁTOROK A NEMZETI RITKABETEGSÉG STRATÉGIÁBAN AZ EUCERD AJÁNLÁSA ALAPJÁN

EUCERD Core Indicators, full version:

http://www.eucerd.eu/wp-content/uploads/2013/06/EUCERD_Recommendations_Indicators_adopted.pdf

Core Indicators

N°4. Adoption of the EU RD definition

Short Definition =

**Definition as laid down in OD Regulation EC 141/2000 &
Cross Border Health Care Directive 2011/24/EU:**

"no more than 5 patients per 10 000 persons,,

Rendben van.

Core Indicators

N°8. NP/NS support to the development of/participation in a comprehensive national and/or regional RD information system

Existence of a nation-wide, comprehensive RD specific information system.

The participation in Orphanet Joint Action is also included.

A Nemzeti Terv támogatja az országos és/vagy regionális regiszterek kialakítását.

Core Indicators

N°9. Existence of Help lines for RD

Refers to Help Lines for professionals only, for patients only and for both. Supported by private, public funding, or both.

**Nemzeti és/vagy regionális segítő vonalak kialakítása folyamatban van.
Alapvetően anyagi kérdés.**

Core Indicators

N°11. Type of classification/coding used by the health care system

Type of coding system(s) used in view of better RD management and ultimately harmonising RD nomenclature

A jelenlegi hivatalos BNO kód még nem tartalmazza az újat, de átvétele napirenden van.

Core Indicators

N°12. Existence of a national policy on registries or data collection on RD

Public support for their development and sustainability

A hazai társadalmi támogatottság egyértelmű.