



PATIENT EMPOWERMENT




TABLE OF CONTENT

- Relevant extracts from the **RECOMMENDATION of the Council of the European Union** on “an action in the field of rare diseases”.
- Relevant extracts from the **RECOMMENDATION of the EUCERD** - European Union Committee of Experts on Rare Diseases – on ‘**Core Indicators**’ for planning, implementing and monitoring national Rare Disease Plan or Strategy.

The EUCERD brought together the 28 EU Member States plus Norway, Iceland and Switzerland, and stakeholders from patients’ organisations, academia and industry.

- Relevant extracts from the **RECOMMENDATION of EUROPLAN** – EU co-funded project aimed at developing and implementing national Rare Disease Plan or Strategy.
- Relevant extracts from **EUROPLAN Indicators**.



Relevant extracts from the
RECOMMENDATION
of the EU COUNCIL
on an action in the field of rare diseases
(2009/C 151/02)
8 June 2009

EU COUNCIL RECOMMENDATION

“HEREBY RECOMMENDS that Member States:

18. Consult patients and patients' representatives on the policies in the field of rare diseases and facilitate patient access to updated information on rare diseases.
19. Promote the activities performed by patient organisations, such as awareness-raising, capacity-building and training, exchange of information and best practices, networking and outreach to very isolated patients.”

Relevant extracts from the
EUCERD CORE INDICATORS for
RD National Plans / Strategies



EUCERD CORE INDICATORS

N°3. Permanent and official patients' representation in plan development, monitoring and assessment

Patients are represented at all stages of plan development and governance, including its monitoring and assessment

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.

EUCERD CORE INDICATORS

17. Existence of programmes to support the integration of RD patients in their daily life

Examples of social services to integrate patients in their daily life are:

- a) educational support for patients, relatives and caregivers
- b) individual support at school, for both pupils with RDs and teachers, including disease-specific good practices
- c) activities aimed to foster higher education for people with rare diseases
- d) supporting mechanisms to participate in work life for people with disabilities

Relevant extracts from the
EUROPLAN RECOMMENDATIONS
**for the development of RD National Plans/
Strategies**



EUROPLAN RECOMMENDATIONS

- R 6.1 Advocacy of patients' needs by patients' associations is recognised as an important element in defining policies on rare diseases; the organisation of a national umbrella organisation that represents the interests of all rare diseases patients is encouraged.
- R 6.2 The patients' organisations are involved in decisions making processes in the field of rare diseases.
- R 6.3 Valid information on rare diseases is produced and made available at national level in a format adapted to the needs of patients and their families.
- R 6.4 National information of interest to patients is communicated to EURORDIS for publication in its website.
- R 6.10 The activities aiming at patients' empowerment carried out by patients' associations are facilitated.

Relevant extracts from the
EUROPLAN INDICATORS
**for the development of RD National Plans/
Strategies**



EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
Promoting the existence of a RD patients' organisation that represents all RD patients' associations	Number of umbrella organisations specific on rare diseases	Process	<input type="checkbox"/> No <input type="checkbox"/> Existing only one organisation <input type="checkbox"/> Existing more than one organisations
	Having a directory of RD Patients' organisations	Process	<input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> In process
	Number of patients' associations	Outcomes	Number of patients associations
	Number of diseases covered by patients' associations	Outcomes	Number of diseases covered by patients' associations
Building - supporting the existence of comprehensive help line for patients	Availability of Help line for RD	Process	<input type="checkbox"/> Own help line <input type="checkbox"/> Referred RD help lines <input type="checkbox"/> Not formal decisions have been taken

EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
Patients' organisations involvement in decisions affecting RD	Permanent and official patients' representatives in plan development, monitoring and assessment	Process	<input type="checkbox"/> Yes, clearly established, substantially implemented and participation reimbursement considered <input type="checkbox"/> Considered in the plan, not effectively implemented <input type="checkbox"/> Not considered
	Participation of patients' organisations in the development of RD research strategies	Process	<input type="checkbox"/> Yes <input type="checkbox"/> Only as observers <input type="checkbox"/> Are consulted before the final document is approved <input type="checkbox"/> No
	Participation of patients organisations in the RD centres of expertise designation and evaluation	Process	<input type="checkbox"/> Yes <input type="checkbox"/> Only as observers <input type="checkbox"/> Are consulted before the final document is approved <input type="checkbox"/> No

EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
<p>Support the activities performed by including patient organisations, such as:</p> <ul style="list-style-type: none"> - Awareness raising - Capacity building and training - Exchange of information and best practices - Networking - Outreach to very isolated patients 	<p>Resource (funding) provided for supporting the activities performed by patient organisations</p>	<p>Outcomes</p>	<p>Number of Euros allocated for activities supporting patients' organisations</p>
	<p>Support to sustainable activities to empower patients, such as:</p> <ul style="list-style-type: none"> - Awareness raising - Capacity building and training - Exchange of information and best practices - Networking - Outreach to very isolated patients 	<p>Outcomes</p>	<p>Number of activities per year sponsored within the plan</p>