



**SOCIAL SERVICES
AND PROGRAMMES
ADAPTED TO
RARE DISEASES**




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- 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:

17. Gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support:
 - (a) the sharing of best practices on diagnostic tools and medical care as well as education and social care in the field of rare diseases.
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

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 4.12 The adoption of an ad hoc coding is promoted, when appropriate, to recognize and appropriately resource and reimburse the special rehabilitation treatments necessary for rare diseases.
- R 6.5 Specialised social services are supported for people living with a chronically debilitating rare disease and their family carers.
- R 6.6 Specialised social services are established to facilitate integration of patients at schools and workplaces.
- R 6.7 A directory of centres providing specialised social services, including those offered by patients' associations, is compiled, kept updated and communicated to national, regional and patients' websites.

EUROPLAN RECOMMENDATIONS

- R 6.8 Interactive information and support services for patients are promoted (such as help lines, e-tools etc).
- R 6.9 Information and education material is developed for specific professional groups dealing with rare diseases patients (e.g. teachers, social workers, etc.).
- 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
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
Compensating disabilities caused by rare diseases	Existence of official programs supporting patients and families with disabilities	Process	<input type="checkbox"/> Not existing, not clearly stated <input type="checkbox"/> Existing, clearly stated, partly implemented and enforced <input type="checkbox"/> Existing, clearly stated and substantially implemented and enforced
	Existence of an official directory of social resources for patients with disabilities	Process	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In preparation

EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
Supporting social services aimed at rare disease patients and their families	Existence of national schemes promoting access of RD patients and their families to Respite Care services	Process	<input type="checkbox"/> Yes <input type="checkbox"/> Yes, and it includes financial support to patients / families <input type="checkbox"/> No <input type="checkbox"/> In preparation
	Existence of public schemes supporting Therapeutic Recreational Programmes	Process	<input type="checkbox"/> Yes <input type="checkbox"/> Yes, and it includes financial support to patients / families <input type="checkbox"/> No <input type="checkbox"/> In preparation
	Existence of programmes to support integration of RD patients in their daily life	Process	<input type="checkbox"/> Yes <input type="checkbox"/> Yes, and it includes financial support to patients / families <input type="checkbox"/> No <input type="checkbox"/> In preparation

EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
Supporting rehabilitation programmes	Existence of programmes to support rehabilitation of RD patients	Process	<input type="checkbox"/> Yes <input type="checkbox"/> Yes, and it includes financial support <input type="checkbox"/> No <input type="checkbox"/> In preparation