



**SUSTAINABILITY
OF INFRASTRUCTURES AND
ACTIVITIES
IN THE FIELD OF 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:

20. Together with the Commission, aim to ensure, through appropriate funding and cooperation mechanisms, the long-term sustainability of infrastructures developed in the field of information, research and healthcare for rare diseases.”

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



EUCERD CORE INDICATORS

N°18. Existence of a policy/decision to ensure long term sustainability of the RD plan/strategy

Short Definition =
Financial commitment for RD care and treatment is clearly defined in the plan /strategy budget

N°19. Amount of public funds allocated to the RD plan/strategy

Overall budget (in EUR) allocated per year. Ensure RD actions include appropriate provisions for their sustainability over time.

EUCERD CORE INDICATORS

N° 20. Specific public funds allocated for RD research

Policy decision(s) to allocate a portion of the National research budget specifically to RD research

N°21. Public funds specifically allocated for RD research actions/projects per year since the plan started

Total amount of public funds (in EUR) allocated to RD research projects or programmes

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



EUROPLAN RECOMMENDATIONS

- R 7.1 The National Plan or Strategy on rare diseases is supported combining national (regular and ad hoc) and European funds, according to the country health system and decision-making processes.
- R 7.2 Possibilities for European funding are exploited for those parts of National Plans or Strategies which are in the scope of the European Social Fund and European Regional Development Fund.
- R 7.3 The cooperation with other member states is envisaged when cross-border health care is needed, in order to address the need for sustainability of common European infrastructures, share costs and maximise the efficacy of initiatives.

EUROPLAN RECOMMENDATIONS

- R 7.4 Participation in the debate on enhanced EU governance is ensured, in order to find agreed and improved mechanisms for the governance of the healthcare, information and research initiatives requiring transnational collaboration.
- R 7.5 Agreements for coordinated projects, including long-term sustainability of common infrastructures, are pursued.

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



EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
<p>Ensure through appropriate funding mechanisms the long-term sustainability of infrastructures developed in the field of:</p> <ul style="list-style-type: none"> - information - research - Healthcare 	<p>Existing policy/decision to ensure long-term sustainability of the RD plan /strategy</p>	<p>Process</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>
	<p>Amount of funds allocated for ensuring RD plan /strategy sustainability</p>	<p>Outcome</p>	<p>Millions of Euros invested per year</p>

EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
<p>Cooperate with other Member States to address the need for sustainability of European-wide research infrastructures, common to all Member States and common to the highest possible number of rare diseases</p>	<p>Existing policy/decision to ensure the contribution to support RD European Infrastructures</p>	<p>Process</p>	<ul style="list-style-type: none"> <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