

# Innovative approach towards the national organization of rare disease management – Slovenian National plan

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**June, 2nd, 2023**

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# Short history

3.7.2009

EN

Official Journal of the European Union

C 151/7

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

THE COUNCIL OF THE EUROPEAN UNION,

Having regard to the Treaty establishing the European Community, and in particular the second subparagraph of Article 152(4) thereof,

Having regard to the proposal from the Commission,

Having regard to the opinion of the European Parliament<sup>(1)</sup>,

Having regard to the opinion of the European Economic and Social Committee<sup>(2)</sup>,

Whereas:

- (1) Rare diseases are a threat to the health of EU citizens insofar as they are life-threatening or chronically debilitating diseases with a low prevalence and a high level of complexity. Despite their rarity, there are so many different types of rare diseases that millions of people are affected.
- (2) The principles and overarching values of universality, access to good quality care, equity and solidarity, as endorsed in the Council conclusions on common values and principles in EU health systems of 2 June 2006, are of paramount importance for patients with rare diseases.
- (3) The Community action programme on rare diseases, including genetic diseases, was adopted for the period 1 January 1999 to 31 December 2003<sup>(3)</sup>. This programme defined the prevalence for a rare disease as affecting no more than 5 per 10 000 persons in the EU. A more refined definition based on updated scientific review, taking into account both prevalence and incidence, will be developed using the Second Community Health Programme<sup>(4)</sup> resources.

<sup>(1)</sup> Legislative resolution of 23 April 2009 (not yet published in the Official Journal).

<sup>(2)</sup> Opinion of 25 February 2009 (not yet published in the Official Journal).

<sup>(3)</sup> Decision No 1295/1999/EC of the European Parliament and of the Council of 29 April 1999 adopting a programme of Community action on rare diseases within the framework for action in the field of public health (1999 to 2003) (OJ L 151, 22.6.1999, p. 1). Decision repealed by Decision No 1786/2002/EC (OJ L 271, 9.10.2002, p. 1).

<sup>(4)</sup> Decision No 1350/2007/EC of the European Parliament and of the Council of 23 October 2007 establishing a second programme of Community action in the field of health (2006-2013) (OJ L 301, 20.11.2007, p. 3).

- (4) Regulation (EC) No 141/2000 of the European Parliament and of the Council of 16 December 1999 on orphan medicinal products<sup>(5)</sup> provides that a medicinal product shall be designated as an 'orphan medicinal product' when intended for the diagnosis, prevention or treatment of a life-threatening or chronically debilitating condition affecting not more than 5 in 10 000 persons in the Community when the application is made.

- (5) It is estimated that between 5 000 and 8 000 distinct rare diseases exist today, affecting between 6 % and 8 % of the population in the course of their lives. In other words, although rare diseases are characterised by low prevalence for each of them, the total number of people affected by rare diseases in the EU is between 27 and 36 million. More of them suffer from less frequently occurring diseases affecting one in 100 000 people or less. These patients are particularly isolated and vulnerable.

- (6) Because of their low prevalence, their specificity and the high total number of people affected, rare diseases call for a global approach based on special and combined efforts to prevent significant morbidity or avoidable premature mortality, and to improve the quality of life and socioeconomic potential of affected persons.

- (7) Rare diseases were one of the priorities of the Community's sixth framework programme for research and development<sup>(6)</sup> and continue to be a priority for action in its seventh framework programme for research and development<sup>(7)</sup>, as developing new diagnostics and treatments for rare disorders, as well as performing epidemiological research on those disorders, require multi-country approaches in order to increase the number of patients for each study.

- (8) The Commission, in its White Paper 'Together for Health: A Strategic Approach for the EU 2008-2013' of 23 October 2007, which develops the EU Health Strategy, identified rare diseases as a priority for action.

<sup>(5)</sup> OJ L 18, 22.1.2000, p. 1.

<sup>(6)</sup> Decision No 1511/2000/EC of the European Parliament and of the Council of 27 June 2000 concerning the sixth framework programme of the European Community for research, technological development and demonstration activities, contributing to the creation of the European Research Area and to innovation (2002 to 2006) (OJ L 212, 29.8.2002, p. 1).

<sup>(7)</sup> Decision No 1982/2004/EC of the European Parliament and of the Council of 18 December 2004 concerning the Seventh Framework Programme of the European Community for research, technological development and demonstration activities (2007-2013) (OJ L 412, 30.12.2004, p. 1).

"The Council Recommendation on European Action in the field of Rare Diseases", adopted by the EU Council in June 2009, recommends Member States to adopt national plans or strategies for rare diseases before end of 2013.

*Definition: A NP/NS is as a set of integrated and comprehensive health and social policy actions for rare diseases (with a previous analysis of needs and resources), to be developed and implemented at national level, and characterized by identified objectives to be achieved within a specified timeframe.*

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1. Plans and Strategies in the Field of Rare Diseases
2. Adequate Definition, Codification and Inventorying of Rare Diseases
3. Research on Rare Diseases
4. Centres of Expertise and European Reference Networks for Rare Diseases
5. Gathering the Expertise on Rare Diseases at European Level
6. Empowerment of Patients' Organisations
7. Sustainability

# Short history



The screenshot shows the EUROPLAN website header with the logo and navigation menu. The main content area is titled 'EUROPLAN background' and contains text about the Council Recommendation on European Action in the field of Rare Diseases, adopted in June 2009. It also includes links to download the 'Communication of the European Commission "Rare Diseases: Europe's challenge"' (2008) and 'The Council Recommendation on an action in the field of rare diseases' (2009).

**EUROPLAN**  
European Project for Rare Diseases National Plans Development

THE PROJECT PARTNERS **EVENTS** CAPACITY BUILDING NATIONAL PLANS DOCUMENTS LINKS

**EUROPLAN PROJECT**

- ▶ EUROPLAN 2012-2015
- ▶ EUROPLAN 2008-2011
- ▶ EUROPLAN BACKGROUND

Home > EUROPLAN Project > EUROPLAN background

## EUROPLAN background

"The Council Recommendation on European Action in the field of Rare Diseases", adopted by the EU Council in June 2009, recommends Member States to adopt national plans or strategies for rare diseases before end of 2013.

EUROPLAN recommendations will provide tools to Member States for developing a plan or strategy, linking with a common framework at the European level.

This "double level" approach is respectful of national decisions but is expected to ensure a coherent and consistent progress in EU rare diseases care.

[Download the "Communication of the European Commission "Rare Diseases: Europe's challenge" \(COM\(2008\).679 final\)" \(2008, November 11 - pdf\)](#)

[Download the "The Council Recommendation on an action in the field of rare diseases \(2009/C 151/02\)" \(2009, June 9 - pdf\)](#)

( Financed within the Programme of Community action in the field of Public Health )

# Short history



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European Project for Rare Diseases National Plans Development

THE PROJECT PARTNERS **EVENTS** CAPACITY BUILDING NATIONAL PLANS DOCUMENTS LINKS

EUROPLAN PROJECT

- ▶ EUROPLAN 2012-2015
- ▶ EUROPLAN 2008-2011
  - Specific objectives
  - Structure of the project
  - Work packages overview
  - Results
- ▶ EUROPLAN BACKGROUND

[Home](#) - [EUROPLAN Project](#) - [EUROPLAN 2008-2011](#)

## EUROPLAN 2008-2011

The European Project for Rare Diseases National Plans Development (EUROPLAN) is a three-year project of the Programme of Community action in the field of Public Health (2003 - 2008), which began in April 2008. The main goal is to provide National Health Authorities with a supporting tools for the development and implementation of National Plans and Strategies for rare diseases (RDs) following the recently agreed European Council Recommendation on an action in the field of RDs (2009/C 151/02). This supporting tools will be composed of three documents focused on defined priority areas: the Recommendations document on recommendations for the definition and implementation of National Plans and Strategies for rare diseases; the report on current practices and relevant cases in the field of rare diseases; and the document on the recommended set of indicators for monitoring and evaluating the implementation of national initiatives.

The National Centre for Rare Diseases (Italian Institute of Health - Istituto Superiore di Sanità, Italy) is the leading partner that organize the contributions from 34 countries and Eurordis (the European Organisation for rare diseases) ensuring a broad representation of different EU contexts and experiences and patients' point of view. In addition, the project ensures an inclusive and wide engagement of stakeholders - Ministries, regional and local authorities, health care planners, programme managers, health care professionals, researchers and patients.

The main goal is to provide National Health Authorities with supporting tools for the development and implementation of National Plans and Strategies for rare diseases following the European Council Recommendation.

# Short history



**EUROPLAN**  
European Project for Rare Diseases National Plans Development

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## EUROPLAN 2012-2015

**EUROPLAN 2012-2015**  
is built to provide technical support for developing and implementing national plans/strategies (NP/NS) on Rare Diseases (RD) in EU Member States, EFTA/EEA and non-EU countries. Integrated, comprehensive, long-term strategy will be proposed in the framework of principles and guidelines of the key policy documents.

**Objectives**

To provide support for the establishment of national plans and strategies for rare Diseases at member state level

1. To establish an interactive rare diseases policy makers public health network: the network will provide technical assistance and capacity building skills to policy makers in charge of developing a NP/NS. Participants will be supported methodologically and technically. A website will be implemented for sharing and disseminate experiences and documents, and activities will be organised to share and exploit experiences, strengthen interactions, provide new skills in developing public health strategies and plans.
2. To produce a complete, coherent and feasible operational proposal for NP/NS: through public health networking and sharing experiences, every participant will contribute to produce a operational proposal for NP/NS, according to specific country features (size, GNP, health care system), selecting EUROPLAN indicators for future data collection, and identifying strengths and critical aspects in developing public health strategies and plans.
3. To support EURORDIS National Conferences: EURORDIS identifies and organises National Conferences (NC) to support the process of elaboration of NP/NS and assess the transferability of EU policy documents in countries that did not organise a EUROPLAN NC and countries that did it but need to sustain the process.

- Built to provide integrated, comprehensive, long-term strategy taking into account the principles and guidelines of the key policy documents.
- Aim 1: To produce a complete, coherent and feasible operational proposal for NP/NS

# Short history



**EUROPLAN**  
European Project for Rare Diseases National Plans Development

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# Short history

## EUROPLAN: A Project to Support the Development of National Plans on Rare Diseases in Europe

D. Taruscio<sup>a</sup> A.E. Gentile<sup>a</sup> M. De Santis<sup>a</sup> R.M. Ferrelli<sup>b</sup> M. Posada de la Paz<sup>d</sup>  
M. Hens<sup>d</sup> J. Huizer<sup>e</sup> L. Fregonese<sup>e</sup> R. Stefanov<sup>f</sup> V. Bottarelli<sup>g</sup> A. Weinman<sup>g</sup>  
Y. Le Cam<sup>g</sup> D. Gavhed<sup>h</sup> P. Mincarone<sup>c</sup> K. Bushby<sup>i</sup> R.G. Frazzica<sup>a</sup> C. Donati<sup>a</sup>  
L. Vitozzi<sup>a</sup> E. Jessop<sup>i</sup>

PRIORITIES of the Council Recommendation on an action in the field of rare diseases (RDs)		EU countries with existing RD National Plans/Strategies								
		Bulgaria	Czech Republic	France	Greece	The Netherlands	Portugal	Slovak Republic	Slovenia	Spain
										
I. Plans and strategies in the field of RDs	(1) Establish and implement plans and/or strategies on RDs	✓	✓	✓	✓	✓	✓	✓	✓	✓
II. Adequate definition, codification and inventorying of RDs	(2) Use an RD common definition of no more than 5 per 10,000 persons	✓	✓	✓	✓	✓	✓	✓	✓	✓
	(3) Adequate coding, trace and recognition in the national healthcare and reimbursement systems			✓		✓*				✓
	(4) Easily accessible and dynamic inventory of RDs	✓	✓	✓	✓	✓	✓		✓	✓
	(5) Specific disease information networks, registries and databases	✓	✓	✓	✓	✓	✓	✓	✓	✓
III. Research on RDs	(6) Identify ongoing research and research resources in the national and Community frameworks	✓	✓	✓	✓	✓	✓	✓	✓	✓
	(7) Identify needs and priorities for basic, clinical, translational, and social research and promote interdisciplinary cooperative approaches	✓	✓	✓	✓	✓	✓	✓	✓	✓
	(8) Foster the participation of national researchers in research projects	✓	✓	✓	✓	✓	✓	✓		✓
	(9) Foster research in the field of RDs	✓	✓	✓	✓	✓	✓			✓
	(10) Research cooperation with third countries			✓			✓			✓

**Fig. 1.**  
Conformity among priorities of the Council Recommendation of 8 June 2009 on an action in the field of rare diseases (2009/c 151/02) and existing National Plans/Strategies in EU Countries in 2012.



# National activities



REPUBLIKA SLOVENIJA  
MINISTRSTVO ZA ZDRAVJE

Štefnova ulica 5, 1000 Ljubljana

T: 01 478 60 01  
F: 01 478 60 58  
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[www.mz.gov.si](http://www.mz.gov.si)

Številka: 024-27/2019/123

## NAČRT DELA NA PODROČJU REDKIH BOLEZNI V REPUBLIKI SLOVENIJI 2021-2030

Ljubljana, november 2021

# National activities

REPUBLICA SLOVENIJA  
MINISTRSTVO ZA ZDRAVJE

Štefnova ulica 5, 1000 Ljubljana

T: 01 478 60 01  
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E: [gg.mz@gov.si](mailto:gg.mz@gov.si)  
www.mz.gov.si

Številka: 024-27/2019/123

Personalizirana - inovativna medicina za RB						Integracija RB v družbo					
Diagnostika za preprečevanje in zdravljenje		Vrhunska zdravstvena oskrba					Deljenje informacij za skupen napredek		Integrirana socialna oskrba in izobraževanje		
Center za nediagnostirane RB	Genomsko predrojno in neonatalno presejanje	Presejanje za RB z začetkom v odrasli dobi v primarnem zdravstvu	Multidisciplinarni timi za obravnavo RB in za nemoten prehod v odraslo dobo	Nacionalne mreže v ERM	Nacionalni koordinacijski center za RB	Dostopnost do zdravil sirot	Nova zdravljena in napredno gensko zdravljenje RB	Integrirana nacionalna baza za RB	Spodbujanje povezovanja bolnikov	Glas bolnikov za oblikovanje politik	Izobraževanje za sodelovanje

Ljubljana, november 2021

# National activities

## Pilar 1 - Personalized - innovative medicine for RD

Objective 1.  
Diagnostics for prevention  
and treatment

Objective 2.  
Superb health care

## Pilar 2 - Integration of RD into society

Objective 3.  
Sharing information for  
common progress

Objective 4.  
Integrated social care  
and education

Personalizirana - inovativna medicina za RB							Integracija RB v družbo				
Diagnostika za preprečevanje in zdravljenje		Vrhunska zdravstvena oskrba					Deljenje informacij za skupen napredek		Integrirana socialna oskrba in izobraževanje		
Center za nedagnosticirane RB	Genosko predrojstno in neonatalno presejanje	Presejanje za RB z začetkom v odrasli dobi v primarnem zdravstvu	Multidisciplinarni timi za obravnavo RB in za nemoten prehod v odraslo dobo	Nacionalne mreže v ERM	Nacionalni koordinacijski center za RB	Dostopnost do zdravil sirot	Nova zdravljena in napredno gensko zdravljenje RB	Integrirana nacionalna baza za RB	Spodbujanje povezovanja bolnikov	Glas bolnikov za oblikovanje politik	Izobraževanje za sodelovanje

# Objective 1. Diagnostics for prevention and treatment

## Activity 1. Center for undiagnosed rare diseases

- A significant proportion of RD patients remains undiagnosed (Despite the fact that we have introduced advanced genomic technologies for diagnosis of genetic diseases in our health care system )



Center za nediagnosticirane RB	Diagnostika za preprečevanje in zdravljenje	Personalizirana - inovativna medicina za RB	
Genomsko predrojno in neonatalno presejanje			
Presejanje za RB z začetkom v odrasli dobi v primarnem zdravstvu			
Multidisciplinarni timi za obravnavo RB in za nemoten prehod v odraslo dobo	Vrhunska zdravstvena oskrba		
Nacionalne mreže v ERM			
Nacionalni koordinacijski center za RB			
Dostopnost do zdravil sirot			
Nova zdravljenja in napredno gensko zdravljenje RB			
Integrirana nacionalna baza za RB	Deljenje informacij za skupen napredek		Integracija RB v družbo
Spodbujanje povezovanja bolnikov			
Glas bolnikov za oblikovanje politik	Integrirana socialna oskrba in izobraževanje		
Izobraževanje za sodelovanje			

# Objective 1. Diagnostics for prevention and treatment

## Activity 1. Center for undiagnosed rare diseases



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## Activity 2. Genomic prenatal and neonatal **screening**

- aim: to develop modern options for primary and secondary prevention of genetic diseases
- project is planned in 2024 – to assess the possibility of using genomic screening tests, both from a professional as well as from social and ethical points of view.

Center za nediagnosticirane RB	Diagnostika za preprečevanje in zdravljenje	Personalizirana - inovativna medicina za RB
Genomsko predrojno in neonatalno presejanje		
Presejanje za RB z začetkom v odrasli dobi v primarnem zdravstvu		
Multidisciplinarni timi za obravnavo RB in za nemoten prehod v odraslo dobo	Vrhunska zdravstvena oskrba	
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Dostopnost do zdravil sirot		
Nova zdravljenja in napredno gensko zdravljenje RB	Deljenje informacij za skupen napredek	
Integrirana nacionalna baza za RB		
Spodbujanje povezovanja bolnikov		
Glas bolnikov za oblikovanje politik		Integrirana socialna oskrba in izobraževanje
Izobraževanje za sodelovanje		
		Integracija RB v družbo

# Objective 1. Diagnostics for prevention and treatment

## Activity 3. Adult-onset rare disease **screening** in primary healthcare

- aim: to enable the early detection of patients and people with a high risk of development RD in adulthood
- secondary aim: to empower the healthy population and primary healthcare to identify genetic risks.
- ongoing project in the primary healthcare: assessing the possibility of a systematic use of family history tool at the primary level of health care for discovering important genetic predisposition for genetic diseases.

Center za nediagnosticirane RB	Diagnostika za preprečevanje in zdravljenje	Personalizirana - inovativna medicina za RB	
Genomsko predrojno in neonatalno presejanje			
Presejanje za RB z začetkom v odrasli dobi v primarnem zdravstvu			
Multidisciplinarni timi za obravnavo RB in za nemoten prehod v odraslo dobo	Vrhunska zdravstvena oskrba		
Nacionalne mreže v ERM			
Nacionalni koordinacijski center za RB			
Dostopnost do zdravih sirot			
Nova zdravljenja in napredno gensko zdravljenje RB			
Integrirana nacionalna baza za RB	Deljenje informacij za skupen napredek		Integracija RB v družbo
Spodbujanje povezovanja bolnikov			
Glas bolnikov za oblikovanje politik	Integrirana socialna oskrba in izobraževanje		
Izobraževanje za sodelovanje			

# Objective 2. Superb health care

## Activity 4. Multidisciplinary teams for RD patient management

- RD patients are mostly treated within the speciality clinics, according to the main symptoms and signs that appear in a certain disease
- many RDs affect different organ systems
- multidisciplinary teams should be organized in such a way that patients are seen by different medical professionals within one team evaluation
- team: team coordinator, 2 MD, specialized for RD, 2 registered nurses, a clinical psychologist, social worker and nutritionist



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Genomsko predrojno in neonatalno presejanje		
Presejanje za RB z začetkom v odrasli dobi v primarnem zdravstvu		
Multidisciplinarni timi za obravnavo RB in za nemoten prehod v odraslo dobo	Vrhunska zdravstvena oskrba	
Nacionalne mreže v ERM		
Nacionalni koordinacijski center za RB		
Dostopnost do zdravil sirot		
Nova zdravljenja in napredno gensko zdravljenje RB	Deljenje informacij za skupen napredek	
Integrirana nacionalna baza za RB		
Spodbujanje povezovanja bolnikov		
Glas bolnikov za oblikovanje politik		Integrirana socialna oskrba in izobraževanje
Izobraževanje za sodelovanje		
		Integracija RB v družbo

# Objective 2. Superb health care

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## Activity 5. National networks in European reference networks

### ERNs in Slovenia

Full membership	Associated membership	National hub
ERN-RND	ERN Skin	ERN BOND
ERN EURO-NMD	ERN GUARD-HEART	ERNICA
MetabERN	ERN CRANIO	ERN EuroBloodNet
ERN ReCONNET	ERN VASCERN	eUROGEN
ERN RITA	ERN LUNG	ERN ITHACA
Endo-ERN		ERN RARE-LIVER
ERN PeadCAN		
ERN EpiCARE		
ERN EYE		
ERN ERKNet		
ERN EURACAN		
ERN-GENTURIS		

University Medical Centre Ljubljana

Institute of Oncology, Ljubljana



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Nacionalne mreže v ERM	Vrhunska zdravstvena oskrba
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Dostopnost do zdravil sirot	
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Integrirana nacionalna baza za RB	
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Glas bolnikov za oblikovanje politik	
Izobraževanje za sodelovanje	Integrirana socialna oskrba in izobraževanje



# Objective 2. Superb health care

## Activity 6. National Coordination Center for Rare Diseases

- to enable the coordinated implementation of the national plan in the future, to identify new needs in the field of RD in Slovenia, to connect all institutions for RD and ensure the sharing of good practices and provision of common standards in patient care
- to be a direct link to the Ministry of Health, and to collaborate in the creation of new health policies AND to ensure a connection with ORPHANET
- Planned after 2025

Center za nediagnosticirane RB	Diagnostika za preprečevanje in zdravljenje	Personalizirana - inovativna medicina za RB	
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Dostopnost do zdravil sirot			
Nova zdravljenja in napredno gensko zdravljenje RB			
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- Planned after 2025

## Activity 7. Access to orphan drugs



## Activity 8. New treatments for RD and advanced gene therapy for RD

- Pilot project planned in 2024 – to assess all aspects in the field AND joining consortium of all stakeholders and institutions being in the field of RD

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# Objective 3. Sharing information for common progress

## Activity 9. Integrated national database for RD

- standardized, accessible and interoperable data sources, including comprehensive overview of the individual disease progression, epidemiology, to be linked with other databases, HIS
- enable international exchange of data, involvement in national and international clinical research
- financial indicators monitoring and optimization
- National Registry for non-malignant RD

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## Activity 10. Encouraging the association of all RD patients

- some RD are so rare, that there are only 1 or 2 patients with the disease in Slovenia and it cannot be expected for them to establish their own association
- National patient alliance should provide assistance and information – continuous additional funding is planned in National Plan

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Glas bolnikov za oblikovanje politik	Integrirana socialna oskrba in izobraževanje		
Izobraževanje za sodelovanje			

# Objective 4. Integrated social care and education

## Activity 11. Patients' voice for policy making

- aim 1: to provide an inclusive environment for the development of social policies and services, actively involving patients and their organizations in identifying the needs of patients and their families
- aim 2: to increase autonomy, improve the quality of life, education, employment and participation of RD patients in Slovenian society.
- collaboration between the National patient alliance and National coordination center for RD (Activity 6)
- Planned after 2025 and continuous after that

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- collaboration between the National patient alliance and National coordination center for RD (Activity 6)
- Planned after 2025 and continuous after that

## Activity 12. Education for cooperation

- The aim is to provide innovative education for healthcare professionals, patients and the general public
- collaboration with the National coordination center for RD (Activity 6)
- Planned after 2026 and continuous after that

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# National activities



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## NAČRT DELA NA PODROČJU REDKIH BOLEZNI V REPUBLIKI SLOVENIJI 2021-2030

Ljubljana, november 2021

Načrt dela na področju redkih bolezni v Republiki Sloveniji 2021 do 2030 je pripravila Delovna skupina za pripravo Načrta dela na področju redkih bolezni za obdobje 2021 do 2030, imenovana s strani Ministrstva za zdravje Republike Slovenije s Sklepom številka C2711-19-653120 (024-27/2019/15) z dne 3. 10. 2019, s Sklepom o spremembah Sklepa št. C2711-19-653120 (024-27/2019/53) z dne 15. 7. 2020 in s Sklepom o spremembi Sklepa št. C2711-19-653120 (024-27/2019/68) z dne 30. 6. 2021.

Člani delovne skupine Ministrstva za zdravje:

- dr. Robert Medved, Ministrstvo za zdravje, vodja;
- mag. Bernarda Kociper, Ministrstvo za zdravje, članica in namestnica vodje;
- prof. dr. Borut Peterlin, Klinični inštitut za medicinsko genetiko, UKC Ljubljana, član;
- Eva Murko, Nacionalni inštitut za javno zdravje, članica;
- prim. mag. Jurij Füst, Zavod za zdravstveno zavarovanje Slovenije, član;
- Alenka Marič Cevzar, Zavod za zdravstveno zavarovanje Slovenije, članica;
- prof. Jože Faganel, Združenje za redke bolezni Slovenije, član;
- Tea Čemigoj Pušnjak, Združenje za redke bolezni Slovenije, članica;
- doc. dr. Urh Grošelj, UKC Ljubljana, član;
- doc. dr. Blaž Koritnik, UKC Ljubljana, član;
- prof. dr. Robert Ekart, UKC Maribor, član;
- prof. dr. Nataša Marčun Varda, UKC Maribor, članica;
- doc. dr. Mojca Žerjav Tanšek, UKC Ljubljana, članica.

# Thank you

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**June, 2nd, 2023**

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