



# Achieving Holistic Person-centred Care to Leave no One Behind

A contribution to improve the everyday life of people  
living with a rare disease and their carers

A Position Paper by EURORDIS and its members

Raquel Castro  
Social Policy Director

CNA-CEF Meeting, Paris, 11 December 2018

**EURORDIS.ORG**



# Thank you to all those who contributed!

Sent to you by email last week!

Condensed in **29 pages only!** :)

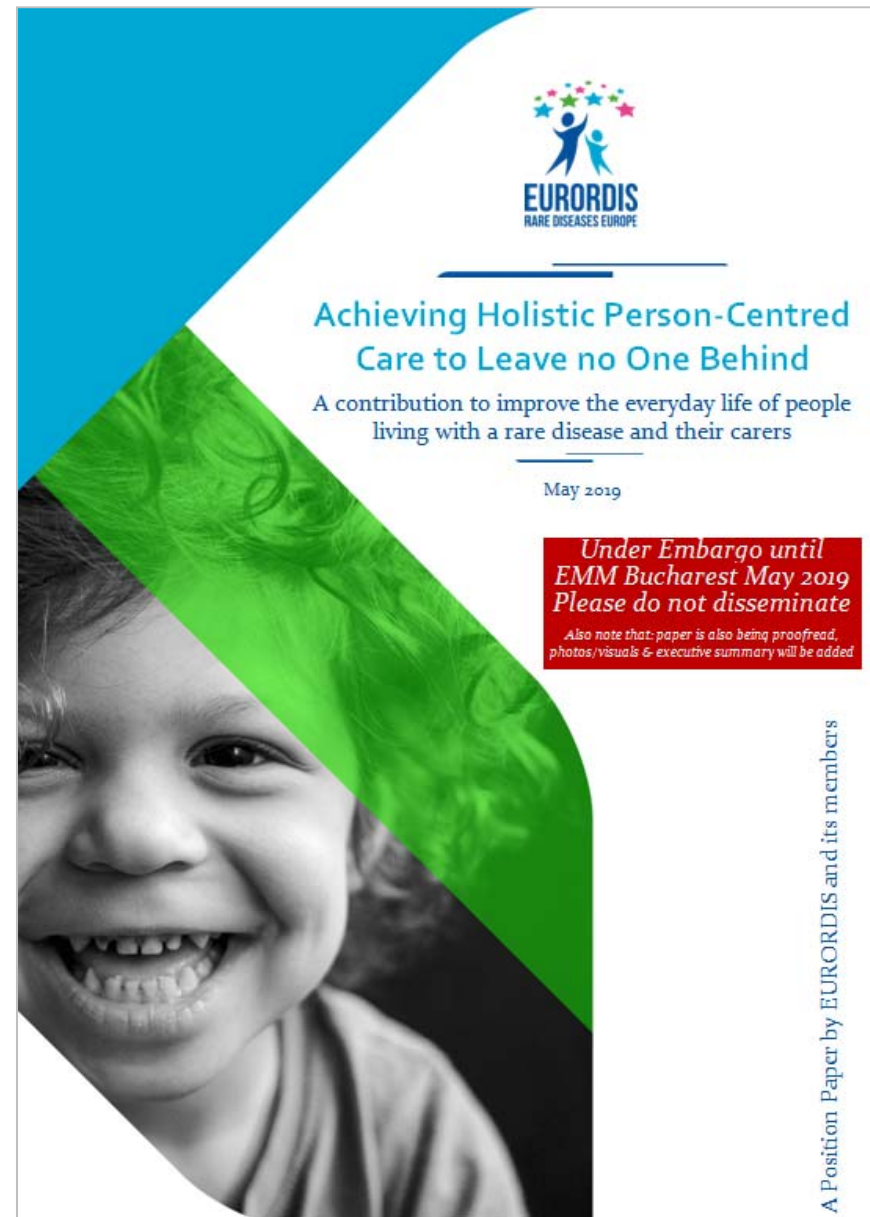
*We could not guess that from the size of the title!*

Well, thecnically

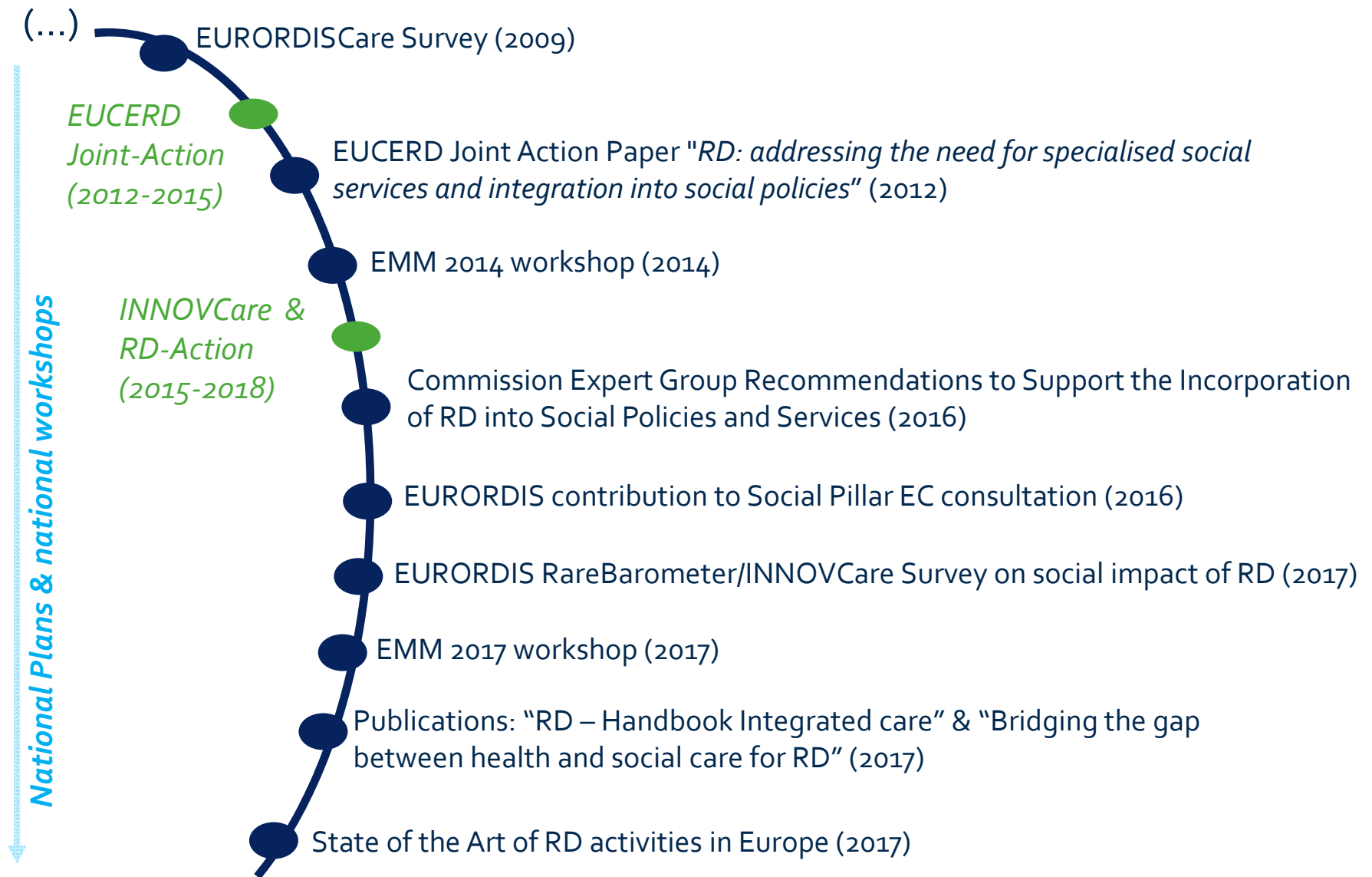
only 20 pages of actual content excluding covers, index and repeated recommendations ;)

And...

You should get a very good grasp by reading pages 3-13 only!



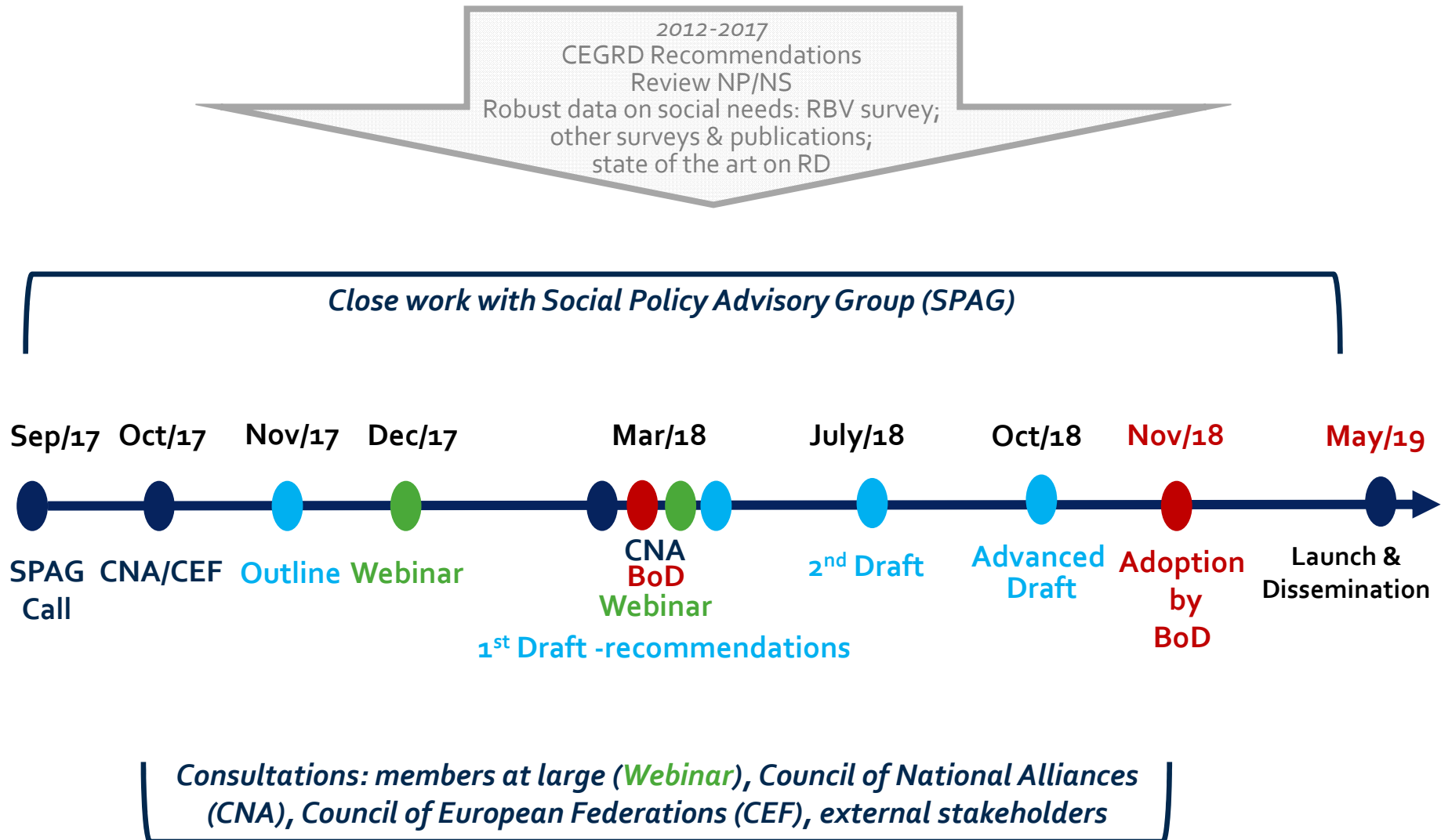
# Key steps building up to this paper



# Strategy for the position paper

- 1. Strong & inclusive process**
- 2. Quality & strategic position paper**
- 3. Strong & wide dissemination**

# 1. Process - timeline



# 1. Process - Consultations

✓ **Council of National Alliances and Council of European Federations**

✓ **European Public Affairs Committee (EPAC)**

✓ **Board of Directors**

✓ **Volunteers - Social Policy Advisory Group (SPAG)**

Beata Boncz, HUFERDIS, Hungary

Dorica Dan, RONARD, Romania – involved in all activities leading to this paper

Giulia Mariani, Italian Tuberos Sclerosis Association, Italy

Gwenn Crohin, ALAN, Luxembourg

Isabel Fernandez, FEDER, Spain

Maria Montefusco, Nordic Council for Welfare, Disability, Sweden

Nataliya Grigovora, Huntington Association Bulgaria, Bulgaria

Silvia van Breukelen & Ildiko Vajda, VSOP, Netherlands

Stephanie Jøker Nielsen, Rare Diseases Denmark

Vlasta Zmazek, Croatian National Alliance for Rare Diseases, Croatia

✓ **Members involved in the consultation (webinar/email)**

Anna Arellanesová and Martina Michalová, Czech Association for Rare Diseases, Czech Republic

Anne Lawlor, 22q11 Ireland

Eleni Antoniou, Cyprus Alliance for Rare Disorders, Cyprus

Geske Wehr and Erik Engel, ACHSE

Ivana Badnjarevic, NORBS, Serbia

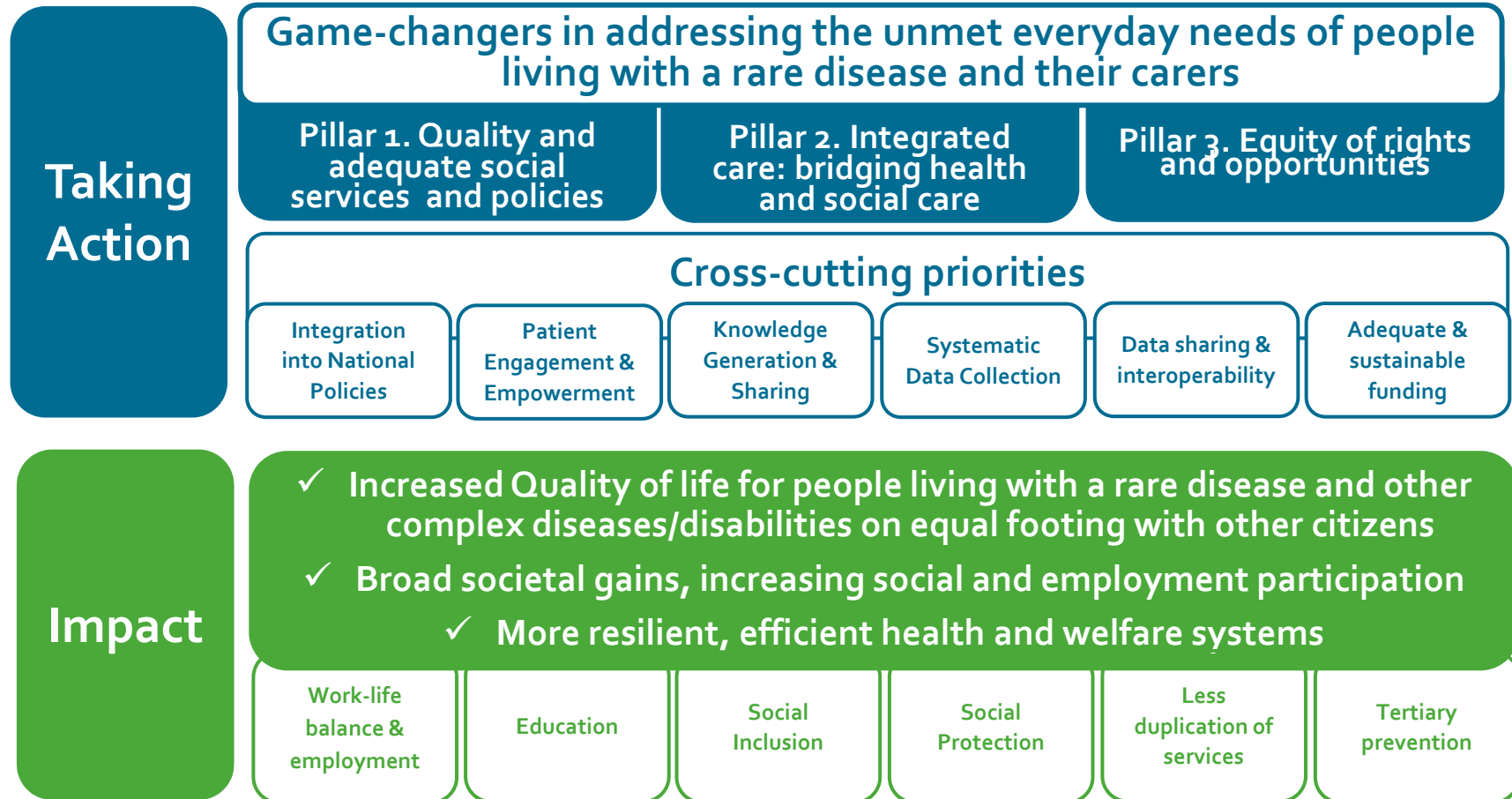
Marleen Kaatee, PSC (Primary Sclerosing Cholangitis) Patients Europe, Netherlands

Nick Meade, Genetic Alliance UK

Simona Bellagambi, UNIAMO, Italy

Ulrike Holzer, Prorare, Austria

## 2. Content – Outline



## 2. Content – Table of contents

### Why this paper?

- 1 **Impact of rare diseases on daily life:** understanding the specific challenges
- 2 **Taking action** can significantly improve the lives of millions of people living with a rare disease in Europe
- 3 **Our recommendations**
- 4 framework of strategies for a comprehensive approach to ensure holistic care for rare diseases
  - 4.1. **Pillar 1: Quality and adequate social services and policies**
  - 4.2. **Pillar 2: Integrated care: bridging health and social care**
  - 4.3. **Pillar 3: Equity of rights and opportunities**
    - 4.3.1. **Disability**, autonomy, accessibility
    - 4.3.2. Adapted and sustainable **employment**
    - 4.3.3. Non-**discrimination**: access to equal opportunities
  - 4.4. Crosscutting priorities
- 5 Conclusion: the time to act is now
- 6 About this position paper & acknowledgments
- 7 Glossary



## 2. Content – Wording choices

*based on input from members, volunteers and policy makers*

- Title: “holistic person-centred care” instead of “social policy” or “social care”
- Using “people living with a rare disease” (and their carers) instead of “patients”
- Using “rare disease organisations” instead of “patient organisations” – *full reference: organisations representing people living with a rare a disease (commonly known as patient organisations and hereinafter referred to as rare disease organisations)*

*To address all health and social stakeholders  
Social and human rights stakeholders don't react well to  
“patients”/“patient organisations”*

## 2. Content – Content choices

- **Most of the content is based on published references, policy documents, surveys, positions**  
**= robust sources**
- **Recommendations are our own, using also CEGRD & INNOVCare recommendations**  
**= our proposed strategies**

## 2. Content – Vision (p. 3, 7)

The ambition of EURORDIS is to have holistic care provided to the 30 million people living with a rare disease in Europe, and to their carers, by 2030.

We ambition to see people living with a rare disease integrated in a society that indeed leaves no one behind.



## 2. Content – Our recommendations (p. 9-12)

1. Making full use of **EU instruments and European networks** to implement holistic care for rare diseases
2. Creating a **supportive political environment at national level** for holistic care for rare diseases
3. **Gathering and disseminating knowledge and good practices**, to ensure that the needs of people living with a rare disease and their carers are adequately addressed by specialised and mainstream services
4. Implementing **specific mechanisms that ensure integrated care** provision to rare diseases
5. Guaranteeing **meaningful engagement** of rare disease organisations and representatives in the design and implementation of policies and services

## 2. Content – Our recommendations (p. 9-12)

6. Implementing specific measures that ensure access of people living with a rare disease and their carers to **adequate social services and social protection**
7. Ensuring the **recognition and adequate compensation of the disabilities** experienced by people living with a rare disease
8. Creating the conditions for people living with a rare disease and their carers to access **adapted and sustainable employment**
9. Implementing specific mechanisms that **empower** people living with a rare disease and their carers, in co-creation and co-delivery with rare disease organisations
10. **Eliminating all types of discrimination**, ensuring that people living with a rare disease have access to social, labour, educational, leisure inclusion on equal footing with other citizens

## 2. Content – Structure of each Pillars (p. 14-23)

- **Presentation of issues (1-1.5 pages)**
- **Recommendations (1-1.5 pages, expect Pillar 3 which has 3 sub-topics each with this structure)**

## 2. Content – What next?

- **Executive summary to be added**
- **Photos and visuals to be improved**
- **Proofreading**
- **Potentially translating parts of the paper**

### 3. Dissemination – next steps

- **Paper under embargo – please do not disseminate yet**
- **February 2019: messages extracted to support RDD**
- **May 2019: position paper launch at EMM 2019 Bucharest**
- **Sharing the paper with other health and social stakeholders**



### 3. Dissemination – next steps

#### Position paper launch at EMM 2019 Bucharest

- **Plenary session**
  - Short **presentations on each pillar + discussions w/ stakeholders** including MEPs
  - Session on **how to use the position paper**
- **Workshop on how to make the best use of the paper:**
  - What are the **quick wins** within our recommendations?
  - Which recommendations can have the **greatest impact**?
  - What are our **5 targets that will allow us to achieve holistic care** by 2030?
  - **Your thoughts on what we should discuss at EMM...**

### 3. Dissemination – next steps

**Your thoughts on dissemination  
& how to make the best use of the paper**



**Thank you!**

[raquel.castro@eurordis.org](mailto:raquel.castro@eurordis.org)

**EURORDIS.ORG**