



# **EURORDIS Position Paper on Social Policy**

**Strategy & Process** 

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# Key moments building up to now

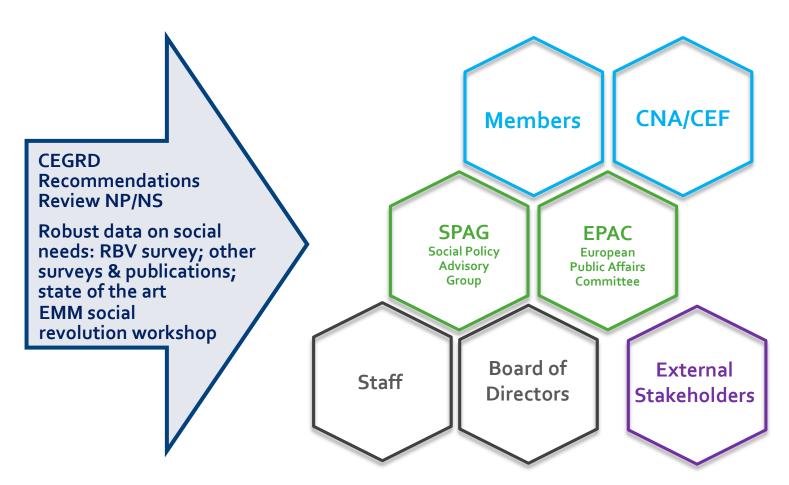
EURORDISCare Survey (2009) **EUCERD** Joint-Action EUCERD Joint Action Paper "RD: addressing the need for specialised social services and integration into social policies" (2012) (2012-2015) EMM 2014 workshop (2014) **INNOVCare & RD-Action** Commission Expert Group Recommendations to Support the (2015-2018) Incorporation of RD into Social Policies and Services (2016) EURORDIS contribution to Social Pillar EC consultation (2016) RareBaromter/INNOVCare Survey on social impact of RD (2017) **National Plans &** national workshops EMM 2017 workshop (2017) Publications: "RD – Handbook Integrated care" & "Bridging the gap between health and social care for RD" (2017) State of the Art of RD activities in Europe (2017)

#### **Position Paper Social Policy**

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

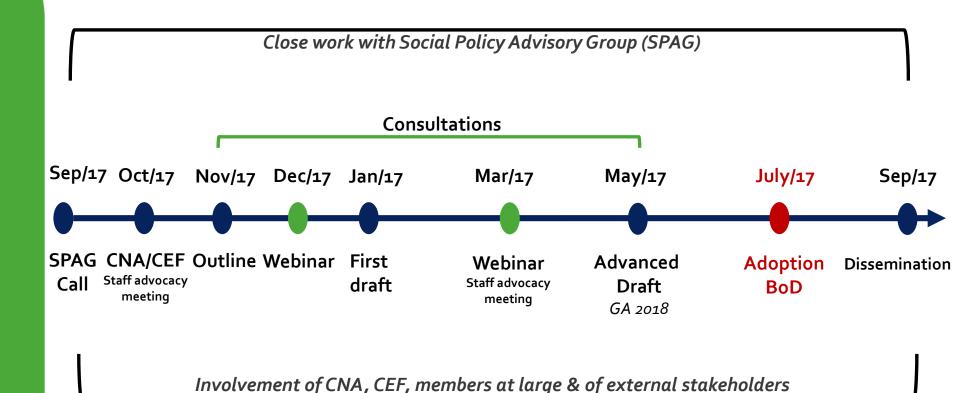


# 1. Strong & inclusive process





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Would like to get directly involved in the drafting?



- "Crystalise" needs
- Focus on game changers
- Propose strategies for implementation & set of recommendations
- Ask "endorsement" from RD and social stakeholders



"Crystalise" needs – robust data

- RareBarometer/INNOVCare survey & other RD surveys at national level
- Key policy documents e.g. Commission Expert Group Recommendations, review of NP/NS
- EURORDIS Social Pillar EC consultation
- State of the Art
- Publications

Do you have robust data to share?



Focus on game changers which can turn into reality at medium-long term Propose strategies & recommendations

Unmet Needs
Economic impact

Data collection
Social impact

Informing Decisions

**Good Practices** 

Patient Centred Holistic

Integrated care

Lifelong
Case management
Multidisciplinary

Specialised Services
Personal Care
Training Professionals

Support

Patient Engagement Social Services Resource Centres

Respite Psychological Support

**Training Patients** 

Mental Health Assessment

Time Burden

Disability Assessment

Varying Invisible

Care Burden

Employment Flexibility
Special leave
Adaptation

Focus on game changers which can turn into reality at medium-long term

- Prioritisation:
  - Survey results & EMM 2017 "Social Revolution" workshop
  - Align with Expert Group recommendations & EU policy agenda
- Cluster in main game changers

Have you done any social positions at national/disease level?



Ask "endorsement" from RD and social stakeholders

- RD stakeholders
- European Patients' Forum
- European Disability Forum
- Eurocarers
- Social Platform
- ...
  Any suggestions of outside stakeholders to involve?



# 2. Strong & wide dissemination





# Recap of questions for you:

- Would like to get directly involved in the drafting?
- Do you have robust data to share?
- Have you done any social positions at national/disease level?
- Any suggestions of outside stakeholders to involve?

Stay tuned to our members news and join the webinars!





# Thank you

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