



Towards a sustainable future for Orphanet

Health Programme & Chronic Diseases DG SANTE

14 Feb 2019

Orphanet: introduction

- *The online European knowledge platform and database for rare diseases and orphan drugs....*
 - Nomenclature (Orphacodes)
 - Data and knowledge: for policy, practice and research
- *Funding: France, EU, Member States*
 - EU funding since 2000 for various & subsequent activities
 - 2018 direct grant: to contribute to consolidation of Orphanet as the European reference source of information on rare diseases.
- *EU Financial Regulation: no structural funding!*

SGPP process until now

- *Aims to identify realistic options for a more sustainable future for Orphanet, also identifying Member States which could be interested in providing contribution to its core functions.*
- *Nov 2018:*
 - Concept paper by INSERM /France
 - Survey – initial exchange of thought on 3 questions
- *Until 22 Jan: Member States respond to eSurvey*
- *14 Feb: SGPP reflection*

Key outcomes eSurvey

- *Detailed responses from 14 Member States*
- *Vast majority of which expressed:*
 - Overall appreciation of Orphanet
 - Continued support for national activities already undertaken
- *Several Member States: principal readiness to contribute to the core functions, either in kind and/or through a financial contribution.*

Financial contribution (Q1)?

- **Yes:**



'A direct financial contribution against services provided by Orphanet could be considered as we indeed make use of several costly services of Orphanet that are impossible to achieve at national level'

- *Administrative rules / fin. resources bottleneck*

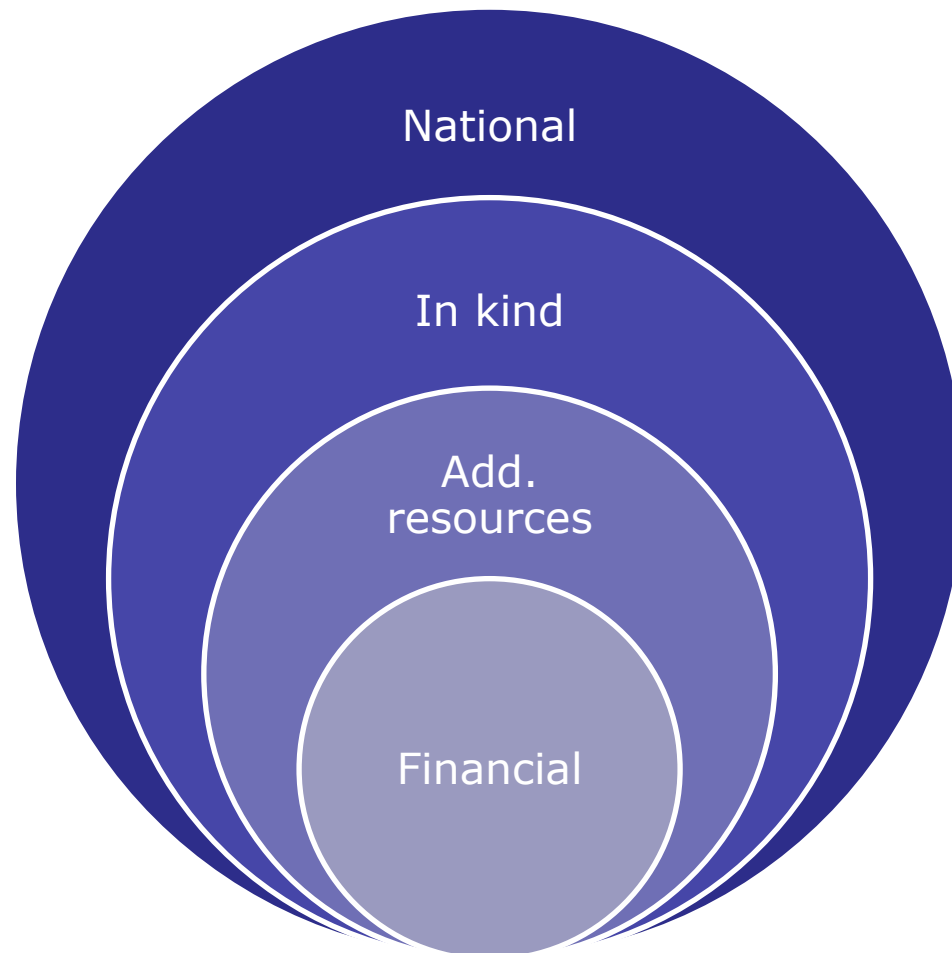
Non-financial contribution (Q2)?

- *Yes:*
 - national experts' time (ten Member States) and
 - sharing IT infrastructure (Fr)
 - Hosting meetings (Be)
- *More clarity about future organisation/structure may open up more possibilities*

Support in other ways (Q3)?

- Ongoing and/or planned national activities
- Participation EU-funded projects (incl. research); board or management activities; IT services.

Opting in to different contributions?



Suggested ways forward

- *Step by step, tailored approach*
- *Orphanet to develop draft Framework Agreement*
 - Allowing for diversity
- *Developing proposal on next steps by June 2019 for SGPP to be consulted again*
- *DG Sante stands ready to advise and help identify new options for sustainability*