

Alternative sources of funding for National Plans for Rare Diseases (NPRD)




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FUNDING

- **Mainly, NPRD have to be funded by the public funding**
 **public commitment from national authorities**
- **Most of the NPRD have been address to the Ministry for Health**
- **We have also to approach the Ministry of Work & Social Affairs and Ministry of Education**

 ***Need to identify key measures, priorities, to transform the needs into projects and look for dedicated funding !***

Actual economic environment

EU ➡ **A large variety and complexity of health care systems**

➔ Different level of development among the MS

➔ Variety of needs and different realities

NPRD:

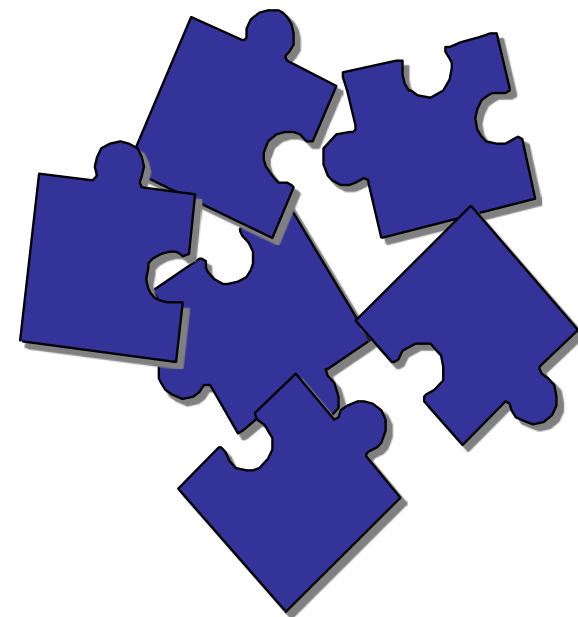
➔ Objectives

➔ Activities

RESOURCES



HR, time, money



PROJECTS

1. Resources/ objectives

2. Example of accessible funding programs

Common objectives of the NPRD

Mainly, the NPRD are concentrated on the following objectives:

1. Centres of Expertise & access to European Reference Networks
2. Improved access to information
3. Improved Access to Orphan Medicinal Products
4. Registries and data collection
5. Research
6. Access to diagnosis for all



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Centres of Expertise

Case study : Romania

National Authority for Scientific Research (ANCS), Intermediate Body for Priority Axis II, has announced the launch of calls for operations:

- **Call O.2.2.1 “existing RD infrastructure development and creation of new infrastructures RD” for public institutions (laboratories, research centers) with a budget of £ 200 million**
- **Call O.2.3.2 "infrastructure Development RD enterprises and creation of new jobs for the RD" for private institutions with a budget of 100 million**

Estimated date of release of the two operations - May 17, 2013

Estimated closing date - June 17, 2013

Source: www.fonduri-ue.ro

Improved access to information

- PO's websites
- Orphanet
- Centres for information
- HelpLines



- Information Campaigns (RDD, EUROPLAN conferences), ***funded through different small/ medium grants, sponsors and industry support.***
- Accredited information services ***might be funded by the national/ local authorities through subventions for social services***

<http://nonprofit.about.com/od/fundraising/a/fundraising101.htm>

Setting sail for Horizon 2020

Europe needs cutting edge research and innovation
Essential to ensure competitiveness, growth and jobs
Vital to tackle pressing societal challenges
3% of GDP invested in R&D: headline target of Europe 2020

A graphic for Horizon 2020 featuring a blue background with a glowing horizon line. A small globe is positioned at the center of the horizon, with the words "HORIZON 2020" in white capital letters across the middle.

HORIZON 2020

Co-operation at international level to



stimulate



better coordinate



maximise output

of rare disease research efforts around the
world



IRDiRC

INTERNATIONAL
**RARE
DISEASES
RESEARCH**
CONSORTIUM
www.irdirc.org

Funding Programs: ex. EEA Grants

EEE Grants and Norway Grants

- **BY WHOM:** Iceland, Liechtenstein, Norway, the EEA countries that are not EU MS
(EEA = 27 EU countries + Iceland, Liechtenstein, Norway)
- **TO WHOM:** provide funding to 15 EU countries in Central and Southern Europe.
- **WHY:** Iceland, Liechtenstein and Norway's contribution to reducing economic and social disparities in the EEA and to the strengthening of bilateral relations with the 15 beneficiary states in Central and Southern Europe.

<http://eeagrants.org/News/2013>

Funding Programs: ex. EEA Grants

- **WHAT:** 32 programme areas within different sectors ranging from environmental protection and climate change to civil society and research.
- **HOW:** All countries have different needs and priorities. Each country agrees on a set of programs with the donor countries based on needs, priorities and the scope for bilateral cooperation.
- **Download overview of all 32 programme areas:**
<http://eeagrants.org/content/download/5976/65820/version/2/file/Programme+Areas+2009-2014.pdf>

Social Impact Bonds (SIBs)

- **Social Impact Bonds (SIBs)** are designed to help reform public service delivery. SIBs improve the social outcomes of publicly funded services by making funding conditional on achieving results.
- *Investors pay for the project at the start, and then receive payments based on the results achieved by the project.*
- *Rather than focusing on inputs (e.g. number of doctors) or outputs (e.g. number of operations), SIBs are based on achieving social ‘outcomes’ (e.g. improved health).*
Outcomes are predefined and measurable.

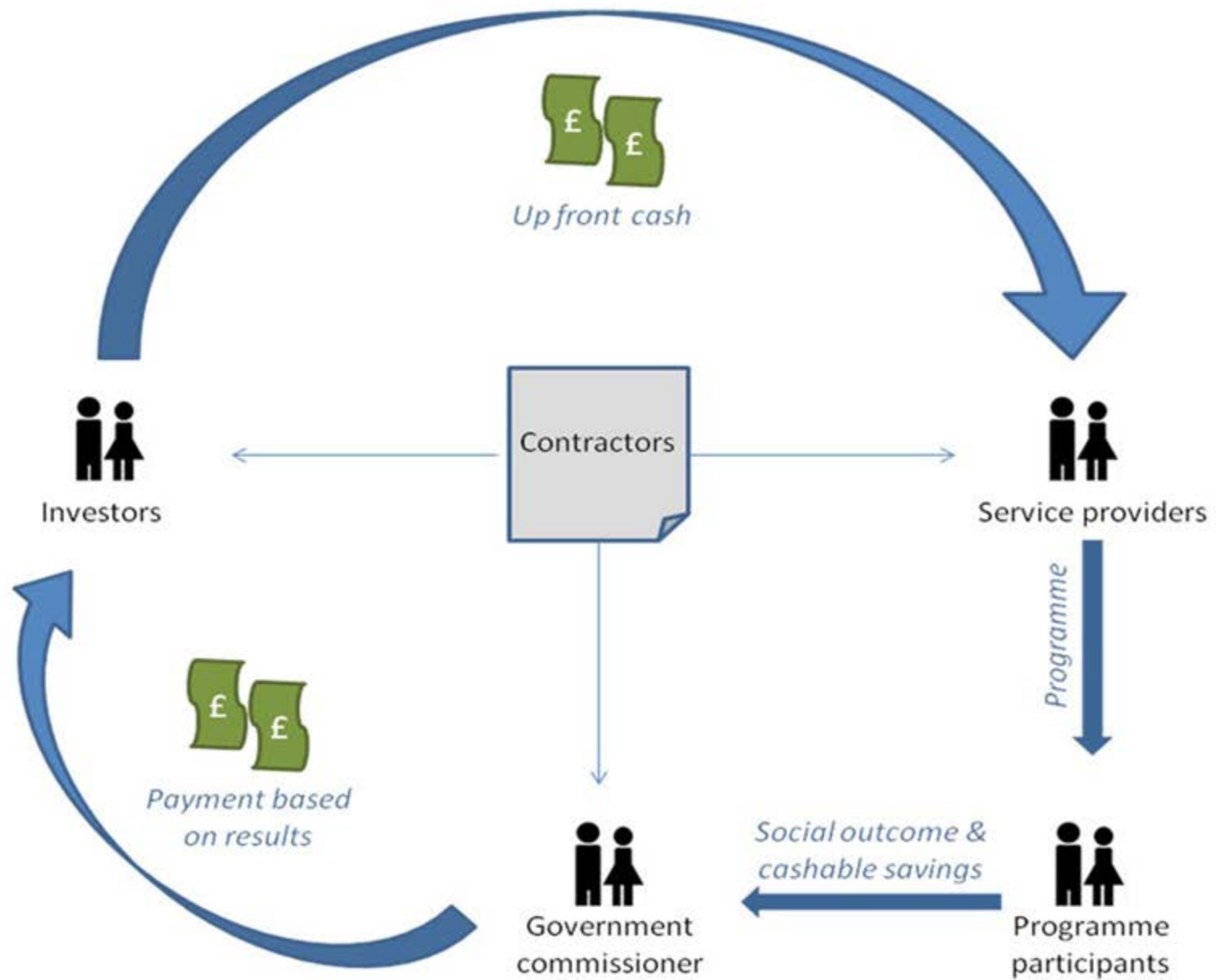
Social Impact Bonds (SIBs)

How to decide whether a SIB is likely to be appropriate:

An organisation commissioning a service or project could consider a SIB when:

- ➔ the desired outcome is clear and measurable (e.g. reducing recidivism)
- ➔ the quality of outcomes can improve
- ➔ there is a desire to increase evidence of effective programs
- ➔ government is looking to transfer financial risk
- ➔ innovative financing

<https://www.gov.uk/social-impact-bonds>



Conclusions

Where to look for funding for the NPRD?

EVERYWHERE!!!

If you follow your dream,
you can reach it !

THANK YOU!



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