Colombia
Implementing a National Rare Disease Plan starting with National Registry

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Ministry of Health and Social Protection

Health=fundamental right
Patients with RD=subjects of special protection

Public/Private Insurers

Package of Benefits

Hospitals/Clinics (Providers)

Universal coverage
Out of pocket exp. < 15%

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Priorities
Decree 1954 of 2012
Mandatory report of all of the providers through insurers

Definition
Rare Diseases
List of Rare Diseases
Model of Attention (networks)

Timeline of the Public Policy
Rare Diseases

2010
Law of Rare Diseases (1392)

2010
Information system for RD

2012
Decree 1954 of 2012
Mandatory report of all of the providers through insurers

2013
National Census
13,100

2013
National Registry

2016
National Plan

1 Health technologies
2 Effective access to health
3 Awareness
4 Financial sustainability
5 Research and training
6 International cooperation

32,883

National board for rare diseases
National Registry of Rare Diseases

Rare Diseases

2016

2019

13,100

32,883

Provision records
Payment records

Minsalud

NHI

Insurers

Certified Providers

Public Health surveillance system

Mandatory

Necessary for payments of some specialized technologies

Instrument for patients

Instrument for patients
| Health technologies | Value-based pricing  
| Special criteria for introducing HT into BP |
|---------------------|--------------------------------------------------|
| **Awareness**        | National Board for rare diseases  
| Patients associations  
| (FECOER/ACOPEL, etc) |
| **Acces/Financial S.** | Reference centers  
| New financial resources  
| Health expenditure control |
| **Research/int. coop** | 4.2 USD million for research 2016  
| WFH (Memorandum of Agreement) |
Challenges

Assure financial resources
Improve effective access
Multi-sector policy

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