

**11<sup>TH</sup> EUROPEAN CONFERENCE  
ON RARE DISEASES &  
ORPHAN PRODUCTS**

**ONLINE**

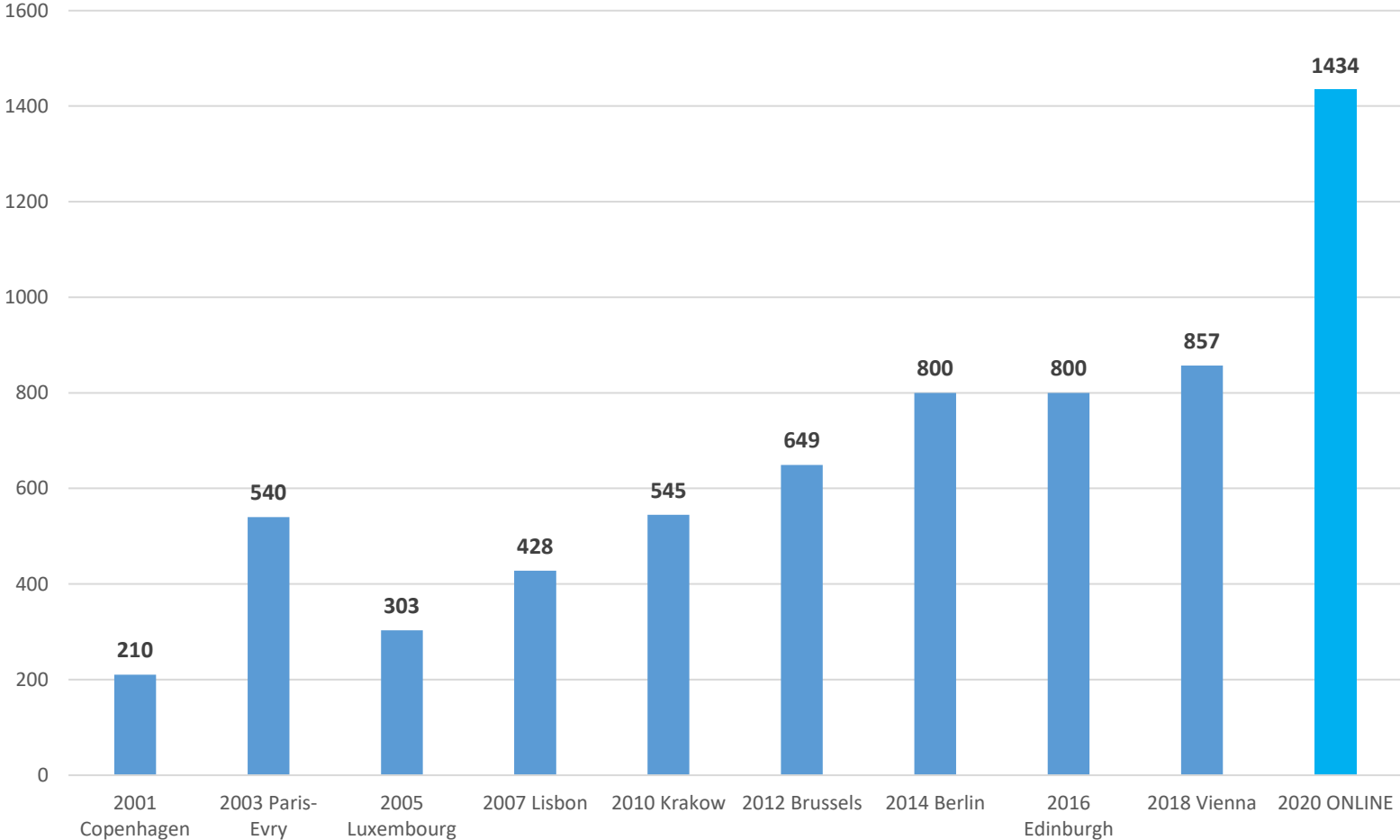


**27 JUNE ▶ 1 JULY 2022**

**MISSION  POSSIBLE**

**PUTTING RARE DISEASE POLICY INTO ACTION**

# ECRD Attendance

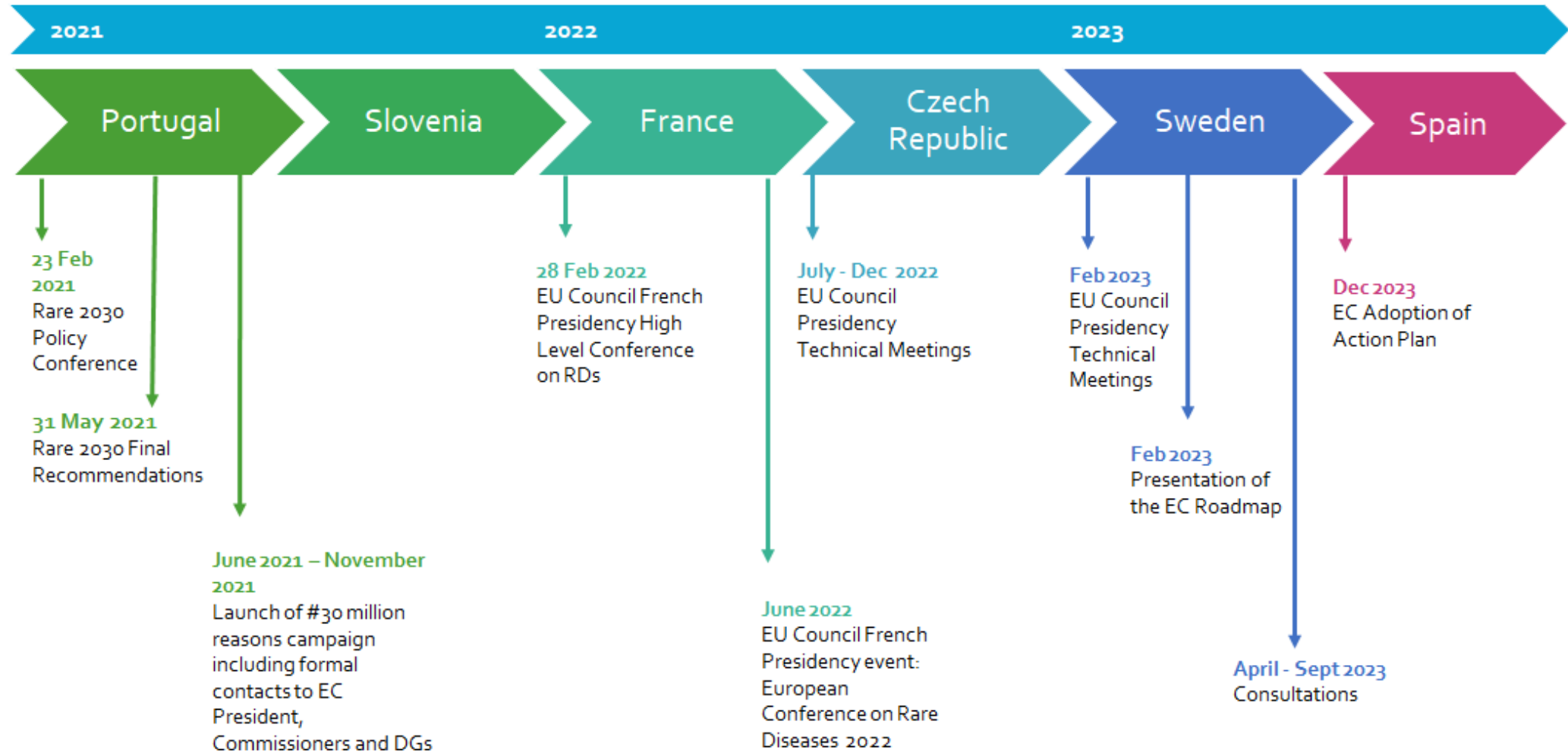


# Programme Outline

Monday 14:00-18:00 CET	Tuesday 14:00-18:00 CET	Wednesday 14:00-18:00 CET	Thursday 14:00-18:00 CET	Friday 14:00-17:00 CET
<b>Focus:</b> Overarching theme, Europe's Action Plan, Planning policies, Cohesive strategy	<b>Goal:</b> Ensuring healthy lives and promoting well-being for all people living with a rare disease at all age	<b>Goal:</b> Reducing inequalities for people living with a rare disease	<b>Goal:</b> Building resilient infrastructure, promoting inclusive and sustainable industry and fostering innovation for people living with a rare disease	<b>Focus:</b> EU at large and international, how to contribute to SDGs, WHO Europe
OPENING PLENARY  Poster Winners Presentation, Orientation & Networking session  Thought leader sessions	2 x parallel sessions  +  2 x parallel sessions	1 plenary session  +  2 x parallel sessions	2 x parallel sessions  +  2 x parallel sessions	Parallel Member State Zoom Meetings  Networking session  CLOSING PLENARY

# Timeline

## Working Proposal for Europe's Action Plan for Rare Diseases



## 8 Rare 2030 Recommendations

1. European/national plans and strategies
2. Diagnosis
3. Access to care
4. Person-centred care
5. Patient Partnerships
6. Research
7. Data
8. AAA Treatments

## 3 Goals in Europe's Action Plan

**GOAL 1:** Ensuring healthy lives and promoting well-being for all PLWRD

**GOAL 2:** Reducing inequalities for PLWRD

**GOAL 3:** Building resilient infrastructure, promoting inclusive and sustainable industry and fostering innovation for PLWRD

## 4 United Nations Sustainable Development Goals



3 GOOD HEALTH AND WELL-BEING

**SDG3:** Ensure healthy lives and promote well-being for all at all ages



9 INDUSTRY, INNOVATION AND INFRASTRUCTURE

**SDG 9:** Build resilient infrastructure, promote inclusive and sustainable industrialisation and foster innovation



10 REDUCED INEQUALITIES

**SDG10:** Reduce inequalities within/among countries



17 PARTNERSHIPS FOR THE GOALS

**SDG17:** Revitalise the global partnership for sustainable development



# Topics Addressed

## Monday

14:00-17:30 CET

**Focus:** Overarching theme, Europe's Action Plan, Planning policies, Cohesive strategy

### Topics addressed:

-EU and national frameworks/plans/strategies/policies

## Tuesday

14:00-18:00 CET

**Goal:** Ensuring healthy lives and promoting well-being for all people living with a rare disease at all age

### Topics addressed:

-Diagnostic testing  
-Screening technologies & early detection  
-Evidence-based care and support for rare disease patients  
-Highly specialised healthcare (European CoE lighthouses)  
-Innovative Therapies

## Wednesday

14:00-18:00 CET

**Goal:** Reducing inequalities for people living with a rare disease

### Topics addressed:

Reducing inequalities in:  
-Accessing health and social care  
-Accessing education  
-Accessing employment  
-The role of data and supporting infrastructures

## Thursday

14:00-18:00 CET

**Goal:** Building resilient infrastructure, promoting inclusive and sustainable industry and fostering innovation for people living with a rare disease

### Topics addressed:

Technical improvements:  
-De-risking product development  
-CBHC directive for CTs and funding mechanisms  
-Fragmentation of the EU market  
Allocative improvements:  
-Distribution of resources for healthcare budgets  
-Benefit corporations  
-Transversal topic: Data

## Friday

14:00-17:00 CET

**Focus:** EU at large and international, how to contribute to SDGs, WHO Europe

### Topics addressed:

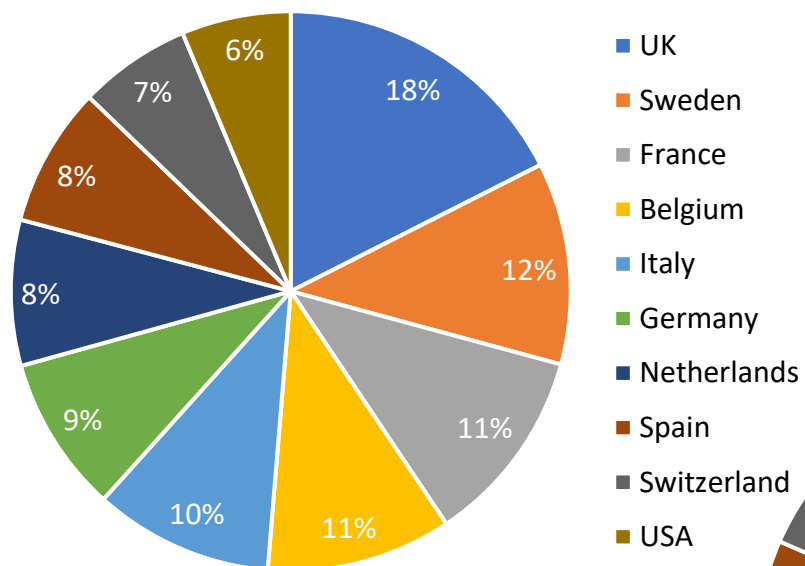
-EU, international and national frameworks /plans/strategies/policies

# What is EURORDIS offering?

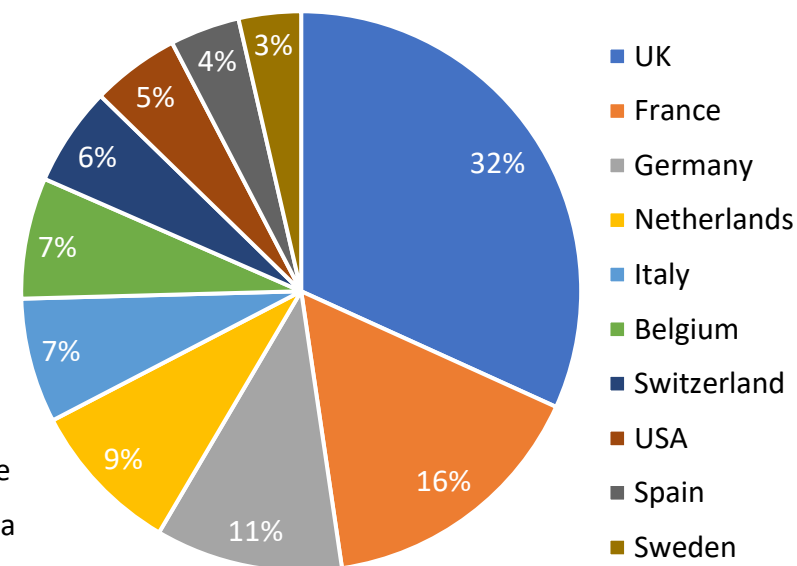
- Platform and technology to host a 90-minute multi-stakeholder discussion on key areas of your national plan (in your native language)
- Help to make your discussion politically relevant > template agenda
- Inclusion of your meeting as part of the official programme
- Note-taking template to capture your key messages
- Inclusion of your key messages in the Executive Summary
- Promotion of the meeting to all pre-registered participants of the conference

# Breakdown by country:

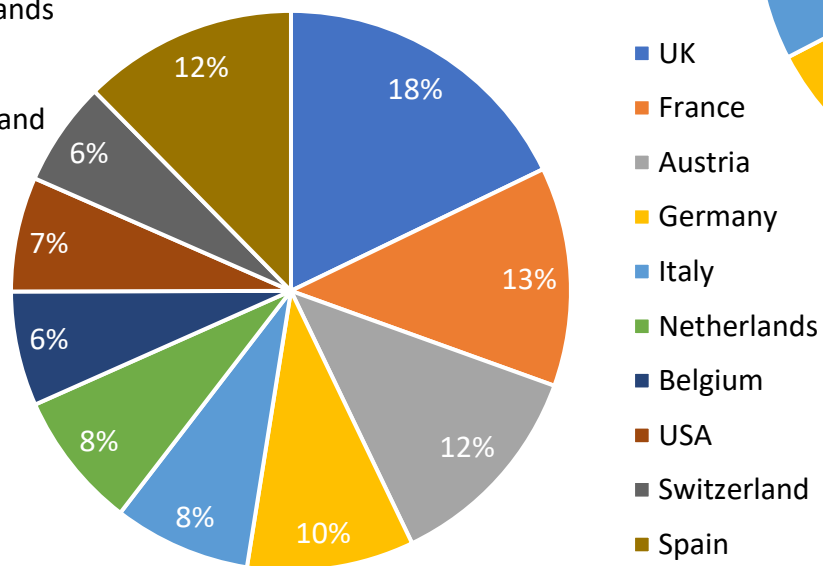
## Participants Online 2020



## Participants Edinburgh 2016



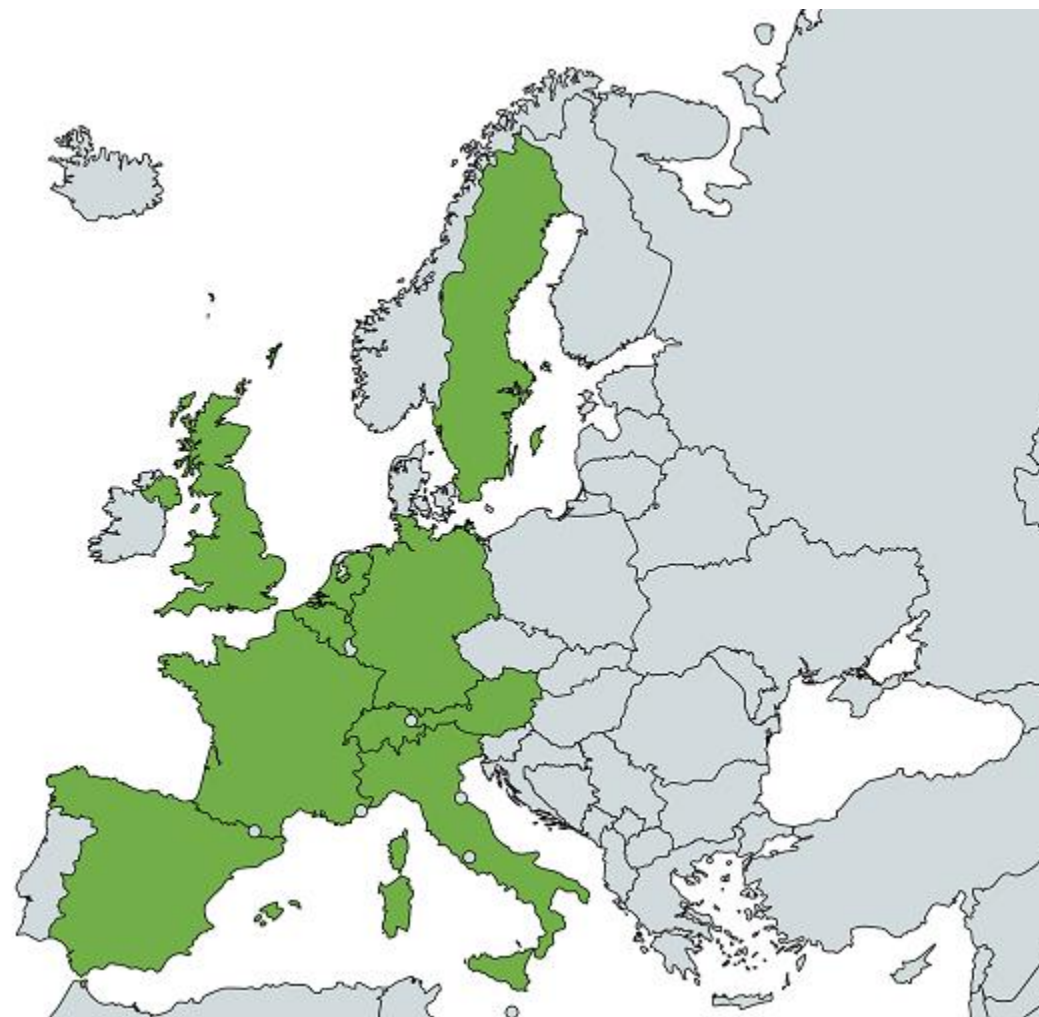
## Participants Vienna 2018



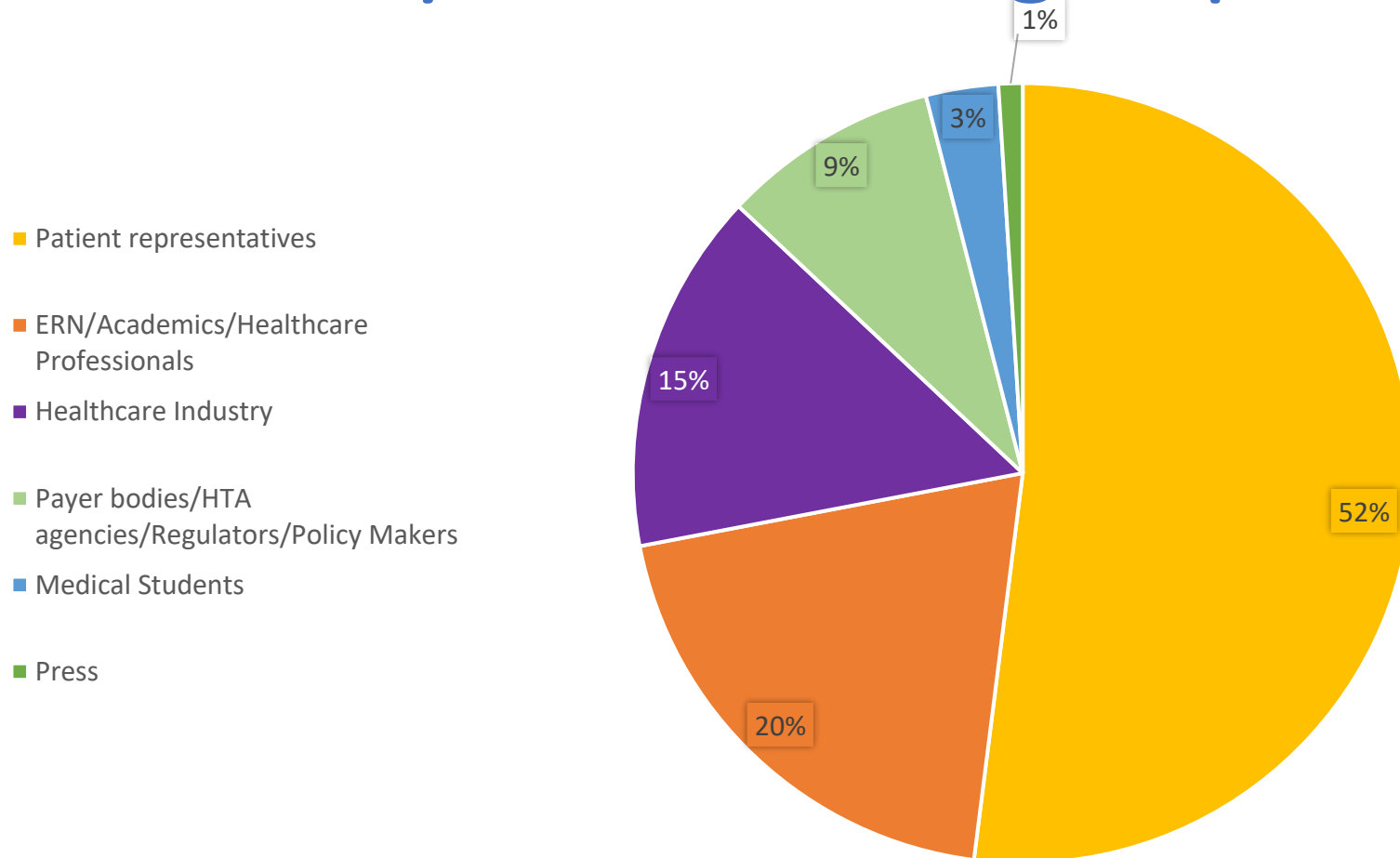


# Overall Top 10:

Country	Participants On Average
United Kingdom	158
France	98
Austria	86
Sweden	76
Germany	74
Italy	69
Belgium	67
Netherlands	64
Switzerland	48
Spain	48



# Breakdown by stakeholder group



- Patient representatives
- ERN/Academics/Healthcare Professionals
- Healthcare Industry
- Payer bodies/HTA agencies/Regulators/Policy Makers
- Medical Students
- Press

# What can you do as a National Alliance?

- Invite your national authority representative(s) and/or your national plan committee members
- Co-create the meeting agenda with your national plan committee members
- Moderate the conversation:
  - o Discuss ways to push forward the key areas of your national plan
  - o Focus on solutions and commitments to implement some of these policies
- Take notes using the template to be provided by EURORDIS
- Send your notes to EURORDIS for inclusion in the ECRD 2022 Executive Summary
- Request interviews with EURORDIS board, staff, VIP speakers or other invited speakers

# What benefits are there for you?

- Increased visibility
- EU context & official labelling
- Follow-up opportunity / check-in after Rare Disease Day
- Prepare for integration of EU policy at national level & vice versa
- Platform and ready-made multi-stakeholder audience
- Another opportunity to grab the attention of your national authorities
- Inclusion in ECRD 2022 Executive Summary
- Potential increased media exposure

# How can we help you?



# More information

If you are interested in taking advantage of this opportunity, contact [sharon.ashton@eurordis.org](mailto:sharon.ashton@eurordis.org)