



RPP-Alpha-1 Global EU Advocacy Webinar

18.30-20.00

31 January 2018



BRUSSELS · BERLIN · LONDON · PARIS · HAMBURG · ROME

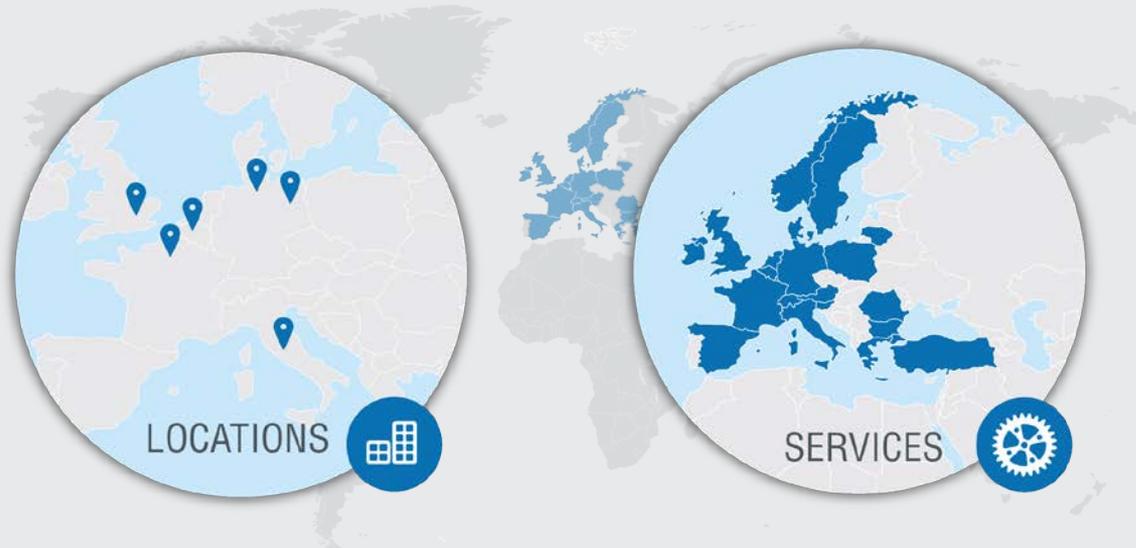
Webinar structure

- Introduction
- Sneak peek on EU public health key actors & decision making processes
- **STEP 1** identify your top political asks & long-term strategy
- **STEP 2** map the policy-makers
- **STEP 3** connect with your policy-makers
- **STEP 4** go live!
- **STEP 5** celebrate European Alpha-1 Awareness Day
- Q&A

INTRODUCTION

Who is RPP and its contribution to the launch of the
Alpha-1 Expert Group Recommendations

RPP Group: A true European Firm



- RPP Group is a consultancy focused on **policy creation and development**, building on our integrated services such as **digital campaigning and visual communications**.
- RPP Healthcare is a member of the RPP Group. Our topical focus and expertise are in **healthcare, well-being, nutrition, R&D, innovation, market access & reimbursement, trade, and internal market policy**.
- RPP Healthcare offers Public Affairs Services in **various European Countries and on EU Level**.

RPP Group offices and services:

- **Brussels (HQ)** – EU Public Affairs Services and Belgian Public Affairs Services
- **Berlin** – Germany Public Affairs Services
- **London** – UK Public Affairs Services
- **Paris** – France Public Affairs Services
- **Rome** – Italy Public Affairs Services
- **Hamburg** – RPP Visual Communications

Introduction

RPP Contribution to EU Rare Disease Space

Legislative Credentials:

1. Worked with EC on inserting Rare Disease definition in Cross Border Healthcare Directive
2. Worked to insert the 'ultra-rare' definition in the Clinical Trials Regulation
3. Developed the term 'treatable rare diseases'

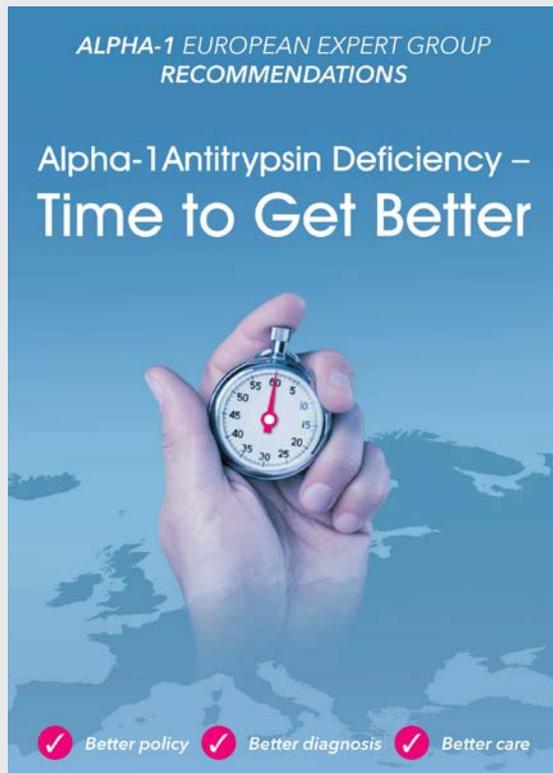
Stakeholder Credentials

1. Represented Patient Groups covering 400+ Rare Disorders
 - Rare Bleeding Disorders, PID's, AATD, Rare Cancers, Childhood Dementia etc.

Impact on Policy

1. Rare Disease Plan Implementation work (Sweden, Denmark, Belgium, Germany)
2. National campaigns pushing for implementation for Newborn screening for SCID
3. Patient Training (Ireland, UK, etc.)
4. Reimbursement in Lithuania

Alpha-1 Expert Group Recommendations 2017



What do we want to achieve?



Empowered Alpha-1 community



Increased funding opportunities for Alpha-1 research



Increased awareness on Alpha-1



Reduced inequalities in Alpha-1 diagnosis, treatment and care



Next Step: European Alpha-1 Awareness Day

On April 23/24 2018 the European Alpha-1 Awareness Day will be celebrated for the first time with the aim to raise awareness on the condition and call on the policy makers to implement the Recommendations developed by the European Alpha-1 Expert Group.

How the EU works and how it can help you to drive a change on a national level?

Competences in public health

EU

- ensuring that all EU policies and actions provide a high level of health protection
- assisting Member States to coordinate their action and collaborate on health
- joint action with member states on 'threats to health' particularly where there is a cross border dimension
- standard setting and regulation in specific areas such as pharmaceuticals, medical devices, blood products, organs for transplantation

National level

- Financing, organising, managing and running health services
- Reimbursement decisions

Post-2020: the EU might setting up of a legal framework for EU cooperation on HTA

EU Institutions role in public health



DG SANTE
DG RESEARCH
EMA

Working Groups
Health Platform



ENVI

Interest Groups



EPSCO

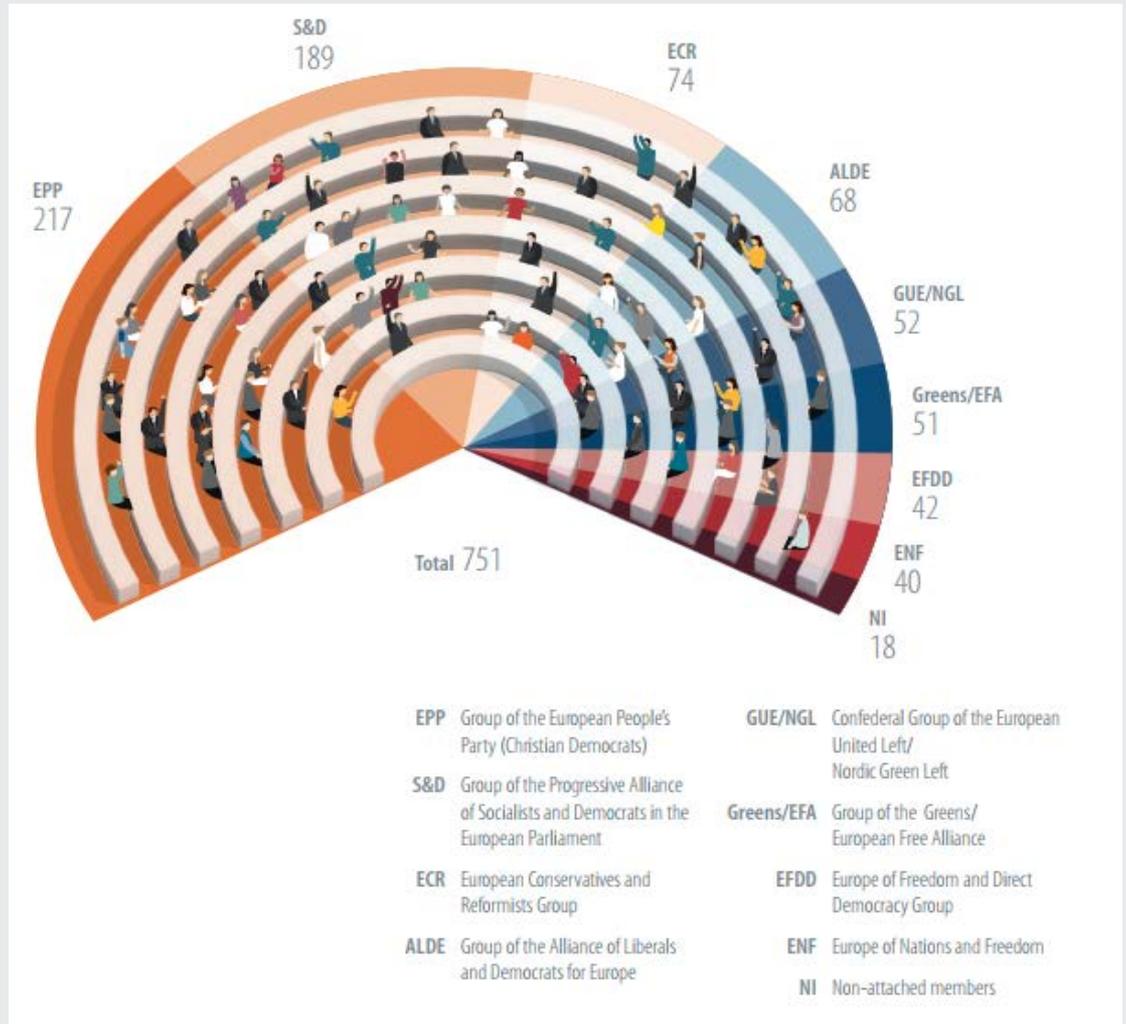
European Parliament

The only directly elected EU body, this represents the EU's 500 million inhabitants.

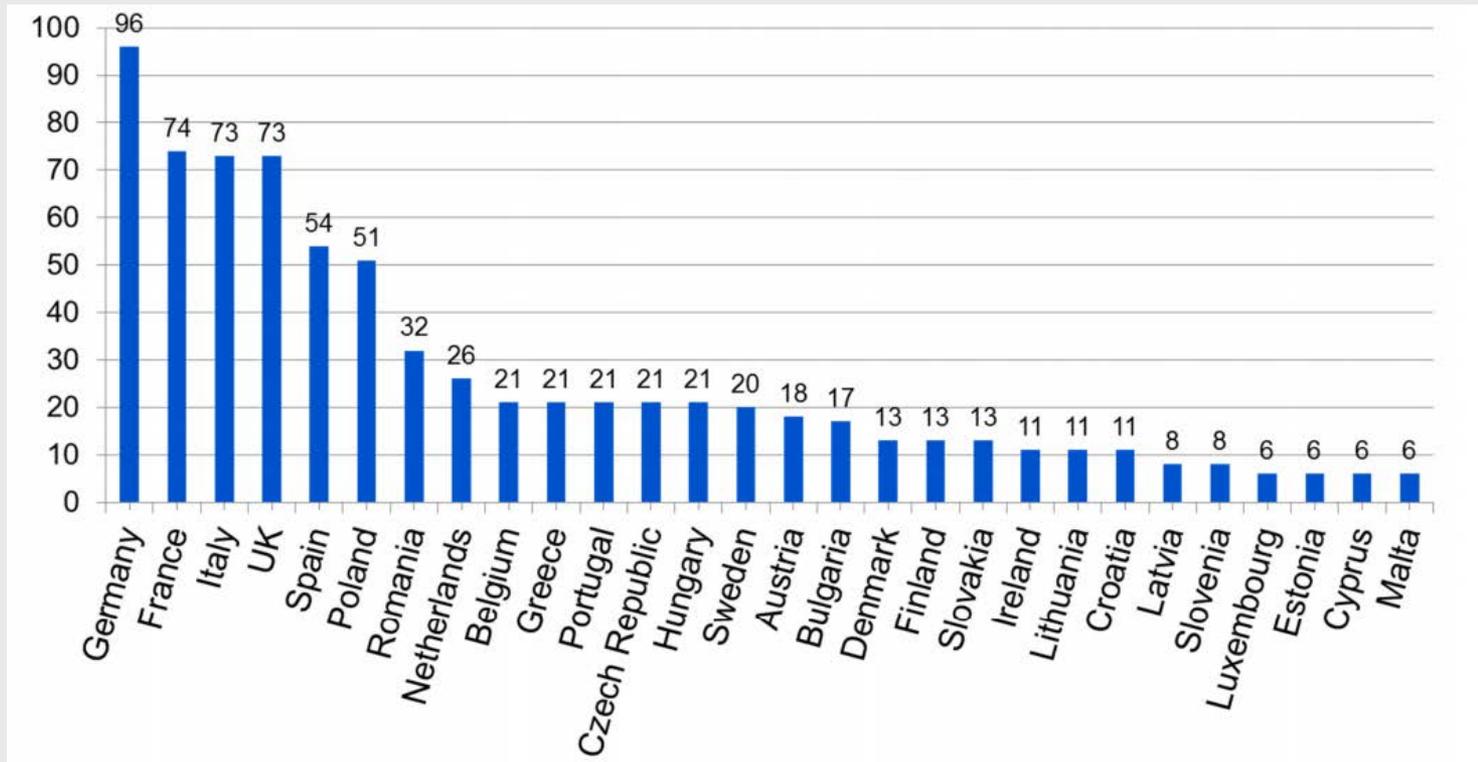
It is a key institution to engage with to drive a change at the national level through the EU



Structure of the European Parliament



Number of seat per Member State *(total 751)*

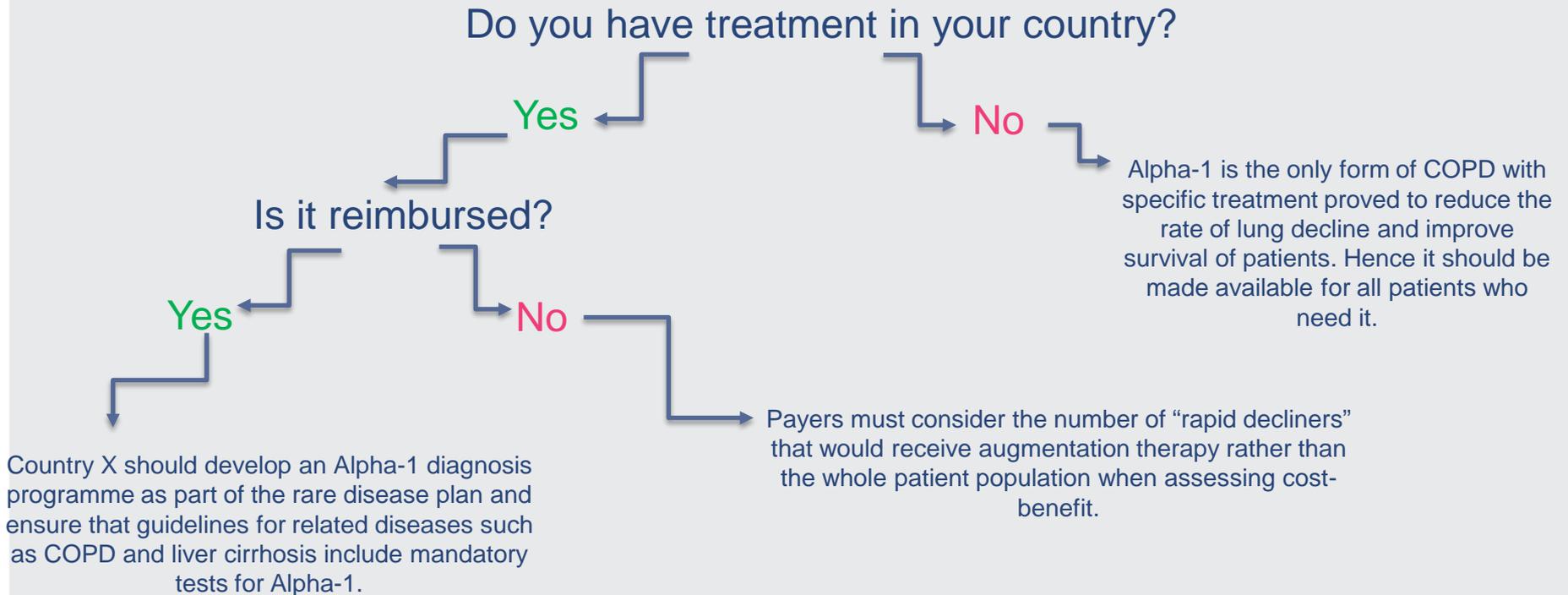


STEP 1: Identify your top political asks & long-term strategy



STEP 1 identify your top political asks & long-term strategy

Understand the environment



Do you have country-specific data? Add it to your message!



Practical task: fill in the table in your checklist

STEP 1 identify your top political asks & long-term strategy

5 min



Key issues in my country	
2018 asks	
Strategic goal	

STEP 2: MAP THE POLICY MAKERS



STEP 2 map the policy-makers

➤ Identify active politicians in health at the national level

- find out who is responsible for rare disease policies: Parliament, Ministry of Health, Medicines Agency etc).
- If you find there is no dedicated department/committee in your country, map politicians active on general public health policies

A tip for finding out relevant stakeholders:
check whether your country has a rare disease plan, who is responsible for its implementation, who is active in related debates



STEP 2 map the policy-makers

➤ Find out who represents your interests at the European Parliament!

A tip: look particularly for those MEPs working in the Committee on Environment, Public health and Food Safety (ENVI)

-> check which political group your MEP belongs to (EPP, S&D are the biggest groups in the Parliament)

Browse map | **Advanced search** | Browse table | Browse Chamber | About MEPs

Surname	Political group
<input type="text"/>	All political groups
Country	Constituency
Romania	
Political bodies	Environment, Public Health and Food Safety
Committees	

Result(s) : 4

	Daciana Octavia SÂRBU Group of the Progressive Alliance of Socialists and Democrats in the European Parliament Romania Partidul Social Democrat
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You are from Bulgaria, Austria, or Romania? These countries have the forthcoming EU Council Presidencies – urge your government to put Alpha-1 and rare diseases on the agenda.

Practical task: fill in the table in your checklist

STEP 2 map the policy-makers

5 min



National representatives	
Members of the European Parliament	
Other	

STEP 3: CONNECT WITH YOUR POLICY MAKERS



STEP 3 connect with your policy-makers

Connect with your identified policy-makers on Social Media (Twitter, Facebook, LinkedIn).

Post your developed political asks, recommendations and photos on social media and don't forget to tag them!

Example of a tweet

Alpha-1 Awareness Day @Alpha1_EEvent · 23 Mar 2017
#Alpha1 European Expert Recommendations are out! Please check it out here:
bit.ly/2mTA1K2 @Alpha1_Global @alpha1bel

Tag relevant organisations/people

3% of COPD patients are *Alpha-1* patients

COPD will be a leading cause of death worldwide by 2020

Alpha-1 is the most widely recognised rare genetic cause of COPD

Alpha-1 is the only form of COPD with specific treatment and with the highest level of data for that treatment

Alpha-1 causes cirrhosis not attributable to alcohol consumption and accelerates progression of other liver diseases

Post a picture – it attracts more attention

Seb Dance MEP, Sirpa Pietikäinen, EU_Health and 6 others

Tag up to 10 organisations/people on the picture



STEP 3 connect with your policy-makers

Before the meeting	
➤ Find out when and how you can meet you MP/MEP. All Members of the European Parliament have national offices; so, you don't need to come to Brussels to meet them)	<input type="checkbox"/>
➤ Book the meeting (don't take no as an answer)	<input type="checkbox"/>
➤ Do your research. Find out what issues your MP/MEP cares about and whether he or she has an active interest in health policies	<input type="checkbox"/>
➤ Know what you want to discuss: take with you the recommendations and key messages to explain why this is important	<input type="checkbox"/>
➤ Practice speaking: develop a brief for 2-3 minutes to quickly and powerfully introduce your issue to your policy maker	<input type="checkbox"/>
During the meeting	
➤ Share your story: facts and figures are important but telling your personal story and showing your commitment is a powerful way to make yourself heard	<input type="checkbox"/>
➤ Be concise: present your case in laconic but engaging way, including an explanation of the issues you are experiencing and your political asks	<input type="checkbox"/>
➤ Make clear and specific requests: having concrete asks to your policy-maker is the best way to encourage a political reply to your issue. Also let your policy maker know about Alpha-1 Awareness Day, ask them to support it.	<input type="checkbox"/>
After the meeting	
➤ Send a thank you email along with a short summary of your key asks and materials	<input type="checkbox"/>
➤ Follow up: keep your policy-maker posted on the developments and have a follow-up meeting to maintain a relationship	<input type="checkbox"/>
➤ Share your success: post an article about the meeting on your website or newsletter, have a social media post thanking your policy-maker for support	<input type="checkbox"/>

STEP 4: GO LIVE



STEP 4 go live!

- **Post recommendations on your website**

- **If you have Facebook or Twitter account, you can:**
 - spread your message!
 - disseminate the Alpha-1 European Recommendations
 - share messages provided by Alpha-1 Global ahead of European Alpha-1 Awareness Day
 - share MEPs video messages developed ahead of EU Alpha-1 Awareness Day
 - Follow Alpha-1 Global on Twitter: [@Alpha1_Global](#), [@Alpha1_EEvent](#)
 - Retweet tweets [@Alpha1_Global](#) to help us spread the word.

If you don't have a Facebook or Twitter account, consider creating one

- **Tell your story on Alpha-1 Global Blog:** www.facebook.com/groups/A1Gleadershipblog/

Practical task: fill in the table in your checklist

STEP 4 go live!

5 min



Social media plan

February

March

April

STEP 5: CELEBRATE ALPHA-1 AWARENESS DAY



STEP 5 celebrate European Alpha-1 Awareness Day

Celebrate online

- Share Alpha-1 Global messages
- Use a banner developed for your country
- Share a developed video message from your MEP
- Write an article to a local newspaper/news portal about Alpha-1 Awareness Day



STEP 5 celebrate European Alpha-1 Awareness Day

Have a community event in April 2018

**Organise an event at
your Parliament**

**Host a lecture/workshop
on Alpha-1 together with
other patient advocates
and/or healthcare
professionals**

**Organise Alpha-1
community lunch with
policy-makers**

**Disseminate Alpha-1
recommendations in your
healthcare setting**

Example of an event at the national parliament

Based on European call for SCID newborn screening, the Spanish NMO organized, in collaboration with RPP, an event in the Congress in Madrid to call for national SCID newborn screening



IMPLANTANDO EL CRIBADO NEONATAL DE LA INMUNODEFICIENCIA COMBINADA GRAVE (IDCG) EN ESPAÑA

POR UNA VIDA MÁS ALLÁ DE 'LA BURBUJA'

¿CUÁNDO?
23 de octubre de 2017, 17:00-19:00

¿DÓNDE?
Congreso de los Diputados

Si desea más información, puede ponerse en contacto con nosotros a través de la dirección de correo electrónico aedip@aedip.com



- MEP-MP connection
- National asks and strategy
- Event
- Press engagement
- Social Media Presence
- Alliance with other NGOs
- Advocacy follow up



Tips for organising a community event

- **Short meetings are best** - half-day or less. If having policy makers or professionals is key to your meeting, find out their schedules before you fix the date, time and length of the meeting. If you hold a day-long meeting, policy makers may only be able to attend for part of the day.
- **Focus on your audience's needs.** State the audience benefit for the event in your promotional materials and introductory welcome on the day. Why is this meeting, and your work, important for them? Focus on your key message and whatever background information your audience needs.
- **A meeting should be a dialogue.** Give stakeholders the chance to react, raise their concerns and provide their perspectives. A workshop format (rather than presentations) provides time for more interaction, although a briefing format may be suitable for shorter, smaller meetings (e.g., lunchtime seminars).
- **Take appropriate printed materials.** Use printed materials during your event, including Alpha-1 Recommendations (include a one-page summary on top).



For other comments and questions please contact
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