

# ADVOCACY TOOLBOX

A guide to influencing political decisions  
that have an impact on Chronic  
Obstructive Pulmonary Disease (COPD)



THE EUROPEAN COPD COALITION



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TOOLS FOR ADVOCATES WORKING ON COPD WITH A MAIN FOCUS ON EU DECISION MAKING LEVEL.

THIS TOOLBOX WAS DEVELOPPED BY THE EUROPEAN COPD COALITION FOR ITS MEMBERS AND SUPPORTERS; ANY PARTS SHOULD NOT BE COPIED WITHOUT PRIOR AUTHORISATION FROM THE EUROEPAN COPD COALITION

# Introduction

**CHALLENGE #2**

**BREATHE NOW.**  
Take a straw and breathe in and out through it for 2 minutes.

- Easy?**  
Please consider that this is the way people with COPD breathe every day.
- Any trouble?**  
Please get your lungs checked.

Please think about the lives of people who struggle with COPD.



**HAVE A VOICE, BE HEARD**

**Advocacy  
Toolbox**

**SUPPORT FOR COPD ADVOCATES**

The European COPD Coalition (ECC) was created to raise awareness about COPD at EU level and to advocate for further and better uptake of the cause from political leaders. We are advocating for stronger EU legislation and policy regarding COPD and as the focus shifts from the European Union to national progress, we support our members and colleagues to advocate for greater action on COPD in their local settings.

ECC offers its members and supporters elements to assist them in their advocacy and communication activities, to raise awareness about COPD, addressing decision makers and politicians so that they take action on COPD.

ECC's toolbox is a support to campaigners, it attempts to present

as many tools as possible, collected from various sources and based on its own experience of advocating for COPD; it is not meant to represent views or to be a manual for the subject matter, but rather help guiding other advocates in their plans to lobby for COPD. No advocacy approach is universally applicable. Please adapt the materials and advice in this Toolbox to fit your unique local situation

It is the result of six years of advocacy activities, supported by members of ECC – it is therefore primarily addressed and available to ECC members and should not be spread publicly without the prior authorisation of ECC's members.



### Example of a visual

Developed for World COPD Day, cover of flyers, brochure and website banner



Advocacy at the European level

# Why do advocacy

Advocacy in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to:

- Have their voice heard on issues that are important to them.
- Defend and safeguard their rights.
- Have their views and wishes genuinely considered when decisions are being made about their lives.

Advocacy can be defined as any activity by an individual or group that aims to influence political, economic, social and institutional decisions.

## Why is it critical to engage in advocacy for COPD?

To address premature death from COPD, quality of life of people living with COPD, the economic burden of the disease and its impact on the labour market, it is essential that

people concerned by COPD engage in communication and activities towards decision makers that will help change the future for those affected by COPD.

A typical form of advocacy is a direct approach made to legislators concerning an issue and an appeal is made to them, however advocacy can take other forms, such as media campaigns, public speaking, commissioning and publishing research and even conducting exit polls.

Effective advocacy builds one's capacity to achieve the greatest good for the greatest number of people and communities one serves. Engaging in public policy advocacy can also raise awareness of your organisation's mission, mobilise your constituents, and attract positive media attention.



## ADVOCACY

Advocacy is a process of supporting and enabling people to: express their views and concerns, access information and services, defend and promote their rights and responsibilities, explore choices and options<sup>1</sup>.

# Advocacy requirement:



Advocating requires strategic planning, considering key questions: What public policy goals do you want to influence and how do they relate to your advocacy issue? What do we want:

- How do these goals relate to your organisational goals and affect the people you serve?
- How will your organisation carry out your advocacy work?
- Who can make it happen (stakeholders) -
- Audience: what do they need to hear? Developing evidence-based messages
- Who do they need to hear it from? Identify the right messenger for your audience
- How can we make sure they hear it? Identify processes, opportunities and entry point
- What do we have? What do we need? Recognize capacities and gaps
- How do we tell if it's working? Monitor and evaluate advocacy

<sup>1</sup> Source: SEAP

# Building a campaign

This toolkit is to explore what individuals and organisation you can do to bring about change; it maps out some key opportunities in which we can advocate for improved prevention and control of COPD.

Advocacy encompasses a wide range of activities that influence decision makers. Advocacy includes traditional activities such as litigation, lobbying, and public education. It can also include capacity building, relationship building, forming networks, and leadership development. Lobbying refers to activities that are intended to influence a specific piece of legislation.

## Eight stages

The development of an advocacy campaign will take place in 8 stages:

1. Select your priorities;
2. Identify your target audience;
3. Develop your message(s);
4. Choose your messenger(s);
5. Identify opportunities and activities for delivering your messages
6. Take stock and identify gaps;
7. Manage risks; and
8. Monitor and evaluate progress and impact

We advise campaigners to select the activities that are most suitable to their setting and resources, and that approaches are tailored to local priorities.

## Select your priorities

Examples:

### Measuring and monitoring the importance of COPD at national level

**Goal:** obtain prevalence, incidence and mortality rates by putting a harmonized data collection system in place, allowing healthcare professionals to easily record findings and numbers.

Promote the implementation of disease registers.

### Raising awareness and secondary prevention

**Goal:** health warnings on tobacco packs should include mentions of COPD (secondary prevention)

### Investing in non-pharmacological treatment

**Goal:** pulmonary rehabilitation will be part of any standard COPD treatment, at EU level



Depending on the outcome you want to reach (e.g a 20% decrease in the number of people dying of COPD by 2050), you could set up many different activities but probably have the resources for only a few. Therefore, you should identify your priorities, in a **SMART** manner: Specific, Measurable, Achievable, Realistic and Time-bound. You should also take into account the political context and opportunities/timing of your initiative.

Remember that evidence will also give your work legitimacy, which is critical to successful advocacy.

- ➔ Cause-based legitimacy draws its strength from the 'morality' of a cause the advocacy project stands for, and not necessarily from a number of individuals or various

groups of people it represents. Many causes started with only minimal support from the public, yet succeed through their 'moral strength'.

- ➔ People-based legitimacy means having the backing of a sufficiently large number of individuals or different groups of people: a constituency.

Keep track of national progress and statistics: when starting your advocacy campaign, you should be aware of key policy measures missing or put in place, identify the gaps; number of people living with and dying of COPD if complement and support government official surveillance, who is most affected by COPD, who is receiving treatment, and which treatments are available, etc.

The campaign needs to be **SMART**

Specific	<ul style="list-style-type: none"> <li>•Lung function testing; free for people who have a smoking history or/and who have been exposed to lung pollutants</li> </ul>
Measurable	<ul style="list-style-type: none"> <li>•Number of people tested, results of the tests, number of healthcare professionals trained to run and understand spirometry test, number of people treated for COPD.</li> </ul>
Achievable	<ul style="list-style-type: none"> <li>•Aim to test a minimum number of people (e.g. 100,000) for the 1<sup>st</sup> year, and gradually increase this figure over a set number of years.</li> </ul>
Realistic	<ul style="list-style-type: none"> <li>•Secure support within the scientific community, patients groups and decision making bodies; set a modest goal for the 1<sup>st</sup> years; evaluate the political context: is the government investing in prevention or only focusing on care, for instance</li> </ul>
Time-bound	<ul style="list-style-type: none"> <li>•Develop a timeline of action with milestones and a clear goal to be achieved by a set date. E.g: all long-term smokers will have performed a spirometry test by 2030.</li> </ul>

## Choose your audience

The advocacy activities are addressed to individuals or groups of people who have the power, or the possibility to influence those who have the power, to implement the change you are working towards.

They must be clearly identified:

- ➔ Who will make the ultimate decision? Will this be submitted to a vote?
- ➔ Who is drafting the texts?
- ➔ Who is providing information to the legislator: experts? Assistants? Other NGOs? Can they hear our messages and relay them too?
- ➔ Who has the ears of the politicians we want to reach?

The audience may change depending on the specific request and message. Some people may be very difficult to approach, some will be approachable only via third parties, one shall persist and try reaching the audience by all means: in writing, during one to one meetings, at public events, or on the phone. Know your representatives: get to know them—and their staffs—first. Visit your representatives' Web sites to learn

**At European Union level, the key targets are:**

**European Commission:** initiates new regulations, directives and decisions but does not vote. Each Member State (28 until June 2019) has a representation in the College of Commissioners. The Health Commissioner until November 2019 is Vytenis Andriukaitis.

their issues and priorities. Invite them to your office/hospital and let them see, firsthand how valuable your work is to the community and to academic excellence. Let them know you want them to support COPD related policies and give them specific ways they can get involved. You can schedule an appointment by calling your legislator's office, or even better, invite your representatives to visit your premises for a special event you have planned.



Commissioner for Health taking a lung test at the European Commission

**European Parliament:** Members of the European Parliament (MEPs) elected at national level, co-legislator, with voting rights.

**Council of the EU / Member States** representatives:, mainly the Health Attachés - co-legislators with voting rights.



Hereunder, we share information and names valid at the time of drafting this manual, please check data, names and contact details with the following links:

European Parliament:

<http://www.europarl.europa.eu/meps/en/map.html>

European Commission:

[https://europa.eu/european-union/index\\_en](https://europa.eu/european-union/index_en)

Council of the European Union and European Council:

<http://www.consilium.europa.eu>

## Prepare your messages

Delivering powerful communications means understanding your audience. If you really want to influence decision-makers you should invest time in determining what motivates and moves your target audience. Just put yourself in the place of the people you are trying to reach. Do they know very much about COPD? Are they busy individuals with

little time to read lengthy letters or documents? If your messages are numerous, vague or too complex they might not grab the attention of your target audience.

Ideally, you need to be able to summarise and present the advocacy message in three or four sharp sentences.

The primary message should include the following:

Statement + evidence + example + goal + action desired

### Example 1

New research finds that 66 million people in Europe may be living with COPD, yet COPD is mostly preventable. Everyone at risk should be offered spirometry, a simple breathing test, reimbursed by national social security, for earlier diagnosis, as COPD is not treatable but manageable with proper treatment, its progression can be halted.

### Example 2:

According to WHO, there are 64 million people living with COPD, this is about 10% of the population. In Europe, studies suggest that COPD kills between 200 000 to 300 000 people every year. The number of deaths from COPD has increased more than 60% over the last 20 years. Without preventive measures, the disease will be the 3rd cause of death by 2030 – tobacco packs must bear the mention "smoking causes COPD".

### Example 3

There is no harmonised, validated prevalence, incidence and mortality data on COPD worldwide. Countries must put in place tools (e.g. registers) to collect monitor and keep track of number of people living with COPD and dying of it, to better identify the scale of the disease and support political actions towards it.

## Talking points and soundbites

Every successful campaign needs a clear identity and a message that the public understands. This means you need logos and slogans that people identify with the campaign. You also must be clear about the message that you want to get across in all the speeches you make or media you produce. The message sums up the key things that you want the public to understand around your issue



### Effective stories:

- are simple, brief
- and personal;
- have a beginning, middle and end;
- have a "punch line";
- do not use real names unless you have been given permission;
- have a message;
- are appropriate and specific;
- show the physician solving a problem or filling a need; and
- illustrate to a potential funder what giving you the funds will mean in real-life terms.

## COPD FACTS

### 300,000 deaths

There are more than 300,000 people who die from COPD every year in Europe, the equivalent of 3 Hiroshima bombs



### 5<sup>th</sup> largest killer



### 4- 10% of adult population lives COPD in Europe



### 62 Million

people living with COPD in Europe (WHO region)



### 3<sup>rd</sup> leading cause of death by 2030



The number of deaths from COPD has increased more than 60% over the last 20 years.



### 3.3 Million people died of COPD in the world in 2015



### 4.7 Billion per year

The total COPD related expenses in euro for outpatient care



COPD now affects men and women almost equally



- COPD is responsible for more deaths than any non-respiratory cancer.
- COPD is the only major cause of death whose incidence is on the increase;
- The primary cause of COPD is tobacco smoke (through tobacco use or second-hand smoke).
- Non-communicable diseases, including COPD account for 63% of the global burden of disease, but receive less than 3% of donor assistance for health.
- Millions of people have COPD, but haven't been diagnosed (the missing millions).

## Strategies to get the message out

**Choose your messengers:** it could be a member of the association, speaking with his/her own words, bringing in a personal story, of the head of the association, a celebrity, a journalist – depending on the audience and the message.

**Working in partnerships:** building strong partnerships, which include a broad range of actors and constituencies, can help to increase the legitimacy and effectiveness of your campaign. The more consensus around a particular area/ask, the stronger the ask becomes. A united approach, when possible, is favourably received by policy makers and governments. Locally, you may find it useful to join forces with colleagues from other respiratory organisations. If a local COPD group is not in place, reaching out to other organisations focused on specific diseases or risk factors is equally effective.

**ECC's partners:** European Respiratory Society (ERS), The European Federation of Allergies and Asthma patients organisations (EFA), the European Chronic Disease Alliance (ECDA), the European Public Health Alliance (EPHA), the European Environmental Bureau (EEB) – ECC's members, individually or together.

### TOOLS

There are a wide variety of avenues to use in getting your message out, including the following:

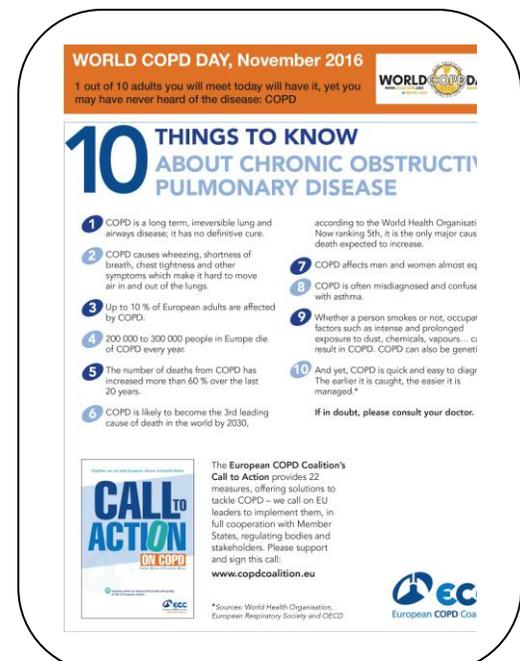
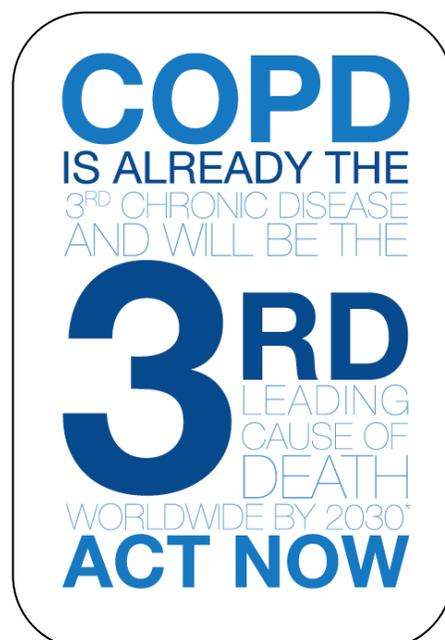
**Newsletter:** your newsletter gives you the “power of the press.” Once you have come up with a message or slogan that is powerful for the cause, use it often and remember to explain what is behind the message.

**Website:** be sure to reproduce on your website your calls, supporting documents, arguments, and be transparent on the campaigns funding, supporters and aims.

**General promotion materials:** flyers, membership renewals, direct mailings for membership drives—all of these materials are opportunities to get your message out. Try these other not-so-common avenues as well:

- ☞ Leave flyers at doctors' offices and other places where people go and wait or at pharmacies.
- ☞ Ask the local grocery store to put your message on their bags for a given length of time.
- ☞ Ask health insurance companies if they could include your message in their newsletters.

### EXAMPLES OF FLYERS



## Use social media

Organisations are increasingly using social media to connect and spread awareness of their cause.

ECC encourages members with regular access to the Internet to set up and maintain social media profiles on platforms such as Facebook, Youtube and Twitter.

A campaign running both through printed communication tools and via social media is very impactful, with a focus on visuals on social media.

Addressing policy makers by including their twitter handle in the tweet (or accompanying media) proves very effective to reach them directly. Include a link to your website article to provide more information than a tweet can contain. Ask for "RT" and make sure you quote your sources, as of courtesy and to show that statement is backed by evidence.

## Letters to politicians

Sending letters to elected or administrations is the most common way of raising awareness and addressing a request. It is customary to either send them by email only or by both ordinary mail and via the internet



## EXAMPLES OF LETTER TO THE EDITOR

European Public Health Alliance, Smoke Free Partnership, European Network on Smoking Prevention and the Framework Convention Alliance

Letter to the editor: Tobacco Product Directive – No surprise that EU Health officials are not listening to tobacco retailers and the tobacco industry: tobacco use kills half of all of its long term consumers

Brussels, 16 November 2011

Dear Sir,

In your article of 10 November 2011 ('Tobacco lobby threatens EU over plain packaging') you state that the Federation of Tobacco Retailers (CEDT) has complained that health officials in the European Commission are not listening to their arguments surrounding the revision of the tobacco products directive.

We - European Public Health Alliance, Smoke Free Partnership, European Network on Smoking Prevention and the Framework Convention Alliance - welcome that the Health Commissioner is willing to put public health first while respecting the value of the Framework Convention on Tobacco Control (FCTC) - international Treaty signed by the European Union.

We would remind tobacco retailers that it should not come as a surprise that health officials are not listening to them. Tobacco use kills half of all consumers and the tobacco industry's business interests directly conflict with the goals of public health - it would therefore be inappropriate to give those who promote its use a seat at the negotiating table.

As Commissioner Dalli said in the same article, 'tobacco is the largest avoidable health risk in Europe'. Respiratory diseases (the major five are Chronic Obstructive Pulmonary Disease, asthma, lung cancer, pneumonia and tuberculosis) cause almost 20% of all deaths worldwide, and account for a financial burden of over €100 billion in Europe alone, due to health care

costs and lost working days<sup>1</sup>. This far outweighs the €20 billion which CEDT President claimed would be lost in European tax revenue from directive revisions and represents just one class of diseases affected by tobacco use.

COPD, a lung and airways disease, affects on its own more than 3.5 million French, 3 million British, and 2.7 million Germans – and has a prevalence ranking between 4 and 10% of the European adult population. WHO estimates that it will be the 3<sup>rd</sup> cause of death worldwide by 2030. The primary cause of COPD is tobacco smoke (through tobacco use or second-hand smoke). The number of deaths from COPD has increased more than 60% over the last 20 years. Today on, the occasion of World COPD day, we trust that health protection and disease prevention will be at the centre of the European Union review of the Tobacco Product Directive, to show support and understanding to millions of sufferers.

So far, Commissioner Dalli has shown himself to be a leader in the fight against tobacco use in Europe. EPHA, SFP, ENSP and FCA look forward to a strong revision of the Tobacco Products Directive and are delighted to hear that the European Union may be looking to follow Australia's lead in implementing plain packaging.

Kind regards,

Monika Kosinska  
 EPHA Secretary General

Florence Bertelotti Kemp  
 Director  
 Smoke Free Partnership

Cornel Radu-Loghin  
 Board Member – Framework  
 Convention Alliance (FCA)  
 Director of Policy and Strategy  
 European Network for  
 Smoking and Tobacco  
 Prevention (ENSP)

## EXAMPLES OF LETTER TO AN MEP



MEP Karl-Heinz Florenz  
European Parliament  
Rue Wiertz, 60  
Altiero Spinelli 10E242  
B-1047 Brussels

Brussels, 13 February 2013

Dear Mr. Florenz, Member of the European Parliament,

We congratulate you for your taking on the role of Shadow Rapporteur, on the Tobacco Products Directive and wish you the very best as you take this exceptional piece of legislation through the legislative process.

We trust that you will thrive to maintain the highest level of patients, consumers and public health's protection whilst debating and reviewing the text, placing public health interest at the centre of the debates, despite the fact that the directive's prime focus is the functioning of the Internal Market.

We hope that when discussing the provisions of the texts, you will bear in mind that tobacco products cause not only cancers, cardiovascular diseases, risks of blindness, fertility issues, but also, major **respiratory diseases**.

It is striking to note that they are **absent from the draft text**, except when lung cancer is mentioned (see page 2, Explanatory Memorandum, Section I, Context of the proposal, paragraph 5).

**Smoking is the main risk factor for COPD, Chronic Obstructive Pulmonary Disease**, an irreversible disease that is not curable and is estimated to affect 10% of the European population. In your country, over 7,603,000 people (source: IGES, Institute for healthcare and Social Research Ltd, Berlin) suffer from COPD. **COPD costs the European Union an average of €10.3 billion euros every year just in care**. Chronic Respiratory Diseases rank 3<sup>rd</sup> in the number of people affected, after cardiovascular diseases and cancer (and before diabetes) and COPD is estimated by WHO to be the 3<sup>rd</sup> leading cause of death by 2030, if nothing is done to reverse the course of the disease. COPD is mostly preventable and TPD is therefore of utmost importance to **protect European citizens from respiratory diseases**. We thank you in anticipation for striving to maintain its strong and constraining provisions, for the benefit of the European people and public health.

Sincerely,

Catherine Hartmann, Secretary General

## Letters to the Editor:

Everyone reads letters to the editor. A good way to “hook” COPD issues and solutions into a letter to the editor is to respond to a big issue that the press is covering showing how COPD may affect one’s life.

**Open editorial** (or: “opposite the editorial page” although or “opinion editorial”)

It can be harder to get your local paper to print an op-ed piece. Here is what will help you get some excellent press coverage via this more in-depth citizen editorial:

- ➔ Have a well known citizen write it.
- ➔ Tie into a major issue facing the city/region/country and show how the patients/healthcare professionals/informal carers address it.

Call the editor and talk to him or her about writing an op-ed piece and find out what topic is likely to be printed and how you can increase your chances.

**Presentations:** Nothing is more effective than personal contact. That’s the upside. The downside is that you can’t reach as many people at once with your message. You’ll need to create and train an entire cadre of supporters and volunteers to get the message out in person.

Civic organisations such as the Lions, Rotary, as well as social rights, in addition to general health organisations always welcome guest speakers. Some of your friends may belong to their clubs and organisations as well. Make a list of all the opportunities there are in your community to get some “face time” and begin scheduling speaking engagements to get your message out.

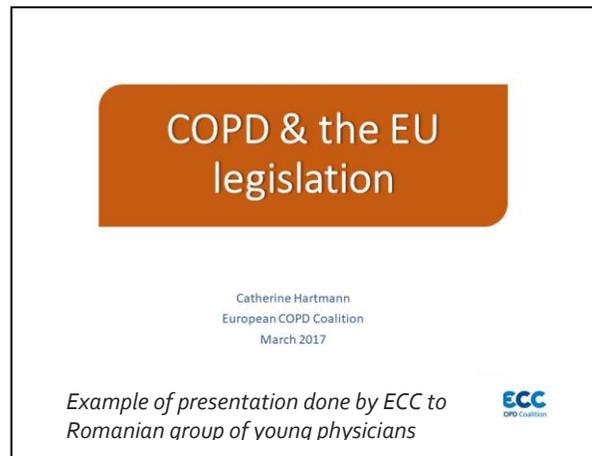
## Lobby

Attend health related legislative sessions, be present during Committee discussions when they are open to the public, send amendments to draft legislation, meet your representatives, follow through with public events, and use the tools mentioned above to echo your views to legislators.

### TOP TIP: GOOD NEGOTIATING

Some steps to prepare for negotiation:

1. Take stock: Be clear on your position and the issue you want to address.
2. Learn as much as you can: conduct research and gather evidence that backs up your position, and have some key facts to hand. Learn as much as you can about the person or organisation you are meeting to understand their position.
3. Develop alternatives: think about a compromise you would be happy with reaching.
4. Get fresh perspectives: share your position with colleagues or allies ahead of your meeting, to get feedback on your approach and negotiating tactics. *Adapted from UNICEF (2010), Advocacy Toolkit: A Guide to Influencing Decisions that Improve Children’s Lives.*



**Radio:** Develop radio spots for airing on local channels. Visit your local radio station and ask them if they would create some Public Service Announcements (PSAs) on COPD as a contribution. If not, ask if they would do so at a discounted price.

Ask the station to develop three or four spots using your message or slogan as a tag line.

It is easier to approach the media with a specific ‘angle’, event or piece of research for journalists to base their writing on. If you struggle to engage the local or national press, you can also self-publish your writing with an online blog, for instance (or in your newsletter).

**Television coverage:** Getting coverage of COPD events is very difficult unless the event is highly unusual. The key is to try to hook the station into covering something that will have significant visual appeal and/or special interest appeal. Talk to the station manager about what kinds of community programmes are most likely to get some air time.

Another television avenue—and one that is easier—is to get time on a local noon show or on public access television. This will give you an opportunity to really get your message across whereas coverage of an event is likely to last no more than 10 seconds.

Another television avenue—and one that is easier—is to get time on a local noon show or on public access television. This will give you an opportunity to really get your message across whereas coverage of an event is likely to last no more than 10 seconds.

Finally, you could consider getting in contact with soap-operas producers to suggest placing a character with COPD. Soap-operas benefit from wide viewing, this helps raising awareness.

## Identify other opportunities and activities for delivering your messages

Where possible you should analyse the political context in which COPD is debated at national, regional and global levels to decide how best to get your message heard by your target audience.

It will simply not be possible to engage in all opportunities at all levels, and spreading your messages too broadly can result in them losing



clarity and appeal.

Delivering your messages carefully and be aware that multiple communication strategies might be needed if you have different target audiences or are engaging at different levels. Advocacy is often most effective when messages are delivered in a variety of ways that reinforce and complement each other.



### IN SUMMARY

To put all the chances on your side to reach your goals through advocacy, you should:

- ➔ Select your priorities
- ➔ Choose your audience
- ➔ Prepare your messages
- ➔ Have evidence, talking points and soundbites
- ➔ Have strategies to get the message out
- ➔ Identify other opportunities and activities for delivering your messages

## ELEMENTS OF A CAMPAIGN

### EXAMPLE/ ADOPTION OF THE REVISED CLEAN AIR DIRECTIVE

#### Recommendations:

In light of the significant health benefits which could result from a more ambitious NEC Directive, several Health and Environmental NGOs recommend:

- Significantly stricter Emission Reduction Commitments (ERC) for 2025 and 2030. The EU Directive should ensure the achievement of WHO recommended levels by 2030. The European Parliamentary Research Service's impact assessment demonstrates that more ambition is possible and can be achieved at the same or lower cost. It shows that reduced consumption of polluting fuels under the EU's new climate and energy policy agreed by the Council in October 2014 would decrease the need and costs for air pollution controls and make further air quality improvements less costly.
- Stricter ERCs for 2020, based on the most recent baseline figures and establishing a linear pathway towards the achievement of the 2025 and 2030 ERCs.
- Legally binding ERCs for 2025 for all pollutants concerned by the Directive.
- Legally binding ERCs for methane and mercury for all three target years (2020, 2025 and 2030). Currently, methane reduction targets are set only for 2030, despite the fact that methane contributes to toxic ground-level ozone. Mercury is left out of the Commission's proposal despite being a toxic and highly trans-boundary pollutant causing great damage to health and ecosystems.
- The rejection of flexibilities such as adjustment of emission inventories and offsetting of emissions between land and sea.

#### Communication tools/media

##### a) Briefing

On 8<sup>th</sup> of July, all EP ENVI committee members received by email a Briefing on COPD & air quality;

##### b) Meetings

ECC secretary General met with 5 MEP assistants, including the Rapporteur of the text to highlight the importance of the Directive, in relation to COPD.

##### c) Website:

We will have an air quality & COPD specific article based on those messages on the ECC website and include a hyperlink into it in tweets & facebook posts.

#### d) Social media

ECC and maybe its members and partners (COPD patients/respiratory doctors) will voice its dissatisfaction addressing members of the European Parliament via their @Twitter profile or their Facebook page.

Allies, such as EPHA, ECDA, maybe ERS and EFA could help promoting both the article and ECC's social media actions.

Tweets:

- . @xxxxxxxxx fight for #cleanair when you vote on ENVI committee this week. #COPD patients' health depends on it!
- Don't exempt #agriculture from #airpollution emission limits!@xxxxxxxxxxxxx. Every sector shd do its bit 4 #respiratory health #COPD
- We want #airquality that is close to levels recommended by #WHO. We count on you @xxxxxxxxxxxxx to fight for #COPD patients!
- Both we and our children have a right 2 #cleanair→ Key 4 adressing #COPD: #Farming sector must do its share & be part of the solution @xxxxxxxxxxxxx!
- Make sure every country does all it can to reduce #airpollution @xxxxxxxxxxxxx. Without it, #COPD patients will suffer more.
- Tweets with voting recommendations on amendments when known.

#### Written/Oral MEP Questions on COPD and air quality - Proposals

Example:

COPD makes it hard to move air in and out of the lungs, which can negatively affect the other organs and patients' health in general. Being exposed to air pollution has a big impact on those suffering from COPD by worsening their conditions. COPD has also an important impact on mental health: fear, anxiety and depression are common in COPD patients.

**As air quality is a key determinant of COPD patients' quality of life, how does the Commissioners responsible for the environment will work together and cooperate for European citizen's health to improve air quality in Europe?**

## EXAMPLE REQUEST FOR AMENDMENTS

### CALL FOR CLEAN AIR July 15<sup>th</sup> ENVI vote on NEC Directive

13 July 2015

Dear MEP,

On 15 July 2015, you will vote on Julie Girling's report concerning the revised National Emission Ceilings (NEC) Directive. On behalf of a coalition of XXX health, environmental and animal welfare organisations, we urge you to stand for ambitious EU action that will benefit people's health, environment and the economy.

**Every year, over 400,000 Europeans die prematurely because of air pollution.** Bad air quality causes illnesses, reduces quality of life, and leads to extra medication, hospital admissions and millions of lost working days. The health-related economic costs of air pollution are enormous, amounting to between €330 billion and €940 billion for the EU in the year 2010 alone in the whole of the EU.<sup>1</sup> This is equivalent to between 3 and 9% of the EU's GDP. Air pollution also impacts Europe's nature and biodiversity, agricultural yields and natural vegetation. Crop yield losses due to air pollution are estimated at €3 billion per year in 2010.

**More ambition is needed, possible and cost-effective.** The Commission's proposal to revise the National Emission Ceilings (NEC) Directive is very welcome but is far from sufficient to solve Europe's air quality problems. The European Parliament's impact assessment shows that the new EU climate and energy policy agreed by the Council in October would lead to significant air quality improvements for lower costs. The benefits for health, the environment and associated costs are shown in the European Environment Bureau's "Air-o-Meter".

**We therefore call upon you to support:**

#### 1. AMBITIOUS & LEGALLY BINDING EMISSION REDUCTION COMMITMENTS FOR 2025

Given the scale of damages caused by air pollution in the EU, the binding 2030 targets are clearly too far away in the future. Legally binding 2025 ERCs as proposed in amendments XX would save 42,865 additional lives of Europeans per year compared to the Commission proposal. See more comparisons [here](#).

- Support **amendments xxx** (legally binding 2025 ERCs)
- Support **amendments xxx** (ambitious 2025 ERCs)
- Reject **amendments xxx** (deletion of 2025 ERCs altogether) and xxx (non binding 2025 ERCs)

#### 2. 2030 EMISSION REDUCTION COMMITMENTS GOING BEYOND THE COMMISSION'S PROPOSAL

Over 260,000 premature deaths would still occur in 2030 even after implementation of the Commission's proposal. Bigger emission reductions would lead to fewer damages and further socio-economic benefits. The 2030 ERCs as proposed in amendments XX would save 19,824 lives of Europeans per year compared to the Commission proposal.

- Support **amendments xxx** (ambitious 2030 ERCs)
- Reject **amendments xxx** (weak 2030 ERCs)

#### 3. AMMONIA EMISSION REDUCTION COMMITMENTS

Ammonia emissions impact Europe's biodiversity as well as health through the formation of particle matter (PM). During days of high air pollution levels, over 50% of PM concentrations can be due to ammonia emitted outside cities, mostly by farms. See [here](#) how ammonia emissions affect human health.

- Support **amendments xxx**
- Reject **amendments xxx**

#### 4. METHANE EMISSION REDUCTION COMMITMENTS

In addition to being a powerful greenhouse gas, methane contributes to the formation of ground level ozone which has severe impact on human health and vegetation. Methane reductions under the NEC Directive would therefore be a necessary and complementary tool to EU climate policies. See here how methane emissions affect human health.

- Support **amendments xxx** (inclusion of methane ERCs for methane)
- Reject **amendments xxx** (deletion of methane ERCs)

#### 5. MERCURY EMISSION REDUCTION COMMITMENTS

Given the transboundary nature of mercury emissions and their significant adverse impacts on human health, the inclusion of mercury emission reduction commitments in the NEC Directive as proposed by the ITRE Committee would be an effective way of protecting human health from dangerous exposure to mercury.

- Support **amendments xxx** (inclusion of mercury ERCs)

#### 6. DELETION OF FLEXIBILITIES

While some degree of flexibility is necessary in a Directive which sets objectives over a very long time scale, it should be strictly limited in order to prevent making the Directive unenforceable and risking losing on health and environmental protection.

- Support **amendments xxx**
- Reject **amendments xxx**

#### 7. EFFECTIVE NATIONAL AIR POLLUTION CONTROL PROGRAMMES (NAPCPS)

Member States should design appropriate, effective and timely measures at national level to improve air quality throughout their territory.

- Support **amendments xxx**
- Reject **amendments xxx**

#### 8. ACCESS TO JUSTICE AND PUBLIC PARTICIPATION AND INFORMATION PROVISIONS

The Directive should facilitate the access to environmental information and the participation of the public in decision making especially as air quality policy directly impacts their wellbeing and health.

- Support **amendments xxx**
- Reject **amendments xxx**

#### 9. OTHER

- Support **amendments xxx** about xxx
- Reject **amendments xxx** about xxx

Thank you in advance for your support.

Yours sincerely,

Signature

## EVENTS TO RAISE AWARENESS AND ADVOCATE - IDEAS

### Spirometry

Offer free lung testing to decision makers and the public at large, in public places and/or administrations; communicate the event in the press (before, after) and post pictures of politicians taking a test. Ex: ERS offered spirometry in tents, in major UK cities: "In addition to being a useful advocacy tool, the spirometry tent represents an unusual occasion for early detection of airway obstruction in large numbers of city residents with an important public health perspective" (extract ERJ)



### Cycling/running/walking

"Legendary Irish cyclist Sean Kelly has been announced as the 2017 champion for the 'Get Breathless for COPD' two-day cycle to raise vital funds for COPD services in Ireland.

The 2017 event, organised by COPD Support Ireland, in partnership with A. Menarini Pharmaceuticals Ireland, will see cyclists of all levels and abilities cycle from Galway to Dublin at the end of June.

Kelly was the world number one for six years in a row with 193 professional victories, and is internationally recognised as the fourth most successful cyclist in the history of the sport."

### Meeting

To mark World COPD Day, associations may hold a public meeting, inviting the press, politicians, patients and healthcare professionals to present a finding, a piece of research, or a policy recommendation, for instance



### Distribute flyers

Hand-out flyers and cards outside main administrations related to health buildings (with proper authorization), wearing cloth with text on COPD.

### Twitter storm

Many associations, individuals, companies, all parties concerned with COPD tweet same agreed messages, visuals and call for actions, for several hours/days – the quantity should be important to reach the "trending" numbers on twitter.



### Stand at fairs/conventions/meetings

Be present at major events in relation with health, physical activity, tobacco control, city/urban planning for instance, to raise awareness about COPD in an informal manner and with very visual outfits and material, to help attract attention.

### Event in pharmacies

Workshops in pharmacies aimed at patients and caregivers to learn about self-care, adherence and active daily life, prevention, early testing for healthy lungs in citizens and support for patients. Collaborating pharmacists and healthcare professionals show patients how to use their inhalers, the benefits of exercise or pulmonary rehabilitation, set up related activities offer tips on quitting smoking, or early detection. *Example from LoveXAir*



### "Breathing Hackathon"

Bringing together designers, technicians, engineers, patients, physicians and entrepreneurs to investigate solutions to many of the problems COPD patients face daily.

Over two days, innovators meet to "hack" into medical equipment for respiratory use such as CPAP devices, oxygen concentrators and sleep monitors in the hopes of integrating different solutions under a common platform and ultimately offering better health outcomes and improved quality of life for patients. *Example from the COPD Foundation*



# Advocacy Toolbox Quarterly

From the European COPD  
Coalition (ECC)

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