2016 IPF Workshop hosted by the EU-IPFF

18-19 November 2016

The funding for the 2016 IPF workshop has been provided by

Boehringer Ingelheim Roche

IPF Workshop background

Participants

EU-IPFF
EUROPEAN IDIOPATHIC PULMONARY FIBROSIS
& RELATED DISORDERS FEDERATION

RespiRARE
Onlus per le malattie rare del polmone

AB FPI
vivre avec la fibrose

FOCUS PATIENT®

Action for Pulmonary Fibrosis

AFEFPI
Asociación de Familiares y Enfermos de Fibrosis Pulmonar Idiopática

Instituto VIDAS RARAS
Instituto Vidas Raras

CASA HUNTER

LFF

ILFA
Irish Lung Fibrosis Association
www.ilfa.ie

"UN RESPIRO DI SPERANZA"
ASSOCIAZIONE DI PAZIENTI ONLUS

Pulmonary Fibrosis
FOUNDATION

LUNGENFIBROSE e.V.

CANADIAN
PULMONARY
FIBROSIS
FOUNDATION

TOWARZYSTWO WSPIERANIA CHORYCH NA IPF
IPF

AMA
fuori dal buio
informazione studio ricerca tutela
malattie orfane e rare

Belgische vereniging
longfibrose

Burson-Marsteller
Burson-Marsteller
Being More

External speakers, sponsors, and organisers

External speakers

- ✓ **Claudia Crocione,** HHT Onlus (IT) and HHT Network Europe
- ✓ **Catalina Panaitescu,** International Primary Care Respiratory Group

Sponsors

- ✓ **Bertrand Verwee,** Roche
- ✓ **Henrik Finnern,** Boehringer Ingelheim
- ✓ **Christine Düdenhoffer,** Boehringer Ingelheim
- ✓ **Lizette Moros,** Boehringer Ingelheim
- ✓ **Kristen Binaso,** Boehringer Ingelheim

Burson-Marsteller

- ✓ **Sylwia Staszak**, Senior Director, Healthcare
- ✓ **Sam Kynman,** Manager
- ✓ **Ana Maria Corca**, Senior Associate
- ✓ **Thomas Kanga-Tona**, Associate
- ✓ **Kristina Belikova,** Junior Consultant
- ✓ **Dennis Abbot,** Manging Director, Communications

Welcome

Carlos Lines Millàn, President, EU-IPFF

One minute silence for Marianne Hoffman

LOT
Austria

Agenda

Day 1		
Time		**Agenda item**
9:00	09:45	**Welcome** - *Introduction from EU-IPFF and B-M* - *Tour-de-table*
09:45	12:00	***Session 1 – Improving GP understanding of a rare condition***
12:00	***13:00***	***Lunch***
13:00	15:00	***Session 2 – Patient's organisations; membership growth and funding for a rare disease organisation***
15:00	***15:30***	***Coffee break***
15:30	17:00	***Session 3 - Breakout sessions*** *Group 1 – Recap on advocacy essentials* *Group 2 – Twitter academy introduction (EN only)* *Group 3 – Interview on camera training (EN only)*
19:00		***Dinner***

Agenda

Day 2		
Time		**Agenda item**
9:00	11:00	***Session 4 - Working together – making the most of resources and tools***
11:00	***11:30***	***Coffee break***
11:30	13:00	***Session 5 - Working together – collaboration beyond EU-IPFF***
13:00	***14:00***	***Lunch and goodbyes***

Practical info

- **Interpretation provided throughout the workshop**
- **Session 3 is break-out groups – interpretation only for break-out group 1**
- **Booklet – languages spoken (for networking without interpretation)**
- **Lunch provided on site**
- **Dinner at 19.00 at restaurant nearby (taxi service provided for those who want it)**

Practical info

- Bathroom can be found to the right of the reception desk
- Red cross on stand-by in one of our meeting rooms
- Side meeting

Tour de table

Name	Organisation	Country
Mike Bray	Action for Pulmonary Fibrosis	United Kingdom
Maria Luisa Parisi	AMA - Fuori dal Buio	Italy
Michel Faucher Viégas	Association Belge contre la Fibrose Pulmonaire Idiopathique	Belgium
Carlos Lines Millán	Association of Patients with Pulmonary Fibrosis and their Families (AFEFPI)	Spain
Françoise Enjalran	Association pour la Fibrose Pulmonaire Idiopathique Pierre Enjalran	France
Gilbert Menou	Association pour la Fibrose Pulmonaire Idiopathique Pierre Enjalran	France
Herman van Lysebeth	Belgische Vereniging voor longfibrose (BVL)	Belgium
Robert Davidson	Canadian Pulmonary Fibrosis Foundation	Canada
Glauco Torres	Casa Hunter	Brazil
Veronika Müller	Department of Pulmonology, Semmelweis University	Hungary
Katarzyna Lewandowska	IPF Patients Society	Poland
Ingeborg Beunders	Focus Patient	Austria
Spyridon Panagiotopoulos	Greek Pulmonary Fibrosis Association	Greece
Amira Awada	Instituto Vidas Raras	Brazil
Regina Próspero	Instituto Vidas Raras	Brazil
Liam Galvin	Irish Lung Fibrosis Association	Ireland
Klaus Geissler	Lungenfibrose e.V.	Germany
Johann Hochreiter	Lungenfibrose Forum Austria	Austria

Name	Organisation	Country
Patti Tuomey	Pulmonary Fibrosis Foundation (PFF)	United States
Adrian Glyn Rosser	Pulmonary Fibrosis Trust	United Kingdom
Grazia Giusti	RespiRARE	Italy
Alessandro Giordani	Un Respiro di Speranza	Italy
Claudia Crocione	HHT Europe Network	Italy
Catalina Panaitescu	International Primary Care Respiratory Group	Romania
Henrik Finnern	Boehringer Ingelheim	
Christine Düdenhoffer	Boehringer Ingelheim	
Lizette Moros	Boehringer Ingelheim	
Kristen Binaso	Boehringer Ingelheim	
Bertrand Verwee	Roche	
Sylwia Staszak	Burson-Marsteller	
Sam Kynman	Burson-Marsteller	
Thomas Kanga-Tona	Burson-Marsteller	
Anamaria Corca	Burson-Marsteller	
Kristina Belikova	Burson-Marsteller	
Dennis Abbott	Burson-Marsteller	

Session 1

Improving GP understanding of a rare condition

Setting the scene

I. About primary care

II. Country specific barriers to diagnosis

III. General barriers to diagnosis of IPF

IV. Rare diseases best practices

I. About primary care

• Access to specialists

Gate-keeping

- Bulgaria
- Denmark
- Estonia
- Finland
- France
- Ireland
- Italy
- Latvia
- Netherlands
- Norway
- Poland
- Portugal
- Romania
- Slovakia
- Slovenia – by 'personal physician' who does not necessarily have to be a GP;
- Spain
- Sweden – 24-hour 'hot lines' where medical advice is provided by registered nurses;
- UK (England)

Direct access

- Austria
- Belgium
- The Czech Republic
- Germany
- Greece

Source:
European Observatory of Health Systems, 2015
CPD Study, 2015

I. About primary care

Primary care

GPs, nurses

- Central part of primary care

Health centres

- In Finland, Greece HCPs provide preventive health services (not necessarily by GP)

I. About primary care

- Typical route by which IPF patient receives diagnosis
- Healthcare system limits choice

Gate-keeping system

Patients must see GP first

Direct access system

Patients may go directly to secondary care

II. Country specific barriers

SPAIN

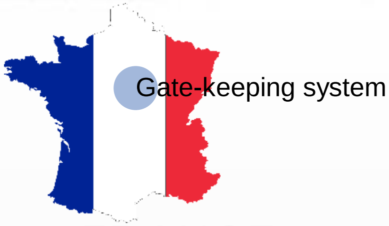
- The number of referrals is relatively low, as less than 6% of the encounters at primary care are referred to another level of care.
- Specialty in family medicine for nurses since 2005 (role of the nurses is expanding - key role in promotion, prevention and follow-up of chronic diseases, community care and home care);

POLAND

- Family medicine belongs to the group of so called “deficit specialties”. The government offers special financial incentives to attract young doctors to this medical field.

ITALY

- The National Agreement, signed after negotiations between a central agency delegated by the government (called SISAC) and the main trade unions of GPs, **defines the criteria for the distribution of primary care professionals on a territorial basis**.
- The Agreement fixes a **maximum number of patients each GP or paediatrician can have on their list: full-time GPs and paediatricians can have respectively up to 1500 and 800 patients. Only one GP can be assigned to a territorial scope of 1000 residents.**



FRANCE

- Cooperation with secondary care and other services is not usual. Joint consultations or replaced specialist care occur very rarely and GPs do not usually take phone advice from specialists.

Source:
[European Observatory of Health Systems](), 2015

II. Country specific barriers

ROMANIA

- Compared to other EU countries, Romania still has the lowest percentage of GDP spent on health (Vladescu et al., 2008).
- **Lack of GPs**

SWEDEN

- Each county council has the freedom to decide how to serve its population in terms of primary care.

AUSTRIA

- Some health insurers restrict patients from switching physicians within a time period of three months.
- 60–70% of the patients visit their usual primary care provider for their common health problems.

THE CZECH REPUBLIC

- In 2007, the average list size of a GP for adults was 1613 patients.
- It is estimated that 80–90% of patients' contacts with GPs are handled solely by them without further referrals to other providers.

Source:
European Observatory of Health Systems, 2015

II. Country specific barriers

BELGIUM

- **There is not any precise definition of the tasks and duties of GPs in Belgium, except a law from 1967 on the continuity of care: GPs must refer their patients to a colleague with the same qualifications when they are not working (Royaume de Belgique, 1967). This is currently not checked extensively.**
- Overall, 88% of all contacts with a GP are handled solely, without a referral, by the physician (Demarest et al., 2006).

GERMANY

- **The medical self-governing bodies, formed by the national associations of doctors and dentists, the German Hospital Federation and the federal associations of health insurance funds, formulate and implement in detail which services will be provided and under what conditions.**

Source:
European Observatory of Health Systems, 2015

III. General barriers to diagnosis of IPF

1. Mandatory/voluntary Continuous Professional Development (CPD)

2. Specific knowledge of the GP about IPF

3. Health system related incentives

4. Culture of interaction

5. The patient’s level of health literacy

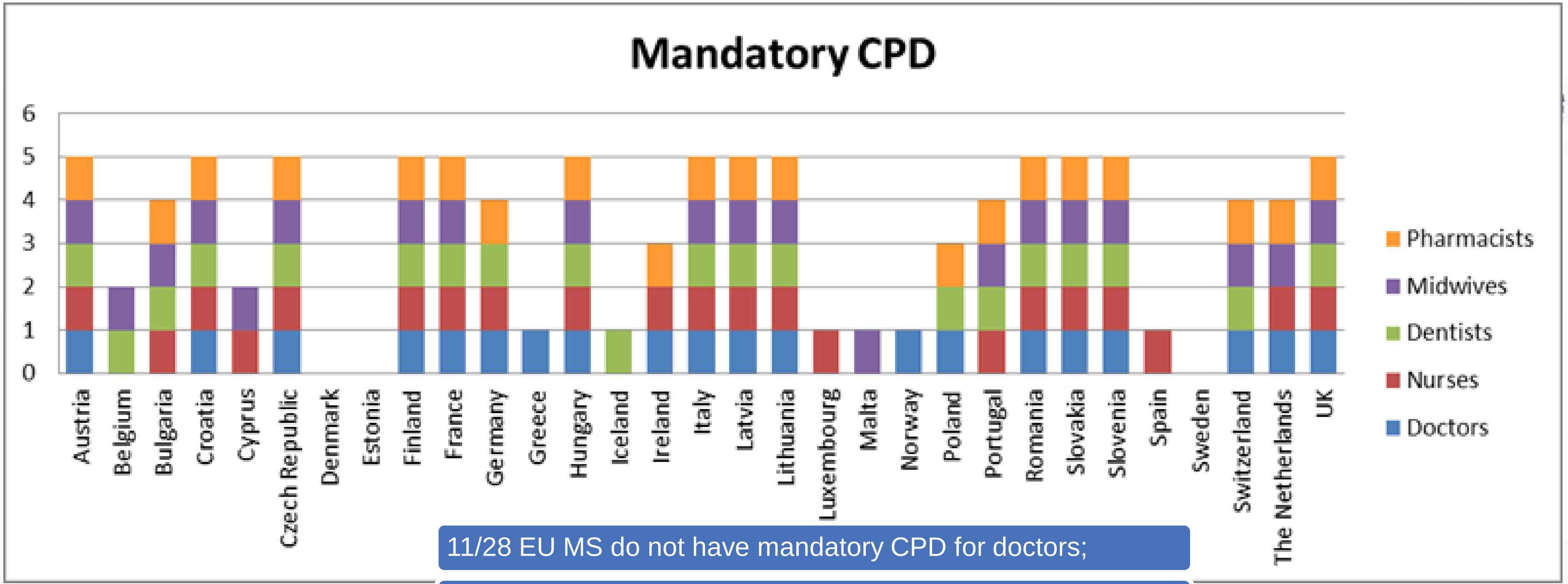
III. General barriers to diagnosis of IPF

1. Mandatory/voluntary Continuous Professional Development (CPD)

What is CPD?

- ethical obligation to ensure professional practice is up-to-date

CPD Study, 2015

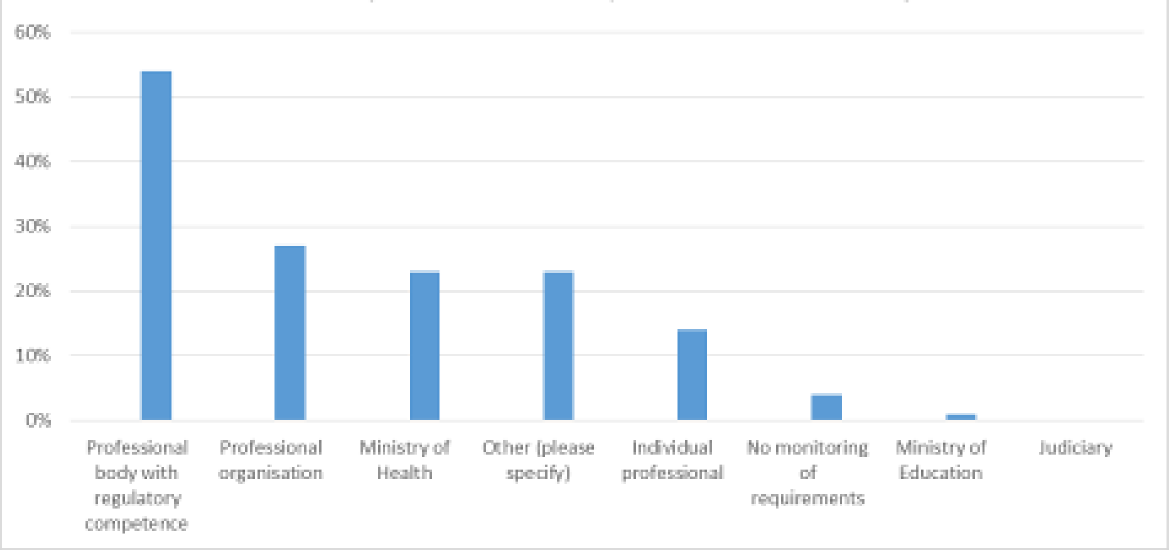


11/28 EU MS do not have mandatory CPD for doctors;

10/28 EU MS do not have mandatory CPD for nurses;

11/28 EU MS do not have mandatory CPD for pharmacists;

CPD Study, 2015



Burson-Marsteller
Being More

A professional who fails to comply with a mandatory CPD requirement **is most likely to**:

face a temporary suspension of their licence to practise

followed by a reprimand by a professional body

and immediate loss of licence.

- **21% respondents in the CPD study (2015) indicated there are no consequences of not complying with a CPD requirement.**

CPD Study, 2015

III. General barriers to diagnosis of IPF continued…

2. Specific knowledge of the GP about IPF

- Many patients with rare diseases will present their symptoms first to a GP. IPF specific information (what distinguishes IPF from other pulmonary diseases) is key.
- Via an authoritative source of information **for the GP**

3. Health system related incentives

- Financial compensation may create incentives to discourage referrals
  Availability of GPs and similar health workforce planning aspects may have an influence

4. Culture of interaction

- between GPs and specialists
- between HCPs and patient associations at political level

5. The patient's level of health literacy

- A global trend

Are we communicating?

Improving GP understanding of a rare condition

- ‘Collectively, rare diseases are not uncommon’, UK Rare Diseases Group
- ‘I am an expert of my own body and you are a medical expert’, EPF
- What could other messages be?

Key messages:

1. Patient empowerment
2. Diagnosis
3. Undiagnosis
4. Coordination of care

Key areas of improvement:

Improving GP understanding of a rare condition

Multilevel governance → Multilevel strategy

TOP-DOWN approach:

- A systematic approach for rare diseases as for the management of chronic conditions
- Engaging with key European stakeholders
  - The European Academy of Teachers in General Practice (EURACT),
  - The European Medical Students Association (EMSA)

+

BOTTOM-UP approach:

- Country specific tailored actions aimed at changing the political discourse about IPF
- Country specific actions aimed at changing the patient-GP interaction experience
  - Capacity building: mapping of national umbrella patient association (IPF patient associations/rare disease associations)
  - Communication training toolkit for patients to practice with the GP

III. Rare diseases best practices

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'RARE – best practice': Platform for sharing best practices for the management of rare diseases

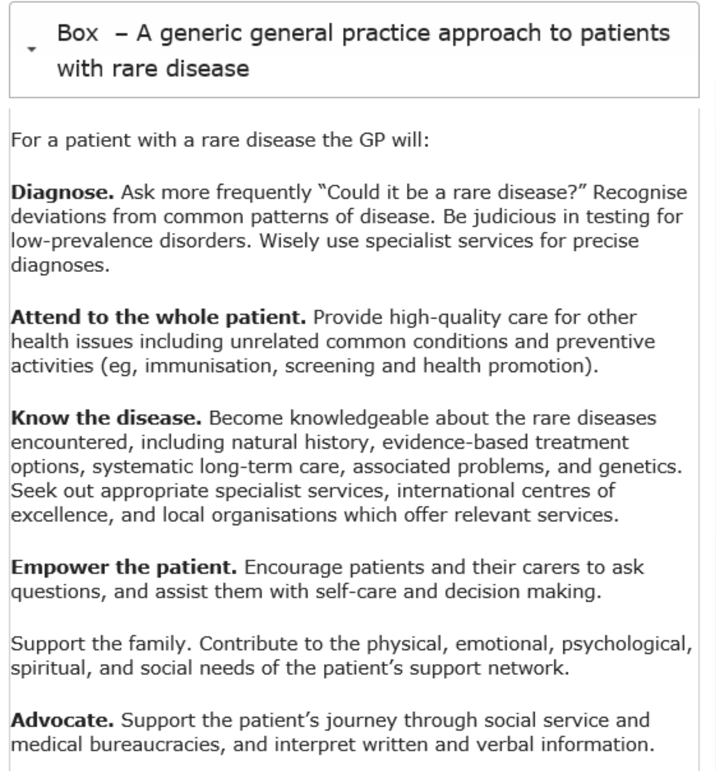
RARE-Bestpractices

A platform for sharing best practices for the management of rare diseases

Coordinated by the Istituto Superiore di Sanità
National Centre for Rare Diseases

Welcome to RareGAP

'The Box' - A generic general practice approach for patients with rare diseases



Box – A generic general practice approach to patients with rare disease

For a patient with a rare disease the GP will:

Diagnose. Ask more frequently "Could it be a rare disease?" Recognise deviations from common patterns of disease. Be judicious in testing for low-prevalence disorders. Wisely use specialist services for precise diagnoses.

Attend to the whole patient. Provide high-quality care for other health issues including unrelated common conditions and preventive activities (eg, immunisation, screening and health promotion).

Know the disease. Become knowledgeable about the rare diseases encountered, including natural history, evidence-based treatment options, systematic long-term care, associated problems, and genetics. Seek out appropriate specialist services, international centres of excellence, and local organisations which offer relevant services.

Empower the patient. Encourage patients and their carers to ask questions, and assist them with self-care and decision making.

Support the family. Contribute to the physical, emotional, psychological, spiritual, and social needs of the patient's support network.

Advocate. Support the patient's journey through social service and medical bureaucracies, and interpret written and verbal information.

Thank you!

2016 IPF Workshop, Brussels

Idiopathic Pulmonary Fibrosis

- a Primary Care perspective -

Catalina Panaitescu
Family Physician
Bucharest, Romania
catalina_panaitescu@yahoo.com


Glasgow
Dublin
Copenhagen
Riga
ATLANTIC OCEAN
London
Amsterdam
Warsaw
Berlin
Brussels
Frankfurt
Kiev
Krakow
Paris
Prague
Lvov
Munich
Vienna
Zurich
Budapest
Odessa
ROMANIA
BUCHAREST
Milan
Zagreb
Belgrade
Lisbon
Barcelona
Madrid
Rome
BLACK SEA
Sofia
Istanbul
MEDITERRANEAN SEA
Athens

Belgian Primary Care Respiratory Group (BPCRG)
http://www.bpcrg.org/

Family Physician Airways Group of Canada
http://www.fpagc.com/

Greek Primary Care Respiratory Group
http://gpcrg.elegeia.gr/

Società Italiana Interdisciplinare per le Cure Primarie
SIICP, http://www.siicp.it/

CAHAG, The Netherlands
http://www.cahag.nl/

RespiRo, Romania
www.respirogrup.ro

GRAP, Spain
http://balearsrespira.blogspot.ro/

Primary Care Respiratory Society UK (PCRS UK)
http://United Kingdomhttp://www.pcrs-uk.org/

What do I like about my ...*?

What I don't like about my ...* and how this could be changed/improved ?

* name the health professional you have in mind when you think at the Primary Care

The characteristics of the discipline of general practice/family medicine are that it:

a) is normally the point of first medical contact within the health care system, providing open and unlimited access to its users, dealing with all health problems regardless of the age, sex, or any other characteristic of the person concerned.

b) makes efficient use of health care resources through co-ordinating care, working with other professionals in the primary care setting, and by managing the interface with other specialities taking an advocacy role for the patient when needed.

c) develops a person-centred approach, orientated to the individual, his/her family, and their community.

d) promotes patient empowerment.

e) has a unique consultation process, which establishes a relationship over time, through effective communication between doctor and patient.

f) is responsible for the provision of longitudinal continuity of care as determined by the needs of the patient.

http://www.woncaeurope.org/sites/default/files/documents/Definition%203rd%20ed%202011%20with%20revised%20wonca%20tree.pdf

PRIMARY CARE = FAMILY MEDICINE = GENERAL PRACTICE

1978 Declaration of Alma-Ata:

- first-contact
- accesible
- continued
- comprehensive
- coordinated

care

http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology

FAMILY MEDICINE / PRIMARY CARE TEAM

Community nurses

Midwives

Physioterapists

Dieticians

THE ROLE OF THE FAMILY DOCTOR / GENERAL PRACTITIONER IN THE IPF:

1. prevention
2. pre-symptomatic detection of disease
3. early diagnosis
4. diagnosis of established disease
5. management of disease
6. management of disease complications
7. rehabilitation
8. palliative care
9. counselling

Adapted after Atun R. What are the advantages and disadvantages of restructuring a health care system to be more focused on primary care services? WHO/Europe, 2004

Barriers to the early diagnosis of IPF in Primary Care

FD related:

- **prevalence**: relatively rare condition, with which FDs have little personal experience
- **misdiagnose** or **underdiagnose**: lack of specificity of symptoms
- **multimorbidity**
- **late refferals** : (above)

Patient related:

- **ignored symptoms**: attributed to age, smoking, other diseases
- **automedication**: antibiotics (!)

Health care system related:

- **limited access** to preliminary diagnostic methods

Learning/action points:

- **red flags to alert FDs**
- **improved access to preliminary diagnostic procedures**
- **patient education**
- **adapted legislation**

Learning/action points

Management of disease and disease complications, rehabilitation, palliative care and counselling)

IPF Muldisciplinary team (MDT)

PC level:

- more information on the likely disease course in people with IPF and the role of treatment modalities
- better knowledge and skills for the diagnosis and therapeutic synthesis in people with multimorbidities
- more support of specialist nursing and palliative care services

Patient level:

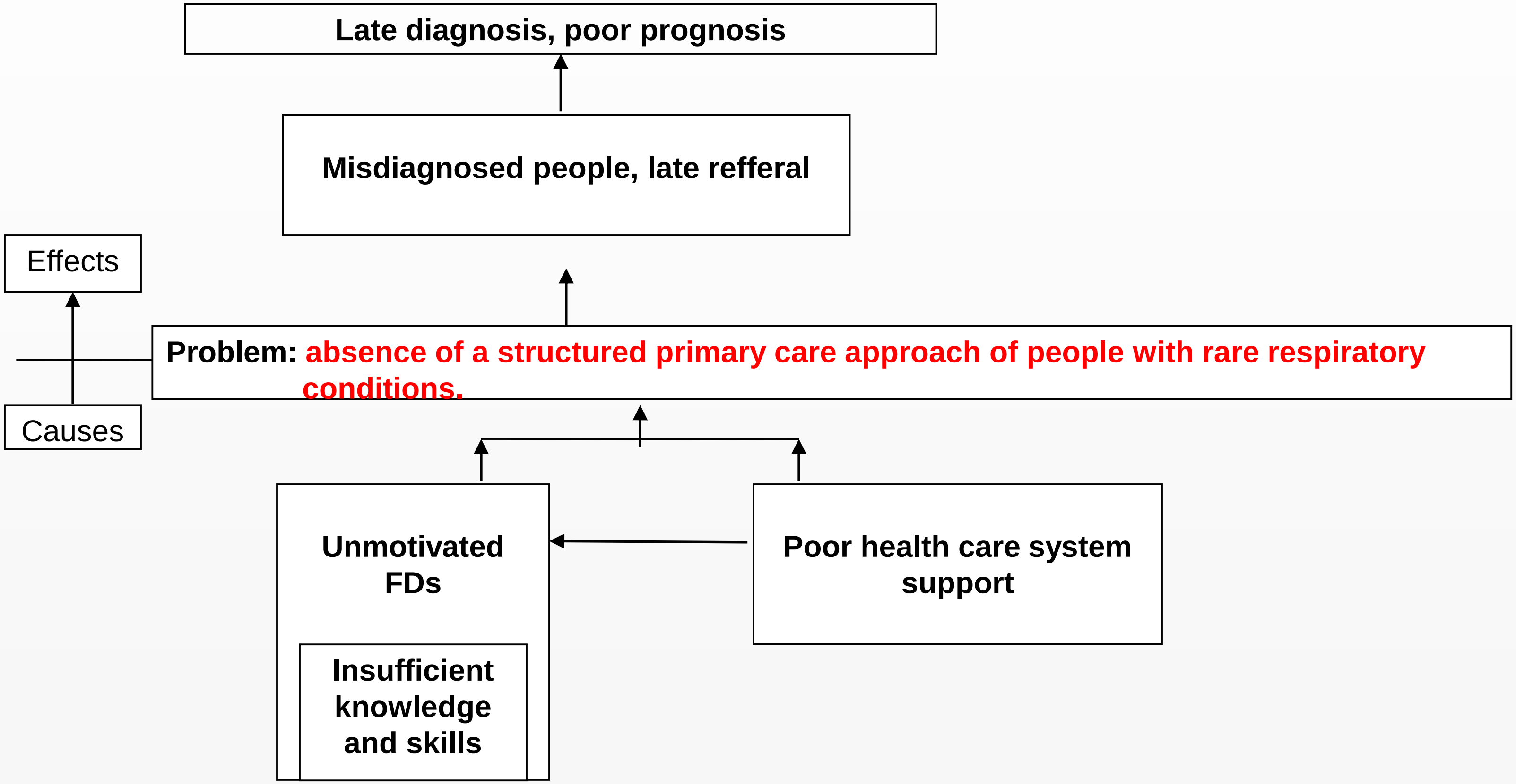
- acces facilities (treatment, follow-up procedures)
- more support of specialist nursing and palliative care services
- better adherence to treatment

Healthcare system level:

- a balance between centralisation and access to practical community care, and virtual MDTs

Adapted after Thickett DR, Kendall C, Spencer LG, Screaton N, Wallace WA, Pinnock H, Bott J, Pigram L, Watson S, Millar AB: Improving care for patients with idiopathic pulmonary fibrosis (IPF) in the UK: a round table discussion, 10.1136/thoraxjnl-2014-206284

Problem tree of the management of people with rare respiratory conditions at primary care level.



Late diagnosis, poor prognosis

Misdiagnosed people, late refferal

Effects

Problem: absence of a structured primary care approach of people with rare respiratory conditions.

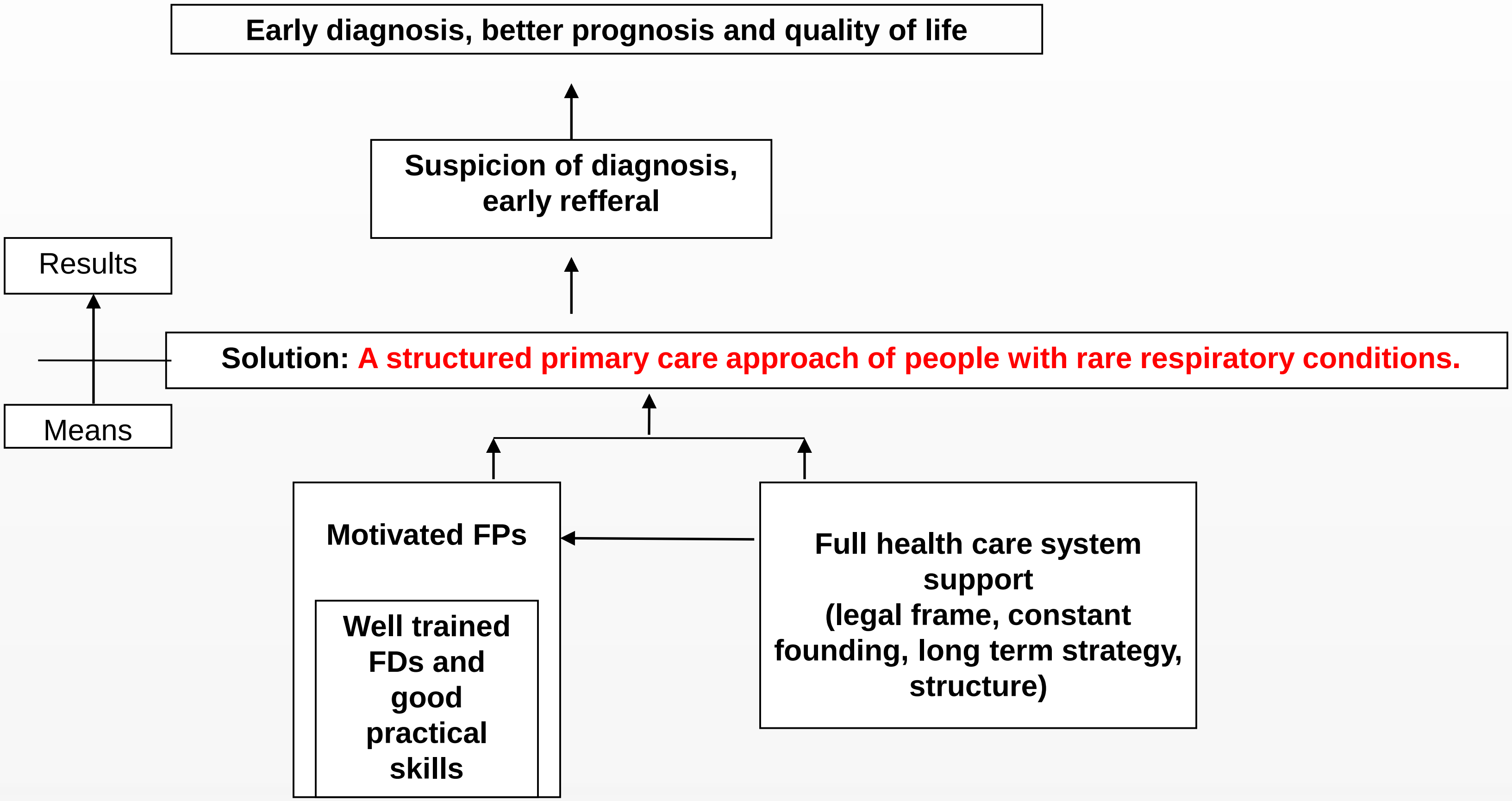
Causes

Unmotivated FDs

Insufficient knowledge and skills

Poor health care system support

Solution tree of the management of people with rare respiratory conditions at primary care level.



Early diagnosis, better prognosis and quality of life

Suspicion of diagnosis, early refferal

Results

Means

Solution: A structured primary care approach of people with rare respiratory conditions.

Motivated FPs

Well trained FDs and good practical skills

Full health care system support (legal frame, constant founding, long term strategy, structure)

Mulțumesc!

Session 1

Improving GP understanding of a rare condition

Guest speaker

Claudia Crocione,
HHT Europe

Federation of patient organizations

What do HHT and IPF have in comon?

- Rare diseases with misleading symptoms
- Life threatening consequences if disease is not diagnosed at an early stage
- GPs **should be** our sentinels for identifying the disease….. But are they?

Let’s face it – GPs aren’t easy to involve…

- GPs do not train specifically on RD.

- If they hear hoofbeats they think horses not zebras

- In general, GPs retreat from chronic complainers (as we rare disease patients without a diagnosis are often seen). The stop listening at a certain point.

- GPs are not prepared to relate to Patient Organizations because they don’t generally see us as peers.

BUT we can’t let this stop us!

Why do you want GP Involvement?

- ***Early diagnosis** – clinical purpose*
- ***Early diagnosis** – psychological impact*
- ***Directing the patient to the best Center of Excellence for the disease***

Your national strategy for GP involvement will depend on the reasons why you need GP involvement.

What is holding you back?

Objective is not clear

- **Lack of funding**
- **Lack of authority**
- **Lack of volunteers**
- **Lack of time**
- **Lack of know how**

Overcoming the obstacles:

Funding:

Gp involvement is one of the few activities in an organization that does not require funding.

Alternative resources are all out there for you to use. Should you have the possibility to find funds for GP involvement many things could be accomplished but lack of funds should not stop you. HHT Europe has no dedicated amount for this activity.

Overcoming the obstacles:

Authority:

1.How authorative you are can depend on how confident you are in proposing your cause and representing your organization.

2. But it also depends on how your are perceived by the GP. Some are very open minded other prefer peer to peer exchange and do not acknowledge Pos too well.

-How can we improve point 1?

-How can we overcome point 2?

Overcoming the obstacles:

Volunteers, Time & Know How:

These are three resources that can be improved quite easily and they are all connected.

1. **Time: we all lack time, we have families, jobs, illness, children, life to deal with. Good outcomes require time investment. So if we can't increase the amount of time what can we do? We increase the number of people and our know how.**
2. **Know-how: good communication, delegating, sharing material, clear objectives. Use a setting such as your national conference to set a pre-conference training session for volunteers.**
3. **People raising: increase the number of people involved. We will discuss a few methods in this session and more general people raising techniques later today.**

1. ***Our Objective is now clear.***
2. ***We can master our limits.***
3. ***Now lets plan our GP involvement.***

Best Practices for GP Involvement

1. Enter the Lion’s den – (GP organizations)

- send a IPF specialist to GP national and regional conferences,
- ask to publish an early diagnosis guideline in their newsletter
- ask the President of the national GP association to establish a partnership for a year to promote IPF in the GP world
- GP organizations have compulsory GP annual training sessions and you could partner with them to hold an IPF training

Best Practices for GP Involvement

2. Get Personal – with individual GPs

- Keep a database of GP's that contact you – communicate with them – invite them to your facebook page.
- Each of them should receive newsletters from your organization.
- they can be involved as local promoters with their colleagues.
- They can help you promote training initiatives.
- Boost their EGO.

Best Practices for GP Involvement

3. Patient Ambassadors

- each of your members, each person that drops you an email, that calls your help line is a possible ambassador for IPF.
- Make it a point of mailing paper copies of brochures along with the guidlines for the disease to every new patient you meet asking them to deliver the material personally to their GP and other GPs in their town, city or area.

Best Practices for GP Involvement

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4. Amplify the benefits of your Annual Conference

- Make sure your annual conference is held in a different city each year.
- Start planning a year before and contact the regional GP organization for that territory.
-Involve them in the event with a pre-session where your specialists can give a seminar only for the local gps.
- This will improve the knowledge of the disease but also the relationship between local GPs and centers of excellence.

Best Practices for GP Involvement

5. *Involve your Centers of Eccellence*

- Many patients do not reach our organizations. Some just refer to specialists in the Centers of Excellence
- Make sure that the director of the center participates in GP involvement handing new patients the same material you give to your new members asking them to deliver to their GPs.

HHT Onlus Results on Gp Training before and after creating a strategy.

2004-2011	2011-2016
No GP training on HHT	110 GPs trained on HHT
No GP Database	400 GPs in database
No publications in GP newsletters	7 publications on HHT in regional GP newsletters
No involvement in HHT National Conferences	Presence of Presidents of Regional GP organizations in 3 National Conferences
No Patients involved in promoting HHT with GPs	80% of contacts have handed material to their GPs.

Any questions?

Would you like to share your best practice?

Thank you.

Claudia Crocione

Managing Director – HHT Europe – Federation of Patient Organizations
Project & Communciation Manager HHT Onlus – Italy
c.crocione@hhtonlus.org – www.hhtonlus.org – mobile. +39.333.2104478

Conclusions

Lunch break

Session 2

Patient's organisations: membership growth and funding for a rare disease organisation

Role of Patients' Organisations

- Why do patients' organisations exist and why is their growth and funding so important?
- An important voice in decision-making for health systems?
- Greater access to information, greater recognition of joint decision-making with HCPs
- Health systems should be built around the needs of the patient? 'Patient-centricity'
- Who coordinates the 'patients' voice'?

The value of the patients' perspective

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- **The patients role within the healthcare system has a unique legitimacy**

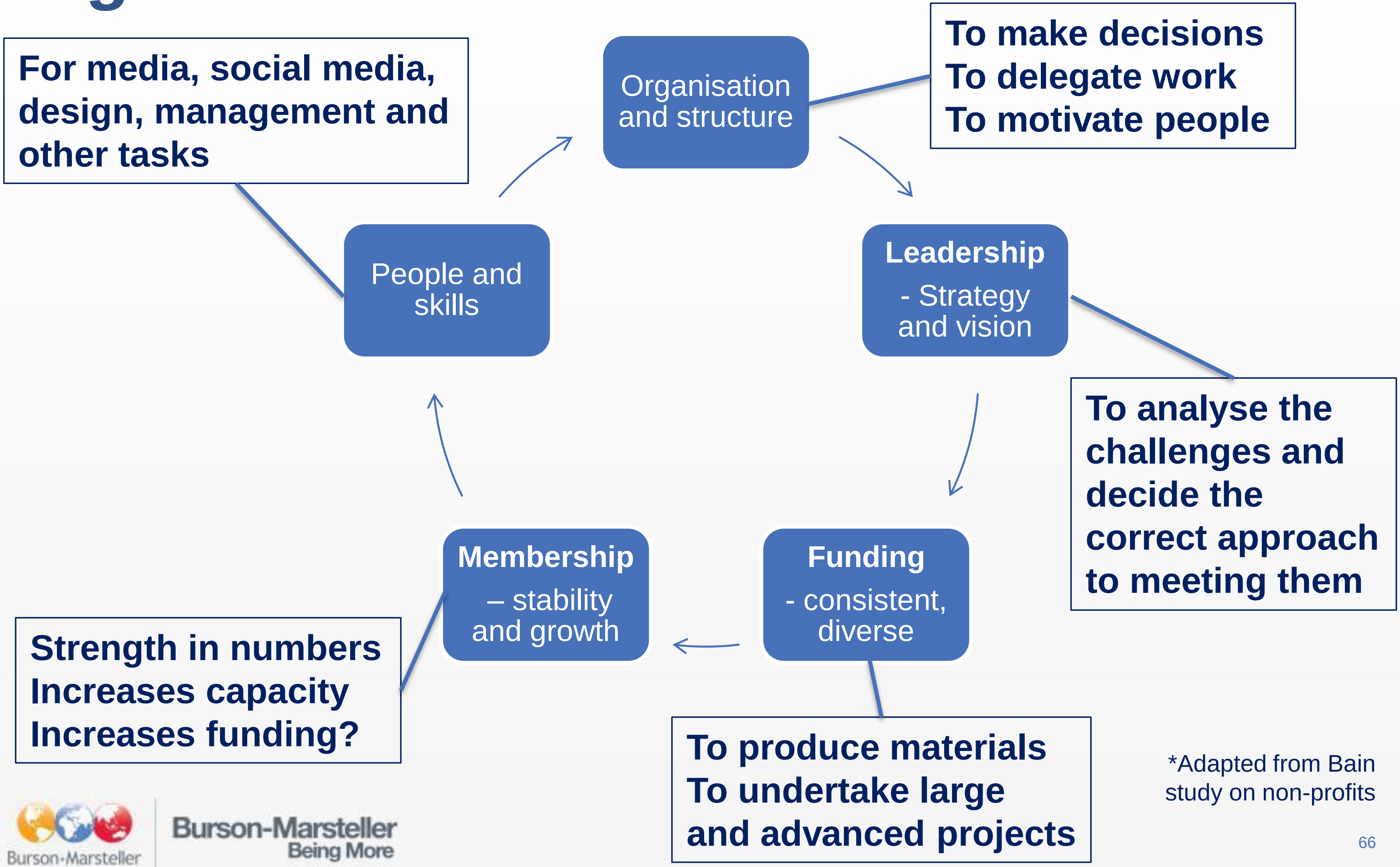
- **'Nothing about us without us'**

- **What should that legitimacy translate into in an ideal world?**

- **Transformed health systems? direction over health policy priorities? greater access to treatment?**

- **For the patients' voice to be recognised as legitimate, patients' organisations need to be robust, independent, free from outside influence, and well-organised.**

Strength of patients' organisations



Organisation and structure

To make decisions
To delegate work
To motivate people

Leadership

- Strategy and vision

To analyse the challenges and decide the correct approach to meeting them

Funding

- consistent, diverse

To produce materials
To undertake large and advanced projects

Membership

– stability and growth

Strength in numbers
Increases capacity
Increases funding?

People and skills

For media, social media, design, management and other tasks

*Adapted from Bain study on non-profits

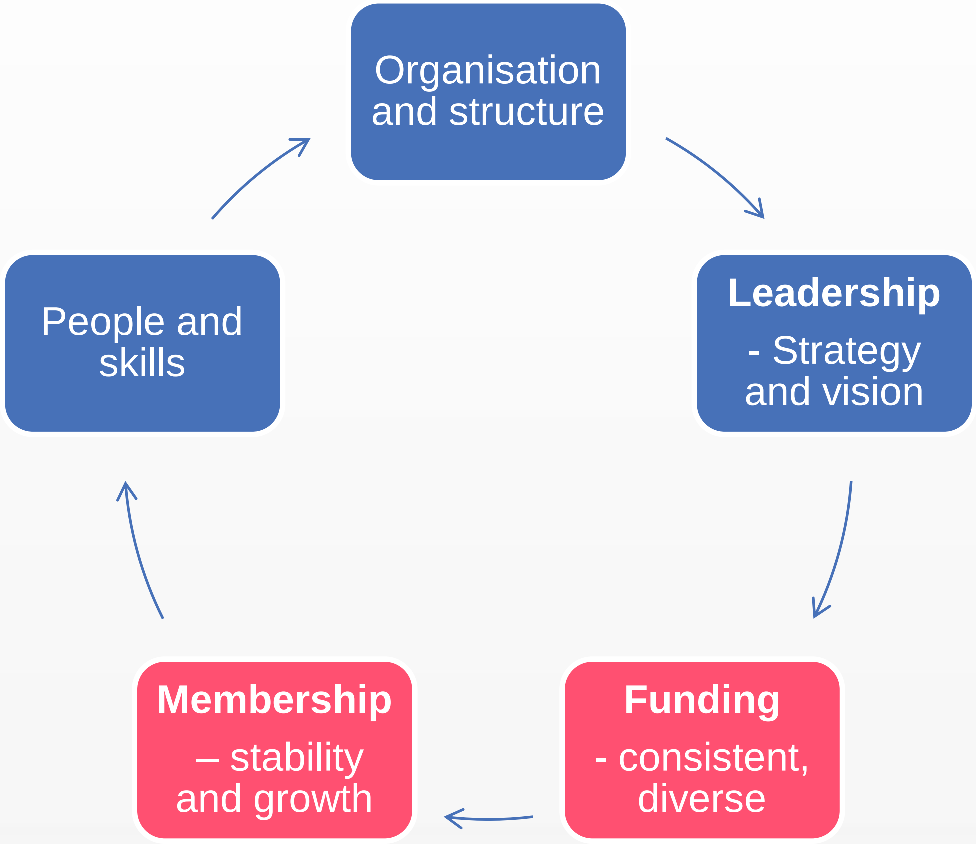
Strength of patients' organisations

Does membership lead to increased funding?

<u>Rare disease context</u>

Funding does not necessarily lead to increased membership

Membership largely defined by prevalence of IPF?



Organisation and structure

Leadership
- Strategy and vision

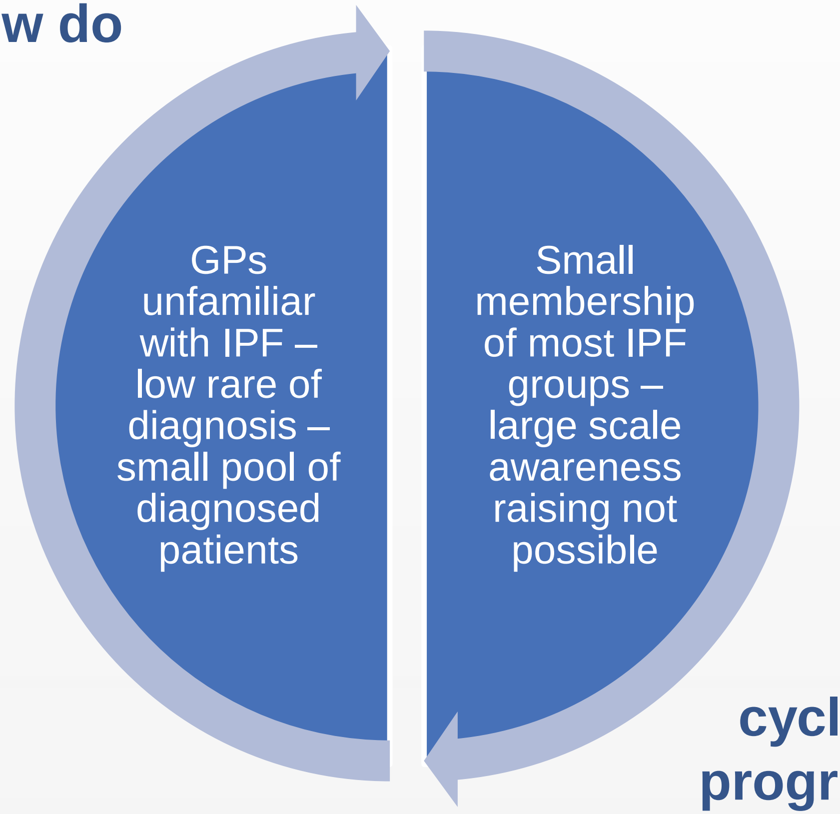
Funding
- consistent, diverse

Membership
– stability and growth

People and skills

Membership growth for rare disease organisations

Rates of diagnosis not good enough – how do we find patients?



GPs unfamiliar with IPF – low rare of diagnosis – small pool of diagnosed patients

Small membership of most IPF groups – large scale awareness raising not possible

Need to break the cycle that is preventing progress for IPF patients

Membership growth for rare disease organisations

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EUROPEAN IDIOPATHIC PULMONARY FIBROSIS
& RELATED DISORDERS FEDERATION

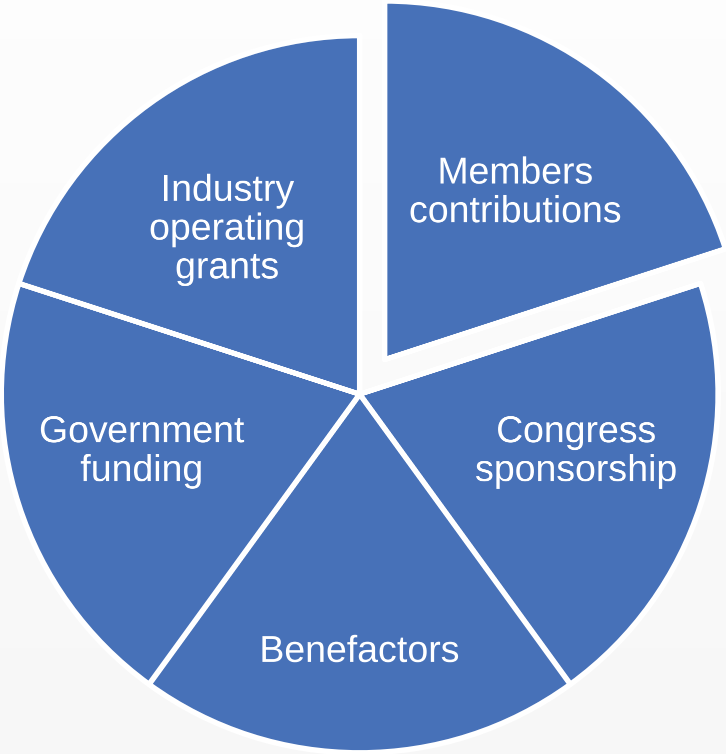
- **Are there practical steps that can be taken to find new members?**

  - **Patient registries**
  - **Patients as ambassadors**

- **Can doctors and the health system help bring diagnosed patients into your groups?**

  - **Automatic that doctors send diagnosed patients straight to patients' organisations?**
  - **Raising awareness of GPs**
  - **Government/Formal listing of patients' organisations**
  - **Researcher registries of patients**

How much does funding rely on membership?



Sources of funding

- Operational funding vs Project funding

  - Industry grants
  - Event sponsorship (industry)
  - Members’ contributions
  - Grassroots fundraising activities
  - Charitable giving
  - Taxes (gift aid etc)
  - Institution grants (i.e. European Commission)
  - Crowdfunding

- Are all available or feasible to all attendees?

- What sources are used?

Working with industry
- a necessity

- Industry funding is essential for most patients' organisations

- Rare diseases organisations simply don't have the numbers or the profile in most countries?

- A decision between existing with their funding or not existing without their funding?

- Not necessarily a problem, though industry sponsors need to treat the relationship with respect and value the organisations' independence

Retaining independence

- **Independence is fundamental to the patient voice being recognised as legitimate**
- **At EU level, great progress has been made in setting out rules and principles that establish and govern ‘independence’**
- **Industry codes of conduct, rules attached to European Commission grants, EPF code of practice**
- **Professionalisation of some groups – not possible for all**
- **If independence is ever called into question, everyone loses**

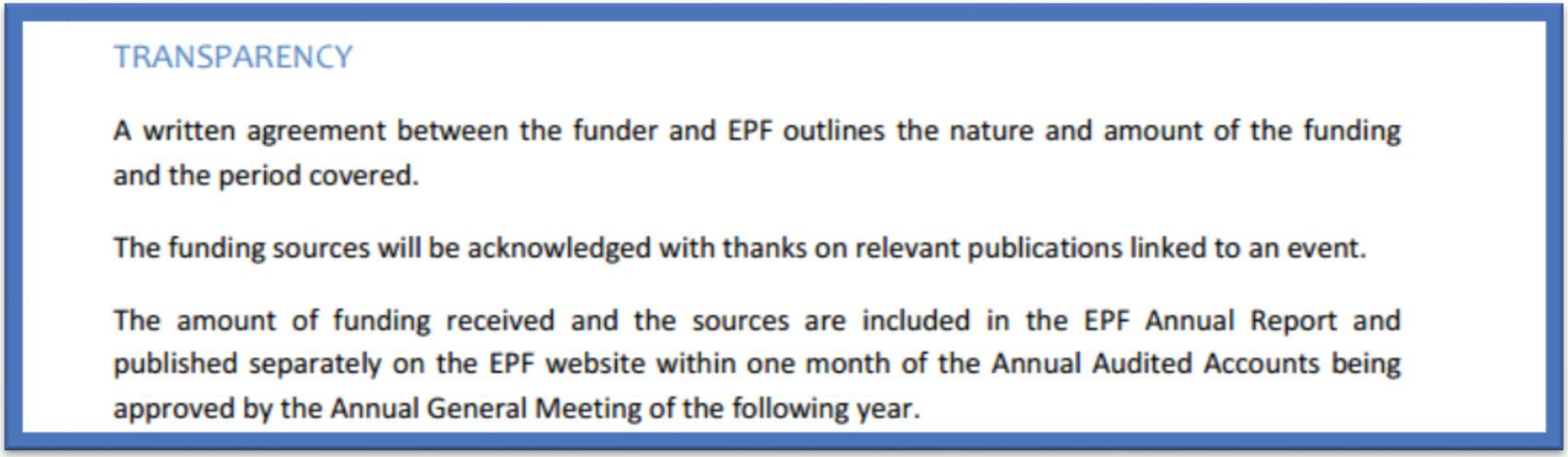
Retaining independence - EU example

EFPIA CODE OF PRACTICE ON RELATIONSHIPS BETWEEN THE PHARMACEUTICAL INDUSTRY AND PATIENT ORGANISATIONS

1. Non-promotion of prescription-only medicines
2. Written agreements
3. Use of logos and proprietary materials
4. Editorial control
5. Transparency
6. Contracted services
7. Single company funding
8. Events and hospitality

What other codes of practice govern your relations with industry?

Retaining independence - EU example



TRANSPARENCY

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The funding sources will be acknowledged with thanks on relevant publications linked to an event.

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Transparency, and other principles

- Transparency recognised at EU level as fundamental to integrity and independence
- Some countries have differing cultures with regards to transparency
- Diversified funding can be an effective measure – feasible for a rare disease organisation?
- Organisational professionalism required to attract further sponsors, and to demonstrate integrity

Non-industry funding

- Rare disease organisations have limited industry options – what else is possible?
- Members' contributions
  - Limits to membership growth?
  - Types of membership
  - Identifying potential members
  - Membership offer
  - Rare connect

Non-industry funding

- <u>Grassroots fundraising activities</u>
  - Individual fundraising targets
  - Prizes for fundraising
  - Work with industry partners to develop fundraising concepts

Non-industry funding

- **Charitable giving**
  - **Dependent on national culture**
  - **Requires rich or famous patients?**
  - **Networking with donor community?**
- **Taxes (gift aid etc)**
  - **Dependent on national system**
  - **Requires donor culture**

Non-industry funding

- Institution grants (i.e. European Commission)
  - Very strict rules attached on recipients?
  - National equivalent to European Commission grants?
- Crowdfunding
  - Free-to-use and accessible platforms available
  - Ideas needed to generate interest

Guest speaker

EU-IPFF
EUROPEAN IDIOPATHIC PULMONARY FIBROSIS
& RELATED DISORDERS FEDERATION

Claudia Crocione,
HHT Europe

Federation of patient organizations

Burson-Marsteller
Burson-Marsteller
Being More

Case study:
HHT Onlus – from theory to facts
2004 - 2011:

- ***Main activity – annual patient conference***
- ***average members: 60***
- ***active volunteers: 2***
- ***ideas: few – facts: none***
- ***average budget € 7000 euro***
- ***relationship with the clinical and scientific community: passive***
- ***level of sense of belonging to organization among patients: low***
- ***general feeling in the organization: low enthusiasm - frustration***

Do any of you feel this way?

The turning point in 2011: let’s be real!

- ***Are we actually fulfilling our mission?***

- ***What is stopping us?***

- ***Should we close the organization or do something about it?***

Start from our mission statements:

HHT Onlus Mission:

- ***Spreading awareness for HHT to promote early diagnosis***

- ***Creating local healthcare for HHT patients***

- ***Helping patients overcome solitude***

- ***Finding a cure***

We asked ourselves what was stopping us from achieving this and the answers were:

Lack of volunteers
Lack of funds
Lack of expertise
Lack of time

……

nobody said: lack of specific goals

The question was:

Are we not accomplishing our mission because we have these limits?

Or

Are those limits there because we are not setting our goals properly (or at all?)

How do you set a goal properly and why?

- Mission statements are just general principals
- For each mission statement you must decide what the means of action are to reach that goal.
- If this is done the little time, work force and funds you have will be well directed and will actually increase.

Example from HHT Onlus:

Mission statement: **overcoming solitude.** The means of action we identified:

- Patient conferences
- Help lines
- Newsletters
- Support groups
- Youth programs
- Social media

So we agree that setting specific goals is the important.

But it is not sufficient.

We must also apply **profit Management skills to non profit organizations**:

How?

1. Set realistic goals and means of action
2. Dedicate/find funds and human resources
3. Use Marketing strategies
4. Measure outcomes to make sure you have a ROI (return on investment)

Let’s see why this is important in non profit management:

Setting realistic and specific goals will support:

Funding:

- grants, sponsors, private companies, foundations only support specific projects. And these have to be thought before hand.

- Individual donors are more likely to fund a project they will see the benefits of in the short term rather than in 10 years so you are more likely to have donations for specific projects from your members.

- The success of a small specific project will enable you to have tangible documentation to repeat it the following year with even more funding.

People Raising and amount of dedicated time

-People are willing to help if they feel directly involved in the outcomes of the project you are promoting. For example parents will volunteer for a youth program, people of a specific area will volunteer if you promote the creation of a Center of Excellence in their area.

-People make time for things they believe in and they relate to personally and specifically.

Expertise:

- Often we do not know what expertise we are lacking. Once we have a specific project we can invest funds to train our volunteers for that specific goal.

  Examples are:

  social media management for an awareness campaign

  team building courses for support group activities

  clinical trial knowledge for patient empowerment

Now lets see how this applies to a real life project:

HHT Onlus Youth Program

Step 1 – setting the goal

General Goal

- ***Overcoming solitude***
- ***Raising awareness***
- ***Supporting self management***

Means of Action: Youth Program

Expected outcomes:

- ***Involving at least 20 young HHT patients age 4 to 18***
- ***Raising a new generation of volunteers***
- ***Collecting information on their needs and expectations***

Step 2. Dedicate or find funding and human resources

-*We budgeted the costs of the program that came out to 3000 euro.*
- *We had no funds to invest on this or human resources*
- *We wrote the project in detail*
-*We promoted the idea through social media, newsletters to out members.*
-*We looked for specific funding for childrens' health programs in foundations*
-*We met with potential sponsors*

-*The result?*
-*9 members volunteered for the program (never active volunteers before)*
-*We invested € 200 for 2 volunteers to participate in a team building course*
-*We found total coverage for all costs as follows.*

Funding

- **Municipality of Bologna** – Children’s library as a location - €600

- **McDonalds** – catering - €600

- **Coop Supermarket Chain** – craft material € 300

- **Charity organization focused on child wellbeing**: €1500 for travel and t-shirts, social program**,** fees for professionals.

- ***No funding from our members in this edition…..***

Step 3: measuring the outcomes after the event

-23 participants (more than expected)

-Survey to parents

-Survey to kids

-Survey to volunteers

Result?

- ***9 out of the 9 volunteers want to work on the next youth program***

- ***The participants age 15 to 18 want to advocate in their schools for HHT (total of 9 youngsters)***

- ***All participants and parents declared it was a very beneficial experience, expectations were met and most will participate in the next edition.***

- ***Parents declared they would be willing to raise funds in their community to improve the program.***

- ***4 more people volunteered for the next edition***

- ***We now have visual material and testimonials to promote the next youth program with sponsors (making it easier)***


www.
.org


HHT onlus


HHT onlus
www.hhtonlus.org
CHIARA
ELENA

What have we actually done?

We have raised volunteers and sense of belonging to the organization.
We have raised funds that otherwise we wouldn't have ever had access to.

While…. Reaching specific goals.

One more word of advice on People Raising:

- People raising is more important than fundraising.
- Possible volunteers must be identified and you can do this only through good listening skills and proper databasing.
- We often expect people to volunteer just because they share our same problem – that is a wrong assumption. If you want to people raise you must alway motivate, encourge, reward and thank and never take their time for granted.

Where this strategy has lead HHT Onlus

2011	2016
2 volunteers	25 volunteers
1 specific activity (conference)	9 specific projects per year
60 members	300 members
78 contacts	1257 contacts
€7,000 budget	€ 42,000 budget
Low enthusiasm	High enthusiasm
No paid staff	1 paid staff member

Thank you.

Claudia Crocione

Managing Director – HHT Europe – Federation of Patient Organizations
Project & Communciation Manager HHT Onlus – Italy
c.crocione@hhtonlus.org – www.hhtonlus.org – mobile. +39.333.2104478

Coffee break

Session 3

Breakout sessions

Group 1

Recap on advocacy essentials

Agenda

- Why is advocacy important to IPF
- Tips and basic principles of advocacy from Burson-Marsteller
  - Development of an advocacy strategy
  - 12 tips for effective lobbying
- Best practice sharing on your own advocacy projects

Why is advocacy important to IPF?

Why is advocacy important to IPF?

The decision of politicians can be crucial to the lives of IPF patients

- **Decisions on healthcare spending**
- **Prioritisation of rare diseases**
- **GP-Specialist access – functioning of health system**
- **Creation (or closing) of specialist centres**

Health Ministers are often not healthcare practitioners, or even interested in healthcare!

Politicians will often have specific conditions they care about due to family experience, though most are not aware of the specificities of conditions

…even more so for rare diseases

Why is advocacy important to IPF?

Local/Regional

- Commissioning services
- Local organisation of health systems
- Local strategies and disease-specific policies

National

- National budget and healthcare spending
- National strategies and disease-specific policies
- HCP education, training and curricula
- Clinical guidance
- National legislation
- R&D programmes
- Pharmaceutical authorisations

International

- R&D programmes (especially EU)
- Global accords and action plans on diseases
- Pharmaceutical authorisations

Why is advocacy important to IPF?

There is a need to understand the process and powers of different layers of government and different areas of responsibility

Why is advocacy important to IPF?

There is a need to know how to influence

Why is advocacy important to IPF?

There is a need to know how to develop an advocacy strategy

Tips and basic principles of advocacy from Burson-Marsteller

Establishing your objective

- What are the needs of your members? What exactly do you want to change?

    - Consultation
    - Strategy meeting
    - Survey

- Are your objectives realistic?

- Can they be achieved via advocacy?

- Are they shared by others? Is collaboration possible?

Establishing your objective

Access to treatment

Disease awareness

Improve HCP education

Clinical Trial Recruitment

Patient education

Increased R&D funding

Employment policies

Patient role in regulation

Prevention & diagnosis

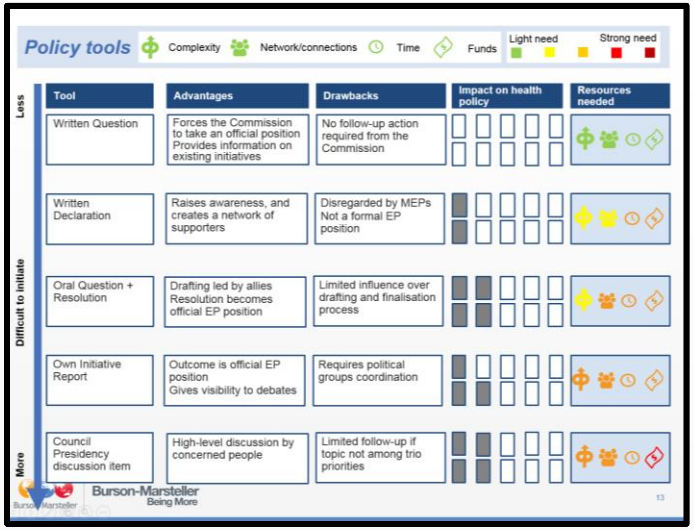
Understanding your environment

- How are the policies affecting your organisation decided?
- How can they be changed?
- What are the entry points for discussion for a patients' organisation?
- Who is influential within the field?
- What other interests and factors are influential on the policy we want to change?

Identifying your tools and tactics

EUROPEAN IDIOPATHIC PULMONARY FIBROSIS & RELATED DISORDERS FEDERATION

- What tactics are feasible for our organisation with its current level of skills?
- What tactics and tools does our political/policy process allow?
- Do we need external support to understand our political/policy process?
- How do we get to a final objective using a series of tools and tactics?



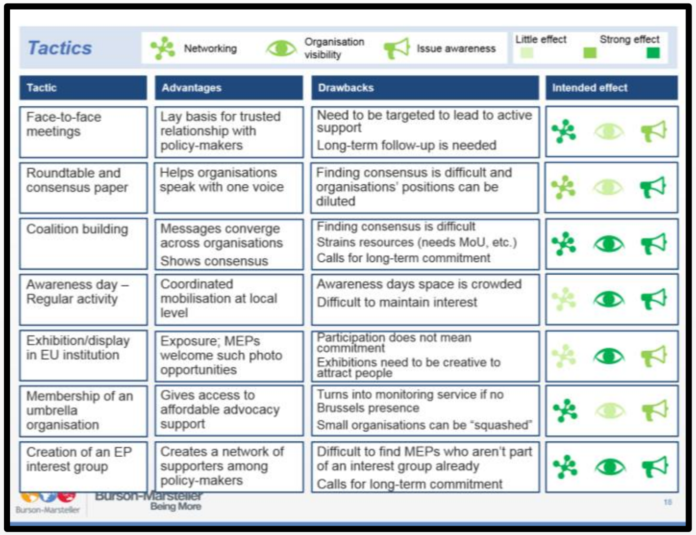
Policy tools

Complexity · Network/connections · Time · Funds — Light need 🟩 🟨 🟧 🟥 🟥 Strong need

Less — Difficult to initiate — More

Tool	Advantages	Drawbacks	Impact on health policy	Resources needed
Written Question	Forces the Commission to take an official position Provides information on existing initiatives	No follow-up action required from the Commission	▯▯▯▯▯ ▯▯▯▯▯	🟩 🟩 🟩 🟩
Written Declaration	Raises awareness, and creates a network of supporters	Disregarded by MEPs Not a formal EP position	▮▯▯▯▯ ▮▯▯▯▯	🟨 🟨 🟧 🟧
Oral Question + Resolution	Drafting led by allies Resolution becomes official EP position	Limited influence over drafting and finalisation process	▮▮▯▯▯ ▮▮▯▯▯	🟨 🟧 🟧 🟧
Own Initiative Report	Outcome is official EP position Gives visibility to debates	Requires political groups coordination	▮▯▯▯▯ ▮▮▯▯▯	🟧 🟧 🟧 🟧
Council Presidency discussion item	High-level discussion by concerned people	Limited follow-up if topic not among trio priorities	▮▮▯▯▯ ▮▮▯▯▯	🟧 🟧 🟧 🟥

Burson-Marsteller Being More 13



Tactics

Networking · Organisation visibility · Issue awareness — Little effect ░ ▒ █ Strong effect

Tactic	Advantages	Drawbacks	Intended effect
Face-to-face meetings	Lay basis for trusted relationship with policy-makers	Need to be targeted to lead to active support Long-term follow-up is needed	█ ░ ▒
Roundtable and consensus paper	Helps organisations speak with one voice	Finding consensus is difficult and organisations' positions can be diluted	▒ ░ █
Coalition building	Messages converge across organisations Shows consensus	Finding consensus is difficult Strains resources (needs MoU, etc.) Calls for long-term commitment	█ █ █
Awareness day – Regular activity	Coordinated mobilisation at local level	Awareness days space is crowded Difficult to maintain interest	░ █ █
Exhibition/display in EU institution	Exposure; MEPs welcome such photo opportunities	Participation does not mean commitment Exhibitions need to be creative to attract people	░ █ ▒
Membership of an umbrella organisation	Gives access to affordable advocacy support	Turns into monitoring service if no Brussels presence Small organisations can be "squashed"	█ ░ ▒
Creation of an EP interest group	Creates a network of supporters among policy-makers	Difficult to find MEPs who aren't part of an interest group already Calls for long-term commitment	█ █ █

Burson-Marsteller Being More 18

Identifying your tools and tactics

Communication materials creation

Event held under auspices of the Government

Awareness day – Regular activity

Letter-writing campaigns

Face-to-face meetings

Exhibition/

display

Speaking opportunity at an event

Roundtable and consensus paper

Membership of an umbrella organisation

Event in national Parliament

Coalition building

Creation of a politician interest group

Establishing tangible goals

- **S**pecific
- **M**easurable
- **A**ssignable
- **R**ealistic
- **T**ime-related

Example

Objective: Improve diagnosis rates of IPF patients

What shapes this issue: Primary care system, Training of GPs, Number of HCPs available, Number of specialist centres and integrated care etc.

How can this be changed? Outreach to GPs directly, CPD and credits, mobilisation of patient advocates, greater use of specialists centres focusing on respiratory diseases, a respiratory diseases strategy? *More health spending*

Who is influential within the field: GPs association, Pulmonologists association, Health Minister, senior civil servants, Finance minister, competing patients' organisations

Other interests and factors: Health budgets, professional competence and competition, doctors working conditions, 'competition of diseases'

Example

Tactics and tools:

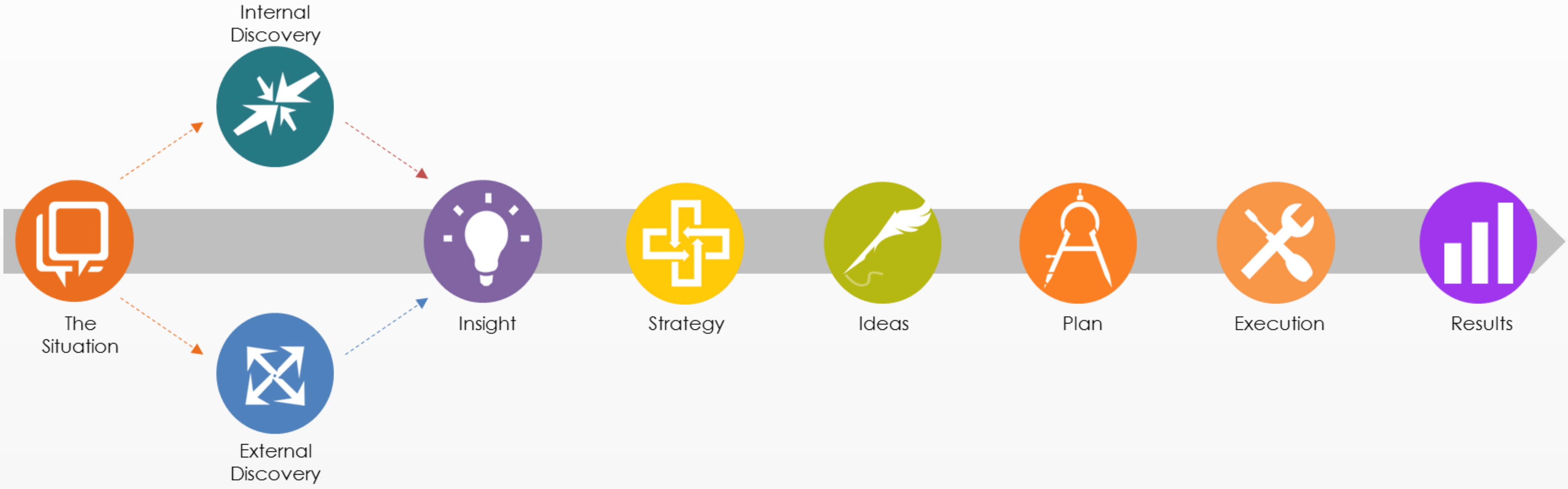
Annual awareness activities in alliance with GPs association

Outreach to politicians interested in respiratory conditions

Alliance with other rare disease organisations (via umbrella group) to draw attention to the needs or rare disease patients and lack of diagnosis

Alliance with other respiratory groups to push politicians to tailor health systems towards a more effective strategy for respiratory conditions

Development of an advocacy strategy



12 tips for effective lobbying

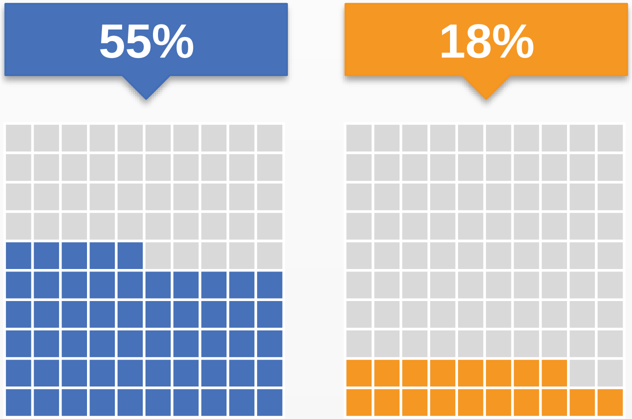
12 tips for effective lobbying

12 TIPS FOR
EFFECTIVE
LOBBYING

1

Be transparent about your interests

A lack of transparency is the most frequently-cited example of ‘poor practice’:



For the corporate sector

For the NGO sector

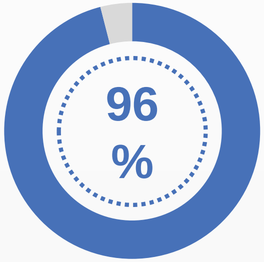
12 tips for effective lobbying

12 TIPS FOR EFFECTIVE LOBBYING

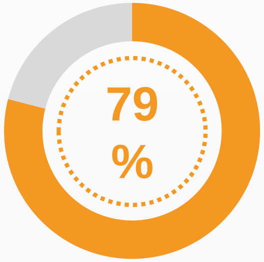
1

Be transparent about your interests

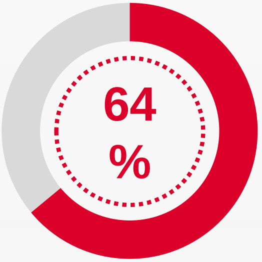
Respondents appreciate transparent lobbying:



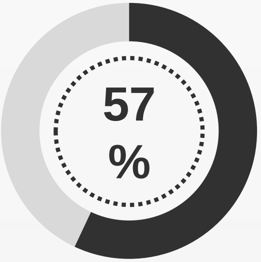
say transparent lobbying helps policy development



say a mandatory register would be useful



say it influences whether a lobbyist obtains a meeting



say being registered as a lobbyist influences whether a lobbyist obtains a meeting

Transparency

EFPIA CODE OF PRACTICE ON RELATIONSHIPS BETWEEN THE PHARMACEUTICAL INDUSTRY AND PATIENT ORGANISATIONS

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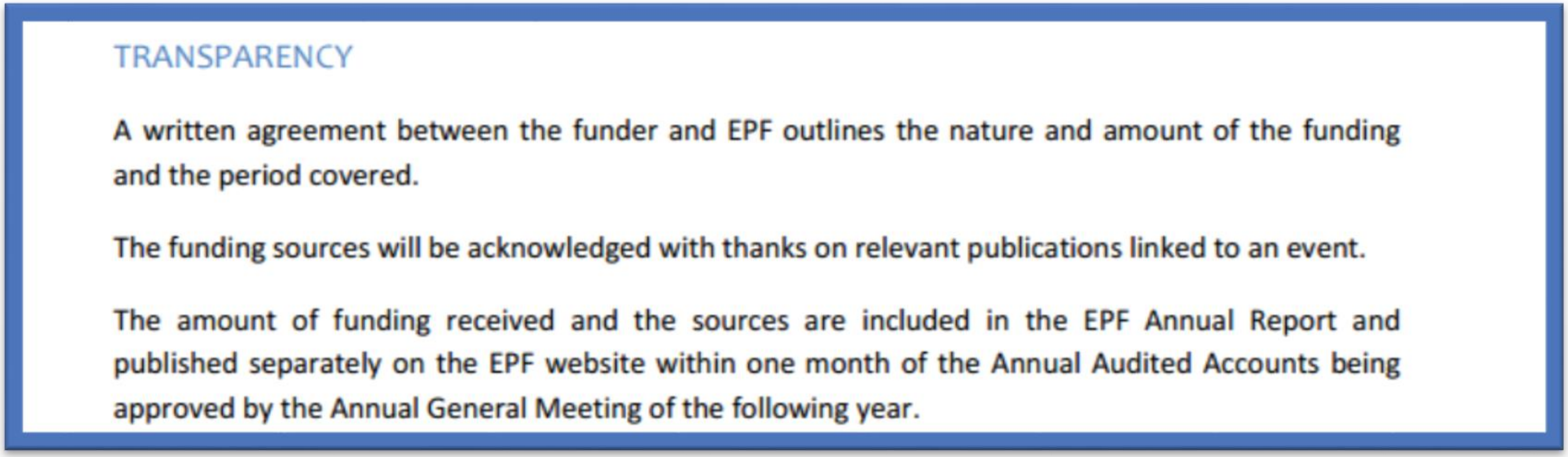
Transparency



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12 tips for effective lobbying

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EFFECTIVE
LOBBYING

2

Be aware that your audience is not only ‘in the room’

“When meeting lobbyists, I…

89%
…report to my hierarchy”

27%
…disclose information if asked”

14%
…systematically note on my website that I had a meeting”

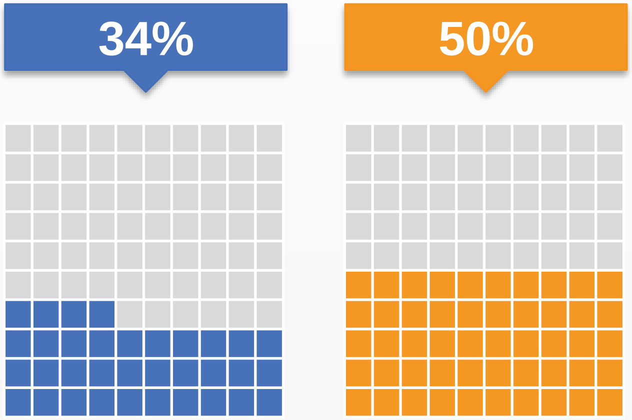
12 tips for effective lobbying

12 TIPS FOR EFFECTIVE LOBBYING

3

Get your timing right

Being too late or too early is a poor practice frequently committed by…



…the corporate sector

…the NGO sector

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LOBBYING

4

Understand the legislative process and its technicalities

Not understanding process is a poor practice frequently committed by…

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LOBBYING

5

Think politically

Seek to identify…

The focus of the political argument

The values and interests involved

The potential for consensus

How a compromise can be built

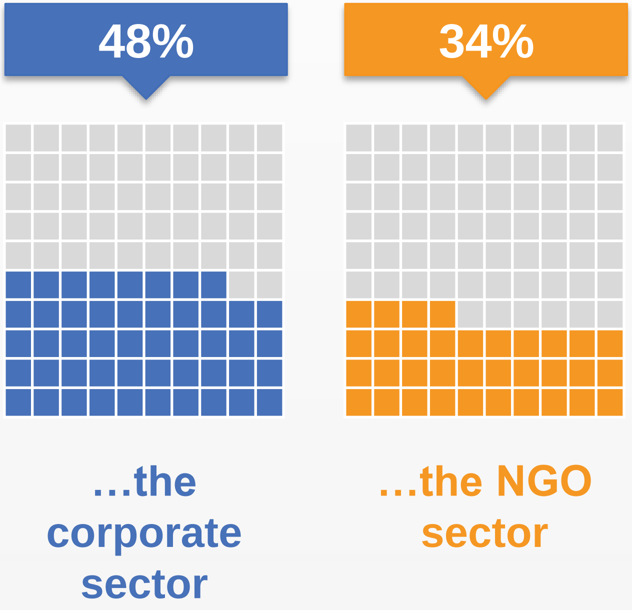
12 tips for effective lobbying

12 TIPS FOR EFFECTIVE LOBBYING

5

Think politically

Being too aggressive is a poor practice frequently committed by…



12 tips for effective lobbying

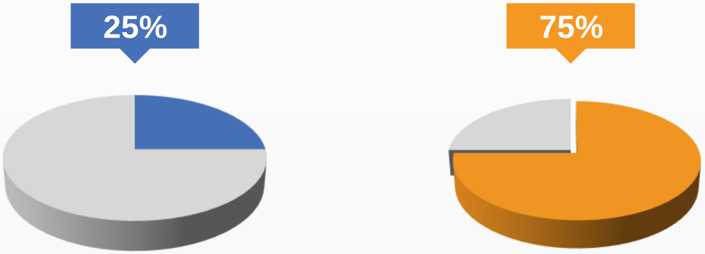
EUROPEAN IDIOPATHIC PULMONARY FIBROSIS & RELATED DISORDERS FEDERATION

12 TIPS FOR EFFECTIVE LOBBYING

6

Back up political arguments with evidence

Basing positions on emotion rather than facts is cited as an example of 'poor practice' by…



…the corporate sector

…the NGO sector

54%

say scientific and educational websites are helpful in making informed decisions

Burson-Marsteller
Being More

12 tips for effective lobbying

12 TIPS FOR EFFECTIVE LOBBYING

7

Identify your audience and set realistic objectives

The best campaigns…

…set clear objectives at the beginning

…adapt to changing political circumstances

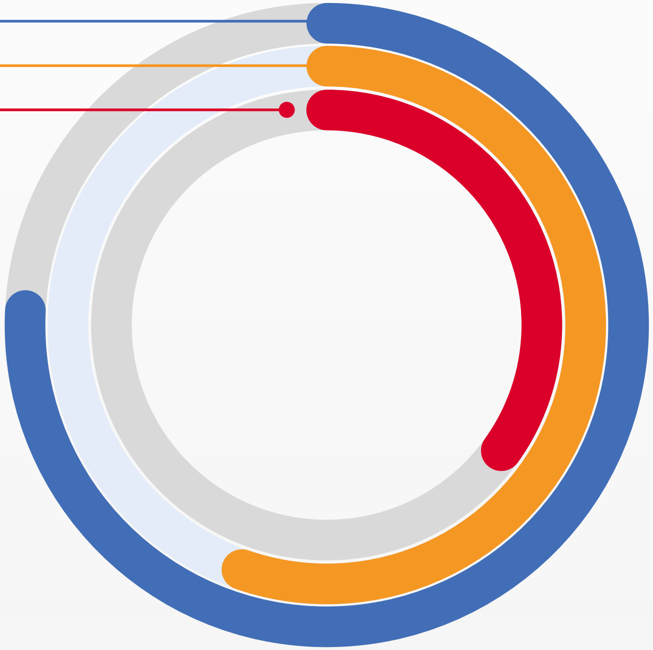
12 tips for effective lobbying

12 TIPS FOR EFFECTIVE LOBBYING

8

Know who you need to talk to – and do it at the right time

Decision-makers are most likely to speak to lobbyists if…



77%

…the topic is in their field of expertise

55%

…the topic is of interest

34%

…there is an ongoing consultation process

12 tips for effective lobbying

12 TIPS FOR EFFECTIVE LOBBYING

9

Mobilise people to act

Decisions are based on a balance of interests – do not act alone:

Find those with the same goals, even if their motivation is different

A varied group can target audiences separately, from different directions

12 tips for effective lobbying

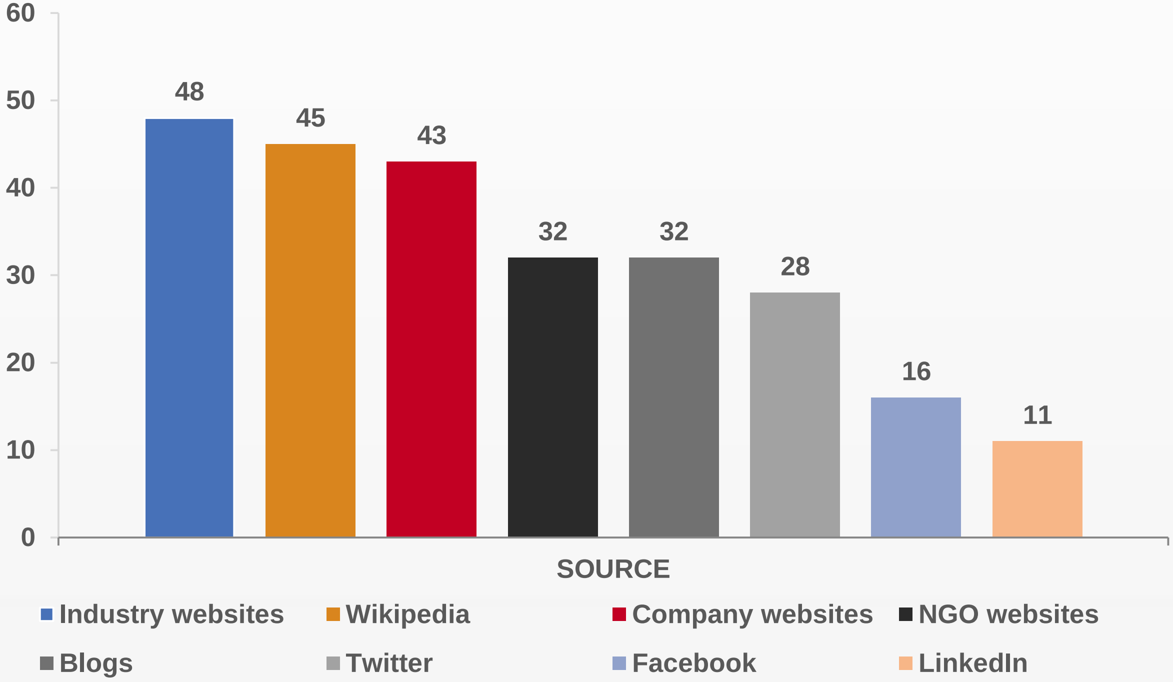
EU-IPFF
EUROPEAN IDIOPATHIC PULMONARY FIBROSIS & RELATED DISORDERS FEDERATION

12 TIPS FOR EFFECTIVE LOBBYING

10

Ensure that your message gets through online

Sources consulted at daily or at least once a week:



Burson-Marsteller Being More

12 tips for effective lobbying

12 TIPS FOR
EFFECTIVE
LOBBYING

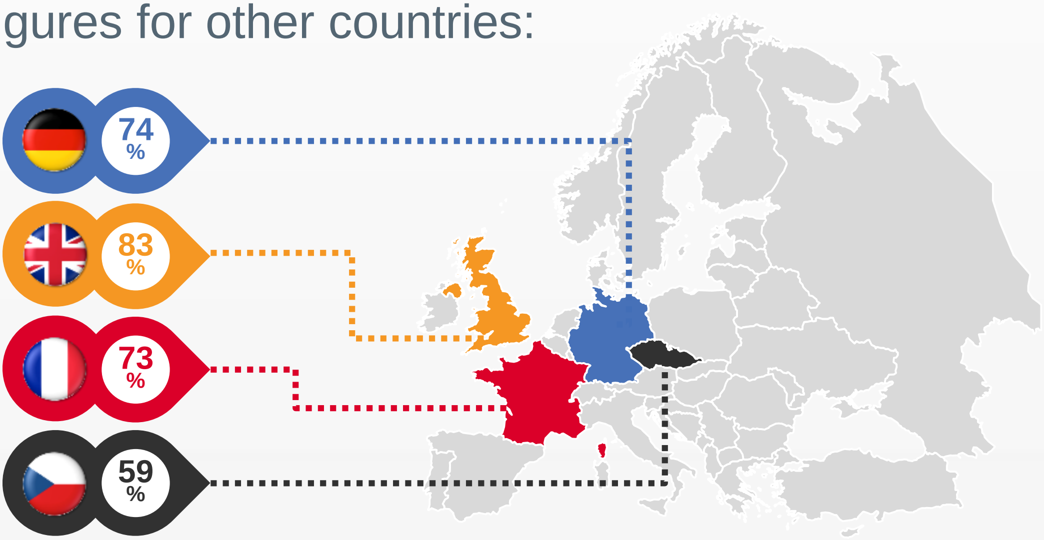
11

Recognise diversity and localise your approach

18%

of Brussels respondents want to be approached in their own language on an issue of national interest

Figures for other countries:

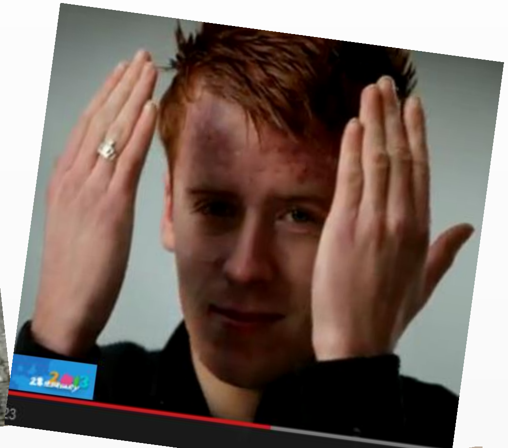


12 tips for effective lobbying

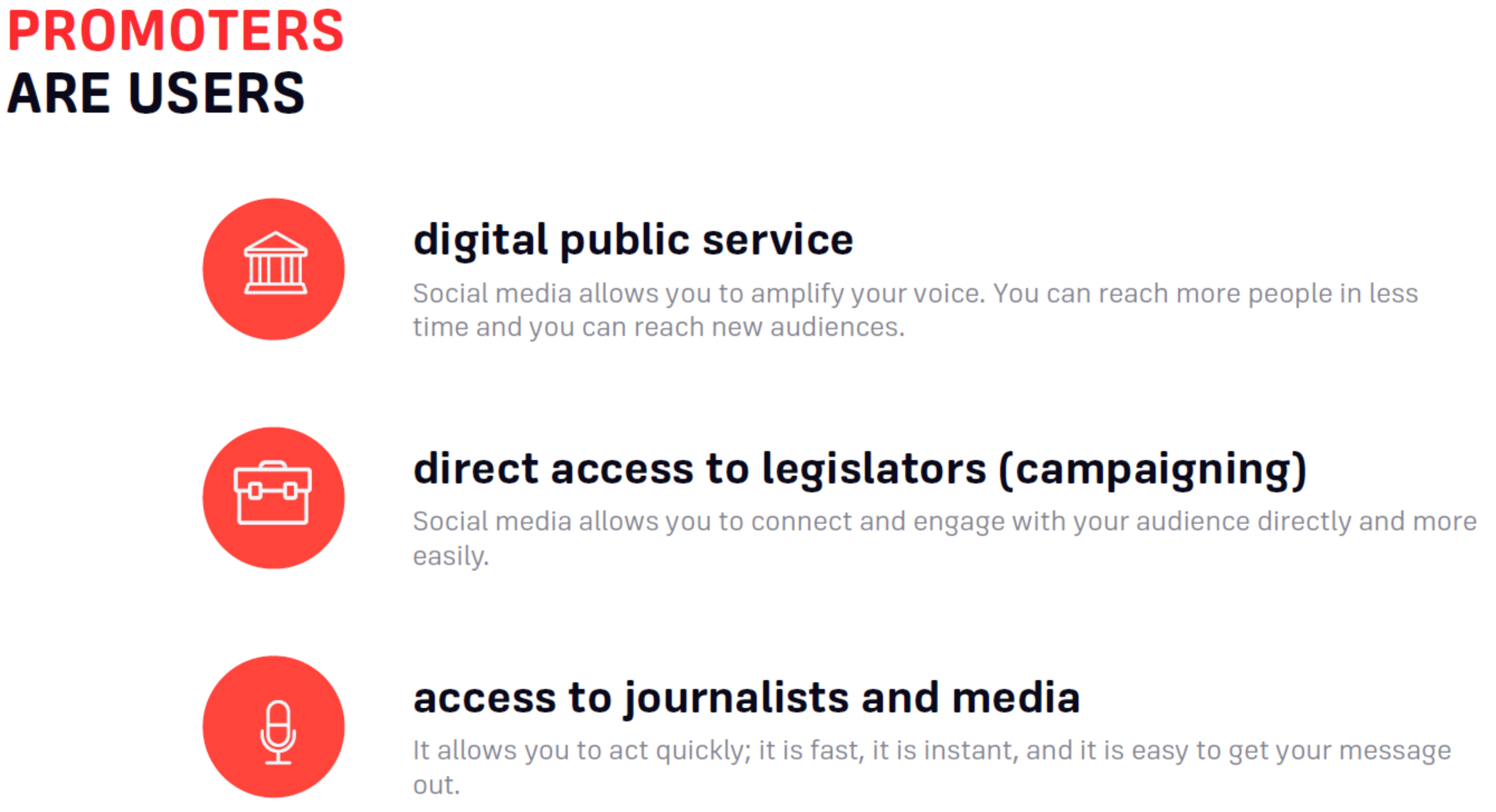
12 TIPS FOR
EFFECTIVE
LOBBYING

12

Be creative and memorable from start to finish



Social media and Advocacy – why?



PROMOTERS
ARE USERS

digital public service

Social media allows you to amplify your voice. You can reach more people in less time and you can reach new audiences.

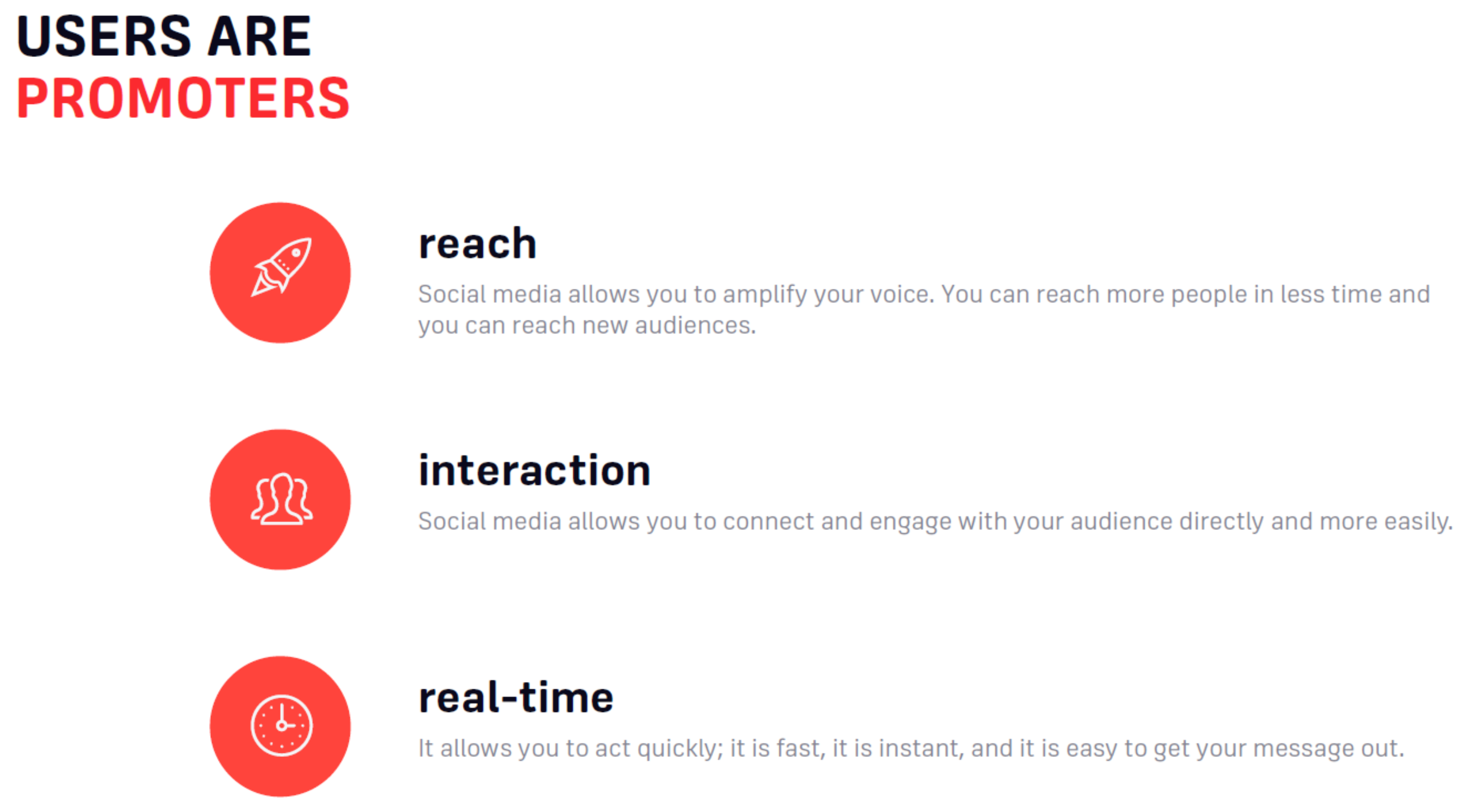
direct access to legislators (campaigning)

Social media allows you to connect and engage with your audience directly and more easily.

access to journalists and media

It allows you to act quickly; it is fast, it is instant, and it is easy to get your message out.

Social media and Advocacy – why?



USERS ARE PROMOTERS

reach

Social media allows you to amplify your voice. You can reach more people in less time and you can reach new audiences.

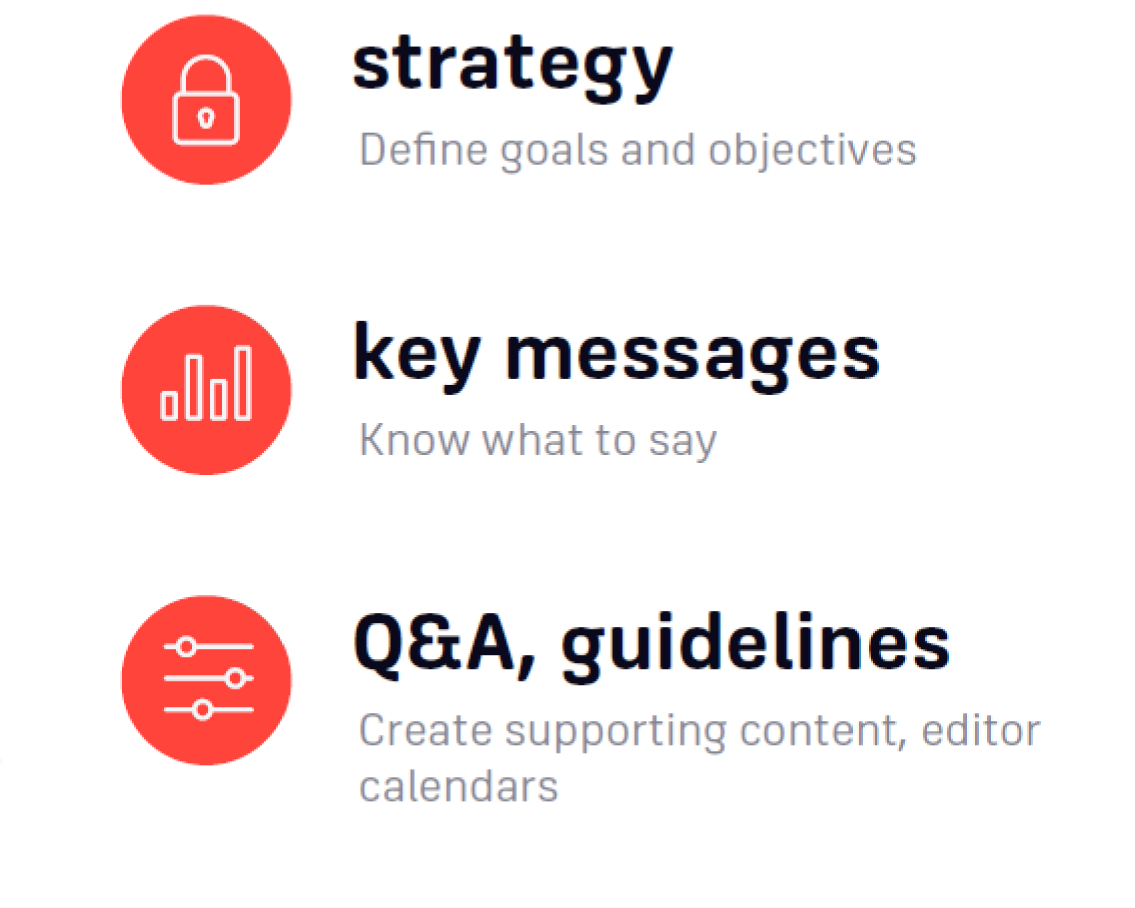
interaction

Social media allows you to connect and engage with your audience directly and more easily.

real-time

It allows you to act quickly; it is fast, it is instant, and it is easy to get your message out.

Social media and Advocacy - basics



strategy

Define goals and objectives

key messages

Know what to say

Q&A, guidelines

Create supporting content, editor calendars

Social media and Advocacy - strategy

SOCIAL MEDIA STRATEGY
IN 8 STEPS

1. defining goals and objectives
2. defining audiences
3. defining channels
4. defining content
5. developing posting plans
6. monitoring and comparing
7. selecting and following metrics (KPI's)
8. keeping up with changes and trends

Social media and advocacy

EU-IPFF
@EU_IPFF

The European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF) is a European federation of national #IPF patient associations

Brussels
Joined June 2016

<u>Tactics/Tools (for Twitter)</u>

- ***Lists of key policy makers and other stakeholders***
- ***Establish connection and perhaps conversation ahead of a big and costly meeting programme***
- ***Develop robust and targeted messaging and use Twitter @ mentions to distribute***
- ***Establish social media ambassadors for each national organisation***

Social media and advocacy

EU-IPFF

@EU_IPFF

The European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF) is a European federation of national #IPF patient associations

Brussels

Joined June 2016

Tactics/Tools (for Twitter)

- ***Use of video – periscope etc***
- ***Sharable content (creativity)***
- ***Hashtags and online references to offline activities***
- ***Create an online record of activities and meeting***
- ***Provide policy makers with photo opportunities (to show how active they are)***

Best practice sharing

Right to Diagnosis and Care of Patients with Idiopathic Pulmonary Fibrosis (IPF): the Italian Experience.

2016 IPF Workshop

18-19 November, Brussels

From European to Italian Context

Advocacy actions: main goals to be achieved

- To present at the Italian National Parliament the European IPF Patient Charter and initiate a dialogue with policy-makers on how to address the existing gaps faced by IPF patients to access optimal care in Italy, with a focus on regional health inequalities;

- To support the requests of the European IPF Patient Charter through the involvement of a large number of decision-makers, patient associations and Italian Scientific Societies;

- To build a network of institutional relations through which it is possible to develop engagement activities on the issues that come out from this important first step.

What has been done and How

Institutional Event:

"Right to Diagnosis and Care of Patients with Idiopathic Pulmonary Fibrosis. The European IPF Patient Charter and Recognition of the IPF as a Rare Disease in all Italians Regions to Overcome the Differences in Treatment".

Rome, Library of the Chamber of Deputies March, 1, 2016.

The event was organized under the **patronage** of:

- *Chamber of Deputies*
- *Ministry of Health*
- *Lazio Region*
- *CNAI*
  Consociazione Nazionale delle Associazioni Infermiere/i
- *Orphanet*
- *FIASO*
  Federazione Italiana Aziende Sanitarie e Ospedaliere
- *EU-IPFF*
  European Idiopathic Pulmonary Fibrosis and Related Disorders Federation
- *SIMER*
  Società Italiana di Medicina Respiratoria

The event is also **supported** by *Centre for Rare Diseases - National Institute of Health (ISS)* and realized with the unconditional support of Roche.

1. Institutional Event: MPs Engagement

L'IPF IN ITALIA: UN APPELLO AI DECISORI POLITICI

Forti della grande attenzione istituzionale ricevuta a Bruxelles, l'appello delle Associazioni dei pazienti si rivolge ora ai Governi dei singoli Stati. **In Italia AMA fuori dal Buio**, individuata quale "associazione pilota" nel dare il via a questa fase nazionale, **propone di avviare un dialogo con i decisori politici nazionali sulle azioni da intraprendere per migliorare la qualità e garantire un accesso equo alle cure a tutti i pazienti** partendo dal recepimento della Carta Europea del Paziente.

In Italia esiste al momento una discriminante disparità di trattamento al livello europeo: solo due regioni su 21, Piemonte e Toscana, riconoscono l'IPF come malattia rara identificando un codice di esenzione che permette ai pazienti di sottoporsi gratuitamente ad esami di controllo e trattamenti. In tutte le altre regioni sono i pazienti e le loro famiglie a doversi far carico degli altissimi costi associati alle cure e al monitoraggio costante dell'evoluzione della patologia e sono le associazioni di pazienti ad offrire loro "supporto".

Da qui la richiesta, ribadita a gran voce da **AMA Fuori dal Buio** e dai numerosi partner promotori della Carta che sostengono i diritti dei malati con IPF, **rivolta ai decisori politici nazionali, di riconoscere l'IPF come malattia rara in tutte le regioni d'Italia per superare le disparità di trattamento e assicurare il diritto alla diagnosi e alla cura a tutti i pazienti, non solo in termini clinici, ma anche assistenziali e di sostegno psicologico.**

SIGN UP!

Firma la Carta dei Pazienti con Fibrosi Polmonare Idiopatica!

Indirizzo Web European IPF Patient Charter
www.ipfcharter.org

EU Members:

Partner nella Promozione della Carta del Paziente:

Con il gratuito patrocinio di:

Con il supporto incondizionato di:

fuori dal buio
informazione studio ricerca tutela
malattie orfane e rare
www.fuoridalbuio.it

Il Diritto alla diagnosi e alla cura dei pazienti con Fibrosi Polmonare Idiopatica

La Carta Europea del Paziente
e il riconoscimento dell' IPF
come malattia rara
in tutte le regioni d'Italia
per superare le disparità
di trattamento

EUROPEAN IPF Patient Charter

- Invitation letter;
- information leaflet;
- For some Members of Parliament, more engaged on the issue of rare diseases, we have preferred a direct engagement with dedicated one-to-one meetings.

2. Institutional Event: Attendees

The event was attended by almost **35** relevant **stakeholders**, among which ***patient associations***, ***scientific societies*** and ***high level policy-makers*** who are active in the health policy and medical field all over the country.

The Patient Associations that attended the event were:

- Respirare Onlus di Catania
- Un respiro di speranza – Associazione di pazienti Onlus di Roma
- Unione Trapiantati Polmone di Padova
- Un Soffio di Speranza – Il Sogno di Emanuela Onlus
- AMMP - Associazione Morgagni Malattie Polmonari
- FIDIC Volontariato Lazio

Overall Results

- European IPF PC has **gained visibility** on all communication materials that have been produced for the event: save the date, invitation, leaflet, invitation letter to MPs, requests for patronage, folders, press kit, roll up.

- Patients Associations, led by *AMA fuori dal buio*, promoter of the event, had the **opportunity to bring the open issues of IPF in Italy to decision makers' attention**. Especially ***the specific request to recognize IPF as a rare disease*** throughout Italy was clearly pointed out during the event as to allow ***fair access to treatment and care to all patients***.

- A short time after the event, on April 5th, Mr. Pierpaolo Vargiu, Member of the Italian Parliament, proposed *a motion that was* ***approved unanimously*** *in the Italian National Low Chamber, leading to the inclusion of IPF in the rare diseases list*.

The Italian Parliament voted the motion that recognises IPF as a rare disease

- As a matter of fact, only Piedmont and Tuscany had previously recognised IPF as a rare disease spontaneously, identifying an exemption code for all health services needed by patients. Now, by accepting the motion at the National Low Chamber, the government has committed to develop information campaigns with the aim of **recognizing the rare disease at a national level.**
- IPF is going to be included in the forthcoming review of the Italian National Plan for Rare Diseases, a ***historical achievement*** that gives hope for a better future to patients, relatives and healthcare professionals. In this long process, patients' associations have played a fundamental role, by informing people, raising awareness of the problem, helping patients and their families and bringing them together.

IPF: a paradigm for the future of the health care system

- As Mr. Vargiu declared during the presentation of his motion at the Low Chamber, “***IPF is a paradigm of the challenge awaiting the Italian Health Care system.*** By preparing to deal with it, we take up the challenge of modernising the system, of trying to provide citizens with the best quality services. ***An important step in the fields of health care assistance, research, and networking among associations***, which can now offer an ever-improving service to their associates, patients and families.”

- Mr. Vargiu then said: “I want to thank *AMA Fuori dal buio* again for its passionate contribution. When the “tenants of the government building” pay attention to the voice of the people outside, it is easier to cooperate to do things that are useful for the Community. This is particularly true for that part of the Community that is “frailer” and needs more attention, i.e. the citizens who need health services.”

From Italian to European Context

- Awareness raising and advocacy actions in Italy have produced significant results: about 90% of Italian MEPs signed the IPF Charter.
- Now we are waiting for European Commission and Council decision about the future of the IPF Charter.

Conclusions

Join us tomorrow at 9:00