

# Perspectives of patients

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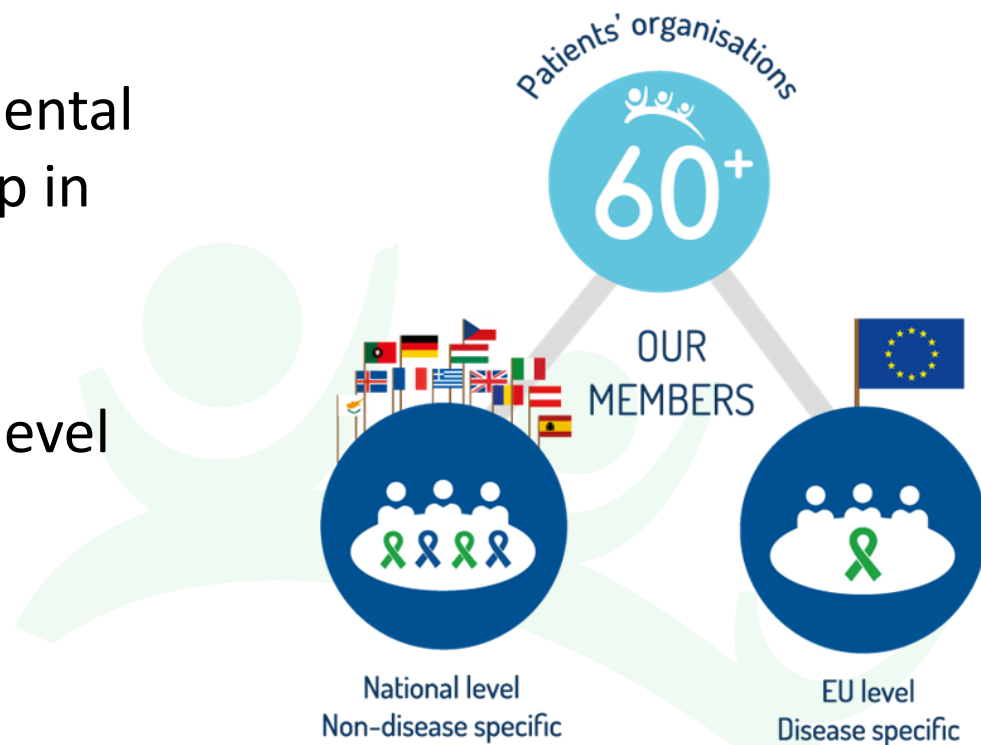
European Commission

24 October 2016, Brussels

“ A STRONG PATIENTS' VOICE TO  
DRIVE BETTER HEALTH IN EUROPE ”

# What is EPF ?

- Independent, non-governmental umbrella organisation set up in 2003
- 67 member organisations – national umbrellas and EU-level disease-specific patient organisations



- **Vision:** All patients in the EU have equitable access to high quality, patient-centred health and social care
- **Mission:** to ensure that the patient community drives policies that enable positive changes for patients to become equal citizens

# Background on cross-border healthcare



Long engagement with the Directive during “legislative journey”, work with EU Institutions and stakeholders

2013-2014 Series of regional seminars

EPF Guide & Recommendations



2008



2011



2012



2013

2015 – 6 national mini-workshops

2 July 2015 – Conference in Brussels

Q3 2017 – Conference with patient organisations



2015



2016



2017

Summary report (March 2015)

EPF position paper (April 2016)

Ongoing request for information

# EPF regional conferences & Workshops

2013: Brussels

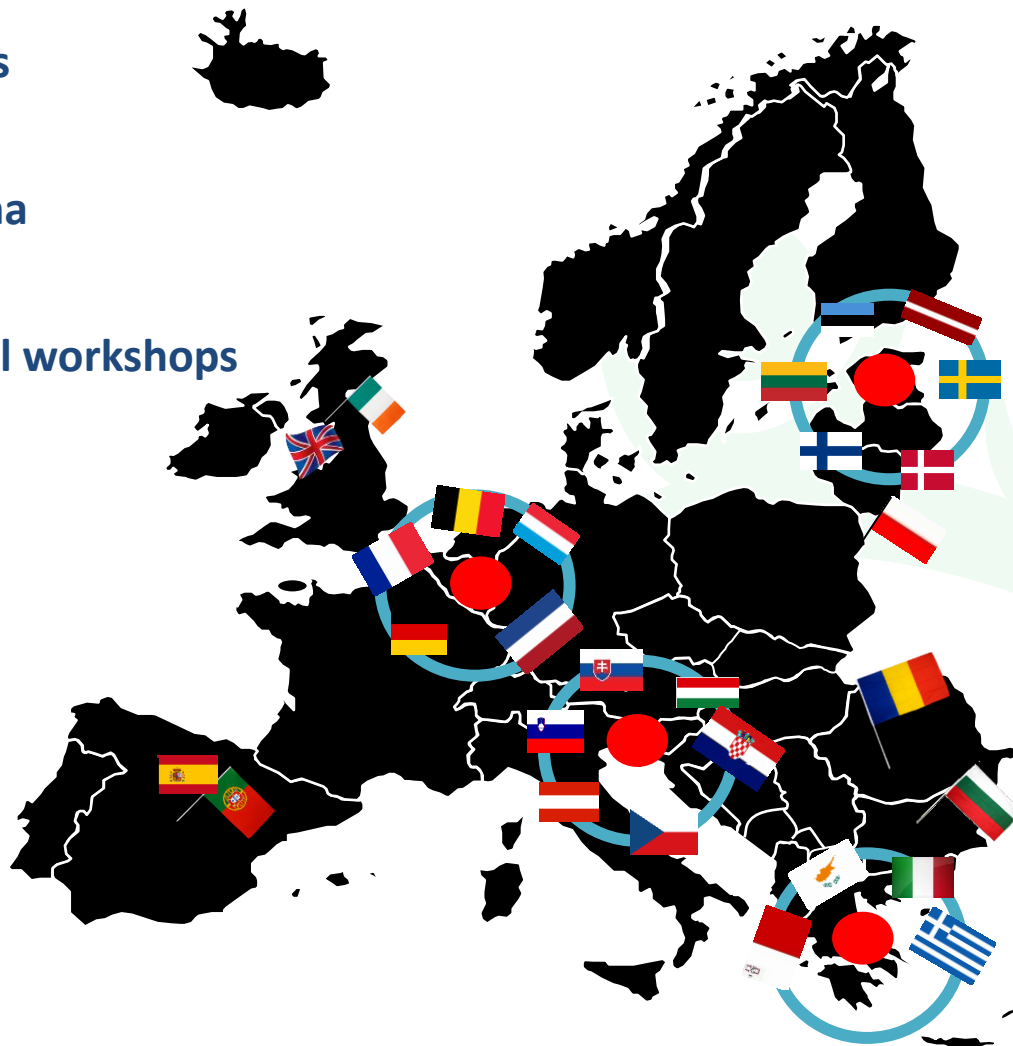
2014: Athens

Ljubljana

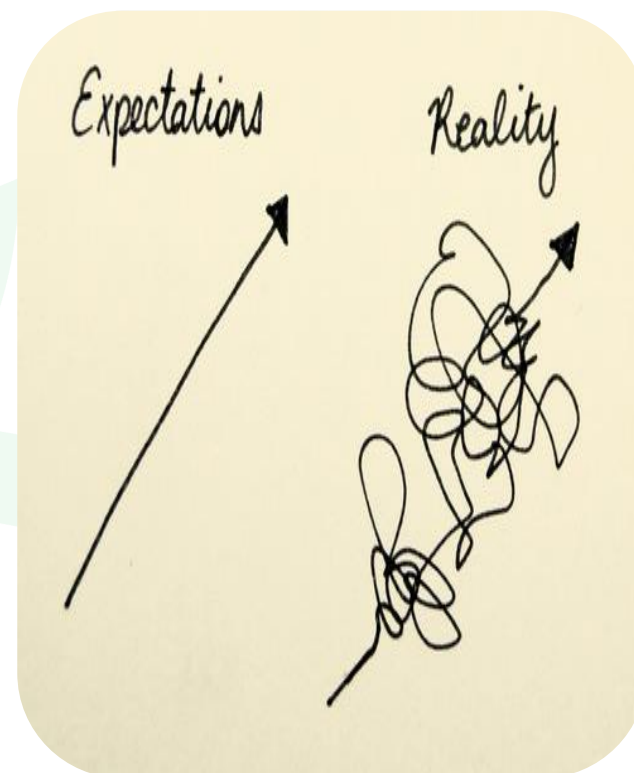
Tallinn

2015: national workshops

- Zagreb
- Madrid
- Warsaw
- Sofia
- Dublin
- Bucharest



- Not yet much practical experience among patient organisations
- Uneven implementation and little involvement of patients
- Benefits: enhancing patients' ability to exercise their rights, transparency of health system
- Concerns: lack of information, access barriers, lack of awareness of Directive (still)



Original purpose of the Directive: clarify patients' legal rights. Based on implementation to date, this objective has not been achieved.

# The patient journey

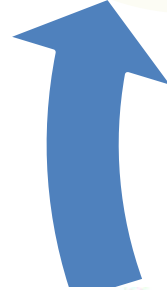
When deciding:  
enabling trust



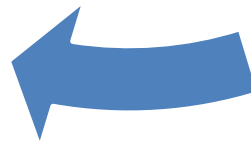
Before leaving:  
mitigating risks



During stay:  
dealing with the  
unexpected



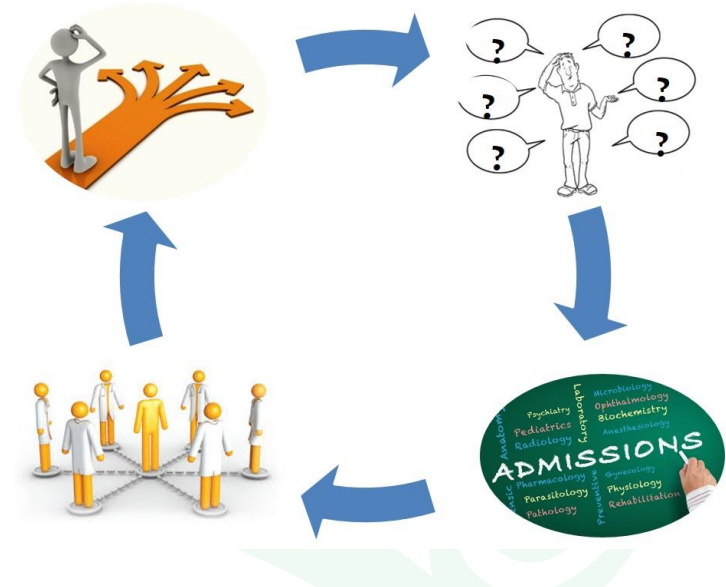
After returning:  
continuity and  
improvement



# Key messages from the patients

## More information provided early on = better

- ✓ Total cost
  - ✓ Patients' rights
  - ✓ What information/documents needed
  - ✓ Communication issues
  - ✓ Whom to turn for help / emergencies
  - ✓ Who is responsible for me, my safety etc. ?
- 
- Need for practical step-by-step guides, checklists
  - Harmonisation of procedures and documents



# And today?

“I cannot find information about reimbursed services ... You have to fill in a form [for prior authorisation] – but for that you already have to know exactly where you want to go, and who is your doctor there.”  
- Estonia

“Health professionals should be more educated about cross-border healthcare.”  
- Austria



“Good: information is in a visible place on the NCP’s website. Bad: the NCP acts more like gatekeeper of the budget rather than in the interest of the patient.”  
- Bulgaria

“Patient organisations, sick funds and healthcare providers should have a role in providing information. Because different people get their information from different sources.”  
- Finland



- Patient organisations seen as important providers of information
- Need to collaborate with medical community in their disease-area and/or with health insurance provides, to improve global awareness
- EPF: continues efforts to raise awareness and support patient organisations' advocacy in Member States – but often hampered by their lack of capacity/resources
- Patient organisations need appropriate resourcing to fulfil their role – could save work from NCPs by informing and supporting patients
- To increase understanding and trust, we recommend dedicated meetings between the relevant government/statutory bodies and patients' representative organisations to define roles and collaboration

- EU guidelines on “core” to be provided to patients + recommendations on good practices, e.g. applying health literacy principles
- Standardised templates for all application forms used by NCPs
- NCPs to be independently assessed using a set of objective performance criteria
- NCPs should engage with patient organisations more - plan joint work, resolve practical issues, develop and review information and service delivery
- Information pooling and sharing: exploiting synergies with national and EU portals on medicines, devices and clinical trials
- Dedicated funding to ensure effective functioning of NCPs, particularly in resource-poor Member States.


# The “Ideal NCP Checklist”

Result of brainstorming and group discussions in all regional & national seminars

Could be used as a basis for performance criteria

Recommendations in four main areas:

- Fundamental principles
- Accessibility & visibility
- Operational
- Information for patients



- The NCP is able to offer informed assistance regarding rare diseases and specialised treatments.
- The NCP works with other stakeholders to identify and implement solutions to mitigate patients' financial difficulties regarding upfront payment, thus upholding the principle of equity of access based on needs, not means.

**Accessibility and visibility**

- The NCP is highly visible, easy to find and to contact, ideally with a name that is easy to recognise.
- The NCP communicates using simple language that all patients can understand.
- The NCP provides information in foreign languages, at least English and relevant minority languages as well as ideally the language(s) of the most common cross-border flows.
- The NCP is accessible in real-life situations, not just via its website or only during office hours.
- The NCP can be accessed via multiple channels – website, email, free telephone line, 24-hour emergency hotline, as well as physical premises with barrier-free access for personal consultations.
- In member states with significantly large rural or dispersed populations there are regional contact points in addition to the central NCP.

**Operation**

- The NCP has transparent procedures and clear timelines.
- The NCP process provides for individualised guidance with case managers.

**The NCP website:**

- ✓ is easy to find through Google
- ✓ is easy to navigate
- ✓ has content that is informative and clearly structured
- ✓ includes visual tools where appropriate, such as infographics and video
- ✓ includes real patients' stories and testimonies
- ✓ includes FAQs, guides and checklists
- ✓ includes a simple mechanism for patients to submit applications
- ✓ has an interactive feedback facility
- ✓ links to other relevant websites, such as the national health authorities, health providers and patient organisations.

- Directive has not (yet) clarified patients' rights
- Patient community identifies key barriers:
  - Perception that some NCPs are not working in patients' interests
  - Perception that governments are reluctant to inform patients
  - Still difficult for patients to find the right information especially re: entitlements, reimbursement
  - Lack of awareness by medical professionals of the option of cbhc
  - Lack of awareness by many patient organisations, despite those who attended EPF seminars say it helped them spread the knowledge
- More needs to be done to ensure patients are well informed about their rights and how to exercise them; and that patient organisations are meaningfully involved at national level in the implementation of the directive.

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**More information**

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