

Realities faced by patients when using the Directive

Kaisa Immonen-Charalambous, Director of Policy
European Patients' Forum

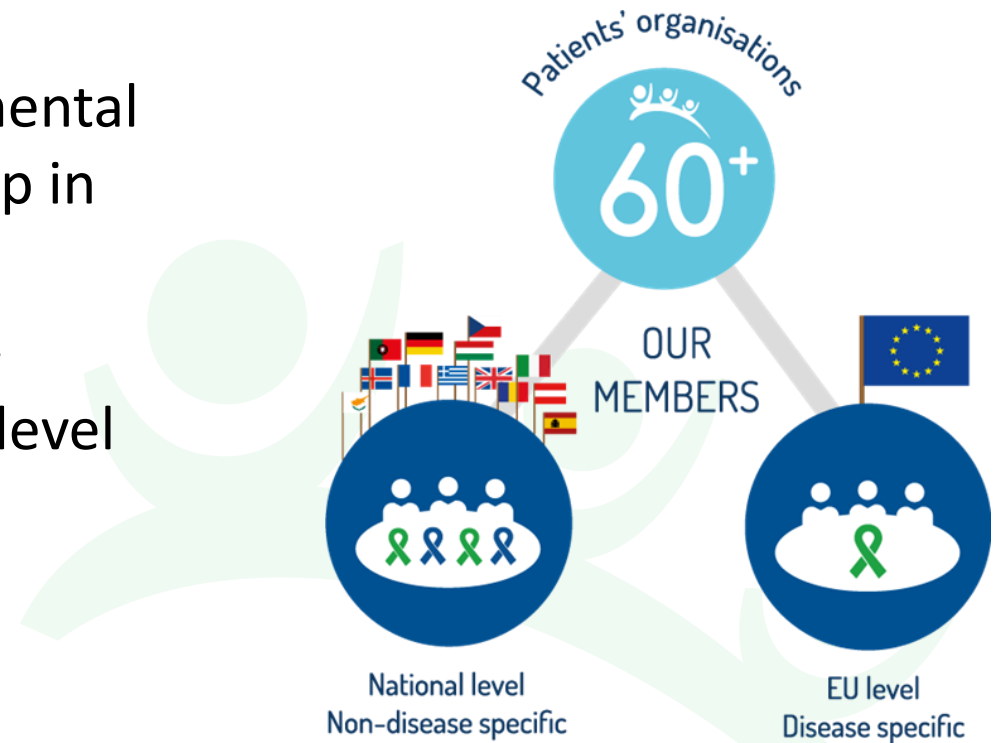
European Commission

16 March 2016, Brussels

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

What is EPF ?

- Independent, non-governmental umbrella organisation set up in 2003
- 65 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

Informal network of patient representatives

2 July 2015 – Conference in Brussels



2014



2015



Summary report (March 2015)

EPF position paper (Jan 2016)

EPF regional conferences & Workshops

2013: Brussels

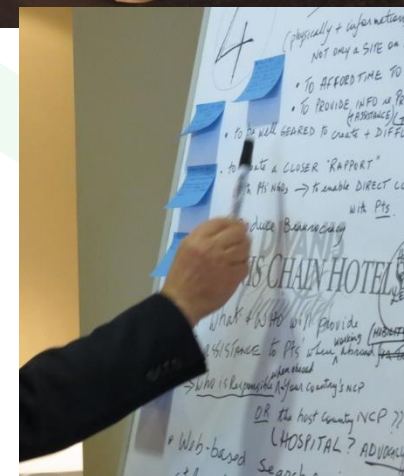
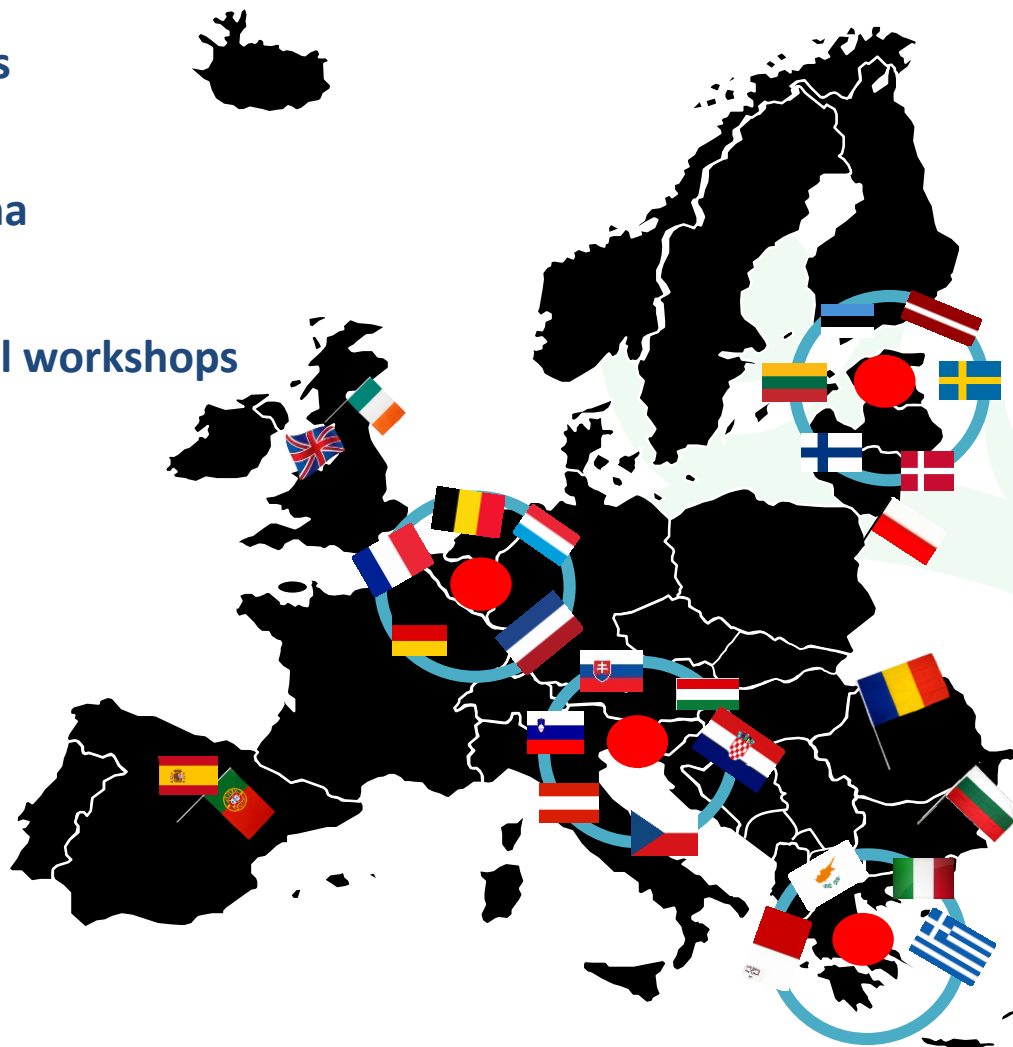
2014: Athens

Ljubljana

Tallinn

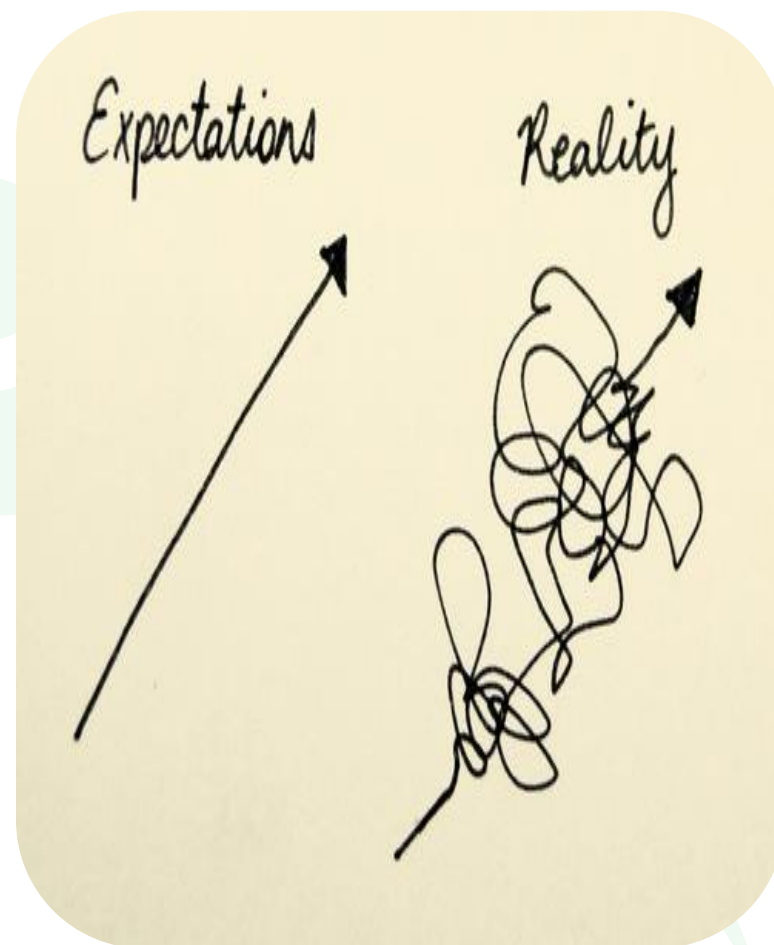
2015: national workshops

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



General feedback from EPF events

- Not yet a lot of practical experience among patient representatives
- Uneven implementation by MS – little involvement of patient organisations
- Potential benefits – patients' ability to exercise of their rights, transparency...
- Key concerns: equity, quality of information, safety & quality of care
- Many uncertainties



The “home” system is complex

- Patients often have to “fight the system” to get care
- Health/social system is difficult to navigate, even for the well informed and well educated... .. let alone those with low health literacy
- Patients face “a labyrinth of confusing, sometimes insufficient and sometimes too detailed information”
- NCPs play a critical role in enabling *meaningful decisions*

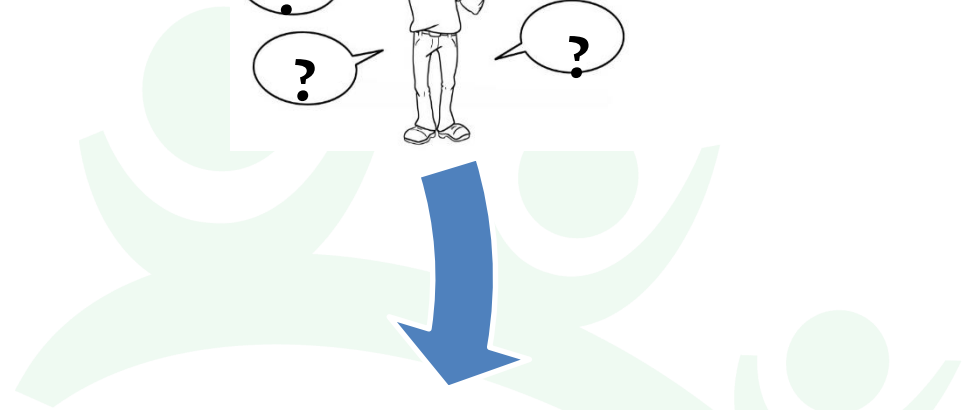


The patient journey

**When deciding:
enabling trust**



**Before leaving:
mitigating risks**



**During stay:
dealing with the
unexpected**



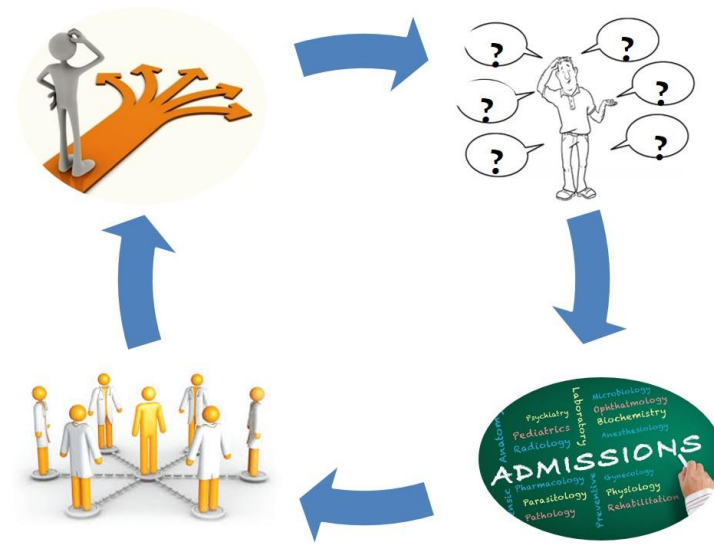
**After returning:
continuity and
improvement**



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



- Transparency: potential for patient & community empowerment
- Knowing your rights and how to make use of them
- But information needs are complex – provision patchy, not geared to patients' needs
- Still lack of clarity on basics, e.g. planned / unplanned treatment
- Patient organisations can play a powerful supporting role towards the patient community & the NCPs

“We have a lot of work to do in terms of basic information to patients about their rights ... very little is known about these at the moment, so we need to rectify this.”

– Patient representative

“The absence of the patient voice is mostly due to lack of information, not due to indifference of patients.”

- Patient representative

Provision of information to enable patients to *make an informed choice* and to *enable them to exercise their rights*

- Healthcare providers
- Standards and guidelines on quality and safety of treatment
- Accessibility of hospitals for persons with disabilities
- Patients' rights, complaints procedures and mechanisms, legal and administrative options for settling disputes
- Entitlements & conditions for reimbursement and the relevant procedures
- Clear distinction shall be made between the rights which patients have by virtue of the Directive and rights arising from Regulation (EC) No 883/2004

Article 6 (1): "Member States shall ensure that the national contact points consult with patient organisations, healthcare providers and healthcare insurers."

- Information (esp. on quality and safety) that is lay-friendly and easily comparable, up to date and accurate
- EU-level guidelines for NCPs on how to provide information to patients
- Standardised templates for all administrative forms
- Simple step-by-step guides on application processes
- “Designed for and by patients”
- User-test information & services – with patient organisations



- Impact assessment of the Directive on equity of access
- Data collection on treatment costs, availability of treatments that are not authorised or available in some MS
- Mechanism for providing financial for patients based on need
 - Implementation of direct cross-border payment systems
- Identification of practices and solutions found in different Member States → sharing, learning

- Patients' free, prompt and timely access to their own medical records
- eHealth and database interoperability – improve global patient records and continuity of care
- Basic financial support to patient organisations to enable them to play their role at national level – supporting both patient communities (less workload for NCP) and NCP (facilitating their work)

Recommendations (iv)

- Ensure consistent quality of NCPs across the EU
- Develop criteria for independent performance assessment
- Develop common operating principles & guidelines
- Possible indicators could be:
 - Timeliness of answers, availability of “fast-track”
 - Clear explanations of all decisions
 - Patient-friendliness
 - Continuous improvement system in place
 - Effective & transparent complaints and feedback process
 - Quality of engagement with patient organisations
 - Collection of key data for assessment of Directive




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.

- EPF believes there is great potential in NCPs to facilitate empowerment of patients and citizens
- This requires sustained collaboration between NCP and patient community – so far, too little patient involvement
- Specific challenges /roadblocks faced by Member States?
- The patient community is keen to get involved at national level both through EPF and directly



Let's work together !

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