Realities faced by patients when using the Directive

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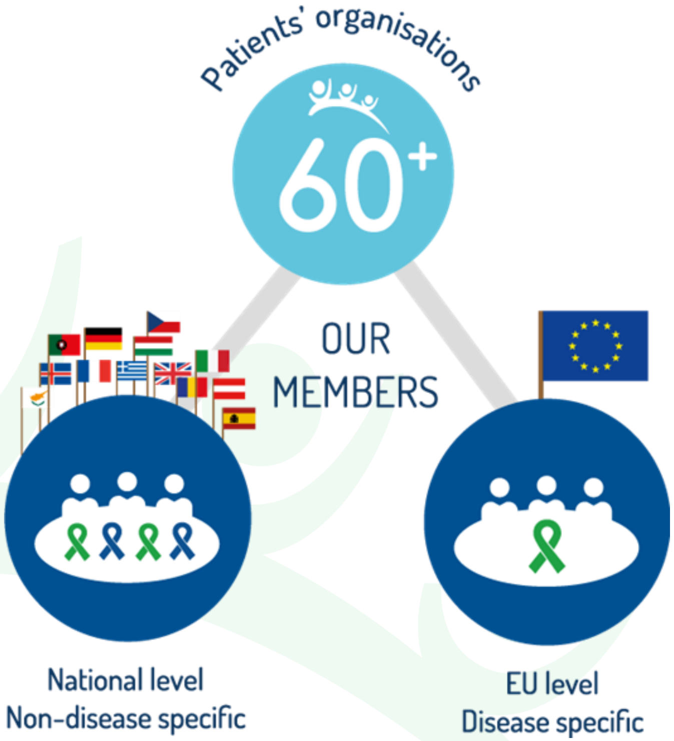
Overview

1. Background & intro
2. Patients’ key concerns
3. The “patient journey”
4. The role of the NCP
5. Challenges
6. Recommendations

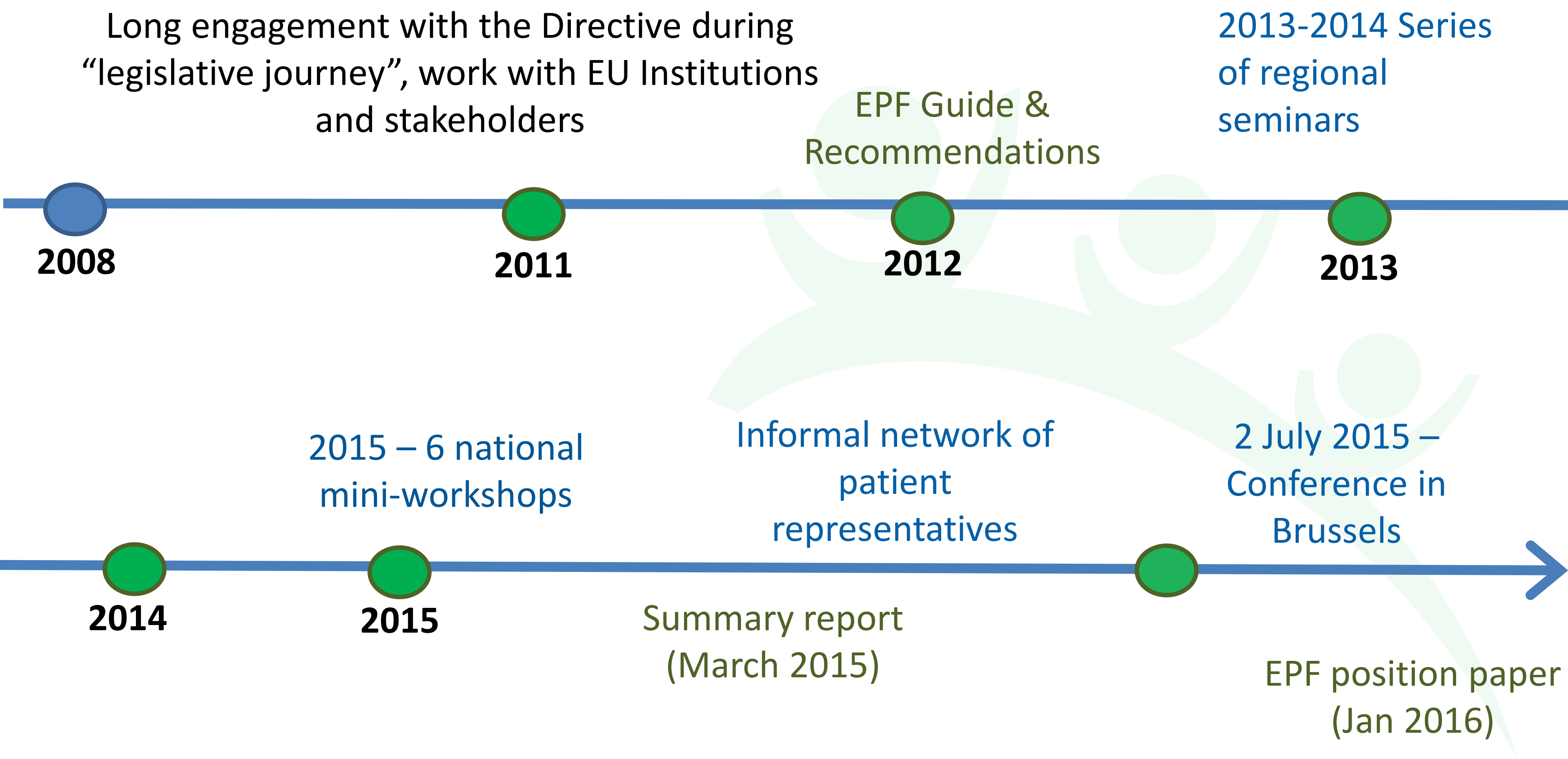
What is EPF ?

- 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

EPF Guide & Recommendations

2013-2014 Series of regional seminars

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

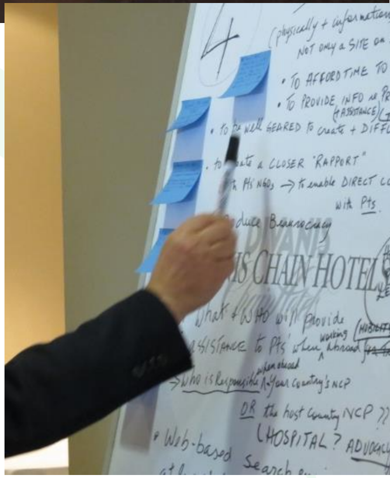
2014: Athens

Ljubljana

Tallinn

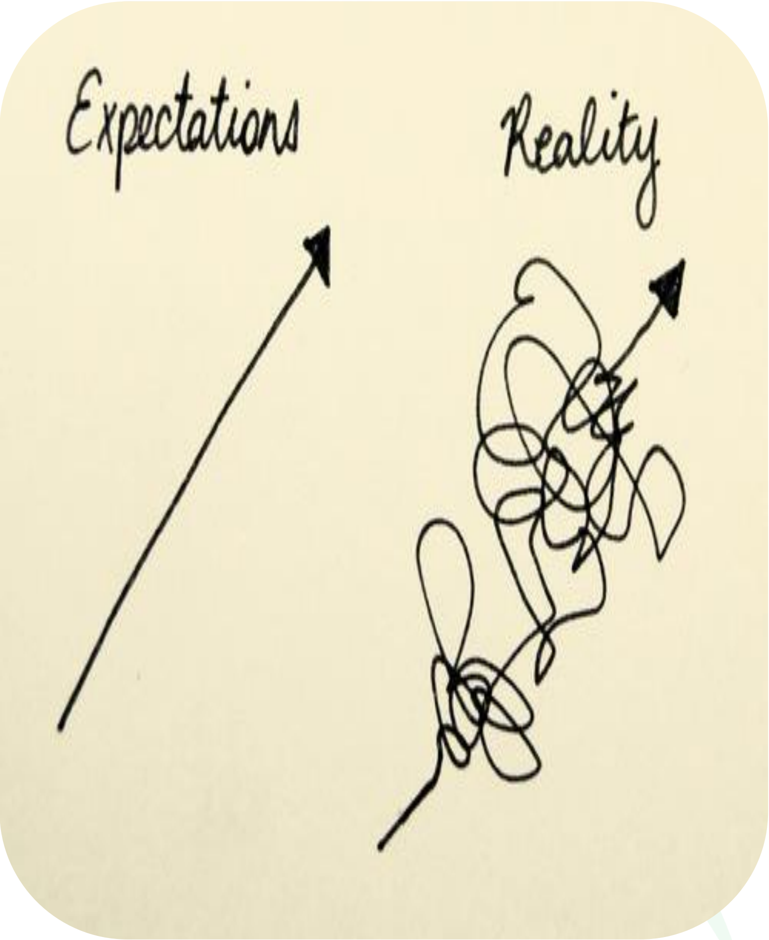
2015: national workshops

- 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

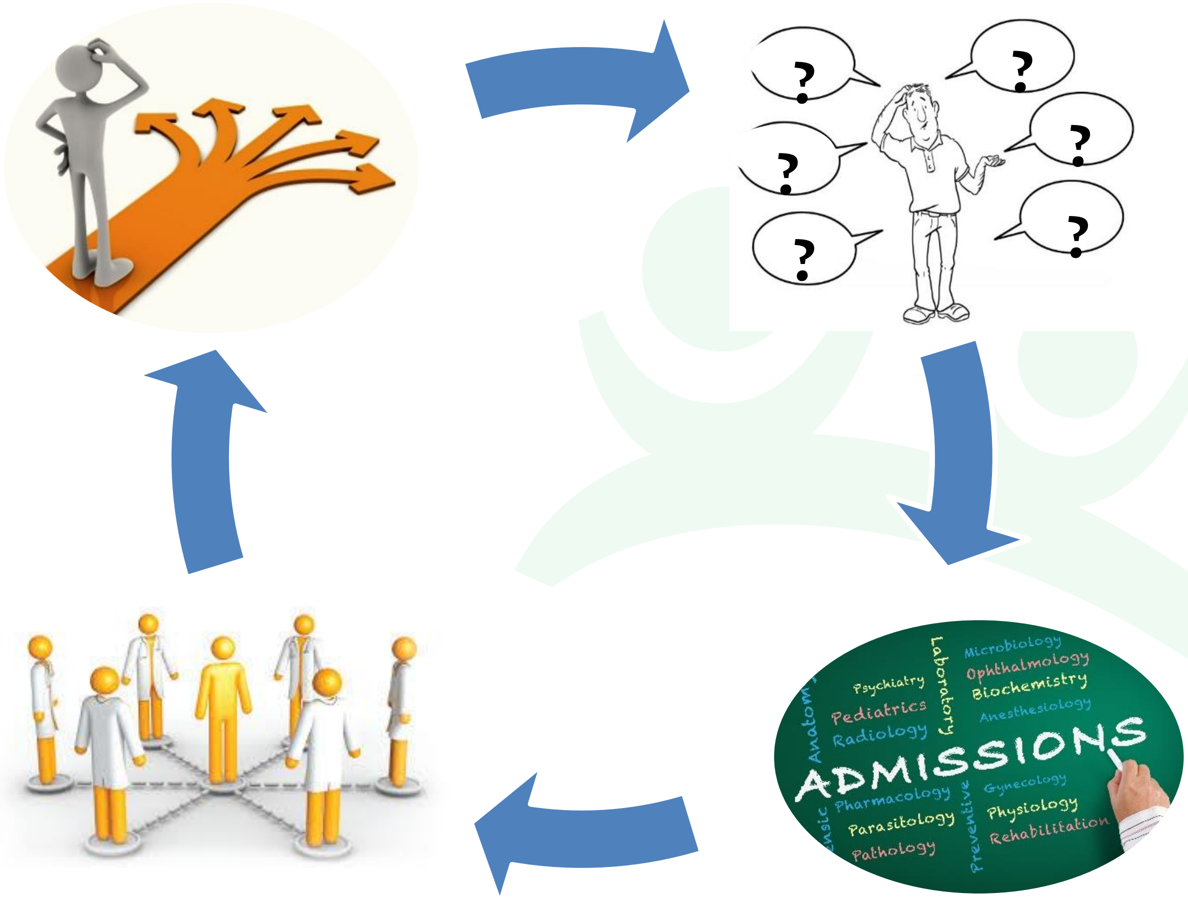


The “home” system is complex

- 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

The patient journey



When deciding:
enabling trust

Before leaving:
mitigating risks

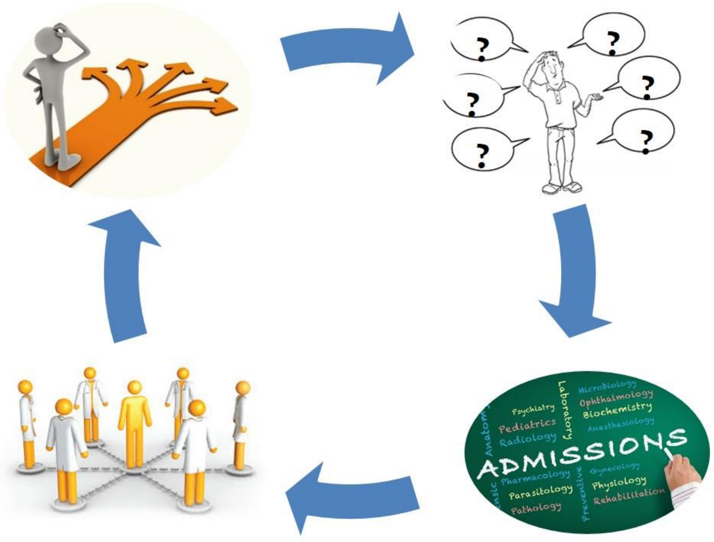
During stay:
dealing with the
unexpected

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, document formats

→ Patient organisations can help – both patients and the NCP

THE ROLE OF THE NCP

NCP responsibilities

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

- Information on healthcare providers, including, on request, on specific providers' right to provide services or any restrictions on its practice
- Information on standards and guidelines on quality and safety of treatment, including supervision and assessment of healthcare providers and which providers are subject to the standards and guidelines, information on the accessibility of hospitals for persons with disabilities
- Information on patients' rights, complaints procedures and mechanisms, legal and administrative options for settling disputes
- Information on patients' rights and entitlements, particularly the conditions for reimbursement and the procedures involved,
- A 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

The NCP should also:

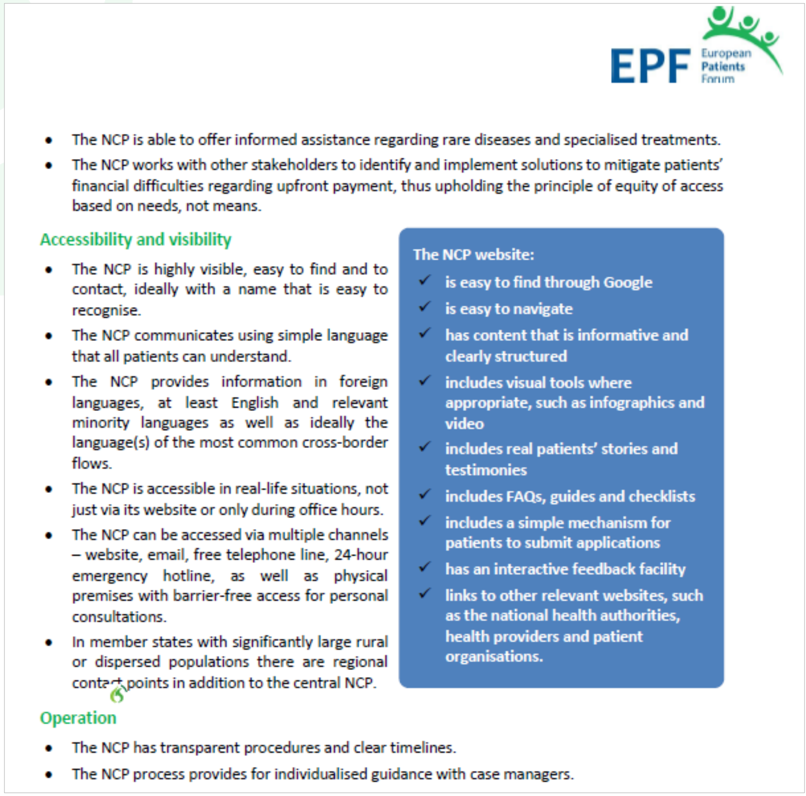
- Consult with patient organisations and other national health stakeholders
- Co-operate with the European Commission
- Exchange information with other National Contact Points

The “Ideal NCP Checklist”

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

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.

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.

Operation

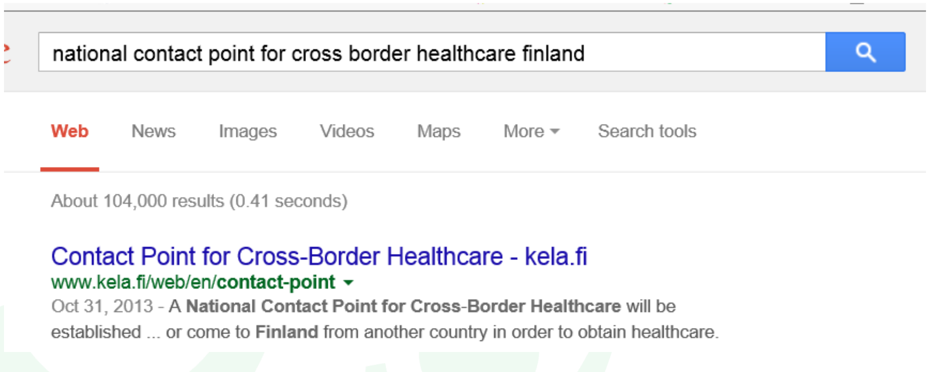
- The NCP has transparent procedures and clear timelines.
- The NCP process provides for individualised guidance with case managers.

Fundamental principles

- Independence – specific mandate and operational budget
- Protection of the patient's interests as priority
- Culture of helping and providing solutions
- Human response, respect for dignity, non-discriminatory
- Trained personnel
- Works with stakeholders to find solutions to ensure the principle of equity of access

Accessibility and visibility

- Highly visible, easy to find
- Accessible in real-life situations: email, free telephone, physical premises
- 24-hour emergency hotline
- Provides info in other languages
- Regional contact points



national contact point for cross border healthcare finland

About 104,000 results (0.41 seconds)

Contact Point for Cross-Border Healthcare - kela.fi
www.kela.fi/web/en/**contact-point**
Oct 31, 2013 - A **National Contact Point for Cross-Border Healthcare** will be established ... or come to **Finland** from another country in order to obtain healthcare.

EU-PATIENTEN.DE

EU-PATIENTEN.DE is a non-competitive platform for providing information to patients and healthcare providers to answer questions all about cross-border healthcare between Germany and other EU countries.

Treatment in Germany

You have health insurance in another Member State

Treatment in another EU country

What possibilities exist to receive treatment in

Information

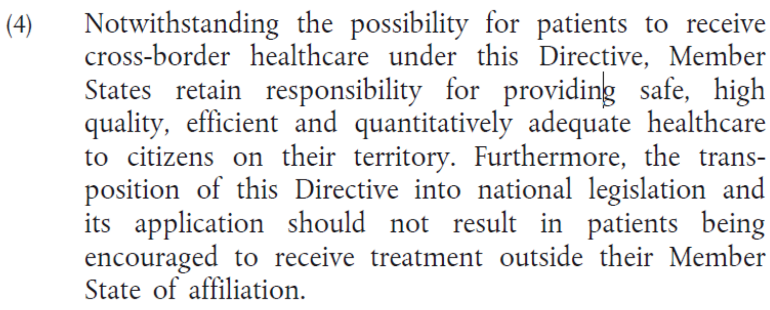
- Accurate, reliable, up-to-date
- Easily understandable
- “Designed for and by patients”
- Simple step-by-step guides on application processes
- FAQs online and in print
- Customised information packages
- Information on ongoing clinical trials
- Website is user-friendly, user-tested, includes a feedback facility

Operation

- Transparent procedures & timelines
- Case managers
- Can deal with legal representatives
- Facilitates translation
- Mediates contacts for the patient, e.g. by liaising with other NCPs re: access to specialist treatment
- Offers support and advice in case of complaints & problems
- Maintains a list of patient organisations
- “One-stop shop” as far as possible

Challenges …

- Requirement not to “encourage” patients to get treatment abroad conflicts with requirement to provide patient-centred information?



(4) Notwithstanding the possibility for patients to receive cross-border healthcare under this Directive, Member States retain responsibility for providing safe, high quality, efficient and quantitatively adequate healthcare to citizens on their territory. Furthermore, the transposition of this Directive into national legislation and its application should not result in patients being encouraged to receive treatment outside their Member State of affiliation.

- NCP only advises – does not have decision-making power (e.g. delays in obtaining approval from insurers…)
- Resourcing – of NCPs and of patient organisations
- Lack of functioning, regular co-operation between NCPs and POs

RECOMMENDATIONS

Recommendations (i)

- Information on quality and safety :
  - That is comparable – across institutions within countries and across countries
  - That lay persons can understand>
- EU-level guidelines on how to provide information to patients
- And guidance for patients on how to read quality/safety info
- Standardised templates for all forms
- User-test the information but also other services, website…
- Work with patient organisations

Recommendations (ii)

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

Recommendations (ii)

- NCPs should be independently assessed for performance
- Possible indicators:
  - Timeliness of answers (1-2 weeks, “fast-track” option)
  - Clear explanations of all decisions
  - Patient-friendliness
  - Continuous improvement system
  - Effective complaints and feedback process
  - Engagement with patient organisations
  - Collects data
  - Highlight any gaps and dysfunction to national and European authorities

Recommendations (iii)

- eHealth and database interoperability – improve global patient records and continuity of care
- Patients' free, prompt and timely access to their own medical records
- Patient Ombudsman at EU / MS levels
- 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)

Final words…

The NCP should be a "gateway" to health rather than a gatekeeper in healthcare

- The patient community is keen to support and get involved at national level
- EPF can link you up with our network of patient leaders in Member States

Let's work together !

THANK YOU FOR YOUR ATTENTION!

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