

# Key findings of EPF regional conferences on cross-border healthcare

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

# Introduction

Brussels – 12/2013

Athens – 04/2014

Ljubljana – 06/2014

Tallinn – 10/2014

National workshops 2015



- Not yet a lot of practical experience among patients
- Primarily patients with rare diseases or in unusual life situations
- Uneven implementation – and little involvement of patient organisations in the process
- Limited previous knowledge – general awareness probably lower
- Potentially benefits patients' exercise of their rights – including the right to receive treatment
- Caveats particularly re: equity of access and quality of information

- Can accelerate access – faster treatment, better treatment
- Financial barriers seen as major threat to equity
- Barriers in access also seen within countries
- Transparency will lead to greater awareness of gaps

“Patients in poorer countries will not be able to afford to access cross-border healthcare in richer countries”

– Patient, Greece

“We intend to examine our “basket of benefits” and compare it with other countries to identify what our patients need, and we will push the authorities to address any important gaps.”

– Patient, Latvia

- 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
- Patient organisations can play a powerful role

“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, Cyprus

“The national patient association can speak with one voice at the political level, but it is also important that every patient organisation interacts with the NCP.”

– Patient, Slovenia

- Patients need to be able to trust that treatment is safe and good quality
- Challenge re: complexity of guidelines
- Continuity of care is a patient safety issue
- Complaints & redress mechanisms need to be transparent
- ERNS have potential to improve quality

“The Directive has highlighted that our countries are not as similar as we would like to think: for example, we have been talking about quality and safety standards as if every Member State has them...”

– Patient, Estonia

“The project to create ERNs is the best possible answer to Euroscepticism.”

– Patient, Slovakia



# THE PATIENT JOURNEY

# When deciding: Enabling trust

- ? Knowing your available treatment options
- ? Safety & quality
- ? Professional qualifications
- ? Knowing the total cost
- ? Patients' rights in the country of treatment

- ✓ Information about all existing treatment options – home & abroad
- ✓ Information on waiting times
- ✓ All information having an impact on safety & quality
- ✓ Cost comparison of various options
- ✓ Comparative information on patients' rights





# Before leaving: Mitigating risks

- ? What information, documents etc. to take
- ? Transfer & translation of medical files
- ? Logistics: travel, accommodation, accompanying persons
- ? Whom to turn to for help
- ? Who will be responsible in case of complications
- ✓ Step-by-step timeline - what happens and when
- ✓ Accurate itemised costs, payment schedule
- ✓ Standardised templates for info
- ✓ Clarity re: follow-up care
- ✓ Check-lists & “travel guides” for patients



# During the stay: Dealing with the unexpected

- ? Do all have a common understanding of treatment, informed consent, special needs, etc.
- ? Unforeseen events
- ? Language/cultural issues
- ? Discrimination by healthcare staff
- ? Ongoing support?
- ✓ All steps documented by HCP
- ✓ Providers should connect with each other
- ✓ Interoperable EHR
- ✓ Identified contact/support person
- ✓ Planning for unforeseen complications
- ✓ Emergency hotline to NCP
- ✓ Harmonised invoices etc.



# After returning: Continuity of care, continuous improvement

- ? Reimbursement – delays, administrative problems
- ? Continuity of care – obtaining prescribed medicines, rehabilitation etc.
- ? Managing side effects or complications
- ? Medical disagreements, diverging guidelines
- ? Continuity of information
- ? Being able to give feedback
- ✓ HCP should give a “package” of documents to patient
- ✓ Quick, simple, clear reimbursement process
- ✓ Easy complaints process with support
- ✓ Evaluation forms to record patient experience + qualitative
- ✓ Patient organisations can publish ‘patient stories’



# RECOMMENDATIONS



- Comparable information on quality and safety :
  - across institutions (within countries) and
  - across EU member states
- encourage convergence of standards & guidelines
- benchmarks and key indicators for quality of care
- Including “patient-centredness” in quality → identification and sharing of good practices & transferability
- Mechanism for addressing patients’ complaints at European level?

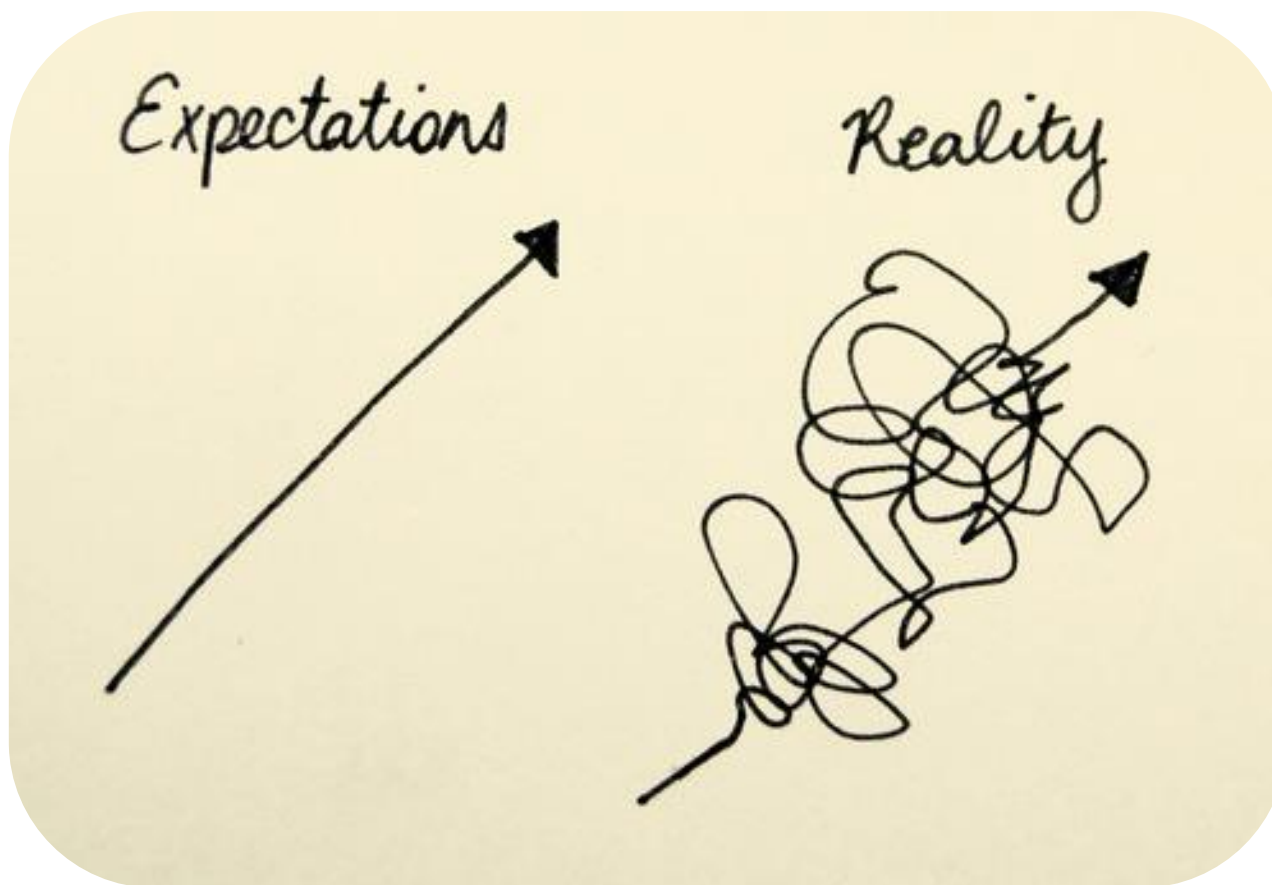
- EU-level guidelines on how to provide information to patients
- Guidelines for patients on how to interpret quality information
- Information ideally at a “one-stop” portal at EU level
- Standardised templates across EU for all forms
- Support for patient organisations as providers of information to patient community – ‘supporting contact points’

- Evidence collection at EU level on inequalities in access to healthcare
- Identification of practices and solutions found in different Member States → sharing, learning
- Data collection on treatment costs
- Data collection on treatments that are not authorised/available in MS
- Mechanism for providing financial for patients based on need
  - Implementation of “prior notification”
  - Use of direct cross-border payment systems
  - “Social funds” approach, linking with social security system?

- eHealth and database interoperability – a priority to improve global patient records and continuity of care
- Patients' free, timely access to their own medical records
- A patient Ombudsman could be set up at European level and in MS
- Basic financial support to patient organisations providing services at national level



# In conclusion



# Thanks to all the people who participated!



## Group 2. Patient oriented

NCP should be powered by patients and special  
trained personnel in patient advocacy  
~~to~~ easily accessible  
providing <sup>multilingual</sup> information Policy Patients Healthcare prof.  
cultural should be taken in consideration  
in NCP

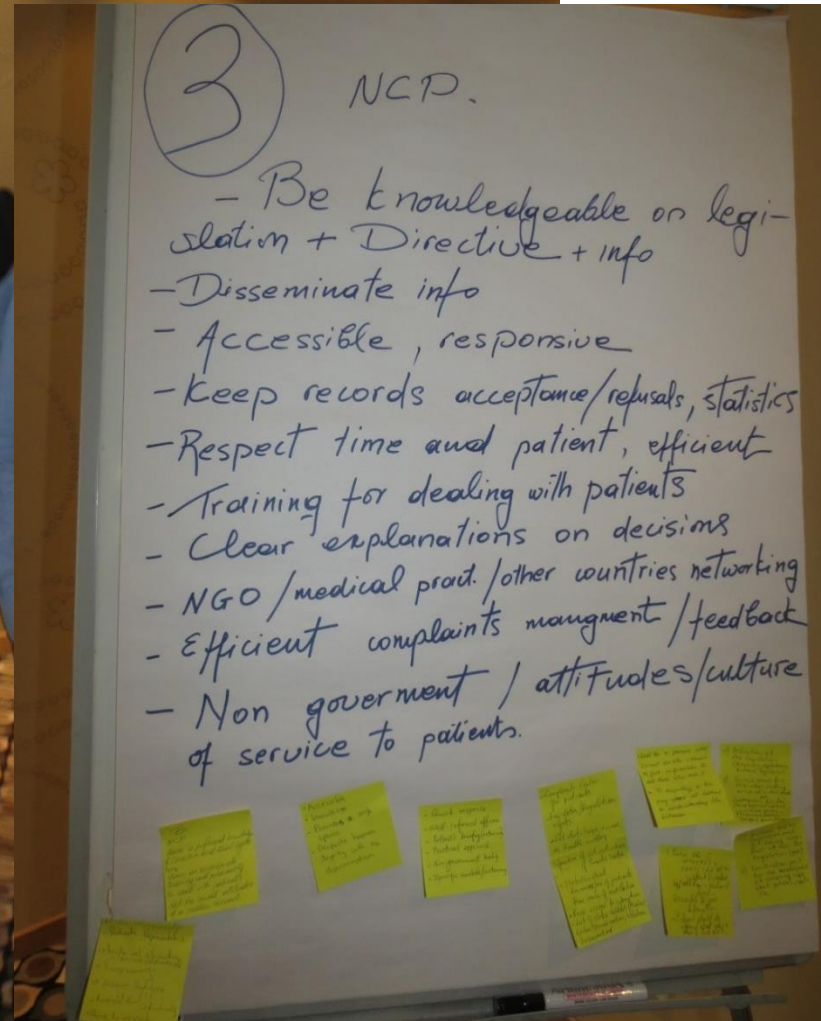
Timely - Quick response

### COMMUNICATIONS TOOLS

- ↳ Website ??
- ↳ Radio / TV (mass media)
- ↳ Hotline / brochures
- ↳ Social Media

Interoperability and information exchange  
among NCPs across EU  
(with data protection)

identity common core packages  
(PROVIDE INFORMATION)



- ## 3 NCP.
- Be knowledgeable on legislation + Directive + info
  - Disseminate info
  - Accessible, responsive
  - Keep records acceptance/refusals, statistics
  - Respect time and patient, efficient
  - Training for dealing with patients
  - Clear explanations on decisions
  - NGO / medical prod. / other countries networking
  - Efficient complaints management / feedback
  - Non government / attitudes/culture of service to patients.

# THANK YOU FOR YOUR ATTENTION!

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**More information**

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