





# THE FIRST DIRECTIVE FOCUSING ON 'PATIENTS' RIGHTS' – WHAT DOES THIS REALLY MEAN FOR PATIENTS?

"Start by doing what's necessary then do what's possible and suddenly you are doing the impossible"

Saint Francis of Assisi

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## The 3 aims of the Directive

- 1. Help patients to exercise their rights to reimbursement for healthcare received in another EU country
- 2.Provide assurance about safety and quality of cross-border healthcare
- 3. Establish formal cooperation between health systems



## Helping patients

Information to patients
 Patients will have to access to all relevant information via National Contact Points



- Rules of reimbursement
  - Clarification of rules patients will know: a, need for prior authorisation; b, reasons for refusal; c, level of reimbursement, and d, need for up-front payment
- Procedural guarantees

Patients will benefit from:
a, clarification of responsibilities; b, clear rules if something goes wrong; c, right to review of administrative decisions; d, right to judicial proceedings

## Rare disease patients



- Easier access to information
  - The National Contact Points will make patients, health professionals and payers of healthcare aware of the possibilities for referral to other MS-s
- Dissemination of expertise
   By means of e-Health tools, databases (Orphanet, etc.) and networking of Centres of Expertise
- Fostering appropriate clinical assessment Decisions about prior authorisation (for diagnosis especially) should be based on appropriate clinical evaluation by experts in that field

## Quality and safety

Transparency and accountability Information on healthcare providers and on standards applied

Member States responsibility
 Refusal of prior authorisation if
 doubts over quality and safety of
 healthcare provider

Cooperation of Member States
 On standards and guidelines on quality and safety



## Cooperation between health systems

- Recognition of prescriptions
   A prescription issued in another country will be more effectively recognised
- European Reference Networks
   They will bring together specialised centres across Europe helping health experts to disseminate information and expertise
- Health Technology Assessment
   A permanent EU structure of cooperation to help decision-makers to make the right decisions on health investment and spending
- E-Health

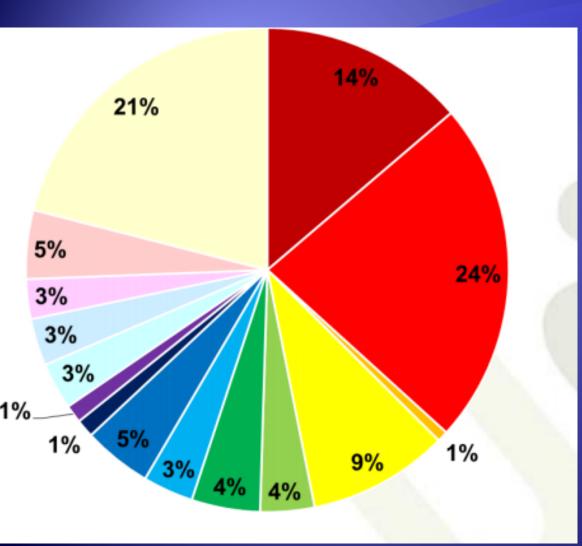
A first step towards "interoperability" of ICT for health at EU level for safety and quality of care, continuity of care, and health research

## We have both the Regulation and the Directive!

- Prior authorisation not needed if treatment is on the « list »
- When on the list, reimbursement on the basis of their cost in country of affiliation

It is possible that patients would find it better to apply for cross border health care under the Regulation than under the new Directive!

### Questions to NCP



14% rights by the Directive 24% rights by the Regulation

1% other NCPs

9% cross-border healthcare services

4% pre-authorization

4% reimbursement procedures

3% HC providers

5% HC services

1% quality and safety

1% prices

3% equity

3% healthcare collaboration

3% complaints

5% general operational questions

21% local and EU healthcare information

# Statistical DATA Hungarians to Abroad

Period: 25.10.2013 - 31.03.2015

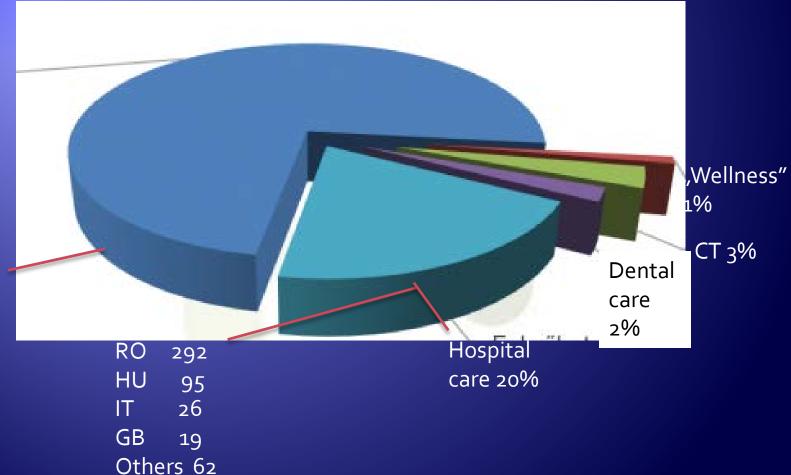
Requests arrived	665
Pre-authorisation needed	662
Without pre-authorisation	3
Authorized	491
Refused	67
Simply not-authorized	62
Process cancelled	45

## Statistical data 2014 from abroad to Hungary

Total: 2519 persons



RO 843 SI 217 HU 183 GB 180 Others 437



Source: OBDK

## Survey of Hungarian Patient Organizations

Have you ever heard about CBHC Directive?	60%
Do you know any patient who tried it	2%
Is there any demand for CHBC in your patient group?	80%
Would you participate in a network to monitor the implementation of the Directive?	100%









- Bureaucratic and too long decision making!
- Patient needs to prepay, than a reimbursement is possible.
- Lack of reaching out to society

### **Facts**

#### The patients are NOT going abroad because:

- The ,bigger' treatments are subject of prior authorisation
- The ,smaller' treatments and/or medicaments and/or medical devices will not be reimbursed (below the limit)
- Extremely high costs of the ,official translation' even higher than the reimbursed amount
- The reimbursed amount is below the real costs which was invoiced and pre-paid to the healthcare provider because of the local "list-prices" of the NHS

#### The healthcare providers are NOT interested in CBHC because:

- They can not invoice the real costs of the interventions unless the patients' budget would allow it – because they have a ,price-list' of NHS and these prices are not reflecting the real costs
- Some countries' patients could not be authorised to treated abroad



# What is the impact for the EU?

- For every patient treated earlier, a gain in EU-wide healthcare efficiency, AND of EU-wide well-being
- Patient-mobility remains limited (currently 1%); but impact for individual patients is high



- No significant impact on national budgets.
- Quality and safety of cross-border care improves
- More clarity for all about rules for reimbursement of care
- Patients have better access to the care they need

## What patient organizations can do?

- Get informed about the content and the implications of the Directive
- Can raise awareness and help patients find the right information
- Propose concrete measures of interest to patients
- Insist on NCP involves the patient organizations as regular partners
- Create guidelines for information to patients
- Feed back experiences to decision makers
- Participate in the ACN supposed EPC-Net ©



### Respond to questions

- 1. Based on your experience, what are the main challenges or concerns in your country for patients willing to travel abroad for care? Have you got any data or significant case history you would like to share?
- The health status of the citizens one of the worst in the
   EU
- The healthcare professionals (HCPs) are underpaid
- The HCPs leave the country + e.g. the family doctors' are
   +60

### Respond to questions

2. What should be done at EU level because the transposition process would not only be a "problem" of single Member States but a coordinated action supervised by the EU institutions?

- elaborate/harmonising quality and safety rules and indicators
- role of NCPs: instead of "gatekeeper" "infocenter" +patient support
- clear distinction between healthcare services under the directive and regulation and border-regions co-operation

### Respond to questions

3. What can we DO and PROPOSE as a group of different stakeholders for a more effective implementation?

- Involve patient organisations (PO) to harmonising the quality and safety rules
- Involve POs to dissemination of CBHC directive
- Continuous training for PO leaders/team leaders update their knowledge and info materials about CBHC

## Thank you for your attention!

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