

# Exploring the role of patient organisations in securing effective implementation of the Directive



EPF Regional Conference on the Cross-border Healthcare Directive  
Athens, 9<sup>th</sup> April 2014

Speakers: Ann Marie Borg & Gertrude Abela

# Outline

A

- **The Directive → a success story?**
- Experiences of *Malta Health Network & Europa Donna Malta* to date
- Opportunities & challenges

B

- **The role of patient groups in the implementation of the Directive**
- Discerning “new” patient rights to patients

C

- **The way forward**
- Conclusions

3.30pm BST Update

## NHS patients to get free healthcare throughout EU

David Batty and agencies  
guardian.co.uk, Wednesday 2 July 2008 12.31 BST

17 February 2008

**NEWS** OF THE  
**WORLD**

"EU TO CRIPPLE NHS – Secret plot will let rich jump queues"

### Cross-Border Healthcare Directive Proceed with Caution

European**Voice**.com

On the road to health harmonisation

By Dave Keating - 11.04.2013 / 04:20 CET

New rules on cross-border healthcare could transform the way EU citizens are treated

**MEDICALTOURISM**  
magazine



Thursday, January 20, 2011 by Ivan Camilleri, Brussels

## EU-wide health-care becomes a reality

‘A breakthrough for all patients’

**TIMESOF  
MALTA.COM**



Patients who have been waiting for years for an operation will be able to seek treatment anywhere in the EU from 2013 and be reimbursed for the fees involved. Photo: Darrin Zammit Lupi

## A. The Directive → a success story?

- A Directive sets the goals to be achieved but Member States have the discretion to choose the means. This may give rise to transposition and implementation difficulties...

EuropeanVoice

Member states fall behind on cross-border healthcare rules

By Dave Keating - 24.10.2013 / 05:56 CET

Only a few member states have set up the required transparency websites and control centres that the law requires to be in force by tomorrow.



# Malta Health Network experiences

- *MHN* experiences/involvement in the pre-/during implementation phase of the Directive:
- MHN organised a seminar on patient' rights and involvement in cross-border healthcare (June 2013)
- MHN attended a briefing on the state of affairs of the Directive's implementation with Active Citizenship Network and DG SANCO – presentation of the “Manifesto for the implementation of the Right of European Patients to make an informed choice” (October 2013)

# EC information brochures on patients' rights in cross-border healthcare

## Know before you go

### Check your treatment plans with your health professional:

- ✓ It is highly recommended that you discuss your planned treatment with your doctor before committing to anything.

### Plan your trip thoroughly:

- ✓ Research your treatment options.
- ✓ Make sure you have a copy of your medical records, information on any medicines you are taking, and any relevant test results.
- ✓ Check whether you will need a referral from a general practitioner to access (or be reimbursed for) specialist care.
- ✓ Check the details of your healthcare provider.

### Check the financial implications with your National Contact Point or insurer:

- ✓ Make sure you know how much your treatment will cost and whether your authorities will pay the costs directly, or will reimburse you some or all of the costs.
- ✓ Check any requirements for pre-treatment authorisation.
- ✓ Remember that some costs (travel, ac-

### Make sure you get the medical follow-up you need:

- ✓ Arrange to get a copy of your record from your healthcare provider.
- ✓ If you get a prescription make sure it is suitable for cross-border use (EU law prescribes certain minimum content to make sure that prescriptions can be recognised in every country).
- ✓ Arrange appropriate medical follow-up with your home system (in advance if necessary).

You can find more information on this subject and also on emergency or unplanned healthcare at [www.europa.eu/youreurope](http://www.europa.eu/youreurope).



European  
Commission

## Seeking healthcare in another EU Member State: your rights

### Did you know?

You have the right to receive medical treatment in another EU Member State and the right to have your home country cover some or all of the costs.

You have the right to be informed about the treatment options open to you, how other EU countries ensure quality and safety in healthcare, and whether a

# European Year of Citizens 2013/ citizen dialogue on the Directive



Malta EU Steering & Action Committee

## 'HEALTHY CITIZENS FOR A HEALTHY EU'

The fifth and last in a series of public debates organised by MEUSAC during the European Year of Citizens took place on October 3 at the Piazza Jean De Valette in Valletta. The debate, themed 'Ċittadini f'saħħithom, Ewropa b'saħħitha', focused on the implementation of Directive 2011/24/EU on the application of patients' rights in cross border healthcare, commonly known as the 'Cross Border Healthcare Directive'. The provisions of the Directive have to be transposed into national law by the Member States by October 25 this year.

The Directive aims to remove the obstacles that European citizens could face when trying to seek care in a Member State other than their home country, by creating clear and harmonised rules about reimbursement for healthcare provided in other Member States and to ensure the necessary requirements for high-quality, safe and efficient healthcare for cross-border care, by giving responsibility for the quality of healthcare to the Member States.

Senior government officials from the Ministry for Health explained to the participants the implications of the Directive and how it will be implemented in Malta, that is, how Maltese citizens will benefit from the opportunities given to them by the Directive, such as:

- Providing clear rules and reliable information to patients regarding access and reimbursement for healthcare received in another EU country.
- Meeting patients' expectations of the highest quality healthcare, which are even higher when they seek treatment away from home. The information given by national contact points on healthcare quality and patient safety will help them make informed choices before going abroad for healthcare.
- Ensuring EU countries work closer together in the interest of patients.
- Clearing up years of legal uncertainty. The new rules also strike the right balance between maintaining the sustainability of health systems while protecting patients' right to seek treatment outside their home country.

The panel members pointed out that thanks to this Directive, Member States shall be obliged to offer all the information that a patient requires on the quality of services, on the hospitals, on the reimbursement system applicable, the buying of prescription medicine in another EU Member State and other information which is extremely relevant to the patient. This will not only put their minds at rest but will help the patients concerned to make the best possible choice regarding their health. All this will be done through the establishment of a National Contact Point that shall be known and accessible to patients and which will be in close collaboration with similar centres in other Member States.

*The Directive on patients' rights in cross-border healthcare represents a landmark in EU health policy as the first major piece of EU legislation on health services. The Directive demands greater transparency - for example on quality and safety standards - from health systems and providers across the EU.*

Jens Beier, European Commissioner for Health,  
European Patients' Forum Conference, Dublin  
May 21, 2011



# Willingness of Maltese citizens to seek healthcare abroad

## **Eurobarometer report on European Union citizenship (2012)**

- Nearly 50% of Maltese citizens who would like more information about their rights as EU citizens say that they would like to know more about receiving medical assistance in another EU MS

*Is this an indication of the way forward with patients using the Directive to exercise their rights as EU citizens? BUT HOW?*



## A window of opportunity or not?

- Malta has a well-established & long-standing cross-border healthcare setup for specialised & oncology care (bi-lateral agreements with the UK).
- What does the Directive add?



# “New” patient right to information From paper → practice?

1.4.2011

EN

Official Journal of the European Union

L 88/45



## DIRECTIVES

DIRECTIVE 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL  
of 9 March 2011  
on the application of patients' rights in cross-border healthcare



- **Article 6** : “Patients are entitled to access all information relevant for making informed decisions on their health and cross-border healthcare options ”
- MALTA’s NCP webpage – user friendly?
- Patient organisations not consulted/involved much in the process

## Europa Donna Malta experiences

- Breast cancer is the most prevalent cancer type in Malta (approx. 300 cases a year).
- **Scenario 1:** Breast reconstruction may take years due to long waiting lists in comparison with the infrastructure available.
- Can this be regarded as “undue delay” under the Directive? The waiting time does not pose a health hazard but has psychological implications!



## Europa Donna Malta experiences

- **Scenario 2:** If there is a better quality & less invasive breast cancer treatment abroad (with a similar intervention covered by Malta's HC basket), will the patient be reimbursed if she gets treated abroad?
- Lack of clarify of information (from Ministry level → patient organisations)
- Hence, difficulties for patient groups to transfer information to end receivers (patient communities)

## Opportunities

- Patient entitlement to clear and comprehensive information
- Mechanisms to ensure remedies & compensation in case of harm
- Patient access to medical records
- Support for patients with rare diseases
- Provides patients with more choice
- Faster treatment access for patients experiencing long waiting times
- Increased transparency of providers & pricing of medical procedures
- MS urged to upgrade & improve national performance → better patient quality of care

## Challenges

- Difficulties for patients to deduce whether treatment is covered in national health basket and reimbursable
- Difficulties in determining pricing of procedures (total cost of procedure from provider abroad & level up to which it is reimbursed nationally)
- Affluent patients benefit the most as they search for the best treatment with latest technologies → amplify existing health inequalities
- Determining “undue delay”
- Continuity of patient care
- Paying for treatment costs upfront

## B. The role of patient groups in the implementation of the Directive



EFCCA



# 1. Capacity building

- **MHN Action Plan:** Each MHN member org. appoints 1 representative as the “Contact Point” for CBHC who will represent that organisation in a MHN sub-committee on CBHC
- 1 representative from MHN will then represent Malta in an (EPF) CBHC informal network composed of patient leaders from all EU MS and wider European health NGOs
- The informal network will facilitate good practice exchanges (lessons learnt), monitor /evaluate implementation & report to the Commission(?)



## 2. Collaboration with national health authorities(NCP)



- Work closely with the local NCP & national health authorities (be active)
- Collaborate with health authorities to ensure that information given to patients is consistent, conveying the right message, readily available & widely disseminated
- Encourage authorities to be more politically committed to patients' rights in CBHC

### 3. EU projects/funding



- This 3rd Health programme gives considerable weight to health systems & can provide funding for initiatives on eHealth cooperation, patient safety and European Reference Networks + grants for evaluation studies on patients' rights & the Directive's implementation

Discerning “new” patients rights to patients –  
the path to patient empowerment?



## C. The way forward

- ✓ Believe that you can make a difference → bring out the positive aspects and benefits of the Directive for patients
- ✓ Recognise barriers hindering the effective implementation of the Directive and find solutions to overcome them





The background of the slide features a light blue gradient. Overlaid on this are several dark silhouettes of hands reaching in from different directions to assemble a cluster of interlocking gears in the center. The gears are of various sizes and are meshed together, symbolizing teamwork and the complex nature of implementation.

# **The success of the Patients' Rights Directive**

**...is tied to  
its correct &  
timely  
implementation**