Raising standards for consumers

COMMENTS

ANEC Contribution to the EC Consultation on the evaluation of Directive 2011/24/EU on patients' rights in cross-border healthcare

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ANEC is supported financially by the European Union & EFTA

Ref: ANEC-PT-2021-HGS-003 02/07/2021

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INTRODUCTION

In addition to the replies provided to the EC questionnaire on the Evaluation of patient rights in cross-border healthcare, we gather in this paper further details from ANEC technical study on cross border healthcare and national experiences with regional cooperation.

In ANEC technical report on cross border healthcare of 2018 we gave an insight into consumer attitudes and experiences of planned and unplanned cross-border healthcare, based on the findings of an ANEC survey of 1,656 EU consumers.

The ability to choose from a wider range of service providers, in other Member States, offers clear potential benefits for patients.

Our study shows however that the number of people receiving medical treatment abroad is low: only 4% had travelled abroad specifically to receive planned medical treatment.

ANEC study suggests that a key barrier to seeking planned treatment abroad is a lack of awareness about rights. The evaluation and future revision of the Directive offer the opportunity to address this weakness and allow for the Directive to work more effectively for consumers.

1 | Patients Rights in Cross border Healthcare

On barriers to healthcare abroad and access to information

Patients have very little information on the outcomes of alternative cross-border treatments. There is concern regarding barriers to cross-border care, but in practice patients will go through or by-pass the barriers without realising. For example, avoid an option because it is more expensive and go for a cheaper option that is less effective or even ineffective.

Recommendations we have gathered from our study:

- EC/institutions need clear strategy to raise awareness of cross-border healthcare options and consumer rights, and to promote the existence of NCPs – with clear guidelines about role and responsibilities.

- Improve interoperability and communication between NCPs, with a central coordinating body.

- Develop a clear code of practice for NCPs with standard operational requirements to ensure consistency of procedures and data collection.

- Explore options for an independent central source of information about healthcare providers in the EU, that allows patients to compare options.

- Consider an EU-wide independent certification scheme for healthcare providers that meet good practice – in terms of information and quality of care.

- Promote the use of ISO Guide 14 on the provision of information.

- EC to investigate with CEN the suitability of a new standard on 'provision of information' –for use by healthcare providers to increase awareness on opportunities and rights in the area of planned cross border healthcare

- Encourage any moves to improve translation/interpreter services for consumer using essential services across borders such as healthcare.

- Consumer and patients' organisations are to also play a role in raising awareness on all issues relating to cross border healthcare.

- Medical insurance should cover treatment that offers the patient the best care that meets their needs, regardless of which EU state it is in and if it is public or private.

Another area given insufficient attention is patients' lack of information on different standards and procedures in different locations. Patients tend to hold false expectations that cross- border healthcare will follow their own state's values.

An additional aspect that could be further investigated is whether citizens believe the reasons for seeking healthcare abroad – as listed in Q7 of the questionnaire - are

considered valid. Also, it could be useful for the Evaluation to gather information on whether citizens expect the same quality of care in another EU state as they get in their own, and/or if they are prepared to travel to another state for healthcare, if they would accept the inconvenience of travel for perceived (1) faster (2) better (3) other benefits.

2 | Rare diseases and International cooperation

We refrain from giving detailed comments on the European Reference Networks (ERNs), as our work does not touch on these tools developed in the directive, despite we acknowledge their importance.

We would still like to share some general comments on international cooperation, as many EU residents seek healthcare also outside of the EU when affected by rare diseases. There are existing knowledge sharing networks well established among medical professionals, and these extend to states across the world outside the EU. Such networks are supported by professional bodies, learned journals, Internet, formal and informal notification and sharing contacts.

Diagnosis is the central engine of good healthcare and EU residents are entitled to expect that knowledge and treatment of rare conditions will be based on world standards.

Further to the ERNs created by the *Directive on patients' rights in cross border healthcare* it is also important that this cooperation is complemented by the participation of the European Union in worldwide cooperation.

3 | Healthcare cooperation between regions

Some examples

On regional cooperation, we give some indicative examples of cross-border projects that could be looked at for good practice.

For example, in 2002, a deal was made between France and Belgium about cross-border care, which was applied on March 2011.

This deal concerned:

- Emergency medical help and interventions
- Disabled people

And since 2014, with the cross-border directive, there are 7 cross-border territories along the Belgian-French border.

Those territories are called ZOAST (for « Zones Organisées d'Accès aux Soins Transfrontaliers », Organised Access Zones for Cross-border Care). They form a collaboration between France and Belgium, where patients living near the border have access to healthcare on both sides of the border (→ Q7).

The ZOAST zones were made under the European Territorial Cooperation, which is now named Interreg. But the Cross-border healthcare Directive made the cooperation easier with a new legal frame (→ for Q4).

There is a treatment equality for those patients (→ Q5). The cost is based on where the care is given, and the reimbursement is given by the patient's social system affiliation. Informatic procedure are also being generalized through the zones.

In 2018, there were 15 653 patients from France in Belgium, and 938 patients from Belgium in France within these zones (for every hospitalization: external care, ambulatory, daycare and classic hospitalizations).

There was no drift observed since the ZOAST launch. People always have the reflex to go to their own health system before going abroad even if the cross border hospital will be closer to their home.

Other examples of cross-border projects we identified (non-exhaustive list):

- TRISAN: A tool to structure and coordinate cross-border health across the Upper Rhine (France, Germany, Switzerland)
- INTERSYC: Healthcare and protection for children between Greece and Bulgaria
- Cooperation And Working Together for health gain and social wellbeing in border areas (CAWT) (Ireland, United Kingdom[1])
- TELEMEDECINE EUROREGION POMERANIA Sharing of data (Germany, Poland)
- IZOM project: tailored healthcare within the Meuse-Rhine Euregio (Belgium, Germany, Nederland)

There seems to be a lot of expertise on cross border facilities in those projects on which to further build the enforcement of the directive.

The Court of Justice of the European Union also ruled many questions on the subject, without the harmonization of social systems, so we also recommend taking caselaw into account if there is a will to harmonize the cross-border procedures.

[1] May have changed since Brexit.

4 | Impact of COVID-19 on cross border healthcare

We do not have data on the impact of COVID-19 on cross border healthcare. Still, in general we feel that pandemics impact more on cross-border mobility than cross-border treatments. Moreover, the main problem was the will of each country to accept people from other countries, with the fear of saturation and not being able to take care of their own citizens. Even within the same countries' hospitals refused to take care of patients from other regions by fear of saturation. Lessons learnt could help improve Member States' cooperation across borders.

ENDS.

ANEC is the European consumer voice in standardisation, defending consumer interests in the processes of technical standardisation and the use of standards, as well as related legislation and public policies.

ANEC was established in 1995 as an international non-profit association under Belgian law and is open to the representation of national consumer organisations in 34 countries.

ANEC is funded by the European Union and EFTA, with national consumer organisations contributing in kind. Its Secretariat is based in Brussels.

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EC Register of Interest Representatives:
Identification number 507800799-30
BCE 0457.696.181

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