



Don't stop us now! The benefits of cross- border cancer care, where patients and knowledge travel easily

PHYSICIANS, RESEARCHERS AND PATIENT ADVOCATES MAKE THE CASE FOR LONG-TERM INVESTMENT IN CROSS-BORDER CANCER TREATMENT AND KNOWLEDGE EXCHANGE.

The EU Cross-Border Healthcare Directive was adopted eight years ago. Where are we today? This session's panelists and the audience reviewed progress, shared examples of what is working, and the challenges that lie ahead to make quality cross-border treatments a reality for all the patients that need them.

Update on Directive on patient rights in Cross-Border Healthcare

The European Commission's Directorate-General for Health and Food Safety gave an update in respect to the Cross-Border Healthcare Directive, originally passed in 2011. The current state of European Reference Networks and the challenges these groups face was reviewed. Naturally, most patients prefer treatment close to home. So the purpose of the EU's Cross-Border Healthcare Directive is not to spark mass movement of patients between countries but rather to address the reality that a significant number of patients face because of where they live, or for specific treatments available to them.

Today, seven million European citizens live in another EU country. Some 30% of the Union's population live

KEY MESSAGE

The EU Cross-Border Healthcare Directive is making cancer care across countries a reality. But major obstacles remain to achieving its full potential, including administrative barriers, low awareness of cross-border treatment options by patients and healthcare professionals, and GDPR issues that restrict sharing of patient data.

near a border area, where it is natural to seek services in the neighbouring country – including healthcare. A further 2 million people benefit from planned or unplanned healthcare in another country. Some seek treatment abroad; others may need help while on holiday or business travel.

The Cross-Border Healthcare Directive was intended to create a smooth experience for citizens seeking treatment in another country by improving arrangements in respect to recognition of medical insurance, and reimbursement and access to treatments in other countries. A growing number of citizens are making use of its provisions.

But there are challenges to giving patients a fully seamless treatment experience in another country. For example, many European citizens who are patients abroad are not aware of their rights provided by the Directive. Clearer information needs to be provided, said the discussants. Agreements are in place, but administrative obstacles remain in some countries, such as easy access to medical records.

It was highlighted that rare disease patients gain particular value from the Cross-Border Healthcare Directive's provisions. This gives such patients access to specialised skills and care that may not be locally



available. But some said that this potential remains untapped as not enough people know of these possibilities and how to access them. Some of the responsibility for improving transparency falls on national systems, who need to make cross-border rights better known to their citizens. Better access to information will open access to care for these patient populations.

See the European Commission's manual for patients' right to access healthcare in any EU country. <http://bit.ly/2VjpQkk>

As healthcare becomes more digital and data-driven, medical knowledge and services have new ways of being shared and travelling to where they are needed. This includes increasing opportunities for patients, including cancer patients, to receive more of their care and treatment at home and in the community setting.

Facilitating greater sharing of knowledge and expertise between countries and centres is among the core goals of the European Reference Networks established by the Cross-Border Healthcare Directive. Launched as an EU initiative in 2017, these are virtual networks that link healthcare providers across Europe. Amongst their aims are to boost the level of professional exchange and facilitate collaborative problem-solving opportunities in respect to complex cases for patients with rare diseases and cancers.

The focus of the European Reference Networks on rare diseases and cancers allows a concentration of knowledge and resources into specialised scientific and clinical areas that simply may not be possible otherwise, especially for smaller countries in the EU. 'Rare' or low-prevalence, complex diseases may have a small patient community per country, but from a European perspective they affect the daily lives of some 30 million EU citizens.

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One participant commented:
*In ten years we will look back and ask,
how could we have done without this?*

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Update on the first wave of European Reference Networks 2017-2019

The first wave of 24 ERNs now links 900 highly-specialised healthcare units in over 300 hospitals in 26 EU countries. They address thematic issues such as rare cancers, bone and blood disorders, childhood cancer and immunodeficiency. ERNs are currently in their start-up phase. The effort is now to embed them into national health systems.

ERN panelists in this session shared their experience of running first-wave ERNs, highlighting achievements and the challenges they see for further developing the Networks.

Challenges include the need to better embed the concept and value of cross-border healthcare within national systems. Long-term, secure and appropriate levels of funding are also required to truly realise the potential of the ERNs.

Many panelists highlighted and agreed on this need for standards and other underpinnings to support clinical data exchange between country health systems. Yet, conversely, they reported that GDPR data privacy regulation appears to be erecting new barriers to medical and patient data exchange. What is needed, they suggested, is a much better system of 'one-time consent' from each patient to make their data available. This will help cross-border digital health work better.

Further developments to focus on in respect to improving cross-border cancer care in Europe included: integrating cross-border healthcare concepts in national health systems and in national cancer plans; appropriate national cancer registration; cancer pathways linked to tumour boards in the country of origin; European S2 Cooperation for planned treatment in EEA countries; and customised information flows for the Clinical Patient Management System for digital records exchange, for example in cross-country case registration.

Colleagues from three pilot ERNs presented their activities:

- » **EURACAN** convenes the largest network of active EU centres managing patients with adult rare solid cancers such as sarcoma, rare brain and spinal cord conditions, rare neuro endocrine, skin, eye, thoracic cancers and others. <http://euracan.ern-net.eu>
- » The **EuroBloodNet** ERN shared its first experiences from its pilot phase. It links 66 multidisciplinary healthcare teams in 15 countries, including access to advanced specialised medical equipment and infrastructure. Together the EuroBloodNet centres address oncological and non-oncological rare hematological diseases including rare anemias, rare coagulation disorders, polycythemia, and myeloid and lymphoid tumours and rare hereditary hemochromatosis. Its members include the European Hematology Association, European Network on Rare and Congenital Anaemias, and several European Patient Advocacy Groups. <http://eurobloodnet.eu>
- » **PaedCAN** is the ERN for paediatric oncology. The network works to increase access to specialised know-how and paediatric oncology treatments. An example of its activity includes its cross-border virtual paediatric oncology tumour board network for sharing expertise and advice. <http://paedcan.ern-net.eu>

Accessing treatment across borders: Don't stop us now!

Hélène le Borgne, Caroline Hager, European Commission Directorate-General for Health and Food Safety

The way forward:

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