Evaluation of patient rights in cross-border healthcare.

Fields marked with * are mandatory.

Introduction

This is the first evaluation carried out by the European Commission to assess the Directive on patients’ rights in cross-border healthcare and whether it makes it easier to access safe and high-quality healthcare abroad.

Under this EU scheme:

- You have the right to get medical treatment, such as a consultation with a specialist, surgery or treatment for a specific condition, in other EU countries
- You can choose between private and public healthcare
- You must pay all healthcare costs upfront and claim reimbursement from your national health system or health insurance provider
- Prescriptions are recognised anywhere in the EU, and national contact points provide you with information on your rights to healthcare abroad.

The Directive complements the EU regulations coordinating social security systems. Under these, you always need prior approval from your health insurance body for planned healthcare abroad. You might also have to pay some costs yourself depending on where you are planning to get treatment.

The Directive also encourages European cooperation by:

- creating European Reference Networks for rare or complex diseases
- promoting both e-health cooperation and healthcare cooperation in EU border regions and between neighbouring countries.

For more information on the evaluation, visit the Have your Say page.

NOTE

- This public consultation does NOT cover emergency treatment in another EU country using the European Health Insurance Card.
The public consultation on creating a European Health Data Space addresses e-health cooperation.

About the survey questions

This survey is divided into five sections:

I. About you
II. Patients’ rights in cross-border healthcare
III. Rare diseases and European Reference Networks
IV. Healthcare cooperation between regions and the impact of COVID-19 on cross-border healthcare
V. Additional comments

About you

Language of my contribution

- Bulgarian
- Croatian
- Czech
- Danish
- Dutch
- English
- Estonian
- Finnish
- French
- German
- Greek
- Hungarian
- Irish
- Italian
- Latvian
- Lithuanian
- Maltese
- Polish
- Portuguese
- Romanian
- Slovak
- Slovenian
I am giving my contribution as
- Academic/research institution
- Business association
- Company/business organisation
- Consumer organisation
- EU citizen
- Environmental organisation
- Non-EU citizen
- Non-governmental organisation (NGO)
- Public authority
- Trade union
- Other

First name
Corinna

Surname
Hartrampf

Email (this won't be published)
corinna.hartrampf@aim-mutual.org

Organisation name
Association Internationale de la Mutualité (AIM)

Organisation size
- Micro (1 to 9 employees)
- Small (10 to 49 employees)
- Medium (50 to 249 employees)
- Large (250 or more)
Transparency register number

*255 character(s) maximum*

Check if your organisation is on the transparency register. It's a voluntary database for organisations seeking to influence EU decision-making.

| 595328413083-91 |

**Country of origin**

Please add your country of origin, or that of your organisation.

<p>| Afghanistan | Djibouti | Libya | Saint Martin |
| Áland Islands | Dominica | Liechtenstein | Saint Pierre and Miquelon |
| Albania | Dominican Republic | Lithuania | Saint Vincent and the Grenadines |
| Algeria | Ecuador | Luxembourg | Samoa |
| American Samoa | Egypt | Macau | San Marino |
| Andorra | El Salvador | Madagascar | São Tomé and Príncipe |
| Angola | Equatorial Guinea | Malawi | Saudi Arabia |
| Anguilla | Eritrea | Malaysia | Senegal |
| Antarctica | Estonia | Maldives | Serbia |
| Antigua and Barbuda | Eswatini | Mali | Seychelles |
| Argentina | Ethiopia | Malta | Sierra Leone |
| Armenia | Falkland Islands | Marshall Islands | Singapore |
| Aruba | Faroe Islands | Martinique | Sint Maarten |
| Australia | Fiji | Mauritania | Slovakia |
| Austria | Finland | Mauritius | Slovenia |
| Azerbaijan | France | Mayotte | South Africa |
| Bahamas | French Guiana | Mexico | South Georgia and the South Sandwich Islands |
| Bahrain | French Polynesia | Micronesia | Somalia |
| Bangladesh | French Southern and Antarctic Lands | Moldova | South Korea |
| Barbados | Gabon | Monaco | |</p>
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The Commission will publish all contributions to this public consultation. You can choose whether you would prefer to have your details published or to remain anonymous when your contribution is published. For the purpose of transparency, the type of respondent (for example, ‘business association, ‘consumer association’, ‘EU citizen’), country of origin, organisation name and size, and its transparency register number, are always published. Your e-mail address will never be published.

Opt in to select the privacy option that best suits you. Privacy options default based on the type of respondent selected.

*Contribution publication privacy settings*
The Commission will publish the responses to this public consultation. You can choose whether you would like your details to be made public or to remain anonymous.

**Anonymous**

Only organisation details are published: The type of respondent that you responded to this consultation as, the name of the organisation on whose behalf you reply as well as its transparency number, its size, its country of origin and your contribution will be published as received. Your name will not be published. Please do not include any personal data in the contribution itself if you want to remain anonymous.

**Public**

Organisation details and respondent details are published: The type of respondent that you responded to this consultation as, the name of the organisation on whose behalf you reply as well as its transparency number, its size, its country of origin and your contribution will be published. Your name will also be published.

- [ ] I agree with the [personal data protection provisions](#)

SECTION II. PATIENTS’ RIGHTS IN CROSS-BORDER HEALTHCARE

Awareness of patients’ rights in cross-border healthcare

Q1. How informed are you about your rights to seek healthcare in another EU country?

- [ ] Not at all
- [ ] To a limited extent
- [ ] To some extent
- [ ] Completely
- [x] To a great extent
- [ ] Don't know / no opinion

Q2. Are you aware that you can get healthcare costs incurred in another EU country reimbursed under the 2 EU schemes described in the introduction (Directive on patients’ rights in cross-border healthcare and EU rules on social security coordination)?

- [x] Yes
- [ ] No
- [ ] Don't know / no opinion

Are you aware of any problems resulting from these EU schemes?
Access to healthcare in another EU country

Q3. In your experience, do the EU schemes (described in the introduction and Q2) meet patients’ needs on accessing healthcare in another EU country?

at most 1 choice(s)

☐ Not at all  ✔ To a great extent
☐ To a limited extent ☐ Completely
☐ To some extent ☐ I don’t know/ No opinion

Please specify

1500 character(s) maximum

Health insurance funds and health mutuals in charge of compulsory health insurance, have always favoured the application of Regulation 883/2004 in the context of cross-border healthcare because it provides the
maximum price security for the patient. This should still be the case in the future. Crossing the border to access healthcare might be necessary for some patients (e.g. patients with ultra-rare diseases). AIM members point out that, especially for these patients but also for others, digitalisation will facilitate treatments by allowing patients to benefit from knowledge abroad without having them to travel. The expertise is centralised, and the treatment is as nearby and local as possible. However, this does bring on new challenges in reimbursement and the need to regulate telehealth and its reimbursement. The directive is important, when it comes to reimbursement of treatment in private hospitals but is less favored because patients have to pay in advance and they don’t know, how much they get reimbursed. Not everybody can afford it.

Q4. In the last 5 years, have you experienced or are you aware of any changes in accessing **planned** healthcare in another EU country as a result of the freedom of choice provided by the Directive?

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<td>Access to better quality of treatment</td>
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<td>Choice of healthcare provider (public or private)</td>
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Other, please specify:

*1500 character(s) maximum*

The information provided to insured persons has improved and has increased the number of requests for reimbursement for treatment abroad. The health crisis caused by the coronavirus has led to border closures which may have made it more difficult for European citizens to travel in general and consequently also to benefit from health care services abroad. However, where cross-border cooperation was already in place, solutions and procedures were quickly found to allow for the continuity of care.

Q5. In your experience, do patients have access to healthcare in another EU country and enjoy the same conditions as residents of that country?

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There are differences between EU Member States. For example, under the coordination regulation 884/2004, Belgian patients travelling to France and vice versa receive the same care and the same tariffs as in their Member State of origin. France and vice versa benefit from the same care and the same tariffs as in their Member State of residence. On the other hand, Belgians receiving care in Germany may, in some cases, have to pay higher fees than German residents because of the non-use of regulatory documents by health care providers, for example. Under Directive 2011/24, Belgians receiving care in the Netherlands are charged flat rates (CAD) which are not reimbursed for Belgian patients. This problem does not exist for Belgian patients in the Netherlands, who use Regulation 883/2004.

One of the points for improvement could be to take into account, both financially (free of charge) and in the statistical registration of the treatment, preventive examinations (e.g. mammography) carried out outside the territory of residence. It could be used within the framework of the implementation of the European plan to combat cancer. This issue mainly concerns border areas.

The legal rules are clear but the practical exercise of these rights is complicated.

Citizens’ experiences with patients’ rights to healthcare abroad

Q7. What are the main reasons why people seek healthcare abroad? Select 2 reasons:

- The closest healthcare provider is in the neighbouring country
- Long waiting times for treatment in home country
- Healthcare services and treatment needed not available in home country
Q8. Healthcare providers (general practitioners, specialist doctors, hospitals, clinics etc.) in the EU country of treatment have to provide cross-border patients with relevant information so they can make informed choices. They must also provide them with the necessary documents so they can get healthcare costs reimbursed and any follow-up treatment back home. Are you aware of patients’ experiences with healthcare providers abroad?

*at most 1 choice(s)*

- Yes
- No
- Don’t know / no opinion

To what extent do patients experience any of the following with healthcare providers abroad?

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<tr>
<td>Healthcare providers give clear information on prices</td>
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<td>Healthcare providers recognise medical documents/tests from the home country</td>
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<td>Healthcare providers transfer medical records or a patient summary to the healthcare provider back home (in either paper or electronic format)</td>
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<td>Healthcare providers issue clear invoices for reimbursement by the patients’ health insurer</td>
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Q9. Are you aware of administrative problems for patients receiving follow-up care at home after treatment abroad, including recognition of prescriptions?

- Yes
Please describe the problems that patients may encounter when seeking follow-up care at home:

1500 character(s) maximum

The prescription issued in one Member State may be difficult to dispense in another Member State because the packaging or dosage is different from one Member State to another or because some medicines can only be dispensed by hospital pharmacies, for example.

When it comes to patients with rare diseases and their relatives, for example, more paramedical care and psychological follow-up should be reimbursed by health insurance funds and health mutuals. In some situations, there is not enough reimbursements and substantial out-of-pocket payments have to be made.

Barriers to healthcare abroad

Q10. In your view, are there barriers to patients seeking healthcare in another EU country?

at most 1 choice(s)

☐ Not at all  ☑ To some extent  ☐ Completely
☐ To a limited extent  ☐ To a great extent  ☐ Don't know / no opinion

In your experience, what are the biggest barriers to cross-border healthcare? Please select a maximum of 5 main barriers:

☑ Lack of information on patients’ rights to healthcare abroad
☑ Lack of information on healthcare providers/treatment options available abroad
☑ Lack of information on the accessibility of hospitals for people with disabilities
☑ Language barriers
☑ Patients have to pay upfront for treatment costs and then seek reimbursement from their own health insurer
☑ Public healthcare providers abroad charge private treatment prices
☑ Uncertainty about the amount that can be reimbursed for healthcare abroad
☑ Uncertainty about the prices charged by healthcare providers abroad
☑ Prior authorisation required for the reimbursement of healthcare costs
☑ Complex administrative procedures for prior authorisation
□ Difficulties in accessing public healthcare providers/treatment options abroad
□ Difficulties in seeking remedies in case of harm arising from healthcare abroad
□ Difficulties in accessing healthcare and insufficient support for those with disabilities
☑ Difficulties in transferring medical records between systems
Lack of follow-up care in the home country
Difficulties in acquiring medicines and medical devices prescribed by a doctor abroad
Complex system of reimbursement used by the health insurer
Translation of medical documents and invoices required by health insurer
Second opinion by foreign specialist not reimbursed
Cross-border teleconsultation (video-consultation and calls) not reimbursed
Reimbursement only if there’s a referral from the general practitioner/specialist doctor in the home country
Other

Information to patients

Q11. Do patients receive information from their healthcare provider on treatment options in another EU country?

Yes
No
Don't know / no opinion

Is the information appropriate and sufficient?

Yes
No
Don't know / no opinion

Q12. In each EU country, there is a national contact point that provides information about cross-border healthcare inside the EU. Did you know that a National Contact Point exists?

Yes
No

Have you contacted a National Contact Point (in your own country or in an EU country of treatment) or checked its website for information?

Yes
No
Q13. How would you assess the information provided by national contact points? Please rank your answer from low (1) to high (5).

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<td>Clarity</td>
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Q14. Was the information in a suitable format for people with disabilities?

- [ ] Yes
- [x] No
- [ ] Don't know / no opinion

Q15. Was the information available in other language(s)?

- [x] Yes
- [ ] No
- [ ] Don't know / no opinion

Q16. Was the information available in a minority language in your country?

- [x] Yes
- [ ] No
- [ ] Don't know / no opinion

Q17. Did the information cover LGBTIQ people (lesbian, gay, bisexual, transgender, intersex and queer)?

- [ ] Yes
- [ ] No
- [x] Don't know / no opinion

Q18. Was it easy to find the following information?

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<td>Healthcare provider in another country is legally registered to provide services</td>
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<td>Complaints and appeals process</td>
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<td>Other</td>
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Please specify:
*1500 character(s) maximum*

We reply as health insurance funds and health mutuals. Some of our members even are national contact point at the same time. The rest has all the information on reimbursement. So it is difficult for us to answer this questions.

Recognition of prescriptions

Q19. Are you aware of the possibility to have your prescription recognised by a pharmacist in another EU country?

*at most 1 choice(s)*

- [X] Yes
- [ ] No
- [ ] Don't know / no opinion

Q20. Are you aware of problems with pharmacists in another EU country not recognising prescriptions?

*at most 1 choice(s)*

- [X] Yes
- [ ] No
- [ ] Don't know / no opinion

Have you experienced any of the following? (more than 1 answer possible)

- [ ] A pharmacist refused prescriptions issued by doctors from another EU country
- [ ] A pharmacist could not verify whether the prescription was issued by a doctor legally entitled to do this for another country
- [ ] A pharmacist could not understand the language of the prescription
- A pharmacist could not understand the doctor’s handwriting
- Prescribed medicine not available
- Substitute medicine not possible in the home country
- Other

Please specify:

1500 character(s) maximum

Prescription can be difficult to deliver because packaging or dosages are different from one Member State to another or because some medicines can only be supplied by hospital pharmacies, for example.

There are also problems with the reimbursement of medicines due to the use of documents that are not recognised in the Member State of insurance.

SECTION III. RARE DISEASES AND EUROPEAN REFERENCE NETWORKS

Rare diseases

Between 5,000 and 8,000 rare diseases affect the daily lives of around 30 million people in the EU. Many of those affected don’t have access to diagnosis and high-quality treatment. The Commission helps EU governments improve the recognition and treatment of these conditions by strengthening European cooperation.

Q21. To what extent are you aware of the possibilities to seek diagnosis and treatment of rare diseases in another EU country with prior approval from your healthcare insurer?

- [ ] Not at all
- [x] To a limited extent
- [ ] Completely
- [ ] To some extent
- [ ] Don’t know / no opinion

Q22. To what extent are you aware of information tools supported by the Commission (e.g. the Orphanet database providing information on rare diseases, the European platform on rare disease registration) that can help improve and share knowledge in the diagnosis of rare diseases?

- [ ] Not at all
- [ ] To a great extent
- [ ] To a limited extent
- [x] Completely
- [ ] Don’t know / no opinion
European Reference Networks

Patients with rare and complex conditions and their doctors can benefit from the expertise and knowledge of highly specialised healthcare centres which are part of the 24 European Reference Networks (ERNs) for rare, low prevalence and complex diseases created by the Directive on patients’ rights in cross-border healthcare.

Q23. Are you aware of the ERNs and their purpose?

at most 1 choice(s)

☑ Yes
☐ No (you will be directed to section IV)

Q24. To what extent do the existing ERNs help health professionals provide diagnosis and treatment options for patients with rare and complex diseases in the EU?

at most 1 choice(s)

☐ Not at all ☐ To a great extent
☐ To a limited extent ☐ Completely
☑ To some extent ☐ Don't know / no opinion

Q25. To what extent do the existing ERNs help generate knowledge and contribute to research on rare and complex diseases in the EU?

at most 1 choice(s)

☐ Not at all ☐ To a great extent
☐ To a limited extent ☐ Completely
☑ To some extent ☐ Don't know / no opinion

Q26. To what extent have ERNs helped achieve the objectives in the following areas?

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</tr>
</tbody>
</table>
### Q26b. Research and innovation

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not at all</th>
<th>To a limited extent</th>
<th>To some extent</th>
<th>To a great extent</th>
<th>Completely</th>
<th>Don’t know / no opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploit innovation in medical science and health technologies</td>
<td></td>
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<tr>
<td>Enhance research on prevention, diagnosis and treatment</td>
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<tr>
<td>Collect, analyse and make health data available</td>
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</tbody>
</table>

### Q26c. Healthcare professionals

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not at all</th>
<th>To a limited extent</th>
<th>To some extent</th>
<th>To a great extent</th>
<th>Completely</th>
<th>Don’t know / no opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exchange knowledge and best practices</td>
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<tr>
<td>Professional training</td>
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<tr>
<td>Mobility of expertise, either virtually (e.g. through online medical consultations) or physically (e.g. through temporary postings of health professionals to other centres within the ERN system)</td>
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</tbody>
</table>

### Q26d. Healthcare systems

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not at all</th>
<th>To a limited extent</th>
<th>To some extent</th>
<th>To a great extent</th>
<th>Completely</th>
<th>Don’t know / no opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make cost-effective use of resources within EU-wide networks to reduce the burden and fill gaps at national level</td>
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<tr>
<td>Help EU countries with an insufficient number of patients with a particular medical condition, or lacking technology or expertise, to provide highly specialised services of high quality</td>
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</tbody>
</table>
Q27. To what extent have EU countries, at national level, helped develop ERNs by:

<table>
<thead>
<tr>
<th>Connecting their national centres of expertise</th>
<th>Not at all</th>
<th>To a limited extent</th>
<th>To some extent</th>
<th>To a great extent</th>
<th>Completely</th>
<th>Don't know / no opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supporting the participation of national centres in ERNs</td>
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<tr>
<td>Disseminating information on ERNs to healthcare providers</td>
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</tr>
<tr>
<td>Disseminating information on ERNs to patients</td>
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</tbody>
</table>

Q28. What do you think are the biggest barriers that healthcare providers and patients face in accessing the expertise of ERNs? (more than 1 answer possible)

<table>
<thead>
<tr>
<th>Lack of awareness/information</th>
<th>For healthcare providers</th>
<th>For patients</th>
<th>Don't know / no opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient geographical coverage of ERNs</td>
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<tr>
<td>Absence of a clear pathway to refer patients to ERNs</td>
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<tr>
<td>Insufficient integration of ERNs in the national health system and lack of support for their activities by the national authorities</td>
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<tr>
<td>Issues related to reimbursement of the health services provided</td>
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<tr>
<td>Non-interoperable IT systems</td>
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<tr>
<td>Administrative burden</td>
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<tr>
<td>Insufficient digital skills</td>
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<tr>
<td>Language</td>
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</tbody>
</table>

SECTION IV. HEALTHCARE COOPERATION BETWEEN REGIONS AND THE IMPACT OF COVID-19 ON CROSS-BORDER HEALTHCARE
A key aim of the Directive is to build and encourage cross-border healthcare cooperation between neighbouring countries and in EU border regions. This includes mutual assistance to help patients access healthcare across borders, concluding agreements on healthcare provision, and exchanging information.

Q29. To what extent have these measures supported cross-border cooperation in healthcare between neighbouring countries and in the border regions over the last 5 years?

<table>
<thead>
<tr>
<th></th>
<th>Not at all/no change</th>
<th>To a limited extent</th>
<th>To a great extent</th>
<th>Don't know / no opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exchanges of information</td>
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<tr>
<td>Exchanges of good practices</td>
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<tr>
<td>Agreements in cooperation in healthcare provision</td>
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</tbody>
</table>

Other, please specify:

1500 character(s) maximum

It is above all European funding that makes it possible to dedicate resources to the implementation of these exchanges and exchanges and cooperation.

For the Franco-Belgian border, a joint commission for monitoring cross-border health agreements has been set up but does not meet regularly.

The health crisis situation encountered with COVID 19 highlighted the importance of cross-border cooperation in the field of prevention (e.g. vaccination) and the provision of care. The mobility of border workers, some of whom are health care workers and patients, makes it indispensable to strengthen information sharing (measures in force, contact tracing, etc.), harmonised communication, cooperation in the provision of care according to the capacities in place, attention to the continuity of care. Existing exchange structures bringing together operators and health authorities must be supported in their work.

Q30. What are the most common barriers facing hospitals, health authorities and health insurers in cross-border healthcare cooperation across border regions?

(more than 1 answer possible)

- Language
- Differences in health systems
- Political commitment
- Resources
- Other

Please specify:

1500 character(s) maximum
- Differences in nomenclature, types of care and funding;
- At the political level, the Franco-Belgian Joint Commission does not monitor the Franco-Belgian health framework agreement. We support regular meetings involving the insurers;
- Hospital policies are considered on a national or regional basis and do not take into account the cross-border agreements and the complementary care available on the other side of the border. Exchanges are then made more difficult by the obligation to refer patients to hospitals on the national territory but further away, or choices to stop activities due to the non-inclusion of the patient base.
- The shortage of medical staff (general practitioners, specialists, nurses) is a difficulty in encouraging openness towards the other side of the border but could also be part of the solution if the mobility of professionals were facilitated in order to create mutual aid and a pooling of resources, cross-border on-call means, shared cross-border on-call duty, etc.

Questions related to the consequences of the COVID-19 pandemic

Q31. Do you think the Directive could help health systems tackle a possible backlog of postponed treatments arising from the pandemic?

at most 1 choice(s)

☑️ Not at all ☐ To a great extent
☐ To a limited extent ☐ Completely
☐ To some extent ☐ Don't know / no opinion

Please specify:

1500 character(s) maximum

All EU Member States have been and are being confronted with the pandemic. Capacity has been reduced throughout the EU. The care postponed during the pandemic is often care that requires follow-up, which is therefore difficult for the patient to envisage at a long distance.

The question is rather to reflect on the organisation of the health system of each Member State and on the management of crises in order to prepare a better response as regards the continuity of care in the future.

Nevertheless, we welcome the commitment of the European Plan to Overcome Cancer (COM(2021)44 final) to strengthen European health and cancer expertise. We call for action be taken to ensure that screening examinations carried out by a socially insured person in a Member State should be free of charge and should be recorded in the data of the State of insurance.

Q32. Have restrictions on free movement during the pandemic, such as travel bans, quarantine or testing requirements, had an impact on access to healthcare in another EU country?

at most 1 choice(s)

☐ Not at all ☐ To a great extent
☑️ To a limited extent ☐ Completely
☐ To some extent ☐ Don't know / no opinion

Please specify:

1500 character(s) maximum
- Differences in nomenclature, types of care and funding;
- At the political level, the Franco-Belgian Joint Commission does not monitor the Franco-Belgian health framework agreement. We support regular meetings involving the insurers;
- Hospital policies are considered on a national or regional basis and do not take into account the cross-border agreements and the complementary care available on the other side of the border. Exchanges are then made more difficult by the obligation to refer patients to hospitals on the national territory but further away, or choices to stop activities due to the non-inclusion of the patient base.
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SECTION V. ADDITIONAL INFORMATION

Q33. Do you have any other comments you wish to share on patients’ rights in cross-border healthcare, rare diseases and ERNs?

2500 character(s) maximum

The closure of borders may have made it more difficult for European citizens in general and consequently also for cross-border health care workers and patients who wanted to receive care abroad.

However, this difficult access to care was also encountered for patients living in the territory, as the infrastructure was reserved for the care of COVID-19 patients.

Where cross-border cooperation already existed, solutions and procedures were quickly found between the partner actors to ensure continuity of care.

Solidarity was even observed in Member States with more hospital capacity.

In the future, we call for better coordination between border Member States to strengthen existing cooperation and cooperation and to consider cross-border health solutions both structurally and in case of crisis situations.

You can also upload a document here. Please note that the uploaded document will be published with your response to the questionnaire.

Only files of the type pdf, txt, doc, docx, odt, rtf are allowed

Contact

sante-cross-border-healthcare@ec.europa.eu