

**Response to Consultation on UK Implementation of Directive 2011/24 EU (on the application of patients' rights in cross-border healthcare).
Cross border healthcare & Patient Mobility**

Submitted by: **Primary Immunodeficiency UK.**

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**Response to consultation
General**

1. What proportionate measures can we take so that all patients/citizens, regardless of age, race or ethnicity, disability, religion or belief, gender, sexual orientation or socio-economic status feel a) reassured they will be treated with respect and their specific needs considered b) they are fully informed to make the right choice for them?

- a) This can be achieved by making the process and decision-making as transparent as possible and by ensuring inclusivity by reaching out to all stakeholders including patient groups as conduits for making this information available to those who might want to use these services.
- b) This can be achieved by providing good quality easily understood information. This should include details of availability, quality and safety.

Responsibilities of Member State of treatment (pages 13 -22)

4. Are there any other "health professions" in the UK to which the provisions of the Directive will apply when treatment is supplied in the UK?

The list given is comprehensive.

Responsibilities of Member State of affiliation (pages 22 -26)

5. Do you agree that this broad requirement would ensure that the NHS is able to deliver the required clarity on entitlements and thereby respond appropriately to patient requests?

Response: We agree with the consultation document view that improved clarity and transparency on entitlement to cross-border health care is needed for patients and that this information should be easily understood and widely accessible not only through the NHS website but through patient support group websites. Greater clarity on entitlements and reimbursement pathways would save clinicians time in dealing with paperwork associated with cross-border care.

Continued

If not what additional measures should be considered to ensure that the NHS is able

to deliver the required clarity on entitlements and thereby respond appropriately to patient request?

Response: Additional measures such as review of information by patient groups, giving timelines for responding to further patient queries are needed.

National Contact Points (pages 26 -27)

6. Do you agree that the Commissioning Board is best placed to deliver the NCP function for England?

Response: Yes as long as there is sufficient capacity within the Commissioning Board to cope with this function especially at a time of major NHS system reform and that there is no blurring of lines on making recommendations on providers. This function should be periodically performance reviewed.

7. What information, and presented in what format(s), do you think patients need to make an informed decision on receiving treatment in another EU Member State?

Response:

Information needed -

- Availability: Where diagnosis and treatment options for a patient's particular condition are available, in what countries and centres.
- Quality: Evidence on outcomes and success rates
- Safety: Information on incidence and spectrum on healthcare associated infections in centres providing the service. This is important information for all patients but especially vital for people whose immune systems are intrinsically compromised.
- How and by what process the recommendations have been reached. It is unclear from the Directive who makes recommendations on potential providers in other countries and how this process works. Clarification on this would be welcomed.
- Clear signposting to further information where needed.

Format - plain language, patient-reviewed; widely available including on-line and printed material taking on board the need to engage with people affected by disabilities and of different languages within the same country.

8. What will be the impact of providing clear and transparent information on the volume of patients who may wish to access cross-border healthcare and the treatments they may wish to obtain? Please provide evidence where possible.

Response: Inequalities exist for people affected by primary immunodeficiencies in terms of quality and levels of diagnosis and treatment. Having clear and transparent information will open up welcomed options for patients seeking the best care. Hopefully it will put increased pressures on countries to improve PID care and to raise standards to those of countries with more appropriate diagnosis and treatment. It will help patients who have particularly rare conditions to access highly specialised centres with a proven track record in treating their condition.

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General principles for reimbursement of costs (pages 28 -33)

9. Do you agree that the NHS Commissioning Board should have discretion to make payments direct to overseas providers, where this would be beneficial for patients with limited financial means?

Response: Yes – so that individuals who are travelling for employment purposes for example can receive continued healthcare, particularly important for chronic conditions. Mobility for employment or personal reasons does not imply that the individual would have recourse to funds required to pay and then seek reimbursement and this would ensure equity of access, reduce costs from avoidance of management of chronic health problems during periods of absence from the home state and reduce morbidity.

10. If so, what safeguards would you like to see put in place?

Response: The process of implementation requires a transparent means testing component, which is evidence based and will be employed across the board. The additional costs which may need to be met by the patient (were the treatment is provided at higher cost than the member state) need to be clear and a mechanism of pre-agreed repayment on reasonable terms and the maximum likely or possible liability.

Healthcare that may be subject to prior authorisation (pages 33 -42)12.

12. Do you agree that the UK should continue to operate a system of prior authorisation for patients requiring certain types of treatment?

13. In addition to specialist services and services such as diagnostics requiring considerable planning and financing what other services might come within the scope of treatments / services that should be subject to prior authorisation?

14. What is the evidence to support this inclusion?

15. Do you have a view on whether or how the Government should adopt the derogation Art.8(6)(d) derogation?

16. Should the derogation (if taken) be limited to the list of highly specialised services only?

Response: We do not agree with the derogation concept, since the timeliness of access shouldn't be the driver and since patients are entitled to receive the same treatment at the cost provided in the member state. Few people will want to travel to receive treatment solely for rapidity (other than surgery) – although some may choose a country with lower infection rates post-op for example. The derogation in principle seems to undermine the purpose of the legislation. Pre-authorisation of as wide a range of services as possible would be the most sensible approach though to ensure that only those areas with the greatest discrepancy in care provision across the EU are subject to case by case review. A set number of cases within a category should then set precedence and a policy.

Administrative procedures (pages 42 -43)

18. Is the current decision making timescale reasonable, or should it be amended?

Response: A time scale of 20 days is reasonable.

Mutual assistance and cooperation (pages 43 -48)

21. What information should be shared between competent authorities on treating practitioners, and in what circumstances?

Response: With patient consent all relevant healthcare information should be disclosed, but this should not put an additional burden of translation or information gathering on either the patient or the physician with ordinary responsibility for the patient in the UK.

22. How do you think the European reference networks and proposed ehealth and health technology assessment networks might best add value to the UK?

Response: We welcome the role of ERNs in advancing the agenda on rare diseases, through EU wide cooperation on specialized healthcare, knowledge sharing and improvement to diagnosis and treatment for all patients regardless of geographical origin.

For people affected by immunodeficiencies this is best implemented through existing collaborative networks such as ESID, IPOPI and the use of information in PID patient registries.

ENDS