Discussion paper

Disclaimer: This paper should be solely regarded as a basis for discussion and cannot in any circumstances be regarded as the official position of the Commission and its services

NATIONAL CONTACT POINT MEETING 2 DECEMBER 2015

NATIONAL CONTACT POINTS AND PROVISION OF INFORMATION

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

1) Summary of obligations in the Directive

The Directive puts the following obligations on National Contact Points (NCP):

- i. to provide patients and health professionals with information on: quality and safety standards and guidelines (including information on which healthcare providers are subject to these standards and guidelines and how compliance with these is monitored) (A4(2)(a)); complaint procedures and mechanism for seeking remedies (A6(3)); patients' rights and entitlements in cross-border healthcare, and any appeal mechanisms (A5(b)); a provider's right to provide services (A6(3)); the details of National Contact Points in other Member States (A6(2)); accessibility of hospitals for persons with disabilities (A4(2)(a)
- ii. to consult with stakeholders (patients, providers, insurers) (A6(1))
- iii. to cooperate closely with each other and the Commission (A6(2))
- iv. to assist each other with supervision of providers and on understanding invoices (A10(1))
- v. to publish the elements which must be contained in cross-border prescriptions (A4 of Directive 2012/52/EU on the recognition of prescriptions).

The Directive also puts certain other obligations related to information on other actors:

- vi. Healthcare providers (whether public or private) should provide information to patients on: treatment options; services provided; quality and safety; prices; authorisation or registration status; insurance or liability cover.
- vii. Member States must give information on: any limitations on incoming patients (A4(3)); all relevant information on prior authorisation (including which healthcare is subject to prior authorisation) (A8(7)); time limits for processing authorisation requests and reimbursement claims (A9(3)).
- viii. Member States are obliged to give information on the right to practise of healthcare professionals via the Internal Market Information system (A10(4)).
 - 2) Main Findings from a recent evaluative study related to NCPs

Awareness of the Directive among Stakeholders

- a) Information and communication activities of National Contact Points and other relevant authorities focused particularly on reaching professional and medical audiences. An attempt to reach the general public was made so far in some countries through mainstream media, this being primarily restricted to the time period of transposition of the Directive into national legislation (i.e. between autumn 2013 and early 2014). Over the past year, patients could consult the websites of healthcare authorities and NCPs for information on cross-border healthcare. Patients have good knowledge of the options available under the Regulation of 2004 linked to the European Health Insurance Card (EHIC) that are considered to be an appropriate tool for seeking healthcare treatment within the European Union. In contrast, this evaluative study found that patients are generally unaware of the existence of the Directive, and thus the least informed stakeholders.
- b) Knowledge-sharing between National Contact Points and their cooperation with relevant authorities and medical organisations is improving. The Directive and its transposition into national law have prompted a number of professional events, seminars and workshops resulting in intense knowledge-sharing among the newly established NCPs and fostering cooperation between NCPs and the relevant national authorities and medical professional organisations. This knowledge sharing exercise may have contributed to the successful implementation of the Directive however it was noted that cooperation among stakeholders is often put in place just to find solutions to single patients' requests and issues and are not aimed at the more general purpose of standardisation of the procedures.

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¹ http://ec.europa.eu/health/cross border care/docs/2015 evaluative study frep en.pdf

Information available to Patients on Cross-border Healthcare

- c) Responsibility for gathering relevant information about healthcare providers abroad, including on the quality of services rendered, and selecting an appropriate facility lies predominantly with the patients. National Contact Points and insurers provide general assistance to patients, however, in some Member States this assistance is not tailored to their specific needs.
- d) Member States increasingly publish the list of treatments which are subject to prior authorisation. This facilitates patients' understanding of which treatments can be received abroad without the need to contact the health insurance providers in advance. Insured residents of Member States are entitled to be reimbursed for a wide range of healthcare services received in another Member State. Beyond inpatient care, a significant proportion of outpatient treatments may also be subject to prior authorisation by the insurer in the Member State of affiliation. A number of NCPs and health insurance providers already publish the lists of treatments considered cost-intensive and thus subject to prior authorisation.

Quality and Safety of Cross-border Healthcare

e) Patients find it challenging to determine the quality and safety of healthcare services. According to Article 4.2 of the Directive, Member States must ensure that healthcare providers offer relevant information to help patients make informed choices concerning cross-border healthcare. However, the measurement and communication of quality and safety information is dependent on national law and, within national borders, patients' choice is largely guided by general practitioners' recommendations and/or other users. It could be necessary to make available to patients suitable tools to enable a quality and safety assessment of providers.

3) Questions to NCPs

- a) In how far do you see added value in working together within this network?
- b) What could be done to help your information needs?
- c) How could NCPs work together to increase patient awareness of the possibilities offered by the Cross-border Healthcare Directive?
- **d)** Would a **list of topics where common approaches in information provision** be helpful to you?
- e) How does the NCP function you represent engage in **meaningful dialogue** with stakeholders (patient organisations, insurers, healthcare providers) on a regular basis (not only regarding consultation for the setting up of the NCP)?

- f) How does the NCP you represent collect **feedback** and act on it (following interactions with users)?
- **g)** How to best ensure **NCP effectiveness**, particularly in terms of satisfaction and understanding of choice from the patient perspective?
- h) Quality and safety: Who sets standards on quality and safety? How are they established? Who monitors compliance with them and how? Which providers are covered by these standards? What happens when standards are not met? Where to seek redress in case of harm?
- i) On **entitlements**: Could a list of main entitlements² and where the exhaustive information is to be found be published on NCP websites?
- j) On running of NCP websites: How to ensure that important information is not missing from the NCP website? How to explore the readability and the accessibility of the websites?
- **k)** How could NCPs help to make available useful information on the national plans of rare diseases and the functioning of the future ERNs? In how far can NCPs influence the good implementation of the **provisions** of Article 13³ of Directive 2011/24/EU **concerning rare diseases**?

² Article 5(b) of Directive 2011/24/EU calls on the Member States to ensure that there are "mechanisms in place to provide patients on request with information on their rights and entitlements in that Member State relating to receiving cross-border healthcare, in particular as regards the terms and conditions for reimbursement of costs in accordance with Article 7(6) and procedures for accessing and determining those entitlements and for appeal and redress if patients consider that their rights have not been respected, in accordance with Article 9. In information about cross-border healthcare, a clear distinction shall be made between the rights which patients have by virtue of this Directive and rights arising from Regulation (EC) No 883/2004".

³ The Commission shall support Member States in cooperating in the development of diagnosis and treatment capacity in particular by aiming to:

⁽a) make health professionals aware of the tools available to them at Union level to assist them in the correct diagnosis of rare diseases, in particular the Orphanet database, and the European reference networks;

⁽b) make patients, health professionals and those bodies responsible for the funding of healthcare aware of the possibilities offered by Regulation (EC) No 883/2004 for referral of patients with rare diseases to other Member States even for diagnosis and treatments which are not available in the Member State of affiliation.