The patients’ rights and cross-border care directive is widely seen as the beginning of a new era for European action in health services. While cross-border care only affects a small percentage of European Union citizens, an important section of the directive provides for a series of collaborative initiatives between Member States. It is this part of the directive that is likely to be highly influential in shaping the manner future health services across the European Union. One such initiative is the establishment of European Reference Networks (ERNs).

Earlier this year, the decisions regulating the setting up and management of ERNs were adopted. These decisions serve to lay down the framework within which ERNs will operate. Much preparatory work has gone into the development of the framework, and there is a general expectation that ERNs will have to meet rigorous standards both to be initially approved as well as on an ongoing basis.

European citizens aspire to have knowledge about where the ‘best’ care for their condition exists within the European Union and increasingly expect to access such care. In this sense, the establishment of ERNs appeals to a populist objective in terms of cross-border care. ERNs undoubtedly also appeal to health-care professionals involved in cutting-edge research and medical education and could place the European Union in a stronger leadership position in medical care for patients with rare and complex diseases?

Natasha Azzopardi-Muscat1,2, Helmut Brand1
1 Department of International Health, Maastricht University, Faculty of Health, Medicine and Life Sciences, CAPHRI School of Public Health and Primary Care, The Netherlands
2 Department of Health Services Management, Faculty of Health Sciences, University of Malta, Msida, Malta

Correspondence: Natasha Azzopardi Muscat, Department of Health Services Management, Faculty of Health Sciences, University of Malta, Mater Dei Hospital, Tal-Qroqq Msida MSD2080, Malta. Tel: +356 234 018 40, Fax: +356 234 018 42, e-mail: natasha.muscat@maastrichtuniversity.nl

Will European Reference Networks herald a new era of care for patients with rare and complex diseases?

The sustainability of ERNs will also depend on the funding for these networks. This is possibly the most serious threat to the project, as there is presently no secure sustainable form of funding available at European level. The stringent budgetary frameworks being applied to health systems at national levels, partly due to pressure being applied through the European semester mechanism, indicate that Member States will find it difficult to spare funds for the maintenance of ERNs.

The impact on equity and health inequalities is another issue meriting close attention. The mechanisms for reimbursement under the cross-border directive pose a barrier for access to care for the following reasons. There is a good possibility that the intervention/treatment sought from a centre of reference may not be provided in the Member State’s package of health-care services. Second, even if the Member State does agree to provide the authorization given the rarity or complexity of the patient’s
condition, difficulties arise in establishing a reimbursement price based on the principle of how much the treatment would have cost in the competent Member State. Cross-border referral to centres of reference may end up being too costly both for a Member State as well as for an individual patient.

Well-designed independent research on the impact of ERNs should be a high priority for European health services research in the coming years. Such research should not only focus on filling gaps in the literature with regards to clinical outcomes and cost effectiveness but should also determine the impact on equity for European citizens. Whether ERNs will herald a new era of care for patients with rare and complex diseases across the European Union depends on the way in which some of the issue discussed above will be tackled.

Conflicts of interest: None declared.

References


