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NEW e-HEALTH SERVICES FOR THE EUROPEAN REFERENCE NETWORK ON RARE ANAEMIAS

JA2015 - GPSD [705038]

| START DATE: | 01/01/2013 |
| END DATE:   | 01/01/2016 |
| DURATION:   | 36 month(s) |
| CURRENT STATUS: | Finalised |
| PROGRAMME TITLE: | Second Programme of Community action in the Field of Health 2008-2013 |
| PROGRAMME PRIORITY: | - |
| CALL: | Promote Health (Hp-2012) |
| TOPIC: | IMPROVE CITIZEN'S HEALTH SECURITY (HS-2012) |
| EC CONTRIBUTION: | 1163274.39 EUR |
| KEYWORDS: | Diagnostic, Patients registries, Rare diseases and disorders, Treatment |
| PORTFOLIO: | Rare diseases |
General objectives

The general objective of e-ENERCA is to provide professionals and patients with e-Health tools to assure the same level of access to rare anaemias (RA) services across Europe. e-Health services will be developed through the implementation of three e-platforms endorsed on the ENERCA website. The specific objectives are: 1) to enhance the creation and use of European inventories to gather updated and reliable data on centres of expertise (CEs) and epidemiological figures 2) To facilitate the continuing medical education and best practices 3) To create a telemedicine platform for the provision of health care and medical advice avoiding the need of physical travelling 4) To promote the recognition of CEs on RA by national health authorities and ENERCA as the European Reference Network for RA 5) To develop e-Health tools in the field of RA and promote their use among the scientific community and patients` associations and 6) to assure the project sustainability in the future.

Strategic relevance and contribution to the public health programme

The strategic relevance of e-ENERCA is the participation of health professionals, patients, health authorities and other stakeholders of all Member states (MS) in the design, validation and implementation of new e-Health services addressed to improve the tackle of rare anaemias (RA). This will be undertaken by assuring the adequacy of the new proposed tools and services with the social, cultural and policy context according to the new Directive on Cross-Border Health Care (2011/24/EU). Moreover, collaborative efforts will be undertaken to create a unique European registry for RA. As a contribution to the programme, e-ENERCA will take an action for decrease the cross-border health threats currently existing for information, samples and patient’s mobility reducing health inequalities between MS. The establishment of a European Reference Network (ERN) in RA will facilitate the effective implementation of the new e-platforms within the context of the 2011/24/EU Directive.

Methods and means

Methods are focused on the implementation of new ENERCA services through e-Health tools. Three different platforms accessible on the ENERCA website (www.enerca.org) will be developed; e-Registry for epidemiological surveillance, e-Learning for distance medical education and Telemedicine for bringing services for diagnosis and clinical advice for RA in distant locations. A legal study will be carried out involving legal issues related to e-Health services. Smartphones/Tablets applications will be developed to increase the impact of the contents among target groups. Two European on-site training courses will be held and yearly European Symposia will be co-organized with national patients associations. The ENERCA
recommendations for recognition of Centres of Expertise will be presented in face-to-face meetings with national stakeholders in at least 10 Member States. Finally, a survey will be conducted to assess the implications of the transposition of Directive 2011/24/EU

Expected outcomes period

The global outcome is the establishment on ENERCA website of communication channels through e-platforms to reach the widest geographical coverage and reduce inequalities across Europe in the tackle of rare anaemias (RA). e-Registry will allow the extraction of epidemiological data on RA for their active surveillance. e-learning will improve continuing medical education independently of the country of practice. Telemedicine will reduce inequalities by bringing healthcare services for RA in distant locations. This will contribute to an earlier diagnosis and to maximize the cost-effective use of resources. Smart Phones/tablets applications will facilitate the accessibility of the contents. Recognition of centres of expertise (CE) for RA will be promoted among European/National stakeholders involved in RD plans by presenting ENERCA recommendations for recognition of CE. Finally, legal studies will provide conclusions about the state of the art of the transposition of Directive 2011/24/EU
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