Communication Factsheet

This document is part of the
Care Pathways Toolkit for **Healthcare Professionals** & **Patient Representatives**

WP6 TASK 6.2

JARDIN

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Communication Factsheet

CONTEXT

The majority of rare diseases are complex in nature. To address their multi-systemic needs requires the coordination of care between many specialists across the care continuum, from primary care, community and social services, through to secondary care and specialists in multiple regional and national centres. In health and social care systems, **a 'care pathway' is a tool to enhance the coordination and quality of care across this continuum, summarising the existing guidelines, and detail what happens, when, and who is responsible at each stage.**

The European Reference Networks (ERNs) are required to exchange, gather and disseminate knowledge, evidence and expertise within and outside the Network, to promote expertise and support healthcare providers. A core activity of the ERNs is to develop and implement clinical guidelines and care pathways.

The ERNs have developed and adopted guidelines and clinical decision support tools and now are ready to turn these into ERN care pathways and are building referral pathways that bridge from grass-root health services into the Networks.

PATIENT JOURNEYS VS CARE PATHWAYS

Patient Journeys map the common needs of a specific patient community along the different stages of their journey, from first symptoms and diagnosis to treatment and follow-up. These needs are identified and described through the eyes of the patients or caregivers (Bolz-Johnson et al. 2019).

Care pathway outline how the needs of a specific patient population should be best met in the health system. They aim to enhance safety, optimise resource usage, ensure evidence-based care, and maximise patient satisfaction and outcomes.

PATIENT INVOLVEMENT IN THE DESIGN OF CARE PATHWAYS

Patient involvement in the development of guidelines and care pathways has been recognised as an essential component to organise health and social services that are tailored to the specific needs of the patient populations (Bombard et al. 2018; Doherty C. et al. 2017; Coulter A. et al. 2014; Baker G.R., et al. 2018).

The experience of people living with a health condition is the foundation for building a care pathway. Speaking directly to those with patients, their families and caregivers can capture the common experiences and shared needs, providing a stronger picture of the realities they face in accessing appropriate and timely care and treatment. As the 'end-users' of care pathways, they play a critical role in co-creating the solutions and designing the 'ideal' pathway.

ABOUT THE JOINT ACTION ON JARDIN: INTEGRATING ERNS INTO NATIONAL HEALTH SYSTEMS.

In October 2017, the ERN Board of Member States (BoMS) established a Working Group on Integration of the ERNs and issued a statement on 25 June 2019 that encouraged Member States to facilitate the integration of ERNs into their healthcare systems by implementing five recommendations, including "creating appropriate patient pathways in order to improve the care and management of patients with rare or complex diseases" (Annex to the Statement on Integration, 2019).

JARDIN was launched at the start of 2024 as a 'Joint Action' to support the coordination of community actions between EU Member States, focusing on the integration of the ERN system into national health systems.

JARDIN is working with the ERNs to support the network develop model (reference) care pathways for identified RDs or groups of RDs, taking into account a patient-centred approach. Specifically, this involves mapping of patients' care trajectories by leveraging the expertise collected from the Networks and patient representatives, to inform the design and development of ERN care pathways.

Throughout the 3 years of the Joint Action, JARDIN is planning to support the development of more than 10 pathways, which may be for individual conditions or for a thematic group of conditions. JARDIN will also be piloting the implementation of some of these care pathways in several Member States.

EURORDIS SUPPORT

EURORDIS is working with the patient leads involved in the development of these pathways in the different European Reference Network to coordinate the mapping of the patient needs to accessing care for the patient populations for the conditions which have been chosen for care pathways to be developed.

For further information please contact EURORDIS' Team at: pem-epags@eurordis.org.

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