INTEGRATED CARE FOR RARE DISEASES: BRIDGING THE GAP TO IMPROVE THE LIVES OF 30 MILLION PEOPLE IN EUROPE

RARE DISEASES

 Rare, complex, chronic, disabling

30 million people affected in Europe

Fewer than 1 in 2000 people affected by each rare disease

No cure for the vast majority and few treatments available

Expertise and knowledge on their consequences are scarce and difficult to access

PEOPLE LIVING WITH A RARE DISEASE AND THEIR CARERS FACE SERIOUS CARE BURDEN

65% have to visit different health, social and local services in a short period of time

67% feel that these services communicate badly between each other

7 in 10 do not feel well informed about their rights

7 in 10 find that organising care is time-consuming; 6 in 10 find it hard to manage

INTEGRATED HEALTH AND SOCIAL CARE IS ESSENTIAL TO ENABLE PEOPLE LIVING WITH A RARE DISEASE TO

- Overcome their care burden and to secure the services and support that they require
- Achieve a quality of life on an equal footing with other citizens
- Participate in society and in the job market to their highest potential
- Fully realise their fundamental human rights

The appointments should be multidisciplinary allowing for the various specialists to see the patient on the same day and place. Besides facilitating communication, it would avoid that the patient has to travel to different appointments and places, being absent from work: loosing income, facing discrimination at the workplace and spending a lot in travel. Female, Portugal

SHARE THIS FACTSHEET TO HELP RAISE AWARENESS OF THE NEED FOR INTEGRATED CARE FOR RARE DISEASES

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INTEGRATED CARE

Integration is a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency.

Sources:

The information contained in this publication does not necessarily reflect the official position of the European Commission.