

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 BURDEN¹

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: losing income, facing discrimination at the workplace and spending a lot in travel". *Female, Portugal*

The European Commission Expert Group on Rare Diseases therefore recommends that "European Member States should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases, supporting them in the full realisation of their fundamental human rights"².

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

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What is 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"³.

Sources:

- ¹ EURORDIS-Rare Diseases Europe (2017). Juggling care and daily life: The balancing act of the rare disease community. <http://bit.ly/SurveyRD>. Survey of over 3000 people, conducted through the EURORDIS survey initiative Rare Barometer Voices: eurordis.org/voices*
- ² Commission Expert Group on Rare Diseases (2016). Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies. <http://bit.ly/CEGRDreco>
- ³ International Journal of Integrated Care (IJIC) (no date). IJIC guidelines for research and theory papers. Adapted from Kodner, D., & Spreeuwenberg, C. (2002).

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Partners:



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