Action Area 3: Integrated and Networked Care



Integrated and Networked Care

FOCUS OF THIS SECTION:

People living with rare diseases need coordinated, person-centred care that addresses their health and wider needs throughout their lives.

Networked care allows countries to build and strengthen capacity while connecting PLWRD and providers to specialized expertise, diagnostic services and care. Rare disease networks enable knowledge sharing and improve access to diagnosis, treatment and care.

3.1 CARE PATHWAYS

After diagnosis, PLWRD need ongoing treatment and follow-up from trained health professionals. Care should be well coordinated, especially when moving between paediatric and adult services or different care settings.

Integrated care pathways should prioritize access to multidisciplinary health, social support and educational services including mental health, rehabilitation, long-term and palliative care, with clear coordination and transitions.

PROPOSED ACTIONS

For Member States:

Develop and implement guidance on coordination of care and social services across the the life-course of PLWRD

Identify opportunities to integrate rare diseases into primary care and community services, while ensuring access to specialized services

Ensure coverage by insurance providers and pay systems, including incentives for multidisciplinary care models and referral and transition pathways

Ensure access to care and support is based on assessed functioning and care needs

Implement social programmes that promote mental health and well-being for PLWRD and their families and caregivers

Support use of care coordinators for medical and social services

For the WHO:

Share good practices of evidence-based models of care across the life-course, including service delivery and interdisciplinary care coordination, emphasizing diagnosis, treatment, rehabilitation, long-term and palliative care for people living with a rare disease.

Provide guidance and technical support to Member States to identify priority areas for intervention and integration into health systems and UHC packages.

For International & National Partners

Increase awareness and support implementation of national care guidelines for rare diseases.

Support the implementation of coordinated care models through clear referral pathways through timely communication, shared care plans and regular exchange of information among health and social-care teams.

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3.2 CENTRES OF EXPERTISE AND NETWORKS

Rare diseases require highly specialized, multidisciplinary expertise. Individual health systems and facilities cannot always provide the full range of services for every condition. Geographical distance and the uneven distribution of expertise can further compound access challenges. A networked approach connects local services with expertise across national, regional and international networks to inform and strengthen care.

Centres of expertise are specialized, multidisciplinary hubs that provide diagnosis, coordinated care, research, training and support for people living with a rare disease. Their effective identification, recognition and collaboration with health professionals, researchers, academic institutions and patient organizations are essential to networked care. Telemedicine and other digital technologies, supported by reliable connectivity, can complement these networks through virtual consultation, referral, care coordination and knowledge-sharing.

PROPOSED ACTIONS

For Member States:

Establish criteria for and recognize national centres of expertise as specialized hubs for rare disease diagnostic, treatment, care, support, research and training.

Support the mapping, integration and connection of national expertise with international networks of experts, researchers, academic institutions and expert centres.

Enable the collaboration of national centres of expertise with regional and international networks by addressing regulatory, legislative, financial and reimbursement barriers.

Develop, use, and monitor digital technologies, including telemedicine and existing health record systems, to improve access to care

For the WHO:

Develop guidance on networked care, including how to recognise centres of expertise and how to support knowledge sharing.

Help identify centres of expertise worldwide that can coordinate diagnosis and care for specific rare diseases, and support countries in building referral networks for virtual consultation and cross-border collaboration.

Provide technical guidance on using digital health in rare disease care, and encourage countries to share what works.

For International & National Partners

Support the creation of networks of experts and multidisciplinary specialized centres for rare diseases by strengthening international collaboration.

Support countries in amplifying research, development, and evaluation of digital care devices and technologies that are low-cost, simple to use, and integrate into existing interprofessional platforms.

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3.3 WORKFORCE

Improving health, well-being and quality of life for people living with rare diseases, their families and caregivers depends on health and care workforces: primary health-care workers help identify rare diseases and provide ongoing care, while specialized multidisciplinary teams provide condition-specific diagnosis and care. These include primary care, clinicians across relevant specialties, nurses and other allied health professionals, geneticists and genetic counsellors, laboratory technicians, and social care providers.

PROPOSED ACTIONS

For Member States:

Strengthen the primary healthcare workforce to suspect and identify rare diseases, initiate appropriate management, provide ongoing care, support transition planning, and ensure timely referral to specialized services, including counselling

Develop and sustain a specialized, multidisciplinary workforce through relevant pre-service competency-based education, specialist training, continuing professional development and lifelong learning in the diagnosis, treatment, and care of rare diseases

For the WHO:

Provide guidance to Member States in building health and care workforce capacity, by promoting, strengthening and developing guidance on the application of competency-based training models required for the diagnosis, treatment and care of rare diseases

Support Member States in curriculum development and implementation of tools including e-learning techniques to build the capacity of primary as well as specialized workforce.

For International & National Partners

Support countries in expanding workforce capacity through initiatives such as development of institutional capacity for training of health personnel, including public health institutions, medical and nursing schools

Facilitate the exchange of information on good practices to support capacity-building, education, and training for primary care and specialized healthcare workers to identify rare diseases and provide specialized, evidence-based interventions to promote diagnosis, treatment and care

AREA 3: INTEGRATED AND NETWORKED CARE

45. A person-centred, integrated approach to care is essential to improve the health, functioning, well-being and quality of life of people living with a rare disease, including their families and caregivers. They require multidisciplinary, evidence-based, integrated and coordinated care through clear protocols, guidelines, standards and pathways throughout the life course and across the continuum of care—from prevention to detection, rehabilitative, long-term, and palliative care. It should integrate health, social care and community services, including occupational and physical therapy, psychosocial counseling, and home care interventions.

46. Challenges exist when responding to the needs of people living with rare diseases, largely due to tensions between equity, affordability, feasibility and sustainability in health systems. Low prevalence numbers for each rare disease require an approach that addresses the system-level barriers and shared challenges including multidisciplinary workforce capacity and competencies.

47. Networked care, which connects existing expertise, is, therefore, a critical feature of rare disease health system responses, enabling countries to build and strengthen capacity locally while connecting people living with a rare disease and providers to specialized expertise, diagnostic services and multidisciplinary care within and beyond national borders. Rare disease networks enable digital consultations and knowledge sharing; they improve access to timely diagnosis, build pathways for the undiagnosed, and embed research and training capacities to improve diagnosis, treatment and care.

3.1 CARE PATHWAYS

48. After a diagnosis has been made, treatment, follow-up and regular review of outcomes should occur under the care of trained health personnel. Effective transition, including from paediatric to adolescent to adult services and across primary, secondary, tertiary care and long-term care, are essential to ensure continuity of care. Transitions should also be planned between home, community, hospital, rehabilitation, palliative and residential care settings.

49. An integrated systems approach ensures that care pathways adapt and integrate the rare disease response to existing services and contextualize the service design within the specific national health-system architecture.

50. Care pathways should be developed, implemented, and regularly reviewed with shared decision-making and individualized care planning. They should prioritize access to multidisciplinary health, and social, community, support and educational services including mental health, psychosocial, rehabilitation, long-term, and palliative care — with clear referral pathways, care-coordination and transition arrangements.

PROPOSED ACTIONS

51. *Member States*
    a. Develop and implement guidance for evidence-based care pathways that integrate within the national healthcare system to foster the coordination of care and social services across the continuum of care and the life-course of people living with a rare disease.
    b. Review existing care structures to identify opportunities for the integration of prevention, early detection and care of people living with a rare disease and any comorbidities into primary care and community services including in maternal, newborn, child, adolescent, adult and older-person health services, while ensuring access to specialized services when needed.
    c. Ensure appropriate coverage by insurance providers and other pay systems of national standards of care, including incentives for multidisciplinary care models, and associated referral and transition pathway protocols.
    d. Ensure that access to care and support services, including home-based care, personal assistance, day care, respite care, rehabilitation including the provision of assistive technologies, and palliative care is based on assessed functioning and care needs rather than age, specific diagnosis or diagnostic status.
    e. Implement social programmes that promote age-responsive mental health and psychosocial support for people living with a rare disease, as well as initiatives that enhance the well-being of their families and caregivers.
    f. Support use of care coordinators to coordinate medical and social services for people living with a rare disease, their families and caregivers.

52. *Secretariat*
    a. Offer technical assistance to Member States by sharing good practices of evidence-based models of care across the life-course, including service delivery and interdisciplinary care coordination, emphasizing diagnosis, treatment, rehabilitation, long-term and palliative care for people living with a rare disease.
    b. Provide guidance and technical support to Member States to identify priority areas for intervention and integration into health systems and UHC packages.

53. *International and national partners*
    a. Increase awareness and support implementation of national care guidelines for rare diseases.
    b. Support countries in the implementation of coordinated care models through clear referral pathways between primary, secondary and specialized care, and among different specialties throughout the life course, through timely communication, shared care plans and regular exchange of information among health and social-care teams.

3.2 CENTRES OF EXPERTISE AND NETWORKS

54. Because rare diseases require highly specialized, multidisciplinary expertise, it may not be feasible for every health system or locality—even in high-income countries—to provide the full range of services for every condition. Geographical distance and the uneven distribution of expertise can further compound access challenges. A networked

approach connects local services with expertise across national, regional and international networks to inform and strengthen care.

55. Centres of expertise are specialized, multidisciplinary hubs that provide diagnosis, coordinated care, research, training and support for people living with a rare disease. Their effective identification, recognition and collaboration with health professionals, researchers, academic institutions and patient organizations are essential to networked care. Telemedicine and other digital technologies, supported by reliable connectivity, can complement these networks through virtual consultation, referral, care coordination and knowledge-sharing.

PROPOSED ACTIONS

56. *Member States*
    a. Establish criteria for and recognize national centres of expertise as specialized hubs for rare disease diagnostic, treatment, care, support, research and training.
    b. Support the mapping, integration and connection of national expertise with international networks of experts, researchers, academic institutions and expert centres.
    c. Enable the collaboration of national centres of expertise with regional and international networks by addressing regulatory, legislative, financial and reimbursement barriers.
    d. Develop, utilize, and monitor digital technologies, including telemedicine and existing health record systems, to improve access to care.

57. *Secretariat*
    a. Develop guidance on networked care, including criteria to recognize centres of expertise, and mechanisms to support knowledge exchange and collaboration.
    b. Facilitate identification of centres of expertise around the world that can coordinate diagnostics and clinical care in specific rare disease subgroups and support Member States in establishing or strengthening referral networks that support virtual consultation, knowledge-sharing and cross-border collaboration.
    c. Provide technical guidance and support for utilizing digital health in rare disease care and encourage Member States to share lessons learned and good practices.

58. *International and national partners*
    a. Support the creation of networks of experts and multidisciplinary specialized centres for rare diseases by strengthening international collaboration.
    b. Support countries in amplifying research, development, and evaluation of digital care devices and technologies that are low-cost, simple to use, and integrate into existing interprofessional platforms.

3.3 WORKFORCE

59. Improving health, well-being and quality of life for people living with rare diseases, their families and caregivers depends on health and care workforces: primary health-care workers help identify rare diseases and provide ongoing care, while specialized multidisciplinary teams provide condition-specific diagnosis and care. These include primary care, clinicians across relevant specialties, nurses and other allied health professionals, geneticists and genetic counsellors, laboratory technicians, and social care providers.

PROPOSED ACTIONS

60. *Member States*
    a. Strengthen the primary healthcare workforce to suspect and identify rare diseases, initiate appropriate management, provide ongoing care, support transition planning, and ensure timely referral to specialized services, including counselling.
    b. Develop and sustain a specialized, multidisciplinary workforce through relevant pre-service competency-based education, specialist training, continuing professional development and lifelong learning in the diagnosis, treatment, and care of rare diseases.

61. *Secretariat*
    a. Provide guidance to Member States in building health and care workforce capacity, by promoting, strengthening and developing guidance on the application of competency-based training models required for the diagnosis, treatment and care of rare diseases.
    b. Support Member States in curriculum development and implementation of tools including e-learning techniques to build the capacity of primary as well as specialized workforce.

62. *International and national partners*
    a. Support countries in expanding workforce capacity through initiatives such as development of institutional capacity for training of health personnel, including public health institutions, medical and nursing schools.
    b. Facilitate the exchange of information on good practices to support capacity-building, education, and training for primary care and specialized healthcare workers to identify rare diseases and provide specialized, evidence-based interventions to promote diagnosis, treatment and care.