Action Area 6: Empowerment, Participation & Support



Empowerment, Participation & Support

FOCUS OF THIS SECTION:

Raise awareness, reduce stigma and discrimination and promote human rights of PLWRD and their carers

Address knowledge gaps with accessible, reliable and culturally appropriate information to empower PLWRD and their families

Support organizations representing PLWRD and other civil society organizations that build capacity, spearhead advocacy and encourage participation of PLWRD

6.1 INFORMATION, EDUCATION AND AWARENESS

Accessible information and education are essential to improve rare disease literacy for PLWRD and their communities so that they understand symptoms, diagnosis, treatment, care, rights and available services, and can participate meaningfully in care and decision-making. Information and education should be available throughout the life course and adapted to language, age, disability, literacy and location.

Public awareness helps reduce stigma, discrimination and misconceptions, promote understanding of rare diseases and advance the rights and well-being of rare disease communities.

PROPOSED ACTIONS

For Member States:

Develop and maintain, update and disseminate accessible information and education materials on rare diseases

Develop and implement culturally appropriate public awareness campaigns on rare diseases, in partnership with PLWRD and representative organizations

For the WHO:

Support Member States to address information and education needs through the dissemination of accurate informative resources on rare diseases

Support global awareness raising initiatives related to rare diseases

For International & National Partners

Increase rare disease health literacy so PLWRD can better understand and manage their condition and navigate health systems

Support the development of tools and training to support early detection and symptoms management.

Raise awareness on the challenges faced by PLWRD, their families and caregivers through national campaigns

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6.2 CAREGIVER SUPPORT

PLWRD often require ongoing care. This care is provided in large part by informal caregivers, most often female. People rely on on unpaid care more when formal care and support services are unavailable or unaffordable. Caregivers need support from other services. Caregiving should be a choice, and should be compatible with employment, education and the caregiver's own health.

Caregivers face challenges such as stress, financial concerns, social isolation and bereavement. Caring for a person living with a rare disease can affect the caregiver's own health, well-being and social relationships. Roles and challenges vary depending on the age of the caregiver and are also different when caring for children, adolescents or older adults.

PROPOSED ACTIONS

For Member States:

Recognize family and other unpaid caregivers in legislation and policy, and develop or strengthen mechanisms to protect caregivers through social and financial benefits

Ensure that caregiver support measures are responsive to their needs

Provide training programmes, on the identification and reduction of caregiver stress.

Identify caregivers through routine health and social care consultations and provide accessible and evidence-based information on available resources in the community such as psychosocial support and respite services

Involve caregivers as partners in care planning, discharge and transitions, with the consent of the person receiving care

For the WHO:

Support Member States in developing and evaluating evidence-based information, data, training programmes and respite services for caregivers.

Where possible, facilitate access to resources for caregivers of people living with a rare disease to reduce emotional stress and improve coping, self-efficacy and well-being.

For International & National Partners

Increase awareness of the impact of caring for people living with a rare disease, including the need to protect caregivers from discrimination and promote their self-advocacy.

Contribute to the implementation of culturally sensitive, context-specific and person-centred training programmes for caregivers to promote well-being and enhance knowledge and caregiving skills throughout the progression of rare diseases.

Support families and caregivers to plan future and emergency care arrangements, including when caregivers age, become ill or die.

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6.3 ACTIVE ENGAGEMENT IN DECISION-MAKING

The meaningful participation of people living with a rare disease in decision-making, including through their representative organizations, can strengthen the effectiveness and accountability of national, regional and international policy and development programmes.

Organizations representing people living with a rare disease play an important role in collecting, analyzing and sharing information on rare diseases and advocating for recognition and inclusion. These organizations serve as a collective and unified voice for the community, raise awareness of rare diseases across all facets of the health system and help inform government and health agencies of the impact of rare diseases on individuals, families, and caregivers.

The active participation of civil society in efforts to address rare diseases, particularly the participation of organizations representing people living with a rare disease, their families and caregivers, improves relevance and acceptability of public health policies, legislation and services, making them responsive to community needs and supportive in assisting individuals to reach the highest attainable standard of health and well-being.

PROPOSED ACTIONS

For Member States:

Facilitate the creation of organizations representing people living with a rare disease to provide a unified voice to the rare disease community and represent their interests in decision-making.

Promote the involvement of representative organizations in policy development to ensure that the voices of those affected by rare diseases are heard and incorporated into decision-making processes

For the WHO:

Provide support and guidance to Member States in meaningfully engaging with people living with a rare disease by generating and leveraging evidence-based information and good practices on engaging lived experience in decision-making processes

Engage and include people with lived experience in decision-making within WHO's own processes on issues that concern them, through meaningful and structured mechanisms

For International & National Partners

Provide a platform for dialogue between associations and organizations of people living with a rare disease, their families and caregivers, health and social workers, government sectors and other relevant actors at international, regional and national levels

AREA 6: EMPOWERMENT, PARTICIPATION AND SUPPORT

94. Lack of knowledge and awareness needs to be addressed at all levels of society to change the major structural and attitudinal barriers to achieving positive health outcomes, reducing stigma and discrimination, improving care and quality of life, and promoting the human rights of people living with a rare disease, their families and caregivers.

95. Accessible, reliable and culturally appropriate information and education are essential to address knowledge gaps, support earlier recognition and referral, improve understanding of diagnosis and care options, and promote equitable access to health and social services. They also empower people living with a rare disease, their families and caregivers to participate meaningfully in care and decision-making, practice self-care, communicate their needs and navigate complex systems.

96. Organizations representing people living with a rare disease and other civil society organizations play a central role in providing support, building capacity, sharing lived experience and spearheading advocacy tailored to national cultural and social contexts. Through public and political awareness-raising, peer support and meaningful participation in policy development, research, service design and decision-making, they can ensure that national responses reflect the needs and priorities of persons living with a rare disease, their families and caregivers.

6.1 INFORMATION, EDUCATION, AND AWARENESS

97. Accessible information and education are essential to improve rare disease literacy among people living with a rare disease, their families and caregivers, health workers, policymakers and communities. They should support understanding of symptoms, diagnosis, treatment, care, rights and available services, and enable meaningful participation in care and decision-making. This could include preventive actions and strategies, such as public health education and counselling. Information and education should be available throughout the life course and adapted to language, age, disability, literacy and location, including for people in rural and underserved communities.

98. Public awareness initiatives, tailored to national cultural and social contexts, should address stigma, discrimination and misconceptions, promote understanding of rare diseases and advance the rights and well-being of rare disease communities.

PROPOSED ACTIONS

99. *Member States*
    a. In collaboration with health workers, people living with a rare disease, families, caregivers and their representative organizations, develop and maintain accessible, evidence-informed information and education materials on rare diseases, including symptoms, identification, diagnosis, treatment, care pathways, available services and rights.

b. Regularly update these materials, adapting them based on target audience and context, and disseminate through trusted, multilingual and accessible channels, including digital platforms, health-care facilities, schools, community and advocacy organizations.
c. Develop and implement sustained, culturally appropriate public awareness campaigns on rare diseases, in partnership with people living with a rare disease, their families, caregivers and representative organizations, to improve understanding, promote early recognition and referral, reduce stigma and discrimination, and advance inclusion and human rights.

100. *Secretariat*

a. Support Member States to address information and education needs through the dissemination of accurate informative resources on rare diseases.
b. Support global awareness raising initiatives related to rare diseases, as appropriate.

101. *International and national partners*

a. Partner with local communities and health workers to increase rare disease health literacy through robust age-responsive education activities that support people living with a rare disease to better understand and manage their condition and their respective health system.
b. Support the development of tools and training to support early detection and symptoms management.
c. Engage all relevant stakeholders, including people with lived experience and their representative organizations, to raise awareness on the specific challenges and needs faced by individuals living with a rare disease, their families and caregivers through national campaigns with the goal of fostering greater understanding and empathy towards those affected by rare diseases.

6.2 CAREGIVER SUPPORT

102. Due to their chronic and progressive nature, people living with a rare disease often require ongoing care that is provided in large part by informal caregivers, most often female. Reliance on unpaid care is greatest where formal care and support services are unavailable or unaffordable. Supporting caregivers therefore requires accessible services that share responsibility for care, so that caregiving is a choice and compatible with employment, education and the caregiver's own health.

103. Challenges for caregivers include stress, role strain, financial burden, social isolation and bereavement. Caring for a person living with a rare disease may affect the caregiver’s own health, well-being and social relationships. Roles and challenges may vary depending on the age of the caregiver and are also different when caring for children, adolescents or older adults.

PROPOSED ACTIONS

104. *Member States*

a. Recognize family and other unpaid caregivers in legislation and policy, and develop, update or strengthen mechanisms to protect caregivers, such as through the implementation of social and financial benefits (e.g., pension, leave or flexible work hours).
b. Ensure that caregiver support measures are responsive to their needs; these may include flexible work and care-leave arrangements, income support, respite care and pension protection, according to national context and resources.
c. Provide training programmes, in collaboration with relevant stakeholders, for health and social care staff in the identification and reduction of caregiver stress.
d. Identify caregivers through routine health and social care consultations and provide accessible and evidence-based information on available resources in the community, such as psychosocial support and respite services and other resources tailored to the needs of caregivers of those living with a rare disease.
e. Involve caregivers as partners in care planning, discharge and transitions, with the consent of the person receiving care.

105. *Secretariat*

a. Support Member States in developing and evaluating evidence-based information, data, training programmes and respite services for caregivers.
b. Where possible, facilitate access to resources for caregivers of people living with a rare disease to reduce emotional stress and improve coping, self-efficacy and well-being.

106. *International and national partners*

a. Increase awareness of the impact of caring for people living with a rare disease, including the need to protect caregivers from discrimination and promote their self-advocacy.
b. Contribute to the implementation of culturally sensitive, context-specific and person-centred training programmes for caregivers to promote well-being and enhance knowledge and caregiving skills throughout the progression of rare diseases.
c. Support families and caregivers to plan future and emergency care arrangements, including when caregivers age, become ill or die.

6.3 ACTIVE ENGAGEMENT IN DECISION-MAKING

107. The meaningful participation of people living with a rare disease in decision-making, including through their representative organizations, can strengthen the effectiveness and accountability of national, regional and international policy and development programmes.

108. Organizations representing people living with a rare disease play an important role in collecting, analyzing and disseminating the limited existing information on rare diseases and advocating for recognition and inclusion. These organizations serve as a collective and unified voice for the community, raise awareness of rare diseases across all

facets of the health system and help inform government and health agencies of the impact of rare diseases on individuals, families, and caregivers.

109. The active participation of civil society in efforts to address rare diseases, particularly the participation of organizations representing people living with a rare disease, their families and caregivers, improves relevance and acceptability of public health policies, legislation and services, making them responsive to community needs and supportive in assisting individuals to reach the highest attainable standard of health and well-being.

PROPOSED ACTIONS

110. *Member States*

a. Facilitate the creation of organizations representing people living with a rare disease to provide a unified voice to the rare disease community and represent their interests in decision-making.
b. Promote the involvement of representative organizations in policy development to ensure that the voices of those affected by rare diseases are heard and incorporated into decision-making processes.

111. *Secretariat*

c. Provide support and guidance to Member States in meaningfully engaging with people living with a rare disease by generating and leveraging evidence-based information and good practices on engaging lived experience in decision-making processes.
d. Engage and include people with lived experience in decision-making within WHO's own processes on issues that concern them, through meaningful and structured mechanisms.

112. *International and national partners*

a. Provide a platform for dialogue between associations and organizations of people living with a rare disease, their families and caregivers, health and social workers, government sectors and other relevant actors at international, regional and national levels.