Global action plan on the public health response to dementia

2017 - 2025
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FOREWORD

Dementia is a major cause of disability and dependency among older adults worldwide, affecting memory, cognitive abilities, and behavior, ultimately interfering with one’s ability to perform daily activities. The impact of dementia is not only significant in financial terms, but also represents substantial human costs to countries, societies, families and individuals.

The global action plan on the public response to dementia 2017–2025 signals an important step forward in achieving physical, mental and social wellbeing for people with dementia, their carers and families. It is an important opportunity for individuals, communities and Member States to realize the vision of a world in which dementia is prevented and people with dementia and their carers receive the care and support they need to live a life with meaning and dignity. The World Health Organization looks forward to fulfilling the ambitious targets presented in the action plan by working alongside Member States and Non-state actors, including people with dementia and their families, to improve the health and wellbeing of those affected by dementia, both for present and future generations.
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OVERVIEW OF THE GLOBAL SITUATION

1. Dementia is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person’s ability to maintain the activities of daily living. Alzheimer disease is the most common form of dementia and may contribute to 60–70% of cases. Other major forms include vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to frontotemporal dementia. The boundaries between different forms of dementia are indistinct and mixed forms often coexist.

2. In 2015, dementia affected 47 million people worldwide (or roughly 5% of the world’s elderly population), a figure that is predicted to increase to 75 million in 2030 and 132 million by 2050. Recent reviews estimate that globally nearly 9.9 million people develop dementia each year; this figure translates into one new case every three seconds. Nearly 60% of people with dementia currently live in low- and middle-income countries and most new cases (71%) are expected to occur in those countries.2,3

3. Crucially, although age is the strongest known risk factor for the onset of dementia, it is not an inevitable consequence of ageing. Further, dementia does not exclusively affect older people, with young onset dementia (defined as the onset of symptoms before the age of 65 years) accounting for up to 9% of cases.4 Some research has shown a relationship between the development of cognitive impairment and lifestyle-related risk factors that are shared with other noncommunicable diseases. These risk factors include physical inactivity, obesity, unbalanced diets, tobacco use and harmful use of alcohol as well as diabetes mellitus and mid-life hypertension. Other potentially modifiable risk factors more specific to dementia include mid-life depression, low educational attainment, social isolation and cognitive inactivity. Additionally, non-modifiable genetic risk factors exist that increase a person’s risk of developing dementia.5 There is also evidence suggesting that overall more women develop dementia than men.6

4. Dementia is a major cause of disability and dependency among older adults worldwide, having a significant impact not only on individuals but also on their carers, families, communities and societies. Dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease.1 In light of the improved life expectancy globally, this figure is expected to increase further.

5. Dementia leads to increased costs for governments, communities, families and individuals, and to loss in productivity for economies.

   - In 2015, dementia costs7 were estimated at US$ 818 billion, equivalent to 1.1% of global gross domestic product, ranging from 0.2% for low- and middle-income countries to 1.4% for high income countries. By 2030, it is estimated that the cost of caring for people with dementia worldwide will have risen to US$ 2 trillion, a total that could undermine social and economic development globally and overwhelm health and social services, including long term care systems specifically.8

   - People with dementia and their families face significant financial impact from the cost of health and social care and from reduction or loss of income. In high-income countries, the costs related to dementia are shared between informal care (45%) and social care (40%). In contrast, in low- and middle-income countries social care costs (45%) pale in comparison to informal care costs.2 The expected disproportionate increase in informal care costs is estimated at US$ 818 billion, equivalent to 1.1% of global gross domestic product, ranging from 0.2% for low- and middle-income countries to 1.4% for high income countries. By 2030, it is estimated that the cost of caring for people with dementia worldwide will have risen to US$ 2 trillion, a total that could undermine social and economic development globally and overwhelm health and social services, including long term care systems specifically.8

7. WHO and the World Bank estimate a need by 2030 for 40 million new health and social care jobs globally and about 18 million additional health workers, primarily in low-resource settings, in order to attain high and effective coverage with the broad range of necessary health services. In addressing dementia, expanding the health and social care workforce with appropriate skill mixes as well as available interventions and services will be essential to prevent, diagnose, treat and care for people with dementia.
VISION, GOALS AND CROSS-CUTTING PRINCIPLES

Vision
8. The vision of the global action plan on the public health response to dementia is a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.

Goal
9. The goal of the global action plan is to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on them as well as on communities and countries.

Cross-cutting principles
10. The global action plan is grounded in the following seven cross-cutting principles.

a. Human rights of people with dementia
Policies, plans, legislation, programmes, interventions and actions should be sensitive to the needs, expectations and human rights of people with dementia, consistent with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments.

b. Empowerment and engagement of people with dementia and their carers
People with dementia, their carers and organizations that represent them should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research of dementia.

c. Evidence-based practice for dementia risk reduction and care
Based on scientific evidence and/or best practice, it is important to develop strategies and interventions for dementia risk reduction and care that are person-centred, cost-effective, sustainable and affordable, and take public health principles and cultural aspects into account.

d. Multisectoral collaboration on the public health response to dementia
A comprehensive and coordinated response to dementia requires collaboration among all stakeholders to improve prevention, risk reduction, diagnosis, treatment and care. Achieving such collaboration requires engagement at the government level of all relevant public sectors, such as health (including alignment of existing noncommunicable disease, mental health and ageing efforts), social services, education, employment, justice, and housing, as well as partnerships with relevant civil society and private sector entities.

e. Universal health and social care coverage for dementia
Designing and implementing health programmes for universal health coverage must include financial risk protection and ensuring equitable access to a broad range of promotive, preventive, diagnostic and care services (including palliative, rehabilitative and social support) for all people with dementia and their carers.

f. Equity
All efforts to implement public health responses to dementia must support gender equity and take a gender-sensitive perspective, keeping in mind all vulnerabilities specific to each national context, consistent with the 2030 Agenda for Sustainable Development, which recognizes that people who are vulnerable, including people with disabilities, older people and migrants, must be empowered.

g. Appropriate attention to dementia prevention, cure and care
Steps to realize this focus include using existing knowledge and experience to improve prevention, risk reduction, care and support for people with dementia and their carers and generation of new knowledge towards finding disease-modifying treatments or a cure, effective risk reduction interventions and innovative models of care.
Effective implementation of the global action plan on the public health response to dementia will require actions by Member States, the Secretariat and international, regional, national and subnational partners. Depending on national context, these partners include but are not limited to:

- development agencies, including international multilateral agencies (for example, OECD, United Nations development agencies and the World Bank), regional agencies (for example, regional development banks), subregional intergovernmental agencies and bilateral development aid agencies;
- academic institutions and research agencies, including the network of WHO collaborating centres for mental health, ageing, disability, human rights and social determinants of health, and other related networks;
- civil society, including people with dementia, their carers and families and associations that represent them, and other relevant organizations;
- the private sector, health insurance, and the media.

The roles of these four groups often overlap and can include multiple actions cutting across the areas of governance, health and social care services, promotion of understanding and prevention in dementia, and information, evidence and research. Country-based assessments of the needs and capacities of different partners will be essential to clarify the roles and actions of stakeholder groups.

Targets included in this global action plan are defined for achievement globally. Each Member State can be guided by these global targets when setting its own national targets, taking into account national circumstances. Each Member State will also decide how these global targets should be adapted for national planning, processes (including data collection systems), policies and strategies.

The global action plan recognizes that each Member State faces specific challenges in implementing these action areas and therefore suggests a range of proposed actions that each Member State will need to adapt to the national context.
The global action plan comprises seven action areas, which form the underlying structural framework:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation
Dementia as a public health priority

16. Given the range of the population affected directly or indirectly by dementia and the complexity of this condition, dementia requires a whole-of-government, broad, multistakeholder, public health approach. Such an approach will lead to a comprehensive response from the health and social care system (both public and private) and other government sectors, and will engage people with dementia and their carers and other relevant stakeholders and partners.

17. Rationale. The development and coordination of policies, legislation, plans, frameworks and integrated programmes of care through a comprehensive, multisectoral approach will support the recognition, and address the complex needs, of people with dementia within the context of each country. This approach is in line with the principle of universal health coverage and the standards outlined in the Convention on the Rights of Persons with Disabilities.

18. Global target 1:
75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.¹

PROPOSED ACTIONS FOR MEMBER STATES

19. Develop, strengthen and implement national and/or subnational strategies, policies, plans or frameworks that address dementia, whether as separate instruments or integrated into other planned actions for noncommunicable diseases, mental health, ageing, and disability (or equivalent). These undertakings should give consideration to equity, dignity and the human rights of people with dementia and support the needs of carers, in consultation with people with dementia and other relevant stakeholders.

20. Promote mechanisms to monitor the protection of the human rights, wishes and preferences of people with dementia and the implementation of relevant legislation, in line with the objectives of the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments. These mechanisms include safeguards for concepts such as legal capacity, self-determination, supported decision-making, and power of attorney, and for protection against exploitation and abuse in institutions as well as in the community.

21. Set up a focal point, unit or functional division responsible for dementia or a coordination mechanism within the entity responsible for noncommunicable diseases, mental health or ageing within the health ministry (or equivalent body), in order to ensure sustainable funding, clear lines of responsibility for strategic planning, implementation, mechanisms for multisectoral collaboration, service evaluation, monitoring and reporting on dementia.

22. Allocate sustainable financial resources that are commensurate with the identified service need and human and other resources required to implement national dementia plans and actions, and set up mechanisms for tracking expenditures on dementia in health, social and other relevant sectors such as education and employment.

23. Offer technical support, tools and guidance to Member States, and strengthen national capacity in:

- leadership within health ministries and other relevant sectors for the development, strengthening and implementation of evidence-based national and/or subnational strategies or plans and associated multisectoral resource planning, budgeting and tracking of expenditure on dementia;

- evaluating and implementing evidence-based options that suit Member States’ needs and capacities and assessing the health impact of public policies on dementia by supporting national and international partners and establishing or strengthening national reference centres, WHO collaborating centres and knowledge-sharing networks;

- coordinating programmes on dementia with those on related noncommunicable diseases, ageing, mental health and health systems, and with service delivery and processes to ensure maximum synergy and optimal use of existing and new resources.

24. Compile and share knowledge and best practices on existing policy documents dealing with dementia, including codes of practice and mechanisms to monitor the protection of human rights and implementation of legislation,

¹ The global target indicators and means of verification are provided in the Appendix.
consistent with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments.

25. Promote and support collaboration and partnerships with countries at international, regional and national levels for multisectoral action in the response to dementia and aligning these with the principle of universal health coverage. Collaboration and partnerships should include all relevant sectors: health, justice and social services sectors, civil society, people with dementia, carers and family members, and organizations in the United Nations system, United Nations interagency groups and intergovernmental organizations.

PROPOSED ACTIONS FOR INTERNATIONAL, REGIONAL AND NATIONAL PARTNERS

26. Create and strengthen associations and organizations of people with dementia, their families and carers, and foster their collaboration with existing disability (or other) organizations as partners in the prevention and treatment of dementia.

27. Motivate and actively engage in dialogue between associations representing people with dementia, their carers and families, health workers and government authorities in reforming health and social laws, policies, strategies, plans and programmes relevant to dementia, while paying explicit attention to the human rights of people with dementia and their carers as well as their empowerment, engagement and inclusion.

28. Support the development and application of national dementia policies, legislation, strategies and plans, and the creation of a formal role and authority for people with dementia and their carers to influence the process of designing, planning and implementing policies, laws and services related to dementia.
29. There is a common misconception that dementia is a natural and inevitable part of ageing rather than a disease process, resulting in barriers to diagnosis and care. The lack of understanding also causes fear of developing dementia and leads to stigmatization and discrimination. Furthermore, people with dementia are frequently denied their human rights in both the community and care homes.

30. Dementia-awareness programmes should foster accurate understanding of dementia and its various subtypes as clinical diseases; reduce stigmatization and discrimination associated with dementia; educate people about the human rights of people with dementia and the Convention on the Rights of Persons with Disabilities; enhance the general population's ability to recognize early symptoms and signs of dementia; and increase the public's knowledge of risk factors associated with dementia, thereby promoting healthy lifestyles and risk reduction behaviour in all.

31. A dementia-friendly society possesses an inclusive and accessible community environment that optimizes opportunities for health, participation and security for all people, in order to ensure quality of life and dignity for people with dementia, their carers and families. Shared key aspects of dementia-friendly initiatives include safeguarding the human rights of people with dementia, tackling the stigmatization associated with dementia, promoting a greater involvement of people with dementia in society, and supporting families and carers of people with dementia. The concept of dementia-friendliness is tightly linked to societies also being age-friendly. Both age- and dementia-friendly initiatives should take into account the fact that a significant number of older people are living alone and are sometimes very isolated.

32. Dementia-awareness campaigns and dementia-friendly programmes that are tailored to the cultural contexts and particular needs of a community can promote enhanced health and social outcomes that reflect the wishes and preferences of people with dementia, as well as improve the quality of life for people with dementia, their carers and the broader community.

33. Rationale. Increasing public awareness, acceptance and understanding of dementia and making the societal environment dementia-friendly will enable people with dementia to participate in the community and maximize their autonomy through improved social participation.

34. Global target 2.1: 100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025.¹

35. Global target 2.2: 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.¹

**PROPOSED ACTIONS FOR MEMBER STATES**

36. In collaboration with people with dementia, their carers and the organizations that represent them, the media and other relevant stakeholders, organize national and local public health and awareness campaigns that are community- and culture-specific. This cooperative action will improve the accuracy of the general public's knowledge about dementia, reduce stigmatization, dispel myths, promote early diagnosis, and emphasize the need for gender- and culturally-appropriate responses, recognition of human rights and respect for the autonomy of people with dementia.

37. Supporting all aspects of the social and built environments, including the provision of amenities, goods and services, in order to make them more inclusive and age- and dementia-friendly, promoting respect and acceptance in a manner that meets the needs of people with dementia and their carers and enables participation, safety and inclusion.

38. Develop programmes, adapted to the relevant context, to encourage dementia-friendly attitudes in the community and the public and private sectors that are informed by the experiences of people with dementia and their carers. Target different community and stakeholder groups, including but not limited to: school students and teachers, police, ambulance, fire brigades, transport, financial and other public service providers, education and faith-based organizations, and volunteers.

**ACTIONS FOR THE SECRETARIAT**

39. Offer technical support to Member States in strengthening global, regional and national capacity:

- to engage and include people with dementia, their carers and organizations that represent them in decision-making within WHO's own processes and on issues that concern them;
- for the selection, formulation, ¹The global target indicator and means of verification are provided in the Appendix.
implementation and dissemination of best practices for awareness-raising and reduction of stigmatization and discrimination towards people with dementia.

40. Building upon the WHO Global Network of Age-friendly Cities and Communities and its dedicated website,1 integrate and link dementia-friendly initiatives by documenting and evaluating existing dementia-friendly initiatives in order to identify evidence of what works in different contexts and disseminate this information.

41. Promote awareness and understanding of dementia, the human rights of people with dementia and the role of families and/or other carers as well as maintain and strengthen partnerships with organizations representing people with dementia and their carers.

42. Develop guidance for Member States on how to implement, monitor and evaluate dementia-friendly initiatives.

PROPOSED ACTIONS FOR INTERNATIONAL, REGIONAL AND NATIONAL PARTNERS

43. Encourage all stakeholders to:

- raise awareness of the magnitude of the social and economic impact of dementia;
- include people with dementia, their carers and families in all aspects of developing and strengthening services that support the autonomy of people with dementia;
- protect and promote human rights of people with dementia and support their carers and their families;
- redress the inequities in vulnerable populations.

44. Ensure that people with dementia are included in activities of the wider community and foster cultural, social and civic participation by enhancing their autonomy.

45. Share in the development and implementation of all relevant programmes to raise awareness about dementia and make communities more dementia-friendly and -inclusive.

Growing evidence suggests an interrelationship between dementia on one side and noncommunicable disease and lifestyle-related risk factors on the other. These risk factors include physical inactivity, obesity, unbalanced diets, tobacco use, harmful use of alcohol, diabetes mellitus and mid-life hypertension. In addition, other potentially modifiable risk factors are more specific to dementia and include social isolation, low educational attainment, cognitive inactivity and mid-life depression. Reducing the level of exposure of individuals and populations to these potentially modifiable risk factors, beginning in childhood and extending throughout life, can strengthen the capacity of individuals and populations to make healthier choices and follow lifestyle patterns that foster good health.

There is growing consensus that the following measures are protective and can reduce the risk of cognitive decline and dementia: increasing physical activity, promotion of cognitively stimulating activities and learning as well as prevention and management of diabetes, hypertension, especially in mid-life, and depression.

By improving the capacity of health and social care professionals to provide evidence-based, multisectoral, gender and culturally-appropriate interventions to the general population, educate about and proactively manage modifiable risk factors for dementia that are shared with other noncommunicable diseases, the risk of developing dementia can be reduced or its progression delayed.

The relevant global targets defined in the Global action plan for prevention and control of noncommunicable diseases 2013–2020 and any future revisions are achieved for risk reduction and reported.

PROPOSED ACTIONS FOR INTERNATIONAL, REGIONAL AND NATIONAL PARTNERS

54. Encourage all stakeholders to engage in activities to:

- promote and mainstream population health strategies that are age-inclusive, gender-sensitive and equity-based at national, regional and international levels in order to support a socially active lifestyle that is physically and mentally healthy for all, including people with dementia, their carers and families;

- take particular actions that have been shown to reduce the risk of dementia, particularly during mid-life;

- support national efforts for prevention and control of noncommunicable diseases in general and dementia in particular, for example, through exchange of information on evidence-based best practices and dissemination of research findings.
Dementia diagnosis, treatment, care and support

55. Dementia is associated with complex needs and high levels of dependency and morbidity in its later stages, requiring a range of health and social care, including long-term care services. People with dementia are also less likely to be diagnosed for comorbid health conditions, which, when left untreated, can cause faster decline, and to receive the care and support they need to manage them. The services that they require include case-finding, diagnosis, treatment (including pharmacological and psychosocial), rehabilitation, palliative/end-of-life care and other support such as home help, transport, food and the provision of a structured day with meaningful activities.

56. People with dementia should be empowered to live in the community and to receive care aligned with their wishes and preferences. To ensure that people with dementia can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity, they need integrated, person-centred, accessible, affordable health and social care, including long-term care. Long-term care covers all activities, whether these are provided by health, social or palliative care services or result from a dementia-friendly environment. Palliative care is a core component of the continuum of care for people living with dementia from the point of diagnosis through to the end of life and into the bereavement stages for families and carers. It provides physical, psychosocial and spiritual support for people with dementia and their carers including support with advance care planning.

57. The global action plan proposes some principles for organizing and developing health and social care, including long-term care systems for dementia. Providing sustainable care across the continuum from diagnosis to the end of life requires: timely diagnosis; the integration of dementia treatment and care into primary care; coordinated continuity of health and social care including long-term care between different providers and system levels, multidisciplinary collaboration and active cooperation between paid and unpaid carers. Planning responses to and recovery from humanitarian emergencies must ensure that individual support for people with dementia and community psychosocial support are widely available.

58. Adequately trained and qualified workforces are required to provide these interventions. The continuity of care between different care providers, multiple sectors and system levels and active collaboration between paid and unpaid carers are crucial, from the first symptoms of dementia until the end of life. Integrated, evidence-based, person-centred care is required in all settings where people with dementia live, ranging from their homes, the community, assisted-living facilities and nursing homes to hospitals and hospices. The skills and capacity of the workforce and services are often challenged by the complex needs of people with dementia.

59. Rationale. The needs and preferences of people with dementia can be met and their autonomy from diagnosis to the end of life respected through integrated, culturally appropriate, person-centred, community-based health, psychosocial, long-term care and support and, where appropriate, the inputs of families and carers.

60. Global target 4: In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025.

PROPOSED ACTIONS FOR MEMBER STATES

61. Develop a pathway of efficient, coordinated care for people with dementia that is embedded in the health and social care system (including long-term care), to provide integrated, person-centred care as and when it is required. The pathway should provide quality care and management that integrates multiple services, including primary health care, home care, long-term care, specialist medical care, rehabilitation and palliative services, household help, food and transport services, other social welfare services and meaningful activities, into a seamless bundle that enhances the capacity and functional ability of people with dementia.

62. Build the knowledge and skills of general and specialized staff in the health workforce to deliver evidence-based, culturally-appropriate and human rights-oriented health and social care, including long-term care services for people with dementia. (Mechanisms may include teaching the core competences of dementia diagnosis, treatment and care in undergraduate and graduate medical and paramedical training, and continuing training programmes for all health and social care professionals, in collaboration with key stakeholders such as regulatory bodies.) Earmark budgets and resources for in-service training for these

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1. All people who are diagnosed should receive appropriate post-diagnostic health and social care.
2. The global target indicator and means of verification are provided in the Appendix.
professionals, or include such budgets and resources in specific programmes.

63. Improve the quality of care towards the end of life by: recognizing advanced dementia as a condition requiring palliative care; promoting awareness about advanced care planning for all people living with dementia to document their wishes for the end of their life; using validated end-of-life pathways and ensuring that people with dementia have their values and preferences respected and are cared for in their place of choice; and providing training for health care professionals and palliative care specialists.

64. Systematically shift the locus of care away from hospitals towards community-based care settings and multidisciplinary, community-based networks that integrate social and health systems and provide quality care and evidence-based interventions.

65. Enhance access to a range of person-centred, gender-sensitive, culturally-appropriate and responsive services including liaison with local nongovernmental organizations and other stakeholders in order to provide information that empowers people with dementia to make informed choices and decisions about their care. Respect their rights and preferences and foster active collaboration between the person with dementia, their families and carers and service providers from the first symptoms through to the end of life.

PROPOSED ACTIONS FOR INTERNATIONAL, REGIONAL AND NATIONAL PARTNERS

69. Support people with dementia and their families and carers, for example, by developing evidence-based, user-friendly information and training tools concerning dementia and available services to allow timely diagnosis and enhance the continued provision of long-term care, or by setting up national helplines and websites with information and advice at local levels.

70. Support the training of health and social care personnel to provide evidence-based treatment and care for people with dementia, by developing training relevant to needs, supporting teaching institutions in revising the contents of curricula so as to place greater emphasis on dementia, and ensuring that people with dementia are engaged, as appropriate, in the development and provision of education and training.

71. Promote community-based rehabilitation as an effective strategy to enable and support people with dementia in preserving their autonomy and rights and ensuring that the person with dementia remains at the centre of all discussions on diagnosis, treatment and care.

ACTIONS FOR THE SECRETARIAT

66. Offer technical support to Member States for documenting and sharing best practices of evidence-based service delivery and care coordination, and provide support to Member States in developing dementia care pathways in line with the principle of universal health coverage.

67. Develop and implement guidelines, tools and training materials, such as model training curricula, covering core competencies relating to dementia for health and social care workers in the field. Provide support to Member States in the formulation of human resource strategies for dementia, including the identification of gaps, specific needs and training requirements for health and social care workers as well as graduate and undergraduate education about integrated provision of long-term care that is person-centred from diagnosis to the end of life.

68. Provide guidance on strengthening the implementation of the dementia component of the WHO Mental Health Gap Action Programme1 to enhance capabilities of existing human resources and train more staff, and on improving the ability to provide quality care and evidence-based interventions through primary health care.

Support for dementia carers

72. Carers can be defined by their relationship to the person with dementia and their care input. Many dementia carers are relatives or extended family members, but close friends, neighbours and paid lay persons or volunteers can also take on responsibilities for caring. Carers are involved in providing “hands-on” care and support for people with dementia or play a significant role in organizing the care delivered by others. Carers often know the person with dementia well, and therefore are likely to have knowledge of and information about the person with dementia that is crucial for developing effective personalized needs-based treatment and care plans. Carers should therefore be considered essential partners in the planning and provision of care in all settings according to the wishes and needs of the person with dementia.

73. It should be noted that being a carer for someone with dementia may affect the carer’s physical and mental health and well-being and social relationships. Health systems must consider both the substantial need of people with dementia for help from others and its significant impact on carers and families, including economic impact. Carers should have access to support and services tailored to their needs in order effectively to respond to and manage the physical, mental and social demands of their caring role.

74. Rationale. The creation and implementation of means to deliver multisectoral care, support and services for carers will help to meet the needs of carers, and prevent a decline in their physical and mental health and social well-being.

75. Global target 5: 75% of countries provide support and training programmes for carers and families of people with dementia by 2025.1

PROPOSED ACTIONS FOR MEMBER STATES

76. Provide accessible and evidence-based information, training programmes, respite services and other resources tailored to the needs of carers to improve knowledge and caregiving skills, such as coping with challenging behaviour, to enable people with dementia to live in the community and to prevent stress and health problems for their carers.

77. Provide training programmes for health care and social care staff for the identification and reduction of stress and burn-out of carers.

78. Develop or strengthen protection of carers, such as social and disability benefits, policies and legislation against discrimination, for example in employment, and support them beyond their caregiving role in all settings.

79. Involve carers in the planning of care, with attention being given to the wishes and preferences of people with dementia and their families.

ACTIONS FOR THE SECRETARIAT

80. Build evidence on and articulate the importance of carers in the lives of people with dementia, while raising awareness about the disproportionate effect on women, and offer technical support to Member States by monitoring trends in availability of carer-support services. Provide support to Member States in developing evidence-based information, training programmes and respite services for carers, using a multisectoral approach, and foster outcome measurement.

81. Facilitate access to affordable, evidence-based resources for carers to improve knowledge and skills, reduce emotional stress and improve coping, self-efficacy and health by making use of information and communication technologies such as Internet and mobile phone technologies (for instance, WHO iSupport2), for education, skills training and social support.

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1. The global target indicator and means of verification are provided in the Appendix.

PROPOSED ACTIONS FOR INTERNATIONAL, REGIONAL AND NATIONAL PARTNERS

82. Increase awareness of the involvement, and its consequences, of carers and families in the lives of people with dementia, protecting them from discrimination, supporting their ability to continue their caregiving in a gender-sensitive manner, and empowering carers with opportunities to develop self-advocacy skills to be able to meet specific challenges in accessing health and social care, including long-term care services.

83. Assist in carrying out appropriate training programmes: for carers and families to enhance knowledge and caregiving skills across the progression of dementia; and on a person-centred approach to promote respect and well-being.
Information systems for dementia

84. Systematic, routine population-level monitoring of a core set of dementia indicators provides the data needed to guide evidence-based actions to improve services and to measure progress towards implementing national dementia policies. By building and/or strengthening information systems for dementia, the functional trajectories of people with dementia, their carers and families can be improved. However, this will require significant changes, while respecting existing regulatory frameworks, to the routine collection, recording, linkage and disaggregation for the sharing of health and administrative data of each encounter of a person with dementia with the health and social care system.

85. Rationale. Systematic monitoring and evaluation of the usage of health and social care systems can provide the best available evidence for policy development and service delivery, and can improve prevention and the accessibility and coordination of care for people with dementia across the continuum, from risk reduction to the end of life.

86. Global target 6:
50% of countries routinely collect a core set of dementia indicators through their national health and social information systems every two years by 2025.1

PROPOSED ACTIONS FOR MEMBER STATES

87. Develop, implement and improve, as needed, national surveillance and monitoring systems, including registers that are integrated into existing health information systems, in order to improve availability of high-quality, multisectoral data on dementia. Enable access to health and social care data and map available services and resources at national and regional levels in order to improve service delivery and coverage across the care continuum from prevention through risk reduction to the end of life.

88. Update or create supportive policy or legislation pertaining to the measurement, collection and sharing of data on health and social care for dementia and integrate this information routinely into national health information systems so as to facilitate routine reporting on dementia.

89. Collect and use the necessary data on epidemiology, care and resources relating to dementia in order to implement relevant policies and plans.

PROPOSED ACTIONS FOR INTERNATIONAL, REGIONAL AND NATIONAL PARTNERS

90. Offer technical support to Members States as they:
- develop and/or reform national data collection systems, including health information systems, in order to strengthen multisectoral dementia data collection;
- build national capacity and resources for systematic collection, analysis and use of dementia specific data through development of targets and indicators that account for national circumstances, yet are aligned as closely as possible with indicators and targets of the global monitoring framework.

91. Develop a core set of indicators in line with this action plan and provide guidance, training and technical assistance on capturing information and facilitating the use of these data to monitor outcomes. WHO’s Global Dementia Observatory provides the mechanism to monitor systematically and facilitate the use of data from these core indicators, offering a platform for the exchange of data and knowledge in order to support evidence-based service planning, sharing of best practices and strengthening of both policies on dementia and health and social care systems.

92. Offer technical support to Member States in generating and providing information for monitoring of global, regional and national targets as required, through the Global Dementia Observatory.

93. Provide support to Member States and the Secretariat in developing tools and strengthening capacity for surveillance and information systems that: capture data on core indicators on dementia; monitor usage of health and social care and support services for people with dementia, carers and families; and enable an assessment of trends over time.

94. Advocate the involvement of people with dementia and their families and carers in the creation, collection, analysis and use of data on dementia.

1. The global target indicator and means of verification are provided in the Appendix.
Dementia research and innovation

95. If the incidence of dementia is to be reduced and the lives of people with dementia are to be improved, research and innovation are crucial, as is their translation into daily practice. It is important not only that funding and appropriate infrastructures for dementia research and innovation are available but also that mechanisms are in place that assist appropriate recruitment of people with dementia, their families and carers into research studies. Research and development costs are higher for dementia than other therapeutic areas, because of lower success rates, longer development times, and low recruitment rates into trials; this disproportion discourages investment in this area. Research is needed to find a cure for dementia, but research is equally needed into prevention, risk reduction, diagnosis, treatment and care, including the disciplines of social science, public health and implementation research.

96. Collaboration among and between Member States and relevant stakeholders, with a particular focus on strengthening North–South, South–South and triangular cooperation, to implement a global dementia research agenda, will increase the likelihood of effective progress globally towards better prevention, diagnosis, treatment and care for people with dementia.

97. There is a growing interest in, and call for, the use of innovative health technologies in prevention, risk reduction, early diagnosis, treatment, care and support relating to dementia. These innovations aim to improve knowledge, skills and coping mechanisms in order to facilitate and support the daily lives of people with dementia and their carers while meeting, in particular, identified needs in an evidence-based and age-, gender- and culturally-sensitive manner.

98. **Rationale**: The successful implementation of research into dementia aligned with identified research priorities and social and technological innovations can increase the likelihood of effective progress towards better prevention, diagnosis, treatment and care for people with dementia.

99. **Global target 7**: The output of global research on dementia doubles between 2017 and 2025.¹

100. Develop, implement and monitor the realization of a national research agenda on prevention, diagnosis, treatment and care of people with dementia in collaboration with academic and research institutions; this work could be stand-alone or integrated into related research programmes that focus on filling gaps in evidence to support policy or practice. Strengthen research capacity for academic collaborations on national priorities for research into dementia by engaging relevant stakeholders, including people with dementia. Relevant steps may include: improving research infrastructure for dementia and related fields, enhancing competence of researchers to conduct high-quality research, and establishing centres of excellence for research into dementia.

101. Increase investment in dementia research and innovative health technologies and improve research and innovative health care for people with dementia.

102. Foster the development of technological innovations that, in terms of design and evaluation, respond to the physical, psychological and social needs of people with dementia, their carers or people at risk of developing dementia; these innovations include but are not limited to diagnosis, disease monitoring and assessment, assistive technologies, pharmaceuticals and new models of care or forecasting/modelling techniques.

103. Following the national ethical requirements for research, promote equitable opportunities and access for people with dementia and their carers to be part of clinical and social research that concerns them.

**PROPOSED ACTIONS FOR MEMBER STATES**

104. Draw up a global research agenda and work together with Member States to strengthen and build capacity in the area of dementia research by incorporating it in national and subnational policies and plans relating to dementia. Advocate increased investment in dementia research, capacities, methods and collaboration in the fields of biomedical and social sciences research, inter alia, through a network of WHO collaborating centres, countries from all WHO regions, and civil society organizations.

**ACTIONS FOR THE SECRETARIAT**

1. The global target indicator and means of verification are provided in the Appendix.
105. Engage relevant stakeholders, including people with dementia and their organizations, in the development and promotion of a global dementia research programme; facilitate global networks for research collaboration; and carry out multisectoral research related to the burden of disease, dementia risk reduction, treatment, care, policy and service evaluation. Promote international cooperation and intercountry exchange of research expertise, policy and practice through the systematic mapping of national investments in research and outputs of that research.

106. Support the inclusion of technological innovation in national and subnational policies and plans on dementia and offer technical support to Member States in developing and strengthening the provision of assistive and innovative technologies to maximize the functional ability of people with dementia, particularly in resource-poor settings.

PROPOSED ACTIONS FOR INTERNATIONAL, REGIONAL AND NATIONAL PARTNERS

107. Support Member States and the Secretariat, where appropriate, by collaborating in setting priorities for dementia research, promoting increased governmental investment, mobilizing and increasing financial support, and disseminating research findings in user-friendly language to policy-makers, the public, people with dementia, their carers and families.

108. Advocate the engagement of people with dementia and their carers in applied research, clinical trials and the evaluation of new technologies that take account of the different physiology, needs and preferences of people with dementia and their carers.

109. Assist in the implementation and evaluation of innovative technologies, community-based service delivery structures and new dementia care concepts. Promote the use of information and communications technology to improve programme implementation, health outcomes, health promotion, monitoring and reporting and surveillance systems, and to disseminate, as appropriate, information on affordable, cost-effective, sustainable and high-quality interventions, best practices and lessons learned in the field of dementia.

110. Strengthen national capacity for research, development and innovation, for all aspects of dementia prevention, risk reduction, treatment and care in a sustainable and cost-effective manner, including the strengthening of institutional capacity and the creation of research fellowships and scholarships.
APPENDICES

WHAGOL(17) Global action plan on the public health response to dementia

The Seventieth World Health Assembly, having considered the draft global action plan on the public health response to dementia 2017–2025,1 decided:
1. to endorse the global action plan on the public health response to dementia 2017–2025;
2. to urge Member States2 to develop, as soon as practicable, ambitious national responses to the overall implementation of the global action plan on the public health response to dementia 2017–2025;
3. to request the Director-General to submit a report on progress made in implementing this decision to the Seventy-third, Seventy-sixth and Seventy-ninth World Health Assemblies.

(Tenth plenary meeting, 31 May 2017 – Committee B, third report)

INDICATORS FOR MEASURING PROGRESS TOWARDS THE DEFINED TARGETS OF THE GLOBAL ACTION PLAN ON THE PUBLIC HEALTH RESPONSE TO DEMENTIA AND MEANS OF VERIFICATION

The indicators offer measures to meet a subset of the information and reporting needs that Member States require to be able to monitor the progress and outcome of their dementia policies and programmes adequately. Given that targets are voluntary and global, each Member State is not necessarily expected to achieve all the specific targets but can contribute to a varying extent towards reaching them jointly. As indicated under action area 6 of the global action plan, the Secretariat will provide guidance, training and technical support to Member States, upon request, on the development of national information systems for capturing data on dementia indicators. WHO’s Global Dementia Observatory provides the mechanism to monitor and facilitate the use of data through a platform for exchanging data and knowledge in order to support evidence-based service planning, sharing of best practices, and strengthening of dementia policies as well as health and long-term care systems. The aim is to build on existing information systems rather than creating new or parallel systems. Baselines for each target will be established early during the implementation phase of the global action plan.

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2. And, where applicable, regional economic integration organizations.
### Action area 1: Dementia as a public health priority

#### Global target

- 75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.

#### Indicator

- Existence of an operational national policy, strategy, plan or framework for dementia, either a stand-alone instrument specific for dementia or integrating dementia into other relevant policies, plans or strategies (for instance, on mental health, ageing, noncommunicable diseases and disability).

For countries with a federated system, the indicator will refer to the availability of dementia policies or plans for 50% or more of the states or provinces within the country.

#### Means of verification

- Physical availability of the policy or plan that incorporates the suggested range of cross-cutting principles and areas to be adapted by Member States, depending on national context.

#### Comments/assumptions/rationale

- Policies or plans on dementia may be stand-alone or integrated into other health, ageing or disability policies or plans. “Operational” means that the national policy, strategy, plan or framework is being used and implemented in the country, and has funds, resources and instructions allocated to implement it.

- Many policies and plans that are older than 10 years may not reflect recent developments in evidence-based practice for treatment and care of people with dementia and international human rights standards. The key principles of dementia care will be in line with the cross-cutting principles and actions of the global action plan.

### Action area 2: Dementia awareness and friendliness

#### Global target

- 100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025.

- 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025.

#### Indicator

- Existence of at least one mass media dementia awareness-raising programme/campaign (run nationwide for example, on television and radio, in print media and/or on billboards for at least three weeks) in the past year/during the most recent survey period.

- Existence of at least one dementia-friendly initiative and/or age-friendly initiative specifically targeting dementia to foster a dementia-inclusive society by 2025.

### Action area 3: Dementia risk reduction

#### Global target

The relevant global targets defined in, and in keeping with, the Global action plan for prevention and control of noncommunicable diseases 2013–2020 and any future revisions are achieved.

### Means of verification

- Inventory of currently implemented dementia-awareness campaigns and dementia/age-friendly initiatives, described project by project.

### Comments/assumptions/rationale

- Raising awareness and changing the social and physical environment are both important. Raising awareness on an individual basis through campaigns will not necessarily result in greater social inclusion in the way that programmes designed for changes to physical and social environments can.

- Awareness-raising campaigns may – and preferably should – cover both universal, population-level strategies (for example, mass media campaigns against dementia stigmatization and discrimination) and those aimed at locally-identified vulnerable groups (for example, the elderly, women, people with low educational attainment, high-risk populations such as smokers and ethnic minorities). Key aspects of these campaigns include: fostering an accurate understanding of dementia and its various subtypes as clinical diseases; reducing stigmatization and discrimination associated with dementia; improving knowledge about the human rights of people with dementia and the Convention on the Rights of Persons with Disabilities; enhancing the general population’s ability to recognize early symptoms and signs of dementia; and increasing the public’s knowledge of risk factors associated with dementia, thereby promoting healthy lifestyles and risk reduction behaviour in all.

- The media play a key role in shaping knowledge, opinions and behaviours, and can be extremely powerful in influencing both individuals and policy makers regarding dementia awareness and understanding. As a result, mass media dementia campaigns should become a key component of raising dementia awareness.

- A “dementia-friendly” society is one that has an inclusive and accessible community environment that optimizes opportunities for health, participation and security for all people, in order to ensure quality of life and dignity for people with dementia and their families and carers. Shared key aspects of dementia-friendly initiatives include: safeguarding the human rights of people with dementia; tackling the associated stigmatization; promoting a greater involvement of people with dementia and their carers in society; and supporting people with dementia to continue to live independent and fulfilling lives in their own communities as well as providing support to their carers and families.

- The choice of a broad indicator (namely, the existence of at least one dementia-friendly initiative) is intended to maximize the impact across a broad range of outputs. The successful implementation of dementia-friendly initiatives requires a multisectoral approach involving governments, civil society and the private sector.
<table>
<thead>
<tr>
<th>Indicator</th>
<th>Means of verification</th>
<th>Comments/assumptions/rationale</th>
</tr>
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<tbody>
<tr>
<td>Numerator: number of people with dementia in a country who have presented to services and received a dementia diagnosis.</td>
<td>Denominator: estimated population-based prevalence of dementia for a country as calculated by WHO as part of the Global Dementia Observatory.</td>
<td>Data may be derived from administrative sources, electronic records and registries. This will be a relative, globally combined measure. All people who are diagnosed should receive appropriate care and support from health and social care services.</td>
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<tr>
<td>75% of countries provide support and training programmes for carers by 2025.</td>
<td>75% of countries provide support and training programmes for carers and families of people with dementia by 2025.</td>
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<tr>
<td>At least one national or several subnational, functioning, support or training programmes are available for carers.</td>
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<td>Inventory of currently implemented programmes for carers.</td>
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<td>Functional programmes are defined as having dedicated financial and human resources, an implementation plan and documented evidence of progress or impact.</td>
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<tr>
<td>Types of programmes or support for carers can include respite care, counselling, and educational training on subjects such as care techniques, non-verbal communication and patient-carer relationship development.</td>
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<td>For countries with a federated system, the indicator will refer to the availability of at least one provincial or state-wide service or programme with complete geographical coverage for 50% or more of the states or provinces within the country.</td>
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**LINKS TO OTHER GLOBAL ACTION PLANS, STRATEGIES AND PROGRAMMES**


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**LIST OF OTHER DOCUMENTS THAT ARE LINKED TO THE GLOBAL ACTION PLAN ON THE PUBLIC HEALTH RESPONSE TO DEMENTIA**


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1 All websites accessed 8 March 2017.

The Global action plan on the public health response to dementia 2017–2025 aims to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on communities and countries. It provides a set of actions to realize the vision of a world in which dementia is prevented and people with dementia and their carers receive the care and support they need to live a life with meaning and dignity.

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