

Draft WHO global action plan on the public health response to dementia 2017-2025

INTRODUCTION

Background

1. In response to paragraph 2 of decision EB139(1)¹, the Secretariat prepared this WHO Discussion Paper (version dated 5 September 2016) which contains a “zero draft” of the global action plan on the public health response to dementia 2017-2025. This WHO Discussion Paper will be used as the basis for informal consultations in September and October 2016 (in accordance with the intergovernmental process announced by the Secretariat in June 2016²) to seek comments from Member States and views from non-State actors on the proposed draft action plan set out below, which will enable the Secretariat to submit a final draft action plan for consideration by Member States to the 140th session of the Executive Board in January 2017.

Mandate

2. In June 2016, the Executive Board at its 139th session adopted decision EB139(1)³, in which, inter alia, it noted that the response to the global burden of dementia can be greatly enhanced by a shared commitment among Member States and all other stakeholders to: put in place the necessary policies and resources for care of people with dementia; promote research; find disease-modifying treatments or cures; and give adequate priority to action against dementia in national and global political agendas. In decision EB139(1), the Executive Board has also requested the Director-General to develop, with the full participation of Member States and in cooperation with other relevant stakeholders, a draft global action plan on the public health response to dementia, with clear goals and targets, for consideration by the Seventieth World Health Assembly, through the Executive Board at its 140th session.

3. The global action plan on the public health response to dementia has close conceptual and strategic links to other global action plans and strategies endorsed by the World Health Assembly including: the WHO Comprehensive Mental Health Action Plan 2013-2020⁴; the WHO Global NCD Action Plan 2013-2020⁵; the WHO Global Disability Action Plan 2014-2021: Better health for all people with disability⁶; the WHO Global Strategy and Plan of Action on Ageing and Health 2016-2020⁷; and the WHO Global Strategy on Human Resources for Health: Workforce 2030⁸. It also draws

¹ Available at http://apps.who.int/gb/ebwha/pdf_files/EB139/B139_DIV2-en.pdf

² See http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/

³ Decision and List of Resolutions of the 139th Session of the WHO Executive Board; 2015

http://apps.who.int/gb/ebwha/pdf_files/EB139/B139_DIV2-en.pdf

⁴ Available at http://www.who.int/mental_health/action_plan_2013/en/

⁵ Available at <http://www.who.int/nmh/publications/ncd-action-plan/en/>

⁶ Available at <http://www.who.int/disabilities/actionplan/en/>

⁷ Available at <http://www.who.int/ageing/global-strategy/en/>

on regional action plans, including the PAHO Strategy and Plan of Action on Dementias in older Persons 2015-2019⁹.

4. The action plan builds upon the work of WHO's report, *Dementia: A Public Health Priority*¹⁰ (2012) and the First Ministerial Conference on the Global Action against Dementia hosted by WHO in Geneva in March 2015¹¹. It also aligns with the WHO Global Dementia Observatory (DGO), a new monitoring and knowledge exchange platform which is currently being developed to support evidence-based dementia service planning and strengthening of policies in health and social care systems for dementia.

5. In keeping with commitments from Heads of State and Government made at the UN General Assembly in September 2015 that no one will be left behind in the 2030 Agenda for Sustainable Development, the action plan also responds to the new global Sustainable Development Goals (SDGs) and its commitment to ensure that all human beings can fulfil their potential in dignity and equality.

General structure of the action plan

6. The action plan is global in its scope and developed through consultation with WHO Member States, organizations of the United Nations system, and non-State actors including nongovernmental organizations, private sector entities, philanthropic foundations, and academic institutions as well as people with dementia, their carers and families. In line with the 2030 Agenda for Sustainable Development, it takes a comprehensive and multisectoral approach with deep interconnections and cross-cutting elements through its action areas, including coordinated services from the health and social sectors, with an emphasis on promotion, prevention, treatment, rehabilitation and care.

7. It also sets out clear actions for Member States, the WHO Secretariat and international, regional and national level partners, and proposes key indicators and targets that can be used to evaluate levels of implementation, progress and impact.

8. The global action plan on the public health response to dementia is designed to provide guidance for the development and implementation of dementia policies in alignment with the principles of universal health coverage and existing national mental health, ageing, noncommunicable disease and disability action plans. It aims to address, for all resource settings, the response of health, social and other sectors, as well as promotion and prevention strategies.

OVERVIEW OF THE GLOBAL SITUATION

9. Dementia is an umbrella term for several progressive diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain the activities of daily living. Alzheimer's 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

⁸ Available at <http://www.who.int/hrh/resources/globstrathrh-2030/en/>

⁹ Available at http://www.paho.org/hq/index.php?option=com_content&view=article&id=11087%3A2015-54th-directing-council&catid=8811%3Adc-documents&Itemid=41537&lang=en

¹⁰ Available at http://www.who.int/mental_health/publications/dementia_report_2012/en/

¹¹ See <http://www.who.int/mediacentre/events/meetings/2015/global-action-against-dementia/en/> and <http://www.who.int/mediacentre/news/releases/2015/action-on-dementia/en/>

bodies, and a group of diseases that contribute to frontotemporal dementia. The boundaries between different forms of dementia are indistinct and mixed forms often co-exist.

10. In 2015, dementia affected 47 million people worldwide (or roughly 5% of the world's elderly population), a figure that is estimated 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, which translates to 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.¹²

11. Crucially, while age is the single most important risk factor for developing dementia, it is not a natural or inevitable consequence of ageing, nor does it exclusively affect older people, with up to 9% of cases being attributable to young onset dementia (i.e. symptom onset before the age of 65).¹³ Some research has shown a relationship between the development of cognitive impairment and cardiovascular and lifestyle-related risk factors, such as hypertension, diabetes mellitus, hypercholesterolemia, tobacco use, and obesity, among others.

12. Dementia is a major cause of disability and dependency among older people worldwide, having a significant impact not only on individuals but also carers, families, communities and societies. Dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease.¹⁴ In light of the improved survival globally, this figure is expected to increase further.

13. Dementia leads to increased long-term care costs for governments, communities, families and individuals, and to losses in productivity for economies:

- In 2015, dementia costs 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.¹⁵ By 2030, the cost of caring for people with dementia worldwide has been estimated at US\$ 2 trillion, a total that could undermine social and economic development globally and overwhelm health and social care systems specifically.
- The indirect costs of care incurred by informal carers and family members result in millions of people living in chronic poverty. 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-

¹² World Health Organization. The epidemiology and impact of dementia: Current state and future trends. Geneva, Switzerland; 2015. Report No.: WHO/MSD/MER/15.3. (http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf, accessed 17 August 2016)

¹³ World Health Organization and Alzheimer's Disease International . Dementia: a public health priority. Geneva: World Health Organization; 2012 (http://www.who.int/mental_health/publications/dementia_report_2012/en/, accessed 17 August 2016).

¹⁴ Prince M, Albanese E, Guerchet M, Prina M. World Alzheimer Report 2014. Dementia and Risk Reduction. An Analysis of Protective and Modifiable Risk Factors. Alzheimer's Disease International, London UK; 2014 (<http://www.alz.co.uk/research/WorldAlzheimerReport2014.pdf>, accessed 17 August 2016)

¹⁵ Prince M, Wimo A, Guerchet M, Ali G, Wu Y, Prina M. World Alzheimer Report 2015. The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Cost and Trends. Alzheimer's Disease International, London UK; 2015

income countries, social care costs (15%) pale in comparison to informal care costs.⁴ The expected disproportionate increase in dementia cases in low- and middle-income countries will contribute further to increasing inequalities between countries and populations.

14. At the same time, the gap is wide between the need for prevention, treatment and care for dementia and the actual provision. Dementia is underdiagnosed worldwide, and, if a diagnosis is made, it is typically at a relatively late stage in the disease process. Long-term care pathways for people with dementia are frequently fragmented if not entirely lacking. Lack of awareness and understanding of dementia are often to blame, resulting in stigmatization and barriers to diagnosis and care. It is also widely recognized that people with dementia are frequently denied their human rights both in the community and in care homes.

15. WHO and the World Bank estimate that 40 million new health and social care jobs globally will be needed by 2030 and about 18 million additional health worker, primarily in low-resource settings to attain high and effective coverage of the broad range of health services. In addressing dementia, scaling up of health and social health workforce with appropriate skill mix as well as available interventions and services be critical to prevent, diagnose, treat or care for people with dementia.

STRUCTURE OF THE GLOBAL ACTION PLAN ON THE PUBLIC HEALTH RESPONSE TO DEMENTIA 2017-2025

Vision

16. A world in which people can live well with or without dementia, and receive the supports they need to fulfil their potential with dignity, respect and equality.

Goals

17. The goal of the global action plan on the public health response to dementia is to decrease the impact of dementia on individuals, families, societies and countries.

Cross-cutting principles

18. The action plan will be informed by the following **seven cross-cutting principles**:

- a) **Human rights of people with dementia:** Policies, plans, programmes, interventions and actions are sensitive to the needs, expectations and human rights of people with dementia and their carers in compliance with the UN Convention on the Rights of Persons with Disabilities.
- b) **Empowerment and engagement of people with dementia and their carers:** People with dementia and their carers should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring, research and evaluation of dementia, as explicitly recognized in the 2030 Agenda for Sustainable Development.
- c) **Evidence-based practice for dementia risk reduction and care:** Strategies and practices for dementia risk reduction and care need to be based on scientific evidence and/or best practice, cost-effectiveness, affordability and public health principles, taking cultural considerations into account to facilitate faster learning and action.

- d) **Multisectoral collaboration on the public health response to dementia:** A comprehensive and coordinated response to dementia requires fostering collaboration between all stakeholders to improve risk reduction and care, with engagement at the government level from all relevant public sectors such as health, social, education, employment, judicial, housing and other relevant sectors, as well as partnerships with relevant civil society and private sector entities.
- e) **Universal health coverage for dementia:** There needs to be equitable access to a full range of health and social care services needed for people with dementia and their carers, regardless of age, gender, socioeconomic status, race, ethnicity or sexual orientation.
- f) **Gender equity:** Recognizing that women are disproportionately affected by dementia, both in developing dementia and as carers, also acknowledged in the 2030 Agenda for Sustainable Development, all efforts to implement public health responses to dementia must be gender sensitive.
- g) **Balance cure and care for people with dementia and their carers:** Finding a balance between utilising existing knowledge, best practice and experience to improve dementia prevention, risk reduction, care and support for people with dementia and their carers on one hand and on the other hand, generating new knowledge directed towards finding disease-modifying treatments or cure, effective risk reduction interventions and innovative models of care.

PROPOSED ACTIONS AND TARGETS FOR MEMBER STATES, SECRETARIAT AND INTERNATIONAL AND NATIONAL PARTNERS

19. Effective implementation of the global action plan on the public health response to dementia will require actions by Member States, the WHO Secretariat as well as international, regional and national partners. These partners include but are not limited to:

- development agencies including international multilateral agencies (for example, the World Bank and United Nations development agencies), regional agencies (for example, regional development banks), sub-regional intergovernmental agencies and bilateral development aid agencies;
- academic and research institutions 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, dementia and related organizations, community-based organizations, human rights-based organizations, faith-based organizations, development and mental health networks and associations of health care professionals and service providers.

20. The roles of these three groups are often overlapping and can include multiple actions across the areas of governance, health and social care services, promotion and prevention in dementia, and information, evidence and research. Country-based assessments of the needs and capacity of different partners will be essential to clarify the roles and actions of key stakeholder groups.

21. Global targets included in this global action plan are defined as global commitments, with each Member State setting its own national targets guided by the global targets, but taking into account national circumstances. Each Member State will also decide how these global targets should

be incorporated into national planning, processes (including data collection systems), policies and strategies.

22. The action plan recognizes that each Member State faces specific challenges in the pursuit of implementing these action areas and therefore provides a suggested range of proposed actions that each Member State can adapt, taking into account national circumstances.

Action Areas

23. The action plan is comprised of the following **seven action areas** which form the underlying structural framework for the proposed actions:

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

Action Area 1: Dementia as a Public Health Priority

24. 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 multi-stakeholder public health approach that is a comprehensive response from the health system, other government sectors, international organizations, family, community, religious institutions, academia, the media, civil society, the private sector and industry.

25. **RATIONALE:** The development of policies, legislation, plans and integrated dementia care programmes through a comprehensive, multisectoral approach to dementia care, treatment and research will support the recognition and address the complex needs of people with dementia within the context of each country, in line with the principle of universal health coverage.

26. **GLOBAL TARGET 1:** 75% of countries will have developed or updated national strategies, policies, plans, or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025¹⁶

PROPOSED ACTIONS FOR MEMBER STATES:

27. Develop, strengthen and implement:
- clear and evidence-based national and/or sub-national strategies, policies or plans that address dementia, whether as independent documents or integrated across health and other sectors that pay explicit attention to equity, dignity and the human rights of people with dementia and their carers and where possible, in consultation with people with dementia.
 - legislation, whether independent legislative documents or integrated into other health or related laws, that protect and promote the human rights of people with dementia and their families.

¹⁶ Global target indicator and means of verification are provided in Appendix

28. Set up a functional dementia division, unit or focal point or coordination mechanism as stand-alone or integrated into the noncommunicable disease, mental health or ageing department within the ministry of health (or equivalent), ensuring clear lines of responsibility for strategic planning, implementation, mechanisms for multisectoral collaboration, service evaluation, monitoring and reporting on dementia.

29. Allocate financial resources that are commensurate to the identified service need as well as human and other resources required to implement evidence-based 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.

PROPOSED ACTIONS FOR THE SECRETARIAT:

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

- leadership within health ministries and other relevant sectors for the development, strengthening and implementation of evidence-based national and/or sub-national strategies or plans and associated multisectoral resource planning, budgeting and expenditure tracking for dementia.
- evaluating and implementing evidence-based options that suit Member States' needs and capacities and in assessing the health impact of dementia public policies by establishing/strengthening national reference centres, WHO collaborating centres and knowledge-sharing networks.

31. Compile and share knowledge and best practices on existing policy documents addressing dementia, including codes of practice and mechanisms to monitor the protection of human rights and implementation of legislation, in line with the Convention on the Rights of Persons with Disability and other international and regional human rights instruments.

32. Foster collaborations and partnerships with countries at international, regional and national levels for multisectoral action to address functional gaps in the response to dementia and aligning with the principle of universal health coverage, including all relevant sectors: health, judicial and social sectors, civil society groups, people with dementia, carers and family members, and organizations in the United Nations system.

PROPOSED ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS:

33. 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.

34. Motivate and actively engage in dialogue between associations representing people with dementia, 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.

35. Advocate for the development and implementation of national dementia policies, legislations, strategies and plans as well as for 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.

Action Area 2: Dementia Awareness and Friendliness

36. Dementia has a significant impact on individuals, communities and societies. It is one of the major causes of disability and dependency among older people worldwide. It is overwhelming not only for people who have it, but also for their carers and families. There is common misbelief that dementia is a natural part of ageing, resulting in stigmatization, barriers to diagnosis and care and loss of human rights.

37. Increased understanding and training in awareness of dementia can promote enhanced health and social outcomes as well as improved quality of life for people with dementia, their carers and the broader community leading to better living experiences and a more inclusive, dementia-friendly community.

38. **RATIONALE:** By increasing public awareness, acceptance and understanding of dementia, people with dementia are enabled to participate in the community and maximise autonomy through improved social participation.

39. **GLOBAL TARGET 2:** 75% of countries will have at least one functioning public awareness campaign on dementia and/or dementia-friendly initiatives to foster a dementia inclusive society by 2025¹⁷

PROPOSED ACTIONS FOR MEMBER STATES:

40. Organize national and local public health and awareness campaigns in collaboration with civil society organizations, major public stakeholders and the media to improve accurate dementia knowledge in the general public, dispel myths and emphasize the need for gender sensitive responses, recognition of human rights and autonomy of people with dementia.

41. Ensure that in communities all aspects of the built environment and the provision of amenities, goods and services are age- and dementia-friendly, inclusive, promoting respect and acceptance in a manner that meets the needs (including co-vulnerabilities) of people with dementia and their carers and enables participation and inclusion.

42. Develop specific dementia training programmes to encourage dementia-friendly attitudes that are informed by the experiences of people with dementia and their carers. Target different community and stakeholder groups including: school students and teachers, first contact community support personnel such as police, transport service and other public service providers, education and cultural organisations as well as volunteers. The private sector should also be encouraged to promote dementia-friendly attitudes.

PROPOSED ACTIONS FOR THE SECRETARIAT:

43. Offer technical support to Member States and strengthen global, regional and national capacity:

¹⁷ Global target indicator and means of verification are provided in Appendix

- To engage people with dementia, their families and carers and organizations that represent them in decision-making within WHO’s own processes and on issues that concern them.
- On the selection, formulation and implementation of best practices for awareness raising and reduction of stigma and discrimination of people with dementia.

44. Based on the WHO global network and interactive platform of age-friendly cities and communities, develop such networks for dementia-friendly initiatives by documenting and evaluating existing dementia-friendly initiatives, to identify evidence of what works in different contexts.

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

PROPOSED ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS:

46. Engage all stakeholders in advocacy:

- To raise awareness of the magnitude of the impact of dementia
- To include persons with dementia, their carers and family members in all aspects of developing and strengthening services that support autonomy
- To support human rights for people with dementia and their carers
- To reduce the gender inequity in dementia and highlight the need for gender sensitive public health responses

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

Action Area 3: Dementia Risk Reduction

48. Evidence for behavioural changes influencing dementia risk reduction and protective factors for dementia are increasing. There is a growing consensus that some protective measures might reduce the risk of cognitive decline – specifically, there is some evidence that physical activity, early-life educational opportunities, management of midlife hypertension, tobacco cessation and a reduction in obesity and diabetes may reduce the risk of cognitive decline.

49. **RATIONALE:** By improving the capacity of health and social care professionals to provide evidence-based, multisectoral, gender sensitive interventions to the general population, educate and proactively manage modifiable dementia risk factors that dementia shares with other noncommunicable diseases, the risk of developing dementia can be reduced or its progression delayed.

50. **GLOBAL TARGET 3:** The global targets defined in the Global Action Plan for Prevention and Control of Noncommunicable Diseases are achieved for risk reduction by 2025¹⁸

PROPOSED ACTIONS FOR MEMBER STATES:

51. Integrate dementia with other noncommunicable disease risk reduction programmes, policies and campaigns across multiple, relevant sectors by promoting a healthy and balanced diet,

¹⁸ WHO global action plan for the prevention and control of noncommunicable disease 2013-2020: http://apps.who.int/iris/bitstream/10665/94384/1/9789241506236_eng.pdf

physically and mentally stimulating activities and life-long social engagement in line with the principle of balancing care and cure.

52. Develop, deliver and promote evidence-based, gender sensitive interventions to health professionals to educate and proactively manage modifiable dementia and NCD risk factors, such as tobacco use, unhealthy diets, harmful use of alcohol and physical inactivity when conducting risk reduction counselling. Routinely update these interventions as new scientific evidence becomes available.

PROPOSED ACTIONS FOR THE SECRETARIAT:

53. Linking to the actions of the WHO noncommunicable disease action plan, the secretariat will offer technical support and strengthen global, regional and national capacity to:

- raise awareness of the links between dementia and other noncommunicable diseases
- integrate the reduction and control of modifiable dementia risk factors into national health-planning processes and development agendas.
- support the formulation and implementation of evidence-based, multisectoral interventions for dementia risk reduction.

54. Strengthen the evidence base and disseminate evidence to support policy interventions for reducing modifiable dementia risk factors by providing a database of available evidence on the prevalence of dementia risk factors and the consequences of reducing them.

PROPOSED ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS:

55. Engage all stakeholders in advocacy to:

- promote and mainstream population health strategies that are gender sensitive at the national, regional and international levels to support a healthy, physically, mentally and socially active lifestyle for all including people with dementia and their carers.
- support national efforts for prevention and control of noncommunicable diseases in general and dementia in particular, inter alia, through exchange of information on evidence-based best practices and dissemination of research findings.

Action Area 4: Dementia Diagnosis, Treatment and Care

56. Dementia is associated with complex needs and high levels of dependency and morbidity during the later stages, requiring a range of health services and long-term-care. These include identification, diagnosis, treatment, rehabilitation and other services such as home help, transport, food, services, and the provision of a structured day with meaningful activities.

57. People with dementia should be empowered to live in the community for as long as possible. To enable them to do so, accessible and affordable treatment and services integrated into health and long-term care are essential. 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 until the end-of-life. Integrated, evidence-based, person-centered care is required in all settings where people with dementia are, ranging from their homes, the community, assisted living facilities, nursing homes, to hospitals and hospices. The skills and capacity of the workforce and services for people with dementia are often challenged by the complex needs of people with dementia.

58. A number of key principles are suggested for organizing and developing the health and long-term care system for dementia. These include, a timely diagnosis; the integration of dementia treatment and care into primary care; continuity of health and long-term care between different providers and system levels, and active collaboration between paid and unpaid care providers.

59. **RATIONALE:** The needs of people with dementia can be met through integrated, person-centred community-based health and long-term care and support. The re-enablement and autonomy of people with dementia within and across health and long-term care services can be respected through person-centred treatment and care plans and, where appropriate, with the inputs of families and carers.

60. **GLOBAL TARGET 4:** In at least half of countries, as a minimum, 50% of people with dementia are diagnosed and receive health and social care services¹⁹

PROPOSED ACTIONS FOR MEMBER STATES:

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

62. Provide education and ongoing training in collaboration with key stakeholder such as regulatory bodies, as a substantial part of the curriculum of all professional staff involved, including physicians, nurses, other medical specialists and long-term care staff in order to ensure a knowledgeable and skilful workforce. Earmarking budgets and resources for in-service training for these professionals.

63. Systematic shifting of the locus of care away from hospitals towards community-based care settings with integrated, community-based networks between social and health systems, providing quality care and evidence-based interventions.

64. Enhance access to a range of person-centred, gender sensitive, responsive services including liaising with local nongovernmental organizations and other stakeholders in order to provide information that empowers people with dementia to make informed choices and decisions around their care that fulfil their needs and respect their rights and preferences along with active collaboration between formal and informal care providers from the first symptoms through to end-of-life.

PROPOSED ACTIONS FOR THE SECRETARIAT:

65. Offer technical support to Members States documenting best practices for evidence-based service delivery models and care coordination and share models of care that have been shown to be effective as Member States develop dementia care pathways in line with the principle of universal health coverage.

66. Develop and implement guidelines, tools and training materials such as model curricula on dementia core competencies for health and long-term care workers in the field and provide

¹⁹ Global target indicator and means of verification are provided in Appendix

technical support to Member States on ability-oriented, person-centred integrated long-term care provision.

67. Provide guidance on strengthening the implementation of the dementia component of Mental Health Gap Action Programme (mhGAP) to enhance Member States' capacity building, and ability to provide quality care and evidence-based interventions through primary health care.

PROPOSED ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS:

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

69. Assist the training of health and social care personnel in providing evidence-based treatment and care for people with dementia, relevant to their roles and responsibilities, by producing training standard needs supporting teaching institutions in revising dementia curricula, and ensuring people with dementia are engaged in the development and provision of education and training.

70. Advocate for community-based rehabilitation as an effective strategy to re-enable and support people with dementia to preserve their autonomy, rights and ensure the person with dementia remains at the centre of all conversations regarding diagnosis, treatment and care.

Action Area 5: Support for Dementia Carers and Families

71. Family carers can be defined by their relationship, living arrangements and care input. Family carers are most often involved in providing "hands-on" care or – also a very significant role – in organizing care delivered by others and are likely to have knowledge of and information on the person with dementia that is critical to developing effective needs-based treatment and care plans. Accordingly, carers and families should be considered essential partners in the planning and provision of care in all settings.

72. It should be noted that being a family carer for someone with dementia may impact on the carer's physical and mental health and also affect the relationships that the carer has with others. Health and long-term care systems must address both the substantial need for help from others that is required by people with dementia and its significant impact on carers and families. Carers and families should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and social demands of their caring role.

73. **RATIONALE:** The creation and implementation of multisectoral care and training programmes for carers will help protect their rights, address their needs, and promote their health and social wellbeing.

74. **GLOBAL TARGET 5:** *75% of countries provide national support and training programmes for carers and families of people with dementia by 2025*²⁰

PROPOSED ACTIONS FOR MEMBER STATES:

²⁰ Global target indicator and means of verification are provided in Appendix

75. Create multisectoral care and training programmes for carers and families to improve knowledge and caregiving skills, improve coping and mental health through counselling and peer-support services. Also create training programmes for healthcare staff for the identification and reduction of carer stress in keeping with the principles of universal health coverage.

76. Assess the impediments experienced by carers in their caregiving responsibilities while recognizing its disproportionate effect on women, and develop or strengthen social and disability benefits, policies and legislation to protect them from discrimination and support their ability to continue their caregiving.

77. Support carers' right to be included in care planning, increase their access to information and a range of respite care services.

PROPOSED ACTIONS FOR THE SECRETARIAT:

78. Advocate the importance of informal carers in the lives of people with dementia while recognizing its disproportionate effect on women and offer technical support to Member States by monitoring trends in availability of carer support services to support Member States' in developing evidence-based information, training programmes and support services for carers and families using a multisectoral approach.

79. Facilitate affordable, evidence-based resources for family and informal carers by making use of information and communication technologies such as the internet/mobile phone technologies, for education, skills training and social support to improve knowledge and caregiving skills, reduce stress and improve coping and health.

PROPOSED ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS:

80. Advocate the importance of carers and families in the lives of people with dementia, the importance of 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 effectively address specific challenges in accessing health services.

81. Assist in carrying out appropriate training programmes for family and informal carers to enhance knowledge and caregiving skills across the progression of dementia and respect for personhood and wellbeing of the person with dementia.

Action Area 6: Information Systems for Dementia

82. Building information systems that enable the best possible trajectories of functional ability of people with dementia, their carers and families will require the fundamental drivers of systems to be aligned to this shared goal. This will require significant changes to the collection, recording, linkage and sharing of health and administrative information that should be routinely collected at each encounter with the health and social care system.

83. **RATIONALE:** Systematic monitoring and evaluation of health and long-term care system usage can provide the best available evidence for policy development and service delivery, which can improve the care accessibility and coordination for people with dementia across the health and long-term care systems.

84. **GLOBAL TARGET 6:** *50% of countries routinely collect a core set of dementia indicators through their national health and social information systems on which they report every two years by 2025*²¹

PROPOSED ACTIONS FOR MEMBER STATES:

85. Implement and improve national surveillance and monitoring systems that are integrated into existing health information systems in order to improve availability of high-quality, multisectoral data on dementia. Create access to health and long-term care data and map available services and resources at national and regional levels to improve service delivery and coverage.

86. Update or create supportive policy or legislative environment pertaining to the measurement, collection and sharing of dementia health and social care data and integrate this information routinely into the national health information system to facilitate routine reporting on dementia.

87. Collect and use data on the epidemiological state of dementia in the country, and on human, financial and other resources needed to implement dementia policies and plans.

PROPOSED ACTIONS FOR THE SECRETARIAT:

88. Offer technical support to Member States as they:

- develop and/or reform national data collection systems, including health information systems, in order to strengthen multisectoral dementia data collection.
- build capacity and resources for dementia-specific data collection, analysis and use through development of national targets and indicators that account for national circumstances, while aligning as closely as possible with the global monitoring framework, including its indicators and targets.

89. Develop the definitions for a core set of dementia indicators in line with this action plan covering the four main areas of dementia to monitor the global dementia situation: epidemiology & impact of dementia, policies, resources, and research & innovation; while facilitating the use of data from these core dementia indicators by developing a knowledge exchange platform through the global dementia observatory to support evidence-based service planning, sharing of best practices, and strengthening of dementia policies as well as health and long-term care systems.

90. Disseminate information on trends in service delivery and human resource capacity to support Member States' in shifting the locus of care away from hospitals and other institutions toward community and primary care settings and identifying training requirements for existing health workforce, undergraduate and graduate training curricula.

PROPOSED ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS:

91. Provide support to Member States and Secretariat with development of tools and strengthen capacity for surveillance & information systems that: capture core indicators on dementia, health and long-term care and support services for persons with dementia, carers and families and enable an assessment of trends over time.

92. Advocate for involving people with dementia, their carers and families in the creation, collection, analysis and use of data on dementia.

²¹ Global target indicator and means of verification are provided in Appendix

Action Area 7: Dementia Research and Innovation

93. If the incidence of dementia is to be reduced, and the lives of people with dementia are to be improved, research and innovation as well as their implementation in daily practice are crucial. 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 carers and families into research studies. A balance is required between research into prevention, treatment, care and cure. Collaboration across Member States and all stakeholders to implement a coordinated strategic dementia global research agenda will increase the likelihood of effective progress toward better prevention, diagnosis, treatment, and care for individuals around the world who are living with dementia.

94. There is a growing interest in, and call for, innovative health technology use in dementia. Social and technological innovation for dementia can include strategies, technology and devices used by health and social care professionals as well as people with dementia, their carers, families and the general population in order to improve knowledge, skills and coping mechanisms as well as to facilitate and support the daily life of people with dementia and their carers.

95. **RATIONALE:** The successful implementation of strategic dementia research and social and technological innovation can increase the likelihood of effective progress toward better prevention, diagnosis, treatment and care for people with dementia.

96. **GLOBAL TARGET 7:** *At least 50% of countries are allocating 1% of their dementia expenditure to dementia research*²²

PROPOSED ACTIONS FOR MEMBER STATES:

97. Formulate a national research agenda on dementia prevention and management that focuses on gaps in evidence to support policy or practice and strengthen research capacity for academic collaborations on national dementia research priorities in engagement with all relevant stakeholders including people with dementia. These may include: improving research infrastructure for dementia and related fields, enhancing competence of researchers to conduct quality dementia research and establishing dementia centres of excellence.

98. Increase investment in dementia research, innovation and its governance as an integral component of the national response to dementia. In particular, allocate budgets to promote projects that generate knowledge about how to translate what is already known about dementia into action and implementation.

99. Foster development of social and technological innovations (including but not limited to assistive technologies, pharmaceuticals, new models of care or forecasting/modelling techniques), in terms of design and evaluation that recognize the different physiology of older men and women.

PROPOSED ACTIONS FOR THE SECRETARIAT:

100. Develop a global research agenda and collaborate with Member States to strengthen and build capacity in the area of dementia research by incorporating dementia research in national and subnational dementia policies and plans and advocate for strengthened dementia research funding,

²² Global target indicator and means of verification are provided in Appendix

capacities, methods and collaboration to foster dementia research, including through a network of WHO collaborating centres, pilot countries from all WHO regions, and civil society organizations.

101. Engage relevant stakeholders, including people with dementia and their organizations, in the development and promotion of a global dementia research agenda, facilitate global networks for research collaboration, and carry out multisectoral research related to burden of disease, advances in dementia risk reduction, treatment, care, policy and service evaluation. Promote international cooperation and exchange of intercountry research expertise, policy and practice via a systematic, reoccurring mapping of national research investment and output in dementia.

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

PROPOSED ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS:

103. Support Member States and the Secretariat where appropriate by collaborating in shaping dementia research priorities, mobilizing financial support, implementing dementia research in different settings and otherwise disseminating research findings in user-friendly language to policy makers, the public, people with dementia, their carers and families.

104. Advocate for 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.

104. Assist in the implementation and evaluation of innovative technologies and community-based service delivery structures and new dementia care concepts.

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APPENDIX

Indicators for measuring progress towards the defined targets of the draft global action plan on the public health response to dementia

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 dementia-specific stand-alone or integrating dementia into other relevant policies, plans or strategies (e.g. for mental health, ageing, noncommunicable diseases, disability)
Means of Verification	Physical availability of the policy/plan and incorporates the most important principles of dementia care via a checklist.
Comments/Assumptions/ Rationale	<p>Policies or plans for dementia may be stand-alone or integrated into other health, ageing, or disability policies or plans. Operational means it is being used and implemented in the country, and has resources and funding to implement it.</p> <p>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 Action Plan.</p> <p>For countries with a federated system, the indicator will refer to the availability of dementia policies/plans for 50% or more of the states/provinces within the country.</p>

Action Area 2: Dementia awareness and friendliness

Global Target	75% of countries will have at least one functioning public awareness campaign on dementia and/or dementia-friendly policy, programme or service to foster a dementia-inclusive society by 2025
Indicator	Existence of either at least one mass media dementia awareness raising programme/ campaign (run nationwide on television, radio, print media and/or billboards for at least three weeks) in the past year/during the most recent survey period or policies, services or programmes designed to change the physical and social environment to make them more dementia friendly and inclusive
Means of Verification	Inventory or project by project description of currently implemented programmes.
Comments/Assumptions/ Rationale	<p>Programmes may – and preferably should – cover both universal, population-level awareness raising strategies (e.g. mass media campaigns against dementia stigma and discrimination) and those aimed at locally identified vulnerable groups (e.g. elderly, women, people with low educational attainment, high risk populations such as smokers, ethnic minorities).</p> <p>The media play a key role in shaping dementia knowledge, opinions and behaviours, and can be extremely powerful in influencing both individuals and policy makers regarding dementia awareness and</p>

	<p>understanding. As a result, mass media dementia campaigns should become a key component of raising dementia awareness.</p> <p>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 stigma associated with dementia, promoting a greater involvement of people with dementia in society, and supporting families and carers of people with dementia. By choosing a broad input indicator (i.e. existence of policies and programmes supporting the creation of dementia-friendly societies) a maximum impact on a broad range of outputs is expected. The successful implementation of dementia-friendly policies requires a multisectoral approach involving governments, civil society and the private sector.</p>
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Action Area 3: Dementia risk reduction

Global Target	The global targets defined in the Global Action Plan for Prevention and Control of Noncommunicable Diseases are achieved for risk reduction by 2025 ²³
Indicator	<p>A 30% relative reduction in prevalence of current tobacco use in persons aged 15+ years</p> <p>A 25% relative reduction in overall mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases</p> <p>At least a 10% relative reduction in the harmful use of alcohol, as appropriate, within the national context</p> <p>A 25% relative reduction in the prevalence of raised blood pressure or contain the prevalence of raised blood pressure according to national circumstances</p> <p>A 10% relative reduction in prevalence of insufficient physical activity</p>
Means of Verification	Reporting provided for the Global Action Plan for Prevention and Control of Noncommunicable Diseases.
Comments/Assumptions/Rationale	There is a growing consensus that some protective measures might reduce the risk of cognitive decline – specifically, there is some evidence that physical activity, early-life educational opportunities, management of midlife hypertension, tobacco cessation and a reduction in obesity and diabetes may reduce the risk of cognitive decline.

²³ WHO global action plan for the prevention and control of noncommunicable disease 2013-2020: http://apps.who.int/iris/bitstream/10665/94384/1/9789241506236_eng.pdf

Action Area 4: Dementia diagnosis, treatment and care

Global Target	In at least half of countries, as a minimum, 50% of people with dementia are diagnosed and receive health and social care services
Indicator	The number of people in a population who accessed the health and/or social care system and received a diagnosis of dementia (all-cause) and received health and/or social services related to dementia
Means of Verification	Numerator: Combination of the diagnostic rate and treatment rate as will be defined and measured by dementia indicators included in the WHO Global Dementia Observatory Denominator: Prevalence rate of dementia as will be defined and measured by dementia indicators for the WHO Global Dementia Observatory.
Comments/Assumptions/ Rationale	The use of administrative data, electronic records or registries are potential sources of data. This will be a relative, globally combined measure.

Action Area 5: Support for dementia carers and families

Global Target	75% of countries provide national support and training programmes for carers and families of people with dementia by 2025
Indicator	At least one national functioning support or training programme is available for carers
Means of Verification	Inventory of currently implemented carer programmes.
Comments/Assumptions/ Rationale	Functional programmes are defined as having dedicated financial and human resources with an implementation plan and documented evidence of progress or impact. Types of programmes or supports for carers can include respite care, counselling, carer educational training such as care techniques, non-verbal communication, patient-carer relationship development. For countries with a federated system, the indicator will refer to the availability of at least one provincial/state-wide service or programme with complete geographic coverage for 50% or more of the states/provinces within the country.

Action Area 6: Information systems for dementia

Global Target	50% of countries routinely collect a core set of dementia indicators through their national health and social information systems on which they report every two years by 2025
Indicator	Core set of identified and agreed upon dementia indicators routinely collected and reported every two years (yes/no)
Means of Verification	Routine reporting and submission of core dementia indicator set to WHO Global Dementia Observatory every two years.
Comments/Assumptions/ Rationale	Core dementia indicators include those relating to specified targets of this action plan, together with other essential indicators of health and social system policy and resources. The data need to

	<p>be disaggregated by sex and age groups. Where needed, surveys can also be used to complement data from routine information systems. The Secretariat will advise countries on a set of core indicators to be collected in consultation with Member States. Data will be collected, analysed and reported by WHO on a global and regional basis (as part of WHO’s Global Dementia Observatory).</p>
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Action Area 7: Dementia research and innovation

Global Target	At least 50% of countries are allocating 1% of their dementia expenditure to dementia research
Indicator	Current expenditure on national dementia research, expressed as a percentage of expenditure on current dementia care
Means of Verification	<p>Numerator: current government expenditure for research in dementia.</p> <p>Denominator: Total current government expenditure on dementia care.</p>
Comments/Assumptions/Rationale	Dementia care and scope of dementia research as will be defined and measured by core dementia indicators for the Global Dementia Observatory.

Links to other global action plans, strategies and programmes

- Political declaration of the High-level Meeting of the United Nations General Assembly on the Prevention and Control of Non-communicable Diseases:
http://www.who.int/nmh/events/un_ncd_summit2011/political_declaration_en.pdf
- Comprehensive mental health action plan 2013-2020:
http://apps.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf
- Global action plan for the prevention and control of noncommunicable disease 2013-2020:
http://apps.who.int/iris/bitstream/10665/94384/1/9789241506236_eng.pdf
- WHO global disability action plan 2014-2021:
<http://www.who.int/disabilities/actionplan/en/>
- PAHO strategy and plan of action on dementias in older persons 2015-2019:
http://www.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=31496&Itemid=270&lang=en
- The global strategy and action plan on ageing and health (2016-2020):
<http://www.who.int/ageing/global-strategy/en/>
- Sustainable Development Goals (SDGs):
<http://www.who.int/topics/sustainable-development-goals/en/>

List of other documents that are linked to the global action plan on the public health response to dementia

- WHO Mental Health Gap Action Programme (mhGAP)- Diagnosis of Dementia:
http://www.who.int/mental_health/mhgap/evidence/dementia/q6/en/
- WHO iSupport: E-programme for Caregivers of People Living with Dementia:
http://www.who.int/mental_health/neurology/dementia/isupport/en/
- WHO Mental Health ATLAS (2014):
http://www.who.int/mental_health/evidence/atlas/mental_health_atlas_2014/en/
- WHO Assessment Instrument for Mental Health Systems (AIMS) Version 2.2:
http://www.who.int/mental_health/evidence/WHO-AIMS/en/
- WHO Service Availability and Readiness Assessment (SARA):
http://www.who.int/healthinfo/systems/sara_introduction/en/
- WHO Quality Rights Toolkit (2012):
http://www.who.int/mental_health/publications/QualityRights_toolkit/en/
- WHO Global Age-Friendly Cities: A Guide (2007):
http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf
- WHO Tobacco use knowledge summaries: tobacco use and dementia
http://www.who.int/tobacco/publications/mental_health/dementia_tks_14_1/en/

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