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

Summary of Comments and Views (not an official document)

Summary of Consultation Process

In June 2016, the Executive Board, at its 139th session, 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.

From July to August 2016, internal consultations were conducted with regional offices and relevant WHO departments at headquarters to support the development of the zero draft global action plan on the public health response to dementia.

The Secretariat subsequently implemented the following consultation process on the “zero draft” of the global action plan with Member States, United Nations agencies and other relevant non-State actors:

- From 5 September 2016 until 15 October 2016, web-based consultation was carried out to seek comments from Member States and views from non-State actors on a WHO Discussion Paper (version dated 5 September 2016) containing a “zero draft” of the global action plan.
- The consultations on webinars occurred with Member States, United Nations agencies and other relevant non-State actors in the American (both in English and Spanish), Eastern Mediterranean and Western Pacific regions, in collaboration with the regional offices.
- From 5 September to 15 October 2016, the “zero draft” was also disseminated and presented to Member States and other relevant stakeholders in a number of meetings as opportunities arose.
- An informal consultation of Member States and other relevant stakeholders was organised on 10 October at WHO headquarters. Forty six Member States and more than 110 other relevant non-State actors participated in this consultation.

In total, feedback on the zero draft was received from 79 Member States, 1 UN agency and 33 relevant non-State actors. Inputs received from Member States and UN agencies are reported together for the sake of brevity.

Overall Feedback on the Action Plan and its Structure

Overall the zero draft of the global action plan on public health response to dementia was thought to be comprehensive, useful and fulfilling a defined need by all stakeholders. Specific suggestions were received on the vision, goal, action areas, indicators and targets as described below.

Member States, UN agencies and non-State actors were in agreement with the overall structure of draft action plan. No recommendations were made to change the structure or include additional appendices.
General Comments on Vision, Goal and Cross-Cutting Principles

Member States and UN agencies

General feedback received was that the plan is comprehensive and covers all key areas relevant to public health response to dementia.

Vision

Comments broadly supported the proposed vision statement and many Member States expressed that it is consistent with most national visions for action on dementia as well as aligning with the actions in the global action plan. Specific recommendations for modifications included:

- To refer to people affected by dementia (which includes people with dementia, their carers and families) in the vision statement and delete reference to people without dementia as the vision may not aim beyond those affected by dementia.
- To explicitly include carers in the vision statement so as to be inclusive of those who may not have dementia but are still affected by it.
- To highlight the importance of autonomy in the vision statement as it is a key principle for people with dementia.
- There were additional suggestions including reference to co-morbid conditions in people with dementia, sustainable development goals (SDGs) and quality of life. These suggestions were incorporated into the strategic actions areas of the global action plan.

Goal

The overarching recommendation was to reframe the goal into a more positive statement reflecting the change the action plan is seeking to achieve while remaining concise. Specific recommendations were:

- To include carers in the goal, as this would be more inclusive of people affected by dementia.
- To use the term ‘communities’ instead of ‘societies’ as this is better understood and reflective of actions in the global action plan.

Cross-Cutting Principles

Comments generally agreed with the seven cross-cutting principles stated in the global action plan. Specific recommendations were made regarding the descriptions of the principles as follows:

- To reframe ‘Universal Health Coverage’ to include the concept of social care because of the nature of care required for dementia, and include explicit reference to financial risk protection with equitable access across the full spectrum of dementia services.
- To ensure terms are consistent with the language of the SDGs and other relevant WHO action plans.
- On the principle of equity, different suggestions were provided, namely whether emphasis on gender equity particularly on gender sensitive interventions should be separate or included within the principle of equity. Another suggestion was to broaden the concept of ‘equity’ beyond gender to include reference to vulnerable populations. It was also suggested to make more explicit
linkages to SDGs within the principle of equity. It was also suggested to emphasise the variation between different regions and income groups.

- To clarify the difference between ‘cure and care’ and paying appropriate attention to both. Focus on dementia prevention/risk reduction was emphasised as an important addition.

**Non-State Actors**

The comprehensiveness of the plan and its human rights based approach was appreciated. Suggestions included more strongly emphasizing implementation of the Convention on the Rights of People with Disabilities for Member States that have ratified the Convention.

**Vision**

Similar to the suggestion by Member States and UN agencies, it was recommended to delete reference to people without dementia and to explicitly include carers in the vision statement. Additional recommendations included:

- To increase readability by reframing the vision into a simpler statement.
- To include the broader concept of social inclusion.
- To stress awareness and risk reduction.
- To include autonomy as it is a key principle for people with dementia.

**Goal**

The general consensus was that the goal is well written but as suggested by Member States and UN agencies, it was recommended that the goal should be reframed into a positive statement to reflect the direction of change the global action plan is seeking. Specific recommendations included:

- To make references to quality of life as a measure of living well.
- To include risk reduction in the goal.
- To include the timeframe of the goal.

**Cross-Cutting Principles**

The overarching feedback was that the cross-cutting principles capture all essential components. Additional recommendations regarding the descriptions of the principles include:

- Within the principle of ‘Evidence-based practices for risk reduction and care’, make reference to a rehabilitative model to emphasize autonomy and decrease dependence or disengagement. It was also suggested to include reference to “cost effectiveness”, “sustainability” and “cultural sensitivity” when describing these practices.
- Within the principle of ‘multi-sectoral collaboration’, emphasize integration and coordination efforts by highlighting the need for alignment of dementia and noncommunicable (NCD) prevention and control efforts.
- To highlight the need for implementation of human rights beyond its inclusion in policies and plans.
- To clarify the difference between ‘cure and care’ and paying appropriate attention to both.
General Comments on Action Areas, Targets and Indicators

Action Area 1: Dementia as a public health priority

Member States and UN agencies

Overall, Member States commented that the actions in this action area were appropriate and valuable. Specific suggestions included:

- To ensure that the cross-cutting principles are integrated and reflected in the actions.
- To further emphasize capacity building and sustainable funding. As an example, it was suggested that it could also be helpful to specify how resources should be allocated and to identify priorities.
- To emphasise allocation of adequate finances for Member States to implement national plans.
- To include the terms “collaboration” and “integration” as it acknowledges jurisdictional interactions and relationships within Member States as well as integration with pre-existing action plans. To better reflect implementation and monitoring of human rights in actions as well as the need to prevent abuse of human rights and to support the legal rights of people with dementia.
- To highlight the inclusion of people with dementia and their carers in the development of policies, plans and strategies.
- For the actions by Secretariat, it was suggested to strengthen the action on facilitating monitoring of objectives.
- A suggestion was made to revise the global target to include assigned funding and infrastructure for national strategies, policies or plans by 2025.

Non-State Actors

General comments were in support of the whole-of-government, broad multi-stakeholder public health approach outlined in this action area. Specific recommendations included:

- To emphasise reporting on how people with dementia are included in the implementation of the UN Convention on the Rights of Persons with Disabilities for Member States that have ratified the Convention.
- To stress the prerequisite for legislation of human rights as it would indicate a right to health and social care be made on a statutory basis to ensure the needs of people living with dementia are met.
- To emphasize addressing the inequality issues in dementia as this can be most effective at expanding margins around human dignity and worth.
- To contextualize the public health approach by acknowledging that dementia occurs across the life-course and intervenes action on the social determinants of dementia. To include programmes for supporting people with early/younger-onset dementia as appropriate.
- To highlight that in all contributions, people with dementia and their carers should be treated as equals in the process.
- To emphasise the provision of legal assistance both for people with dementia and their carers for them to know and exercise their rights.
- For the Secretariat to include an action on provision of technical support on systematic collection of data, monitoring use of services and progress (including for human rights) to support follow-up actions in dementia. It was suggested for the global target 1 to be revised and to set the target at 100% of Member States having a national policy/plan by 2025. It was also suggested to consider two-tiered targets based on the baseline status and resources in the Member States – one for high-income countries and another for low- and middle-income countries.
**Action Area 2: Dementia awareness and friendliness**

**Member States and UN agencies**

Many comments were provided on the importance and value of this action area. Specific recommendations included:

- To provide more clarity regarding dementia awareness versus dementia-friendliness.
- To emphasize active community participation as crucial, particularly for low- and middle-income countries. Further, to highlight and identify communities taking action, particularly with regard to creating dementia-friendly communities.
- To highlight stigma reduction and reference human rights of people with dementia, including the UN Convention on the Rights of Persons with Disabilities.
- To stress the need for tolerance and acceptance of people with dementia and the need for inclusion and the fair and equal treatment of people with dementia.
- To consider adding reference to ‘age-friendly’ in addition to dementia-friendly communities as this will have great benefits for people with dementia and their carers/families.
- To highlight the importance of spreading and sharing information about best practices.
- To emphasize the role of the private sector in contributing to dementia-friendly communities.
- To support a broader spectrum of civil society including people with dementia who can provide support in the design and dissemination of tools and interventions designed to increase dementia awareness and reduce stigma.
- For the Secretariat, it was suggested to consider developing an information sharing network for dementia-friendly initiatives that would be useful to provide further guidance as well as on how to measure ‘dementia-friendliness’.
- For global target 2, it was suggested to increase the global target to 100% of Member States having a functioning public awareness campaign by 2025. It was also suggested to have separate targets for dementia awareness and dementia-friendliness.

**Non-State Actors**

While agreeing with Member States on the importance of highlighting community approaches that aim towards dementia-friendliness, it was additionally suggested that there was a need to identify key leaders and dementia champions at a local level. Specific recommendations included:

- To include, “promotion of early detection and diagnosis” as an important purpose of the dementia awareness campaigns.
- To emphasize the role of Member States in facilitating the development of outcome indicators with a bottom-up approach by the community and to promote the use of such indicators for baseline assessments, target setting, monitoring and evaluation and strengthening of collaboration with all stakeholders in the community.
- To highlight the importance of media in awareness raising efforts.
- To underline the responsibility of non-healthcare private sector entities in actions that support dementia awareness and friendliness.
- To emphasize engagement of all stakeholders in awareness-raising.
- To highlight the wide role of civil societies in supporting the design and dissemination of tools and interventions in dementia.
- To highlight the need for public health campaigns to education and reduce further stigmatization of people with dementia.
To stress the necessity of educating and involving the younger population in training and developing programmes on dementia.

To effectively reflect the reality of low- and middle-income countries, where awareness remains a significant challenge.

To consider the inclusion of interim targets to ensure that progress against this target is driven across the timeframe of this action plan. It will also be important to ensure that in assessing progress against this target, that attention is paid to the content of campaigns and the nature of initiatives, and these are evaluated for their impact.

**Action Area 3: Dementia risk reduction**

**Member States and UN agencies**

Member States generally welcomed the linkage of dementia risk reduction to the NCD action plan. Suggestions were made to link this action area more closely to Action Area 2 and to mirror the priority of the dementia risk factors more consistently across the two areas. Specific suggestions included:

- To strengthen the global action plan by including or emphasizing the effect of harmful use of alcohol, metabolic risk factors such as hypertension and diabetes, physical inactivity and unbalanced diets.
- To highlight preventive measures such as ‘health promotion’, ‘smoke-free lives’, cognitive stimulation and social engagement and to further emphasize policy actions that countries can take, for example, tobacco control and alcohol harm reduction policies that contribute not only to dementia risk reduction but also wider NCD areas.
- To stress that risk reduction interventions need to be culturally sensitive, follow a life-course approach and should become a core component of dementia training for health professionals.
- To promote the evidence base on associated risk factors at country and regional levels. Further, to promote safe environments, and occupational settings to reduce the exposure to risk factors.
- To include the concept of health promotion as it is essential for preventing and treating dementia and encouraging healthier behaviours.
- For the Secretariat to support the sharing of Member States’ approaches to risk reduction, both in terms of policies and campaigns. It was also suggested to develop guidelines to assist Member States in implementing risk reduction during midlife to prevent/delay the onset or mitigate the impact of dementia.
- To consider adding dementia to the NCD action plan during its mid-term review in 2018 along with a measurable target or discuss it during the third high-level meeting of NCDs in 2018.
- For global target 3, it was suggested to consider modifying the NCD targets to make them more achievable and comparable across Member States. It was also proposed to clarify the targets with respect to the proposed timeline; the choice and selection of indicators; and the definition of indicators.

**Non-State Actors**

Similar to comments from Member States, non-State Actors suggested addition of dementia to the NCD action plan and also welcomed the emphasis on dementia risk reduction and its linkage to policies, programmes, actions and global targets related to NCDs. Editorial suggestions were to align the priority of risk factors consistently across the dementia global action plan while emphasizing the level of evidence supporting dementia risk reduction. Specific recommendations included:
• To strengthen the action plan further by emphasizing the treatment of hypertension, diabetes and depression; as well as cognitive stimulation and social engagement as means to decrease dementia risk; by including medication induced dementia, environmental factors and head injuries as potential risk factors.

• To include public awareness on the link between physical health and brain health and highlight the potential cost savings when addressing dementia risk factors as compared to having to provide treatment and care for dementia.

• To highlight the need for generally equitable risk reduction programmes rather than only on gender-sensitivity.

• For global target 3, recommendation was made to review some of the NCD targets as they were considered too low (e.g. 10% reduction of physical inactivity) as well as to not only focus on risk factors that dementia shares with other NCD but also address cognitive and social aspects. It was also suggested to consider creating short term targets to monitor progress.

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**Action Area 4: Dementia diagnosis, treatment, care and support**

**Member States and UN agencies**

Overall comments for this action area were that it was comprehensive and identified the right key principles while showing some gaps that needed to be addressed. The recommendations provided for this action area included:

• To emphasize integration with existing relevant action plans to build on and align with those approaches as appropriate.

• To make the language of the action area more consistent with the principle of universal health coverage.

• To make reference to providing services for people with dementia who are particularly vulnerable during humanitarian emergencies and disasters.

• To add an action(s) regarding palliative and end-of-life care and make reference to it throughout the action plan, considered especially important given that dementia currently has no known treatment.

• To strengthen the linkage between co-morbidities and dementia and recognize social isolation.

• To highlight investment in diagnostic tools and availability of disease-modifying agents.

• To strengthen actions on timely, formal diagnosis in primary health care as a crucial mechanism for people with dementia to access information, post-diagnostic treatment, care and support through the different levels within the health system.

• To emphasize the role of other health and social care professionals apart from physicians and nurses as equal partners in dementia care.

• To highlight that care pathways should be personalised and integrated depending on the needs of the person with dementia.

• To highlight the need for rights-based social protection which can be used in mitigating risk factors for dementia, as well as in treatment and care following diagnosis.

• For global target 4, recommendations were made to review the indicator as the care population would necessarily be a subset of the diagnosed population, therefore would be necessary to separate the diagnosed population target from the cared population target and clarify the means of verification; It was also suggested to emphasize screening for dementia for people over the age of 65 at the primary care level; and, to specify the timeframe to achieve the target.
Non-State Actors

The focus on shifting toward community-based integrated care outlined in the action area was well received. The recommendations provided for this action area included:

- To provide more clarity around what is meant by long-term care within the context of dementia.
- To emphasize the need for “coordinated and collaborative care” within the actions, in recognition of the difficulties in bridging health and social care.
- To further stress the need for training in knowledge and skills on dementia for general and specialized health workers.
- To highlight the need for support immediately after diagnosis which include enablement, disability support and rehabilitation to support people with dementia to continue to live their lives.
- To incorporate a measure of quality of care outcomes in dementia.
- To include the need for equitable global access to dementia medication.
- For global target 4, to consider creating a two-tiered goal for countries that are more advanced in their diagnostic rates and to separate the diagnostic target from the care target; to consider including the establishment of a multidisciplinary care pathway to support rehabilitation and independence; and, to align the target with NCD and Ageing action plan targets to coordinate and maximize synergy across countries.

Action Area 5: Support for dementia carers

Member States

Overall, there was agreement that this is an important action area. Specific feedback included addition of certain terms, for example, adding ‘support’ when care was mentioned and adding ‘social’ care along with health care. Other feedback included:

- To ensure consistent use of terminology with regard to carers and provide definitions.
- To create specific action related to healthcare workers’ identification of carer stress to promote carer health and social wellbeing.
- To reference the importance of dementia carers and families being enabled to live healthy lifestyles to enhance their own health and wellbeing.
- To separate out actions related to carer coping and mental health supports from carer training.
- To highlight the need for social and financial benefits to support carers in their duties. Facilitating ‘respite care’ or short term care cover for carers to be highlighted.
- To emphasize that training is also needed in the health and social care sector for professional carers so that the burden is not all on informal care.
- To emphasise establishment of day care centres at primary health-care level for people with dementia contributing to the long-term decrease of indirect costs and burden on carers.
- To highlight the importance of specifying the rights of people with dementia extends to all people with dementia, including those who may not be part of families that are formally recognized by the state — single people; lesbian, gay, bisexual and transgender individuals; widows and people living in informal settlements with dementia.
- For global target 5, it was suggested to remove reference to ‘national’ as this may restrict as civil society organizations can provide this support to carers.
Non-State Actors

This action area was welcomed and feedback focused on providing community support services and financial support to help carers in their role. Other feedback included:

- To clearly separate supports for families and carers from supports to people with dementia.
- To recognize that people with dementia and their carers are experts in relation to the lived experience of dementia and they need formal recognition as care partners and primary stakeholders in dementia care. They should be considered essential partners, therefore, include collaboration as a term used together with planning and provision of care in all settings.
- To highlight the importance of adequate levels of services for the person with dementia which must be incorporated into any discussion of supports for carers.
- To highlight that the informal carer at home needs to be given the same importance as in an institution and social life of the carer needs to be given importance for better interaction and sharing.
- To consider the infrastructure and care provision currently available in low resource countries where informal carers play a significant role and therefore require further support and training.
- For global target 5, it was suggested that the target could aim at 100% of countries to ensure that no one is left behind. It was suggested to consider inclusion of use of any national support and training programmes by carers in the global target 5.

Action Area 6: Information systems for dementia

Member States and UN agencies

Overarching comments were that the approach for this action area provide evidence-based, systematic monitoring and evaluation actions that are supported by Member States. Specific recommendations included:

- To strengthen the action area by mentioning the importance of patient-reported or carer-reported outcome measures. These data are considered important in measuring the impact of countries' dementia strategies, policies and actions and are not routinely incorporated into dementia standard measures.
- To consider inclusion of development of registries that integrate into existing health information systems as a means of national monitoring and surveillance of dementia.
- To keep in mind existing regulatory frameworks and establish legislation that protects personal data.
- To highlight the need to build infrastructure to support longitudinal data collection, particularly for resource poor countries.
- To reiterate the need to link and share clinical and social data in order to improve care, effectiveness and quality.
- To highlight possible IT solutions for patients and carers.
- To emphasize the linkage to the Global Dementia Observatory in supporting the measurement of all global and national targets.
- To ensure no duplication of effort across different international partners and stakeholders.
- To consider expanding the focus of the action area beyond monitoring and evaluation of function and usage to other information such as surveillance of potentially modifiable risk factors, age-friendly communities etc, using tools already established by WHO.
Non-State Actors

In general, comments strongly support this action area and the role of the Secretariat in facilitating cross-national comparison of data. As suggested by Member States and UN Agencies, it was recommended to include the development of registries and/or observatories within national surveillance and monitoring systems. Other specific recommendations included:

- To highlight the need for psychosocial data, quality of care measures, caregiving and lived experiences to gain a better understanding of the holistic needs of people with dementia and their carers and to use as benchmarks for continuously improving treatment and care services.
- To encourage the development and use of outcome measures in addition to process measures.
- To highlight that data collection should be made simple and in ways that can be easily adapted to specific regions and populations.
- To link to the SDGs’ call for strengthening the disaggregation/stratification of data by age.
- To focus on capturing data related to the co-morbid conditions that occur with dementia.
- For global target 6, to consider splitting the target based on the resource or baseline level of countries

Action Area 7: Dementia research and innovation

Member States and UN agencies

Member States highlighted the importance of increased investment in dementia research and development and the need for matching the amount of dementia research funding to its level of priority. Specific recommendations included:

- To emphasize the need for research in dementia, providing more background to contextualize difficulties with cost and recruitment in dementia.
- To highlight the need for international collaborations, stronger research partnerships and information/data sharing across Member States.
- To facilitate translation of what is already know about dementia into action and implementation. In particular, mutual learning and support of resource poor settings and countries with less advanced dementia care systems in place.
- To clarify the definition and examples of technological innovation, gender equity in the context of innovation and to consider broadening this definition.
- To consider including patient/carer-reported outcome measures and an action to enhance participation in clinical research trials for people with dementia.
- To emphasize the need for further research in risk reduction.
- For global target 7, while several Member States particularly welcomed or agreed with the target, several comments raised concern with respect to defining and measuring Member States’ national dementia spending. In addition, some perceived the target as being too ambitious and requested further clarifications as to what the timeframe was for achieving this target and the rationale for choosing 1%.

Non-State Actors

In general, non-State actors welcomed the target and actions on increasing dementia research investment and developing national dementia research agendas. Comments also indicated appreciation for the call for greater collaboration across Member States and for recruitment into and inclusion of individuals with dementia, their carers and families in research studies. Specific recommendations included:
To emphasize the shortage of evidence-based care and support interventions and need for translational research.

To highlight the need for international collaborations, stronger research partnerships and information/data sharing with appropriate infrastructure to do so.

To encourage the sharing of both positive and negative research results to support learning.

To encourage the use of evidence-based technology for community-based care that meets the needs of people with dementia.

To highlight that dementia research should not have an upper age limit in order to represent the population more appropriately.

To support the development and growth of early stage researchers in the field.

To highlight integration with academic and research institutes in providing evidence-based education on clinical care and training.

Editorial comments included adding examples for types of research to be considered, clarifications on definitions for social/technological innovation (dementia carer); and the suggestion to avoid terminology around “finding a balance” as this might be perceived as a redistribution of existing funding rather than an increase in investment.

For global target 7, some concerns were raised with respect to its achievability/feasibility and lack of clear-cut definition of dementia expenditure, especially highlighting that often health care expenditures for people with dementia are due to comorbid conditions rather than being attributable to dementia alone. It was also suggested to highlight in the global target that research should be expanded beyond bio-medical cure or treatment to prevention and care. Another suggestion was to consider including further clarification regarding the average percentage of research budget allocated toward dementia in comparison to other conditions.
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