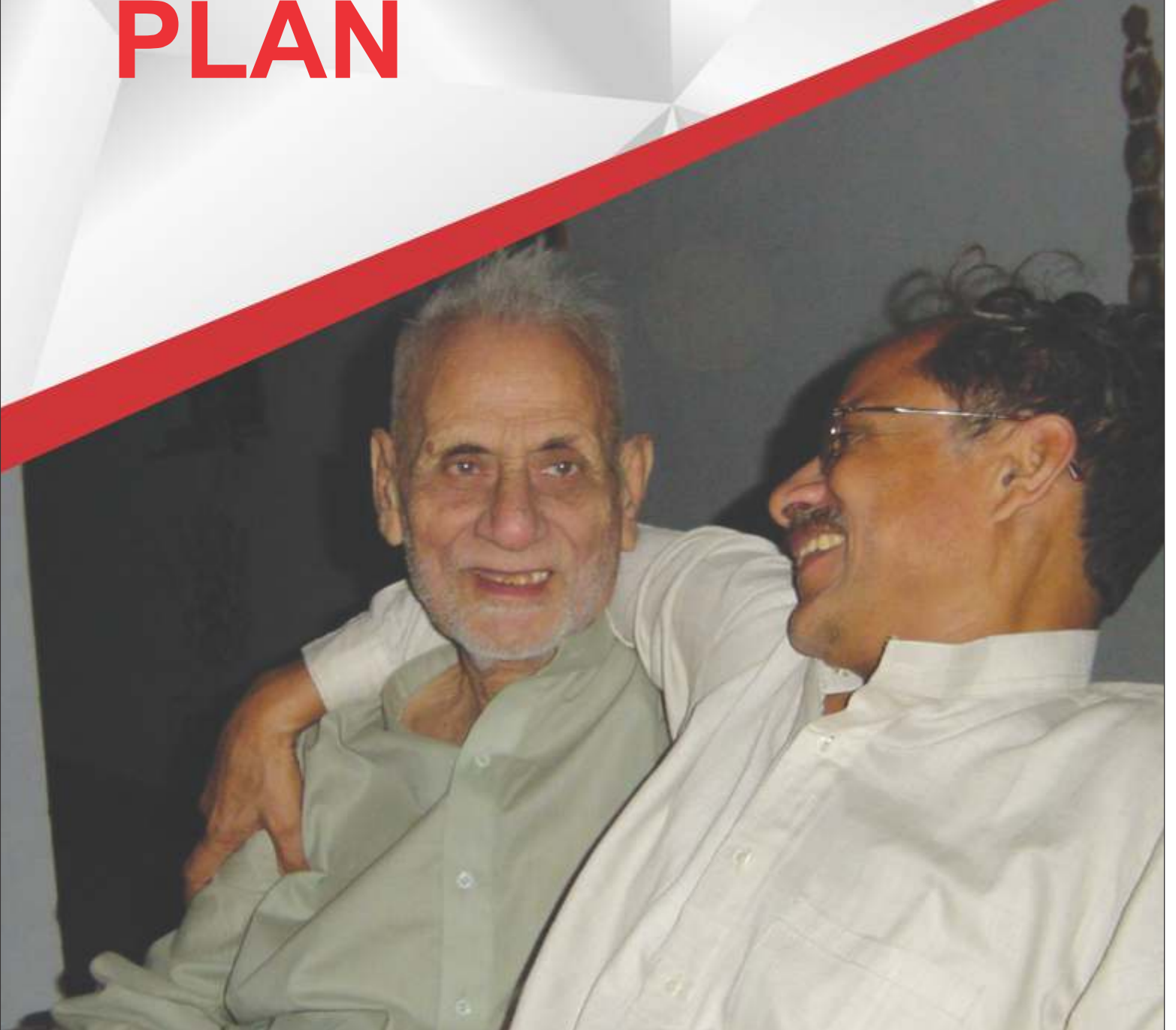


# PUNJAB DEMENTIA PLAN



GOVERNMENT OF THE PUNJAB



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**September 2022**

## **Punjab Dementia Plan**

### **Drafted By**

Dr. Hussain Jafri, Secretary General, Alzheimer's Pakistan

**September** 2022

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## Message



### **Chaudhry Pervaiz Elahi**

**Chief Minister**

**Punjab**

I am extremely pleased on the launch of the Punjab Dementia Plan. It is very heartening that Punjab will now join the international community that has developed dementia plans, which is the first big step in supporting and achieving the WHO Global Action Plan on the Public Health Response to Dementia (2017-2025).

Dementia is one of the most significant global health and social crises of the 21st century as the world is aging and diseases that mainly affect elderly like Alzheimer's disease and Dementias are on the rise. Aging does not cause dementia, but advanced age increases risk. The average life span of Pakistanis is increasing thus making us vulnerable to this debilitating group of diseases. This plan marks a big milestone in providing the required medical and social services to the elderly and people living with dementia and their care givers in the Punjab province.

Taking this opportunity, I would like to thank Dr. Yasmin Rashid, Minister of Specialized Healthcare & Medical Education Punjab for her years' long work in highlighting this important health issue in Pakistan and also for taking the lead and working towards making dementia a priority in Pakistan. I would also like to thank Dr. Hussain Jafri, Secretary General, Alzheimer's Pakistan for leading and drafting the national dementia plan.



## Message



### **Dr. Yasmin Rashid**

**Minister of Specialized Healthcare & Medical Education  
Punjab**

In May 2017, the World Health Organization (WHO) Member States adopted the global action plan on the public health response to dementia (2017-2025) during the 70th World Health Assembly. The aim of the global plan is to improve the lives of people with dementia, their families and the people who care for them, while decreasing the impact of dementia on communities and people.

I have been advocating for the cause of Alzheimer's Disease and Dementias in Pakistan for over two decades. WHO recognizes dementia as a public health priority as it is one of the most significant global health and social crises of this century. Pakistan is the fifth most populous country in the world and the majority of our older adult population are vulnerable to dementia and other chronic conditions. It is estimated that there were around 374,060 people with dementia in Pakistan in 2019, this number projected to increase to 1,350,453 by 2050. Therefore, we need to address this rapidly growing health problem through culturally acceptable, specific and cost-effective approaches. The Punjab Dementia Plan will help the government to develop comprehensive plans and activities to address the needs of the people with dementia and their care givers. It would also help us in setting up plans and services for diagnosis, treatment and care for Dementia in Pakistan.

I would like to extend my gratitude to Chaudhry Pervaiz Elahi, Chief Minister Punjab for his patronage and launching the Punjab Dementia Plan. Moreover, I would also like to thank Dr. Hussain Jafri, Secretary General, Alzheimer's Pakistan for taking the lead on this initiative and drafting this much needed plan for the province. Lastly, I would also like to thank all the national and international experts that have volunteered their time and energy to ensure that we got this plan right.



## Vision

Provide comprehensive and sustainable dementia prevention, diagnosis, care, rehabilitation and supportive services across Punjab, to improve the quality of life of people with dementia and their families.

## Mission

To make dementia a provincial health priority and channel the flow of required resources to provide awareness, prevention options, timely diagnosis and management, support services, research, capacity building and policy development for dementia. The government to spearhead the move towards prioritizing dementia, while engaging all relevant stakeholders across the public and private sectors.

## Guiding Principles

The following would be the guiding principles of the Punjab Dementia Plan:

- Human rights and/or dignity of people with dementia and their carers.
- Engagement and empowerment of people with dementia.
- Evidence-based practices for dementia risk reduction and care, where possible.
- Multi sectoral collaboration on the public health response to dementia.

## Background

Dementia is a collective term for progressive degenerative brain syndromes which affects memory, thinking, behavior and emotions. Alzheimer's disease and vascular dementia are the most common causes of dementia, accounting for up to 90% of dementia cases. Dementia results when the underlying causes damage brain cells and disrupt the transmission of brain signals. Brain tissue shrinks and symptoms appear. Dementia affects memory as well as a range of cognitive and other abilities that include language, judgment and perception [1].

Behavioral and psychological symptoms are also common in dementia, including depression, hallucinations, delusions, agitation, aggression, or apathy. These cognitive and behavioral changes result in difficulties in Activities of Daily Living (ADLs), such as caring for one self, cooking, managing a household and planning activities [2].

Healthcare services in Pakistan have improved significantly over the past couple of decades, resulting in improved life expectancy, thus leading to an increased number of older people in the country. Pakistan is currently the fifth most populous in the world and belongs to a group of only 15 countries worldwide that have more than 10 million older people (age 60+). The older adult population comprises 7% (12.5 million) of the total population of Pakistan, the majority of which are vulnerable to dementia and other chronic conditions [3].

Punjab is the biggest province of Pakistan with a large population of over 110 million people and faces issues related to ageing, chronic diseases and dementia.

Pakistan therefore, needs culturally acceptable, specific and cost-effective approaches to address Alzheimer's and the related disorders that cause dementia. This Punjab dementia plan document will facilitate setting up of dementia friendly community centers that allow synergy of family and community support systems with appropriate medical care services at all levels. Strengthening preventive measures, risk reduction, timely detection, access to the best medical, care and improving social support services, which includes dementia care skills research and information management related to dementia, are important over-arching objectives of this

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[1] Piggott, M.A. & Court, J. (2008) 'Neurochemical pathology of neurodegenerative disorders of old age'. In Jacoby, R., Oppenheimer, C., Dening, T., and Thomas, A. (Eds) (2008) Oxford Text book of Old Age Psychiatry. Oxford: Oxford University Press, pp.85-101.

[2] Prince, M., et al. (2014) Dementia UK Update: Second Edition, London: Alzheimer's Society.

[3] Zaidi, A., S. Stefanoni and H. Khalil (2019) "Moving from the Margins: Promoting and Protecting the Rights of Older Persons in Pakistan"



## Current Situation

Dementia is one of the most significant global health and social crises of the 21st century. The World Health Organization (WHO) has recognized dementia as a public health priority. Every three seconds someone in the world develops the condition. It is estimated that in 2019 there were 57.4 million people with dementia in the world. This number would increase to 83.2 million in 2030, 116.0 million in 2040 and 152.8 million in 2050. There will be more women with dementia than men with dementia globally in 2050 (female to male ratio of 1.67) [4]. Currently 60% of the people who live with dementia are in the low and middle income countries (LMICs) [5] and this proportion is expected to rise to 71% by 2050. It is estimated that globally 75% of people with dementia have not received a diagnosis, this is as high as 90% in low and middle income countries [6]. The developing world continues to share the greater burden of the condition yet these countries are only starting to recognize the need to address dementia-related issues and in most cases, services have yet to develop. Dementia is listed by WHO as the world's seventh leading cause of death and is recognized as a major cause of disability and dependence among older adults [7]. Despite its prevalence, dementia is a silent killer, as stigma, particularly in countries like Pakistan, continues to be a major barrier to diagnosis, treatment and care. Moreover, dementia's prevalence is growing rapidly as the global population ages.

In 2017, around 12.5 million people in Pakistan were above the age of 60 years, and this figure is likely to rise to approximately 40 million by 2050. This fast growing number of older people is resulting in the rapid increase of people with dementia in Pakistan. Pakistan is only starting to experience issues associated with the social and economic rights of older people, and still has a long way to go. Pakistan ranks very low in Global Age Watch Index: 92 out of 96 countries, which means that the social and economic rights of older people are inadequately considered, thus the country continues to lag behind other countries in the region. As of today, the government of Pakistan has developed three important national level policies and legislative instruments to protect the rights of the older people, which include the 1999 National Policy for the Promotion of Better Health of the Elderly; the 2004 National Policy of Older People; and, the 2007 Senior Citizens' Bill.

Unfortunately, none of these national instruments have been approved by parliament and consequently, none of them has been implemented [8]. Therefore, there is a dearth of policy support and services for Pakistan's aging population including limited awareness and understanding of dementia. This contributes to the limited resources to deal with this rising epidemic. Lack of formal social services, along with limited health literacy within local communities may contribute to worse outcomes for people living with dementia in Pakistan. Alzheimer Disease International (ADI), in their 2018 report on Global estimates of informal care, estimates that around 99% of people with dementia in South Asia live at home and the remainder lives in care homes [9].

This highlights the paucity of required services available in these countries, as well as the nature of care provision, which is predominantly family-based. Select and / or small social classes of South Asian communities have access to resources, information and specialist



Source: Alzheimer's Disease International

[4] Nichols E et al (2022). Estimation of the Global Prevalence of Dementia in 2019 and Forecasted Prevalence in 2050: An Analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health* 2022; Online First: 1-21.

[5] ALZHEIMER'S DISEASE INTERNATIONAL Report FROM PLAN TO IMPACT IV (2021), Progress towards targets of the WHO Global action plan on dementia

[6] ADI World Alzheimer's Report 2021, Journey through the diagnosis of dementia

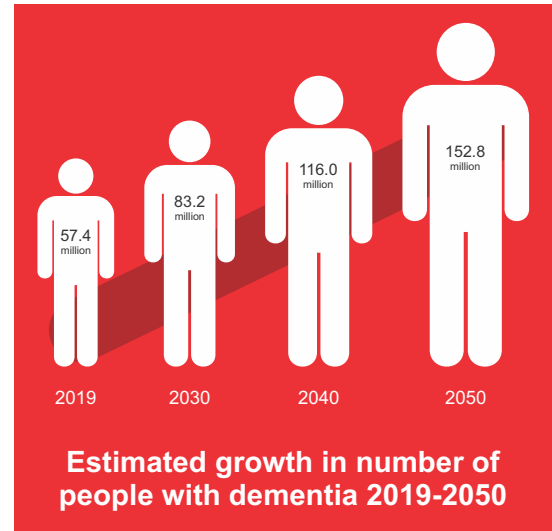
[7] World Health organization <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death#:~:text=In%202019%2C%20Alzheimer's%20disease%20and,forms%20of%20dementia%20are%20women.>

[8] Zaidi, A., S. Stefanoni and H. Khalil (2019) "Moving from the Margins: Promoting and Protecting the Rights of Older Persons in Pakistan"

[9] Alzheimer's Disease International Report Global estimates of informal care (2018)

treatment and care offered by private clinics. However, even if such resources are available, the lack of understanding of dementia and the stigma associated with its diagnosis often precludes accessing the resources. The vast majority of people with dementia are not linked in to any formal diagnostic, treatment and care system as the cost remains beyond their financial capacity.

The lack of awareness and social and health services for the growing population of older people in Pakistan, who are the most vulnerable to dementia, remains to be comprehensively addressed through a National Health Strategy.

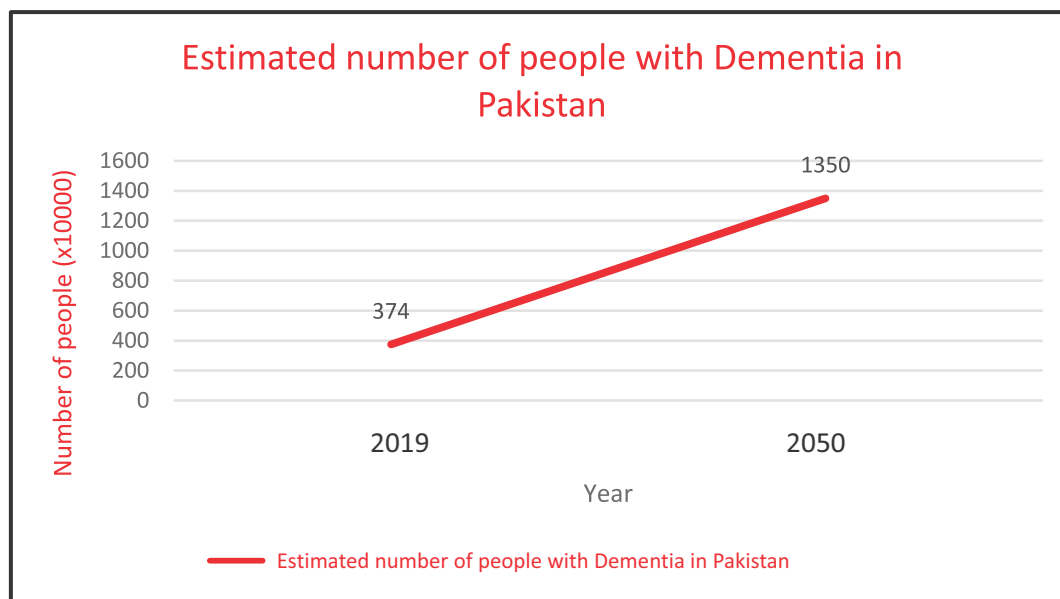


## Dementia in Pakistan

There were 374,060 people with dementia in Pakistan in 2019, which is projected to increase to 1,350,453 in the 2050. The percentage of projected increase in the number of dementia cases is estimated to be 261% , which will carry huge social and economic cost to the community and the government [4].

The data emerging from Pakistan’s 2017 census highlights that the number of older people in the country may be far higher than previously anticipated, thus resulting in increased number of people with dementia in the country. According to the Alzheimer’s Disease International’s 2018 report on “From Plan to Impact”, the diagnosis rate in the LMICs is a mere 10% [5], which means that only a very small fraction of people with dementia receive a proper diagnosis in Pakistan, thus leaving the vast majority undiagnosed, untreated and un cared for.

### Health Strategy.



Furthermore, in 2014, Alzheimer's Disease International calculated that the costs associated with dementia are significant, with estimates indicating that US\$ 642 million being spent in the year on the condition in Pakistan.

These costs related to informal care (such as unpaid family carers), social care (community and residential care), and medical care (primary and secondary care) [10].

**Table 1:**

Estimated Costs of Dementia in Y2015 (Million)			
Medical	Non-Medical	Informal Care	Total
Rs. 35,200 M	Rs. 17,380 M	Rs. 88,660 M	Rs. 141,240 M
25% (US\$ 160 M)	12.3% (US\$ 79 M)	62.7% (US\$ 403 M)	(US\$ 642 M)

*Dollar to Rs: 1: 220.00*

Previously, the governments in Pakistan have not addressed the issue of the rising prevalence of dementia and people living with the condition and their families have thus struggled to find appropriate care and services. These have mainly been provided by Alzheimer's Pakistan (a non-governmental organization working for Alzheimer's and related dementias) on a limited scale in a few cities in Pakistan.

Another key issue to address is the change in Pakistani society that is creating the need for additional formal care (i.e. home support, day care, long term care) outside the immediate family structure. These changes include migration into the cities and others countries with resulting smaller living spaces, generational splits, and the increasing participation of women in the workforce.

This changing scenario demands that the government and society of Pakistan prepare themselves for a serious challenge in the years to come. To begin to address this challenge the Punjab Dementia Plan is expected to receive a commitment for an annual budget from the government. The plan aims to strengthen the resolve of the government of the Punjab to ensure funding, capacity building and research to transform the lives of people at risk of or living with dementia, from prevention to care and support in the advanced stages.

## What is the Punjab Dementia Plan?

Dementia costed the global economy USD\$1.3 trillion in 2021, rising to US\$2.8 trillion by 2030 per year [11]. The world is only now starting to appropriately acknowledge the negative impact of dementia across sectors and social situations. The WHO adopted the Global Action Plan on the Public Health Response to Dementia 2017-2025 and Pakistan is also a signatory to this plan that was adopted by the WHO Member States at the 70th World Health Assembly in May 2017 [12].

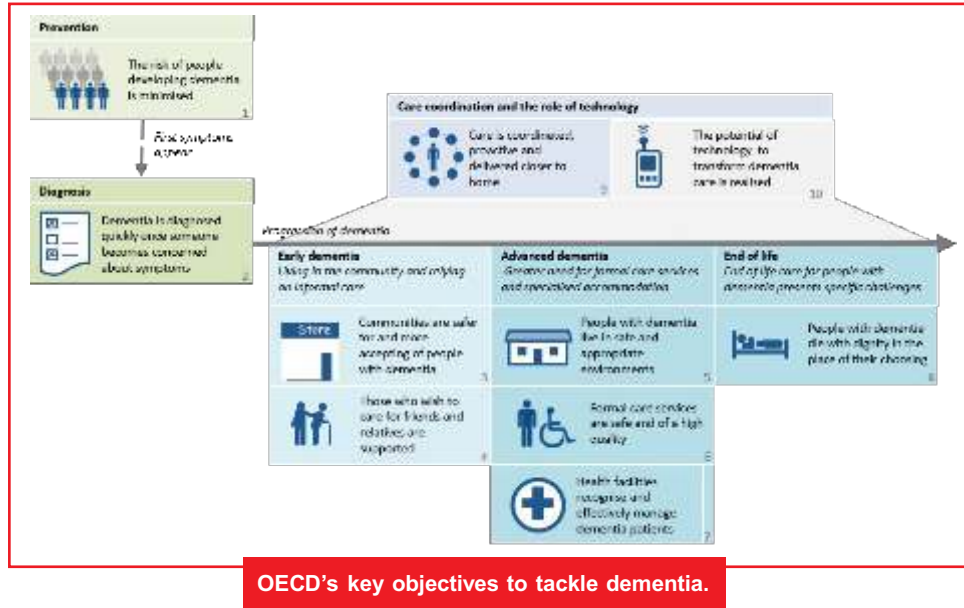
The 18th Amendment to the Constitution of Pakistan in 2010 gives provinces the autonomy and devolution of legislative and executive authority in many sectors, including health. Therefore, in the formal follow-up to the guidelines that were laid out at the 70th World Health Assembly, Punjab province has set out to develop and implement a Provincial Plan with the aim of providing a comprehensive and sustainable strategy to address dementia in the Punjab province.

[10]ALZHEIMER'S DISEASE INTERNATIONAL Dementia in the Asia Pacific Region(2014)

[11]WHO Global Dementia Status Report 2021.

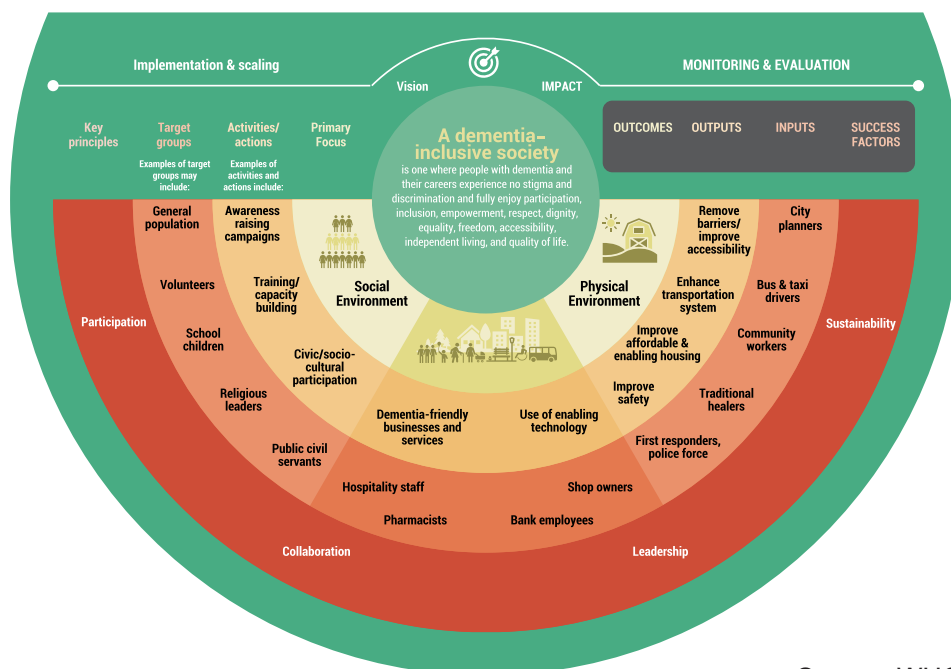
[12]Towards a dementia plan: a WHO guide (2018)

The Punjab Dementia Plan is the first step to initiate transformation towards ensuring comprehensive dementia services at all stages of the condition in the country and it is expected that other provinces will also develop similar provincial dementia plans.



This plan outlines the government's commitment to provide the required resources to address the problems of dementia based on WHO Global Action Plan on the Public Health Response to Dementia 2017- 2025 and Organization for Economic Co-operation and Development's (OECD) key objectives to tackle dementia [13].

Moreover, the Punjab Dementia Plan is also providing foundation for the development of a dementia-inclusive society (DFI). According to WHO, DFI is one in which people with dementia and their carers fully participate in society and have a place in it. They enjoy respect, freedom, dignity, equality, accessibility and quality of life. It is one where they are empowered to live independently, free from stigma, discrimination, exploitation, violence or abuse [14].



Source: WHO

[13] OECD Quality Indicators for Dementia - <https://www.oecd.org/els/health-systems/item-4c-hcqi-dementia-oecd.pdf>

[14] Towards a dementia inclusive society. WHO toolkit for dementia -friendly initiatives (2021)

Following are the seven core action areas that have been outlined by the WHO in the Global Action Plan that will form the framework of the Punjab Dementia Plan:

## Core Action Areas Guiding The Punjab Dementia Plan

- Dementia as a public health priority
- Dementia awareness and friendliness
- Dementia risk reduction
- Dementia diagnosis, treatment, care and support
- Support for dementia carers
- Information systems for dementia
- Dementia research and innovation

The Punjab Dementia Plan is based on WHO's core action areas [15] and is the first step to initiate transformation towards ensuring comprehensive dementia services at all stages of the condition.

The plan has targets for each action area and will be monitored periodically.



Source: World Health Organization (WHO, 2017)<sup>[15]</sup>

[15]WHO global action plan of the public health response to dementia 2017 - 2025.

## Actionable Areas

Given below are the suggested targets and corresponding activities in relation to the suggested actionable areas of WHO Dementia Global Action Plan:

**Table 2: Dementia targets and suggested activities**

ACTION AREAS	TARGETS BY 2025*	SUGGESTED ACTIVITIES
<b>1. DEMENTIA AS A PUBLIC HEALTH PRIORITY</b>	Punjab will have developed and launched its own comprehensive Dementia program, by 2025	<ul style="list-style-type: none"> <li>• Declare dementia as a public health priority</li> <li>• Develop a comprehensive response through multi-sectoral approach, involving a health and social care continuum</li> <li>• Punjab to develop PC1 to provide comprehensive Dementia services in the province.</li> </ul>
<b>2. DEMENTIA AWARENESS AND FRIENDLINESS</b>	a)30% of cities in Punjab will have at least few dementia- friendly initiatives b)30% of cities in province shall have Alzheimer's Pakistan chapters, thus providing some public- awareness campaigns on dementia to foster a dementia inclusive society by 2025.	<ul style="list-style-type: none"> <li>• Increased awareness on healthy life style awareness</li> <li>• Increase dementia literacy among public</li> <li>• Activities related to reduction of stigma around dementia</li> <li>• Develop and ensure availability of dementia awareness multi-media packages customized to low resource settings.</li> <li>• Initiate dementia- friendly programs to sensitize the community</li> <li>• Launch mass level awareness campaigns with special focus on younger generation</li> <li>• Collaborate with and assist Alzheimer's Pakistan to establish information counseling and awareness centers at district levels</li> </ul>
<b>3. DEMENTIA RISK REDUCTION **</b>	a)In at least 30% of the cities, premature mortality reduction from Non Communicable Diseases (NCD) by 10% b)In at least 30% of the cities, reduce the rise of obesity and diabetes c)In at least 30% of the cities, physical activity increase by 10% d)In at least 30% of the cities, reduce the	<ul style="list-style-type: none"> <li>• Adopt literature related to comprehensive healthy lifestyle with a focus on 'brain health' in at least in 30% of cities in the province</li> <li>• Establish NCD screening centers in at least 25% of all health facilities in respective cities,</li> <li>• Promote healthy lifestyle through guidelines to quit smoking and alcohol consumption</li> <li>• Promotion of healthy food options</li> <li>• Promotion of reduction in salt intake</li> <li>• Promotion of physical activity amongst youth the specially in educational institutions</li> <li>• Promotion of strategies to reduce transfat intake</li> <li>• Provision of NCD medicines at district level</li> </ul>

Table 2: Dementia targets and suggested activities

ACTION AREAS	TARGETS BY 2025*	SUGGESTED ACTIVITIES
	<p>rise of blood pressure by 10%</p> <p>e)In at least 30% of the cities, reduce sodium intake by 10%</p> <p>f)In at least 30% of the cities, reduce tobacco use by10%</p> <p>g)In at least 30% of the cities, receive drug therapy &amp; counseling to reduce cardiovascular risk.</p> <p>h)In at least 30% of the cities, improve availability, affordability of NCD medicines.</p>	
<p><b>4. DEMENTIA DIAGNOSIS TREATMENT, CARE AND SUPPORT</b></p>	<p>a)In at least 30% of the cities,50% of the public sector hospitals providing diagnosis services to people with dementia.</p> <p>b)In at least one city, a geriatric service with dementia care and treatment services is established.</p> <p>c) In at least 30% of the cities, capacity building and training of specialists (neurologists, geriatricians, &amp; psychiatrists) through regular yearly trainings.</p> <p>d)In at least 30% of the cities, capacity building and training of General Practitioners through regular programs.</p> <p>e)In at least 30% of the cities, capacity building and training of</p>	<ul style="list-style-type: none"> <li>• Ensure the establishment of at least one geriatric service in the provinces providing dementia care and treatment services.</li> <li>• Assess and allocate required hospital beds at for geriatric and dementia care services</li> <li>• Ensure the establishment of memory clinics at all tertiary care and district level hospitals in at least 25% of the cities</li> <li>• Ensure people with dementia get early diagnos and have standard treatment care protocols</li> <li>• In at least 25% of the cities, establish Dementia day care centers at District levels in collaboration with Alzheimer's Pakistan</li> <li>• Provide training in collaboration with specialists societies (neurologists, Psychiatrists, medicine) to the healthcare providers in diagnosis and support services.</li> </ul>

Table 2: Dementia targets and suggested activities

ACTION AREAS	TARGETS BY 2025*	SUGGESTED ACTIVITIES
	paramedical staff through regular yearly training	
<b>5. SUPPORT FOR DEMENTIA CARERS</b>	In at least 30% of the cities, provide support and training programs for carers and families of people with dementia through Alzheimer's Pakistan by 2025.	<ul style="list-style-type: none"> <li>• Medical care expenses through Insaf Sehat Card /medical insurance provided to PWD</li> <li>• Establish in collaboration with Alzheimer's Pakistan:               <ul style="list-style-type: none"> <li>- Dementia outreach home care service</li> <li>- Dementia Care Skills Training Program for formal and informal care workers</li> <li>- Information, counseling and awareness centers at district levels</li> </ul> </li> <li>• Incorporate a chapter in school curricula on dementia.</li> <li>• Judiciary to draw up standard procedures for civil disputes related to dementia affected people</li> </ul>
<b>6. INFORMATION SYSTEMS FOR DEMENTIA</b>	30% of cities routinely collect a core set of dementia indicators through a provincial registry incorporating health and social information	<ul style="list-style-type: none"> <li>• Establish sentinel dementia surveillance system in 50 % of districts in the provinces.</li> </ul>
<b>7. DEMENTIA RESEARCH AND INNOVATION</b>	In 30% of cities research activities will be initiated. The research to be conducted in collaboration with Alzheimer's Pakistan & other leading research institutions & individuals. Priority research areas to include dementia patient-centric care, awareness and understanding, prevention, quality of care, improving living conditions of people with dementia and care givers and pharmacological and non-pharmacological research. Develop capacity and capability for dementia related research	<ul style="list-style-type: none"> <li>• Mobilize financial resources to prepare, to test and to evaluate cost benefits analysis and exploring and including assistive devices, comprehensive care models, processes to support dementia friendly institutions.</li> <li>• Development of screening and diagnostic tools for people with dementia and their carers</li> <li>• Undertake a gap analysis for dementia research</li> <li>• Establishment of online dementia research repository etc.) in collaboration with Alzheimer's Pakistan.</li> <li>• Establishing Dementia registry of people with dementia for improved access to diagnosis, treatment and care services.</li> <li>• Initiate dementia research trainings of health professionals and students by including research projects and audits into training programs</li> <li>• Prioritized dementia relevant clinical trials, community trials, cost effective analysis and systems-policy analysis</li> </ul>



**Table 2: Dementia targets and suggested activities**

ACTION AREAS	TARGETS BY 2025*	SUGGESTED ACTIVITIES
		<ul style="list-style-type: none"> <li>• Develop resources mobilization hubs to discover new treatments, processes or new dementia-friendly models</li> <li>• Carryout research on psychosocial aspects of dementia</li> </ul>

*Notes: \*There is dearth of baseline data available in Pakistan, therefore, while at the implantation phase of this plan, the baseline data may also be collected and then monitored accordingly. \*\*There are a number of other targets also present but this document focuses on selected issues only.*

## Way Forward

Dementia is not only a global problem but it is becoming a national public health challenge in Pakistan as well. This highlights the need for relevant strategic actions for people with dementia and their family carers. In this regard, the Punjab Dementia Plan outlines a structure that harnesses and gives synergy to WHO's Global Action Plan on Dementia — Call for Action in ensuring dementia service delivery at all levels of health delivery system. It also identifies the core values, guiding principles and strategies aimed at providing the much needed dementia care services in Punjab. The document also provides a comprehensive dementia plan implementation framework to achieve the stated policy vision and guiding public health principles such as prevention/risk reduction, early detection-diagnosis, access to best medical care, social support services, dementia research and information system.

The Punjab Dementia Plan is the first step to initiate transformation towards ensuring comprehensive dementia services. It outlines the government's commitment to provide the required resources to address the problems of dementia in the province. After the adoption and launch of the Punjab Dementia Plan, the Punjab government through respective departments, would initiate a multi-sectorial collaboration involving all the key stakeholders including health & social services departments, medical and care staff, service providers and people with dementia and their families through Alzheimer Pakistan. Through this consultative process, a detailed operational plan shall be developed based on the dementia targets and activities given above in Table 2. The detailed operation plans would then be funded by the Punjab government. It is imperative that the Punjab Dementia Plan is driven by people with dementia and their families and there is an adequate provision of resources to the health and care systems in tackling dementia.



**SPECIALIZED HEALTHCARE & MEDICAL EDUCATION DEPARTMENT**  
Government of the Punjab.