Rapid Synthesis

Identifying Performance Measures, Indicators and Targets to Monitor and Evaluate Dementia Strategies

6 April 2018

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EVIDENCE >> INSIGHT >> ACTION

Rapid Synthesis:
Identifying Performance Measures, Indicators and Targets to Monitor and Evaluate Dementia
Strategies
Three-day response

6 April 2018

McMaster Health Forum

> The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

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Timeline

> Rapid syntheses can be requested in a three-, 10-or 30-business-day timeframe. This synthesis was prepared over a three-business-day timeframe. An overview of what can be provided and what cannot be provided in each of the different timelines is provided on McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

Merit review

> Our 10- and 30-business-day rapid syntheses are reviewed by a small number of policymakers, stakeholders and researchers in order to ensure scientific rigour and system relevance. Our three-business-day rapid syntheses do not undergo merit review given the compressed timeline in which they are produced.

KEY MESSAGES

Question
- What performance measures, indicators and targets can be used to measure, monitor and evaluate the performance of dementia strategies?

Why the issue is important
- Dementia is a complex condition and while the experience is individual, the disease eventually progresses to a person not being able to care for themselves and requiring assistance with all aspects of their daily life.
- Common symptoms of all forms of dementia include memory loss, frequent difficulty in finding words or understanding what others are saying, not being able to perform routine tasks, and changes in personality or mood.
- In 2016 it was estimated that 564,000 Canadians were living with dementia, that there are approximately 25,000 new cases diagnosed every year and that by 20131 the prevalence of dementia is projected to increase by 66% to 937,000.
- As the disease progresses, individuals require more intensive forms of care (e.g., supports from health and social systems for help with basic activities of daily living) and the total health system and out-of-pocket costs to caregivers is currently estimated at $10.4 billion per year in Canada, and expected to increase by 60% to $16.6 billion by 2031.
- System-level strategies have been identified as a critical component for making progress towards enhancing care for people living dementia and their caregivers, and a key component of this is the monitoring and evaluation of the performance of the dementia strategies.

What we found
- Given the lack of available research evidence, we focused on identifying dementia strategies in Canada and in other countries, which included conducting targeted website searches for dementia strategies in Canada and internationally.
- For each dementia strategy identified, we extracted information related to performance measures, indicators for those measures, and targets for any identified indicators.
- We found seven dementia strategies in Canada (including a federal act that has set a requirement to develop and implement a national strategy), of which few explicitly provided performance measures, indicators and targets.
- For other countries, we extracted information about performance measures, indicators and targets from 11 national dementia strategies.
- Similar to the strategies identified for Canada, there was limited information explicitly relevant to performance measures, indicators and targets, but we extrapolated information about these from descriptions of the goals and priorities in the strategy whenever possible.

QUESTION

What performance measures, indicators and targets can be used to measure, monitor and evaluate the performance of dementia strategies?

WHY THE ISSUE IS IMPORTANT

Dementia is a complex condition and refers to "progressive brain syndromes which affect memory, thinking, behavior and emotion."(1) While the experience of dementia is different for each person, it eventually progresses to an individual not being able to care for themselves and requiring assistance with all aspects of their daily life.(1) Accounting for approximately 50% to 60% of all cases of dementia, Alzheimer's disease is the most common of the more than 100 known forms of dementia. Common symptoms of all forms of dementia include memory loss (e.g., inability to recall details of recent events or conversations, not recognizing or knowing family members' names), frequent difficulty in finding words (e.g., with pauses or substitutions when finding words) or understanding what others are saying, not being to perform routine tasks, and changes in personality or mood.(1; 2)

Dementia already affects many Canadians and as the proportion of older adults in the Canadian population continues to grow, the number affected by it will also continue to grow. For example, it has been found that the average age of onset of dementia is 80 years of age,(3) and also that the proportion of the population over the age of 80 is expected to grow from 27.5% in 2012 to 32% in 2036.(4; 5) In 2016 it was estimated that 564,000 Canadian were living with dementia, that there will be approximately 25,000 new cases diagnosed yearly, and that by 2031 the prevalence of dementia will increase to 937,000 (a 66% increase).(6)

Box 1: Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does <u>not</u> contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

Rapid syntheses can be requested in a three-, 10- or 30-business-day timeframe. An overview of what can be provided and what cannot be provided in each of these timelines is provided on the McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response)

This rapid synthesis was prepared over a three-business-day timeframe and involved three steps:
1) submission of a question from a policymaker or stakeholder (in this case, Alberta Health);
2) identifying, selecting, appraising and synthesizing relevant research evidence about the question; and
3) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence.

A fourth step of finalizing the rapid synthesis based on the input of at least two merit reviewers was not included for this rapid synthesis as it is not included in the scope of work for a three-business-day timeline.

In addition to the growing prevalence of dementia, it is both a complex and expensive condition to manage. As the disease progresses in an individual, they require more intensive forms of care, including personalized care plans, training and support for caregivers, and eventually intensive supports from health and social systems for help with basic activities of daily living.(7) As a result, the total health system and out-of-pocket costs to caregivers is currently estimated at $10.4 billion per year in Canada, which is expected to increase by 60% to $16.6 billion by 2031.(6)

Given this, creating system-level strategies has been identified as a critical component for making progress towards enhancing care for people living dementia and their caregivers.(1; 8) In Canada, Alberta (which is where this rapid synthesis was requested from) recently developed a strategy and action plan.(9) The plan

identifies several goals and enablers to achieving those goals. Of the enablers, one is to "implement a comprehensive measurement, monitoring and reporting framework to guide implementation of the Strategy." To support the implementation of that plan, this rapid synthesis was requested to identify performance measures, approaches or frameworks that can be used to measure, monitor and evaluate the performance of dementia strategies.

WHAT WE FOUND

From the database searches outlined in Box 2, we only found eight documents with some relevance. Given this, we focused on identifying dementia strategies in Canada and from other countries. This included conducting targeted website searches for provincial and territorial dementia strategies in Canada, and reviewing specific dementia strategies identified through the Global Dementia Observatory and Alzheimer's Disease International.(1; 10) For each strategy identified, we extracted information related to performance measures, indicators for those measures and targets for any identified indicators.

From our searches, we found seven dementia strategies in Canada, which included a federal act that has set a requirement to develop and implement a national strategy (see Table 1). Of these, few explicitly provided performance measures, indicators and targets, but we have extrapolated information for some in Table 1 based on the descriptions of the goals and priorities provided in strategies. For other countries, we extracted information about performance measures, indicators and targets from 11 national dementia strategies in Table 2 that we identified from the Global Dementia Observatory and Alzheimer's Disease International.(1; 10) Similar to the strategies identified for Canada, there was limited information explicitly relevant to performance measures, indicators and targets, but we extrapolated information about these from descriptions of the goals and priorities in the strategy whenever possible.

Box 2: Identification, selection and synthesis of research evidence

We identified research evidence (systematic reviews and primary studies) by searching (in April 2018) Health Systems Evidence (www.healthsystemsevidence.org) and PubMed. In Health Systems Evidence we searched for [(strategy OR strategies) AND (performance OR measur* OR "monitor and evaluate" OR "monitoring and evaluation")] AND [Non-communicable diseases, Alzheimer's and other dementias]. In PubMed we searched for [(dementia OR alzheimer*) AND (strategy OR strategies) AND (performance OR measur* OR "monitor and evaluate" OR "monitoring and evaluation") AND policy].

The results from the searches were assessed by one reviewer for inclusion. A document was included if it fit within the scope of the questions posed for the rapid synthesis.

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool, and the proportion of the included studies that were conducted in Canada.

The AMSTAR tool rates overall methodological quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered "high scores." A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8).

Table 1: Performance measures, indicators and targets used to measure, monitor and evaluate the performance of dementia strategies in Canada

Canadian jurisdictions	Performance measures	Indicators	Targets
National (2017)(11; 12) *Note that the information in this row is based on: 1) a federal act that has set a requirement to develop and implement a national strategy (which is not a strategy itself); and 2) a report from the Standing Senate Committee on Social Affairs, Science and Technology focused on developing a national strategy. However, given that these documents include activities and goals towards developing a national strategy, we included them in the analysis.	• As there is not yet a national dementia strategy in place, no performance measures identified, but *An Act Respecting a National Strategy for Alzheimer's Disease and Other Dementias, 2017* indicated that a national strategy to address all aspects of Alzheimer's disease and other forms of dementia should include: 1) developing specific national objectives in order to improve the situation for people living with Alzheimer's disease and other forms of dementia and decreasing the societal burden of these diseases; 2) encouraging greater investment in all areas of research related to Alzheimer's and other forms of dementia; 3) coordinating with international bodies to address Alzheimer's disease and other forms of dementia; 4) assisting provinces to develop and disseminate evidence-based clinical guidelines; 5) assisting provinces to assess and disseminate best practices (e.g., for integrated care approaches, chronic disease prevention and management and coordination of care and support in the community) that can be used to improve quality of life for people living with dementia and their caregivers;	• As there in not yet a national dementia strategy in place, no indicators were identified.	• As there in not yet a national dementia strategy in place, no targets were identified.

	6) assisting provinces to develop and disseminate information to health professionals and the general public about the prevention and management of and early intervention for Alzheimer's disease and other forms of dementia; and 7) making recommendations for the development of national evidence-based guidelines for standards of dementia care. • Moreover, the Standing Senate Committee on Social Affairs, Science and Technology identified that key goals of a national dementia strategy could include: 1) increasing investment in research; 2) improving public awareness to reduce stigma; 3) enhancing health human resources; 4) early and improved diagnosis; 5) greater support for informal caregivers; 6) integrating health services; 7) emphasis on home and community care; and 8) affordable housing.		
British Columbia (2012; 2016)(13; 14)	• No performance measures identified, but priorities (which could be used as broad performance measures) focus on: 1) increasing prevention and early intervention; 2) improving person-centred care; and 3) increasing system capacity and accountability.	• Indicators were identified for the priorities: 1) health promotion information, expansion of community support programs (e.g., Alzheimer Society's First Link), access to information on managing dementia, and advanced care planning; 2) interprofessional dementia education, clinical guidelines for medication use in dementia care, care coordinator for patients and their families, and end-of-life care; 3) housing options, strategies in hospitals and emergency departments for care for older adults,	• Targets associated with the indicators were identified for parts of the priorities: 1) website (HealthLink BC, SeniorsBC, and Home and Community Care) and print resource updates with information on brain health, o expansion of the Alzheimer Society's First Link;

		measures of quality dementia care, and research supports for dementia.	2) implementation of interprofessional dementia care training P.I.E.C.E.S.TM Canada (Physical, Intellectual, Emotional health, Capabilities, Environment, Social self) program; and 3) screening and assessment (48/6 Model of Care) of older adults in acute inpatient settings.
Alberta (2017)(9)	• No performance measures identified, but outcomes (which could be used as broad performance measures) focus on: 1) increasing awareness and prevention; 2) supporting persons living with dementia and their caregivers in the community; 3) early diagnosis and intervention; and 4) timely access to integrated interprofessional care.	• Indicators were identified for the outcomes: 1) information and education provision for the public, and dementia awareness programs for employers; 2) health and social supports (e.g., respite), promote dementia supportive culture, mental health and behavioural supports, and review provincial policies that impact persons living with dementia; 3) information and education provision for persons living with dementia and their caregivers, primary-care supports across the dementia-care continuum, resources and models to support primary-care teams in early diagnosis of dementia, best practices across settings, Advanced Care Planning at time of diagnosis, and accessibility of specialists; and 4) health- and social-system navigation, transitions across settings, rehabilitation services across settings, evidence-informed care, and appropriate use of medication (e.g., antipsychotics).	• Targets associated with the indicators were not identified.
Saskatchewan	• No dementia strategy identified	-	-
Manitoba (2002; 2014) (15; 16)	• No performance measures identified, but nine strategic issues (which could be used as broad performance measures) in 2002 focus on: 1) improving education; 2) creating diagnosis guidelines; 3) developing standards across programs and services; 4) improving caregiver supports; 5) improving programs and services;	• Indicators were not identified for the nine strategic issues. • Indicators were not identified for the themes outlined in the 2014 framework. • However, the framework does recognize gaps and opportunities to address each of the themes.	• Targets associated with the strategic issues were identified: ○ creation of First Link® program (strategy 1); ○ *Caregiver Recognition Act* and establishment of the Caregiver Advisory Committee (strategy 3); ○ web-based caregiver resources (strategy 4); ○ primary-care reform to improve access to care (e.g., nurse

	6) creating models of care to support interprofessional collaboration; 7) enhancing equitable access to primary and specialty care; 8) health workforce; and 9) research, monitoring and evaluation. • The 2014 framework for Alzheimer's disease and other dementias identifies strategic themes: 1) increasing awareness and education; 2) early diagnosis and intervention; 3) improving disease management, care and support; 4) improving end-of-life care; and 5) improving research and evaluation.		practitioner primary-care model in personal care homes and communities (strategies 5-6); o Aging in Place Strategy to improve supports in the communities (strategies 5-6); o improved programs and services for older adults (e.g., PRIME Health Centre and Hospital Home Teams) in communities (strategies 5-6); o expanding Geriatric Mental Health supports in communities (strategy 7); o interprofessional dementia care training (e.g., P.I.E.C.E.S.^{TM} and Enhanced Orientation Program for Nurses New to Long Term Care) (strategy 8); o primary healthcare staffing initiative, which increased nursing care hours to 3.6 hours, per resident, per day (strategy 8); and o no targets identified for strategies 2 and 9.
Ontario (2017) (17)	• No performance measures identified, but 10 key investments (which could be used as broad performance measures) focus on: 1) expanding community programs; 2) enhancing caregiver supports (e.g., respite); 3) enhancing education and training for caregivers; 4) increasing training for primary-care providers; 5) expanding behavioural supports in home and community care; 6) expanding behavioural supports in long-term care;	• Indicators were identified for the key investments: 1) dementia programs (e.g., day, evening and overnight, including transportation); 2) access to respite supports (e.g., in-home and overnight); 3) in-person and web-based educational supports for caregivers; 4) tools and supports for primary-care providers; 5) supports in home and community care to manage dementia; 6) supports in long-term care homes to manage dementia; 7) models that improve diagnosis and management of disease; 8) care for newly diagnosed patients;	• Targets associated with the indicators were identified for some of the goals: o increase dementia funding for the dementia strategy by $101 million over three years to support ▪ 46 First Link navigators, ▪ up to 58 full-time employees who can work in the community to support people with responsive behaviours, ▪ up to 150 full-time employees in long-term care, ▪ expanding community programming,

	7) building models of care for specialized clinics (e.g., memory clinic); 8) improving patient navigation; 9) expanding geriatric medicine and psychiatric training; and 10) increasing public awareness.	9) specialist capacity; and 10) education campaigns.	▪ education and training for 8,261 new care partners (continuing education for 7,630 continuing-care partners), ▪ data collection and analysis of Primary Care Collaborative Memory Clinics, and ▪ training for up to 20,000 front-line staff.
Quebec	• The strategy identified seven priority areas for action: 1) raising awareness, informing and mobilizing; 2) providing access to personalized, coordinated assessment and treatment services for people with Alzheimer's and their caregivers; 3) promoting quality of life and providing access to home-support services and a choice of high-quality alternative living facilities for those in advanced stages of Alzheimer's; 4) promoting high-quality therapeutically appropriate end-of-life care that respects people's wishes, dignity and comfort; 5) treating caregivers as partners who need support; 6) developing and supporting training programs; and 7) mobilizing all members of the university, public and private sectors for an unprecedented research effort.(18)	• While specific indicators were not identified, objectives were provided for each of the seven priority areas against which the strategy could be evaluated: 1) promoting a better understanding of Alzheimer's disease and support for necessary changes to how services are organized, and research for all aspects of the disease, and raising awareness about risk factors and protective factors to help delay the onset of Alzheimer's; 2) improving and simplifying access to a process for assessing cognitive function and diagnosing Alzheimer's, providing access to integrated case management as soon Alzheimer's is diagnosed, providing flexible coordination of services, and adapting structure of services to regional contexts; 3) enabling families to continue to care for loved ones with Alzheimer's at home, providing a variety of choices for alternative living facilities that are suited to an individual's needs, ensuring that facilities have the necessary programs and services to support those with Alzheimer's, and encouraging the training of staff and managers to care for, support and encourage the involvement of families and caregivers for people at any stage of the disease; 4) encouraging the preparation of end-of-life instructions, encouraging the documentation of desired intensity of treatment, evaluating and improving end-of-life care across the province, improving detection and treatment of pain in those unable to express themselves, establishing best practices for end-of-life treatment of	• Targets associated with the indicators were not identified.

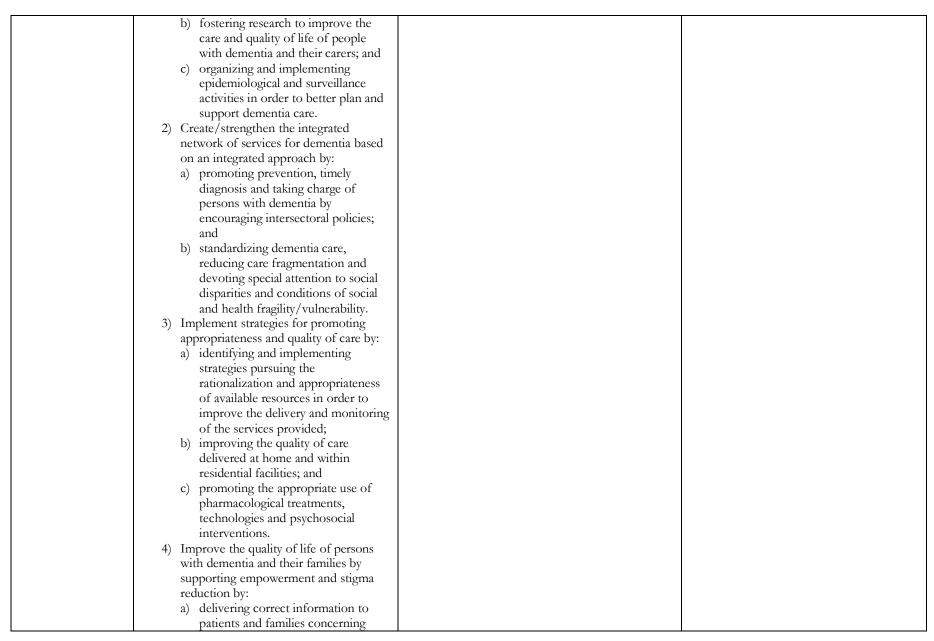|			
		Alzheimer's, training health professionals in ethical reasoning and palliative end-of-care for Alzheimer's, and informing families and caregivers about disease progression and treatment choices; 5) enhancing ministry policy on home support, designing systematic tools for evaluating caregiver needs to develop a complimentary service plan, offering proactive and preventive services to caregivers once Alzheimer's is diagnosed; providing access to psycho-educational and counselling services for caregivers, developing respite and supportive-care services for caregivers, and making social and financial programs accessible and easy to use; 6) investing in training to enhance quality of care and role of managers, monitoring training in Alzheimer's disease at colleges and universities and in on-the-job training for care facilities, using data from monitoring to guide a training strategy, developing and implementing this training strategy in the public and private sectors, attracting people to training sessions who may be reluctant to take part in the activity, developing clinical guidelines and tools for Alzheimer's, and designing and implementing a variety of incentives to take part in training; and 7) promoting planning and organizing of research and dissemination of knowledge of Alzheimer's disease, enabling people with Alzheimer's and their families to express their needs, ensuring dissemination of best practices, and increasing capacity in all areas and approaches related to Alzheimer's disease.(18)	
New Brunswick (2017) (19)	• The aging strategy calls for the development of a provincial dementia strategy, which includes identifying indicators to support monitoring and evaluation of the strategy.		-
Nova Scotia (2017) (20-22)	• No performance measures identified, but priorities (which could be used as	• The action plan is based on a three-year timeframe, with monitoring and evaluation included to measure progress:	• Targets associated with the indicators were not identified.

	broad performance measures) focus on: 1) enhancing timely access to care (early diagnosis and intervention); 2) improving capacity for coordinated care; and 3) increasing public awareness.	1) best practice toolkit (2015-16), dementia protocols in 811 service (2015-16), revise programs (Supportive Care and Caregiver Benefit) (2015-16), provincial palliative-care strategy for end-of-life care (2015-16), First Link program (2016-17), electronic medical records (2016-17), assessment approach for families and caregivers (2016-17), home- and facility-based respite care (2016-17), program and service review of Health and Wellness and Community Services (2016-17); 2) culturally appropriate programs and supports (2015-16), policy and procedures review with a focus on dementia (2016-17), inventory of current programs and services (2016-17), collaborative primary-care demonstration sites (2016-17), dementia care pathway (2017-18); and 3) education campaign (2015-16); develop pan-Canadian webinars (2015-16), practical skills training for caregivers (2015-16), evaluate and create an inventory of existing information resources (2016-17), train families and caregivers through the Alzheimer's Society (2016-17), educate healthcare providers (2016-17), information sharing among organizations (2016-17), increase access to information resources (e.g., Canadian Consortium on Neurodegeneration in Aging and brainXchange) (2016-17). • Monitoring and evaluation includes: determine what data to collect (2015-16); develop research priorities (2015-16); and evaluation of dementia strategy (2016-17).	
Prince Edward Island	• No dementia strategy identified	-	-
Newfoundland and Labrador	• No dementia strategy identified	-	-

Table 2: Performance measures, indicators and targets used to measure, monitor and evaluate the performance of dementia strategies in select international jurisdictions

International jurisdictions	Performance measures	Indicators	Targets

Cuba (2103) (23)	• Performance measures for the strategy (referred to as objectives in the strategy) include:
	1) improve care for dementia patients and their families;
	2) prevent cognitive impairment and dementia;
	3) detect cognitive impairment early;
	4) reduce stigma around dementia;
	5) increase professional development;
	6) train families in patient care;
	7) promote basic, clinical and epidemiological research on dementia; and
	8) familiarize health teams with laws protecting the rights of older adults and people with cognitive impairment.
		• Indicators were divided by input (structure), process and outcomes indicators.
		1) Input (structure)
		  o existence of municipal memory clinic;
		  o existence of a memory clinic in every polyclinic;
		  o easy access to memory clinics and removal of architectural barriers in health centres;
		  o existence of school for caregivers in each health area served by a polyclinic;
		  o existence of senior centres for patients with mental incapacity in every municipality;
		  o existence of residential facilities for dementia patients who need care in nursing homes;
		  o existence of a hospital-based memory clinic;
		  o creation and training of a health team for the memory clinic;
		  o easy access to memory clinics and removal of architectural barriers to them.
		2) Process
		  o existence of program in polyclinics and at the municipal level to train primary-care personnel, caregivers and families;
		  o number of caregivers trained;
		  o at least one area of research related to aging and dementia (at primary and secondary levels of care);
		  o existence of social support networks for patients;
			• Targets associated with the indicators were not identified.

		- inter-sectoral participation in caregiving for older adults with dementia or cognitive impairment. 3) Health outcomes - dementia incidence rate; - dementia prevalence rate; - dementia mortality rate; - one-year hospitalization rate from complications; - unintentional injury rate; - percent patient satisfaction with services provided.	
England (2015) (24)	No performance measures identified but key aspirations included in the Prime Minister's 2020 dementia challenge (which could be used as broad performance measures) focus on: 1) risk management and reduction; 2) improving diagnosis; 3) enhanced support after diagnosis; 4) expanding support for carers; 5) expanding care at home; 6) high-quality, personalized care in hospitals and care homes; 7) reducing inappropriate prescribing of antipsychotic medication; 8) enhancing dementia education, training and workforce; 9) promoting awareness and understanding and social action among individuals, communities and businesses; 10) increase investments in dementia-related research.	- While no indicators were identified for the key aspirations, a number of indicators could be extrapolated from the aspirations and targets: - information and education campaigns to improve public awareness; - timeliness of assessment and diagnostic services; - access to their own general practitioner; - adherence of care to NICE quality standards; - compliance of NHS staff with Care Quality Commission Care Certificate; - number of hospitals and care homes that meet criteria of a dementia-friendly health and care setting; - prescription rates of antipsychotics for people with dementia; - rates of inappropriate prescribing; - participation and volunteering in local Dementia Action Alliances and dementia-related NGOs; - proportion of population living in Dementia Friendly Communities; - investment in dementia research; - open access publications on dementia; and - participation rates in dementia research.	- Targets associated with the key aspirations, include: - by 2020, the national average for an initial assessment should be six weeks following a referral from a general practitioner; - by 2020 everyone will have access to a named general practitioner with overall responsibility and oversight for their care; - by 2020, every person diagnosed with dementia has access to meaningful care following diagnosis; - by 2020 all NHS staff should have received training on dementia appropriate to their role; - by 2020 all hospitals and care homes should meet the agreed criteria to be a dementia-friendly health and care setting; - by 2020, there should be a significant reduction in inappropriate prescribing of anti-psychotic medication; - by 2020, 50% of people in England should be living in communities recognized as Dementia Friendly Communities;

			- increased involvement of voluntary and civil society organizations in local Dementia Action Alliances; - double the research investment in dementia by 2025 and establish an international dementia institute in England; - by 2020 there should be open access to all publicly funded research publications on dementia; and - by 2020, 25% of people diagnosed with dementia registered on Join Dementia Research and 10% participating in research.
France (2014) (25)	No performance measures identified but Neurodegenerative diseases plan 2014-2019 has three main priorities (which could be used as broad performance measures) that focus on: 1) improving diagnosis and management of patients; 2) ensuring the quality of life of patients and their caregivers; and 3) developing and coordinating research.	No specific indicators were identified for the main priorities, however the plan includes a list of 96 action items from which some indicators can be extrapolated, such as early dementia diagnoses, quality of dementia services, access to high-quality care, and investment in dementia research.	Targets associated with performance measures or indicators were not identified.
Italy (2014) (26)	No performance measures were identified, but some of the four objectives and the priorities associated with them could serve as the basis for performance measures include those listed below (note that the following is taken directly from the publication outlining the strategy with minor formatting and wording changes so quotes have not been used). 1) Promote health- and social-care interventions and policies by: a) increasing knowledge of the general population, patients, families, and health professionals concerning prevention, timely diagnosis, treatment and care of dementias;	- No specific indicators were identified for the objectives or their associated priorities, although some indicators such as amount invested in research for 1b, rates of early diagnosis for 1c, adherence to clinical guidelines for 2b and 3c, and quality of life for 4b could be extrapolated. - It is noted that a national dementia information system was to be created to monitor the progress of the strategy.	Targets associated with performance measures or indicators were not identified.

	b) fostering research to improve the care and quality of life of people with dementia and their carers; and
	c) organizing and implementing epidemiological and surveillance activities in order to better plan and support dementia care.
	2) Create/strengthen the integrated network of services for dementia based on an integrated approach by:
	  a) promoting prevention, timely diagnosis and taking charge of persons with dementia by encouraging intersectoral policies; and
	  b) standardizing dementia care, reducing care fragmentation and devoting special attention to social disparities and conditions of social and health fragility/vulnerability.
	3) Implement strategies for promoting appropriateness and quality of care by:
	  a) identifying and implementing strategies pursuing the rationalization and appropriateness of available resources in order to improve the delivery and monitoring of the services provided;
	  b) improving the quality of care delivered at home and within residential facilities; and
	  c) promoting the appropriate use of pharmacological treatments, technologies and psychosocial interventions.
	4) Improve the quality of life of persons with dementia and their families by supporting empowerment and stigma reduction by:
	  a) delivering correct information to patients and families concerning		

	dementias and available services to allow timely diagnosis; b) improving the quality of life of people with dementia and their social integration, also by promoting strategies of personal and familial engagement; and c) empowering persons and communities involving families and associations in services planning.		
Japan (27)	• Seven priority areas of the 2015 revision of the plan focus on: 1) raising social awareness; 2) appropriate and timely medical/social care; 3) improvement of care for early onset dementia; 4) carer support; 5) elderly and dementia friendly communities; 6) research and establishment of prevention, diagnosis, treatment and rehabilitation; and 7) placing importance on the views of people with dementia and carers.	• No indicators were identified for the 2015 revision of the strategy.	• No targets were identified for the 2015 revision of the strategy.
Netherlands (2009) (28; 29)	• No performance measures identified, but priorities (which could be used as broad performance measures) focus on: 1) improving coordination of care; and 2) enhancing guidance and support for people living with dementia and their families and caregivers.	• Specific indicators were not identified.	• Targets associated with the performance measures were identified and include: 1) dementia best practices available to all care providers (either in book or online formats) by 2009, and coordinated dementia care options (including insurance) by 2011; and 2) case management as part of the overall coordination of dementia care provided by 2011.
Northern Ireland (2011) (30)	• No performance measures identified, but objectives for the strategy (which could be used as broad performance measures) focus on:	• No indicators were identified	• No targets were identified

	o reducing the risk or delaying the onset of dementia; o raising awareness; o promoting early assessment and diagnosis; o supporting people with dementia; o supporting carers; o establishing legislation; and o investing in research.		
Scotland (2017) (31)	• No performance measures identified, but objectives for the strategy (which could be used as broad performance measures) focus on: o early diagnosis and active patient involvement; o early access to good quality, person-centred care; o expanding supports available in the home; o improving access to palliative care and end-of-life care; o enhance delivery of person and family-centred care; o protecting people's right to good-quality, dignified, safe and therapeutic treatment; and o expanding access to community supports.	• Indicators were identified for some of the objectives: o accessibility of post-diagnostic support; o care coordination post-diagnosis provided by a Link Worker; o setting of post-diagnostic services; o timeliness of discharge from acute-care facilities; o rates of unscheduled bed days; o length of stay in hospital; o quality of palliative and end-of-life care; o staff adherence to standards of care for dementia in acute care; o uptake of technology by people with dementia and their carers; and o investments in dementia research.	• Targets associated with the indicators were identified for some of the goals: o guaranteed minimum of one year of appropriate post-diagnostic support with a Link Worker; o relocate post-diagnostic services into primary-care settings; o reduce delayed discharge, avoidable admissions and inappropriately long hospital stays; o everyone with a diagnosis of dementia and those who care for them are aware of, and have access to, a range of proven technologies to enable people with dementia to live safely and independently; o commission and publish a renewed study on trends in the prescribing of psychoactive medications of people with dementia; and o commission renewed study to assess dementia prevalence.
Sweden (2010) (32) *Note that the Statement of Government Policy from 17 September 2017 indicated that a new national dementia strategy is being developed.(33)	• Performance measurement in Sweden is tracked through the Swedish Dementia Registry (SveDem), which was established in May 2007. • The goal of SveDem is to follow dementia patients through the continuum of care provided by specialist, primary care and nursing-home units.	• The list of variables tracked in SveDem after diagnosis of dementia include: o social security number; o date of registration; o time needed for diagnosis; o sex; o age; o living condition (own home, nursing house, don't know, with a prompt for living alone or with someone);	• No targets identified

	• Registration in SveDem is logged at the time of diagnosis, but those with mild cognitive impairment are not registered. • To ensure high-quality care, each patient is recommended to have an annual follow-up and seven clinical indicators are tracked for follow-up in SveDem. • Once a person living with dementia moves to a nursing home, a separate set of indicators related to nursing care are collected.	o day care (yes/no/don't know); o home care (yes/no/don't know); o family history of dementia (yes/no/don't know); o body mass index; o type of dementia; o diagnostic work-up – e.g., blood test, clock test, CT, MRI, lumbar puncture, positron emission tomography/single photon emission computed tomography, electroencephalography, advanced cognitive testing, assessment by occupational therapist, assessment by physiotherapist, assessment by speech therapist (yes/no/don't know); o total number of diagnostic tests; o Mini Mental State Examination score; o Medication – e.g., cholinesterase inhibitors, n-methyl-D-aspartate antagonist, antidepressants, antipsychotics, anxiolytics, hypnotics, cardiovascular drugs (yes/no/don't know); o possession of driving licence; o possession of weapon licence; o total number of drugs; o death (yes/no); and o time to death (months). • The longer list of variables collected after moving to nursing care are provided in a supplementary file from the publication describing SveDem.(32)	
Switzerland (2013) (25)	• No performance measures identified, but four action areas (which could be used as broad performance measures) focus on: 1) enhancing information and education provision; 2) delivery services based on need; 3) improving quality of care and healthcare-provider skills; and 4) data collection and knowledge transfer.	• Indicators were identified for some of the objectives: o public awareness; o quality of care indicators; o extent of coordination of care; o appropriate discharge planning; o rates of diagnosis; o early diagnosis and intervention; o interprofessional training in dementia; o training of families and caregivers; and	• No targets identified

		o research papers on treatment models.	

Wales (2018) (34)	• No performance measures identified, but priorities (which could be used as broad performance measures) focus on:
	  o risk reduction and delaying onset;
	  o raising awareness and understanding;
	  o recognition and identification;
	  o early assessment and diagnosis;
	  o living as well as possible for as long as possible with dementia;
	  o the need for increased support; and
	  o supporting the implementation of the plan.
		• Indicators for some of the priorities and targets include:
		  o prevention and risk reduction of dementia;
		  o availability of dementia supports;
		  o training of GPs in identifying, diagnosing and managing dementia;
		  o access to early assessment and diagnosis;
		  o dementia diagnoses;
		  o patient satisfaction;
		  o admissions to acute-care facilities;
		  o prescription rates for antipsychotics;
		  o duration of treatment of antipsychotics;
		  o attendance at public trainings in dementia care; and
		  o public knowledge of dementia and dementia care.
			• Targets associated with the performance measures:
			  o increase reporting of people who follow 'good healthy lifestyle' behaviours;
			  o increase the number of dementia friends and dementia-friendly/supportive communities and organizations in Wales;
			  o increase the number of general practitioners who undertake training in the early identification, effective management, advice and support for people with dementia and their carers;
			  o every person referred for an assessment of dementia received a first assessment by 28 days and a working/preliminary diagnosis within 12 weeks (when it is clinically possible to do so);
			  o increase the number of people formally diagnosed with dementia from 51% in 2016, by three percentage points annually;
			  o percentage of people who rate the care and support they have received as excellent or good;
			  o delaying care home and/or hospital admission;
			  o reduction in the percentage of people with a diagnosis of dementia prescribed antipsychotic medications and a reduction in the duration of treatment; and
			  o by 2019, 75% of the public that NHS staff interact with should be trained to an appropriate level of dementia care.

20

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Evidence >> Insight >> Action

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