

### Editor's key points

- ▶ Given the growing number of persons with dementia managed in the community, indicators to measure the quality of primary care provided to patients with dementia based on routinely collected data are needed to support quality initiatives and monitoring.
- ▶ Primary care and dementia indicators were used to create a framework for the primary care of patients with dementia, resulting in the identification of 34 indicators measurable in administrative data. Among these indicators, access to a regular primary care provider, continuity of care, early-stage diagnosis, and access to home care were consistently rated as priorities by stakeholders.
- ▶ With the growing role of primary care providers in managing the care of patients with dementia, routine monitoring of relevant and targeted indicators will become increasingly important. It is hoped that this framework can provide a solid footing to facilitate this goal and support primary care providers and teams in implementing initiatives to improve and monitor the care of persons with dementia.

# Quality indicator framework for primary care of patients with dementia

Nadia Sourial PhD Claire Godard-Sebillotte MD PhD  
Susan E. Bronskill PhD Geneviève Arsenault-Lapierre PhD  
Georgia Hacker MSc Isabelle Vedel MD MPH PhD

## Abstract

**Objective** To develop a framework of population-based primary care quality indicators adapted to patients with dementia and to identify a subset of stakeholder-driven priority indicators.

**Design** Framework development was carried out through the selection of an initial framework based on a rapid review and identification of relevant indicators and enrichment based on existing dementia indicators and guidelines. Prioritization of indicators was carried out through a stakeholder survey.

**Setting** Ontario, Quebec, New Brunswick, and Saskatchewan.

**Participants** Stakeholders in community dementia care (N=109) including clinicians, patients, caregivers, decision makers, and managers.

**Main outcome measures** Primary care quality indicators.

**Results** The framework comprised 34 indicators across 8 domains of quality (access, integration, effective care, efficient care, equity, safety, population health, and patient-centred care). Access to a regular primary care provider, continuity of care, early-stage diagnosis, and access to home care were consistently rated as priorities. Equitable care was a specific priority among patients and caregivers; clinicians reported avoidable hospitalizations as among their priorities.

**Conclusion** A framework of indicators was established for persons with dementia that adds an important dimension to existing primary care and dementia quality indicators by providing primary care and population-based perspectives. This framework could set a foundation for the ongoing monitoring of primary care practices and policies for persons with dementia at a population level.

# Référentiel d'indicateurs de la qualité des soins primaires aux patients atteints de démence

Nadia Sourial PhD Claire Godard-Sebillotte MD PhD  
Susan E. Bronskill PhD Geneviève Arsenault-Lapierre PhD  
Georgia Hacker MSc Isabelle Vedel MD MPH PhD

## Résumé

**Objectif** Élaborer un référentiel d'indicateurs populationnels de la qualité des soins primaires adaptés aux patients atteints de démence et déterminer un sous-groupe d'indicateurs prioritaires aux yeux des intervenants concernés.

**Type d'étude** L'élaboration du référentiel a été effectuée en établissant un référentiel initial fondé sur une revue et une identification rapides d'indicateurs pertinents, et en le peaufinant en fonction de lignes directrices et d'indicateurs existants sur la démence. La priorisation des indicateurs a été effectuée au moyen d'un sondage auprès d'intervenants concernés.

**Contexte** L'Ontario, le Québec, le Nouveau-Brunswick et la Saskatchewan.

**Participants** Des intervenant engagés dans les soins communautaires pour la démence (n=109), y compris des cliniciens, des patients, des aidants, des décideurs et des gestionnaires.

**Principaux paramètres à l'étude** Des indicateurs de la qualité des soins primaires.

**Résultats** Le référentiel comptait 34 indicateurs dans 8 domaines de la qualité (accès, intégration, efficacité des soins, efficience des soins, équité, sécurité, santé populationnelle et soins centrés sur le patient). L'accès à un professionnel des soins primaires attiré, la continuité des soins, le diagnostic à un stade précoce et l'accès à des soins à domicile étaient constamment cotés comme étant des priorités. Des soins équitables étaient une priorité particulière chez les patients et les aidants; les cliniciens signalaient l'évitement des hospitalisations comme figurant parmi leurs priorités.

**Conclusion** Un référentiel d'indicateurs a été établi pour les personnes atteintes de démence; il ajoute une dimension importante aux indicateurs actuels de la qualité des soins primaires pour la démence en dégagant les points de vue particuliers des soins primaires et de la population. Ce référentiel pourrait servir de fondement à la surveillance continue des pratiques en soins primaires et des politiques pour les personnes atteintes de démence au niveau de la population.

## Points de repère du rédacteur

► Compte tenu du nombre croissant de personnes atteintes de démence qui sont prises en charge dans la communauté, des indicateurs de la qualité des soins primaires prodigués à ces patients, fondés sur des données recueillies systématiquement, sont nécessaires pour appuyer les initiatives et la surveillance concernant la qualité.

► Des indicateurs liés aux soins primaires et à la démence ont servi à produire un référentiel spécifique aux soins primaires prodigués aux patients atteints de démence et à identifier 34 indicateurs mesurables dans les données administratives. Parmi ces indicateurs, l'accès à un professionnel des soins primaires attiré, la continuité des soins, le diagnostic à un stade précoce et l'accès à des soins à domicile étaient constamment cotés comme étant des priorités par les intervenants concernés.

► Étant donné le rôle grandissant des professionnels des soins primaires dans la gestion des soins aux patients atteints de démence, la surveillance systématique d'indicateurs pertinents et ciblés deviendra de plus en plus importante. Il est à espérer que ce référentiel offrira un solide fondement pour faciliter l'atteinte de cet objectif, et soutiendra les professionnels et les équipes des soins primaires dans la mise en œuvre d'initiatives visant à améliorer et à surveiller les soins aux personnes atteintes de démence.

Dementia, including Alzheimer disease, has been recognized by the World Health Organization as a global public health crisis.<sup>1,2</sup> Half a million Canadians live with dementia, a number expected to double over the next generation.<sup>3</sup> Moreover, more than 60% of persons with dementia live at home and are cared for in the community.<sup>4</sup> There is growing consensus in Canada and elsewhere that family physicians, with the support of other health care professionals, are ideally positioned to provide a person-centred approach with respect to the prevention of dementia and to the diagnosis, treatment, and follow-up of most persons with dementia.<sup>5-9</sup> Given the growing role of primary care in the care of the population with dementia, it is essential to monitor and evaluate ongoing quality initiatives or policy interventions aimed at improving the quality of care of persons with dementia in primary care. Quality indicators that align with stakeholders' needs and can be measured routinely using readily available sources are necessary to ensure feedback and improvement are continuous and decision making is efficient and timely.<sup>10,11</sup>

Within the primary care literature, several general frameworks have been proposed to measure the quality of primary care.<sup>12-14</sup> However, it is unclear whether these frameworks are applicable or appropriate for persons with dementia; incorporate indicators relevant to dementia and of importance to stakeholders; and have indicators that can be measured using routinely collected data such as health administrative data. In addition, within the dementia literature, work on indicators has focused on clinical processes of care assessed primarily through chart review.<sup>15-19</sup> While these indicators provide an essential component of the evaluation of the quality of care provided to patients with dementia, they cannot easily be measured routinely.

This study aimed to develop a framework of primary care quality indicators for persons with dementia based on health administrative data and to identify stakeholder-relevant priority indicators for ongoing quality monitoring in this population.

## — Methods —

Our methodologic approach for the development and prioritization of quality indicators for primary care of patients with dementia involved 3 steps: a rapid review for the selection of an initial framework, an iterative expert consultation for the selection and enrichment of indicators, and a stakeholder survey for the prioritization of indicators. Previous studies have demonstrated the suitability of a rapid review and expert consensus to adapt and develop a new framework for health practice improvement.<sup>20,21</sup>

### Selection of an initial framework

A rapid review of published and gray literature on frameworks for health system or primary care performance was conducted.<sup>22,23</sup> As described by Tricco et al, "rapid reviews

are a form of knowledge synthesis in which components of the systematic review process are simplified or omitted to produce information in a timely manner."<sup>22</sup> This review strategy was selected to ensure timely knowledge transfer of the final framework and indicators to the decision makers and other stakeholders involved in the research. The review process was streamlined by limiting the search by date (articles from between 2008 and 2018), conducting the study selection with 1 reviewer (N.S.), and conducting data abstraction with 1 reviewer (N.S.) and 1 verifier (I.V.). This rapid review methodology has previously been found to be the most common and the most accepted.<sup>22</sup>

Search criteria and detailed review methods are provided in Supplemental Text 1, available from **CFPlus**.<sup>\*</sup> The following exclusion criteria were applied to the identified records: not a primary care framework (either a framework not including primary care or any set of indicators without a formal framework), frameworks entirely disease- or population-specific aside from dementia (eg, cancer, diabetes, maternal or child health), frameworks not operationalized with specific indicators, framework indicators not measurable using administrative data, or frameworks not appropriate for the Canadian health system context.

One reviewer (N.S.) screened the records based on the title, abstract, and full text using the above criteria. Of the eligible records remaining, 2 reviewers (1 of whom was N.S.) independently scored the frameworks based on the following categories: comprehensiveness of the framework in terms of the number of quality domains and indicators, focus of the framework on patient-level indicators (rather than practice-level or system-level), pertinence of the framework indicators to the population with dementia, and measurability using health administrative data. All 4 categories were scored on a scale of 1 (low) to 4 (high). In the case of disagreements between the 2 reviewers, a third reviewer (I.V.) was consulted. The selected framework corresponded to the one that was most optimal based on the scores and its overall clinical pertinence and suitability.

### Indicator identification and enrichment

Following the selection of a framework, an assessment of the appropriateness and feasibility of indicators within the framework was conducted by a panel of 8 experts consisting of family physicians, geriatricians, health service researchers, and biostatisticians involved in the ROSA (Research on Organization of Healthcare Services for Alzheimers) team within the CCNA (Canadian Consortium on Neurodegeneration in Aging).<sup>24</sup> Indicators were retained based on the following inclusion criteria: appropriate for an older population or population with

<sup>\*</sup>Supplemental Texts 1 and 2, Supplemental Figure 1, and Supplemental Tables 1, 2, 3, and 4 are available from <https://www.cfp.ca>. Go to the full text of the article online and click on the **CFPlus** tab.

dementia; not specific to a single disease or subgroup other than dementia (eg, cancer, diabetes); measurable at the patient level; and potentially measurable using health administrative data. The process for assessing and selecting indicators was iterative and was conducted over 18 months until consensus was achieved.

During this process our expert panel raised concerns about the absence of dementia-specific indicators in the primary care frameworks, in contrast to other chronic diseases such as diabetes, and the need to enrich the framework based on Canadian guidelines and practices. The panel first prioritized the recommendations from the Canadian Consensus Conference on the Diagnosis and Treatment of Dementia meetings, as indicators developed within these meetings represented a Canadian consensus on targets for the quality of dementia care.<sup>5-9</sup> We also reviewed dementia indicators related to the Assessing Care of Vulnerable Elders quality indicator measurement set for dementia, as it represents the most widely cited set of quality indicators for dementia in the United States,<sup>15,17</sup> with a strong influence on Canadian practice. Additional sources were also reviewed based on the panel's expert knowledge of dementia indicators measured using administrative data in Canada, including a dementia report by the Canadian Institute for Health Information,<sup>4</sup> dementia care quality standards by Health Quality Ontario (HQP),<sup>25</sup> and a 2015 study conducted in British Columbia by Sivananthan et al that assessed dementia care in the community using administrative data and was based on provincial dementia guidelines.<sup>26</sup>

### Stakeholder prioritization

A survey of the selected indicators was initially distributed to stakeholders present at a preplanned council meeting of the ROSA-CCNA research team in June 2017.<sup>24</sup> Stakeholders included clinicians, patient and caregiver representatives (eg, from the Alzheimer Society of Canada), managers from integrated health networks, and government representatives from the ministries of health of 4 Canadian provinces (Ontario, Quebec, New Brunswick, and Saskatchewan) (Supplemental Text 2, available from **CFPlus**\*). The survey was pretested with 3 stakeholders (2 physicians and 1 patient representative) for clarity and face validity. Labeling of some indicators was subsequently revised based on feedback from stakeholders to ensure clarity and ease of understanding (eg, *continuity of care* was relabeled as *coordination between health care providers*). Stakeholders were asked to identify a maximum of 10 indicators among the set presented that were most important from their points of view. At the stakeholders' request, the survey was also distributed to their colleagues within their own organizations. This form of snowball sampling<sup>27</sup> allowed us to reach a broader network of relevant stakeholders.<sup>28</sup> The survey was available in both English and French.

Demographic information on province, type of stakeholder, age group, and sex were collected. The frequency with which each indicator was selected as a priority

was calculated overall and by stakeholder group. We selected 60% as a threshold to represent common priority indicators. This threshold emerged from the results as an appropriate cutoff in the ranking of priority indicators overall and by stakeholder group, and it allowed us to retain a list of 10 common and stakeholder-specific priorities. Cross-stakeholder comparisons in priority indicators were tabulated to determine overall and stakeholder group-specific priorities.

This study was approved by the research ethics board of the Centre intégré universitaire de santé et de services sociaux for West-Central Montréal in Quebec.

## — Results —

### Framework development

The literature review yielded a total of 358 peer-reviewed citations and 18 additional records obtained through backward citation searches, gray literature searches, and expert consultation (Supplemental Figure 1, available from **CFPlus**\*). After duplicates were removed and eligibility criteria were assessed, the full-text articles of 67 records were assessed. Of these, 18 references referring to 14 distinct operationalized frameworks were considered eligible for inclusion (Supplemental Table 1, available from **CFPlus**\*).<sup>11,14,25,29-43</sup>

Among these eligible frameworks, the HQO Primary Care Performance Measurement Framework<sup>35</sup> was selected as the initial framework, as it scored highly across all 4 prespecified categories of comprehensiveness (4 of 4), focus on patient-level indicators (3 of 4), pertinence to the population with dementia (3 of 4), and measurability using administrative data (3 of 4) (Supplemental Table 1). It also aligned closely with seminal theoretical frameworks, such as the Institute of Medicine's 6 aims for improvement<sup>12</sup> and the Institute for Healthcare Improvement Triple Aim,<sup>29</sup> and it had been validated within a Canadian health care context.

Seventeen of the set of 199 HQO indicators were retained based on the inclusion criteria:

- Access: access to a regular primary care provider, after-hours access to the regular primary care provider, access to an interprofessional primary care team, visits to the regular primary care provider, and nonurgent visits to the emergency department;
- Integration: continuity of care, telephone calls between the regular primary care provider and specialists, potentially avoidable hospitalizations, visits to the regular primary care provider within 7 days following a hospitalization, and readmission to the hospital within 30 days following a hospitalization;
- Effective care: annual visit to the regular primary care provider;
- Efficient care: annual cost of health services;
- Population health: yearly flu shot and other recommended immunizations;



- Safety: potentially inappropriate prescriptions for medications associated with serious side effects prescribed by the regular primary care provider;
- Patient-centred care: access to palliative end-of-life care provided by the regular primary care provider; and
- Equity: equitable care across all patients.

Excluded indicators were mainly practice-level indicators (eg, percentage of primary care organizations reporting that they monitor adherence to infection prevention and control policies and procedures), self-reported survey indicators for which there could be no equivalent health administrative measure (eg, percentage of patients who report that their family physicians or nurse practitioners involve them as much as they want in decisions), or indicators referring to specific disease subcohorts other than dementia (eg, diabetes, hypertension, cancer) or younger populations (eg, children, perinatal health).

Seventeen additional indicators based on existing dementia indicators, guidelines, and expert opinion met the inclusion criteria and were added to the framework:

- Integration: length of time spent in hospital in the year following diagnosis of dementia;
- Effective care: diagnosis at an early stage of disease, dementia diagnosed by the regular primary care provider, requests for blood tests originating from the regular primary care provider, medications prescribed for dementia, first medication for dementia prescribed by the regular primary care provider, referrals to specialists in dementia originating from the regular primary care provider, and referrals to other specialists originating from the regular primary care provider;
- Efficient care: duplication of medical tests;
- Safety: having a high number of medications; and
- Patient-centred care: access to counseling for patients, access to counseling for caregivers, access to home care, access to long-term care, number of days spent in long-term care, number of days spent in hospital in the last 3 months of life, and dying at home (Figure 1).<sup>4-9,15,17,25,26</sup>

Indicators were matched to the most relevant domain within the framework. Literature sources, suggested

**Figure 1. Framework of primary care quality indicators for patients with dementia**

Access	Integration	Effective care	Efficient care	Population health	Safety	Patient-centred care
Access to a regular primary care provider	Continuity of care	Diagnosis at an early stage of disease	Annual cost of health services	Yearly flu shot (immunization for influenza)	Having a high number of medications	Access to counseling for patients
After-hours access to the regular primary care provider	Telephone calls between the regular primary care provider and specialists	Dementia diagnosed by the regular primary care provider	Duplicate medical tests	Other recommended immunizations	Potentially inappropriate prescriptions for medications associated with serious side effects prescribed by the regular primary care provider	Access to counseling for caregivers
Access to an interprofessional primary care team	Length of time spent in hospital in the year following diagnosis of dementia	Requests for blood tests originating from the regular primary care provider				Access to home care
Visits to the regular primary care provider	Potentially avoidable hospitalizations	Medications prescribed for dementia				Access to long-term care
Nonurgent visits to the emergency department	Visit to the regular primary care provider within 7 days following a hospitalization	First medication for dementia prescribed by the regular primary care provider				Number of days spent in long-term care
	Readmission to the hospital within 30 days following a hospitalization	Annual visit to the regular primary care provider				Access to palliative end-of-life care provided by the regular primary care provider
		Referrals to specialists in dementia originating from the regular primary care provider				Number of days spent in hospital in last 3 months of life
		Referrals to other specialists originating from the regular primary care provider				Support for dying at home
Equity						
Equitable care across all patients						

operational definitions, and administrative data sources for each indicator are provided in Supplemental Table 4, available from **CFPlus**.<sup>\*</sup> Administrative data sources are cited for operationalization in Ontario and Quebec. As many data were derived from the Canadian Institute for Health Information, indicators may potentially be measurable in provinces other than Ontario and Quebec. Administrative data sources for Ontario and Quebec are described in Supplemental Tables 2 and 3, respectively, which are available from **CFPlus**.<sup>\*</sup>

Our final framework included 34 indicators across 8 domains of performance (access, integration, effective care, efficient care, equity, safety, population health, and patient-centred care) (**Figure 1**).

### Stakeholder prioritization

Overall, 109 stakeholders completed the survey. Participants were mainly evenly distributed (numerically) across Ontario, Quebec, and New Brunswick; and were predominantly women, English-speaking, and between 35 and 64 years of age (**Table 1**). Half of the participants were clinicians; 18% were persons with dementia or caregiver representatives, 13% were health care managers, and 7% were government representatives (**Table 1**). The most frequently prioritized indicators among all participants were access to a regular primary

care provider (81.7%), coordination between health care providers (77.1%), access to home care (75.2%), early-stage diagnosis (71.6%), and avoidable hospitalizations (63.3%) (**Figure 2**).

A comparison of priorities across stakeholder groups is presented in **Table 2**. We found that access to a regular primary care provider, coordination between health care providers, access to home care, and early-stage diagnosis were common priorities among all stakeholder groups (**Table 2**). Avoidable hospitalizations were a greater concern among clinicians, while equitable care was considered a highly important indicator by persons with dementia and caregiver representatives. Finally, government representatives rated referrals to specialists in dementia by the regular primary care provider among their priorities.

## — Discussion —

We developed a framework of 34 quality indicators for the primary care of patients with dementia that are measurable in routinely collected administrative data. By leveraging an existing primary care performance measurement framework and quality indicators in dementia care, we arrived at a set of indicators that were both relevant to primary care and adapted to the population with dementia.

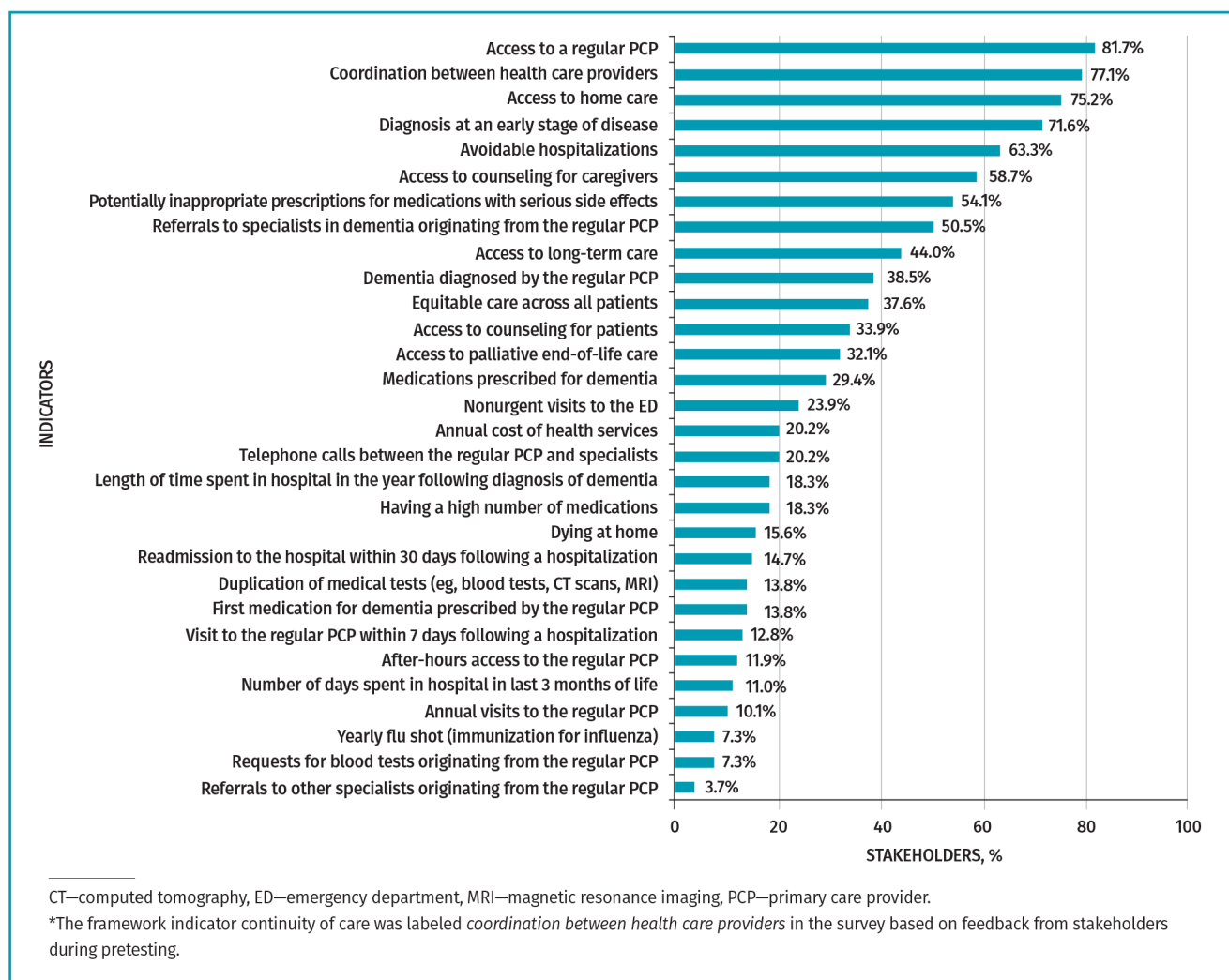
Our rapid review confirmed the paucity of dementia indicators in current primary care quality improvement frameworks. These frameworks did not capture specific elements of dementia care, limiting their use and scope. Among the operationalized primary care frameworks reviewed, while most contained indicators on the prevention or management of chronic diseases such as diabetes, cancer, and hypertension, indicators relating to dementia were generally absent. Even within the HQO primary care framework that we assessed as most appropriate and relevant to use as a basis for our framework, only 1 of the original HQO indicators was directly focused on dementia care (proportion of persons with dementia receiving annual follow-up).<sup>35</sup> This is consistent with reports citing the lack of consideration of dementia as a common chronic disease among older adults and its lack of representation in studies and discussions on chronic disease management.<sup>44,45</sup> This important gap highlights the need to bring dementia management to the forefront of chronic disease management in primary care.

The few indicators proposed within the dementia literature that could be measurable with administrative data either lacked a theoretical framework or were limited in number.<sup>25,26,41,42</sup> Our framework provides an extension to this by considering a rich number of primary care-specific and dementia-relevant indicators across several domains of performance. The application of this framework also has the potential to facilitate ongoing evaluation efforts to support the management

**Table 1. Characteristics of survey participants: N=109.**

CHARACTERISTIC	PARTICIPANTS, n (%)
Female sex	79 (72.5)
English as first language	71 (65.1)
Age, y	
• <35	14 (12.8)
• 35-44	31 (28.4)
• 45-54	30 (27.5)
• 55-64	24 (22.0)
• ≥65	7 (6.4)
• Missing	3 (2.8)
Province	
• New Brunswick	39 (35.8)
• Quebec	38 (34.9)
• Ontario	31 (28.4)
• Saskatchewan	1 (0.9)
Stakeholder group	
• Clinician	54 (49.5)
• Person with dementia or caregiver representative	20 (18.3)
• Manager	14 (12.8)
• Government representative	8 (7.3)
• Other	13 (11.9)

**Figure 2. Proportion of stakeholders considering each indicator a key indicator:** Based on pretest feedback, 4 indicators (access to an interprofessional primary care team, visits to the regular primary care provider, other recommended immunizations [eg, pneumococcal bacteria and shingles], and number of days spent in long-term care) were considered similar in concept to other indicators and omitted from the stakeholder survey for clarity in identifying areas of priority.



of patients with dementia in primary care. For example, a study by our research team that operationalized and applied this framework to assess sex differences in primary care management for persons with dementia in Ontario<sup>46</sup> brought to light the need to develop care plans and interventions that consider the influence of sex and gender on the need for services.

While we strove to develop a comprehensive set of indicators, we also considered the value in prioritizing a subset of these indicators that could feasibly be measured on an ongoing basis. Our stakeholder consultation allowed us to get a “pulse” on what end users wanted to know and measure. Among the priorities identified, continuity of care (described as *coordination between health care providers* in the survey) was unanimously reported as a key quality indicator among all stakeholders. This finding is consistent with an international comparison of primary care quality indicators that

found that primary care providers perceived continuity of care as the most important dimension of quality of care.<sup>39</sup> Stakeholder-specific priorities were also brought to light. These differences point to underlying targets and goals specific to individual stakeholder groups and highlight the importance of involving all types of end users in the research process and in knowledge translation and exchange activities<sup>47</sup> to ensure that all perspectives are included. Establishing subsets of indicators tailored to specific stakeholder priorities may also confer benefit in responding to specific quality improvement goals in the primary care of patients with dementia.

## Limitations

Several limitations should be acknowledged. First, the streamlined process of the rapid review may have missed some eligible frameworks. However, the use of a backward citation tracking approach and expert committee

**Table 2.** Comparison of selected indicator priorities across stakeholder groups: *In each stakeholder group, percentages are shown for indicators that were selected as priorities by at least 60% of participants in that group.*

INDICATOR	CLINICIANS (n=54), %	GOVERNMENT REPRESENTATIVES (n=8), %	MANAGERS (n=14), %	PERSONS WITH DEMENTIA OR CAREGIVER REPRESENTATIVES (n=20), %	OTHER (n=13), %
Coordination between health care providers*	75.9	75.0	71.4	80.0	84.6
Diagnosis at an early stage of disease	68.5	75.0	64.3	85.0	69.2
Access to home care	72.2	62.5	85.7	90.0	61.5
Access to a regular primary care provider	81.5	NA	92.9	90.0	76.9
Access to counseling for caregivers	NA	62.5	64.3	60.0	61.5
Potentially inappropriate prescriptions for medications associated with serious side effects	66.7	NA	64.3	60.0	NA
Avoidable hospitalizations	75.9	NA	NA	NA	61.5
Referrals to specialists in dementia by the regular primary care provider	NA	62.5	NA	NA	NA
Dementia diagnosed by the regular primary care provider	NA	NA	NA	NA	61.5
Equitable care across all patients	NA	NA	NA	60.0	NA

NA—not applicable.  
 \*The indicator *continuity of care* was labeled *coordination between health care providers* in the survey based on feedback from stakeholders during pretesting. Other indicators were also framed slightly differently in the survey compared with the framework (eg, the indicator *potentially avoidable hospitalizations* was labeled *avoidable hospitalizations* in the survey).

allowed us to mitigate this risk. Second, the addition of dementia indicators was based on a review of consensus guidelines and highly cited dementia quality indicators in Canada and the United States and not through a comprehensive systematic review. Future research could validate the comprehensiveness of the proposed framework through the incorporation of a systematic review of dementia quality indicators. Third, as the goal of this work was to create a framework of quality indicators that could be routinely measured using existing health administrative data, self-reported or process-based indicators not adapted to be measured in administrative databases were excluded from our framework. It would therefore seem advisable that quality improvement or monitoring initiatives be complemented with other data sources such as patient chart reviews and surveys to provide these additional perspectives when needed.<sup>11</sup> In addition, other jurisdictions may have access to other routinely collected data, (eg, nurse practitioner visits). In such cases, this framework could be expanded to include additional indicators as new data sources become available. Finally, regular consultations with a large and representative group of stakeholders would be beneficial in ensuring continual stakeholder engagement and priority setting for quality improvement goals.

## Conclusion

With the growing role of primary care in managing dementia, routine monitoring of relevant and targeted indicators will become increasingly important.<sup>48</sup> It is hoped that this framework can provide a solid footing to facilitate this goal and support primary care providers and teams in implementing initiatives to improve and monitor the care of persons with dementia. The identification of priority indicators will also help primary care providers, program evaluators, and researchers narrow targets for quality improvement. Overall, this framework may help create a feasible approach to ongoing quality monitoring of the management of patients with dementia in primary care at a population level and support the identification and scale-up of policies and programs with the most potential to optimize care provided to this vulnerable population.

**Dr Nadia Sourial** is Assistant Professor in the Department of Management, Evaluation and Health Policy at the School of Public Health at the University of Montréal in Quebec. **Dr Claire Godard-Sebillotte** is Assistant Professor in the Division of Geriatric Medicine at McGill University in Montréal. **Dr Susan E. Bronskill** is Scientist in the Institute of Health Policy, Management and Evaluation in the Dalla Lana School of Public Health at the University of Toronto in Ontario. **Dr Geneviève Arseneault-Lapierre** is Senior Research Associate in the Lady Davis Institute for Medical Research at the Jewish General Hospital in Montréal. **Georgia Hacker** is a research assistant and **Dr Isabelle Vedel** is Associate Professor, both in the Department of Family Medicine at McGill University.

### Acknowledgment

We acknowledge the key input of experts **Dr Howard Bergman** and **Dr Tibor Schuster** in assisting in the selection of relevant and feasible indicators for our framework. We also thank **Marine Hardouin** for her role as a reviewer during the rapid review and performing



the analyses from the survey. We express our sincere thanks to **Dr Vladimir Khanassov**, **Dr Dan Murphy**, and **Beatrice Débarges** for their time and input in pretesting the survey questionnaire. We acknowledge the assistance of **Genevieve Gore**, Research Librarian, in helping develop the search criteria for the literature review, and **Mary Henein** and **Laura MacLagan** in supporting the operationalization of indicators. All persons who have contributed substantially to this work have been listed. This work was supported through Canadian Institutes for Health Research (CIHR) Vanier Canada Graduate Scholarships and a CIHR grant for the Canadian Consortium on Neurodegeneration in Aging (CCNA). The CCNA is supported by a grant from the CIHR with funding from several partners. A preliminary version of the framework and stakeholder priorities was presented at the Canadian Association for Health Services and Policy Research conference in 2017 and 2018 and the North American Primary Care Research Group Annual Meeting in 2017 and 2018. The final framework has not been presented at a meeting or submitted elsewhere.

# Contributors

**Dr Nadia Sourial** made substantial contributions to the conception and design of the study; analysis and interpretation of data; and the drafting, revision, and final approval of the manuscript. **Dr Claire Godard-Sebillotte** contributed to the conception and design of the study; interpretation of data; and drafting, revision, and final approval of the manuscript. **Dr Susan E. Bronskill** contributed to the interpretation of data and revision and final approval of the manuscript. **Dr Genviève Arsenault-Lapierre** contributed to the interpretation of data and revision and final approval of the manuscript. **Georgia Hacker** made substantial contributions to the interpretation of data and the revision and final approval of the manuscript. **Dr Isabelle Vedel** contributed to the conception and design of the study; interpretation of data; and drafting, revision, and final approval of the manuscript.

# Competing interests

None declared

# Correspondence

**Dr Nadia Sourial**; e-mail [nadia.sourial@umontreal.ca](mailto:nadia.sourial@umontreal.ca)

# References

1. Alzheimer's Disease International, World Health Organization. *Dementia: a public health priority*. Geneva, Switzerland: World Health Organization; 2012. Available from: <https://extranet.who.int/agefriendlyworld/wp-content/uploads/2014/06/WHO-Dementia-English.pdf>. Accessed 2014 Dec 1.
2. Prince M, Guerchet M, Prina M. The epidemiology and impact of dementia: current state and future trends. WHO Thematic Briefing. Geneva, Switzerland: World Health Organization; 2015. Available from: [https://www.researchgate.net/profile/Matthew-Prina/publication/277217355\\_The\\_Epidemiology\\_and\\_Impact\\_of\\_Dementia\\_-\\_Current\\_State\\_and\\_Future\\_Trends\\_WHO\\_Thematic\\_Briefing/links/556482b608ae89e758fd8f4f/The-Epidemiology-and-Impact-of-Dementia-Current-State-and-Future-Trends-WHO-Thematic-Briefing.pdf](https://www.researchgate.net/profile/Matthew-Prina/publication/277217355_The_Epidemiology_and_Impact_of_Dementia_-_Current_State_and_Future_Trends_WHO_Thematic_Briefing/links/556482b608ae89e758fd8f4f/The-Epidemiology-and-Impact-of-Dementia-Current-State-and-Future-Trends-WHO-Thematic-Briefing.pdf). Accessed 2022 Aug 22.
3. Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. *World Alzheimer Report 2016. Improving healthcare for people living with dementia. Coverage, quality and costs now and in the future*. London, UK: Alzheimer's Disease International; 2016. Available from: <https://www.alz.co.uk/research/world-report-2016>. Accessed 2022 Jun 16.
4. *Dementia in home and community care*. Ottawa, ON: Canadian Institute for Health Information; 2018. Available from: <https://www.cihi.ca/en/dementia-in-canada/dementia-across-the-health-system/dementia-in-home-and-community-care>. Accessed 2022 Aug 24.
5. Organizing Committee, Canadian Consensus Conference on the Assessment of Dementia. Assessing dementia: the Canadian consensus [editorial]. *CMAJ* 1991;144(7):851-3.
6. Patterson CJ, Gauthier S, Bergman H, Cohen CA, Feightner JW, Feldman H, et al. The recognition, assessment and management of dementing disorders: conclusions from the Canadian Consensus Conference on Dementia. *CMAJ* 1999;160(12 Suppl):S1-15.
7. *Third Canadian Consensus Conference on Diagnosis and Treatment of Dementia. March 9-11, 2006. Montreal, Quebec. 146 Approved recommendations. Final—July 2007*. Toronto, ON: Mount Sinai Hospital. Available from: <https://sinaigeriatrics.ca/wp-content/uploads/2017/05/2007-CCCDFinal.pdf>. Accessed 2022 Aug 15.
8. Moore A, Patterson C, Lee L, Vedel I, Bergman H. Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia. Recommendations for family physicians. *Can Fam Physician* 2014;60:433-8 (Eng), e244-50 (Fr).
9. Ismail Z, Black SE, Camicioli R, Chertkow H, Herrmann N, Laforce R Jr, et al. Recommendations of the 5th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia. *Alzheimers Dement* 2020;16(8):1182-95. Epub 2020 Jul 29.
10. Perry M, Drasković I, van Achterberg T, van Eijken M, Lucassen P, Vernooij-Dassen M, et al. Development and validation of quality indicators for dementia diagnosis and management in a primary care setting. *J Am Geriatr Soc* 2010;58(3):557-63. Epub 2010 Feb 22.
11. Broemeling AM, Watson DE, Black C, Wong ST. Measuring the performance of primary healthcare: existing capacity and potential information to support population-based analyses. *Health Policy* 2009;5(Spec no):47-64.
12. Institute of Medicine Committee on Quality of Health Care in America. *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academies Press (US); 2001.
13. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff (Millwood)* 2008;27(3):759-69.
14. *Prevention quality indicators technical specifications updates - version v2020 (ICD 10-CM/PCS), July 2020*. Rockville, MD: Agency for Healthcare Research and Quality; 2020. Available from: [https://qualiindicators.ahrq.gov/archive/pqi\\_techspec/icd10\\_v2020](https://qualiindicators.ahrq.gov/archive/pqi_techspec/icd10_v2020). Accessed 2022 Aug 15.
15. Odenheimer G, Borson S, Sanders AE, Swain-Eng RJ, Kyomen HH, Tierney S, et al. Quality improvement in neurology: dementia management quality measures. *J Am Geriatr Soc* 2014;62(3):558-61. Epub 2014 Jan 7.
16. Wenger NS, Young RT. Quality indicators for continuity and coordination of care in vulnerable elders. *J Am Geriatr Soc* 2007;55(Suppl 2):S285-92.
17. Feil DG, MacLean C, Sultzer D. Quality indicators for the care of dementia in vulnerable elders. *J Am Geriatr Soc* 2007;55(Suppl 2):S293-301.
18. Gnanadesigan N, Fung CH. Quality indicators for screening and prevention in vulnerable elders. *J Am Geriatr Soc* 2007;55(Suppl 2):S417-23.
19. Shrank WH, Polinski JM, Avorn J. Quality indicators for medication use in vulnerable elders. *J Am Geriatr Soc* 2007;55(Suppl 2):S373-82.

20. Dy SM, Taylor SL, Carr LH, Foy R, Pronovost PJ, Ovreteit J, et al. A framework for classifying patient safety practices: results from an expert consensus process. *BMJ Qual Saf* 2011;20(7):e18-24. Epub 2011 May 24.
21. Slade SC, Philip K, Morris ME. Frameworks for embedding a research culture in allied health practice: a rapid review. *Health Res Policy Syst* 2018;16(1):29.
22. Tricco AC, Antony J, Zarin W, Striffler L, Ghassemi M, Ivory J, et al. A scoping review of rapid review methods. *BMC Med* 2015;13:224.
23. Langlois EV, Straus SE, Antony J, King VJ, Tricco AC. Using rapid reviews to strengthen health policy and systems and progress towards universal health coverage. *BMJ Glob Health* 2019;4(1):e001178.
24. Team 19: Research on Organization of Healthcare Services for Alzheimers. *Assessing care models and policies implemented in primary health care for persons with neurocognitive disorders*. Montréal, QC: Canadian Consortium on Neurodegeneration in Aging; 2018. Available from: <http://ccna-cnv.ca/theme-3-quality-life/team-19/>. Accessed 2018 Dec 20.
25. Health Quality Ontario. *Evidence to improve care. Quality standards*. Dementia. Toronto, ON: Queen's Printer for Ontario; 2018. Available from: <https://www.hqontario.ca/Evidence-to-Improve-Care/Quality-Standards/View-all-Quality-Standards/Dementia>. Accessed 2018 Mar 5.
26. Sivananthan SN, Laverne MR, McGrail KM. Caring for dementia: a population-based study examining variations in guideline-consistent medical care. *Alzheimers Dement* 2015;11(8):906-16. Epub 2015 May 5.
27. Patton MQ. *Qualitative evaluation and research methods*. 2nd ed. Newbury Park, CA: Sage Publications; 1990.
28. Naderifar M, Goli H, Ghaljaei F. Snowball sampling: a purposeful method of sampling in qualitative research. *Strides Dev Med Education* 2017;14(3):e67670. Epub 2017 Sep 30.
29. Stiefel M, Nolan K. *A guide to measuring the triple aim: population health, experience of care, and per capita cost*. IHI Innovation Series white paper. Cambridge, MA: Institute for Healthcare Improvement; 2012.
30. Stiefel M, Nolan K. Measuring the triple aim: a call for action [commentary]. *Popul Health Manag* 2013;16(4):219-20.
31. Carinci F, Van Gool K, Mainz J, Veillard J, Pichora EC, Januel JM, et al. Towards actionable international comparisons of health system performance: expert revision of the OECD framework and quality indicators. *Int J Qual Health Care* 2015;27(2):137-46. Epub 2015 Mar 10.
32. Aggarwal M, Hutchison BG. *Toward a primary care strategy for Canada*. Ottawa, ON: Canadian Foundation for Healthcare Improvement; 2012.
33. Primary health care in Canada. A chartbook of selected indicator results, 2016. Ottawa, ON: Canadian Institute for Health Information; 2016. Available from: [https://secure.cihi.ca/free\\_products/Primary%20Health%20Care%20in%20Canada%20-%20Selected%20Pan-Canadian%20Indicators\\_2016\\_EN.pdf](https://secure.cihi.ca/free_products/Primary%20Health%20Care%20in%20Canada%20-%20Selected%20Pan-Canadian%20Indicators_2016_EN.pdf). Accessed 2022 Aug 22.
34. Turner M, D'Silva J, Tipper B, Krylova O, Webster G. Assessing primary healthcare using pan-Canadian indicators of health and health system performance. *Healthc Q* 2013;16(2):9-12.
35. Haj-Ali W, Hutchison B; Primary Care Performance Measurement Steering Committee. Establishing a primary care performance measurement framework for Ontario. *Healthc Policy* 2017;12(3):66-79.
36. Levesque JF, Pineault R, Provost S, Tousignant P, Couture A, Borgès Da Silva R, et al. Assessing the evolution of primary healthcare organizations and their performance (2005-2010) in two regions of Québec province: Montréal and Montérégie. *BMC Fam Pract* 2010;11:95.
37. Levitt CA, Nair K, Dolovich L, Price D, Hilts L. Refinement of indicators and criteria in a quality tool for assessing quality in primary care in Canada: a Delphi panel study. *Fam Pract* 2014;31(5):607-21. Epub 2014 May 21.
38. Stukel TA, Croxford R, Rahman F, Bierman AS, Glazier RH. Variations in quality indicators across Ontario physician networks. Toronto, ON: ICES; 2016. Available from: <https://www.ices.on.ca/Publications/Atlases-and-Reports/2016/Variations-in-Quality-Indicators-Across-Ontario-Physician-Networks>. Accessed 2022 Aug 21.
39. Rotar Pavlič D, Sever M, Klemenc-Ketiš Z, Švab I. Process quality indicators in family medicine: results of an international comparison. *BMC Fam Pract* 2015;16:172.
40. *Pan-Canadian primary health care indicator update report*. Ottawa, ON: Canadian Institute for Health Information; 2012. Available from: [https://secure.cihi.ca/free\\_products/Pan-Canadian\\_PHC\\_Indicator\\_Update\\_Report\\_en\\_web.pdf](https://secure.cihi.ca/free_products/Pan-Canadian_PHC_Indicator_Update_Report_en_web.pdf). Accessed 2022 Aug 22.
41. *Priority setting for healthcare performance measurement - Alzheimer's disease*. Washington, DC: National Quality Forum; 2014. Available from: [http://www.qualityforum.org/priority\\_setting\\_for\\_healthcare\\_performance\\_measurement\\_alzheimers\\_disease.aspx](http://www.qualityforum.org/priority_setting_for_healthcare_performance_measurement_alzheimers_disease.aspx). Accessed 2020 Jan 1.
42. *Dementia data collection reference guide. Version 1.0.1*. Cambridge, MA: International Consortium for Health Outcomes Measurement; 2017. Available from: <https://ichom.org/files/medical-conditions/dementia/dementia-reference-guide.pdf>. Accessed 2020 Dec 1.
43. Health Quality Ontario. A primary care performance measurement framework for Ontario. Report of the Steering Committee for the Ontario Primary Care Performance Measurement Initiative: phase one. Toronto, ON: Queen's Printer for Ontario; 2014. Available from: <http://www.hqontario.ca/portals/0/documents/pr/pc-performance-measurement-report-en.pdf>. Accessed 2022 Aug 22.
44. O'Neill D. Stroke and dementia are also chronic diseases [letter]. *BMJ* 2011;342:d1154.
45. Lepore M, Shuman SB, Wiener JM, Gould E. *Challenges in involving people with dementia as study participants in research on care and services*. Washington, DC: Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services; 2017. Available from: <https://aspe.hhs.gov/system/files/pdf/256696/Session%205%20Background.pdf>. Accessed 2019 Jan 1.
46. Sourial N, Vedel I, Godard-Sebillotte C, Etches J, Arsenault-Lapierre G, Bronskill SE. Sex differences in dementia primary care performance and health service use: a population-based study. *J Am Geriatr Soc* 2020;68(5):1056-63. Epub 2020 Feb 5.
47. Jull J, Giles A, Graham ID. Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implement Sci* 2017;12(1):150.
48. Alzheimer's Disease International publication team. *From plan to impact. Progress towards targets of the Global Action Plan on Dementia*. London, UK: Alzheimer's Disease International; 2018. Available from: <https://www.alz.co.uk/adi/pdf/from-plan-to-impact-2018.pdf>. Accessed 2022 Aug 18.

This article has been peer reviewed.

Cet article a fait l'objet d'une révision par des pairs.

*Can Fam Physician* 2022;68:e270-8. DOI: 10.46747/cfp.6809e270