

Supplemental Text 1: Literature review search strategy and results on existing primary care performance frameworks

The literature search was performed using the MEDLINE (Ovid) and EMBASE databases with assistance from a specialized health librarian. The search included the following general concepts: “primary health care”, “performance”, “framework or indicators”. Specific keywords and results from the search are provided below. The search was limited to publications written in English between 2008 and 2018 and the North American context. The lower date limit was selected based on the publication of the Institute for Health Care Information (IHI)’s Triple Aim Initiative, which constituted a seminal work on the elaboration of frameworks in primary care.⁵ Grey literature was also searched by reviewing reports and recommendations from international, national and state/provincial institutes focused on health system performance and quality. A backward citation tracking approach and expert consultation was also used to ensure any other potentially relevant frameworks were also included in the review.

Database: Embase <1996 to 2018 Week 09>

Search Strategy:

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1  exp primary health care/ (125207)
2  (primary health care or primary healthcare or primary care).m_titl. (46293)
3  1 or 2 (130151)
4  performance measurement system/ (3858)
5  (primary care performance or health system performance or healthcare performance or
health care performance or framework or indicators).mp. (334077)
6  (framework or indicators or performance).m_titl. (173590)
7  health care delivery/ (124000)
8  4 or 7 (127672)
9  3 and 5 and 6 and 8 (179)
10 limit 9 to (english and yr="2008 - 2018") (102)
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Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations,
Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions(R) <1946 to February 21, 2018>
Search Strategy:

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- 1 exp primary health care/ (134814)
 - 2 (primary health care or primary healthcare or primary care).m_titl. (45109)
 - 3 1 or 2 (148157)
 - 4 Quality indicators, Health Care/ (13530)
 - 5 (primary care performance or health system performance or healthcare performance or health care performance or framework or indicators).mp. (392530)
 - 6 (framework or indicators or performance).m_titl. (204851)
 - 7 "Delivery of Health Care"/ (78084)
 - 8 4 or 7 (91018)
 - 9 3 and 5 and 6 and 8 (423)
 - 10 limit 9 to (yr="2008 - 2018" and english) (256)
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SURVEY QUESTIONNAIRE

Choosing key indicators of care management in primary care for persons newly diagnosed with dementia

The goal of this survey is to get your input on which measures of care management for patients newly diagnosed with dementia in primary care are most important from your point of view.

As key stakeholders, your participation will be essential in deciding which measures should be prioritized and evaluated on a regular basis.

This survey should take around **15 minutes** to complete.

Your participation in this survey is completely voluntary. By completing this questionnaire, you consent to participate in this study. There are no known risks, side effects or disadvantages associated with this research study. We will ensure the confidentiality of the information collected. The information will, in no case, be transmitted to other persons not involved in this study. This survey has been approved by the research ethics committee of the Canadian Consortium of Neurodegeneration in Aging.

If you have questions about this survey or study, please contact Dr. Isabelle Vedel (isabelle.vedel@mcgill.ca) or Ms. Nadia Sourial (nadia.sourial@mail.mcgill.ca).

Thank you for your participation!

Demographic information for statistics purposes:

From what perspective are you answering this survey (check only 1)?

- ☐ As a patient / caregiver representative (e.g. Alzheimer Societies)
- ☐ As a clinician
- ☐ As a government representative
- ☐ As a manager
- ☐ Other

Please select your age group:

- ☐ Less than 35
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65 and over



ROSA
Research on Organization
of Healthcare Services for
Alzheimers
Recherche en organisation
des services sur l'Alzheimer



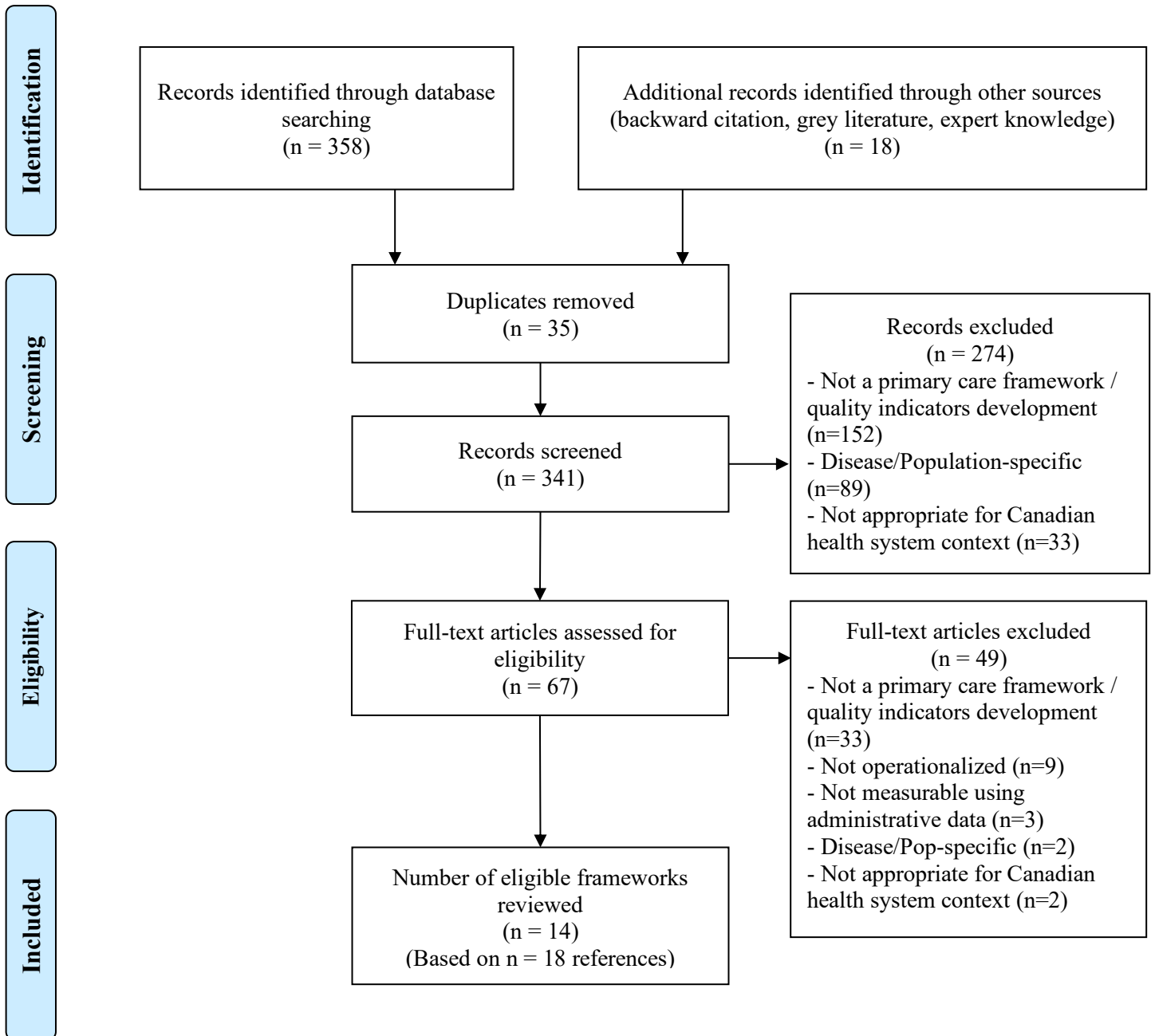
Indicator of care management in primary care for persons newly diagnosed with dementia	Check (✓) a maximum of 10 indicators that you feel are most important
1. Access to a regular family doctor (or nurse practitioner)	
2. Avoidable hospitalizations	
3. Non-urgent visits to the Emergency Department of the hospital	
4. Diagnosis at an early stage of the disease	
5. After-hours access to the regular family doctor	
6. Coordination between different health care providers	
7. Readmission to the hospital within 30 days following a hospitalization	
8. Visit to the regular family doctor within 7 days following a hospitalization	
9. Referrals to specialists in dementia (geriatrician, neurologist, psychiatrist) originating from the regular family doctor	
10. Referrals to other specialists (e.g. cardiologist, oncologist) originating from the regular family doctor	
11. Requests for blood tests originating from the regular family doctor	
12. Phone calls between the regular family doctor and specialists	
13. Dementia diagnosed by the regular family doctor	
14. Medications prescribed for dementia (e.g. Exelon®, Reminyl®, Aricept®, Ebixa®)	
15. First medication for dementia prescribed by the regular family doctor	
16. Annual visits to the regular family doctor	
17. Annual cost of health services	
18. Duplication of medical tests (e.g. blood tests, CT / MRI scans)	

19. Length of time spent in hospital in the year following diagnosis of dementia	
20. Equitable care across all patients (e.g. age, sex, income, region, immigrant status)	
21. Yearly flu shot (immunization for influenza)	
22. Potentially inappropriate prescriptions for medications (e.g. benzodiazepines, antipsychotics, anticholinergics, tricyclic antidepressants, trazodone) associated with serious side effects	
23. Having a high number of medications	
24. Access to counselling for patients	
25. Access to counselling for caregivers	
26. Access to home care	
27. Access to long-term care	
28. Access to palliative end-of-life care	
29. Number of days spent in hospital in last 3 months of life	
30. Dying at home	

Thank you for your participation!

COMMENTS:

Supplemental Figure 1: PRISMA flow diagram for selection of eligible primary care frameworks



Supplemental Table 1: Scoring of eligible primary care frameworks

Name of framework / Description of indicators	Comprehensiveness	Focus on patient-level	Pertinence for older population	Measurability in administrative data	Publication (First author; year)
(1=low to 4= high)					
Primary care performance measurement framework (HQO)	4	3	3	3	HQO 2014 ⁴³ , Haj-Ali 2017 ³⁵
Toward a Primary Care Strategy for Canada (CFHI)	4	3	3	2	CFHI 2012 ³²
Quality indicators of health system performance (IC/ES)	2	4	2	4	Stukel 2016 ³⁸
Health System Performance Measurement Framework (CIHI)	4	2	2	3	CIHI 2012 ⁴⁰ , 2016 ³³ , Terner 2013 ³⁴
Triple Aim Initiative (IHI)	3	3	2	2	Stiefel 2012 ²⁹ , 2013 ³⁰
Health Care Quality Indicators Project (OECD)	2	3	2	3	Carinci 2015 ³¹
Quality Standards for Dementia: Care for People Living in the Community (HQO)	2	3	3	2	HQO 2018 ²⁵
Performance of primary healthcare Organizations (INSPQ)	3	2	2	3	Levesque 2010 ³⁶
AHRQ Prevention Quality Indicators (AHRQ)	2	3	1	3	AHRQ 2018 ¹⁴
Primary health care performance measures (British Columbia U)	3	2	2	2	Broemeling 2009 ¹¹
Quality Book of Tools (McMaster U)	3	1	2	1	Levitt 2014 ³⁷
Process quality indicators in family Medicine (QUALICOPC study)	2	1	1	1	Pavlic 2015 ³⁹
National Quality Forum	4	4	4	1	NQF 2014 ⁴¹

International Consortium for Health Outcomes Measurement	1	4	4	1	ICHOM 2017 ⁴²
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Abbreviations: IHI, Institute for Healthcare Improvement; OECD, Organization for Economic Cooperation and Development; AHRQ, Agency for Healthcare Research and Quality; CFHI, Canadian Foundation for Healthcare Improvement; CIHI, Canadian Institute for Health Information; HQO, Health Quality Ontario; INSPQ, Institut national de santé publique du Québec; QUALICOPC, Quality and Costs of Primary Care in Europe; NQF, National Quality Forum; ICHOM, International Consortium for Health Outcomes Measurement

Supplemental Table 2: Description of databases for operationalization of framework indicators in Ontario

Database	Description
Registered Persons Database (RPDB) - ON	The RPDB provides basic demographic information (age, sex, location of residence, date of birth, and date of death for deceased individuals) for those issued an Ontario health insurance number. The RPDB also indicates the time periods for which an individual was eligible to receive publicly funded health insurance benefits and the best known postal code for each registrant on July 1st of each year.
Ontario Health Insurance Plan (OHIP) - ON	The OHIP claims database contains information on inpatient and outpatient services provided to Ontario residents eligible for the province's publicly funded health insurance system by fee-for-service health care practitioners (primarily physicians) and "shadow billings" for those paid through non-fee-for-service payment plans. Billing codes on the claims (OHIP fee codes) identify the care provider, their area of specialization and the type and location of service. OHIP billing claims also contain a 3-digit diagnosis code - the main reason for the service - captured using a modified version of the ICD, 8th revision coding system.
Client Agency Program Enrollment (CAPE) - ON	The CAPE file is a registry of all patients who have ever been rostered to receive care from a particular physician in Ontario, documents the time period in which a patient was rostered to a specific physician, and the associated primary care organization (e.g., Family Health Group (FHG), Family Health Network (FHN), Family Health Organization (FHO)).
Discharge Abstract Database (DAD) - CIHI	The DAD is compiled by the Canadian Institute for Health Information and contains data on acute care hospital admissions. This includes clinical data (diagnoses, procedures and interventions), demographics, and administrative data (institution/hospital number, admission category and length of

	stay).
National Ambulatory Care Reporting System (NACRS) - CIHI	The NACRS is compiled by the Canadian Institute for Health Information and contains clinical (diagnoses and procedures), demographic, and administrative information for all patient visits made to hospital- and community-based ambulatory care centres (i.e., emergency departments, day surgery units, hemodialysis units, and cancer care clinics).
Ontario Drug Benefit (ODB) - ON	The ODB database contains prescription medication claims for those covered under the provincial drug program, mainly: those aged 65 years and older, nursing home residents, patients receiving services under the Ontario Home Care program, those receiving social assistance, and residents eligible for specialized drug programs. Records include drug identifier, patient, pharmacy and physician identifiers, long-term care indicator, and date of dispensation.
Home Care Database (HCD) - ON	The HCD captures all publicly funded home care services provided or coordinated in Ontario, and contains information on clients, admission, assessments, diagnostic and surgical procedures, and service delivered.
Continuous Care Reporting System (CCRS) - CIHI	The CCRS and CCRS-LTC data are compiled by the Canadian Institute for Health Information and include demographic and clinical assessment data (on the physical, functional, cognitive, and social domains of health). Data are ascertained using the Resident Assessment Instrument Minimum Data Set (RAI-MDS) version 2.0 which is administered by trained healthcare professionals.
Resident Assessment Instrument for Home Care (RAI-HC) - ON	The RAI-HC gathers information on residents in publicly funded home care programs in Ontario and includes demographic and clinical assessment data (on the physical, functional, cognitive, and social domains of health).
ICES Physician Database (IPDB) - ON	The IPDB contains information about physicians practicing in Ontario, including information on demographics (age, gender, year of graduation, school of graduation); specialty (functional

	and certified); location of practice; and measures of physician activity (billings and workload data).
National Rehabilitation Reporting System (NRS) - CIHI	The NRS is compiled by the Canadian Institute for Health Information and contains data collected on admission and discharges of adult inpatient rehabilitation patients for specialized facilities or hospital units with designated rehabilitation beds.
Ontario Mental Health Reporting System (OMHRS) - ON	The OMHRS is compiled by the Canadian Institute for Health Information (CIHI) and contains administrative, clinical (diagnoses and procedures), demographic, and administrative information for all admissions to adult designated inpatient mental health beds.
Office of the Registrar General (ORGD) Vital Statistics Database - ON	The ORGD Vital Statistics Database contains information on all deaths registered in Ontario starting on January 1, 1990. Information on the causes of death (immediate, antecedent, and underlying) recorded on the death certificate are captured.

Supplemental Table 3: Description of databases for operationalization of framework indicators in Quebec

Database	Description
Banque de données commune des urgence (BDCU)	Contains personal information on episodes of care and services provided by a person registered in the emergency department
Maintenance et exploitation des données pour l'étude de la clientèle hospitalière (MED-ECHO)	Contains personal clinical and administrative information related to the care and services provided to a person admitted to the hospital or registered for day surgery in a Quebec hospital
Performance hospitalière (APR-DRG)	Contains personal clinical and administrative information related to the care and services rendered to a person admitted or registered for day surgery in a Quebec hospital center (extracted

	from MED-ÉCHO) to which is added other information related to the groupings assigned by the APR-DRG software, the calculation of the relative intensity level of the resources used (NIRRU) and other management indicators
Registre des événements démographiques (RED)	Personal demographic information, including death (date and cause) on the population of Quebec
Système d'information sur la clientèle et les services des CSSS - mission CLSC (I-CLSC)	Contains personal information and providing data on requests for services, users and interventions concerning services offered in Centre services sociaux et de sante (CSSS) (Centre local des services communautaire (CLSC) mission). The database is used to describe the services provided on the front line
Fichier des services pharmaceutiques couverts par la RAMQ	The pharmacy services file contains information on pharmacy services provided under the public drug insurance plan administered by the RAMQ
Fichier sur les périodes d'admissibilité à l'assurance médicaments de la RAMQ	The Drug Benefit Eligibility Periods file contains information on the drug benefit eligibility periods of insured persons
Fichier sur les services médicaux rémunérés à l'acte par la RAMQ	Contains fee-for-service billing information from health professionals' claims submitted to RAMQ
Fichier d'inscription des personnes assurées (FIPA)	Demographic information on persons receiving services including date of birth and death, sex, postal code of residence.

[Supplemental Table 4: Source and suggested operationalization of framework indicators by Health Quality Ontario domain of quality](#)

HQO Domain	Indicator	Suggested operational definition	Available databases for operationalization in Ontario	Available databases for operationalization in Quebec	Indicator Source(s)
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ACCESS	Access to a regular primary care provider	UPC index > 0.5 ^a OR Rostering or virtual rostering with a primary care provider (e.g. family physician, nurse practitioner)	OHIP, CAPE, IPDB	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵ HQO 2018 ²⁵
	After-hours access to the regular primary care provider	After-hours visits made to the regular primary care provider	OHIP, CAPE, IPDB	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵
	Access to an interprofessional primary care team	Type of primary care group affiliation	CAPE	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵ HQO 2018 ²⁵
	Visits to the regular primary care provider	Visits to the regular primary care provider	OHIP, IPDB, CAPE	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵
	Non-urgent visits to the ED	Visits to the ED with CTAS ^b level 4 (less urgent) or 5 (not urgent)	NACRS	BDCU	HQO 2017 ³⁵ CIHI 2018 ⁴
INTEGRATION	Continuity of care	Bice-Boxerman Continuity of Care index ^c	OHIP	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵
	Phone calls between the regular primary care provider and specialists	Phone calls between the regular primary care provider and specialists	OHIP, CAPE, IPDB	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵

	Length of time spent in hospital in the year following diagnosis of dementia	Number of days spent in acute care hospital	DAD	MED-ECHO	HQO 2018 ²⁵
	Potentially avoidable hospitalizations	Ambulatory care sensitive conditions (ACSC) ^d acute care hospitalizations	DAD	MED-ECHO	HQO 2017 ³⁵ CIHI 2018 ⁴
	Visit to the regular primary care provider within 7 days following a hospitalization	Visits to the regular primary care provider within 7 days following an acute care hospitalization	DAD, OHIP, CAPE, IPDB	MED-ECHO, Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵
	Readmission to the hospital within 30 days following a hospitalization	Readmission to the hospital within 30 days following a hospitalization	DAD	MED-ECHO	HQO 2017 ³⁵
EFFECTIVE CARE	Diagnosis at an early stage of the disease	Age at first case ascertainment of dementia	DAD, OHIP, ODB, RPDB	FIPA	ACOVE 2007 ¹⁷ CCCDTD 2020 ⁹ CIHI 2018 ⁴
	Dementia diagnosed by the regular primary care provider	First case of dementia ascertained by the regular primary care provider	OHIP, CAPE, ODB, IPDB	Fee-for-service medical services (RAMQ)	CCCDTD 199 ⁵ CCCDTD 2014 ⁸

Receipt of blood tests	Receipt of blood tests	To be determined	To be determined	CCCDTD 2007 ⁷ CCCDTD 1999 ⁶ Sivananthan et al. 2015 ²⁶
Medications prescribed for dementia	Drug therapies dispensed for dementia such as cholinesterase inhibitors (e.g. Rivastigmine, Galantamine, Donepezil) or memantine for 65+	ODB	Pharmaceutical services (RAMQ)	CCCDTD 1999 ⁶
First medication for dementia prescribed by the regular primary care provider	Dispensed cholinesterase inhibitors (e.g. Rivastigmine, Galantamine, Donepezil) or memantine for 65+ by the regular primary care provider	ODB, CAPE, OHIP, IPDB	Pharmaceutical services (RAMQ) Fee-for-service medical services (RAMQ)	CCCDTD 1999 ⁶ ACOVE 2007 ¹⁷ CCCDTD 2014 ⁸
Annual visit to the regular primary care provider	Visits to the regular primary care provider in the last 12 months	OHIP, CAPE, IPDB	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵ ACOVE 2007 ¹⁷

	Referrals to specialists in dementia originating from the regular primary care provider	Visits to cognition specialists (e.g. geriatrician, neurologist, psychiatrist)	OHIP	Fee-for-service medical services (RAMQ)	CCCDTD 1991 ⁵ Sivananthan et al. 2015 ²⁶ CCCDTD 1999 ⁶
	Referrals to other specialists originating from the regular primary care provider	Visits to other specialists (e.g. cardiologist, oncologist)	OHIP	Fee-for-service medical services (RAMQ)	Sivananthan et al. 2015 ²⁶ CCCDTD 1999 ⁶
EFFICIENT CARE	Annual cost of health services	Annual cost of health services	DAD, CCRS, NACRS, OHIP, HCD, ODB, OMHRS, NRS (Wodchis et al. 2016) ^e	APR-DRG, RAMQ, BDCU, MED-ECHO, I-CLSC	HQO 2017 ³⁵
	Duplicate medical tests	Receipt of duplicate medical tests (e.g. blood tests, brain CT/MRI scans)	To be determined	To be determined	CCCDTD 2014 ²³ Sivananthan et al. 2015 ²⁶ ACOVE 2007 ¹⁷
POPULATION HEALTH	Yearly flu shot (immunization for influenza)	Receipt of an influenza vaccine	To be determined	Pharmaceutical services (RAMQ)	HQO 2017 ³⁵ ACOVE 2007 ¹⁷
	Other recommended immunizations	Receipt of another recommended vaccine (e.g. pneumococcal, shingles)	To be determined	Pharmaceutical services (RAMQ)	HQO 2017 ³⁵ ACOVE 2007 ¹⁷

SAFETY	Having a high number of medications	Number of medications dispensed concurrently or over a specified period of time	ODB	Pharmaceutical services (RAMQ)	CCCDTD 2020 ⁹ ACOVE 2007 ¹⁷
	Potentially inappropriate prescriptions for medications associated with serious side effects prescribed by the regular primary care provider	Dispensed potentially inappropriate medications (e.g. benzodiazepines, antipsychotics, anticholinergics, tricyclic antidepressants, trazodone)	ODB, CAPE	Pharmaceutical services (RAMQ)	HQO 2017 ³⁵ CCCDTD 2007 ⁷ Sivananthan et al. 2015 ²⁶ ACOVE 2007 ¹⁷
PATIENT-CENTERED CARE	Access to counselling for patients	Visits for patient counselling	To be determined	Fee-for-service medical services (RAMQ)	CCCDTD 1999 ⁶ DMWG 2014 ¹⁵ Sivananthan et al. 2015 ²⁶ ACOVE 2007 ¹⁷
	Access to counselling for caregivers	Visits for caregiver counselling	To be determined	Fee-for-service medical services (RAMQ)	CCCDTD 1999 ⁶ DMWG 2014 ¹⁵ Sivananthan et al. 2015 ²⁶ ACOVE 2007 ¹⁷
	Access to home care	Use of home care services	HCD	I-CLSC	CCCDTD 1999 ⁶ DMWG 2014 ¹⁵ Sivananthan et al. 2015 ²⁶

	Access to long-term care	Admission to long-term care	CCRS-LTC	To be determined	HQO 2018 ²⁵
	Number of days spent in long-term care	Number of days spent in long-term care	CCRS-LTC	To be determined	CIHI 2018 ⁴
	Access to palliative end-of-life care provided by the regular primary care provider	Visits for palliative care	OHIP, CAPE, DAD, HCD	Fee-for-service medical services (RAMQ)	HQO 2017 ³⁵ DMWG 2014 ¹⁵ CCCDTD 2007 ⁷
	Number of days spent in hospital in last 3 months of life	Number of days spent in acute care hospital in last 3 months of life	DAD	MED-ECHO,	Expert Committee
	Dying at home	Place of death (e.g. acute care hospital, home, other)	CCRS-LTC, HCD, RAI, RPDB, ORGD, DAD	RED	Expert Committee
EQUITY	Equitable care across all patients	Stratification by specific/available sociodemographic variables (e.g. age, sex, income, region, immigrant status)	OHIP	FIPA	HQO 2017 ³⁵

Footnote:

CAPE: Client Agency Program Enrolment; OHIP: Ontario Health Insurance Plan; IPDB: ICES Physician Database; NACRS: The National Ambulatory Care Reporting System; DAD: Discharge Abstract Database; ODB: Ontario Drug Benefit; HCD: The Home

Care Database; CCRS-LTC: Continuing Care Reporting System; RAI: Resident Assessment Instrument; NRS: National Rehabilitation Reporting System; OMHRS: Mental Health Reporting System; RPDB: Registered Persons Database; ORGD: Vital Statistics - Death (Office of the Registrar General - Deaths); UPC: Usual Provider of Care; CTAS: Canadian Triage Acuity Scale

MED-ECHO: Maintenance et exploitation des données pour l'étude de la clientèle hospitalière; BDCU: Banque de données communes des urgences; I-CLSC: Système d'information sur la clientèle et les services des CSSS - mission CLSC; RAMQ: Régie de l'assurance maladie du Québec; FIPA: Fichier d'inscription des personnes assurées; APR-DRG: All Patient Refined Diagnosis Related Groups; RED : Registre des événements démographiques.

* Memantine not covered in the Ontario Drug Formulary through the Ontario Drug Benefit Program, and therefore does not appear in the ODB

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