

Putting the Patient First: A Scoping Review of Patient Desires in Canada

Donner la priorité au patient : examen de la portée des souhaits des patients au Canada

ALLIE PECKHAM, JAMES G. WRIGHT, HUSAYN MARANI, REHAM ABDELHALIM,
DARA LAXER, SARA ALLIN, NADIA ALAM AND GREG MARCHILDON

Appendix 1. Example search strategy (OVID Medline)

#	Searches	Results
1	("patient*" or "client*" or "consumer*" or "user*" or "inpatient*" or "outpatient*").tw,kf.	6,327,236
2	exp "patients"/ or exp "clients"/ or exp "consumers"/ or exp "users"/ or exp "inpatients"/ or exp "outpatients"/	60,940
3	1 or 2	6,342,453
4	("unpaid car*" or "nonpaid car*" or "family car*" or "informal car*" or "non-professional car*" or "voluntary car*" or "parent* car*" or "spous* car*" or "spous* support*" or "young car*" or "child car*" or "carer*" or "caregiver*" or "guardian" or "person most knowledgeable").tw,kf.	81,197
5	exp Caregivers/	31,272
6	4 or 5	89,526
7	("healthy" or "walking well" or "able-bod*" or "able" or "chronic* ill*" or "chronic disease" or "acute life threatening" or "acute non-life threatening" or "terminal* ill*" or "terminal" or "comorbid" or "co-morbid" or "multimorbid" or "multi-morbid" or "mental* ill*" or "addict*" or "cognitiv* impair*" or "disabled" or "frail" or "palliative" or "dependent" or "independent" or "convalescent" or "recovering").tw,kf.	3,607,449
8	exp "healthy"/ or exp "walking well"/ or exp "able bodied"/ or exp "disabled"/ or exp "chronically ill"/ or exp "acute life threatening"/ or exp "acute non-life threatening"/ or exp "terminally ill"/ or exp "comorbid"/ or exp "multimorbid"/ or exp "mentally ill"/ or exp "addict"/ or exp "cognitively impaired"/ or exp "frail"/ or exp "palliative"/ or exp "dependent"/ or exp "independent"/ or exp "convalescent"/ or exp "recovering"/	315,754
9	7 or 8	3,862,863
10	3 or 6 or 9	9,079,380
11	("Perception*" or "Expectation*" or "Preferences" or "Perspective*" or "Opinion*" or "View*" or "Notion*" or "Satisfaction" or "Attitude*" or "Understanding" or "Knowledge of" or "Knowledge" or "Disposition*" or "Reaction*" or "Experience*").tw,kf.	4,114,913

#	Searches	Results
12	"Canada".tw,kf.	75,537
13	("Healthcare" or "Health care" or "Medical care" or "Health care system" or "Healthcare system" or "Health near/1 system").tw,kf.	526,683
14	exp "healthcare"/ or exp "health care"/ or exp "medical care"/ or exp "health care system"/ or exp "health system"/	988,883
15	13 or 14	1,321,662
16	10 and 11 and 12 and 15	4,922
17	limit 16 to (English language and yr="2013 -Current" and English and (comparative study or government publications or journal article or observational study or personal narratives or "review" or systematic reviews or technical reports)	2,232

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Appendix 2. Tally of included articles by health state and age

Life stage	Health state						
			Walking well	Acute life-threatening	Mental/cognitive health and addictions	Chronic health	Palliative care
Pediatric	Broadly defined results						
	Subpopulation results	LGBTQ					
		Ethnic minorities, immigrants, refugees					
		Vulnerably housed					
		Rural and remote					
		Indigenous					

Life stage	Health state							
			Walking well	Acute life-threatening	Mental/cognitive health and addictions	Chronic health	Palliative care	
Youth/ Children	Broadly defined results		I	II	III	IIII		
	Subpopulation results	LGBTQ	I					
		Ethnic minorities, immigrants, refugees						
		Vulnerably housed			I			
		Rural and remote						
		Indigenous		II		I	I	
Young Adult	Broadly defined results		I		IIII	III		
	Subpopulation results	LGBTQ						
		Ethnic minorities, immigrants, refugees				I		
		Vulnerably housed			I			
		Rural and remote					I	
		Indigenous		II		I		
Adult	Broadly defined results		IIII, IIIII, IIIII, III	IIII	IIII, III	IIII, IIIII, IIIII, IIIII, IIIII, IIIII, III, II		
	Subpopulation results	LGBTQ	IIII, I	I	II	IIII		
		Ethnic minorities, immigrants, refugees	IIII, IIIII, III			III		
		Vulnerably housed	IIII			II	I	
		Rural and remote	I				II	
		Indigenous	IIII, I			I	III	

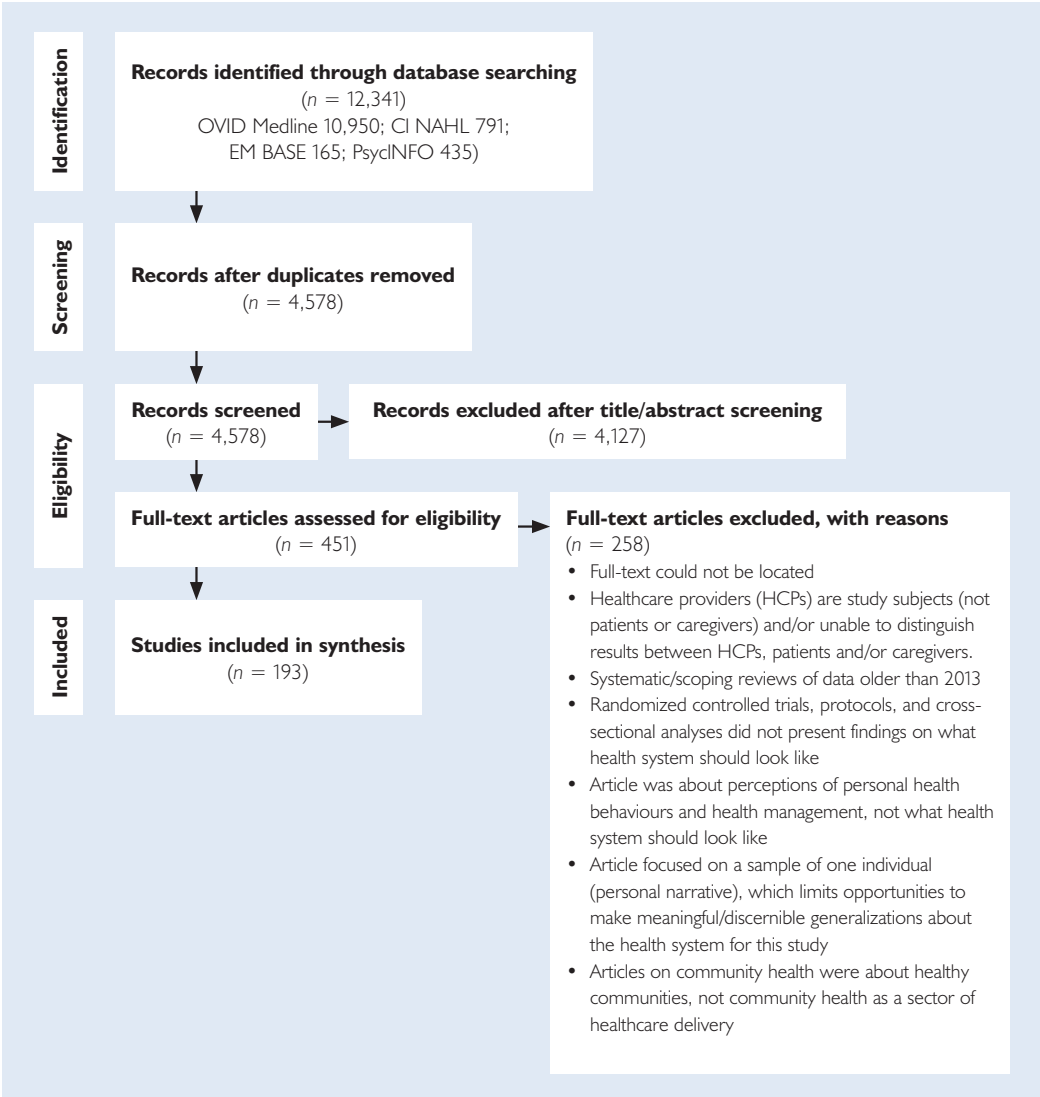
Life stage	Health state						
			Walking well	Acute life-threatening	Mental/cognitive health and addictions	Chronic health	Palliative care
Geriatric/ Older Adult	Broadly defined results		IIII, II	I	I	IIII, IIII	
	Subpopulation results	LGBTQ					
		Ethnic minorities, immigrants, refugees	I			I	
		Vulnerably housed					
		Rural and remote	I			I	
		Indigenous					
Caregivers/ Parents	Broadly defined results		IIII, I	IIII, II	III	IIII, IIII, IIII, IIII, IIII, I	
	Subpopulation results	LGBTQ					
		Ethnic minorities, immigrants, refugees	I			I	
		Vulnerably housed					
		Rural and remote	I			I	
		Indigenous				I	

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Appendix 3. PRISMA Flow Diagram



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Appendix 4. Summary of articles

Author(s)	Year	Study location	Study aim
Abdul-Razzak et al. (17)	2014	Hamilton, Ontario and Calgary, Alberta (3 Canadian academic tertiary hospitals)	Understand patient perspectives on physician behaviours during EOL communication; the results are intended to provide practical knowledge and insights that can be incorporated into a physician's clinical practice
Abdul-Razzak et al. (18)	2016	Hamilton, Ontario and Calgary, Alberta (3 academic tertiary hospitals)	Understand patient perspectives on physician behaviours that help or hinder EOL communication
Abelson et al. (19)	2018	Ontario	Capture citizens' perspectives about mammography screening and how to best support informed decision making within the context of organized screening programs
Abelson et al. (20)	2018	Ontario	Address gaps in current evidence on mammography/questions about the net benefits of organized screening; women's current screening practices; and knowledge, attitudes and values toward screening to support informed decision making in this area
Adams et al. (21)	2013	Ontario, The Hospital for Sick Children	Understand the usefulness and preferred content of comprehensive care plans by exploring the perceptions of parents and HCPs of children with medical complexity
Albrecht et al. (22)	2017	Edmonton, Alberta (specialized pediatric ED)	Describe caregivers' experiences of pediatric acute gastroenteritis and identify their information needs, preferences and priorities
Aragon et al. (23)	2013	British Columbia	Understand the perspectives of women, HCPs and support persons regarding the use of birth plans

Author(s)	Year	Study location	Study aim
Ashworth (24)	2018	Canada	Identify the factors affecting Aboriginal peoples' attitudes toward and experiences in accessing oral health services in Canada in an attempt to contribute to the discussion of how oral health professionals can better support this population's oral health
Aston et al. (25)	2014	Canada	Better understand the personal, social and institutional hospital experiences of children with IDs, their parents and the nurses who cared for them (focus on relationships and how participants interacted with others in the hospital, including HCPs, clients and family members)
Bainbridge et al. (26)	2018	Ontario (22 hospices)	Capture the EOL care experiences across various settings from bereaved caregivers of individuals who died in residential hospice
Bainbridge et al. (27)	2017	Ontario	Assess the usefulness of qualitative survey data for quality improvement
Ballantyne et al. (28)	2015	Calgary, Alberta and Hamilton, Ontario	Investigate the barriers to and facilitators of attendance at Canadian neonatal follow-up programs, taking into consideration both mothers' and HCPs' perspectives
Banner et al. (29)	2015	British Columbia (2 rural hospitals)	Examine the qualitative findings from a 16-month mixed methods randomized controlled trial examining the impact of a virtual cardiac rehabilitation program
Barbita and Neves-Silva (30)	2017	Ontario	Highlight patient and caregiver perspectives on telehomecare
Barnieh et al. (31)	2014	Atlantic, British Columbia, Ontario, The Prairies, Quebec, The Territories	Synthesize the views of Canadian patients on or nearing dialysis and those who care for them (in order to support treatment decision making, enhance communication, address psychosocial well-being and improve patient satisfaction)
Barry (32)	2018	Burnaby and Surrey, British Columbia	Determine patients' perception of the efficacy, safety and quality of NHPs and characterize NHP use
Bauer et al. (33)	2014	Ontario	Document the extent of trans-specific negative ED experiences and of ED avoidance
Baumbusch et al. (34)	2019	Western and central Canada (British Columbia, Ontario, Manitoba, Quebec)	Explore the experiences of parents of children with rare diseases navigating the health system
Benoit et al. (35)	2016	St. John's, Newfoundland; Montreal, Quebec; Kitchener (including Waterloo and Cambridge), Ontario; Wood Buffalo (Fort McMurray) and Calgary, Alberta; Victoria, British Columbia	Examine unmet healthcare needs of adult sex workers and investigate whether their reasons for not accessing healthcare are different from those of other Canadians

Author(s)	Year	Study location	Study aim
Blanchette et al. (36)	2014	Toronto, Ontario (Princess Margaret Cancer Centre)	Describe patients' knowledge, attitudes and expectations toward genomic testing in cancer
Bombard et al. (37)	2014	Ontario	Explore citizens' informed and reasoned values and expectations of personalized medicine, a timely yet novel genomics policy issue
Brazil et al. (38)	2013	Sudbury, Sault Ste. Marie, North Bay and Timmins, Ontario	Compare the experiences of rural and urban family caregivers providing EOL care
Brownlie et al. (39)	2017	Ontario	Enhance youth services addressing substance use in Ontario
Burge et al. (40)	2014	Nova Scotia	Examine the relationship between the location where the decedent received the majority of care during the last 30 days of life and the informant's perception of the extent of unmet need experienced
Bungay (41)	2013	Western Canadian inner-city neighbourhood	Examine women's experiences of and decision making about engagement with the healthcare system, and analyze these experiences within a wider socio-political context to understand how these contexts shape healthcare and opportunities for health among street-involved women
Brunings et al. (42)	2013	British Columbia (rural/small urban areas)	Explore and describe patients' perspectives on quality of hepatitis C virus healthcare in rural viral hepatitis clinics in British Columbia
Bye and Aston (43)	2016	Nova Scotia	Share one mother's (child with ID) personal story about her journey through the Canadian healthcare system in Nova Scotia
Cable-Williams and Wilson (44)	2017	Ontario (3 LTC facilities)	Identify how four cultural influences in Canadian LTC facilities affect the awareness of impending death and initiation of palliative care for residents 85 years old and older
Carusone et al. (45)	2017	Toronto, Ontario (Casey House)	Identify gaps in hospital discharge practices and design interventions to improve outcomes
Clark et al. (46)	2013	Kamloops, British Columbia	Determine how urban Aboriginal youth identify their health needs within a culturally centred model of health and wellness; create new knowledge and research capacity by and with urban Aboriginal youth and urban Aboriginal HCPs
Coffey et al. (47)	2017	Ontario	Explore parent preferences around disclosure and views on including children
Colpitts and Gahagan (48)	2016	Truro (rural) and Halifax (urban), Nova Scotia	Offer an overview of the findings of a scoping review and community consultations aimed at developing strengths-based approaches to understanding LGBTQ pathways to health in Nova Scotia
Corosky and Blystad (49)	2016	Arviat, Nunavut	Generate youth-focused evidence on experiences of SRHR relating to access to care in Arviat in order to better inform locally authored interventions geared toward improving youth SRHR

Author(s)	Year	Study location	Study aim
Dale et al. (50)	2017	Vancouver General Hospital, British Columbia; The Hospital for Sick Children and the Children's Hospital of Eastern Ontario, Ontario	Obtain a better understanding of the needs of Canadian mechanical VAAs to provide transition services responsive to VAAs' and caregiver-identified needs
Dalpe et al. (51)	2017	Quebec	Analyze perspectives of women and decision makers about genetic testing and insurance as well as general insurability questions in the context of a risk stratification approach to breast cancer screening and prevention
Davison and Jhangri (52)	2014	Canada	Investigate the knowledge and attitudes of First Nation adults to organ donation and transplant
Denison et al. (53)	2014	Northern region of a western Canadian province (2 urban Aboriginal health centres)	Report findings from a study examining the impact of the threat of child removal on Aboriginal women's experiences accessing healthcare services
Dhaliwal et al. (54)	2017	Pediatric weight centres in Edmonton, Alberta; Shapedown and Vancouver, British Columbia; and Hamilton, Ontario	Explore parents' reasons for discontinuing tertiary-level care for pediatric weight management
Digel Vandyk et al. (55)	2018	Ontario	Explore the experiences of persons who frequently visit the ED for mental health-related reasons
Donnelly et al. (56)	2016	Vancouver, British Columbia	Explore the roots of stigma and its impact on health services and resource seeking as experienced by HIV-infected members of marginalized communities in Vancouver
Downie (57)	2017	Ontario	Explore personal difficulties in the patient experience with recurrent <i>C. difficile</i> infection in Canada
Du Mont et al. (58)	2017	Ontario	Explore the presentation, socio-demographic, assault, assault and service use characteristics of Indigenous women compared to non-Indigenous adult and adolescent women
Dubé et al. (59)	2018	Canada	Explore vaccine hesitancy among Canadian parents and examine factors associated with a parent's intention to vaccinate his/her child
Duhoux et al. (60)	2017	Toronto and Ottawa, Ontario; Vancouver, British Columbia	Determine the reasons contributing to having, and examine the determinants of UMHCNs among adults who are homeless or vulnerably housed in three Canadian cities
Durocher et al. (61)	2017	Canadian university-affiliated teaching hospital	Examine how the intersection of various social and political influences shapes discharge planning and rehabilitation practices in ways that may not meet the espoused aims of rehabilitation programs or the preferences of older adults and their families
Duthie et al. (62)	2017	Montreal, Quebec	Explore cancer patients' experience with multimodal treatments – that is, treatments for multiple chronic conditions as well as issues related to navigating the healthcare system

Author(s)	Year	Study location	Study aim
Dyason et al. (63)	2015	Calgary, Alberta	Describe who participates in advance care planning and decision making for patients in LTC and designated assisted living
Easley et al. (64)	2013	Canada (majority from Ontario)	Describe the survivorship experience of young adult patients with thyroid cancer
Easley et al. (65)	2016	Canada	Explore patient perspectives on and experiences with the coordination and continuity of cancer care
Etchegary et al. (66)	2015	St. John's and Grand Falls-Windsor, Newfoundland	Provide information about research programs in the province, provide the public with a space for asking questions and solicit public opinions about genetic testing and research
Farjou et al. (67)	2014	Canada (3 pediatric oncology centres)	Describe the healthcare experiences of teenagers with cancer
Fitch et al. (68)	2013	Canada	Explore the perspectives of cancer patients concerning the conversations that happen about sexuality following a cancer diagnosis in daily practice
Floyd and Sakellariou (69)	2017	Vancouver, British Columbia	Show lived experiences of refugees and the strategies these people might develop in their efforts to access healthcare
Freeman et al. (70)	2013	Southwestern Ontario	Examine the healthcare-related experiences of individuals who have lost their family physicians
Furlotte et al. (71)	2016	Ontario, British Columbia and Alberta	Describe expectations, concerns and needs regarding LTC homes and homecare services of 12 older lesbian and gay couples living in Canada
Gauthier-Boudreault et al. (72)	2017	Eastern Townships, Montérégie, Mauricie and Centre-du-Québec, Quebec	Document the needs of parents and young adults with profound ID during and after the transition to adulthood by exploring their transitioning experience and factors that influenced it
Gemmell et al. (73)	2017	Southern Manitoba	Assess Hutterites' views of genetic counselling services; compare their views to those obtained in a study of rural Midwestern US residents
Gervais et al. (74)	2016	Quebec	Explore where fathers fit in the actions of perinatal HCPs and what the needs of the father are
Ghazzawi et al. (75)	2016	Ontario (stroke rehabilitation facility)	Fully understand the dynamic complexity of the stroke rehabilitation system and how to better integrate in-patient and community settings to support continuity of care
Goel et al. (76)	2013	Ontario	Describe the experiences of a group of new immigrants and caregivers of new immigrants who were subject to the 3-month waiting period for the Ontario Health Insurance Plan and needed to access healthcare services during that time
Goodman et al. (77)	2017	Vancouver, British Columbia (inner city)	Explore the healthcare experiences of Aboriginal peoples who use illicit drugs and/or illicit alcohol living in Vancouver's inner city
Graham et al. (78)	2013	Northern British Columbia	Explore the meaning of a healthy lifestyle for this population and the barriers they experience to healthy living

Author(s)	Year	Study location	Study aim
Green and Vandall-Walker (79)	2016	Northwestern Ontario	Explore patients' needs and experiences with receiving tube feeding
Green et al. (80)	2016	Southwestern Ontario	Describe the primary care experience of adults in custody in a provincial correctional facility in Ontario in the 12 months prior to admission
Gregory et al. (81)	2013	Newfoundland (large tertiary care hospital)	Explore patients' perceptions of waiting for bariatric surgery, the meaning and experience of waiting and the psychosocial and behavioural impact of waiting for treatment and identify HCP and health system supportive measures that could potentially improve the waiting experience
Grigorovich (82)	2015	Ontario	Examine experiences outside of PHC contexts or the perspectives of older healthcare users
Grigorovich (83)	2015	Ontario	Deepen existing knowledge by demonstrating how chronic illness and sexual minority status can further exacerbate the consequences of rationing public care
Griscti et al. (84)	2016	Nova Scotia (regional hospital)	Understand the experiences of chronically ill patients and registered nurses in negotiating patient care in hospital
Grohmann et al. (85)	2017	Ontario (diabetes education programs in 11 primary care sites)	Explore patients' perspectives on care received from diabetes education teams (a registered nurse and a registered dietitian) integrated into primary care
Gucciardi et al. (86)	2015	Southern Ontario	Explore the implementation processes of integrating specialized diabetes teams into primary care in southern Ontario
Guilcher et al. (87)	2013	Northern Ontario	Explore the experiences of participants in a chronic disease self-management program via telehealth (tele-CDSMP) and identify facilitators and barriers to inform future tele-CDSMP delivery models
Gutman et al. (88)	2018	Canada	Describe the perspectives of children with CKD and their parents with regard to communication and decision making
Hammond et al. (89)	2017	Canada (4 First Nations communities)	Explore survivorship experiences of First Nations women with cancer and their caregivers; drawing from a larger data set on survivorship, identify several major barriers to cancer communication and support in First Nations communities
Han and Olliffe (90)	2015	Greater Vancouver Area, British Columbia	Describe Korean-Canadian immigrants' help seeking and self-management for their suicidal behaviour
Harrington et al. (91)	2013	Ontario	Examine the factors associated with difficulty accessing specialist services and the reasons why particular subpopulation groups report experiencing difficulties
Harrison et al. (92)	2015	Calgary, Alberta (multidisciplinary CKD clinic)	Understand perceptions of CKD patients about ePHRs and describe characteristics associated with their expressed intent to use an ePHR

Author(s)	Year	Study location	Study aim
Hayeems et al. (93)	2015	Greater Toronto Area, Ontario and Montreal, Quebec	Investigate Canadian public expectations and values regarding the types of conditions that should be included in newborn screening and whether parents should provide consent
Heaman, et al. (94)	2015	Winnipeg (inner city), Manitoba	Explore the perceptions of women living in inner-city Winnipeg about barriers, facilitators and motivators related to their use of prenatal care
Heard et al. (95)	2018	Manitoba	Describe the pediatric transgender population accessing healthcare through the Manitoba Gender Dysphoria Assessment and Action for Youth (GDAAY) program and report youth's experiences accessing healthcare in Manitoba
Henderson et al. (96)	2018	Alberta	Optimize HPV vaccination rates and thereby decrease the burden of HPV-related illness, including high-morbidity surgical procedures and chemoradiotherapy
Herron and Skinner (97)	2013	Peterborough, Ontario	Understand the multifaceted ways in which emotions shape and are shaped by experiences of aging and caring at the interpersonal, household and community scales
Heyland et al. (98)	2017	Canada (12 acute care hospitals)	Explore the internal consistency of patients' (or their family members') stated values and the relationship between these values and expressed preferences
Higginbottom et al. (99)	2015	Alberta	Identify the nature of communication difficulties in maternity services from the perspectives of immigrant women, HCPs and social service providers in a small city in southern Alberta
Higginbottom et al. (100)	2016	Canadian province (metropolitan city and rural town)	(1) Generate new understanding of the processes that perpetuate immigrant disadvantages in maternity healthcare and (2) devise potential interventions that might improve maternity experiences and outcomes for immigrant women in Canada
Hodgetts et al. (101)	2013	Alberta	Increase knowledge and understanding of how families with children with autism spectrum disorder experience family-centred care in Alberta
Hole et al. (102)	2015	Interior of British Columbia	Examine practices within one hospital to see whether and how cultural safety for Aboriginal patients could be improved
Holroyd-Leduc et al. (103)	2017	Alberta	Review current research evidence and conduct multistakeholder dialogue on the potential gaps in, facilitators of and barriers to the provision of caregiver supports
Hulme et al. (104)	2016	Central Toronto, Ontario	Better understand Chinese and South Asian immigrants' – the largest and most underscreened immigrant groups according to national and provincial statistics – perceptions of breast and cervical cancer screening
Huynh (105)	2018	Manitoba	Explore youth's perceptions of diabetes management
Jacklin et al. (106)	2017	British Columbia, Alberta, Ontario	Examine the healthcare experiences of Indigenous people with type 2 diabetes to understand how such determinants are embodied and enacted during clinical encounters

Author(s)	Year	Study location	Study aim
James-Abra et al. (107)	2015	Ontario	Better understand the experiences of trans persons in healthcare
Jessri et al. (108)	2013	Edmonton, Alberta	Explore from Middle Eastern mothers' perspectives the experience of breastfeeding and their perceptions of attributes of the healthcare system, community and society on their feeding decisions after migration to Canada
Kalocsai et al. (109)	2018	Toronto, Ontario	Offer a novel analysis of the complexities involved in building positive family-provider relationships in the intensive care unit through the consideration of not only communication but also other important aspects of family-provider interactions, including family integration, collaboration and empowerment
Katz et al. (110)	2014	Quebec	Understand how patients wish to communicate or to be communicated with (looking into e-patients)
Keller and Meaney (111)	2017	Eastern Canada (supraregional hospital)	Examine patient experiences of hospital-based discharge preparation for referral for follow-up homecare services; identify aspects of discharge preparation that will assist patients with their transition from hospital-based care to home-based follow-up care
Kelley et al. (112)	2018	Ontario and Manitoba	Create palliative care programs for First Nations communities based on participatory action research (PAR)
Kelly et al. (113)	2014	Newfoundland and Labrador	Explore the public's knowledge and attitudes regarding the role of the community pharmacist and determine their likelihood of using expanded pharmacist services
Kingston et al. (114)	2015	Alberta	Describe women's reported willingness to disclose mental health concerns during screening and factors associated with this
Kirst et al. (115)	2017	Ontario	Examine Ontarians' support and predictors for targeted health equity interventions versus universal interventions
Koehn et al. (116)	2016	British Columbia	Investigate how older residents in assisted living facilities experience quality of life and what role (if any) the physical environment has in this
Kowal et al. (117)	2015	Edmonton, Alberta	Understand information-gathering and decision-making processes of immigrant mothers for scheduled childhood vaccines, vaccination during pregnancy, seasonal flu and pandemic vaccination
Kuluski et al. (118)	2013	Ontario	Explore the types of goals that were important for older persons with multimorbidities from the perspectives of patients, their caregivers and physicians; compare goals across each patient, caregiver and physician triad to determine alignment
Kuluski et al. (119)	2013	Continuing care/rehabilitation hospital in Canada	Investigate what is important in care delivery from the perspective of hospital in-patients with complex chronic disease, a currently understudied population
Kuluski et al. (120)	2017	Northwestern Ontario	Understand the hospital experience of carers (e.g., family members) of patients with alternate levels of care (delayed hospital discharge) and cognitive impairment who were waiting for LTC from the hospital
Lafortune et al. (121)	2015	Mid-sized urban and rural communities in Ontario	Develop system improvements to community-based primary healthcare (CBPHC)

Author(s)	Year	Study location	Study aim
Law et al. (122)	2015	Toronto, Ontario	Understand LGBTQ patients' perceptions of their experiences related to disclosure of sexual identity to their primary care provider
Le Dorze et al. (123)	2014	Montreal, Quebec	Explore the factors that facilitate or hinder participation according to people who live with aphasia
Lee et al. (124)	2014	Toronto	Explore the experiences of immigrant Chinese women accessing maternity care and using maternity health services in Canada
Lind et al. (125)	2014	Calgary, Alberta	Understand parents' perspectives on the acceptability of adding an annual influenza immunization to the immunization program that is currently delivered in Alberta schools and obtained suggestions for structuring such a program
Lindsay et al. (126)	2016	Greater Toronto Area, Ontario	Explore gender and sex differences in experiences of transitioning to adult healthcare among young adults with acquired brain injury who take part in a coordinated model of transitional care
Liu and McDaniel (127)	2015	Greater Toronto Area, Ontario	Explore the experiences of Chinese family caregivers, including the challenges, needs and service gaps encountered, while providing care for immigrant seniors with heart disease and stroke
Logie et al. (128)	2016	Toronto, Ontario	Explore experiences of social support group participation among LGBTQ African and Caribbean newcomers and refugees in an urban Canadian city
Loignon et al. (129)	2015	Quebec	Explore barriers to responsive care for undeserved persons (poverty) with a view to developing equity-focused primary care
Longard et al. (130)	2016	Eastern Canada (tertiary care centre)	Understand parents' experiences of managing their child's postoperative pain at home
Lukewich et al. (131)	2015	Across Canada	Describe chronic pain self-management from the perspective of individuals living with chronic pain in the context of primary care nursing
Lum et al. (132)	2016	Greater Niagara Region, Ontario	Examine the lived experiences of immigrants living in a small urban centre with regard to the PHC system
MacDougall et al. (133)	2014	Ontario	Understand the perspectives of Ontario parents regarding the advantages and disadvantages of adding influenza immunization to the currently existing Ontario school-based immunization programs
MacRae (134)	2015	Nova Scotia, Canada	Investigate older women's experiences with and views of physicians
MacRae (135)	2016	Nova Scotia	Investigate older women's perceptions of their interactions with physicians and identify what older women want from physicians
Marchand et al. (136)	2016	Canada (2012 Canadian Community Health Survey-Mental Health data)	Determine, using data from a nationally representative survey, the Canadian Community Health Survey-Mental Health, the prevalence of perceived prejudice by HCPs and its relationship with mental disorders

Author(s)	Year	Study location	Study aim
Marsh et al. (137)	2014	Toronto, Ontario	Determine patient satisfaction and patients' preferences for follow-up method (Web-based or in-person) after total joint arthroplasty
Massé and Déry (138)	2014	Quebec	(1) Analyze the receptiveness of the population of French-speaking Quebecers to certain ethical principles promoted by public health authorities during the A(H1N1) vaccination campaign; (2) add to the limited number of empirical studies that examine the population's perception of ethical values
McCloskey et al. (139)	2015	New Brunswick	Investigate the experiences and opinions of those who must wait in hospital for alternate services
McIntyre et al. (140)	2014	London, Ontario	Explore the self-perceived influences among older adults in deciding whether to take the seasonal influenza vaccine
Melhem and Daneault (141)	2017	Montreal, Quebec	Explore the needs of cancer patients in palliative care and determine how care providers, including family physicians, could meet these needs more fully
Mfofo-M'Carthy (142)	2014	Toronto, Ontario	Present findings from research on the lived experiences of individuals from ethnic minority backgrounds who have been the subject of a community treatment order in Toronto and their perceptions of its impact on their lives
Miedema et al. (143)	2013	New Brunswick and Greater Toronto Area, Ontario	Explore the impact geography, specifically living in rural areas, has had on access to healthcare services for young adult cancer survivors
Molino and Fletcher (144)	2018	Southern Ontario	Examine the caregiving responsibilities of mothers from southern Ontario during the time from diagnosis to after their children's pediatric cancer treatment (how mothers provide care during child's treatment)
Montague et al. (145)	2017	Canada (2016 Health Care in Canada Survey)	Define stakeholders' perceptions on all contemporary EOL options
Moore et al. (146)	2017	Canada	Develop an approach for anticipated extremely preterm birth involving consultations with parents and healthcare providers
Moravac (147)	2018	Toronto, Ontario	Investigate the factors influencing the decision-making processes regarding breast and cervical cancer screening for women in homeless shelters and women with severe mental health issues
Morgan et al. (148)	2014	Saskatoon, Saskatchewan (Rural and Remote Memory Clinic)	Explore the experiences of rural family caregivers in the period leading up to a diagnostic assessment of dementia at a Canadian memory clinic for their family member, as well as six months after diagnosis
Murray-Davis et al. (149)	2014	Ontario	Understand how pregnant women in Ontario decide to give birth at home or hospital and why they choose one birthplace over another (sample drawn from 85 midwifery practices in Ontario across six Ontario geographic regions determined by the Association of Ontario Midwives)
Nekolaichuk et al. (150)	2013	Canada (2 unspecified hospital sites)	Understand patients' experiences of attending an individual psycho-oncology counselling service in a comprehensive cancer centre in Canada

Author(s)	Year	Study location	Study aim
Nelson and Wilson (151)	2018	Prince George, British Columbia	Examine perceived barriers to healthcare access for urban Indigenous people in light of how colonialism impacts Indigenous peoples in their everyday lives
Nguyen et al. (152)	2016	Ontario	Explore self-management from the perspectives of youth, parents and HCPs in transition to adult healthcare
Nicholas et al. (153)	2013	3 Canadian cities: Fredericton, New Brunswick; Edmonton, Alberta; Saskatoon, Saskatchewan	Examine parents' interest and perspectives related to online diabetes resources
Nicholas et al. (154)	2016	Large city in western Canada	Examine experiences of street-involved youth who use hospital EDs and factors affecting ED use
Nicholas et al. (155)	2016	2 Canadian tertiary-level pediatric hospitals	Investigate perspectives of ED care for children with ASD through interviews with children with ASD and parents of children with ASD
Oosterveer and Young (156)	2015	Northwest Territories	Document and analyze the challenges in accessing PHC services by Indigenous people in remote communities in Canada's Northwest Territories from the perspective of users and providers of PHC services
Pedersen et al. (157)	2014	Winnipeg, Manitoba	Delineate the role of the oncology patient navigator, drawing from the experiences and descriptions of younger women with breast cancer
Pedersen et al. (158)	2015	Vancouver, British Columbia	Assess attitudes toward sharing of personal health information through a provincial EHR
Perez et al. (159)	2016	4 Canadian cities: Edmonton, Alberta; Hamilton, Ontario; Montreal, Quebec; Vancouver, British Columbia	Explore reasons for and facilitators of enrolment in pediatric weight management from the parental perspective
Pighini et al. (160)	2014	Western Canada	Examine the experiences of parents of children deemed at risk for developmental delays or disabilities who had received early intervention services (birth to age 3) in a large urban location in order to understand what works in early interventions
Pike et al. (161)	2013	Newfoundland and Labrador	Gain a more thorough understanding of why parents choose to give their children NHPs, parents' sources of information about NHPs and the extent of disclosure and conversation with family doctors about the use of NHPs
Pitt et al. (162)	2016	Montreal, Quebec (food bank)	Identify low-income working families' health challenges and understand their barriers and facilitators to navigating those challenges
Ploeg et al. (163)	2017	Hamilton, Ontario and Edmonton, Alberta	Explore the experience of managing multiple chronic conditions in the community from the perspectives of older adults with multiple chronic conditions, family caregivers and HCPs working in a variety of settings
Potestio et al. (164)	2015	Public venue in Calgary, Alberta	Engage the public to understand how to improve the care of critically ill patients

Author(s)	Year	Study location	Study aim
Premji et al. (165)	2017	Calgary, Alberta	Explore mothers' experience of caring for their late preterm infants in the community
Prorok et al. (166)	2017	Ontario (Kingston, Bancroft, Belleville)	Examine the PHC experience of persons with dementia and their caregivers in Ontario
Rice and Webster (167)	2017	Northern Ontario	Examine the challenges involved in providing and receiving primary care for complex chronic conditions in two remote resource communities in northern Ontario
Rink et al. (168)	2017	Montreal, Quebec	(1) Report the narrative experiences of refugee claimant families who were denied healthcare services in Montreal following June 2012 when the Government of Canada severely restricted the scope of the Interim Federal Health Program, which had hitherto provided coverage for the healthcare needs of refugee claimants; (2) describe the predominant barriers to accessing healthcare services and understanding their impact using thematic analysis; and (3) derive concrete recommendations for child HCPs to improve access to care for refugee claimant children
Roberge et al. (169)	2016	Quebec (3 primary care clinics)	Explore the perceived needs of, barriers to and facilitators of the delivery of mental healthcare for patients with coexisting common mental disorders and chronic diseases in primary care from the clinician and patient perspectives
Robinson et al. (170)	2017	British Columbia	Describe the experiences of bereaved family caregivers whose terminally ill family members with advanced cancer were successful in achieving a desired home death
Rochette et al. (171)	2014	Montreal, Quebec	Document the ethical issues regarding the systematic inclusion of relatives as clients in the post-stroke rehabilitation process
Ross et al. (172)	2018	Ontario	Explore the service experiences of low-income LGBTQ people in accessing mental healthcare
Roulston (173)	2018	Edmonton, Alberta; Toronto, Ontario; Montreal, Quebec	Understand the steps that need to be taken to ensure that Canadians can access high-quality palliative care services as part of Canada's universal healthcare model
Royall et al. (174)	2017	Hamilton, Ontario	Capture insights for the development of new obesity management services from both providers and patients in a progressive, city-wide organization
Saroa et al. (175)	2018	Alberta (2 large cancer centres), English speaking	Determine the information needs and preferences of patients who had HPV-associated head and neck cancer and were aged 18–65 years in the post-treatment phase of recovery
Schein and Travers (176)	2017	Ontario	Identify the perspectives of trans men who have sex with men on barriers to and facilitators of HIV and STI testing
Schneeberg et al. (177)	2014	8 vaccination centres across Canada (British Columbia, Manitoba, Ontario, Quebec, Nova Scotia)	Improve understanding of factors influencing pneumococcal vaccination among older adults to improve vaccine uptake

Author(s)	Year	Study location	Study aim
Shaw et al. (178)	2015	Calgary, Alberta	Explore patient perspectives on the responsiveness of the Alex Seniors Clinic (a clinic that offers a patient-centred multidisciplinary care team model for primary care) to their stated health needs
Simon et al. (179)	2015	12 acute care hospitals in Canada	Explore seriously ill older hospitalized patients' and their family members' perspectives on the barriers to and facilitators of advance care planning
Sinclair et al. (180)	2015	Bone marrow transplant clinic of a large urban outpatient cancer care centre in western Canada (Calgary, Alberta)	Better understand the importance and efficacy of addressing spiritual issues within an interdisciplinary bone marrow transplant clinic from the perspectives of patients and HCPs
Smith-Carrier et al. (181)	2017	Toronto, Ontario	Explore unpaid caregivers' perceptions of and experiences with home-based primary care programs in Toronto
Stacey et al. (182)	2016	Nova Scotia, Ontario, Quebec (3 ambulatory cancer programs)	Assess patient and family member experiences with telephone cancer treatment symptom support
Stewart et al. (183)	2013	Canada (specific location unspecified)	Assess the health and healthcare inequities experienced by affected children and their parents
Summerhurst et al. (184)	2017	London, Ontario	Understand adolescent perceptions of what was most helpful and most challenging about mental health treatment for mood and/or anxiety disorders
Tait Neufeld (185)	2014	Winnipeg, Manitoba	Describe the experiences of First Nations and Metis women with gestational diabetes mellitus
Tamaian et al. (186)	2017	Canada	Qualitatively assess patients' negative experiences with the medical system that may lead to feelings of institutional betrayal
Taneja et al. (187)	2019	London, Ontario (mid-sized Canadian urban community)	Describe how lay people understand and make decisions for life-sustaining interventions when engaging in advance care planning
Thronsdon et al. (188)	2016	Winnipeg, Manitoba	Explore the factors that influence the perceptions and health behaviours of patients after elective ad hoc percutaneous coronary interventions
Tobon et al. (189)	2015	1 of 5 children's mental health agencies in Ontario, Canada	Examine continuity of care in children's mental healthcare
Tomasone et al. (190)	2017	All of Canada, including Quebec (Quebec City)	Explore factors related to service adoption among non-users of counselling services offered to facilitate physical activity participation among persons with physical disabilities and the barriers to and facilitators of maintaining service participation among adopters
Topf et al. (191)	2013	Western Canada	Gain a better understanding of the experiences of family caregivers when circumstances prevented a desired home death for a family member with advanced cancer

Author(s)	Year	Study location	Study aim
Torti et al. (192)	2017	Alberta, Canada	Explore patients' perspectives on the role of primary care in obesity management and their experience with existing resources, with a view to developing an improved understanding of this perspective and more effective management strategies
Tremblay et al. (193)	2016	4 Canadian tertiary-level, multidisciplinary weight management clinics (Edmonton, Alberta; Shapedown, British Columbia; Hamilton, Ontario; Montreal, Quebec)	Characterize parents' recommendations for enhancing tertiary-level health services for managing pediatric obesity in Canada
Turcotte et al. (194)	2015	Quebec	Explore the participation needs of older adults with disabilities as perceived by the older adults themselves, their caregivers and HCPs
Vahabi and Lofters (195)	2016	Greater Toronto Area, Ontario	Explore Muslim immigrant women's views on cervical cancer screening and the acceptability of HPV self-sampling
Vaillancourt et al. (196)	2017	Toronto (St. Michael's Hospital) and Ottawa (Ottawa Montfort Hospital)	Define outcomes of ED care that are valued by patients discharged from the ED, with the goal of informing the development of a patient-reported outcome measure for ED care
Vermeir et al. (197)	2018	Nova Scotia	Explore the barriers trans adults encounter when pursuing primary and emergency care in Nova Scotia
Viveiros and Darling (198)	2018	Ottawa, Ontario	Explore what factors midwifery recipients perceive as preventing or facilitating access to mental healthcare in the perinatal period
Wagner et al. (199)	2016	"A multicultural Canadian city" (likely Toronto)	Examine the attitudes and beliefs of HCPs toward people living with HIV through the use of focus groups
Wagner et al. (200)	2017	Quebec	Explore young adults' initiation of substance misuse treatment
Wang and Kwak (201)	2015	Toronto, Ontario	Analyze the healthcare-seeking behaviour of South Korean immigrants in Toronto and how transnationalism shapes post-migration health and health management strategies
Watt et al. (202)	2013	Canada (6 Canadian pediatric oncology centres)	Describe Chinese and South Asian immigrant parents' experiences of family-centred care in pediatric oncology settings in Canada
Webster et al. (203)	2015	Ontario	Provide new insights on the perspectives, needs and preferences of patients with complex health and social needs
Weingarten et al. (204)	2014	Edmonton, Alberta	Examine children's perspectives of and satisfaction with their pain management in the ED
Wetterlin et al. (205)	2014	Canada-wide	Explore youth experiences with traditional and online mental health resources and investigate youth expectations for mental health websites

Author(s)	Year	Study location	Study aim
Wilson et al. (206)	2013	Alberta	Determine the public opinion on the topic of death hastening and EOL plans
Wood et al. (207)	2016	Winnipeg, Manitoba	Explore women's experiences of choosing to plan a birth at an out-of-hospital birth centre, as well as how women make the choice to plan for an out-of-hospital birth and the meaning that they ascribe to this decision-making process
Woodgate et al. (208)	2017	Manitoba	Examine the experiences of access to PHC by African immigrant and refugee families
Zheng et al. (211)	2018	Hamilton, Ontario (McMaster Children's Hospital PICU)	To understand patient, family caregiver and clinician impressions of early mobilization and the use of in-bed cycling as a method of mobilization

CKD = chronic kidney disease; ED = emergency department; EOL = end-of-life; ePHR = electronic personal health record; HCP = healthcare provider; HIV = human immunodeficiency virus; HPV = human papillomavirus; ID = intellectual disability; LTC = long-term care; NHP = natural health product; PHC = primary healthcare; PICU = pediatric intensive care unit; SRHR = sexual and reproductive health and rights; STI = sexually transmitted infection; UMHCN = unmet healthcare need; VAA = ventilator-assisted adolescent.