Rapid Synthesis

Determining the Features of Person-centred Models of Care that Patients Value

29 March 2018

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Rapid Synthesis:
Determining the Features of Person-centred Models of Care that Patients Value

30-day response

29 March 2018

McMaster Health Forum

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

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Timeline

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

KEY MESSAGES

Question
- What features of person-centred models of care do patients, families and caregivers value?

Why the issue is important
- Providing care that is person-centred is a key goal for provincial and territorial health systems in Canada, which is demonstrated by a number of provinces across Canada having recently put forward legislation or key strategies working towards this aim.
- While previous and ongoing reforms have focused on improving the health of British Colombians while enhancing patient experience, data from surveys conducted in British Columbia (where this rapid synthesis was requested from) show that there remains room for improvement.
- The prioritization of person-centred care is therefore critical for transforming the health system into one that puts people at the centre of care, and in turn helps to work towards achieving the goals set out in the triple aim outcomes (i.e., enhancing patient experience, improving the health of British Columbians and reducing costs).
- However, to ensure that any new delivery models reflect the needs and preferences of patients, it is also important to identify what features of person-centred care are valued by patients, their families and their caregivers.

What we found
- We identified 21 relevant documents that discussed the features of person-centred models of care valued by patients, families and caregivers, including 17 systematic reviews, two non-systematic reviews (a critical synthesis and a review article), and two citizen panel summaries.
- Findings from these documents were categorized according to the ten pillars of College of Family Physicians of Canada's patient-centred medical home model and summarized in terms of general findings about the pillar and in relation to one or more of the six main health-system sectors (i.e. home- and community-care, primary care, specialty care, long-term care, rehabilitation care, and public health).
- There was general consensus across the included documents that patients, family members and caregivers valued three key features of person-centred care: 1) strong communication skills among healthcare professionals to facilitate shared decision-making and positive patient-provider relationships; 2) having some degree of control over decisions about their health and their treatment plan; and 3) being treated as an individual with unique preferences and needs, rather than simply as a patient with a disease.
- In addition, patients regarded team-based primary care as especially desirable due to perceived benefits of better collaboration among care providers, and supported nurse practitioners taking on a greater role in delivering care, either as a primary-care provider or as someone patients can easily contact to ask questions without needing to make an appointment.
- Some of the included documents also collected the opinions of patients, family members and caregivers about specific interventions that they think could be used to enhance person-centred care at the system, organizational and/or provider level, including providers educating patients on their illness and implementing the patient-centred medical-home model.
- Finally, one systematic review indicated that healthcare providers found it difficult to deliver effective family-centred care within a pediatric critical care setting due to a lack of knowledge, skills or available resources.
- However, a non-systematic review found that using decision supports (e.g., research summaries, guidelines that incorporate evidence about patient preferences, and mentorship and training opportunities), facilitating a culture of continuous improvement and prioritizing the triple aim outcomes act as facilitators for the integration of patient values into care delivery.

QUESTION

What features of person-centred models of care do patients, families and caregivers value?

WHY THE ISSUE IS IMPORTANT

Providing care that is person-centred is a key goal for provincial and territorial health systems in Canada.(1) This is demonstrated by a number of provinces having recently put forward legislation or key strategies working towards this aim. For example, in 2014, the Ministry of Health of British Columbia (where this rapid synthesis was requested from) released their strategic plan, *Setting Priorities for the B.C. Health System*, which posited that the province's health system needed improvement with respect to meeting the needs of key patient populations.(2) The plan listed providing patient-centred care as one of the eight priorities for the healthcare system and reiterated its importance in the 2015 report - *B.C. Health System Strategy Implementation*.(3)

Indeed, data from recent surveys conducted in British Columbia support this prioritization and show that there remains some room for improvement towards making care more patient centred. Specifically, a recent survey on the acute inpatient care in British Columbia found that many aspects of patient experience, including the continuity of care and information sharing, remain unsatisfactory to patients.(4) In addition, while 64% of seniors in British Columbia report that they were very or completely satisfied with the quality of healthcare received in the past 12 months, this figure is below both the Canadian average (67%) and the international average of 11 Commonwealth countries (76%).(5)

In general, person-centred care engages individuals as partners to ensure that the care they receive considers

individual preferences, needs and values.(6) The patient-centred medical-home model developed by the College of Family Physicians of Canada (CFPC) provides a framework to deliver such care. The model has 10 pillars:
1) providing patient-centred care;
2) providing access to a most-responsible care provider;
3) delivering care using teams;
4) ensuring timely access to care;
5) providing comprehensive and coordinated care;
6) ensuring the continuity of care;
7) using electronic medical records to support patients;
8) supporting education, training and research;
9) evaluating and supporting ongoing improvements; and

10) ensuring strong internal and external supports.(7)

In addition, while the operationalization of patient-centred medical-home model vary widely, it is generally agreed that core principles of are wide-ranging and include team-based care, patient-centred orientation toward the whole person, care that is coordinated across all elements of the healthcare system and the patient's community, enhanced access to care that uses alternative methods of communication, and a systems-based approach to quality and safety.(8)

Several systematic reviews and key studies have found that patient-centred medical-home models that consist of many or all of the pillars listed above have many benefits, including:

- increased access to specialists;
- improved patient and clinician experience and satisfaction;
- better use of information-sharing technology to deliver care;
- improved coordination of care;
- enhanced delivery of preventive services; and
- reduced hospitalizations and emergency department visits.(8-14)

However, to ensure that any new delivery models reflect the needs and preferences of patients, it is also important to identify what features of person-centred care are valued by patients, their families and their caregivers.

WHAT WE FOUND

Through our searches (see Box 2 for details) we identified 21 relevant documents that discussed the features of person-centred models of care valued by patients, families and caregivers. To be included, documents had to offer evidence related to aspects of person-centred care (or other variations of the term,

Box 2: Identification, selection and synthesis of research evidence

Box 2: Identification, selection and synthesis of research evidence

We identified research evidence (systematic reviews and primary studies) by searching (in February 2018) Health Systems Evidence (www.healthsystemsevidence.org) and PubMed. In Health Systems Evidence, we used the following search strategy: (patient centered OR patient centred OR people centered OR people centred OR family centered OR family centred OR caregiver centered OR caregiver centred). We also applied the following filters: under domain 'any delivery arrangement' and under document type 'overviews of systematic reviews,' 'systematic reviews of effects' and 'systematic reviews addressing other questions.' In PubMed, we used the following search strategy: (satisfaction OR experience OR preference OR value) AND (person*centered OR person*centred OR patient*centered OR patient*centred OR family*centered OR family*centred OR caregiver*centered OR caregiver*centred OR patient*partnership*) and applied filters for systematic reviews and limiting publication dates to the last 10 years.

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

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool (see the Appendix for more detail), and the proportion of the included studies that were conducted in Canada. For primary research (if included), we documented the focus of the study, methods used, a description of the sample, the jurisdiction(s) studied, key features of the intervention, and key findings. We then used this extracted information to develop a synthesis of the key findings from the included reviews and primary studies.

such as family-centred care) valued by patients and families, or evidence on the interventions that patients, family members and caregivers felt could be used to provide or enhance person-centred care. Based on this criterion, we included 17 systematic reviews,(8; 13; 15-29) two non-systematic reviews, (30; 31) and two citizen panel summaries.(32; 33) While the citizen panel summaries focus on Ontario, we included them given that they are specifically focused on the question posed for this rapid synthesis. In assessing the methodological quality of the 17 included systematic reviews, we found two older (with their searches having been conducted more than five years ago) low-quality,(20; 28) seven medium-quality (three older and four recent),(17-19; 22-25) and eight high-quality (five older and three recent) systematic reviews.(8; 13; 15; 16; 21; 26; 27; 29)

We categorized findings from these included documents according to the 10 pillars of CFPC's patient-centred medical-home model that are listed above.(7) Within each pillar we outline general findings that relate to the pillar, as well as those that relate specifically to one or more of the six main health-system sectors (i.e. home and community care, primary care, specialty care, long-term care, rehabilitation care, and public health).

There was general consensus across the included documents on which aspects of person-centred care are valued by patients, family members and caregivers. These are summarized in Table 1. In particular, the documents identified three aspects that were consistent across different populations and sectors of care. First, strong communication skills were consistently reported as the most important, or among the most important qualities desired in healthcare professionals, as this was seen as being important for facilitating shared decision-making and positive patient-provider relationships.(15; 18; 20; 21; 25) Second, patients expressed that they preferred to have some degree of control over decisions about their health and their treatment plans.(15; 16; 20; 33) Third, patients consistently reported that they wished to be treated as individuals with unique preferences and needs, rather than simply as a patient with a disease.(15; 18; 19; 21; 25; 27)

The findings also suggested that patients generally valued the pillars of the CFPC's medical-home delivery model. Of note, patients regarded team-based primary care as especially desirable due to perceived benefits of better collaboration among care providers and greater continuity of and access to care.(30; 32; 33) Two citizen panels, which consulted panellists for values and preferences about various features of approaches to delivering person-centred care, found that panelists felt that nurse practitioners could take a greater role in delivering care, either as primary-care providers or as someone patients can easily contact to ask questions without needing to make an appointment.(32; 33) The panellists also thought that electronic health records and other technology are important for enhancing care for both the provider and the patient. In particular, panellists viewed interoperable electronic health records as facilitators of communication between different providers, which in turn panellists thought would enhance the coordination and continuity of care.(32; 33) Most panellists were also in favour of technology that could be used by patients to schedule appointments online. discuss health issues that do not necessitate appointments, and support patients to manage their own care.(32; 33) Additionally, most panellists were supportive of patient access to medical records as they believed that this would improve communication and patient education.(23; 32; 33) However, one recent medium-quality systematic review noted that providers should give clear explanations of health information found in the medical files, as some patients reported feeling fear and worry without such knowledge.(23) Lastly, one older, medium-quality systematic review and one of the citizen panel summaries found that respondents valued the involvement of citizens, patients and family members in developing person-centred care models.(22; 32)

Some of the identified documents also discussed specific interventions that patients, family members and caregivers felt could be used to enhance person-centred care, which we summarize in Table 2. It should be noted that the findings in Table 2 are not an exhaustive review of the evidence about such interventions, but rather those that were identified in literature on patient and family values. Interventions in Table 2 range from the provider to the system level, with many interventions examining the interactions between the provider and the patient. In particular, two medium-quality systematic reviews (one older and one recent) and both of the citizen panel summaries noted that patients felt that their needs were better served when providers took time to educate them about their illness, treatments and expectations about future care.(24; 25; 32; 33) At the organizational level, two older systematic reviews (one high quality and one medium quality) focused on family-centred care (e.g., where the care provided addresses the needs of the entire family and not just the patient) suggested that such a care model in specialty settings had negative impacts on patient-provider relationships, and did not adequately address all the personal, social and financial needs of the families.(21; 22) Lastly, several documents examined the patient-centred medical-home model, as a specific system-level intervention,(8; 13; 30) and the results were mixed. Although one older non-systematic review and two older high-quality systematic reviews found that patients receiving care through the patient-centred medical-home model were generally more satisfied with their care, the non-systematic review also indicated that the model resulted in lower satisfaction with wait times and mixed results for satisfaction with the coordination of care.

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It should be noted that the definition of a 'patient-centred medical home' is vague, and that its operationalization can take many different forms, which may explain some variability in the results.(8; 30) Moreover, several documents indicated that the current ability to measure patient satisfaction is limited, as there are no gold-standard instruments and few tools for specific populations or sectors of care.(17; 26; 29)

In addition to the key findings detailed in Tables 1 and 2, one older, high-quality systematic review and one non-systematic review discussed facilitators and barriers to the successful implementation of person-centred care interventions. The systematic review indicated that healthcare providers found it difficult to deliver effective family-centred care within a pediatric critical care setting due to a lack of knowledge, skills or available resources.(21) However, the non-systematic review discussed several methods to address these barriers and to facilitate the integration of patient preferences and needs into evidence-based practice.(31) First, decision supports, such as research summaries, guidelines that incorporate evidence about patient preferences, and mentorship and training opportunities, can help providers assess and deliver care that respects patient preferences.(31) Second, facilitating a culture of continuous improvement through support from organizational leadership and by setting clear expectations for evidence-based practice in performance appraisals, was identified as an important priority for healthcare organizations.(31) Lastly, health systems that prioritize the triple aim outcomes can further encourage the integration of patient values into care delivery.(31)

Table 1: Summary of key findings about features of person-centred models of care that patients, families and caregivers value

Pillar	Key findings

Provide patient-centred care	*General findings:*
	• One recent high-quality systematic review, one older low-quality systematic review and one older high-quality systematic review found that most patients prefer to have some degree of control over decisions made about their healthcare.(15; 16; 20)
	• Three older reviews (one low quality, one medium quality and one high quality) and two recent reviews (one medium and one high quality) found that youth and adult patients regarded communications skills as being especially important, as they can facilitate shared decision-making and positive patient-provider relationships.(15; 18; 20; 21; 25)
	• Three older (one medium quality and two high quality) and three recent (two medium quality and one high quality) systematic reviews reported that patients valued being treated as unique individuals and having their preferences taken into account.(15; 18; 19; 21; 25; 27)
	   o Specifically, the older medium-quality review reported that for youth this meant being treated as a friend and having providers account for their personal history and aspirations as part of their care.(18)
	
	Sector-specific findings:
	• A preference for greater patient control over decisions regarding their healthcare was identified from the evidence in relation to care in three sectors (home and community care, primary care and specialty care).
	   o In the home- and community-care sector, one older high-quality systematic review found that older patients generally wanted greater flexibility in how they spent their care allowances to match the intensity and type of care needed, however this preference ranged widely across patients.(16)
	   o In the primary-care sector, a citizen panel convened with panellists from Ontario about strengthening patient-centred care found that panellists valued health education and information provision as an approach to help them make informed decisions.
	   o In the specialty-care sector, according to one older low-quality systematic review, patients undergoing cancer treatments or invasive procedures were more likely to prefer autonomous decision-making than other populations.(20)
	• One older high-quality systematic review found that patients and parents receiving family-centred care (i.e., care for the entire family, not just the hospitalized child) in pediatric critical care (i.e., specialty care) identified honesty, respect, time and positive relationships to be key facilitators to ensuring effective communication with providers.(21)

Provide access to the most-responsible care provider	*Sector-specific findings:* • In primary care, one older non-systematic review and two summaries of citizen panels focused on strengthening patient-centred primary care in Ontario, found that adult and pediatric primary-care patients were supportive of having a most-responsible care provider who would provide and coordinate care with a larger team of providers. Panellists of both citizen panels were supportive of having nurse practitioners act as their primary-care providers.(30; 32; 33)

Deliver care using teams	*Sector-specific findings:* • In primary care, one older non-systematic review and two summaries of citizen panels found that patients were supportive of receiving team-based primary care. In particular, panellists of one citizen panel found team-based care attractive as they wanted the ability to easily seek second opinions from other providers. Panellists of the other citizen panel expressed that they preferred team-based care as it enhances collaboration among health professionals and may improve patient health. Two panellists shared stories of how such collaboration from a team-based model was able to catch and stop the progression of a chronic condition.(30; 32)

Ensure timely access to care	*Sector-specific findings:*
	• In primary care, one older medium-quality systematic review and both of the panel summaries found that patients valued having timely access to a healthcare provider.(18; 32; 33)
	   o In particular, the citizen panel summaries noted that panellists recognized they did not always require access to a physician for primary care and were supportive of receiving care from other trained providers such as nurse practitioners and/or pharmacists to ask questions or determine if a medical issue merits an appointment with a physician.(32; 33)
	   o Findings from one of the citizen panels indicated that panellists agreed that appointments should be scheduled through a triage process in which patients with the most severe conditions are seen first.(33)
	• For primary care, one older medium-quality systematic review and both of panel summaries found that patients were supportive of having flexible appointment options that facilitate access to same- or next-day appointments through advance access scheduling options.(18; 32; 33)
	• The older medium-quality systematic review indicated that youth preferred having appointments that could be scheduled around school time, from a convenient location and that are affordable (although the latter finding is less relevant to the Canadian context where primary care is publicly insured).(18)

Provide comprehensive and coordinated care	*Sector-specific findings:* • Both of the panel summaries found that primary-care patients valued having coordinated and continuous care between all those involved in providing care.(32; 33) • In particular, panellists felt that having interoperable electronic health records would help health professionals coordinate care.(33) • Panellists also supported "one-stop shops" in which patients could conveniently see both primary-care providers and specialists and get laboratory work done at the same location.(33)
Ensure continuity of care	*Sector-specific findings:* • One of the panel summaries found that primary-care patients valued continuous care with one provider, and as noted above, panellists agreed that this provider did not have to be a physician.(32) • The other citizen panel summary identified a concern from one panellist that that young adults receiving primary care can fall between the cracks when transitioning to different care providers, as adult care settings may not have appropriate protocols in place to work with youth.(33) • One recent medium-quality systematic review on women receiving specialty care for miscarriages found that many patients valued medical follow-ups after pregnancy loss and felt frustrated by the lack of further professional support or information after the initial appointment.(25)
Use electronic medical records to support patients	*General findings:* • Both of the panel summaries found that panellists felt that interoperable electronic health records would help health professionals coordinate care, minimize miscommunications and improve patient outcomes. Panellists also noted that these health records would also ensure continuation of care with other providers when their usual health provider is not available.(32; 33)

	• Both citizen panel summaries and one recent medium-quality systematic review found that people were generally supportive of patient access to their own medical records, as it would help improve communication and patient education.(23; 32; 33) • The citizen panels also found that most panellists supported other technology that would help patients manage their own care, including online scheduling and the ability to use email or the telephone to discuss health issues.(32; 33) • Conversely, some citizen panellists were concerned that having access to their health records may result in undue worry among citizens. This concern was supported by a recent medium-quality systematic review. Although only a minority of patients (12% to 16%) who were surveyed about theoretical access to medical records felt that this would be an issue, some patients who actually read medical notes reported feeling fear and worry when not given clear explanations of the particular health information by care providers.(23; 32; 33) • One recent medium-quality systematic review examining patient access to medical files found that patients expressed worries about the privacy, confidentiality and security of their medical information, and some preferred that sensitive information be coded.(23)
Support education, training and research	• No evidence related to patient or citizen values was identified for this pillar.
Evaluate and support ongoing improvements	*Sector-specific findings:* • One of the panel summaries found that panellists valued accountability to meeting patient expectations in primary care. Specifically, panellists were supportive of decision-makers engaging citizens to select indicators that are relevant and understandable to patients.(32) • The same panel summary found that panellists valued an increased level of citizen engagement in planning and implementing patient-centred primary care.
Ensure strong internal and external supports	• No evidence related to patient or citizen values was identified for this pillar.

Table 2: Summary of key findings of patient, family and caregiver values about specific interventions that support the delivery of person-centred models of care

Pillar	Key findings

Provide patient-centred care	*General findings:*
	• One recent medium-quality systematic review and two citizen panel summaries found that patients felt that education (to help patients and family members manage their health condition) was an important aspect of facilitating informed decision-making and patient-centred care. In particular, during the citizen panels on primary care, panellists expressed the need for more education on both preventing and treating illnesses.(25)
	    o One recent medium-quality systematic review found that patients who had access to their medical files felt that this facilitated patient education and autonomy. Additionally, patients felt that these files could serve as reliable back-ups in case they received inadequate information from physicians or needed to recall insights from the visit.
	• One recent, medium-quality systematic review found that patients felt that access to their own medical records improved patient-provider communication.
	• Other traits of healthcare providers that patients value include respect, compassion, responsiveness and competence.(15; 18; 22)
	
	Sector-specific findings:
	• With respect to communication:
	    o one older, high-quality systematic review found that a family-centred care delivery model had negative impacts on communication and relationships with healthcare providers in a pediatric critical-care setting (i.e. specialty care);(21)
	    o one recent medium-quality systematic review examining the perspectives of patients experiencing miscarriages and their partners suggested that providers in specialty care could enhance patient experience by improving their ability to discuss patients' distress and break the news of pregnancy loss in the presence of the partner;(25) and
	    o according to one recent medium-quality review, surgical patients in the specialty-care sector felt comforted by physical contact from a care provider (e.g., through a comforting touch from a nurse).(19)
	• With respect to recognizing the patient as an individual with unique needs:
	    o one older high-quality systematic review examining consumer-directed care (a method of delivering home care) for older patients recommends that such programs offer options ranging from full-case management (by another party) to self-directed care, and that programs should offer the ability for older adults to choose which specific service areas they would like to have greater control over;(16)
	    o one older high-quality systematic review found that pediatric critical-care providers (i.e., specialty-care providers) should recognize that patient needs are dependent on individual and cultural factors, and that the needs of a hospitalized child differ based on characteristics like age, illness severity and length of stay;(21) and
	    o one older high-quality systematic review suggested that the individual needs and goals of stroke rehabilitation patients can be fulfilled by collaborating with the patient to identify the outcomes they most value.(27)

Provide access to the most-responsible care provider	*Sector-specific findings:* • One older non-systematic review found that adult and pediatric primary-care patients were more satisfied with care received through a 'medical-home' delivery model, but that satisfaction was lower for patients with a greater severity of illness.(30)

Deliver care using teams	*Sector-specific findings:* • The non-systematic review found that both adult and pediatric primary-care patients reported more positive healthcare interactions with the patient-centred medical-home approach, but satisfaction was lower for patients with a greater severity of illness.(30)
Ensure timely access to care	*Sector-specific findings:* • The non-systematic review found that those receiving care from a patient-centred medical-home model reported lower satisfaction with wait times, and the model was less likely to be accessible for children who either did not have insurance, were from low-income households, had severe conditions, or were of a minority background.(30)

Provide comprehensive and coordinated care	*Sector-specific findings*
	• Mixed findings were reported for the effect of patient-centred medical-home models on patient-perceived levels of primary-care coordination. While one older non-systematic review found that the patient-centred medical-home model resulted in lower levels of satisfaction with the coordination of care and referrals, an older high-quality systematic review found that it had a positive effect on patient-perceived levels of care coordination.(13; 30)
	• Two high-quality systematic reviews (one older, one recent) examined interventions to improve care coordination in specialty-care settings.(22; 29)
	   o The older medium-quality systematic review found that a family-centred care delivery model did not adequately address all the personal, social and financial needs of families in a pediatric critical-care setting.(22)
	   o The recent high-quality systematic review found that patient navigators, who guide patients through the healthcare system (e.g., connect them with financial support, obtain interpreter services), can improve patient satisfaction for cancer care.(29)

Ensure continuity of care	*Sector-specific findings:* • One older medium-quality systematic review focusing on the transition from pediatric to adult care for youth with chronic conditions detailed several patient recommendations for a smoother transition. Patients stated that they would like to acquire skills for autonomous behaviour (e.g., knowing how to schedule an appointment) before the transition begins. Patients also wished to know more about adult care prior to the transition. In particular, they recommended joint visits with child-care providers to adult-care settings and mentorship programs with patients who have already transitioned to adult care.(24) • One older low-quality review found that people with chronic conditions receiving specialized community-based care appreciated that this model of care provides repeated and longer-term access to providers as compared to hospital care, and that it helped them build a rapport with their providers.(28) • Two recent systematic reviews (one high-quality, one medium-quality) identified interventions to improve the continuity of specialty care.(25; 29) o The medium-quality review found that patients experiencing miscarriages would appreciate follow-up phone calls, appointments, or home visits.(25)
Use electronic medical records to support patients	*General findings:* • Both of the panel summaries found that panellists felt that interoperable electronic health records would help health professionals coordinate care, minimize miscommunications and improve patient outcomes. Panellists also noted that these health records would also ensure continuation of care with other providers when their usual health provider is not available.(32; 33) • The citizen panels also found that most panellists supported technology that would help patients manage their own care, including patient portals, online scheduling and the ability to use email or the telephone to discuss health issues.(32; 33)

	• Conversely, other panellists were concerned that having access to their health records may result in undue worry among citizens. This concern was supported by a recent, medium-quality systematic review, which reported that patients who read medical notes reported feeling fear and worry if not given clear explanations of the particular health information by care providers.(23; 32; 33) • One recent medium-quality systematic review examining patient access to medical files found that patients expressed worries about the privacy, confidentiality and security of their medical information, and some preferred that sensitive information be coded.(23)
Support education, training and research	• No evidence related to patient or citizen values was identified for this pillar.
Evaluate and support ongoing improvements	*General findings:* • Three recent (two high-quality, one medium-quality) systematic reviews found that there are limitations in the ability to measure patient satisfaction and values as there are no gold-standard instruments, and there is a paucity of tools available to measure satisfaction with specific patient populations.(17; 26; 29) *Sector-specific findings* • One of the panel summaries found that panellists had mixed opinions about whether public reporting on primary care would be useful.(32)
Ensure strong internal and external supports	• No evidence related to patient or citizen values was identified for this pillar.

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APPENDICES

The following tables provide detailed information about the systematic reviews and primary studies identified in the rapid synthesis. The ensuing information was extracted from the following sources:

- systematic reviews - the focus of the review, key findings, last year the literature was searched, and the proportion of studies conducted in Canada; and
- findings from two citizen panels - the focus of the citizen panels, methods used, study sample, jurisdiction studied, key features of the intervention and the key findings.

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

All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Appendix 1: Summary of findings from systematic reviews about features of person-centred models of care that patients value

Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
Literature review	Effectiveness of the patient-centred medical home model on patient-related outcomes (30)	The patient-centred medical-home (PCMH) model is a holistic, team-based model of primary care that seeks to address the difficulty of coordinating and integrating care for patients with chronic conditions. In this model, the patient's personal physician is responsible for providing all the healthcare needs across the entire life course of the patient, or arranging care with other qualified professionals. This model intends to improve value, access, timeliness, equity and efficiency of care. This review examined the effectiveness of the PCMH model. Sixty-one studies were identified. There were four types of study outcomes. Eighteen studies examined access to PCMH for different population groups. These studies mainly focused on children with special healthcare needs, and found that approximately 50% of these children had access to the medical home. Uninsured children, children from lower-income households, children with more severe conditions, and children of a minority background were less likely to have access to a medical home. Twenty-three studies examined the service utilization of those enrolled in a PCMH model; once again, most of these studies focused on children. All but three studies found greater use of appropriate services and decreased use of inappropriate services by pediatric and adult PCMH patients compared to the comparison group. Exceptions included immunization rates among children and ER visits among adults for one study. Three studies looked at patient satisfaction with the PCMH model. Overall, both adult patients and parents of child patients were satisfied and reported positive healthcare interactions. There were lower levels of satisfaction reported for the coordination of referrals, wait times and cultural sensitivity. Those with a greater severity of illness as well as parents of older children also had lower levels of satisfaction. Seven studies examined the effect of the PCMH model on quality and lifestyle-related outcomes. The results were mixed, with half of the studies finding positive improvements, and the other half finding no significant associations. Lastly, 11 studies examined multiple outcomes, which included patient satisfaction, quality of care, access and service utilization. PCMH was associated with improved outcomes for patient satisfaction, quality of life, appropriate service utilization, and access to care. There were multiple limitations. Most of the studies employed a cross-sectional design that collected self-reported responses. Additionally, there is no universal framework of the PCMH model, resulting in significant variation in how PCMH components are defined and operationalized. Further research should examine individual components of the PCMH model to determine how it works.	n/a	No rating tool available for this type of document	n/a

Systematic review	Identify instruments that can be used to measure patient satisfaction in healthcare services (17)	This systematic review sought to determine the properties and quality of instruments used to assess patient satisfaction for healthcare services. The review identified 37 studies which evaluated 34 different instruments. Most papers had either a good or fair score as per the COSMIN guide to assessing methodological quality of psychometric analysis. The review did not find a gold standard for assessing patient satisfaction. Nonetheless, across the papers and tools, there was a consensus on the fact that satisfaction is a multidimensional construct. However, it remains unclear which essential dimensions must be included in a patient-satisfaction instrument. Many tools included the dimensions of patient-healthcare professional interactions, the physical environment, and the internal management process. Tools tailored to specific services, like home care, tended to use other more specific dimensions. The review emphasized that the concept of satisfaction changes across cultures, patient profiles, and type of service examined. Furthermore, user satisfaction is only one facet of delivering high-quality patient-centred care. Limitations to the review included the fact that the included studies largely looked at structural validity and internal consistency, but failed to examine other factors recommended by the COSMIN checklist for validation (e.g., reliability, criterion validity).	2013	7/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail
Systematic review	Define domains and indicators of youth-friendly care from the perspective of youth (18)	The review sought to identify domains and indicators of delivering youth-friendly care by examining the perspectives of youth users of the healthcare system. In this review, youth was defined as those aged 10-24. The review identified 22 studies, 15 which utilized quantitative methods, six with qualitative methods and one with mixed methodology. From these studies, the review identified eight domains for positive experience of care by youth: accessibility of healthcare, staff attitudes, communication, medical competency, guideline-driven care, age appropriate environments, youth involvement in healthcare, and health outcomes. These domains should be included in any instrument designed to measure youth-friendly healthcare. Factors which were inversely associated with the satisfaction of healthcare services included the severity of mental health problems, low quality of life, and length of treatment. The authors noted that these eight domains fit well into the World Health Organization (WHO) framework for delivering adolescent-friendly healthcare. However, the WHO framework is geared toward lower-income countries, while the authors argue that these eight domains can be applied universally. Limitations to this review included the small number of studies, the heterogeneity of adolescent health needs and issues across different countries, and the fact that there is no universally accepted definition of satisfaction.	2011	6/9 (AMSTAR rating from McMaster Health Forum)	3/22
Systematic review	Determine how the patient defines person-centred care in the context of perioperative nursing (19)	This review seeks to define person-centred care from the perspective of the patient in the perioperative nursing context. Perioperative nurses provide direct care to surgical patients during the intraoperative period, and are also responsible for preoperative assessments and postoperative evaluations. The review identified 23 articles which, together, revealed four themes to person-centred care. First, patients want to be recognized as a unique entity, and to be allowed to be the person that they want to be. This includes treating patients with dignity and respect, and taking their suffering seriously. Second, patients want to be considered important and have their personal wishes taken into account. This could be fulfilled with nurses devoting time and attention to discussing the operation and identifying the small	2014	5/9 (AMSTAR rating from McMaster Health Forum)	2/23

		details that are important for the patient. Third, patients find that the presence of a perioperative nurse is calming and prevents feelings of loneliness, which may speed up recovery. Lastly, patients find it comforting to be close to and to be touched by the perioperative nurse during anesthesia and surgery. The review's findings may have been biased by the authors' pre-understanding of person-centred care in a perioperative context.			
Systematic review	Construct a taxonomy of aspects of healthcare delivery valued by patients (15)	This systematic review sought to identify and construct a taxonomy of patient expectations, values, and preferences of healthcare delivery. The review identified 22 studies which either covered values relating to the patient and their personal context, the characteristics of the professional valued by patients, or the interactions between the patient and the professional. The review found seven key elements which each fit under one of the three aforementioned categories of determinants. There were two values relating to the patient and personal context: uniqueness (respecting the patient as a whole person) and autonomy (respecting the patient's capacity for making decisions on their treatment and care.) There were three values relating to characteristics of professionals valued by patients: compassion, professionalism (in technical, communication and collaboration skills), and responsiveness (the committed and responsible execution of care). Lastly, there were two values relating to patient-professional interactions: partnership (mutual respect and interdependency) and empowerment (enabling patients to keep control in their situation). The authors found that all seven key elements were interconnected, and proposed a general sequence. The recognition by professionals of the patient's uniqueness and autonomy leads to the professional behaving compassionately, professionally, and responsively, which creates an interaction based on partnership and empowerment. Some limitations to the review and taxonomy included the fact that few studies looked at values defined by the patient and that there is a lack of clear definitions for terms like 'values', 'needs' and 'preferences'.	2014	8/9 (AMSTAR rating from McMaster Health Forum)	1/22
Literature review	Summarize how patient preferences can be integrated into evidence-based practice (31)	This review sought to summarize research on patient preferences and discuss its implications upon nursing. There is a perceived tension between delivering patient-centred care and evidence-based practice. The review posited that the concept of patient preferences could be used to link the two concepts, as research demonstrates that patients who receive their preferred treatment have better health outcomes than those who don't. Barriers to incorporating patient preferences into care include resource and time pressures placed upon healthcare providers, difficulty assessing patient values and preferences, and different perceptions of evidence. Furthermore, guidelines currently do not generally include patient preferences. The review identified that four elements are needed to integrate patient preferences into evidence-based practice: healthcare redesign, decision support, empowered organizational cultures, and informed and empowered nurses. There are numerous interventions based off these elements, including using evidence-based decision support systems to clarify patient preferences, executing continuous outcome evaluations, and supporting nurses with educational programming and time.	n/a	No rating tool available for this type of document	n/a
Systematic review	Determine patient role preferences with respect to decisions on	Recently, healthcare providers have been moving towards involving patients in making decisions about their health. However, some patients may prefer to delegate decisions to healthcare providers. This	2007	2/9 (AMSTAR rating	Not reported in detail

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	treatment and screening (20)	review sought to determine trends in patient role preferences regarding healthcare decisions across time, measures, and patient populations. The review identified 115 studies. Overall, 63% of the studies reported that a majority of patients preferred sharing decisions with physicians. Patient role preferences change across time. Specifically, 43% of studies before 1990 indicated that a majority of patients preferred shared or autonomous decision-making, compared to 71% after 1999. There were also differences in role preferences across study populations. About three-quarters of studies which examined patients with cancer or undergoing invasive procedures found that patients preferred to have shared or autonomous decision-making. This is in comparison to about half of the studies examining non-disease specific study populations or utilizing hypothetical scenarios. Lastly, results were affected by the wording of the questions and answer options of tools employed in the studies. A higher percent of respondents indicated a preference in sharing decisions when the stem of the question affirmed sharing decisions, or when the measure's answer options included an explicit option to share decisions. Studies that used hypothetical vignettes had inconsistent findings. Ultimately, the review recommended that healthcare providers learn communication tactics to identify patient preferences and preferred decision roles across their entire trajectory of care. The review concluded that more work is needed to define the construct of decision-making. Furthermore, researchers should look into how patients perceive the decision process, and how a patient's role preference may vary as their health status changes.		from McMaster Health Forum)	
Systematic review	Explore the attitudes and experiences of healthcare professionals and parents with respect to family-centred care in pediatrics (22)	The family-centred care-delivery model plans care around the whole family, and not just around the child patient. This review sought to explore the attitudes and experiences of healthcare providers and parents towards family-centred care. The review found 15 studies, from which four themes were identified: communication, healthcare professional and parent relationships, care for parents, and resource availability. The review found that universally, family-centred care had negative impacts on communication, relationships, personal and social needs, and financial resources. Furthermore, the effectiveness of family-centred care varies depending on the demographic characteristics of the child, the parents, and the healthcare professionals. Oftentimes, healthcare professionals wanted to deliver effective family-centred care, but found that this was difficult due to a lack of knowledge, skills, time or available resources. The review made several recommendations. These include enhancing parental involvement at program planning and development committees, and including meals and living facilities for parents. The review noted several limitations, including that there were no randomized controlled trials found, and that most trials employed convenience sampling.	2009	7/9 (AMSTAR rating from McMaster Health Forum)	2/15
Systematic review	Identify facilitators of smooth transitions from child- to adult-centred care (24)	Patients sometimes experience difficulty transitioning from child- to adult-centred care. Sometimes, this could be due to hearing negative anecdotes about adult-centred care, or being unwilling to sever ties with a child-care practitioner who the patient has come to trust. This paper sought to identify factors that could lead to a smoother transition to adult-centred care. The review identified 46 articles which explored one or more of the following four themes: patients' feelings and concerns; patient recommendations; outcomes after transition; and effects of the mode of transfer.	2009	5/9 (AMSTAR rating from McMaster Health	Not reported in detail

				Forum)	
		The review made five recommendations. First, the transition from child- to adult-centred care should be presented as a normative event. Second, practitioners should clarify and discuss patient expectations about the transition process. Third, child-care practitioners should begin preparing patients early to ensure that the patient has the necessary knowledge and skills for autonomous behaviour when the transition begins. Fourth, practitioners should engage patients when planning the specific steps involved in the transition. Last, adult-centred care practitioners should provide patients with an optimal transition environment and adequate resources to help them deal with the changes. The review noted that the included papers focused on physical chronic illnesses, so results may not be generalizable to other conditions.			
Systematic review	Explore attitudes, experiences and implementation processes of family-centred care (21)	This review sought to summarize study findings concerning the attitudes, experiences and implementation processes of family-centred care in a pediatric critical-care setting. The review identified 30 articles. From these, the review identified eight facets of the experience: entry into the hospital, journeying through unknown waters, information, relationships, the hospital, the possibility of death, religion and spirituality, and the journey home. Each facet was broken down into themes, and then into individual categories, and then lastly, into study-specific findings. The review found that communication is pivotal for the operationalization of family-centred care. Factors that facilitated positive communication experiences included honesty, respect, time and positive relationships. Parental satisfaction with care also correlated with communication, information and relationships. The needs of the parents (e.g., nutritional, financial, religious) were dependent on many individual and cultural factors. Similarly, the needs and experiences of the hospitalized child were also influenced by individual characteristics like age, illness severity, medications taken, and length of stay. The review noted that parents experience high degrees of psychological distress in the form of shock, grief, avoidance behaviours and PTSD. The review noted several limitations. Most studies employed convenience sampling, and most studies were dominated by females from nuclear, white, literate families. Future research should compare how family nurses produce positive or negative experiences across different countries, contexts and healthcare settings.	2011	8/9 (AMSTAR rating from McMaster Health Forum)	2/30
Systematic review	Identify tools that help clinicians assess patient preferences and priorities for multimorbidity in a primary-care setting (26)	It is difficult to manage multiple medications for multimorbid patients. For instance, having to take multiple medications can decrease patient compliance, which in turn, may reduce the effectiveness of care. The review found eight original studies and two discussion papers. The review only found one tool that recorded priorities and preferences for multimorbid patients in primary-care settings. There were also no studies that assessed the impact of using these tools on patient-relevant health outcomes. The review's findings were limited, as all included studies were of low to moderate quality, and employed a cross-sectional design.	2015	10/10 (AMSTAR rating from McMaster Health Forum)	0/8
Systematic review	Describe approaches to implement primary-	There are many ways to define and operationalize patient-centred medical homes (PCMH). This review defines PCMH interventions as having the following characteristics: team-based care; having at least two	2011 for PubMed	9/10 (AMSTAR	2/21

	centred medical homes, and summarize patient and staff experiences, processes of care, and clinical and economic outcomes (13)	of four elements focused on how to improve organization of care (the four elements being enhanced access, coordinated care, comprehensiveness, and systems-based approach to improving quality and safety); a sustained partnership; and having an intervention that involves structural changes to the traditional practice. The review included 60 articles which represented 31 unique studies. Of these 60 articles, 44 examined the effectiveness of PCMH, and 31 sought to describe the PCMH model. The review found that PCMHs described in the studies tended to be organized around multidisciplinary teams. Furthermore, the models often aimed to address comprehensive health needs, like multiple chronic illnesses. The models also developed ongoing relationships between care teams and individual patients through the use of care plans or comprehensive assessments. Healthcare providers working in a PCMH model engaged in care coordination with community services or with other sectors of care. The model also often enhanced access to healthcare services through telephone visits. The PCMH interventions also often employed a systems-based approach to improving care quality and safety (e.g., using evidence-based guidelines and identifying high-risk patients). The review found moderately strong evidence that the medical home has a small positive effect on patient experiences (e.g. patient satisfaction, patient-perceived levels of care coordination), and small to moderate positive effects on the quality of preventive care services. There was low-quality evidence that staff experiences improved by a small to moderate degree. The review was unable to make conclusions about the clinical and economic outcomes given the insufficient amount of evidence available on these topics. The authors cautioned that the aforementioned findings should be considered preliminary. The authors also noted that the definition of PCMH varies widely, so outcomes may vary between each individual model. Lastly, there was heterogeneity in study designs, studied populations and outcomes in the included studies.	2012 for Cumulative Index to Nursing & Allied Health Literature, and the Cochrane Database of Systematic Reviews	rating from McMaster Health Forum)	
Systematic review	Identify patient-centred outcome measures and interventions for strokes (27)	The paper aimed to identify outcomes used to assess the effectiveness of stroke interventions. Both quantitative data and thematic analyses were included. The review identified 22 articles describing 21 unique studies. The quality of the included studies was mixed. There were three outcome measures identified. Two of them, the Subjective Index of Physical and Social Outcome, and the Stroke Impact Scale, amalgamated a wide range of outcomes, including social and recreational outcomes. The third tool, Communication Outcome after Stroke scale, assessed the patients' perceptions of their communication skills following stroke. Four of the included studies assessed one of the three interventions: a two-day residential family intervention that aimed to equip carers with improved communication skills; a psychosocial intervention to improve social support and self-efficacy in older patients; and a family-centred home rehabilitation program. These interventions shared key elements, including delivery in the patients' own home, the intensive nature of the intervention, the close involvement of family members, and the delivery of the intervention by trained experts. From the 21 included studies, three categories of themes were identified: meaningfulness and relevance, quality, and communication. The category of meaningfulness and relevance concerns whether patients	2010	8/10 (AMSTAR rating from McMaster Health Forum)	1/22

		are receiving care that reflects their needs and priorities. In other words, is the care being done *to* the patient, or *for* or *with* the patient? Achieving this can be facilitated by actively engaging families, carers and patients in determining their care. The category of quality concerns how much patients value being able to conduct activities in the same manner as before the stroke. It goes beyond the frequency of being able to participate in an activity, to the quality of how they conduct the activity. Thus, outcome measures should include a subjective assessment of patients' perceptions of the quality of their post-stroke activities. Communication refers to the inclusion/exclusion of patients with stroke-related communication impairments from active involvement in stroke research and delivering stroke care. To overcome this challenge, effective communication methods should be taught early in the rehabilitation process, as oftentimes, carers are resistant to learning new, more effective methods later on. From these findings, the paper proposed that evidence-based, stroke-specific patient-centred care should: identify individuals' communication skills and utilize effective communication strategies; identify outcomes valued and prioritized by the patient; identify outcomes that reflect the quality of participation; monitor outcomes at appropriate times in the rehabilitation process; and use the resulting information to inform the decision-making process.			
Systematic review	Determine user preferences for and satisfaction with services associated with consumer-directed care programmed for older people (16)	The paper sought to identify user preferences for consumer-directed care among older people in order to make recommendations on developing consumer-directed care models for older adults. Consumer-directed care seeks to place control over home-based care in the hands of the consumers. This concept can manifest through many different approaches. The search identified 17 studies which reported on three categories of large-scale implementation programs: the US Consumer Directed Personal Assistance Schemes, the US Cash and Counselling programs, and the UK Individual Budgets programs. The Consumer-Directed Personal Assistance Services included a variety of programs which differed in the scope and support provided. Cash and Counselling programs provided counselling assistance to help people with disabilities with decision-making, planning and fund management. The Individual Budgets programs offered users the ability to self-assess, self-define needs and desired outcomes, and to decide how they want these outcomes to be achieved. The review concluded that older people's preferences, needs and contexts vary widely. Factors which affect user preferences include self-confidence, skills, health status, quality of available adult social care, and access to publicly funded aged care. Overall, older people wanted greater involvement in care-related decision-making, in facets like flexibility in spending their care allowances and control in employing personal-care workers. However, to address the variation in user preferences, consumer-directed care should be offered alongside a number of other service options ranging from full case management to self-direction. Furthermore, programs could offer the ability for older adults to choose which specific service areas they would like to have greater control in. Designers should also factor in social and community supports as older people may have less access to support from families and friends than the general population. Programs should also consider that older peoples' health status can change quickly, so safeguards like systematic risk assessment strategies need to be included.	2011	8/9 (AMSTAR rating from McMaster Health Forum)	0/17

		Only English language articles were included, possibly limiting the interventions identified. Furthermore, some papers utilized evaluation measures that had not undergone reliability or validity analysis. Future research should focus on what matters most to older people who seek to maintain independence.			
Systematic review	Determine the effectiveness of a patient navigator on patient satisfaction in adult patients in ambulatory-care settings (29)	Patient navigators are trained individuals who help patients overcome barriers to care and guide them through the healthcare system. Their role may entail providing financial support, scheduling services, and/or interpreter services. The review sought to determine the effectiveness of a patient navigator on patient satisfaction in adult patients in ambulatory-care settings. The review identified two randomized controlled trials, one quasi-experimental pre-post-test design study, and one cohort study for inclusion. All four studies were determined to be of adequate quality. The four studies provided modest evidence that patients are generally more satisfied when they are connected to a patient navigator. In cancer care, care coordination and patient care outcomes improve when patient navigators are involved. Furthermore, the four studies demonstrated some evidence of navigators improving screening rates, outcomes of care, continuity of care, patient empowerment, and anxiety levels. However, the included studies varied widely in intervention design, study design, and study quality. Furthermore, the included studies were limited to cancer care. Additionally, none of the tools in the studies were specifically designed and validated for measuring patient satisfaction with respect to patient navigators. Future research should focus on developing a standardized and validated tool for measuring patient navigator interventions. More RCTs are needed to confirm findings on the effectiveness of a patient navigator.	2015	8/10 (AMSTAR rating from McMaster Health Forum)	1/4
Systematic review	Provide an overview of aspects of care valued by women and their partners when faced with early pregnancy complications; identify potential targets for improvement in early pregnancy healthcare (25)	This review sought to identify which aspects of care are valued by women and their partners when experiencing miscarriage, recurrent miscarriage or ectopic pregnancy. The review identified 27 studies for inclusion. None of the studies discussed ectopic pregnancies. From these studies, the review found 24 important aspects of care that fell under the eight dimensions of patient centredness. The dimensions are: respect for patients' values, preferences and needs; coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of significant other; continuity and transition; and access to care. The most frequently reported aspect of care was "being treated as an individual person experiencing a significant life event rather than a common condition." Aspects where more than 50% of respondents reported negative experiences were identified as targets for improvement. The review identified four aspects that could be targeted for improvement: understandable information provision about the etiology of pregnancy; staff discussing patients' distress; informing patients on pregnancy loss in the presence of friend or partner; and staff performing follow-up telephone calls to support their patients after a miscarriage. Future qualitative studies should explore how to improve the identified targets for improvement, and to explore the perspectives of women and their partners for ectopic pregnancy.	2017	6/9 (AMSTAR rating from McMaster Health Forum)	3/27

| Systematic review | Patient perspective on the effects of medical record accessibility (23) | This systematic review sought to understand the patients' perspective on accessibility to personal medical files. Over the last decade, the patient-provider dynamic has evolved to emphasize patient autonomy and view patients as partners who share decision-making ability with the provider. Giving patients information on their illness and treatment options is considered integral to the patient's ability to make decisions regarding their health. As such, it has been theorized that sharing the personal medical file with patients can bring many benefits, including facilitating physician-patient communication and trust, increasing adherence to therapy, and reducing medical errors.

The review identified 12 articles. These included four explorative studies, one longitudinal study, one qualitative study, two quasi-experimental studies, three non-systematic reviews and one systematic review. When surveyed about their theoretical opinions, patients were generally supportive of open visit notes, and felt that these notes could improve communication and patient education. One study found that only a minority of patients (12% to 16%) thought that open visit notes would increase worry among patients.

Those who actually gained access to their medical files had positive experiences. Patients reported easier communication and greater trust in physicians, and felt that these files could serve as reliable backups in case they received inadequate information from physicians or needed to recall insights from the visit. Patients also felt increased control over their health.

However, some patients mentioned experiencing fear and confusion while reading medical files when they were not given clear explanations by their physicians about their medical information, or felt that physicians had documented information in a biased manner. Furthermore, patients expressed worries about the privacy, confidentiality and security of their personal information, and some preferred that sensitive information be coded.

Potential limitations of the systematic review include possible publication bias and nonresponse bias in many of the included studies. | 2016 | 6/9 (AMSTAR rating from McMaster Health Forum) | 0/12 |
| Systematic review | Summarize the current evidence for the patient-centred medical-home model in a primary-care setting (8) | The patient-centred medical home (PCMH) is a model of primary care that centralizes care and medical records to improve patient and staff experiences, patient outcomes, safety, and system efficiency. While the definitions and operationalizations of the PCMH model vary widely, it is generally agreed that the core principles of PCMH are wide-ranging team-based care, patient-centred orientation toward the whole person, care that is coordinated across all elements of the healthcare system and the patient's community, enhanced access to care that uses alternative methods of communication, and a systems-based approach to quality and safety.

The review found 27 published studies and 31 ongoing studies. The strength of evidence was low or insufficient for most outcomes. The review sought to answer four questions. The first question explored the effects of the PCMH on patient and staff experiences, process of care, clinical outcomes, and economic outcomes. The review found moderately strong evidence that PCMH improves patient experiences and preventive care services. There was less robust evidence in favour of better staff experiences. There was no evidence that PCMH had an effect on total costs, possibly because current studies are underpowered. The authors were unable to determine a precise estimate for the effect of PCMH on healthcare use. | 2011 | 8/10 (AMSTAR rating from McMaster Health Forum) | 2/27 |

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		The review found several gaps in the literature. First, most studies evaluated effects of the PCMH model on older adults with multiple chronic illnesses. There were few studies that looked at pediatric or general adult primary-care populations. Additionally, there was little data of the effect of the PCMH model on staff retention and unintended consequences. The second question examined how individual PCMH components have been implemented. There was wide variability in the characteristics of the studied PCMH interventions. Most studies reported implementing most of the seven major medical-home domains, but varied considerably in how they addressed other major components (e.g., enhancing access to care). The third question asked what financial models and implementation strategies have been used to support uptake. Few studies provided details of how medical homes were financial supported. Financial models included enhanced fee-for-service, additional per-member per-month payments, and payments linked to quality and efficiency targets. The fourth question explored the designs of ongoing studies and the characteristics of the studied PCMH intervention. There were 31 ongoing studies scheduled to conclude within the next two years. However, only two of the 31 studies were RCTs. The review suggested that future studies report the details of the PCMH interventions and use a more consistent set of outcome measures and nomenclature. Ultimately, the reviewers were unable to determine the most beneficial components of the PCMH model. The review was limited in that the study designs and intervention characteristics varied widely, making it difficult to formulate generalizable conclusions. Furthermore, no standard nomenclature or measures exist for many aspects of the PCMH model, meaning that papers that used different terminology may have been missed.			
Systematic review and qualitative meta-synthesis	Explore patient and provider experiences of specialized community-based care interventions and healthcare delivery models, in the context of patient-centredness (28)	Specialized community-based care (SCBC) aims to help patients manage chronic diseases by formalizing the link between primary-care providers and community providers with specialized training. This review sought to synthesize research on patient and provider experiences of SCBC interventions in the context of patient-centredness principles. Twenty-nine studies met the inclusion criteria. Three themes were identified. First, the patients' health beliefs affect their participation. SCBC interventions generally helped patients learn more about their condition. SCBC interventions should take care in delivering information in an understandable format, and ensuring that they help patients acquire self-care management kills. The second theme explored the patients' experiences with community-based care versus hospital-based care. Patients generally noted that hospital care often focused on the disease state and was not individualized to each patient. Patients who preferred community-based care indicated that they valued the repeated and longer access to knowledgeable providers in SCBC, compared to hospital services. This helped them build a rapport with their providers and take a more active role in their care. Additionally, the social support from SCBC interventions reduced their sense of isolation and increased their confidence. The presence of other patients and providers was also often crucial to their motivation. The last theme concerned how patients and providers value the role of nurses differently. Patients saw nurses as key supports for self-management, and nurses reported that encouraging self-management was	2012	3/9 (AMSTAR rating from McMaster Health Forum)	Not reported in detail

| | | a key part of their role. However, the review cautions that nurses should not use a one-size-fits-all approach to self-management, as this may lead to a failure to incorporate patients' perspectives in self-management counselling. Nurses also reported that building rapport was an important part of their role that helped tailor care to their patients' needs. Lastly, while some patients perceived nurses as having greater expertise than they were allowed to exercise, others felt that nurses had limited expertise and should make referrals to other practitioners when the limits to the nurse's knowledge or scope of practice were reached.

Ultimately, patients with chronic diseases reported greater satisfaction when SCBC helped them better understand their diagnosis, facilitated increased socialization, helped them manage their own care, and assisted them in overcoming psychological and social barriers. | | | |

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Appendix 2: Summary of findings from citizen panels about features of person-centred models of care that patients value

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Enhancing access to patient-centred primary care in Ontario (32)	*Publication date:* 2016 *Jurisdiction studied:* Ontario, Canada *Methods used:* Citizens participated in a day-long deliberation to provide their views and experiences about the issue, and learn from research evidence and from the views of others.	Citizens recruited from across Ontario	The citizen brief used to inform the dialogue outlined the key pillars of the patient-centred medical-home model. These include: 1) providing patient-centred care; 2) providing access to a most-responsible care provider; 3) delivering care using teams; 4) ensuring timely access to care; 5) providing comprehensive and coordinated care; 6) ensuring the continuity of care; 7) using electronic medical records to support patients; 8) supporting education, training and research; 9) evaluating and supporting ongoing improvements; and 10) ensuring strong internal and external supports.	Panellists identified four challenges to enhancing access to patient-centred primary care. First, patients have inconsistent access to primary-care providers. This could be attributed to a variety of reasons, including the fact that many practices do not accept new patients. Second, primary care does not comprehensively address patients' needs, like accessing services from the home- and community-care sector. Third, individuals do not always view themselves as accountable for their own health. Fourth, technology is adopted slowly and inconsistently implemented across primary-care settings. One example is the fact that there is no universal electronic health records system used across all of Ontario. Panellists identified several important elements to addressing these issues. First, efforts should focus on ensuring all Ontarians receive the care they need when they need it. One particularly favoured approach to improving the timeliness of care was having nurse practitioners act as their primary-care providers. Panellists also wished to see increased coordination between their primary-care provider and their specialists. Second, panellists wished to put the patient at the centre of care. This could be achieved by helping patients self-manage their conditions. Third, panellists indicated that the system should be held accountable to meeting patient expectations. Most panellists agreed that this would involve using measurements that reflect citizen values in public reports. Overall, panellists valued collaboration between providers and with the patient, education of patients to manage their own care, and respecting citizens' values and preferences. Panellists identified two factors through which the elements above could be implemented. First, panellists emphasized that electronic health records (for both providers and patients) could help with the coordination of care and could help patients take a more active role in their care. Second, citizens should be engaged in planning and implementing such a model of care to ensure that it fulfils citizen values and needs.
Building a Primary-Care 'Home' for Every Ontarian (33)	*Publication date:* 2016 *Jurisdiction studied:* Ontario, Canada	Citizens recruited from across Ontario	The citizen brief used to inform the dialogue outlined the key pillars of the patient-centred medical-home model. These include:	Panellists identified five barriers to implementing primary-care homes in Ontario. First, healthcare providers do not coordinate well with each other, partly due to a lack of using electronic health records to communicate with each other.

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	Methods used: Citizens participated in a day-long deliberation to provide their views and experiences about the issue, and learn from research evidence and from the views of others.		1) providing patient-centred care; 2) providing access to a most-responsible care provider; 3) delivering care using teams; 4) ensuring timely access to care; 5) providing comprehensive and coordinated care; 6) ensuring the continuity of care; 7) using electronic medical records to support patients; 8) supporting education, training and research; 9) evaluating and supporting ongoing improvements; and 10) ensuring strong internal and external supports.	Second, patients have limited access to their health records, making it difficult for them to share findings with other providers. Third, it is difficult to access primary care, in terms of both time and distance. Fourth, panellists generally did not feel that their needs and perspectives were considered while receiving healthcare. Fifth, the current care received does not adequately address the social determinants of health. The panellists also discussed three elements of a potential approach to facilitate the implementation of primary-care homes in Ontario: ensuring that Ontarians receive the needed care within a timely manner; putting the patient at the centre of care; and ensuring that care is linked across providers, teams and settings. Panellists valued the following aspects of healthcare delivery: access to care (with those most in need prioritized); competence/expertise of healthcare providers in both technical and patient-engagement skills; trusting relationships with healthcare providers; collaboration among patients, providers and organizations; and collaboration between the health system and other sectors (e.g. education). Panellists then discussed potential barriers and facilitators to the implementation of primary-care homes. First, panellists suggested that incentives should be introduced to encourage care providers to work collaboratively with each other and with the patients. Second, panellists wanted the system to adopt new booking, referral and communication platforms. Lastly, panellists believed that the widespread implementation and use of electronic health records are integral to achieving many of the elements listed above.

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