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## Toward an interprofessional shared decision making support tool for primary care patients with complex care needs: a participatory systematic mixed studies review protocol

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# Toward an interprofessional shared decision making support tool for primary care patients with complex care needs: a participatory systematic mixed studies review protocol

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#### Abstract

#### INTRODUCTION

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Patients with complex care needs suffer from combinations of multiple chronic conditions, mental health problems, drug interactions and social vulnerability, which can lead to health care services overuse, underuse or misuse. Typically, these patients, their families, their caregivers, and their practitioners (hereafter stakeholders), face interprofessional and patient-practitioner interactional issues related to stakeholders' personal uncertainty regarding possible options (decisional conflict). Gaps in knowledge, values clarification and social support in situations where options need to be deliberated (decisional needs) hamper effective decision support interventions. This review aims to: (a) identify decisional needs of patients with complex care needs, from the perspective of stakeholders; (b) build a taxonomy of these decisional needs; (c) prioritize decisional needs; and (d) design a decision support tool to help address stakeholders' decisional conflicts.

#### METHODS AND ANALYSIS

This theory-driven review will be based on the Interprofessional Shared Decision Making (IP-SDM) model and the Ottawa Decision Support Framework. Applying a participatory research approach, we will identify potentially relevant studies through a comprehensive literature search; select relevant ones using eligibility criteria inspired from our previous scoping review on patients with complex care needs; appraise quality using the Mixed Methods Appraisal Tool; conduct a 3-step synthesis (sequential exploratory mixed methods design) to build taxonomy of key decisional needs; and design an IP-SDM decision support tool based on these results.

#### ETHICS AND DISSEMINATION

Our review will produce a working taxonomy of key decisional needs for primary care patients with complex care needs (ontological contribution), allowing our team to design an innovative

IP-SDM support tool for addressing decisional conflict of multiple stakeholders (practical contribution). We will be the first team to adapt the IP-SDM model for patients with complex care needs (theoretical contribution). Knowledge users will facilitate the implementation of the tool, and disseminate the results in the Canadian primary care network.

**Trial registration number:** Our protocol is registered with PROSPERO (registration number CRD42015020558).

## Strengths and limitations of this study

- Our review will clarify decisional needs of primary care patients with complex care needs to inform the design of an innovative support tool for addressing stakeholders' decisional conflict.
- This work will be conducted with a participatory research approach involving multiple stakeholders', including patients' perspectives.
- Large team governance can be an issue; thus, an executive task force will carry out the review.
- There is a two-way knowledge gap that our systematic review will help to fill: firstly, the majority of intervention studies address simple care needs rather than complex ones; and secondly, current systematic reviews typically focus on one condition and one homogeneous population.
- The studies heterogeneity challenge will be raised by using an innovative mixed methods design 3-step synthesis to build a taxonomy presenting various key decisional needs configuration.

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## Introduction

#### **Rationale for the review**

The concept of 'patients with complex care needs' refers to people who suffer from combinations of multiple chronic conditions, mental health issues, drug interactions, social vulnerability, and who are associated with health care services overuse, underuse or misuse <sup>1-3</sup>. However, this does not fully capture the complex care needs experience that encompasses individual (patient and practitioner), interpersonal (patient-practitioner or interprofessional), organizational (e.g., resources), and socio-cultural characteristics (e.g., values)<sup>2 4-6</sup>. Typically, patients with complex care needs, their families, their caregivers, and their practitioners (hereafter stakeholders), face interactional issues related to stakeholders' personal uncertainty or disagreements regarding possible options (decisional conflict). Gaps in knowledge of situations where options need to be deliberated (decisional needs) hamper effective decision support interventions for these patients.

Team members contributed to a pilot project that sought to identify characteristics of patients with complex care needs and possible interventions <sup>78</sup>. A case series<sup>7</sup> and a scoping review<sup>8</sup> revealed that interprofessional coordination of care and lack of stakeholders' agreement are two major issues affecting this population. Stakeholders' experience decisional conflict usually associated with knowledge, expectations, personal values, social support and a variety of personal, socio-cultural and clinical characteristics. Three individual evaluation tools of complex care needs <sup>9-11</sup> and one study about patient preference in the context of multi-morbidity were identified <sup>12 13</sup>. In the literature, we found no specific decision support tool that can facilitate shared decision making between a patient with complex care needs, their families and caregivers, and a multidisciplinary team (health and social primary care services). Thus, our target population, patients with complex care needs, can benefit from an interprofessional shared decision making tool (decision support tool) that accounts for the knowledge, values and preferences of all stakeholders <sup>14</sup>.

## Interprofessional Shared Decision Making (IP-SDM) model

Shared Decision Making (SDM) is a process where one patient and one health professional work together to make a healthcare choice; it is essential for informed consent and patient centred care

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<sup>15 16</sup>. Decision aids are a type of decision support tool that fosters shared decision making. As defined by the IPDAS (International Patient Decision Aid Standards)<sup>17</sup> they support a 5-step iterative decision-making process: (a) help patients and professionals identify a decision point and its related options; (b) help them to exchange information about the benefits and limitations of each option; (c) help patients clarify and communicate personal values and preferences; (d) help patients deliberate with diverse professionals about options; and (e) help patients make an informed value-based decision. A Cochrane systematic review of 110 randomized controlled trials provides strong evidence for the effectiveness of SDM and decision support tools <sup>18-21</sup>. Such tools (a) improve decision quality (increase knowledge of options and reduce personal uncertainty and decisional regret); (b) improve patient engagement in healthcare; (c) decrease non-effective healthcare choices. Decision support tools are also effective interventions to improve interactions, patient satisfaction, self-care, and patient-reported outcomes <sup>20 22-27</sup>. In addition, SDM tools have the potential to reduce inequities in health <sup>28</sup>. Therefore, industrialised countries such as Australia<sup>29</sup>, UK<sup>30</sup> and USA<sup>31</sup> are currently implementing large SDM initiatives.

SDM is the most effective decision making process when careful deliberation is needed to address uncertainties inherent to evidence-based medicine, and to weigh the risks and benefits of patients' healthcare choices (based on their values and preferences). Many factors may influence the choices individuals make and the roles they attribute to others and to themselves in the context of interprofessional care <sup>32-35</sup>, which justifies framing this review with the Interprofessional Shared Decision Making (IP-SDM) model (Figure 1) <sup>36</sup>.

The Interprofessional Shared Decision Making (IP-SDM) model extends the SDM beyond the patient-health professional dyad to interprofessional (IP) teams<sup>36 37</sup>. In addition to its interprofessional component, this model proposes to include family members and potential caregiver in a patient-centered process. The IP-SDM also takes into account the environmental complexity in which the SDM takes place (socio-cultural norm, organizational routines, and institutional structure). This model is particularly relevant to help IP teams respond to decisional needs of patients with complex care needs as it helps the stakeholders reach informed value-based decisions <sup>36-38</sup>.

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#### Decisional needs assessment

A decisional need is usually derived from a needs assessment that addresses or focuses on situations where multiple options need to be deliberated. Assessing decisional needs is needed in order to elaborate effective decision support, even more so when an interprofessional team is required to provide decision support to a patient (e.g., IP-SDM tool). Decision support interventions address stakeholders' personal uncertainty (decisional conflict). Indeed, unmet decisional conflict affects the decision quality (e.g., uninformed, not congruent with values and unsupported socially). This in turn may affect behaviour (e.g., uptake and maintenance of the chosen option), lead to negative emotions (e.g., decision regret) and impact health care use (e.g., overuse, underuse and misuse). The Ottawa Decision Support Framework (ODSF) informs the conduct of the decisional needs assessment and thus the design of decision support tools (Figure 2)<sup>39</sup>.

The initial step in the IP-SDM tool development is a decisional needs assessment for primary care patients with complex care needs, which answers the following questions: What are the types of decisions stakeholders have to make? Which decisions are most frequent? Which decisions are the most difficult to make and why? What do the stakeholders need to better support regarding the interprofessional shared decision making process (e.g., information, values clarification, social support or else)? What is currently being done? What are the barriers and facilitators for applying this decision support? Several strategies could be mobilized to assess the stakeholders' decisional needs<sup>14 40</sup>. A systematic review is a good first step.

#### **Review question and objectives**

Our overall review question is: What are, from the perspective of stakeholders, the key decisional needs of patients with complex care needs? In line with the Knowledge Translation (KT) cycle <sup>41</sup>, the purpose of our systematic review is to provide the needed groundwork to identify decisional needs of patients with complex care needs to inform the design of an IP-SDM decision support tool (KT tool). With a task force and a multidisciplinary team including patients, practitioners, researchers, and knowledge users in community-based primary health care, this review aims to: (1) Identify decisional needs of patients with complex care needs from the perspective of stakeholders;

(2) Build a taxonomy of these decisional needs;

(3) Prioritize decisional needs;

(4) Design a decision support tool (with a user-centered approach) to help reconcile stakeholders' decisional conflicts.

#### Methods

This review will use a multipronged approach. First, we will conduct a theory-driven systematic mixed studies review (including qualitative, quantitative and mixed methods studies) <sup>42</sup>. Mixed studies reviews provide a rich and highly practical understanding of complex health issues <sup>43-48</sup>. Second, we will use an organizational participatory research approach to determine key decisional needs. Finally, we will apply a user-centered design approach to elaborate the prototype of a first decision support tool for patient with complex care needs.

We will thus blend research with action using a number of iterative cycles, thereby producing knowledge that can inform healthcare practices <sup>49-52</sup>. It consists of doing research with patients and practitioners, rather than on them; it is a strategy for organizational change and practice improvement <sup>52-56</sup>. It also supports the idea of producing and designing decision support tools that respond to the needs and perspectives of the knowledge users rather than producing tools that they need to adapt to. Both approaches are complementary and suitable for this review as the pilot project emerged from practice. A multidisciplinary team mixing scientific and practical knowledge is necessary to achieve our objectives. Team members are knowledge users, researchers and collaborators with practical knowledge (practitioners and patient partners). Our knowledge users are the directors and the members (clinicians, patients and managers) of the four Quebec network of Practice Based Research Networks (PBRN)<sup>57</sup> and the Ouebec SPOR SUPPORT Unit (SPOR standing for Strategy for Patient Oriented Research). Our end users are the patients, families, caregivers and practitioners. In partnership with knowledge users, we will systematically search, identify, select, appraise, and synthesize qualitative and quantitative evidence. An executive task force will lead the review and mobilize the participatory review team (knowledge users, co-researchers, patient experts, and international experts).

#### Information sources and search strategy

Building on our previous work <sup>7 8</sup>, the concept map and the search strategy was written and tested in collaboration with specialized librarians. Based on the scoping review <sup>7</sup>, we anticipate

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retrieving about 4500 potentially relevant database records (authors, title, source, abstract) in MEDLINE (Ovid), Embase (Ovid), PsycINFO (Ovid), CINAHL (EBSCOhost) and Social Sciences Citation Index (SSCI). In addition, our librarians will provide guidance in searching the grey literature using Google Scholar, Conference Proceedings Citation Index-Science (CPCI-S) and specialized websites. After the selection stage, other potentially relevant records will be sought by tracking citations of included studies using Scopus, up to saturation (no additional studies found). Our team members and the first authors of included studies will be emailed to request additional records or bibliographies.

#### Eligibility criteria and identification of potentially relevant studies

Eligibility criteria will be inspired from the previous scoping reviews on patients with complex care needs <sup>8</sup> with a focus on interactional and decisional issues. A study will be included if it is a French, English, or Spanish language empirical study about:

- Patients with complex care needs (population with at least one of the following characteristics: multiple chronic conditions; mental health issues; drug interactions; social vulnerability; or health care services overuse, underuse and misuse);
- (2) Primary health care setting;
- (3) Interpersonal relationships (reciprocal interaction of two or more persons, e.g., interprofessional, or professional-patient, patient-family or professional-family);
- (4) Decisional needs (factors associated with stakeholders' decisional conflict and affecting the decision making process regarding situations where multiple options are possible).

We expect to identify about 300 potentially relevant studies. We will use EndNote (reference management software) to remove duplicates and store records with indexing terms. For each record, two reviewers will independently assign codes according to our eligibility criteria using specialized software (DistillerSR). For each code, we will measure the agreement between reviewers (kappa) <sup>58 59</sup>. When reviewers disagree, the record will be included in the following selection process.

### Selection of relevant studies (coding full-text documents)

We anticipate including 150 relevant studies as follows. The two reviewers will independently code each full text paper identified in the previous step. As with identification, inter-reviewer agreement will be measured. Disagreements that are not resolved easily will be referred to a third party  $^{60}$ .

#### Critical appraisal of included studies

Critical appraisal is a core component of systematic reviews <sup>41 60</sup>. It provides a rationale to break down the synthesis of included studies by level of quality. We will use the Mixed Methods Appraisal Tool (MMAT) <sup>44 61 62</sup>, a unique validated tool for critically appraising the quality of qualitative, quantitative and mixed methods studies in systematic mixed studies reviews <sup>63</sup>. Using the 2011 version of the MMAT <sup>64</sup> appraisal form and user-manual, two reviewers will independently appraise included studies. As with selection, inter-reviewer agreement will be measured, and disagreements resolved. In line with the GRADE system, results will be expressed using two categories, weak/conditional or strong (qualitative or quantitative or mixed) evidence.

#### Synthesis design

Included studies will be described in a summary table <sup>60 63 65</sup>. Then, guided by a sequential mixed methods design <sup>42 48 66</sup>, we will conduct a 3-step synthesis.

Step 1: Objective 1 -Identify decisional needs from the perspectives of multiple stakeholders For each included study, two reviewers will independently list decisional needs using a deductive/inductive qualitative thematic analysis with specialized software (NVivo 11)<sup>67-70</sup>. For each decisional need (e.g., goal setting), the facilitators (e.g., interpreter) and barriers (e.g., language) influencing the decision will be listed, including stakeholders' information needs (e.g., options list with their potential benefits and harms), values, preferences and sources of support.

Data extraction: A hybrid thematic analysis (deductive/inductive) will be used. All articles will be coded using predefined themes (codebook) derived from the IP-SDM model and the ODSF (framework for decisional needs assessment)<sup>40</sup>, as well as themes suggested by the data; thus, creating an inventory of decisional needs and their facilitators and barriers. A comparative

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analysis will be conducted to explore similarities/differences between patients' and practitioners' perspectives. Consistency and rigor will be ensured via a process of combining interpretations and dialogues <sup>69 71</sup>. Executive task force team members will examine the inventory and written interpretations, and ask the reviewers to explain strengths and limitations of their interpretations (trustworthiness) and to suggest alternative interpretations.

Data synthesis: A summary table of the analysis will be made by systematically noting the following for all decisional needs: label, definition, patients' and practitioners' perspectives, facilitators that simplify patients' decisions, barriers that make decisions difficult with patients, key excerpts of articles broken down by decisional need (illustrative examples), and GRADE. The summary table will be posted on our review blog, and the team will provide feedback. Given the feedback, some of the decisional needs will be revised, and modifications will be discussed. Then, a harmonization of themes will be conducted <sup>72</sup>. For each term, the usage will be confirmed in reference to documents on decision making (distinguishing accurate from improper usage), and accurate usages will be adopted to avoid ambiguity.

#### Step 2: Objective 2 – Build a taxonomy of decisional needs

The Configurational Comparative Method (CCM) is a case-based analysis useful for building taxonomies <sup>73 74</sup>. For this review, each included study will be a case. Using CCM, we will determine commonalities in the relationships between decisional needs, their facilitators and barriers. We will use CCM to test relationships between decision-related variables using Boolean algebra. CCM is appropriate for two reasons: the theory-driven approach and the heterogeneity of study designs.

Data extraction: We will use a data extraction form to ensure a systematic process <sup>75</sup>. Then, we will conduct a quantitative content analysis <sup>76</sup>. The codebook will contain categories listed in step-one (deductive coding), and will be tested by two coders using a random sample of 10% of our cases (studies). For each case, the two coders will independently assign text excerpts to codes (variables and values). This will produce a table of raw data. Inter-coder agreement will be measured (kappa). Disagreements that are not resolved easily will be referred to a third party. For each code with less than substantial agreement (kappa<0.61) <sup>59</sup>, the codebook will be revised

(label, definition and key extracts) and an additional random sample of cases (10%) will be coded.

Data synthesis: Data will be discussed by executive task force members, to produce a table of binary variables with cases in rows and variables in columns. Then, we will conduct the CCM <sup>73</sup> <sup>74</sup>, group similar cases in sets, and produce a table of configurations of decisional needs (sets in rows, variables in columns). Results will be interpreted by going back and forth between configurations and cases. The configurations will allow us to 'pose more focused questions' on the cases <sup>74</sup>. Configurations of decisional needs and interpretations will be reviewed. The configurations of decisional needs will be posted on the blog, and feedback provided by the team. Discrepancies that are not resolved easily will be referred to a third party. The synthesis will produce a comprehensive taxonomy of decisional needs for primary care patients with complex care needs.

#### Step 3: Objective 3 - Determine key decisional needs

The taxonomy will be discussed in a half-day workshop with team members, and a penultimate taxonomy will be posted on the blog. Then, the importance of decisional needs (taxonomy elements) will be rated by the team with a blog-embedded web-questionnaire and a 5-item Likert scale (from 'not important at all' to 'extremely important'). Discrepancies (e.g., a need with a variety of ratings from low to high importance) that are not resolved easily will be referred to a third party. This will produce a taxonomy of key decisional needs, facilitators and barriers. The taxonomy will be compared to the qualitative results of a provincial Demonstration Project of the Quebec SPOR SUPPORT Unit funded by CIHR (Canadian Institutes of Health Research), Quebec Ministry of Health and FRQS (Quebec Research Fund). The demonstration project, conducted by co-authors of this review, focuses on primary care patients with complex care needs. In this other project, semi-structured interviews and focus group will be done with patients/relatives, health/social professionals and decision makers to explore their perspectives of decisional needs of patients with complex care needs. The demonstration project and this systematic review will be done concurrently to validate emerging decisional needs. This will give a deeper and broader understanding to better inform the design of an IP-SDM decision support tool.

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#### **Objective 4 - Design an IP-SDM decision support tool**

In a second workshop, participants will determine how results can inform the design of an initial version (V1) of the proposed IP-SDM support tool. Note that given the difficulty in assembling all team members at the same time, this workshop will be held twice: once with local team members and once with international experts (online). Having designed V1 of the tool, we will proceed with its diffusion, dissemination and implementation.

Diffusion, our broadest strategy, will involve raising general awareness about our results and the tool through conference presentations and publications based on International Patient Decision Aid Standards (IPDAS)<sup>1</sup>. Dissemination, a more active and targeted strategy, will consist of reaching other Knowledge Users through websites, listservs, and peer networks through the Canadian primary care and SPOR networks. Implementation in clinical settings will be conducted within the Demonstration Project of the Quebec SPOR SUPPORT Unit. This project will begin in 2017, and consists of three sequential phases: the identification of profiles of these patients with complex care needs in administrative databases, an intervention in clinical settings and a pilot pragmatic trial. Our IP-SDM decision support tool will be a component of a case management intervention in the second phase; our review is, thus, timely. In this phase, an ecological content validation will be conducted in six clinical settings <sup>77</sup>. Practitioners, patients and caregivers will be asked to assess V1 (relevance, clarity and representativeness of its elements). Based on results, we will produce a modified version (V2). Then, using a web-application (app) version of V2, usability will be tested <sup>78 79</sup>. The app will be integrated in the case management intervention. After the demonstration project, the four Ouebec PBRNs will be the primary settings targeted for scaling up the implementation of the tool. They include 49 clinics, including most of the Quebec family medicine teaching units (FMUs). These academic units include leaders from multiple professions who have the potential to influence practitioners in other primary care settings.

## **Discussion and dissemination**

Patients with complex care needs are associated with unmet health care needs, overuse, underuse or misuse of health care services, low quality of care, and increased costs of health systems <sup>80-82</sup>.

<sup>&</sup>lt;sup>1</sup> http://www.ipdas.ohri.ca/

Given the aging population and rising rates of chronic disease, the number of patients with complex care needs is growing <sup>3 83 84</sup>. This review and its ensuing tool has the potential to improve the quality of health care they receive.

This systematic review will identify decisional needs of patients with complex care needs from the perspective of stakeholders (substantive contribution). The result of our analysis will offer a working taxonomy of key decisional needs for primary care patients with complex care needs (ontological contribution). We will be the first team to adapt the IP-SDM model for patients with complex care needs (theoretical contribution). The taxonomy of key decisional needs will help to design an innovative IP-SDM support tool (practical contribution). This tool will frame stakeholders' decisional needs, help them understand options (e.g., watchful waiting) and patients' goals, and find the common ground crucial for improving patient-practitioner and interprofessional interactions, quality of decisions and care <sup>85</sup>.

Our systematic review will contribute to bridge two knowledge gaps: on the one hand, the majority of intervention studies address simple care needs rather than complex ones; on the other hand, current systematic reviews typically focus on one condition and one homogeneous population <sup>86-90</sup>. The studies' heterogeneity challenge will be addressed by using an innovative mixed methods design 3-step synthesis to build a taxonomy presenting various key decisional needs' configurations.

Previous studies showed that patients with complex care needs are typically facing interactional issues, which justifies framing this proposal within the IP-SDM model. Strong evidence shows that SDM support tools improve patient-practitioner interactions and decision quality, and reduce ineffective care <sup>20 91-93</sup>. However, we know of no decision support tool that could facilitate shared decision making between patients with complex care needs and multiple professionals. The unique contribution of our review will be to enhance decision support for these patients.

As with all systematic reviews, due to publication bias, our work will be biased toward positive results. This limitation will be reduced by validating the results with the knowledge users and the qualitative results of a provincial Demonstration Project of the Quebec SPOR SUPPORT Unit

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(semi-structured interviews and focus group will be done with patients with complex care needs, relatives, health/social professionals and decision makers to explore their perspectives of decisional needs of patients with complex care needs).

This review emerged from two Quebec PBRNs' pilot work, addresses an important issue for stakeholders and is a priority of the Quebec Ministry of Health <sup>94</sup>. In line with Canadian Institutes for Health Research (CIHR) priorities<sup>2</sup>, patient perspectives will be included in this review given our organizational participatory research and our user-centered design approaches. Results will be disseminated across Quebec PBRNs and the Canadian primary care network. The tool will be used in the Quebec-SPOR SUPPORT Unit's Demonstration Project. Our multidisciplinary team (family medicine, nursing, pharmacology, public health, psychology, and social work) is ideal for achieving our objectives, and for implementing the proposed tool in Quebec and disseminating it across Canada.

## SYSTEMATIC REVIEW STATUS

The review is currently in the protocol and search strategy updating phase. We are testing the search strategy in Ovid MEDLINE (2017/02/06). We expect to complete the selection of relevant studies in 2017 and design the first version of the IP-SDM support tool in 2018.

## ABBREVIATIONS

- CIHR : Canadian Institutes of Health Research
- FRQS: Fond de recherche du Québec Santé
- IP-SDM: Interprofessional Shared Decision Making
- KT: Knowledge Translation
- ODSF: Ottawa Decision Support Framework
- PBRN: Practice Based Research Network
- SPOR: CIHR Strategy for Patient Oriented Research

<sup>&</sup>lt;sup>2</sup> <u>http://www.cihr-irsc.gc.ca/e/193.html</u>

## **KEY TERMS**

• KNOWLEDGE USERS: The directors and the members (clinicians, patients, managers) of the four Quebec PBRNs and the Quebec SPOR SUPPORT Unit.

• MULTIDISCIPLINARY TEAM: Patients, practitioners, knowledge users and researchers.

• PRIMARY CARE: Community based primary health care.

• STAKEHOLDERS: Patients with complex care needs, families, caregivers and practitioners.

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## AUTHOR CONTRIBUTIONS

PP, FL and MB conceived and designed the review with input from all team members. MB drafted the manuscript. All authors (MB, PP, FL, JH, GG, RES, MEP, BMC, BMD, BPL, CY, DB, GJ, GA, GR, GV, GS, HC, KB, KE, KI, LB, LC, LMT, MC, NQ, PR, RB, RE, SI, SN, TD, TM, VI, VB, WM) read, critically revised, and approved the final manuscript. Team members are (i) knowledge users (BMC, BMD, DB, JH, LMT, RE, SI), (ii) researchers (MB, PP, FL, GG, RES, MEP, BPL, CY, GA, GR, HC, KE, LB, LC, VI.), (iii) collaborators (GJ, GS, GV, KB, KI, MC, NQ, RB, TD) and (iv) international experts (PR, SN, TM, VB, WM).

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## **COMPETING INTERESTS**

The authors declare no competing interests.

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## REFERENCES

- 1. Grant RW, Ashburner JM, Hong CS, et al. Defining patient complexity from the primary care physician's perspective: A cohort study. *Ann Intern Med* 2011;155(12):797-804.
- Schaink AK, Kuluski K, Lyons RF, et al. A scoping review and thematic classification of patient complexity: Offering a unifying framework. *Journal of Comorbidity* 2012;2(1):1–9.
- 3. Smith S, Soubhi H, Fortin M, et al. Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. *BMJ* 2012; 345(e5205).
- 4. Loeb DF, Bayliss EA, Binswanger IA, et al. Primary care physician perceptions on caring for complex patients with medical and mental illness. *J Gen Intern Med* 2012;27(8):945-52.
- 5. Safford MM, Allison JJ, Kiefe CI. Patient complexity: More than comorbidity. The vector model of complexity. *J Gen Intern Med* 2007;22(Suppl 3):382-90.
- 6. Johnson DR, Ziersch AM, Burgess T. I don't think general practice should be the front line: Experiences of general practitioners working with refugees in South Australia. *Australia and New Zealand health policy* 2008;5.
- 7. Martello C, Bessière G, Bigras M, et al. What Do We Mean When We Say "This Patient is Complex"? . NAPCRG Annual Conference (North American Primary Care Research Group). New York, 2014.
- 8. Pluye P, Bessière G, Bigras M, et al. Characteristics of Complex Care Needs and Interventions Suited for Patients With Such Needs: A Participatory Scoping Review. NAPCRG Annual Conference (North American Primary Care Research Group). New York, 2014.
- 9. Laerum E, Steine S, Finset A. The Patient Perspective Survey (PPS): A new tool to improve consultation outcome and patient involvement in general practice patients with complex health problems. *Patient Educ Couns* 2004;52(2):201-07.
- 10. Peek CJ. Integrating care for persons, not only diseases. J Clin Psychol Med Settings 2009;16(1):13-20.
- 11. Stiefel FC, Huyse FJ, Söllner W, et al. Operationalizing integrated care on a clinical level: The INTERMED project. *Med Clin North Am* 2006;90(4):713-58.
- 12. Fried TR, Tinetti M, Agostini J, et al. Health outcome prioritization to elicit preferences of older persons with multiple health conditions. *Patient Educ Couns* 2011;83(2):278-82.
- Mangin D, Stephen G, Bismah V, et al. Making patient values visible in healthcare: a systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity. *BMJ Open* 2016;6(6):e010903.
- 14. St-Jacques S, Grenier S, Charland M, et al. Decisional needs assessment regarding Down syndrome prenatal testing: a systematic review of the perceptions of women, their partners and health professionals. *Prenat Diagn* 2008;28(13):1183-203.
- 15. Weston WW. Informed and shared decision-making: the crux of patient-centered care. *CMAJ* 2001;165(4):438-9.
- 16. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns* 2006;60(3):301-12.

- 17. Volk RJ, Llewellyn-Thomas H, Stacey D, et al. Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids. *BMC Med Inform Decis Mak* 2013;13 Suppl 2:S1.
- Legare F, Ratte S, Stacey D, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 2010(5):CD006732.
- 19. Legare F, Stacey D, Turcotte S, et al. Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev* 2014(9):CD006732.
- 20. Stacey D, Legare F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2014(1):CD001431.
- Stacey D, Courtemanche C, Barry M, et al. Cochrane review of patient decision aids for treatment or screening decisions: Update in 2012 reveals 24 new trials for 110 total. 2013 International Shared Decision Making Conference. Lima, Peru., 2013.
- 22. Coleman K, Austin B, Brach C, et al. Evidence on the Chronic Care Model in the new millennium. *Health Affairs* 2009;28(1):75-85.
- 23. Legare F, Stacey D, Briere N, et al. Healthcare providers' intentions to engage in an interprofessional approach to shared decision-making in home care programs: a mixed methods study. *J Interprof Care* 2013;27(3):214-22.
- 24. Légaré F, Witteman H. Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. *Health affairs (Project Hope)* 2013;32(2):276-84.
- 25. Hibbard J, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Affairs* 2013;32(2):207-14.
- 26. Legare F, Dodin S, Stacey D, et al. Patient decision aid on natural health products for menopausal symptoms: randomized controlled trial. *Menopause international* 2008;14(3):105-10.
- 27. Labrecque M, Paunescu C, Plesu I, et al. Evaluation of the effect of a patient decision aid about vasectomy on the decision-making process: a randomized trial. *Contraception* 2010;82(6):556-62.
- 28. Melbourne E, Roberts S, Durand MA, et al. Dyadic OPTION: Measuring perceptions of shared decision-making in practice. *Patient Educ Couns* 2011;83(1):55-7.
- 29. Shared Decision Making: Australian Commission on Safety and Quality in Health Care; 2017 [Available from: <u>https://www.safetyandquality.gov.au/our-work/shared-decision-making/</u> accessed 2 Fev 2017.
- 30. Shared Decision Making: National health service (NHS); 2016 [Available from: <u>http://sdm.rightcare.nhs.uk/</u> accessed 2 Fev 2017.
- 31. The SHARE Approach: Agency for Healthcare Research and Quality (AHRQ); 2016 [Available from: https://www.ahrq.gov/professionals/education/curriculumtools/shareddecisionmaking/index.html accessed 2 Fev 2017.
- 32. Bujold M. Patient's representation of illness as an interdisciplinary communication channel [Article in French]. *Anthropologie et Sociétés* 2008;32(HS):18-25.
- 33. Bujold M. Le patient intégrateur: analyse de l'articulation d'une pluralité de voix / voies dans une clinique intégrative québécoise. Université Laval, 2011.

## BMJ Open

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3	34. Buiold M. Ethnon
4	and heterono
5	2015.26(A).10
6	2013;20(4):14
/	35. Gaboury I, Bujold
0	integrative he
9 10	36. Legare F, Stacey I
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12	2011;25(1):18
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30	41. Straus SE, Tetroe
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32	42. Pluye P, Hong QN
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36	43. Grant M. Booth A
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- 35. Gaboury I, Bujold M, Boon H, et al. Interprofessional collaboration within Canadian integrative healthcare clinics: Key components. *Soc Sci Med* 2009;69(5):707-15.
- 36. Legare F, Stacey D, Pouliot S, et al. Interprofessionalism and shared decision-making in primary care: A stepwise approach towards a new model. *J Interprof Care* 2011;25(1):18-25.
- 37. Legare F, Stacey D, Graham ID, et al. Advancing theories, models and measurement for an interprofessional approach to shared decision making in primary care: a study protocol. *BMC Health Serv Res* 2008;8:2.
- 38. Muntinga ME, Hoogendijk EO, van Leeuwen KM, et al. Implementing the chronic care model for frail older adults in the Netherlands: study protocol of ACT (frail older adults: care in transition). *BMC Geriatr* 2012;12:19.
- 39. Légaré F, O'Connor A, Graham I, et al. Supporting patients facing difficult health care decisions: use of the Ottawa Decision Support Framework. *Canadian Family Physician* 2006;52(4):476-77.
- 40. Jacobsen MJ, O'Connor AM, Stacey D. Decisional Needs Assessment in Populations. A workbook for assessing patients' and practitioners' decision making needs. University of Ottawa1999 [updated 2013] [Available from: <u>https://decisionaid.ohri.ca/docs/implement/Population\_Needs.pdf</u> accessed Feb 2 2017.
- 41. Straus SE, Tetroe J, Graham I. Defining knowledge translation. *Canadian Medical Association Journal* 2009;181(3-4):165-68.
- 42. Pluye P, Hong QN. Combining the power of stories and the power of numbers: Mixed methods research and mixed studies reviews. *Annu Rev Public Health* 2014;35:29-45.
- 43. Grant M, Booth A. A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Info Libr J* 2009;26(2):91-108.
- 44. Pluye P, Gagnon MP, Griffiths F, et al. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *Int J Nurs Stud* 2009;46(4):529-46.
- 45. Pope C, Mays N, Popay J. Synthesizing qualitative and quantitative health evidence: A guide to methods. Berkshire: Open University Press 2007.
- 46. Sheldon TA. Making evidence synthesis more useful for management and policy-making. *J Health Serv Res Policy* 2005;10(3 Suppl. 1):1-5.
- 47. Pluye P, Hong Q, I. V. The plurality of review methods and synthesis methods: Opening-up the definition of systematic reviews [invited peer-reviewed paper on knowledge syntheses]. *J Clin Epi* In Press.
- 48. Hong QN, Pluye P, Bujold M, et al. Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Systematic Reviews* (Accepted).
- 49. What are the key processes associated to outcomes of participatory research with health organizations? A participatory systematic mixed studies review. NAPCRG annual meeting (North American Primary Care Research Group); 2013 Ottawa.

- 50. Pluye P, Nadeau N, Lehoux P. Comment favoriser la recherche clinique en pédopsychiatrie? Une expérience de recherche-action collaborative. *Sante Mentale Quebec* 2001;26(12):245-66.
- 51. Cargo M, Mercer S. The value and challenges of participatory research: Strengthening its practice. *Annu Rev Public Health* 2008;29(1):325-50.
- 52. Waterman H, Tillen D, Dickson R, et al. Action Research: A systematic review and guidance for assessment. *Health Technol Assess* 2001;5(23):iii-157.
- 53. Argyris C, Putnam R, Smith D. Action science : Concepts, methods, and skills for research and intervention. San Francisco, CA: Jossey-Bass 1985.
- 54. Munn-Giddings C, McVicar A, Smith L. Systematic review of the uptake and design of action research in published nursing research, 2000-2005. *J Res Nurs* 2008;13(6):465-77.
- Munten G, Van Den Bogaard J, Cox K, et al. Implementation of evidence-based practice in nursing using action research: A review. *Worldviews Evid Based Nurs* 2010;7(3):135-57.
- 56. Soh K, Davidson P, Leslie G, et al. Action research studies in the intensive care setting: A systematic review. *Int J Nurs Stud* 2011;48(2):258-68.
- 57. Davis MM, Keller S, DeVoe J, et al. Characteristics and lessons learned from practicebased research networks (PBRNs) in the United States. *J Healthc Leadersh* 2012;2012(4):107-16.
- 58. Garson DG. Reliability analysis. Statnotes: Topics in multivariate analysis. In: Garson DG, ed. Raleigh: North Carolina State University, 2010.
- 59. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977;33(1):159-74.
- 60. Higgins J, Green S. Cochrane handbook for systematic reviews of interventions Version 5.1.0 [updated March 2011]: The Cochrane Collaboration; 2011 [Available from: <u>http://www.cochrane-handbook.org</u> accessed Mar 1 2013.
- 61. Pace R, Pluye P, Bartlett G, et al. Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *Int J Nurs Stud* 2012;49(1):47-53.
- 62. Souto RQ, Khanassov V, Hong QN, et al. Systematic mixed studies reviews: Updating results on the reliability and efficiency of the mixed methods appraisal tool. *International journal of nursing studies* 2015;52:500-01.
- 63. Crowe M, Sheppard L. A review of critical appraisal tools show they lack rigor: Alternative tool structure is proposed. *J Clin Epidemiol* 2011;64(1):79-89.
- 64. Pluye P, Robert E, Cargo M, et al. Proposal: A mixed methods appraisal tool for systematic mixed studies reviews Department of Family Medicine, McGill University, Montreal, Canada.2011 [Available from: <u>http://mixedmethodsappraisaltoolpublic.pbworks.com</u>. Archived by WebCite® at <u>http://www.webcitation.org/5tTRTc9vl</u> accessed Feb 2 2017.
- 65. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in systematic reviews: Final report. Swindon: ESRC Methods Programme 2006.
- 66. Creswell J, Plano Clark V. Designing and conducting mixed methods research. Thousand Oaks: Sage 2010.
- 67. Bazeley P, Jackson K. Qualitative Data Analysis with NVivo: Colorado and University of Colorado: SAGE Publications Ltd 2013.

## BMJ Open

- 68. Bujold M. Nvivo: a support tool for qualitative analysis. Workshop guide. Montreal, Canada: CAQI 2016.
- 69. Boyatzis RE. Transforming qualitative information: Thematic analysis and code development. Thousand Oaks: Sage 1998.
- 70. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *Int J Qual Methods* 2006; 5(1).
- 71. Sullivan P. Qualitative data analysis using a dialogical approach. London: Sage 2012.
- 72. Pavel S, Nolet D. Handbook of terminology. Ottawa: Minister of Public Works and Government Services Canada, 2001.
- 73. Rihoux B, Marx A. QCA, 25 years after "The Comparative Method": Mapping, challenges, and innovations. *Polit Res Q* 2013;66(1):167-235.
- 74. Rihoux B, Ragin C. Configurational comparative methods. Thousand Oaks: Sage 2009.
- 75. Cochrane Effective Practice and Organisation of Care Review Group. Data collection checklist Ottawa, Canada: Cochrane Effective Practice and Organisation of Care Review Group; 2002 [Available from: http://epoc.cochrane.org/sites/epoc.cochrane.org/files/uploads/datacollectionchec klist.pdf accessed Feb 10 2017.
- 76. Neuendorf KA. The content analysis guidebook. Thousand Oaks: Sage 2002.
- 77. Haynes SN, Richard DCS, Kubany ES. Content validity in psychological assessment: A functional approach to concepts and methods. *Psychol Assess* 1995;7(3):238-47.
- 78. Nielsen J. Usability engineering. Boston: Academic Press 1994.
- 79. Rubin J, Chisnell D. Handbook of usability testing: How to plan, design, and conduct effective tests 2nd ed. Indianapolis: Wiley 2008.
- 80. Rich E, Lipson D, Libersky J, et al. Coordinating care for adults with complex care needs in the patient-centered medical home: Challenges and solutions [White Paper]. Rockville, MD: U.S. Department of Health and Human Services Agency for Healthcare Research and Quality; 2012 [updated 2012; cited 2013 Dec 12]. Available from: http://pcmh.ahrq.gov/sites/default/files/attachments/Coordinating%20Care%20fo r%20Adults%20with%20Complex%20Care%20Needs.pdf accessed Feb 10 2017.
- 81. Rich EC, Lipson D, Libersky J, et al. Organizing care for complex patients in the patientcentered medical home. *Ann Fam Med* 2012;10(1):60-62.
- 82. Schoen C, Osborn R, Squires D, et al. New 2011 survey of patients with complex care needs in 11 countries finds that care is often poorly coordinated. *Health Aff* 2011;30(12):2437-48.
- 83. Hudon C, Chouinard M-C, Couture M, et al. Partners for the optimal organisation of the healthcare continuum for high users of health and social services: protocol of a developmental evaluation case study design. *BMJ open* 2014;4(12):e006991.
- 84. Katerndahl DA, Wood R, Jaen CR. A method for estimating relative complexity of ambulatory care. *Ann Fam Med* 2010;8(4):341-47.
- 85. Coiera E. When conversation is better than computation. *Journal of the American Medical Informatics Association* 2000;7(3):277-86.
- 86. Beaulieu MD, Proulx M, Jobin G, et al. When is knowledge ripe for primary care? An exploratory study on the meaning of evidence. *Eval Health Prof* 2008;31(1):22-42.

- 87. de Bruin S, Versnel N, Lemmens L, et al. Comprehensive care programs for patients with multiple chronic conditions: A systematic literature review. *Health Policy* 2012;107(2-3):108-45.
- 88. Kamerow D. How can we treat multiple chronic conditions? *BMJ* 2012;344(e1487).
- 89. Ouwens M, Wollersheim H, Hermens R, et al. Integrated care programmes for chronically ill patients: A review of systematic reviews. *Int J Qual Health Care* 2005;17(2):141-46.
- 90. Upshur R, Tracy C. Chronicity and complexity: Facing the challenges of chronic disease in primary care. *Can Fam Physician* 2008;54(12):1655-8.
- 91. Shi L. The impact of primary care: A focused review. *Scientifica* 2012;2012.
- 92. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. *Milbank Q* 2005;83(3):457-502.
- 93. Stacey D, Légaré F, Col N, et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane Library* 2014.
- 94. Ministère de la santé et des services sociaux du Québec. Plan stratégique 2015-2020: Québec: Gouvernement du Québec; 2015 [Available from: <u>http://publications.msss.gouv.qc.ca/msss/fichiers/2015/15-717-02W.pdf</u> accessed 10 Feb 2017.

#### FIGURES

#### Figure 1. The InterProfessional Shared Decision Making (IP-SDM) model

Patie	nt/Family team	Interpro	ofessional team	
	Initiator of SI	OM process		
Family/Surrogate/ Significant others	Patient	Decision coach	Health care professional(s)	
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© Légaré F, Stacey D, and IP Team, 2010. Available from www.ohri.ca/decisonaid.

#### Figure 2. The Ottawa Decision Support Framework (ODSF)



AM O'Connor, Ottawa Decision Support Framework to Address Decisional Conflict. © 2006. Available from https://decisionaid.ohri.ca/docs/develop/ODSF.pdf

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5	Section and topic	Item No	Checklist item - http://www.bmj.com/content/349/bmj.g7647	Check
6	Administrative information			
7	Title			
8	Identification	15	Identify the report as a protocol of a systematic review	1
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10	Update	10	If the protocol is for an update of a previous systematic review,	$\checkmark$
11			identify as such	
12	Registration	2	If registered, provide the name of the registry (such as PROSPERO)	$\checkmark$
14			and registration number	·
15	Authors:			
16	Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol	,
17			authors: provide physical mailing address of corresponding author	$\checkmark$
18	Contributions	2h	Describe contributions of protocol authors and identify the	
19	contributions	50	guaranter of the review	$\checkmark$
20				
21	Amendments	4	If the protocol represents an amendment of a previously completed	/
22			or published protocol, identify as such and list changes; otherwise,	$\checkmark$
23			state plan for documenting important protocol amendments	
24	Support:			
25	Sources	5a	Indicate sources of financial or other support for the review	$\checkmark$
26	Sponsor	5b	Provide name for the review funder and/or sponsor	$\checkmark$
21	Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in	,
20			developing the protocol	$\checkmark$
30	Introduction			
31	Bationale	6	Describe the rationale for the review in the context of what is	
32	Rationale	0	already known	$\checkmark$
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34	Objectives	/	Provide an explicit statement of the question(s) the review will	,
35			address with reference to participants, interventions, comparators,	$\checkmark$
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Methods			
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	
Study records:			
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)	
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	

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5		15b	If data are appropriate for quantitative synthesis, describe planned	
6			summary measures, methods of handling data and methods of	,
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10		15C	Describe any proposed additional analyses (such as sensitivity or	
11			subgroup analyses, meta-regression)	
12		15d	If quantitative synthesis is not appropriate, describe the type of	
13			summary planned	
14	Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication	/
16			bias across studies, selective reporting within studies)	V
17	Confidence in cumulative	17	Describe how the strength of the body of evidence will be assessed	
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## Decisional needs assessment of patients with complex care needs in primary care: a participatory systematic mixed studies review protocol

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17 18	9	
19 20	10	Abstract
21	11	INTRODUCTION
22 23	12	Patients with complex care needs (PCCNs) often suffer from combinations of multiple chronic
24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44	13	conditions, mental health problems, drug interactions and social vulnerability, which can lead to
	14	health care services overuse, underuse or misuse. Typically, PCCNs face interactional issues and
	15	unmet decisional needs regarding possible options in a cascade of interrelated decisions involving
	16	different stakeholders (themselves, their families, their caregivers, their health care practitioners).
	17	Gaps in knowledge, values clarification and social support in situations where options need to be
	18	deliberated hamper effective decision support interventions. This review aims to: (1) assess
	19	decisional needs of PCCNs from the perspective of stakeholders; (2) build a taxonomy of these
	20	decisional needs; and (3) prioritize decisional needs with knowledges users (clinicians, patients
	21	and managers).
	22	
	23	METHODS AND ANALYSIS
	24	This review will be based on the Interprofessional Shared Decision Making (IP-SDM) model and
46	25	the Ottawa Decision Support Framework. Applying a participatory research approach, we will
47 48	26	identify potentially relevant studies through a comprehensive literature search; select relevant
49 50 51 52 53	27	ones using eligibility criteria inspired from our previous scoping review on PCCNs; appraise
	28	quality using the Mixed Methods Appraisal Tool; conduct a 3-step synthesis (sequential
	29	exploratory mixed methods design) to build taxonomy of key decisional needs; and integrate
55	30	these results with those of a parallel PCCNs' qualitative decisional need assessment (semi-
56 57 58 59 60	31	structured interviews and focus group with stakeholders).

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ETHICS AND DISSEMINATION

2017-06-27

#### This systematic review, together with the qualitative study, will produce a working taxonomy of key decisional needs (ontological contribution), to inform the subsequent user-centered design of an IP-SDM support tool for addressing PCCNs' decisional needs with multiple stakeholders (practical contribution). We will adapt the IP-SDM model, normally dealing with a single decision, for PCCNs who experience cascade of decisions involving different stakeholders (theoretical contribution). Knowledge users will facilitate dissemination of the results in the Canadian primary care network. Trial registration number: Our protocol is registered with PROSPERO (registration number CRD42015020558). Strengths and limitations of this study This review will clarify decisional needs of patients with complex care needs (PCCNs) to •

- This review will clarify decisional needs of patients with complex care needs (PCCNs) to
   inform the subsequent user-centered design of an Interprofessional Shared Decision Making
   (IP-SDM) support tool for addressing PCCNs' decisional needs with multiple stakeholders.
- This work will be conducted with a participatory research approach involving multiple
  knowledge users', including patients' perspectives.
  - Large team governance can be an issue; thus, an executive task force will carry out the
     review.
- There is a two-way knowledge gap this systematic review will help to fill: firstly, the majority
   of intervention studies address simple care needs rather than complex ones; and secondly,
   current systematic reviews typically focus on one condition and one homogeneous
- $\frac{4}{5}$  24 population.
  - The studies heterogeneity challenge will be raised by using an innovative mixed methods
     design 3-step synthesis to build a taxonomy presenting various key decisional needs
     configuration.

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Introduction

**Rationale for the review** 

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Community-based primary health care (hereafter, primary care) plays a key role regarding

this does not fully capture the complex care needs experience that encompasses individual

(e.g., resources), and socio-cultural characteristics (e.g., values)<sup>46-8</sup>. Typically, PCCNs face

interactional issues related to personal uncertainty or disagreements regarding possible options

(decisional conflict) and unmet decisional needs (e.g., knowledge acquisition, clarification of

values and preferences, support, and resources). The complexity of decision-making could be

exacerbated by a cascade of interrelated decisions involving different stakeholders (PCCNs, their

situations of complex care needs <sup>1-3</sup>. Patients with complex care needs (PCCNs) often suffer from

combinations of multiple chronic conditions, mental health problems, drug interactions and social

vulnerability, which can lead to health care services overuse, underuse or misuse <sup>145</sup>. However,

(patient and practitioner), interpersonal (patient-practitioner or interprofessional), organizational

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families, their caregivers, their health care practitioners, etc.). Gaps in knowledge, values clarification and social support in these situations where multiple options need to be deliberated (decisional needs) hamper decision support interventions. In a quality improvement process, a group of health and social primary care practitioners, patients and researchers from Practice Based Research Networks (PBRNs) identified the necessity to better understand PCCNs' decisional needs. Team members contributed to a pilot project that sought to identify characteristics of PCCNs and possible support interventions <sup>910</sup>. A case series<sup>9</sup> and a scoping review<sup>10</sup> revealed that interprofessional coordination of care and lack of stakeholders' agreement are two major issues affecting this population. It is necessary to better understand the decisional needs of PCCNs associated with mismatched knowledge, expectations, personal values, as well as social support related to a variety of personal, socio-cultural and clinical characteristics. Three individual evaluation tools of complex care needs <sup>11-13</sup> and one study about patient preference in the context of multi-morbidity were identified <sup>1415</sup>. In the literature, we found no tool to facilitate shared decision making between PCCNs, their families and caregivers, and health care providers. Thus, our target population, PCCNs, may benefit from

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a decisional needs assessment to inform the design of an interprofessional shared decision

2 making tool that accounts for their knowledge, values and preferences<sup>16</sup>.

3 In

#### Interprofessional Shared Decision Making (IP-SDM) model

Shared Decision Making (SDM) is a process where one patient and one health professional work together to make a healthcare choice: it is essential for informed consent and patient centred care <sup>17-22</sup>. Industrialised countries such as Australia<sup>23</sup>, UK<sup>24</sup> and USA<sup>25</sup> are currently implementing large SDM initiatives. SDM is an effective decision making process when careful deliberation is needed to address uncertainties inherent to evidence-based medicine, and to weigh the risks and benefits of patients' healthcare choices (based on their values and preferences). Many factors may influence the choices individuals make and the roles they attribute to others and to themselves in the context of interprofessional care <sup>26-29</sup>, which justifies framing this review with the Interprofessional Shared Decision Making (IP-SDM) model <sup>30</sup>. 

The IP-SDM model extends the SDM beyond the patient-health professional dvad to interprofessional (IP) teams <sup>30-32</sup>. In addition to its interprofessional component, this model proposes to include family members and potential caregivers in a patient-centered process (Figure 1). This model aims to stimulate deliberation and reach a common understanding among patients, family/surrogate/significant others, decision coaches, and health care professionals. The IP-SDM model follows a patient-centered step by step process: (1) choose a decision to make and explore related options; (2) exchange information; (3) clarify values and preferences; (4) assess the feasibility of the decision; (5) choose the preferred decision option; (6) implement the decision; (7) assess the outcome. Based on the IP-SDM model interventions have been developed for specific decision-making situations. For example, a study is currently under way to scale up and evaluate the implementation of IP-SDM intervention for frails elderly clients or their caregivers facing a decision about staving at home or moving elsewhere <sup>33 34</sup>. The IP-SDM also takes into account the environmental complexity in which the SDM takes place (socio-cultural norm, organizational routines, and institutional structure). This model is particularly relevant to help IP teams respond to decisional needs of PCCNs as it helps the stakeholders reach informed value-based decisions <sup>30 31 35</sup>. Typically, the IPSDM is used for one decision. We will be the first
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team to adapt this model for PCCNs who experience complex interrelated decisions involving
 different stakeholders with various opinions.

# 4 Decisional needs assessment

A decisional need is usually derived from a needs assessment that addresses or focuses on a situation where multiple options need to be deliberated. Assessing decisional needs is needed in order to elaborate effective decision support, even more so when an interprofessional team is required to provide decision support to a patient. A decisional needs assessment is particularly relevant for PCCNs, such as prioritizing a cascade of complex decisions that involve multiple stakeholders. Decision support interventions address stakeholders' decisional needs (decisional conflict, lack of knowledge and information exchange, values, expectation and preferences clarification, support and resource). Indeed, unmet decisional needs affects the decision quality (e.g., uninformed, incongruent with values and unsupported socially). This in turn may affect behaviour (e.g., uptake and maintenance of the chosen option), lead to negative emotions (e.g., decision regret) and impact health care use (e.g., overuse, underuse and misuse). The Ottawa Decision Support Framework (ODSF) informs the conduct of the decisional needs assessment <sup>36</sup> 

The decisional needs assessment for PCCNs will answers the following questions: What are the types of decisions have to make complex care needs situations? Which decisions are most frequent? Which decisions are the most difficult to make and why? How these decisions are interrelated? Who are the stakeholders involved in the decision? What is needed to better support regarding the interprofessional shared decision making process (e.g., information, values clarification, social support or else)? What is currently being done? What are the barriers and facilitators for applying this decision support? Several strategies could be mobilized to assess decisional needs of a population<sup>16 38</sup>. One of them consists to review the existing information (i.e. previous studies)<sup>16</sup>. 

29 Review question and objectives

Our overall review question is: What are, from the perspective of stakeholders, the key decisional
 needs of patients with complex care needs (PCCNs)? In line with the Knowledge Translation
 (KT) cycle <sup>39</sup>, the purpose of our systematic review is to provide the needed groundwork to assess

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# 1 decisional needs of PCCNs. With a task force and a multidisciplinary team including researchers

- 2 and knowledge users in community-based primary health care (see table 1), this review aims to:
- 3 (1) Assess decisional needs of PCCNs from the perspective of stakeholders;
- 4 (2) Build a taxonomy of these decisional needs;

(3) Prioritize decisional needs with knowledges users (clinicians, patients, managers).

# 7 Methods

8 This review will use a multipronged approach. First, we will conduct a systematic mixed studies 9 review (including qualitative, quantitative and mixed methods studies)<sup>40</sup>. Mixed studies reviews 10 provide a rich and highly practical understanding of complex health issues <sup>41-46</sup>. Second, we will 11 use an organizational participatory research approach, involving researchers and knowledge users 12 (clinicians, patients, managers), to determine key decisional needs.

We will, thus, blend research with action using a number of iterative cycles, thereby producing knowledge that can inform healthcare practices <sup>47-50</sup>. Organizational participatory research consists of doing research with patients and practitioners, rather than on them; it is a strategy for organizational change and practice improvement <sup>50-54</sup>. It also supports the idea of producing knowledge that respond to the needs and perspectives of the knowledge users rather than producing knowledge to which they need to adapt. This approach is suitable for this review as the pilot project emerged from practice. A multidisciplinary team blending scientific and practical knowledge is necessary to achieve our objectives (table 1). Team members are researchers with various expertise, and knowledge users (directors and clinicians, patients and managers of the four Quebec network of Practice Based Research Networks (PBRN)<sup>55</sup> and the Quebec SPOR SUPPORT Unit (SPOR standing for Strategy for Patient Oriented Research). In partnership with knowledge users, we will systematically search, identify, select, appraise, and synthesize qualitative and quantitative evidence. An executive task force will lead the review and mobilize the participatory review team (knowledge users, co-researchers, patient experts, and international experts). 

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3 4	1	Information sources and search strategy
5	2	Building on our previous work <sup>9 10</sup> , the concept map and the search strategy was written and
6 7	3	tested in collaboration with specialized librarians. Based on the scoping review <sup>9</sup> , we anticipate
8 9	4	retrieving about 4500 potentially relevant database records (authors, title, source, abstract) in
10 11	5	MEDLINE (Ovid), Embase (Ovid), PsycINFO (Ovid), CINAHL (EBSCOhost) and Social
12 13 14	6	Sciences Citation Index (SSCI). In addition, our librarians will provide guidance in searching the
	7	grey literature using Google Scholar, Conference Proceedings Citation Index-Science (CPCI-S)
15 16	8	and specialized websites. After the selection stage, other potentially relevant records will be
17 18	9	sought by tracking citations of included studies using Scopus, up to saturation (no additional
19	10	studies found). Our team members, including knowledge users, will be emailed to request
20	11	additional records or bibliographies.
22 23	12	
24 25	13	Eligibility criteria and identification of potentially relevant studies
26 27 28 29 30 31 32 33 34 35 36 37	14	Eligibility criteria will be based upon the previous scoping reviews on PCCNs <sup>10</sup> with a focus on
	15	interactional and decisional issues. A study will be included if it is a French, English, or Spanish
	16	language empirical study about:
	17	(1) Patients with complex care needs (any study dealing directly or indirectly with PCCNs or a
	18	population with at least one of the following characteristics: multiple chronic conditions;
	19	mental health issues; drug interactions; social vulnerability; or health care services overuse,
	20	underuse and misuse);
38 39	21	(2) Primary health care setting (any study dealing directly with primary health care setting or
40 41	22	indirectly, e.g., links between primary care and secondary or tertiary care setting)
42 43	23	(3) Interpersonal relationships (reciprocal interaction of two or more persons, e.g.,
44	24	interprofessional, or professional-patient, patient-family or professional-family);
45 46	25	(4) Decisional needs (frequent or difficult decisions regarding situations where multiple options
47 48	26	are possible, factors affecting the decision making process, decisional conflict, support and
49 50	27	resources used or needed to improve decision quality, barriers and facilitators to using
51 52	28	decision supports).
53	29	
54 55	30	We expect to identify about 300 potentially relevant studies. We will use EndNote (reference
56 57 58 59	31	management software) to remove duplicates and store records with indexing terms. For each

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record, two reviewers will independently assign codes according to our eligibility criteria using specialized software (DistillerSR). For each code, we will measure the agreement between reviewers (kappa)<sup>56 57</sup>. When reviewers disagree, the record will be included in the following selection process.

#### Selection of relevant studies (coding full-text documents)

We anticipate including 150 relevant studies as follows. The two reviewers will independently code each full text paper identified in the previous step. As with identification, inter-reviewer agreement will be measured. Disagreements that are not resolved easily will be referred to a third party 58.

#### **Critical appraisal of included studies**

Critical appraisal is a core component of systematic reviews <sup>39 58</sup>. It provides a rationale to break down the synthesis of included studies by level of quality. We will use the Mixed Methods Appraisal Tool (MMAT)<sup>42 59 60</sup>, a unique validated tool for critically appraising the quality of qualitative, quantitative and mixed methods studies in systematic mixed studies reviews <sup>61</sup>. Using the 2011 version of the MMAT <sup>62</sup> appraisal form and user-manual, two reviewers will independently appraise included studies. As with selection, inter-reviewer agreement will be measured, and disagreements resolved.

#### Synthesis design

Included studies will be described in a summary table <sup>58 61 63</sup>. Then, guided by a sequential mixed methods design <sup>40 46 64</sup>, we will conduct a 3-step synthesis. 

 Step 1: Objective 1 -Assess decisional needs of PCCNs from the perspective of stakeholders For each included study, two reviewers will independently list decisional needs using a deductive/inductive qualitative thematic analysis with specialized software (NVivo 11)<sup>65-68</sup>. For each decisional need (e.g., goal setting), type of stakeholder (e.g. patient), the facilitators (e.g., interpreter) and barriers (e.g., language) influencing the decision will be listed, including stakeholders' information needs (e.g., list of option with their, respective, potential benefits and harms), values, preferences and sources of support.

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Data extraction: A hybrid thematic analysis (deductive/inductive) will be used. All articles will be coded using predefined themes (codebook) derived from the IP-SDM model and the ODSF (framework for decisional needs assessment)<sup>38</sup>, as well as themes suggested by the data; thus, creating an inventory of decisional needs and their facilitators and barriers. All team members. including knowledge users, will have the opportunity to discuss and refine the code book during online workshops with the executive task force. Consistency and rigor will be ensured via a process of combining interpretations and dialogues <sup>67 69</sup>. Executive task force team members will examine the inventory and written interpretations, and ask the reviewers to explain strengths and limitations of their interpretations (trustworthiness) and to suggest alternative interpretations. A comparative analysis will be conducted to explore similarities/differences among stakeholders' perspectives. Using NVivo 11, the qualitative data (excerpt of the selected studies) will be assigned to the following 'type of stakeholder' attribute value: patients, family, caregivers, practitioners, others. This will allow us, for example, to compare the perceptions that patients have of their decisional needs with those of practitioners. We will also assign other categories of attributes (e.g., types of practitioners) to the data. Data synthesis: A summary table of the analysis will be made by systematically noting the following for all decisional needs: label, definition, type of stakeholder, facilitators that simplify patients' decisions, barriers that make decisions difficult with patients, key excerpts of articles broken down by decisional need (illustrative examples). The summary table will be posted on our review blog, and the team members (researchers and knowledge users) will provide feedback. Given the feedback, some of the decisional needs will be revised, and modifications will be discussed. Then, a harmonization of themes will be conducted  $^{70}$ . For each term, the usage will be confirmed in reference to documents on decision making (distinguishing accurate from improper usage), and accurate usages will be adopted to avoid ambiguity. Step 2: Objective 2 – Build a taxonomy of decisional needs The Configurational Comparative Method (CCM) is a case-based analysis useful for building

taxonomies <sup>7172</sup>. For this review, each included study will be a case. Using CCM, we will 

determine commonalities in the relationships between decisional needs, their facilitators and

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barriers. We will use CCM to test relationships between decision-related variables using Boolean
algebra. The main steps of a CCM analysis are: defining conditions and outcomes, extracting
data, preparing a truth table (cases in row, and conditions and outcome in columns), performing
data minimization with specialized software (QCA-GUI), and interpreting results. CCM is
appropriate for two reasons: the theory-driven approach (IP-SDM) and the heterogeneity of study
designs. The conditions and outcomes will be determined following the qualitative synthesis of
the included studies.

Data extraction: We will use a data extraction form to ensure a systematic process <sup>73</sup>. Then, we will conduct a quantitative content analysis <sup>74</sup>. The codebook will contain categories listed in step-one (deductive coding), and will be tested by two coders using a random sample of 10% of our cases (studies). For each case, the two coders will independently assign text excerpts to codes (variables and values). This will produce a table of raw data. Inter-coder agreement will be measured (kappa). Disagreements that are not resolved easily will be referred to a third party. For each code with less than substantial agreement (kappa< 0.61)<sup>57</sup>, the codebook will be revised (label, definition and key extracts) and an additional random sample of cases (10%) will be coded.

Data synthesis: Data will be discussed by executive task force members, to produce a table of binary variables with cases in rows and variables in columns. Then, we will conduct the CCM <sup>71</sup> <sup>72</sup>, group similar cases in sets, and produce a table of configurations of decisional needs (sets in rows, variables in columns). Results will be interpreted by going back and forth between configurations and cases. The configurations will allow us to 'pose more focused questions' on the cases <sup>72</sup>. Configurations of decisional needs and interpretations will be reviewed. The configurations of decisional needs will be posted on the blog, and feedback provided by the team members. Discrepancies that are not resolved easily will be referred to a third party. The synthesis will produce a comprehensive taxonomy of decisional needs for PCCNs. 

29 Step 3: Objective 3 - Determine key decisional needs

The taxonomy will be discussed in half-day workshops with team members, and a penultimate
taxonomy will be posted on the blog. Then, the importance of decisional needs (taxonomy

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elements) will be rated by the team members with a blog-embedded web-questionnaire and a 5item Likert scale (from 'not important at all' to 'extremely important'). Discrepancies (e.g., a
need with a variety of ratings from low to high importance) that are not resolved easily will be
referred to a third party. This will produce a taxonomy of key decisional needs, facilitators and
barriers.

The taxonomy will be compared and integrated with the results of a parallel qualitative decisional need assessment of PCCNs that is part of the provincial "Demonstration project" of the Quebec SPOR SUPPORT Unit funded by CIHR (Canadian Institutes of Health Research), Quebec Ministry of Health and FRQS (Quebec Research Fund). In this parallel qualitative study, conducted by co-authors of this review, semi-structured interviews and focus group will be done with patients/relatives, health and social primary care practitioners and decision makers to empirically assess decisional needs of PCCNs. This qualitative study will involve four expert patients, including one who is participating in all stages of the systematic review. The qualitative decisional need assessment and this systematic review will be done concurrently to validate emerging decisional needs. This will give a deeper and broader understanding to better inform the subsequent user-centered design of an IP-SDM support tool. 

 

# 19 Discussion and dissemination

Patients with complex care needs (PCCNs) are associated with unmet health care needs, overuse, underuse or misuse of health care services, low quality of care, and increased costs of health systems <sup>75-77</sup>. Given the aging population and rising rates of chronic disease, the number of PCCNs is growing <sup>2 5 78</sup>. This systematic review, together with the parallel qualitative study, will contribute to the assessment of decisional needs of PCCNs from the perspective of stakeholders (substantive contribution). The ultimate result of this work will be a working taxonomy of key decisional needs of PCCNs (ontological contribution). We will adapt the IP-SDM model, normally dealing with a single decision, for PCCNs who experience a cascade of complex interrelated decisions involving different stakeholders with various opinions (theoretical contribution). The taxonomy of key decisional needs will inform the subsequent user-centered design an IP-SDM support tool (practical contribution). This tool will frame PCCNs' decisional needs, help stakeholders prioritize decisions and understand options and PCCNs' goals, and

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facilitate finding a common ground crucial for improving patient-practitioner and
 interprofessional interactions, quality of decisions and care <sup>79</sup>.

This systematic review will help bridge two knowledge gaps: on the one hand, the majority of intervention studies address simple care needs rather than complex ones; on the other hand, current systematic reviews typically focus on one condition and one homogeneous population <sup>80-</sup> <sup>84</sup>. The studies' heterogeneity challenge will be addressed by using an innovative mixed methods design 3-step synthesis to build a taxonomy presenting various key decisional needs' configurations.

Previous studies showed that PCCNs are typically facing interactional issues, which justifies framing this proposal within the IP-SDM model. Evidence shows that SDM support tools improve patient-practitioner interactions and decision quality, and reduce ineffective care <sup>3 85-87</sup>. However, we know of no decision support tool that could facilitate shared decision making between PCCNs and multiple professionals. One contribution of this review will be to enhance decision support for these patients.

As with all systematic reviews, due to publication bias, this work will be biased toward positive results and runs a risk of conflating pre-determined outcomes that were identified by authors of the studies with the decisional needs of PCCNs. This limitation will be reduced by validating the results with the knowledge users (clinicians, patients and managers) and the qualitative results of the Demonstration project of the Quebec SPOR SUPPORT Unit).

This review emerged from two Quebec PBRN pilot work, addresses an important issue for
knowledges users and is a priority of the Quebec Ministry of Health <sup>88</sup>. In line with Canadian
Institutes for Health Research (CIHR) priorities<sup>1</sup>, patients' perspectives will be included in this
review given our organizational participatory research approach and our user-centered design.
Diffusion will involve raising general awareness about our results through conference
presentations and publications. Dissemination, a more active and targeted strategy, will consist of

<sup>&</sup>lt;sup>1</sup> <u>http://www.cihr-irsc.gc.ca/e/193.html</u>

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1					
2 3 1	1	reaching other knowledge users through websites, listservs, and peer networks through Quebec			
5	2	PBRNs and the Canadian SPOR networks.			
6 7	3				
8 9	4				
10 11	5	SYSTEMATIC REVIEW STATUS			
12	6	The review is currently in the protocol and search strategy updating phase. We are testing the			
13 14	7	search strategy in Ovid MEDLINE (2017/02/06). We expect to complete the selection of relevant			
15 16 17	8	studies in 2017 and design the first version of the IP-SDM support tool in 2018.			
17 18	9				
19	10	ABBREVIATIONS			
20 21 22 23	11	CIHR : Canadian Institutes of Health Research			
22 23	12	• FRQS: Fond de recherche du Québec – Santé			
24 25 26 27	13	IP-SDM: Interprofessional Shared Decision Making			
	14	KT: Knowledge Translation			
28	15	ODSF: Ottawa Decision Support Framework			
29 30 31 32	16	PCCNs : Patients with complex care needs			
	17	PBRN: Practice Based Research Network			
33 34	18	SPOR: CIHR Strategy for Patient Oriented Research			
35					
35 36 37 38 39	19	KEY TERMS			
	20				
40 41	21	• KNOWLEDGE USERS: The directors and the members (clinicians, patients, managers) of th			
42	22	four Quebec PBRNs and the Quebec SPOR SUPPORT Unit.			
43 44	23	• TEAM MEMBERS: all co-authors (knowledge users and researchers) and collaborators (see			
45 46	24	acknowledgements).			
47 48	25	• PRIMARY CARE: Community based primary health care.			
49	26	• STAKEHOLDERS: Patients with complex care needs, their families, their caregivers, their			
50 51	27	health care practitioners or any other people involved in decisions-making related to their			
52 53	28	complex care needs (e.g. surrogate, significant others, case manager, decision coach, navigator,			
54 55	29	mediator, interpreter).			
56 57					
57 58					
59 60					

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Duong, Jewish General Hospital, Montreal, Canada; and Fanny Hersson, Department of Family
Medicine, McGill University, Canada).

# 9 AUTHOR CONTRIBUTIONS

PP, FL and MB conceived and designed the review with input from all team members. MB drafted the manuscript. All authors (MB, PP, FL, JH, GG, RES, MEP, MCB, MDB, PLB, YC, BD, JG, AG, RG, VG, SG, CH, BK, EK, IK, BL, CL, MTL, CM, QN, RP, BR, ER, IS, NS, DT, MT, IV, BV, MW) read, critically revised, and approved the final manuscript and will participate to workshops. Executive task force are (MB, PP, RES). Team members are (i) knowledge users (JH, MCB, MDB, BD, BK, IK, MTL, CM, ER, IS, NS, RG, SG); (ii) co-researchers (FL, GG, MEP, PLB, YC, JG, AG, VG, CH, EK, BL, CL, ON, RP, BR, DT, MT, IV, BV, MW, BPL, CY, GA); (iii) international experts (RB, RP, NS, MT, BV, MW). The executive team is doing the bulk of the work. GG participated intensively in the systematic search strategy planning and operationalisation. The authors of this systematic review who are also involved in the qualitative decisional need assessment study are MEP, FL (co-leaders), MB, CH, PP (co-researchers) and BD, MDB (knowledge users).

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30KRS-367087. CIHR had no role in the development of this protocol.

# **29 COMPETING INTERESTS**

30 The authors declare no competing interests.

# Table 1 The multidisciplinary expertise of the research team and collaborators

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EXPERTISE	NAMES*	Ν			
Home health care	Beaulieu, M-C.; Duong, S.; Kremer, B.; Poitras, M-E.	4			
Interprofessional /	Beaulieu, M-C.; Bujold, M.; Couturier, Y.; Haggerty, J.; Légaré, F.;	7			
Integrated care	Poitras, M-E.; Vedel, I.				
Knowledge transfer and	Bigras, M.; Boulet, A.; Bujold, M.; Bush, P.L.; Duong, S.; Giguere,				
participatory research	A.; Grad, R.; Goulet, S.; Granikov, V.; Haggerty, J.; Kremer, B.;				
	Kroger, E.; Légaré, F.; Lussier, M-T.; Martello, C.; Pluye, P.; Pratt,				
	R.; McLauchlin, L.R.; Samson, I.; Senn, N.; Tsujimoto, M.;				
	Ventelou, B.; Vedel, I.; Wensing, M.				
Patients with complex	Bigras, M.; Boulet, A.; Bujold, M.; Couturier, Y.; Débarges, B.;	26			
care needs	Duong, S.; Goulet, S.; Grad, R.; Granikov, V.; Hudon, C.; Kremer,				
	B.; Kroger, E.; Lebouché, B.; Loignon, C.; Lussier, M-T.;				
	McLauchlin, L.R.; Martello, C.; Poitras, M-E.; Pluye, P.; Pratt, R.;				
	Rosenberg, E.; Samson, I.; Senn, N.; Ventelou, B.; Tsujimoto, M.;				
	Vedel, I.; Wensing, M.				
Patient and partner	Bujold, M.; Bush, P.L.; Débarges, B.; Granikov, V.; Loignon, C.;	8			
engagement	Pluye, P.; Poitras, M-E.; Samson, I.				
Populations in situations	Couturier, Y.; Giguere, A.; Hudon, C.; Loignon, C.; Lebouché, B.;	10			
of vulnerability	Kroger, E.; Rosenberg, E.; Tsujimoto, M.; Samson, I.; Ventelou, B.				
Shared Decision Making	Bujold, M.; Légaré, F.; Haggerty, J.; Hudon, C.; Giguere, A.;	11			
	Lussier, M-T.; Pluye, P.; Poitras, M-E.; Rosenberg, E.; Senn, N.;				
~ · · · ·	Wensing, M.				
Systematic mixed	Bujold, M.; Bush, P.L.; El Sherif, R.; Gore, G.; Kroger, E.;	13			
studies reviews	Lebouche, B.; Legare, F.; Pluye, P.; Rihoux, B.; Rosenberg, E.;				
T 11 1 1	Tang, D.; Vedel, I.; Wensing, M.				
Tool development and	Bujold, M.; El Sherit, R.; Grad, R.; Giguere, A.; Lussier, M-1.;	11			
validation	Legare, F.;, Li Iang, D.; Pluye, P.; Pratt, R.; Senn, N.; Wensing, M.	N			
PROFESSION	NAMES*	N			
Biology	Bujold, M.; Debarges, B.; Giguere, A.	3			
Computer science	lang, D.,	1			
Epidemiology	Haggerty, J.; El Sherif, R.; , Kröger, E.	3			
Librarianship	Gore, G.; Granikov, V.	2			
Medicine	Bigras, M.; Beaulieu, M-C.; Beaulieu, M.D.; Goulet, S.; Grad, R.;	19			
	Hersson, F.; Hudon, C.; Lebouché, B.; Légaré, F.; Lussier, M-T.;				
	Martello, C.; McLauchlin, L.R.; Pluye, P.; Pratt, R.; Rosenberg, E.;				
	Samson, I.; Senn, N.; Ventelou, B.; Wensing, M.				
Nursing	Boulet, A.; Poitras, M-E.;	2			
Occupational/physical	Bush, P.L.	1			
therapy					
Pharmacy	Duong, S.; Kroger, E.	2			
Public health	Legare, F.; Loignon, C.; Pluye, P.; Vedel, I.; Wensing, M.	5			
Social work and social	Bujold, M.; Couturier, Y.; Gagnon, J.; Hudon, C.; Loignon, C.;	6			
sciences	Rihoux, B.				

\*Alphabetical order

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Figure 1 legend. The Interprofessional Shared Decision Making (IP-SDM) model was designed

to broaden the perspective of shared decision making (SDM) beyond the patient-practitioner dyad
 and include interprofessional (IP) teams. For more details on the IP-SDM model, please

4 consult the following website:

http://www.decision.chaire.fmed.ulaval.ca/en/research/projects/interprofessional-approaches/

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2		
3 4	1	REFERENCES
5	2	1. Grant RW, Ashburner JM, Hong CS, et al. Defining patient complexity from the primary
6	3	care physician's perspective: A cohort study. Ann Intern Med 2011;155(12):797-804.
/ 8	4	2. Katerndahl DA, Wood R, Jaen CR. A method for estimating relative complexity of
9	5	ambulatory care. <i>Ann Fam Med</i> 2010;8(4):341-47.
10	6	3. Shi L. The impact of primary care: A focused review. <i>Scientifica</i> 2012;2012.
11	7	4. Schaink AK, Kuluski K, Lyons RF, et al. A scoping review and thematic classification of
12	8	patient complexity: Offering a unifying framework. Journal of Comorbidity
13	9	2012;2(1):1-9.
15	10	5. Smith S, Soubhi H, Fortin M, et al. Managing patients with multimorbidity: systematic
16	11	review of interventions in primary care and community settings. <i>BMJ</i> 2012;
17	12	345(e5205).
18 10	13	6. Loeb DF, Bayliss EA, Binswanger IA, et al. Primary care physician perceptions on caring
20	14	for complex patients with medical and mental illness. J Gen Intern Med
21	15	2012;27(8):945-52.
22	16	7. Safford MM, Allison JJ, Kiefe CI. Patient complexity: More than comorbidity. The vector
23	17	model of complexity. <i>J Gen Intern Med</i> 2007;22(Suppl 3):382-90.
24 25	18	8. Johnson DR, Ziersch AM, Burgess T. I don't think general practice should be the front line:
26	19	Experiences of general practitioners working with refugees in South Australia.
27	20	Australia and New Zealand health policy 2008;5.
28	21	9. Martello C, Bessière G, Bigras M, et al. What Do We Mean When We Say "This Patient is
29	22	Complex"? . NAPCRG Annual Conference (North American Primary Care Research
31	23	Group). New York, 2014.
32	24	10. Pluye P, Bessière G, Bigras M, et al. Characteristics of Complex Care Needs and
33	25	Interventions Suited for Patients With Such Needs: A Participatory Scoping Review.
34 25	26	NAPCRG Annual Conference (North American Primary Care Research Group). New
36	27	York, 2014.
37	28	11. Laerum E, Steine S, Finset A. The Patient Perspective Survey (PPS): A new tool to
38	29	improve consultation outcome and patient involvement in general practice patients
39	30	with complex health problems. <i>Patient Educ Couns</i> 2004;52(2):201-07.
40 41	31	12. Peek CJ. Integrating care for persons, not only diseases. J Clin Psychol Med Settings
42	32	2009;16(1):13-20.
43	33 24	The INTERMED project Mod Clip North Am 2006:00(4):712 59
44	34 25	14 Fried TD Tinetti M Agestini L et al Health outcome prioritization to elicit preferences of
40 46	33 26	older parsons with multiple health conditions. <i>Datient Educ Cours</i> 2011;82(2):278
47	30	
48	38	02. 15 Mangin D. Stenhen C. Rismah V. et al. Making nationt values visible in healthcare: a
49	30	systematic review of tools to assess nationt treatment priorities and preferences in
50 51	40	the context of multimorbidity <i>BMI Open</i> 2016;6(6):e010903
52	41	16 St-Jacques S Grenier S Charland M et al Decisional needs assessment regarding Down
53	42	syndrome prenatal testing: a systematic review of the perceptions of women their
54	43	partners and health professionals. <i>Prenat Diagn</i> 2008-28(13)-1183-203
55 56	44	17. Weston WW. Informed and shared decision-making: the crux of patient-centered care.
57	45	<i>CMAI</i> 2001:165(4):438-9.
58		
59		
60		

2		
3	1	18. Makoul G. Clayman ML. An integrative model of shared decision making in medical
4	2	encounters. Patient Educ Couns 2006:60(3):301-12.
5	3	19 Legare F Ratte S Stacey D et al. Interventions for improving the adoption of shared
0 7	4	decision making by healthcare professionals. Cochrane Database Syst Rev
8	5	2010(5)·CD006732
9	6	20 Legare F. Stacey D. Turcotte S. et al. Interventions for improving the adoption of shared
10	7	decision making by healthcare professionals. Cochrane Database Syst Pay
11	0	2014(0).CD006722
12	8	2014(9):CD006/32.
13	9	21. Legare F, witteman H. Snared decision making: Examining key elements and barriers to
15	10	adoption into routine clinical practice. Health affairs (Project Hope) 2013;32(2):276-
16	11	
17	12	22. Melbourne E, Roberts S, Durand MA, et al. Dyadic OPTION: Measuring perceptions of
18	13	shared decision-making in practice. <i>Patient Educ Couns</i> 2011;83(1):55-7.
19	14	23. Shared Decision Making: Australian Commission on Safety and Quality in Health Care;
20	15	2017 [Available from: <u>https://www.safetyandquality.gov.au/our-work/shared-</u>
21	16	decision-making/ accessed 2 Fev 2017.
23	17	24. Shared Decision Making: National health service (NHS); 2016 [Available from:
24	18	http://sdm.rightcare.nhs.uk/ accessed 2 Fev 2017.
25	19	25. The SHARE Approach: Agency for Healthcare Research and Quality (AHRQ); 2016
26	20	[Available from: https://www.ahrq.gov/professionals/education/curriculum-
27	21	tools/shareddecisionmaking/index.html accessed 2 Fey 2017.
28	22	26. Bujold M. Patient's representation of illness as an interdisciplinary communication
29 30	23	channel [Article in French]. Anthropologie et Sociétés 2008:32(HS):18-25.
31	24	27. Bujold M. Le natient intégrateur: analyse de l'articulation d'une pluralité de voix / voies
32	25	dans une clinique intégrative québécoise Université Laval 2011
33	26	28 Buiold M Ethnomedical ethics with regard to national plurivocality: between autonomy
34	20	and heteronomy [Article in French] Journal International de Rioéthique
35	27	
30	20	2015,20(4).19-50.
38	29	29. Gaboury I, Bujolu M, Booli H, et al. Interprofessional conaboration within Canadian
39	30 21	Integrative heatincare chinics: Key components. <i>Soc Sci Med</i> 2009;09(5):707-15.
40	31	30. Legare F, Stacey D, Poullot S, et al. Interprofessionalism and shared decision-making in
41	32	primary care: A stepwise approach towards a new model. J Interprof Care
42	33	2011;25(1):18-25.
43 11	34	31. Legare F, Stacey D, Graham ID, et al. Advancing theories, models and measurement for
45	35	an interprofessional approach to shared decision making in primary care: a study
46	36	protocol. <i>BMC Health Serv Res</i> 2008;8:2.
47	37	32. Interprofessional Approaches to Shared Decision Making (IP-SDM) 2017 [Available
48	38	from:
49	39	http://www.decision.chaire.fmed.ulaval.ca/en/research/projects/interprofessional-
50 51	40	approaches/ accessed 2017-06-1.
52	41	33. Legare F, Briere N, Stacey D, et al. Implementing shared decision-making in
53	42	interprofessional home care teams (the IPSDM-SW study): protocol for a stepped
54	43	wedge cluster randomised trial. <i>BMJ open</i> 2016;6(11):e014023.
55	44	34. Legare F, Stacey D, Briere N, et al. Healthcare providers' intentions to engage in an
56	45	interprofessional approach to shared decision-making in home care programs: a
5/ 59	46	mixed methods study. <i>J Interprof Care</i> 2013:27(3):214-22.
50 59	-	
60		
		10

Bujold M. et al – A participatory systematic mixed studies review protocol

1		-9
2		
3	1	35. Muntinga ME, Hoogendijk EO, van Leeuwen KM, et al. Implementing the chronic care
4	2	model for frail older adults in the Netherlands: study protocol of ACT (frail older
5	3	adults: care in transition) <i>BMC Geriatr</i> 2012:12:19
0 7	1	26 Lágará F. O'Connor A. Graham L et al Supporting nationts facing difficult health care
8	т с	degiciones use of the Ottawa Degicion Supporting patients facing uniform family
9	5	Development of the Ottawa Decision Support Framework. Cunutian Fumily
10	6	Physician 2006;52(4):476-77.
11	/	37. OHRI. Ottawa Decision Support Framework 2015 [Available from:
12	8	https://decisionaid.ohri.ca/odst.html accessed June 27 2017.
13	9	38. Jacobsen MJ, O'Connor AM, Stacey D. Decisional Needs Assessment in Populations. A
14 15	10	workbook for assessing patients' and practitioners' decision making needs.
15 16	11	University of Ottawa1999 [updated 2013] [Available from:
17	12	<u>https://decisionaid.ohri.ca/docs/implement/Population_Needs.pdf</u> accessed Feb 2
18	13	2017.
19	14	39. Straus SE, Tetroe J, Graham I. Defining knowledge translation. Canadian Medical
20	15	Association Journal 2009;181(3-4):165-68.
21	16	40. Pluye P, Hong ON. Combining the power of stories and the power of numbers: Mixed
22	17	methods research and mixed studies reviews. Annu Rev Public Health 2014:35:29-
23 24	18	45.
25	19	41 Grant M Booth A A typology of reviews: An analysis of 14 review types and associated
26	20	methodologies <i>Health Info Libr I</i> 2009:26(2):91-108
27	20	A2 Pluve P Cagnon MP Criffiths F et al. A scoring system for appraising mixed methods
28	21	research and concomitantly appraising qualitative quantitative and mixed methods
29	22	neimary studies in mixed studies reviews. Int LNurs Stud 2000,46(4),520.46
30	23	2 Done C. Move N. Doney, I. Symthesizing analitative and quantitative health avidence.
32	24	43. Pope C, Mays N, Popay J. Synthesizing quantative and quantitative health evidence: A
33	25	guide to methods. Berkshire: Open University Press 2007.
34	26	44. Sheldon 1A. Making evidence synthesis more useful for management and policy-making.
35	27	J Health Serv Res Policy 2005;10(3 Suppl. 1):1-5.
36	28	45. Pluye P, Hong Q, I. V. The plurality of review methods and synthesis methods: Opening-
37	29	up the definition of systematic reviews [invited peer-reviewed paper on knowledge
30 30	30	syntheses]. <i>J Clin Epi</i> In Press.
40	31	46. Hong QN, Pluye P, Bujold M, et al. Convergent and sequential synthesis designs:
41	32	implications for conducting and reporting systematic reviews of qualitative and
42	33	quantitative evidence. Systematic Reviews (Accepted). 🛛 🦯 🔪
43	34	47. What are the key processes associated to outcomes of participatory research with
44	35	health organizations? A participatory systematic mixed studies review. NAPCRG
40 46	36	annual meeting (North American Primary Care Research Group); 2013 Ottawa.
40 47	37	48. Pluye P, Nadeau N, Lehoux P. Comment favoriser la recherche clinique en
48	38	pédopsychiatrie? Une expérience de recherche-action collaborative. Sante Mentale
49	39	<i>Ouebec</i> 2001:26(12):245-66.
50	40	49 Cargo M Mercer S The value and challenges of narticinatory research. Strengthening its
51	<u>4</u> 1	nractice Annu Roy Public Hoalth 2008:29(1):325-50
52	41 1/2	50 Waterman H. Tillen D. Dickson R. et al. Action Research: A systematic review and
53 54	т <u>с</u> 12	guidance for accomment Health Technol Access 2001.E(22).iii 1E7
55	т <u>ј</u> ЛЛ	Sumance for assessment. <i>Incului reclinior Assess</i> 2001, 3(23). <sup>III-137</sup> .
56	44 15	ond intervention. Son Francisco, CA, Jossey Page 1005
57	45	and intervention. San Francisco, CA: Jossey-Bass 1985.
58		
59		
60		

1		
2		
3	1	52. Munn-Giddings C. McVicar A. Smith L. Systematic review of the uptake and design of
4	2	action research in nublished nursing research 2000-2005 <i>LRes Nurs</i>
5	2	2008-13(6)-465-77
6 7	3	2000,15(0).405-77.
/ 0	4	53. Munten G, van Den Bogaard J, Cox K, et al. Implementation of evidence-based practice in
o Q	5	nursing using action research: A review. Worldviews Evid Based Nurs 2010;7(3):135-
10	6	57.
11	7	54. Soh K, Davidson P, Leslie G, et al. Action research studies in the intensive care setting: A
12	8	systematic review. Int J Nurs Stud 2011;48(2):258-68.
13	9	55. Davis MM, Keller S, DeVoe J, et al. Characteristics and lessons learned from practice-
14	10	hased research networks (PBRNs) in the United States I Healthe Leadersh
15	11	2012·2012(4)·107-16
16	11	2012,2012(4).107-10.
17	12	56. Garson DG. Renability analysis. Stathotes: Topics in multivariate analysis. In: Garson DG,
18	13	ed. Raleigh: North Carolina State University, 2010.
19	14	57. Landis JR, Koch GG. The measurement of observer agreement for categorical data.
20	15	<i>Biometrics</i> 1977;33(1):159-74.
21	16	58. Higgins J, Green S. Cochrane handbook for systematic reviews of interventions Version
22	17	5.1.0 [updated March 2011]: The Cochrane Collaboration; 2011 [Available from:
23	18	http://www.cochrane-handbook.org accessed Mar 1 2013.
25	19	59 Pace R Pluve P Bartlett C et al Testing the reliability and efficiency of the pilot Mixed
26	20	Mothods Appraical Tool (MMAT) for systematic mixed studios review. Int I Nurs Stud
27	20	2012 AO(1) A7 52
28	21	2012;49(1):47-53.
29	22	60. Souto RQ, Khanassov V, Hong QN, et al. Systematic mixed studies reviews: Updating
30	23	results on the reliability and efficiency of the mixed methods appraisal tool.
31	24	International journal of nursing studies 2015;52:500-01.
32	25	61. Crowe M, Sheppard L. A review of critical appraisal tools show they lack rigor:
33	26	Alternative tool structure is proposed. <i>J Clin Epidemiol</i> 2011;64(1):79-89.
34 25	27	62. Pluve P. Robert E. Cargo M. et al. Proposal: A mixed methods appraisal tool for
36	28	systematic mixed studies reviews Department of Family Medicine McGill University
37	20	Montroal Canada 2011 [Available from:
38	29	http://miyodmothedeenpreiselteelpublicaphyorks.com Archived by WebCite@ at
39	30	<u>Inter://Intxeumethousappraisantooipublic.pdworks.com</u> . Archiveu by webchew at
40	31	<u>http://www.webcitation.org/5t1R1c9y1</u> accessed Feb 2 2017.
41	32	63. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in
42	33	systematic reviews: Final report. Swindon: ESRC Methods Programme 2006.
43	34	64. Creswell J, Plano Clark V. Designing and conducting mixed methods research. Thousand
44	35	Oaks: Sage 2010.
45	36	65. Bazeley P. Jackson K. Qualitative Data Analysis with NVivo: Colorado and University of
46	37	Colorado: SAGE Publications Ltd 2013
47 78	38	66 Buiold M Nyivo: a support tool for gualitative analysis Workshop guide Montreal
40 49	20	Consider CAOL 2016
50	39	Canada: CAQI 2016.
51	40	67. Boyatzis RE. Transforming qualitative information: Thematic analysis and code
52	41	development. Thousand Oaks: Sage 1998.
53	42	68. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid
54	43	approach of inductive and deductive coding and theme development. Int J Qual
55	44	<i>Methods</i> 2006; 5(1).
56	45	69. Sullivan P. Qualitative data analysis using a dialogical approach. London: Sage 2012
57		(activitie and analysis asing a dialogical approach. Benach. Suge Bolb.
58		
59 60		
00		

# BMJ Open

2		
3	1	70. Pavel S, Nolet D. Handbook of terminology. Ottawa: Minister of Public Works and
4	2	Government Services Canada, 2001.
5 6	3	71. Rihoux B, Marx A. OCA, 25 years after "The Comparative Method": Mapping, challenges,
7	4	and innovations. <i>Polit Res (</i> ) 2013:66(1):167-235.
8	5	72. Rihoux B. Ragin C. Configurational comparative methods. Thousand Oaks: Sage 2009.
9	6	73 Cochrane Effective Practice and Organisation of Care Review Group Data collection
10	7	checklist Ottawa Canada: Cochrane Effective Practice and Organisation of Care
11	8	Review Group: 2002 [Available from:
12	g	http://epoc.cochrane.org/sites/epoc.cochrane.org/files/uploads/datacollectionchec
14	10	klist ndf accossed Feb 10 2017
15	10	74 Nouendorf KA. The content analysis guidebook. Thousand Oaks: Sage 2002
16	11	74. Neuenuoni KA. The content analysis guidebook. Thousand Oaks: Sage 2002.
17	12	75. KICH E, LIPSOH D, LIDEISKY J, et al. Coordinating care for adults with complex care needs
18	15	In the patient-centered medical nome: chanenges and solutions [white Paper].
19	14	Rockville, MD: U.S. Department of Health and Human Services Agency for Healthcare
20	15	Research and Quality; 2012 [updated 2012; cited 2013 Dec 12]. Available from:
22	16	http://pcmh.ahrq.gov/sites/default/files/attachments/Coordinating%20Care%20fo
23	17	<u>r%20Adults%20with%20Complex%20Care%20Needs.pdf</u> accessed Feb 10 2017.
24	18	76. Rich EC, Lipson D, Libersky J, et al. Organizing care for complex patients in the patient-
25	19	centered medical home. <i>Ann Fam Med</i> 2012;10(1):60-62.
26	20	77. Schoen C, Osborn R, Squires D, et al. New 2011 survey of patients with complex care
28	21	needs in 11 countries finds that care is often poorly coordinated. <i>Health Aff</i>
29	22	2011;30(12):2437-48.
30	23	78. Hudon C, Chouinard M-C, Couture M, et al. Partners for the optimal organisation of the
31	24	healthcare continuum for high users <mark>of he</mark> alth and social services: protocol of a
32	25	developmental evaluation case study design. <i>BMJ open</i> 2014;4(12):e006991.
33	26	79. Coiera E. When conversation is better than computation. Journal of the American
35	27	Medical Informatics Association 2000;7(3):277-86.
36	28	80. Beaulieu MD, Proulx M, Jobin G, et al. When is knowledge ripe for primary care? An
37	29	exploratory study on the meaning of evidence. <i>Eval Health Prof</i> 2008;31(1):22-42.
38	30	81. de Bruin S, Versnel N, Lemmens L, et al. Comprehensive care programs for patients with
39	31	multiple chronic conditions: A systematic literature review. <i>Health Policy</i>
40 41	32	2012:107(2-3):108-45.
41	33	82. Kamerow D. How can we treat multiple chronic conditions? <i>BMI</i> 2012:344(e1487).
43	34	83 Ouwens M Wollersheim H Hermens R et al Integrated care programmes for
44	35	chronically ill nations: A review of systematic reviews Int I Qual Health Care
45	36	2005.17(2).141.46
46	27	2003,17 (2),111 10. 94 Unchur D. Tragy C. Chronicity and complexity: Facing the challenges of chronic disease
47	37 20	in primary care Can Fam Dhusisian 2009.54(12).1655.9
40 ⊿0	20 20	III pi lillar y care. Cull Full Physician 2006;54(12):1055-6.
<del>-</del> 50	39	85. Stacey D, Legare F, Coi NF, et al. Decision alus for people facing health treatment or
51	40	screening decisions. <i>Locarane Database Syst Rev</i> 2014(1):LD001431.
52	41	86. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health.
53	42	Milbank Q 2005;83(3):457-502.
54	43	87. Stacey D, Légaré F, Col N, et al. Decision aids for people facing health treatment or
55 56	44	screening decisions. <i>The Cochrane Library</i> 2014.
57	45	88. Ministère de la santé et des services sociaux du Québec. Plan stratégique 2015-2020:
58	46	Québec: Gouvernement du Québec; 2015 [Available from:
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The Interprofessional Shared Decision Making (IP-SDM) model was designed to broaden the perspective of shared decision making (SDM) beyond the patient-practitioner dyad and include interprofessional (IP) teams. For more details on the IP-SDM model, please consult the following website: http://www.decision.chaire.fmed.ulaval.ca/en/research/projects/interprofessional-approaches/

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Checklist	Page / Line (Main document)	Section and topic	Item No	Checklist item ( <u>http://www.bmj.com/content/349/bmj.g7647</u> )
		Administrative informatio	n	
		Title:		
$\checkmark$	Page 1 - Line 2	Identification	1a	Identify the report as a protocol of a systematic review
n/a		Update	1b	If the protocol is for an update of a previous systematic review, identify as such
$\checkmark$	Page 3 - Lines 10-11	Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number
		Authors:		
✓	Page 1 - Lines 4-30 Page 2 - Lines 1-8	Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author
$\checkmark$	Page 15 - Lines 9-22	Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review
n/a		Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
		Support:		
√	Page 15, lines 2-3 and 25-27	Sources	5a	Indicate sources of financial or other support for the review
✓	Page 15, lines 2-3	Sponsor	5b	Provide name for the review funder and/or sponsor
√	Page 15, lines 25-27	Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
		Introduction		
√	Page 4, lines 3-31 to page 5, lines 1-2	Rationale	6	Describe the rationale for the review in the context of what is already known
$\checkmark$	Page 6, lines 29-32 Page 7, lines 1-5	Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
		Methods		
<ul> <li>✓</li> </ul>	Page 8, lines 13-28	Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review
✓	Page 8, lines 1-11	Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage

√	Page 8, lines 1-31 and page 9, lines 1-10	Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
	p	Study records:		· · · · · · · · · · · · · · · · · · ·
√	Page 8, lines 30-31 and page 9, lines 1-4	Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review
✓	Page 9, lines 1-19	Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)
✓	page 10, lines 1-9	Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators
√	Page 10, lines 27-31	Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications
√	Page 11, lines 2-7 Page 11, lines 29-31 Page 12, lines 1-5	Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale.
√	Page 9, 12-19	Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis
✓	Page 9, lines 21-23 Page 11, lines 19-27 Page 11, lines 29-31 Page 12, lines 1-5	Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised
n/a			15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as $I^2$ , Kendall's $\tau$ )
n/a			15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)
✓	Page 10, line 18-26		15d	If quantitative synthesis is not appropriate, describe the type of summary planned
n/a		Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)
√	Page 9, lines 12-19	Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)

# **BMJ Open**

# Decisional needs assessment of patients with complex care needs in primary care: a participatory systematic mixed studies review protocol

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Bujold M. et al – A participatory systematic mixed studies review protocol

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17 18	9	
19 20 21 22 23	10	Abstract
	11	INTRODUCTION
	12	Patients with complex care needs (PCCNs) often suffer from combinations of multiple chronic
24 25	13	conditions, mental health problems, drug interactions and social vulnerability, which can lead to
26 27	14	health care services overuse, underuse or misuse. Typically, PCCNs face interactional issues and
28	15	unmet decisional needs regarding possible options in a cascade of interrelated decisions involving
30	16	different stakeholders (themselves, their families, their caregivers, their health care practitioners).
31 32 33 34	17	Gaps in knowledge, values clarification and social support in situations where options need to be
	18	deliberated hamper effective decision support interventions. This review aims to: (1) assess
35 36	19	decisional needs of PCCNs from the perspective of stakeholders; (2) build a taxonomy of these
37	20	decisional needs; and (3) prioritize decisional needs with knowledges users (clinicians, patients
38 39 40 41	21	and managers).
	22	
42 43	23	METHODS AND ANALYSIS
44 45	24	This review will be based on the Interprofessional Shared Decision Making (IP-SDM) model and
46	25	the Ottawa Decision Support Framework. Applying a participatory research approach, we will
47 48 49 50 51 52 53 54 55 56 57	26	identify potentially relevant studies through a comprehensive literature search; select relevant
	27	ones using eligibility criteria inspired from our previous scoping review on PCCNs; appraise
	28	quality using the Mixed Methods Appraisal Tool; conduct a 3-step synthesis (sequential
	29	exploratory mixed methods design) to build taxonomy of key decisional needs; and integrate
	30	these results with those of a parallel PCCNs' qualitative decisional need assessment (semi-
	31	structured interviews and focus group with stakeholders).
58 59 60		

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1	ETHICS AND DISSEMINATION	
2	This systematic review, together with the qualitative study (approved by the CIUSSS-SLSJ	
3	ethical committee), will produce a working taxonomy of key decisional needs (ontological	
4	contribution), to inform the subsequent user-centered design of a support tool for addressing	
5	PCCNs' decisional needs (practical contribution). We will adapt the IP-SDM model, normally	
6	dealing with a single decision, for PCCNs who experience cascade of decisions involving	
7	different stakeholders (theoretical contribution). Knowledge users will facilitate dissemination of	
8	the results in the Canadian primary care network.	
9		
10	Trial registration number: Our protocol is registered with PROSPERO (registration number	
11	CRD42015020558).	
12		
13	Strengths and limitations of this study	
14	• This work will be conducted with a participatory research approach involving multiple	
15	knowledge users', including patients' perspectives.	
16	• Large team governance can be an issue; thus, an executive task force will carry out the	
17	review.	
18	• The studies heterogeneity challenge will be raised by using an innovative mixed methods	
19	design 3-step synthesis to build a taxonomy presenting various key decisional needs	
20	configuration.	

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Introduction

**Rationale for the review** 

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Community-based primary health care (hereafter, primary care) plays a key role regarding

this does not fully capture the complex care needs experience that encompasses individual

(e.g., resources), and socio-cultural characteristics (e.g., values)<sup>46-8</sup>. Typically, PCCNs face

interactional issues related to personal uncertainty or disagreements regarding possible options

(decisional conflict) and unmet decisional needs (e.g., knowledge acquisition, clarification of

values and preferences, support, and resources). The complexity of decision-making could be

families, their caregivers, their health care practitioners, etc.). Gaps in knowledge, values

(decisional needs) hamper decision support interventions.

exacerbated by a cascade of interrelated decisions involving different stakeholders (PCCNs, their

clarification and social support in these situations where multiple options need to be deliberated

In a quality improvement process, a group of health and social primary care practitioners, patients

and researchers from Practice Based Research Networks (PBRNs) identified the necessity to

better understand PCCNs' decisional needs. Team members contributed to a pilot project that

and a scoping review<sup>10</sup> revealed that interprofessional coordination of care and lack of

sought to identify characteristics of PCCNs and possible support interventions <sup>910</sup>. A case series<sup>9</sup>

stakeholders' agreement are two major issues affecting this population. It is necessary to better

personal values, as well as social support related to a variety of personal, socio-cultural and

clinical characteristics. Three individual evaluation tools of complex care needs <sup>11-13</sup> and one

study about patient preference in the context of multi-morbidity were identified <sup>1415</sup>. In the

understand the decisional needs of PCCNs associated with mismatched knowledge, expectations,

situations of complex care needs <sup>1-3</sup>. Patients with complex care needs (PCCNs) often suffer from

combinations of multiple chronic conditions, mental health problems, drug interactions and social

vulnerability, which can lead to health care services overuse, underuse or misuse <sup>145</sup>. However,

(patient and practitioner), interpersonal (patient-practitioner or interprofessional), organizational

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literature, we found no tool to facilitate shared decision making between PCCNs, their families
and caregivers, and health care providers. Thus, our target population, PCCNs, may benefit from

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a decisional needs assessment to inform the design of an interprofessional shared decision

2 making tool that accounts for their knowledge, values and preferences<sup>16</sup>.

3 Inte

### Interprofessional Shared Decision Making (IP-SDM) model

Shared Decision Making (SDM) is a process where one patient and one health professional work together to make a healthcare choice: it is essential for informed consent and patient centred care <sup>17-22</sup>. Industrialised countries such as Australia<sup>23</sup>, UK<sup>24</sup> and USA<sup>25</sup> are currently implementing large SDM initiatives. SDM is an effective decision making process when careful deliberation is needed to address uncertainties inherent to evidence-based medicine, and to weigh the risks and benefits of patients' healthcare choices (based on their values and preferences). Many factors may influence the choices individuals make and the roles they attribute to others and to themselves in the context of interprofessional care <sup>26-29</sup>, which justifies framing this review with the Interprofessional Shared Decision Making (IP-SDM) model <sup>30</sup>. 

The IP-SDM model extends the SDM beyond the patient-health professional dvad to interprofessional (IP) teams <sup>30-32</sup>. In addition to its interprofessional component, this model proposes to include family members and potential caregivers in a patient-centered process (Figure 1). This model aims to stimulate deliberation and reach a common understanding among patients, family/surrogate/significant others, decision coaches, and health care professionals. The IP-SDM model follows a patient-centered step by step process: (1) choose a decision to make and explore related options; (2) exchange information; (3) clarify values and preferences; (4) assess the feasibility of the decision; (5) choose the preferred decision option; (6) implement the decision; (7) assess the outcome. Based on the IP-SDM model interventions have been developed for specific decision-making situations. For example, a study is currently under way to scale up and evaluate the implementation of IP-SDM intervention for frails elderly clients or their caregivers facing a decision about staving at home or moving elsewhere <sup>33 34</sup>. The IP-SDM also takes into account the environmental complexity in which the SDM takes place (socio-cultural norm, organizational routines, and institutional structure). This model is particularly relevant to help IP teams respond to decisional needs of PCCNs as it helps the stakeholders reach informed value-based decisions <sup>30 31 35</sup>. Typically, the IPSDM is used for one decision. We will be the first 

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team to adapt this model for PCCNs who experience complex interrelated decisions involving
 different stakeholders with various opinions.

# 4 Decisional needs assessment

A decisional need is usually derived from a needs assessment that addresses or focuses on a situation where multiple options need to be deliberated. Assessing decisional needs is needed in order to elaborate effective decision support, even more so when an interprofessional team is required to provide decision support to a patient. A decisional needs assessment is particularly relevant for PCCNs, such as prioritizing a cascade of complex decisions that involve multiple stakeholders. Decision support interventions address stakeholders' decisional needs (decisional conflict, lack of knowledge and information exchange, values, expectation and preferences clarification, support and resource). Indeed, unmet decisional needs affects the decision quality (e.g., uninformed, incongruent with values and unsupported socially). This in turn may affect behaviour (e.g., uptake and maintenance of the chosen option), lead to negative emotions (e.g., decision regret) and impact health care use (e.g., overuse, underuse and misuse). The Ottawa Decision Support Framework (ODSF) informs the conduct of the decisional needs assessment <sup>36</sup> 

The decisional needs assessment for PCCNs will answers the following questions: What are the types of decisions have to make complex care needs situations? Which decisions are most frequent? Which decisions are the most difficult to make and why? How these decisions are interrelated? Who are the stakeholders involved in the decision? What is needed to better support regarding the interprofessional shared decision making process (e.g., information, values clarification, social support or else)? What is currently being done? What are the barriers and facilitators for applying this decision support? Several strategies could be mobilized to assess decisional needs of a population<sup>16 38</sup>. One of them consists to review the existing information (i.e. previous studies)<sup>16</sup>. 

# 29 Review question and objectives

Our overall review question is: What are, from the perspective of stakeholders, the key decisional
 needs of patients with complex care needs (PCCNs)? In line with the Knowledge Translation
 (KT) cycle <sup>39</sup>, the purpose of our systematic review is to provide the needed groundwork to assess

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decisional needs of PCCNs. With a task force and a multidisciplinary team including researchers 

and knowledge users in community-based primary health care (see table 1), this review aims to:

(1) Assess decisional needs of PCCNs from the perspective of stakeholders;

(2) Build a taxonomy of these decisional needs:

(3) Prioritize decisional needs with knowledges users (clinicians, patients, managers).

#### Methods

This review will use a multipronged approach. First, we will conduct a systematic mixed studies review (including qualitative, quantitative and mixed methods studies)<sup>40</sup>. Mixed studies reviews provide a rich and highly practical understanding of complex health issues <sup>41-46</sup>. Second, we will use an organizational participatory research approach, involving researchers and knowledge users (clinicians, patients, managers), to determine key decisional needs.

We will, thus, blend research with action using a number of iterative cycles, thereby producing knowledge that can inform healthcare practices <sup>47-50</sup>. Organizational participatory research consists of doing research with patients and practitioners, rather than on them; it is a strategy for organizational change and practice improvement <sup>50-54</sup>. It also supports the idea of producing knowledge that respond to the needs and perspectives of the knowledge users rather than producing knowledge to which they need to adapt. This approach is suitable for this review as the pilot project emerged from practice. A multidisciplinary team blending scientific and practical knowledge is necessary to achieve our objectives (table 1). Team members are researchers with various expertise, and knowledge users (directors and clinicians, patients and managers of the four Quebec network of Practice Based Research Networks (PBRN)<sup>55</sup> and the Quebec SPOR SUPPORT Unit (SPOR standing for Strategy for Patient Oriented Research). In partnership with knowledge users, we will systematically search, identify, select, appraise, and synthesize qualitative and quantitative evidence. An executive task force will lead the review and mobilize the participatory review team (knowledge users, co-researchers, patient experts, and international experts). 

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3	1	Information sources and search strategy
4 5	2	Building on our previous work <sup>9 10</sup> , the concept map and the search strategy (see table 2) was
6 7	3	written and tested in collaboration with specialized librarians. Based on the scoping review <sup>9</sup> , we
8 9	4	anticipate retrieving about 4500 potentially relevant database records (authors, title, source,
10 11	5	abstract) in MEDLINE (Ovid), Embase (Ovid), PsycINFO (Ovid), CINAHL (EBSCOhost) and
12	6	Social Sciences Citation Index (SSCI). No search date limit will be used. In addition, our
13 14	7	librarians will provide guidance in searching the grey literature using Google Scholar,
15 16	8	Conference Proceedings Citation Index-Science (CPCI-S) and specialized websites. After the
17 18	9	selection stage, other potentially relevant records will be sought by tracking citations of included
19	10	studies using Scopus, up to saturation (no additional studies found). Our team members,
20 21	11	including knowledge users, will be emailed to request additional records or bibliographies.
22 23	12	
24 25	13	Eligibility criteria and identification of potentially relevant studies
26 27	14	Eligibility criteria will be based upon the previous scoping reviews on PCCNs <sup>10</sup> with a focus on
28	15	interactional and decisional issues. A study will be included if it is a French, English, or Spanish
29 30	16	language empirical study about:
31 32	17	(1) Patients with complex care needs (any study dealing directly or indirectly with PCCNs or a
33 34	18	population with at least one of the following characteristics: multiple chronic conditions;
35	19	mental health issues; drug interactions; social vulnerability; or health care services overuse,
36 37	20	underuse and misuse);
38 39	21	(2) Primary health care setting (any study dealing directly with primary health care setting or
40 41	22	indirectly, e.g., links between primary care and secondary or tertiary care setting)
42	23	(3) Interpersonal relationships (reciprocal interaction of two or more persons, e.g.,
43	24	interprofessional, or professional-patient, patient-family or professional-family);
45 46	25	(4) Decisional needs (frequent or difficult decisions regarding situations where multiple options
47 48	26	are possible, factors affecting the decision making process, decisional conflict, support and
49 50	27	resources used or needed to improve decision quality, barriers and facilitators to using
51	28	decision supports).
52 53	29	
54 55	30	We expect to identify about 300 potentially relevant studies. We will use EndNote (reference
56 57 58 59 60	31	management software) to remove duplicates and store records with indexing terms. For each

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record, two reviewers will independently assign codes according to our eligibility criteria using 

specialized software (DistillerSR). For each code, we will measure the agreement between

reviewers (kappa)<sup>56 57</sup>. When reviewers disagree, the record will be included in the following selection process.

#### Selection of relevant studies (coding full-text documents)

We anticipate including 150 relevant studies as follows. The two reviewers will independently code each full text paper identified in the previous step. As with identification, inter-reviewer agreement will be measured. Disagreements that are not resolved easily will be referred to a third party 58.

#### **Critical appraisal of included studies**

Critical appraisal is a core component of systematic reviews <sup>39 58</sup>. It provides a rationale to break down the synthesis of included studies by level of quality. We will use the Mixed Methods Appraisal Tool (MMAT)<sup>42 59 60</sup>, a unique validated tool for critically appraising the quality of qualitative, quantitative and mixed methods studies in systematic mixed studies reviews <sup>61</sup>. Using the 2011 version of the MMAT <sup>62</sup> appraisal form and user-manual, two reviewers will independently appraise included studies. As with selection, inter-reviewer agreement will be measured, and disagreements resolved.

#### Synthesis design

Included studies will be described in a summary table <sup>58 61 63</sup>. Then, guided by a sequential mixed methods design <sup>40 46 64</sup>, we will conduct a 3-step synthesis. 

 Step 1: Objective 1 -Assess decisional needs of PCCNs from the perspective of stakeholders For each included study, two reviewers will independently list decisional needs using a deductive/inductive qualitative thematic analysis with specialized software (NVivo 11)<sup>65-68</sup>. For each decisional need (e.g., goal setting), type of stakeholder (e.g. patient), the facilitators (e.g., interpreter) and barriers (e.g., language) influencing the decision will be listed, including stakeholders' information needs (e.g., list of option with their, respective, potential benefits and harms), values, preferences and sources of support.

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Data extraction: A hybrid thematic analysis (deductive/inductive) will be used. All articles will be coded using predefined themes (codebook) derived from the IP-SDM model and the ODSF (framework for decisional needs assessment)<sup>38</sup>, as well as themes suggested by the data; thus, creating an inventory of decisional needs and their facilitators and barriers. All team members. including knowledge users, will have the opportunity to discuss and refine the code book during online workshops with the executive task force. Consistency and rigor will be ensured via a process of combining interpretations and dialogues <sup>67 69</sup>. Executive task force team members will examine the inventory and written interpretations, and ask the reviewers to explain strengths and limitations of their interpretations (trustworthiness) and to suggest alternative interpretations. A comparative analysis will be conducted to explore similarities/differences among stakeholders' perspectives. Using NVivo 11, the qualitative data (excerpt of the selected studies) will be assigned to the following 'type of stakeholder' attribute value: patients, family, caregivers, practitioners, others. This will allow us, for example, to compare the perceptions that patients have of their decisional needs with those of practitioners. We will also assign other categories of attributes (e.g., types of practitioners) to the data. Data synthesis: A summary table of the analysis will be made by systematically noting the following for all decisional needs: label, definition, type of stakeholder, facilitators that simplify patients' decisions, barriers that make decisions difficult with patients, key excerpts of articles broken down by decisional need (illustrative examples). The summary table will be posted on our review blog, and the team members (researchers and knowledge users) will provide feedback. Given the feedback, some of the decisional needs will be revised, and modifications will be discussed. Then, a harmonization of themes will be conducted  $^{70}$ . For each term, the usage will be confirmed in reference to documents on decision making (distinguishing accurate from improper usage), and accurate usages will be adopted to avoid ambiguity. 

Step 2: Objective 2 – Build a taxonomy of decisional needs

The Configurational Comparative Method (CCM) is a case-based analysis useful for building

taxonomies <sup>7172</sup>. For this review, each included study will be a case. Using CCM, we will 

determine commonalities in the relationships between decisional needs, their facilitators and

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barriers. We will use CCM to test relationships between decision-related variables using Boolean algebra. The main steps of a CCM analysis are: defining conditions and outcomes, extracting data, preparing a truth table (cases in row, and conditions and outcome in columns), performing data minimization with specialized software (QCA-GUI), and interpreting results. CCM is appropriate for two reasons: the theory-driven approach (IP-SDM) and the heterogeneity of study designs. The conditions and outcomes will be determined following the qualitative synthesis of the included studies.

Data extraction: We will use a data extraction form to ensure a systematic process <sup>73</sup>. Then, we will conduct a quantitative content analysis <sup>74</sup>. The codebook will contain categories listed in step-one (deductive coding), and will be tested by two coders using a random sample of 10% of our cases (studies). For each case, the two coders will independently assign text excerpts to codes (variables and values). This will produce a table of raw data. Inter-coder agreement will be measured (kappa). Disagreements that are not resolved easily will be referred to a third party. For each code with less than substantial agreement (kappa< 0.61)<sup>57</sup>, the codebook will be revised (label, definition and key extracts) and an additional random sample of cases (10%) will be coded.

Data synthesis: Data will be discussed by executive task force members, to produce a table of binary variables with cases in rows and variables in columns. Then, we will conduct the CCM <sup>71</sup> <sup>72</sup>, group similar cases in sets, and produce a table of configurations of decisional needs (sets in rows, variables in columns). Results will be interpreted by going back and forth between configurations and cases. The configurations will allow us to 'pose more focused questions' on the cases <sup>72</sup>. Configurations of decisional needs and interpretations will be reviewed. The configurations of decisional needs will be posted on the blog, and feedback provided by the team members. Discrepancies that are not resolved easily will be referred to a third party. The synthesis will produce a comprehensive taxonomy of decisional needs for PCCNs.

Step 3: Objective 3 - Determine key decisional needs

The taxonomy will be discussed in half-day workshops with team members, and a penultimate taxonomy will be posted on the blog. Then, the importance of decisional needs (taxonomy

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elements) will be rated by the team members with a blog-embedded web-questionnaire and a 5item Likert scale (from 'not important at all' to 'extremely important'). Discrepancies (e.g., a
need with a variety of ratings from low to high importance) that are not resolved easily will be
referred to a third party. This will produce a taxonomy of key decisional needs, facilitators and
barriers.

The taxonomy will be compared and integrated with the results of a parallel qualitative decisional need assessment of PCCNs that is part of the provincial "Demonstration project" of the Quebec SPOR SUPPORT Unit funded by CIHR (Canadian Institutes of Health Research), Quebec Ministry of Health and FRQS (Quebec Research Fund). In this parallel qualitative study, conducted by co-authors of this review, semi-structured interviews and focus group will be done with patients/relatives, health and social primary care practitioners and decision makers to empirically assess decisional needs of PCCNs. This qualitative study will involve four expert patients, including one who is participating in all stages of the systematic review. The qualitative decisional need assessment and this systematic review will be done concurrently to validate emerging decisional needs. This will give a deeper and broader understanding to better inform the subsequent user-centered design of an IP-SDM support tool. 

### 19 Ethics and dissemination

Patients with complex care needs (PCCNs) are associated with unmet health care needs, overuse, underuse or misuse of health care services, low quality of care, and increased costs of health systems <sup>75-77</sup>. Given the aging population and rising rates of chronic disease, the number of PCCNs is growing <sup>2 5 78</sup>. This systematic review, together with the parallel qualitative study, will contribute to the assessment of decisional needs of PCCNs from the perspective of stakeholders (substantive contribution). The qualitative study was approved by the scientific and ethical committee of the "Centre Intégré Universitaire de Santé et Service Sociaux du Saguenav-Lac-Saint-Jean" (Integrated University Centre of Health and Social Services). The ultimate result of this work will be a working taxonomy of key decisional needs of PCCNs (ontological contribution). We will adapt the IP-SDM model, normally dealing with a single decision, for PCCNs who experience a cascade of complex interrelated decisions involving different stakeholders with various opinions (theoretical contribution). The taxonomy of key decisional

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needs will inform the subsequent user-centered design an IP-SDM support tool (practical contribution). This tool will frame PCCNs' decisional needs, help stakeholders prioritize decisions and understand options and PCCNs' goals, and facilitate finding a common ground crucial for improving patient-practitioner and interprofessional interactions, quality of decisions and care <sup>79</sup>.

7 This systematic review will help bridge two knowledge gaps: on the one hand, the majority of 8 intervention studies address simple care needs rather than complex ones; on the other hand, 9 current systematic reviews typically focus on one condition and one homogeneous population <sup>80-</sup> 10 <sup>84</sup>. The studies' heterogeneity challenge will be addressed by using an innovative mixed methods 11 design 3-step synthesis to build a taxonomy presenting various key decisional needs' 12 configurations.

Previous studies showed that PCCNs are typically facing interactional issues, which justifies framing this proposal within the IP-SDM model. Evidence shows that SDM support tools improve patient-practitioner interactions and decision quality, and reduce ineffective care <sup>3 85-87</sup>. However, we know of no decision support tool that could facilitate shared decision making between PCCNs and multiple professionals. One contribution of this review will be to enhance decision support for these patients.

As with all systematic reviews, due to publication bias, this work will be biased toward positive results and runs a risk of conflating pre-determined outcomes that were identified by authors of the studies with the decisional needs of PCCNs. This limitation will be reduced by validating the results with the knowledge users (clinicians, patients and managers) and the qualitative results of the Demonstration project of the Quebec SPOR SUPPORT Unit).

This review emerged from two Quebec PBRN pilot work, addresses an important issue for
knowledges users and is a priority of the Quebec Ministry of Health <sup>88</sup>. In line with Canadian
Institutes for Health Research (CIHR) priorities<sup>1</sup>, patients' perspectives will be included in this

<sup>&</sup>lt;sup>1</sup> http://www.cihr-irsc.gc.ca/e/193.html
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1		
2 3 4 5 6 7 8 9	1	review given our organizational participatory research approach and our user-centered design.
	2	Diffusion will involve raising general awareness about our results through conference
	3	presentations and publications. Dissemination, a more active and targeted strategy, will consist of
	4	reaching other knowledge users through websites, listservs, and peer networks through Quebec
10 11	5	PBRNs and the Canadian SPOR networks.
12	6	
13 14	7	SYSTEMATIC REVIEW STATUS
15 16	8	The review is currently in the protocol and search strategy updating phase. We are testing the
17 18 19 20	9	search strategy in Ovid MEDLINE (2017/02/06). We expect to complete the selection of relevan
	10	studies in 2017 and design the first version of the IP-SDM support tool in 2018.
20	11	
21 22 23 24 25	12	ABBREVIATIONS
24 25	13	CIHR : Canadian Institutes of Health Research
26 27	14	• CIUSSS-SLST : Centre Intégré Universitaire de Santé et Service Sociaux du Saguenay-Lac-
28	15	Saint-Jean (Integrated University Centre of Health and Social Services).
29 30	16	• FRQS: Fond de recherche du Québec – Santé
31 32	17	IP-SDM: Interprofessional Shared Decision Making
33 34	18	KT: Knowledge Translation
35	19	ODSF: Ottawa Decision Support Framework
30 37	20	PCCNs : Patients with complex care needs
38 39 40 41	21	PBRN: Practice Based Research Network
	22	SPOR: CIHR Strategy for Patient Oriented Research
42 43		
44 45	23	KEY TERMS
46 47	24 25	• KNOWLEDGE USERS: The directors and the members (clinicians, patients, managers) of the
48 ⊿9	26	four Quebec PBRNs and the Quebec SPOR SUPPORT Unit.
50	27	• TEAM MEMBERS: all co-authors (knowledge users and researchers) and collaborators (see
51 52 53 54 55 56 57 58 59	28	acknowledgements).
	29	• PRIMARY CARE: Community based primary health care.
	30	• STAKEHOLDERS: Patients with complex care needs, their families, their caregivers, their
	31	health care practitioners or any other people involved in decisions-making related to their
60		1

complex care needs (e.g. surrogate, significant others, case manager, decision coach, navigator, mediator, interpreter).

#### **ACKNOWLEDGEMENTS**

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**AUTHOR CONTRIBUTIONS** 

PP, FL and MB conceived and designed the review with input from all team members. MB drafted the manuscript. All authors (MB, PP, FL, JH, GG, RES, MEP, MCB, MDB, PLB, YC, BD, JG, AG, RG, VG, SG, CH, BK, EK, IK, BL, CL, MTL, CM, QN, RP, BR, ER, IS, NS, DT, MT, IV, BV, MW) read, critically revised, and approved the final manuscript and will participate to workshops. Executive task force are (MB, PP, RES). Team members are (i) knowledge users (JH, MCB, MDB, BD, BK, IK, MTL, CM, ER, IS, NS, RG, SG); (ii) co-researchers (FL, GG, MEP, PLB, YC, JG, AG, VG, CH, EK, BL, CL, QN, RP, BR, DT, MT, IV, BV, MW, BPL, CY, GA); (iii) international experts (RB, RP, NS, MT, BV, MW). The executive team is doing the bulk of the work. GG participated intensively in the systematic search strategy planning and operationalisation. The authors of this systematic review who are also involved in the qualitative decisional need assessment study are MEP, FL (co-leaders), MB, CH, PP (co-researchers) and BD, MDB (knowledge users).

### **FUNDING STATEMENT**

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# **COMPETING INTERESTS**

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1 The authors declare no competing interests.

Ν 

Table 1 The multidisci	plinary expertise of the research team and collaborators
EXPERTISE	NAMES*
Home health care	Beaulieu, M-C.; Duong, S.; Kremer, B.; Poitras, M-E.
Interprofessional /	Beaulieu, M-C.; Bujold, M.; Couturier, Y.; Haggerty, J.; Légaré, F.
Integrated care	Poitras, M-E.; Vedel, I.
Knowledge transfer and participatory research	Bigras, M.; Boulet, A.; Bujold, M.; Bush, P.L.; Duong, S.; Giguere A.; Grad, R.; Goulet, S.; Granikov, V.; Haggerty, J.; Kremer, B.; Kroger, E.; Légaré, F.; Lussier, M-T.; Martello, C.; Pluye, P.; Pratt R.; McLauchlin, L.R.; Samson, I.; Senn, N.; Tsujimoto, M.; Ventelou, B.; Vedel, I.; Wensing, M.
Patients with complex	Bigras, M.; Boulet, A.; Bujold, M.; Couturier, Y.; Débarges, B.;

	Ventelou, B.; Vedel, I.; Wensing, M.	
Patients with complex	Bigras, M.; Boulet, A.; Bujold, M.; Couturier, Y.; Débarges, B.;	26
care needs	Duong, S.; Goulet, S.; Grad, R.; Granikov, V.; Hudon, C.; Kremer,	
	B.; Kroger, E.; Lebouché, B.; Loignon, C.; Lussier, M-T.;	
	McLauchlin, L.R.; Martello, C.; Poitras, M-E.; Pluye, P.; Pratt, R.;	
	Rosenberg, E.; Samson, I.; Senn, N.; Ventelou, B.; Tsujimoto, M.;	
	Vedel, I.; Wensing, M.	
Patient and partner	Bujold, M.; Bush, P.L.; Débarges, B.; Granikov, V.; Loignon, C.;	8
engagement	Pluye, P.; Poitras, M-E.; Samson, I.	
Populations in situations	Couturier, Y.; Giguere, A.; Hudon, C.; Loignon, C.; Lebouché, B.;	10
of vulnerability	Kroger, E.; Rosenberg, E.; Tsujimoto, M.; Samson, I.; Ventelou, B.	
Shared Decision Making	Bujold, M.; Légaré, F.; Haggerty, J.; Hudon, C.; Giguere, A.;	11
	Lussier, M-T.; Pluye, P.; Poitras, M-E.; Rosenberg, E.; Senn, N.;	
	Wensing, M.	
Systematic mixed	Bujold, M.; Bush, P.L.; El Sherif, R.; Gore, G.; Kroger, E.;	13
studies reviews	Lebouché, B.; Légaré, F.; Pluye, P.; Rihoux, B.; Rosenberg, E.;	
	Tang, D.; Vedel, I.; Wensing, M.	
Tool development and	Bujold, M.; El Sherif, R.; Grad, R.; Giguere, A.; Lussier, M-T.;	11
validation	Légaré, F.;, Li Tang, D.; Pluye, P.; Pratt, R.; Senn, N.; Wensing, M.	
PROFESSION	NAMES*	Ν
Biology	Bujold, M.; Débarges, B.; Giguere, A.	3
Computer science	Tang, D.,	1
Epidemiology	Haggerty, J.; El Sherif, R.; , Kröger, E.	3
Librarianship	Gore, G.; Granikov, V.	2
Medicine	Bigras, M.; Beaulieu, M-C.; Beaulieu, M.D.; Goulet, S.; Grad, R.;	19
	Hersson, F.; Hudon, C.; Lebouché, B.; Légaré, F.; Lussier, M-T.;	
	Martello, C.; McLauchlin, L.R.; Pluye, P.; Pratt, R.; Rosenberg, E.;	
	Samson, I.; Senn, N.; Ventelou, B.; Wensing, M.	
Nursing	Boulet, A.; Poitras, M-E.;	2
Occupational/physical	Bush, P.L.	1
therapy		
Pharmacy	Duong, S.; Kroger, E.	2
Public health	Légaré, F.; Loignon, C.; Pluye, P.; Vedel, I.; Wensing, M.	5
Social work and social	Bujold, M.; Couturier, Y.; Gagnon, J.; Hudon, C.; Loignon, C.;	6
sciences	Rihoux, B.	

\*Alphabetical order

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2	
3 1	Table 2 – Search Strategy in Medline - Concent man (Concents #1 and #2 and #3 and #4)
4 2	Table 2 Search Strategy in Medinie - Concept map (Concepts #1 and #2 and #5 and #4)
5 2	CONCEPT #1 DATIENTS WITH COMPLEX CADE NEEDS
6	CONCEPT #1 - PATIENTS WITH COMPLEX CARE NEEDS
7	1 (complex adj4 (problem* or issue* or patient? or need? or care or existence? or experience? or live? or realit* or isourney? or situation?)) to bltf
8	2 complex case? mp
9	
10	3 (complexity adj4 (clinical or patient? or science or theory)).mp.
12	4 ((high-effort or burden or complicated or demanding) adj patient?).mp.
13	5 exp Vulnerable Populations/
14	6 poverty/ or poverty areas/ or unemployment/ or homeless persons/ or homeless youth/ or exp *aged/ or frail
15	elderly/ or exp "Emigrants and Immigrants"/ or minority groups/ or exp disabled persons/ or drug users/ or
16	medically uninsured/ or refugees/ or exp culture/
17	7 (poverty or disadvantaged or underserved or under served or indigen* or tribe? or tribal or native? or aboriginal*
18	or low income* or unemploy* or underemploy* or under employ* or homeless* or street people or street person?
19	or (social* adj (isolat* or stigma*)) or inequalit* or uninsured or underinsured or under insured or uneducated or
20	low* educat* or poor* educat* or lilitera* or (low adj2 litera*) or functional* impair* or disabled or disabilit* or handiaan* or physical* aballanga* or mantal* aballanga* or ((drug or substance) adj (abuse* or addiat* or
21	dependent or habit? or "uses")) or minorit* or emigra* or immigra* or migra* or foreigner* or refugee*) ti ab kf
22	8 (vulnerab* or aged or elderly or frail* or senior?) ti
23	0 ((frail* or valuers)* or at risk or high risk or low function or dependent) adi2 (older or older* or conjor* or
25	9 ((fiait' of vulnerab' of at fisk of high fisk of low function of dependent) adj2 (older of elder' of senior' of nation the senior' of a senior' of senio
26	10 (cald or (cultural* adi3 divers*) or multicultur* or intercultur* or (natient* adi cultur*) or (cultural* adi3
27	(background* or differen*)) or ethnocultural* or (cultural* adj (aware* or competen* or appropriate* or relevan*
28	or safe* or train*))).ti,ab,kf.
29	11 (vulnerab* adj (patient? or population? or social*)).ti,ab,kf.
30	12 sensitive population?.ti.ab.kf.
31	13 ((Frequent or high) adi? (attendt or consult*)) ti ab kf
32	13 ((1 requeir of mgn) adj2 (attend of consult )).tt,ab,ki.
34	14 ("frequent visit*" or "frequent flyer*" or "heavy user*" or "repeat use").ti,ab,kf.
35	15 ((((frequen* or high) adj2 (user* or utili*)) or "high use" or "frequent use") adj3 (patient* or hospital* or
36	emergency or ED or services)).ti,ab,kf.
37	16 "revolving door".ti.ab.kf.
38	17 "frequent hospitali#ation*" ti ah kf
39	17 nequent nospitation,ab,ki.
40	18 ((preventable or avoidable) adj2 (utili* or visit* or nospitali* or consultation*)).u,ab,ki.
41	19 (high adj2 risk adj3 hospitali#ation*).ti,ab,kf.
42	20 ("frequent use*" or "frequent utilis*" or "high use*" or "high utili*").kf.
43 44	21 mental disorders/ or mental health/
45	
46	22 ((mental* or psychiatric) adj (health* or disorder* or disease* or ill*)).ti.
47	23 comorbidity/
48	24 (comorbidit* or multi* morbidit* or multimorbidit*).ti,ab,kf.
49	25 exp polypharmacy/
50	
51	26 exp drug interactions/
52	27 exp "Drug-Related Side Effects and Adverse Reactions"/
53 54	28 (adverse adj (effect? or event? or reaction?)) ti
54 55	20 (multi* adj (theran* or treatment* or drug? or mediantion?)) or not mharmaa*) ti ah lef
56	27 ((multi-au) (metap- or treatment- or urug? or medication?)) or porypharmac*).tt,ao,ki.
57	30 drug* interact*.ti,ab,kt.
58	31 exp complementary therapies/

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	32 exp herbal medicine/
	33 ((alternative* or complementar* or folk* or herbal or integrat* or natural or non-prescription or over the
	counter or traditional) adj2 (health* or medication* or medicine* or product* or remedy or remedies or therap* or
	treatment*)).ti,ab,kf.
	34 or/1-33
1	
	CONCEPT #2 - PRIMARY HEALTH CARE
	35 exp Primary Health Care/
	36 exp Primary Care Nursing/
	37 exp General Practice/
	38 Community Health Services/
	39 exp Community Pharmacy Services/
	40 Community Mental Health Services/
	41 Community Health Nursing/
	42 Social Work/
	43 General Practitioners/
	44 Physicians, Family/
	45 Physicians, Primary Care/
	46 Social Workers/
	47 (primary care or primary health care or primary healthcare or community nursing or family practice or general
	practice or family medicine or family physician* or family practitioner* or family doctor* or general physician* or
	general practitioner* or community based medicine or community mental health service* or community mental
	health nursing or community health nursing or community health service* or community pharmac* or primary
	nreation or primory prestitionart or perchalogists or coaid complexity or coaid more a family or (compound) 10
	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)) ti ab kf
	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)).ti,ab,kf. 48 or/35-47
2	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)).ti,ab,kf. 48 or/35-47
2	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)).ti,ab,kf. 48 or/35-47 CONCEPT #3 - INTERPERSONAL RELATIONS
2	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)).ti,ab,kf. 48 or/35-47 CONCEPT #3 - INTERPERSONAL RELATIONS 49 exp Interpersonal Relations/
2	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)).ti,ab,kf. 48 or/35-47 CONCEPT #3 - INTERPERSONAL RELATIONS 49 exp Interpersonal Relations/ 50 exp patient care team/
2	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)).ti,ab,kf. 48 or/35-47 CONCEPT #3 - INTERPERSONAL RELATIONS 49 exp Interpersonal Relations/ 50 exp patient care team/ 51 (exp nurses/ or exp physicians/ or pharmacists/ or social workers/ or (nurse* or pharmacist* or physician* or psychologist* or social worker* or clinician* or doctor* or practitioner* or gps or health care professional* or healthcare professional* or health care provider* or healthcare provider* or ((primary care or primary healthcare or
2	practice or primary practitioner* or psychologist* or social service* or social work* or (communit\$3 adj5 nurse?)).ti,ab,kf. 48 or/35-47 CONCEPT #3 - INTERPERSONAL RELATIONS 49 exp Interpersonal Relations/ 50 exp patient care team/ 51 (exp nurses/ or exp physicians/ or pharmacists/ or social workers/ or (nurse* or pharmacist* or physician* or psychologist* or social worker* or clinician* or doctor* or practitioner* or gps or health care professional* or healthcare professional* or health care provider* or healthcare provider* or ((primary care or primary healthcare or primary health care) adj provider*) or resident*).ti.) and (exp patients/ or caregivers/ or exp Family/ or (patient* or parameters or nearple or experiment).ti.)
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Bujold M. et al – A participatory systematic mixed studies review protocol

59 exp decision making/ or informed consent/ or exp problem solving/ or (exp patient preference/ and patient			
education as topic/)			
60 ((patient* adj3 (voice* or perspective*)) or preference* or deliberation* or navigat* or accommodation* or			
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63 34 and 48 and 57 and 62

64 Limit 63 to (English or French or Spanish)

**Figure 1 legend.** The Interprofessional Shared Decision Making (IP-SDM) model was designed to broaden the perspective of shared decision making (SDM) beyond the patient-practitioner dyad and include interprofessional (IP) teams. For more details on the IP-SDM model, please consult the following website:

http://www.decision.chaire.fmed.ulaval.ca/en/research/projects/interprofessional-approaches/

1. Grant RW, Ashburner JM, Hong CS, et al. Defining patient complexity from the primary

Page 22 of 29

REFERENCES

#### care physician's perspective: A cohort study. Ann Intern Med 2011;155(12):797-804. 2. Katerndahl DA, Wood R, Jaen CR. A method for estimating relative complexity of ambulatory care. Ann Fam Med 2010;8(4):341-47. 3. Shi L. The impact of primary care: A focused review. *Scientifica* 2012;2012. 4. Schaink AK, Kuluski K, Lyons RF, et al. A scoping review and thematic classification of patient complexity: Offering a unifying framework. *Journal of Comorbidity* 2012;2(1):1-9. 5. Smith S, Soubhi H, Fortin M, et al. Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. BMJ 2012; 345(e5205). 6. Loeb DF, Bayliss EA, Binswanger IA, et al. Primary care physician perceptions on caring for complex patients with medical and mental illness. J Gen Intern Med 2012:27(8):945-52. 7. Safford MM, Allison JJ, Kiefe CI. Patient complexity: More than comorbidity. The vector model of complexity. [Gen Intern Med 2007;22(Suppl 3):382-90. 8. Johnson DR, Ziersch AM, Burgess T. I don't think general practice should be the front line: Experiences of general practitioners working with refugees in South Australia. Australia and New Zealand health policy 2008;5. 9. Martello C, Bessière G, Bigras M, et al. What Do We Mean When We Say "This Patient is Complex"? . NAPCRG Annual Conference (North American Primary Care Research Group). New York, 2014. 10. Pluve P. Bessière G. Bigras M. et al. Characteristics of Complex Care Needs and Interventions Suited for Patients With Such Needs: A Participatory Scoping Review. NAPCRG Annual Conference (North American Primary Care Research Group). New York, 2014. 11. Laerum E, Steine S, Finset A. The Patient Perspective Survey (PPS): A new tool to improve consultation outcome and patient involvement in general practice patients with complex health problems. *Patient Educ Couns* 2004;52(2):201-07. 12. Peek CJ. Integrating care for persons, not only diseases. J Clin Psychol Med Settings 2009;16(1):13-20. 13. Stiefel FC, Huyse FJ, Söllner W, et al. Operationalizing integrated care on a clinical level: The INTERMED project. Med Clin North Am 2006;90(4):713-58. 14. Fried TR, Tinetti M, Agostini J, et al. Health outcome prioritization to elicit preferences of older persons with multiple health conditions. Patient Educ Couns 2011;83(2):278-82. 15. Mangin D, Stephen G, Bismah V, et al. Making patient values visible in healthcare: a systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity. BMJ Open 2016;6(6):e010903. 16. St-Jacques S, Grenier S, Charland M, et al. Decisional needs assessment regarding Down syndrome prenatal testing: a systematic review of the perceptions of women, their partners and health professionals. *Prenat Diagn* 2008;28(13):1183-203. 17. Weston WW. Informed and shared decision-making: the crux of patient-centered care. CMAJ 2001;165(4):438-9.

# BMJ Open

1		
2		
3	1	18. Makoul G, Clayman ML. An integrative model of shared decision making in medical
4 5	2	encounters. Patient Educ Couns 2006;60(3):301-12.
6	3	19. Legare F, Ratte S, Stacey D, et al. Interventions for improving the adoption of shared
7	4	decision making by healthcare professionals. <i>Cochrane Database Syst Rev</i>
8	5	2010(5):CD006732.
9	6	20. Legare F. Stacey D. Turcotte S. et al. Interventions for improving the adoption of shared
10	7	decision making by healthcare professionals <i>Cochrane Database Syst Rev</i>
11	, 8	
12 13	9	201 Légaré F. Witteman H. Shared decision making: Examining key elements and harriers to
14	10	21. Degare 1, writeman 11. Shared decision making. Examining Key elements and barriers to adoption into routing clinical practice. Health affairs (Project Hone) 2013:32(2):276-
15	10	84
16	11	22 Melhourne E. Boherte S. Durand MA, et al. Duradie ODTION, Measuring percentions of
17	12	22. Melbourne E, Roberts S, Duranu MA, et al. Dyauic OF HON. Measuring perceptions of
18	13	Shared decision-making in practice. <i>Patient Educ Couris</i> 2011;05(1):55-7.
19 20	14	23. Shared Decision Making: Australian Commission on Safety and Quality in Health Care;
21	15	2017 [Available from: <u>https://www.safetyandquality.gov.au/our-work/shared-</u>
22	16	decision-making/ accessed 2 Fev 2017.
23	17	24. Shared Decision Making: National health service (NHS); 2016 [Available from:
24	18	http://sdm.rightcare.nhs.uk/ accessed 2 Fev 2017.
25	19	25. The SHARE Approach: Agency for Healthcare Research and Quality (AHRQ); 2016
20 27	20	[Available from: <u>https://www.ahrq.gov/professionals/education/curriculum-</u>
28	21	tools/shareddecisionmaking/index.html accessed 2 Fev 2017.
29	22	26. Bujold M. Patient's representation of illness as an interdisciplinary communication
30	23	channel [Article in French]. Anthropologie et Sociétés 2008;32(HS):18-25.
31	24	27. Bujold M. Le patient intégrateur: analyse de l'articulation d'une pluralité de voix / voies
32	25	dans une clinique intégrative québécoise. Université Laval, 2011.
১১ 34	26	28. Bujold M. Ethnomedical ethics with regard to patient plurivocality: between autonomy
35	27	and heteronomy [Article in French]. Journal International de Bioéthique
36	28	2015;26(4):19-36.
37	29	29. Gaboury I, Bujold M, Boon H, et al. Interprofessional collaboration within Canadian
38	30	integrative healthcare clinics: Key components. <i>Soc Sci Med</i> 2009;69(5):707-15.
39	31	30. Legare F, Stacey D, Pouliot S, et al. Interprofessionalism and shared decision-making in
40 41	32	primary care: A stepwise approach towards a new model. / Interprof Care
42	33	2011;25(1):18-25.
43	34	31. Legare F, Stacey D, Graham ID, et al. Advancing theories, models and measurement for
44	35	an interprofessional approach to shared decision making in primary care; a study
45	36	protocol. BMC Health Serv Res 2008:8:2.
40 47	37	32. Interprofessional Approaches to Shared Decision Making (IP-SDM) 2017 [Available
48	38	from:
49	39	http://www.decision.chaire.fmed.ulaval.ca/en/research/projects/interprofessional-
50	40	approaches / accessed 2017-06-1
51	41	33 Legare F Briere N Stacey D et al Implementing shared decision-making in
52 52	42	interprofessional home care teams (the IPSDM-SW study): protocol for a stepped
53 54	43	wedge cluster randomised trial <i>BMI onen</i> 2016:6(11):e014023
55	Δ <i>Λ</i> .	34 Legare F. Stacey D. Briere N. et al. Healthcare providers' intentions to angage in an
56	17 15	interprofessional approach to charad decision-making in home care programs: a
57	т.) Л.6	mixed methods study <i>Unterprof Care</i> 2012,27(2),214,22
58	40	$m_{\lambda} \in u m_{\lambda} = m_{\lambda} = m_{\lambda} = p_{\lambda} = p_$
59 60		
50		

# **BMJ Open**

2		
3	1	35. Muntinga ME, Hoogendijk EO, van Leeuwen KM, et al. Implementing the chronic care
4	2	model for frail older adults in the Netherlands: study protocol of ACT (frail older
5	3	adults: care in transition) <i>BMC Geriatr</i> 2012:12:19
7	ع 4	36 Légaré F. O'Connor A. Graham L et al Sunnorting natients facing difficult health care
8	т 5	docisions: uso of the Ottawa Docision Support Framowork Canadian Family
9	5	Dhusisian 2006.52(4).476.77
10	6	Physician 2006;52(4):476-77.
11	/	37. OHRI. Ottawa Decision Support Framework 2015 [Available from:
12	8	https://decisionaid.ohri.ca/odsf.html accessed June 27 2017.
13	9	38. Jacobsen MJ, O'Connor AM, Stacey D. Decisional Needs Assessment in Populations. A
14	10	workbook for assessing patients' and practitioners' decision making needs.
15	11	University of Ottawa1999 [updated 2013] [Available from:
17	12	https://decisionaid.ohri.ca/docs/implement/Population_Needs.pdf accessed Feb 2
18	13	2017.
19	14	39. Straus SE, Tetroe I, Graham I, Defining knowledge translation, <i>Canadian Medical</i>
20	15	Association Journal 2009:181(3-4):165-68.
21	16	40 Pluve P Hong ON Combining the power of stories and the power of numbers. Mixed
22	17	methods research and mixed studies reviews. Annu Roy Public Health 2014:35:29-
23	10	
24 25	10	TJ. 41 Crent M. Dooth A. A typology of reviews. An analysis of 14 review typos and associated
26	19	41. Grant M, booth A. A typology of reviews: All analysis of 14 review types and associated
27	20	methodologies. Health Injo Libr J 2009;26(2):91-108.
28	21	42. Pluye P, Gagnon MP, Griffiths F, et al. A scoring system for appraising mixed methods
29	22	research, and concomitantly appraising qualitative, quantitative and mixed methods
30	23	primary studies in mixed studies reviews. <i>Int J Nurs Stud</i> 2009;46(4):529-46.
31	24	43. Pope C, Mays N, Popay J. Synthesizing qualitative and quantitative health evidence: A
32	25	guide to methods. Berkshire: Open University Press 2007.
33 34	26	44. Sheldon TA. Making evidence synthesis more useful for management and policy-making.
35	27	J Health Serv Res Policy 2005;10(3 Suppl. 1):1-5.
36	28	45. Pluye P, Hong Q, I. V. The plurality of review methods and synthesis methods: Opening-
37	29	up the definition of systematic reviews [invited peer-reviewed paper on knowledge
38	30	syntheses]. <i>J Clin Epi</i> In Press.
39	31	46. Hong ON, Pluve P. Bujold M. et al. Convergent and sequential synthesis designs:
40	32	implications for conducting and reporting systematic reviews of qualitative and
41 12	33	quantitative evidence Systematic Reviews (Accented)
43	34	47 What are the key processes associated to outcomes of participatory research with
44	25	health organizations? A participatory systematic mixed studies review NADCDC
45	33	annual masting (North American Drimory Care Descareh Croup), 2012 Ottown
46	30	40 Plane P. Nadaz, N. Laha, P. Caravarat fa a davala valuarla alta in and
47	37	48. Pluye P, Nadeau N, Lenoux P. Comment favoriser la recherche clinique en
48	38	pedopsychiatrie? Une experience de recherche-action collaborative. Sante Mentale
49 50	39	<i>Quebec</i> 2001;26(12):245-66.
50	40	49. Cargo M, Mercer S. The value and challenges of participatory research: Strengthening its
52	41	practice. <i>Annu Rev Public Health</i> 2008;29(1):325-50.
53	42	50. Waterman H, Tillen D, Dickson R, et al. Action Research: A systematic review and
54	43	guidance for assessment. <i>Health Technol Assess</i> 2001;5(23):iii-157.
55	44	51. Argyris C, Putnam R, Smith D. Action science : Concepts, methods, and skills for research
56	45	and intervention. San Francisco, CA: Jossev-Bass 1985.
5/		
50 50		
60		

# BMJ Open

2		
3	1	52. Munn-Giddings C, McVicar A, Smith L. Systematic review of the uptake and design of
4	2	action research in published nursing research, 2000-2005. <i>J Res Nurs</i>
5 6	3	2008;13(6):465-77.
7	4	53. Munten G. Van Den Bogaard I. Cox K. et al. Implementation of evidence-based practice in
8	5	nursing using action research: A review. <i>Worldviews Evid Based Nurs</i> 2010;7(3):135-
9	6	57
10	7	54 Soh K Davidson P Leslie G et al Action research studies in the intensive care setting. A
11	, 8	sustematic review. Int I Nurs Stud 2011:48(2):258-68
12	g	55 Davis MM Keller S DeVoe L et al Characteristics and lessons learned from practice.
14	10	based research networks (DRDNs) in the United States I Healths Leadersh
15	10	2012-2012(4), 107 1(
16	11	2012;2012[4]:107-16.
17	12	56. Garson DG. Reliability analysis. Statnotes: Topics in multivariate analysis. In: Garson DG,
18	13	ed. Raleign: North Carolina State University, 2010.
19	14	57. Landis JR, Koch GG. The measurement of observer agreement for categorical data.
20 21	15	<i>Biometrics</i> 1977;33(1):159-74.
22	16	58. Higgins J, Green S. Cochrane handbook for systematic reviews of interventions Version
23	17	5.1.0 [updated March 2011]: The Cochrane Collaboration; 2011 [Available from:
24	18	http://www.cochrane-handbook.org accessed Mar 1 2013.
25	19	59. Pace R, Pluye P, Bartlett G, et al. Testing the reliability and efficiency of the pilot Mixed
26	20	Methods Appraisal Tool (MMAT) for systematic mixed studies review. Int J Nurs Stud
27	21	2012;49(1):47-53.
20 29	22	60. Souto RQ, Khanassov V, Hong QN, et al. Systematic mixed studies reviews: Updating
30	23	results on the reliability and efficiency of the mixed methods appraisal tool.
31	24	International journal of nursing studies 2015;52:500-01.
32	25	61. Crowe M. Sheppard L. A review of critical appraisal tools show they lack rigor:
33	26	Alternative tool structure is proposed. <i>J Clin Epidemiol</i> 2011:64(1):79-89.
34 25	27	62. Pluve P. Robert E. Cargo M. et al. Proposal: A mixed methods appraisal tool for
36	28	systematic mixed studies reviews Department of Family Medicine. McGill University.
37	29	Montreal, Canada 2011 [Available from:
38	30	http://mixedmethodsappraisaltoolpublic.phworks.com. Archived by WebCite® at
39	31	http://www.webcitation.org/5tTRTc9vLaccessed Feb 2 2017
40	32	63 Ponay I Roberts H Sowden A et al Guidance on the conduct of narrative synthesis in
41 42	32	systematic reviews: Final report Swindon: FSRC Methods Programme 2006
43	37	64. Croswall I. Plano Clark V. Dosigning and conducting mixed methods research. Thousand
44	25	Orker Sage 2010
45	33	Udris: Sage 2010.
46	30	65. Bazeley P, Jackson K. Quantative Data Analysis with NVIVO: Colorado and University of
47	3/	Colorado: SAGE Publications Ltd 2013.
48	38	66. Bujold M. Nvivo: a support tool for qualitative analysis. Workshop guide. Montreal,
49 50	39	Canada: CAQI 2016.
51	40	67. Boyatzis RE. Transforming qualitative information: Thematic analysis and code
52	41	development. Thousand Oaks: Sage 1998.
53	42	68. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid
54	43	approach of inductive and deductive coding and theme development. Int J Qual
55	44	<i>Methods</i> 2006; 5(1).
56 57	45	69. Sullivan P. Qualitative data analysis using a dialogical approach. London: Sage 2012.
58		
59		
60		

## BMJ Open

1		
2	1	70 Pavel S Nolet D Handbook of terminology Ottawa: Minister of Public Works and
4	2	Government Services Canada. 2001.
5 6	3	71. Rihoux B, Marx A. OCA, 25 years after "The Comparative Method": Mapping, challenges,
7	4	and innovations. <i>Polit Res Q</i> 2013;66(1):167-235.
8	5	72. Rihoux B, Ragin C. Configurational comparative methods. Thousand Oaks: Sage 2009.
9	6	73. Cochrane Effective Practice and Organisation of Care Review Group. Data collection
10	7	checklist Ottawa, Canada: Cochrane Effective Practice and Organisation of Care
12	8	Review Group; 2002 [Available from:
13	9	http://epoc.cochrane.org/sites/epoc.cochrane.org/files/uploads/datacollectionchec
14	10	<u>klist.pdf</u> accessed Feb 10 2017.
15	11	74. Neuendorf KA. The content analysis guidebook. Thousand Oaks: Sage 2002.
17	12	75. Rich E, Lipson D, Libersky J, et al. Coordinating care for adults with complex care needs
18	13	in the patient-centered medical home: Challenges and solutions [White Paper].
19	14	Rockville, MD: U.S. Department of Health and Human Services Agency for Healthcare
20 21	15	Research and Quality; 2012 [updated 2012; cited 2013 Dec 12]. Available from:
22	16	http://pcmh.ahrq.gov/sites/default/files/attachments/Coordinating%20Care%20fo
23	17	<u>r%20Adults%20with%20Complex%20Care%20Needs.pdf</u> accessed Feb 10 2017.
24	18	76. Rich EC, Lipson D, Libersky J, et al. Organizing care for complex patients in the patient-
25 26	19	centered medical home. Ann Fam Med 2012;10(1):60-62.
27	20	77. Schoen C, Usborn R, Squires D, et al. New 2011 survey of patients with complex care
28	21	needs in 11 countries finds that care is often poorly coordinated. <i>Health Aff</i>
29	22	2011;30(12):2437-48.
30 31	23 24	70. Hudoli C, Choulliard M-C, Coulure M, et al. Partners for the optimal organisation of the healthcare continuum for high users of health and social services; protocol of a
32	24	developmental evaluation case study design <i>BML ener</i> 2014;4(12):0006991
33	25	79 Cojera F. When conversation is better than computation. <i>Journal of the American</i>
34	20	Medical Informatics Association 2000.7(3):277-86
35 36	28	80 Beaulieu MD Proulx M Johin G et al When is knowledge rine for primary care? An
37	29	exploratory study on the meaning of evidence. Eval Health Prof 2008:31(1):22-42.
38	30	81. de Bruin S. Versnel N. Lemmens L. et al. Comprehensive care programs for patients with
39	31	multiple chronic conditions: A systematic literature review. <i>Health Policy</i>
40 ⊿1	32	2012;107(2-3):108-45.
42	33	82. Kamerow D. How can we treat multiple chronic conditions? <i>BMJ</i> 2012;344(e1487).
43	34	83. Ouwens M, Wollersheim H, Hermens R, et al. Integrated care programmes for
44	35	chronically ill patients: A review of systematic reviews. Int J Qual Health Care
45 46	36	2005;17(2):141-46.
47	37	84. Upshur R, Tracy C. Chronicity and complexity: Facing the challenges of chronic disease
48	38	in primary care. Can Fam Physician 2008;54(12):1655-8.
49	39	85. Stacey D, Legare F, Col NF, et al. Decision aids for people facing health treatment or
50 51	40	screening decisions. Cochrane Database Syst Rev 2014(1):CD001431.
52	41	86. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health.
53	42	Milbank Q 2005;83(3):457-502.
54	43	87. Stacey D, Légaré F, Col N, et al. Decision aids for people facing health treatment or
55 56	44	screening decisions. <i>The Cochrane Library</i> 2014.
57	45	88. Ministère de la santé et des services sociaux du Québec. Plan stratégique 2015-2020:
58	46	Québec: Gouvernement du Québec; 2015 [Available from:
59 60		
00		

1	Bujold M. et al – A participatory systematic mixed studies review protocol 201	7-08-22
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Patie	nt/Family team	Interpro	fessional team	
	Initiator of SD	M process		
Family/Surrogate/ Significant others	Patient	Decision coach	Health care professional(s)	
4>	Decision to be made	******	+	1
<b>↓</b>	Information exchange	÷	Ţ	
+	Values/preferences	Ţ	1	
<b>↓</b>	Feasibility	÷	Ţ	Tin
÷>	Preferred choice	÷	Ţ	
-	Actual choice	+	+	<b>↓</b>
<b>~</b>	Implementation	<b>«</b>	>	

The Interprofessional Shared Decision Making (IP-SDM) model was designed to broaden the perspective of shared decision making (SDM) beyond the patient-practitioner dyad and include interprofessional (IP) teams. For more details on the IP-SDM model, please consult the following website: http://www.decision.chaire.fmed.ulaval.ca/en/research/projects/interprofessional-approaches/

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Checklist	Page / Line (Main document)	Section and topic	Item No	Checklist item ( <u>http://www.bmj.com/content/349/bmj.g7647</u> )	
		Administrative informatio	n		
		Title:			
$\checkmark$	Page 1 - Line 2	Identification	1a	Identify the report as a protocol of a systematic review	
n/a		Update	1b	If the protocol is for an update of a previous systematic review, identify as such	
✓ 	Page 3 - Lines 10-11	Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number	
		Authors:			
√	Page 1 - Lines 4-30 Page 2 - Lines 1-8	Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	
$\checkmark$	Page 15 - Lines 9-22	Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	
n/a		Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	
		Support:			
√	Page 15, lines 2-3 and 25-27	Sources	5a	Indicate sources of financial or other support for the review	
$\checkmark$	Page 15, lines 2-3	Sponsor	5b	Provide name for the review funder and/or sponsor	
✓	Page 15, lines 25-27	Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	
		Introduction			
✓	Page 4, lines 3-31 to page 5, lines 1-2	Rationale	6	Describe the rationale for the review in the context of what is already known	
$\checkmark$	Page 6, lines 29-32 Page 7, lines 1-5	Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	
		Methods			
✓	Page 8, lines 13-28	Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	
✓	Page 8, lines 1-11	Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage	

<b>√</b>	Page 8, lines 1-31 and page 9, lines 1-10 page 17, Table 2	Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
		Study records:		
~	Page 8, lines 30-31 and page 9, lines 1-4	Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review
✓	Page 9, lines 1-19	Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)
✓	page 10, lines 1-9	Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators
~	Page 10, lines 27-31	Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications
<b>v</b>	Page 11, lines 2-7 Page 11, lines 29-31 Page 12, lines 1-5	Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale.
<b>v</b>	Page 9, 12-19	Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis
<b>v</b>	Page 9, lines 21-23 Page 11, lines 19-27 Page 11, lines 29-31 Page 12, lines 1-5	Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised
n/a			15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as $l^2$ , Kendall's $\tau$ )
n/a			15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)
✓	Page 10, line 18-26		15d	If quantitative synthesis is not appropriate, describe the type of summary planned
n/a		Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)
~	Page 9, lines 12-19	Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)