

# Recommendations for patient engagement in patient-oriented emergency medicine research

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## ABSTRACT

**Objective:** To make pragmatic recommendations on best practices for the engagement of patients in emergency medicine (EM) research.

**Methods:** We created a panel of expert Canadian EM researchers, physicians, and a patient partner to develop our recommendations. We used mixed methods consisting of 1) a literature review; 2) a survey of Canadian EM researchers; 3) qualitative interviews with key informants; and 4) feedback during the 2017 Canadian Association of Emergency Physicians (CAEP) Academic Symposium.

**Results:** We synthesized our literature review into categories including identification and engagement, patients' roles, perceived benefits, harms, and barriers to patient engagement; 40/75 (53% response rate) invited researchers completed our survey. Among respondents, 58% had engaged patients in research, and 83% intended to engage patients in future research. However, 95% stated that they need further guidance to engage patients. Our qualitative interviews revealed barriers to patient engagement, including the need for training and patient partner recruitment.

Our panel recommends 1) an overarching positive recommendation to support patient engagement in EM research; 2) seven policy-level recommendations for CAEP to support the creation of a national patient council, to develop, adopt and adapt training material, guidelines, and tools for patient engagement, and to support increased patient engagement in EM research; and 3) nine pragmatic recommendations about engaging patients in the preparatory, execution, and translational phases of EM research.

**Conclusion:** Patient engagement can improve EM research by helping researchers select meaningful outcomes, increase

social acceptability of studies, and design knowledge translation strategies that target patients' needs.

## RÉSUMÉ

**Objectif:** L'étude visait à formuler des recommandations pragmatiques sur les pratiques exemplaires en matière d'engagement des patients à la recherche en médecine d'urgence (MU).

**Méthode:** Un groupe formé d'experts en recherche en MU au Canada, de médecins et d'un patient en tant que partenaire de recherche a été formé dans le but d'élaborer des recommandations. Pour ce faire, le groupe a appliqué différentes méthodes : 1) une revue de littérature; 2) une enquête parmi les chercheurs en MU au Canada; 3) des entretiens de type qualitatif avec des informateurs clés; 4) une démarche de rétroaction durant le Symposium académique 2017 de l'Association canadienne des médecins d'urgence (ACMU).

**Résultats:** La revue de la littérature a permis de classer les éléments recueillis en différentes catégories : la recherche de patients partenaires et leur engagement; le rôle des patients; la perception des avantages et des inconvénients de l'engagement des patients ainsi que des obstacles à sa réalisation. Dans l'ensemble, 53 % (40/75) des chercheurs invités à participer à l'enquête ont rempli le questionnaire. Parmi les répondants, 58 % avaient déjà une expérience de l'engagement des patients à des études et 83 % avaient l'intention de se lancer dans cette voie. Toutefois, 95 % des répondants ont déclaré qu'ils avaient besoin davantage d'indications pour trouver des patients partenaires aptes et disposés à s'engager activement. Les entretiens de type qualitatif ont fait ressortir des obstacles à l'engagement des patients, dont le besoin

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de formation et de recrutement de patients en tant que partenaires de recherche. Devant cet état de faits, le groupe propose donc : 1) une recommandation générale concrète visant à susciter l'engagement des patients à la recherche en MU; 2) sept recommandations de nature politique afin d'aider l'ACMU à soutenir la formation d'un conseil national de patients; à faciliter l'élaboration, l'adoption et l'adaptation de matériel didactique, de lignes directrices et d'outils sur l'engagement des patients, et à favoriser l'engagement des patients à la recherche en MU; et 3) neuf recommandations pragmatiques sur l'engagement des patients durant les

phases de préparation et de réalisation des études en MU ainsi que d'application des connaissances.

**Conclusions:** L'engagement des patients peut améliorer la recherche en MU en aidant les chercheurs à tenir compte de résultats significatifs pour les patients, accroître l'acceptabilité sociale des études et faciliter l'élaboration de stratégies d'application des connaissances qui répondent aux besoins des patients.

**Keywords:** patient engagement, emergency medicine, knowledge translation, patient-oriented research

## INTRODUCTION

Patient engagement in research is defined as research being carried out “with” or “by” patients rather than “to,” “about,” or “for” them.<sup>1</sup> Patients' personal knowledge and experience of specific research topics have the potential to improve research quality by ensuring that methods are acceptable, that outcomes are patient-centred, and by increasing patient participation.<sup>2</sup> Patients can also make research content and language more accessible to patients.<sup>3,4</sup> Patient engagement in research is not a new phenomenon. It is rooted in the civil rights movement in the 1960s that led towards more patient empowerment.<sup>5</sup> In 2011, the Canadian Institutes of Health Research (CIHR) launched its Strategy for Patient-Oriented Research (SPOR). Researchers applying for funding related to this strategy must demonstrate how patients are an integral part of the research team.<sup>6</sup> In the context of CIHR requirements and increasing positive evidence for patient engagement in research, Canadian emergency medicine (EM) researchers must have access to methods and tools adapted to their context to know how to better engage patients in research.

EM research has contextual factors that make patient engagement challenging.<sup>7</sup> The short duration of visits and the chaotic conditions prevalent in emergency departments (EDs) make it difficult to recruit and engage patient partners.<sup>7</sup> The vulnerability of patient groups consulting the ED (e.g., frail elderly, low health literacy) also add an extra challenge to engaging patients as research partners. Interestingly, these are the same reasons why EM research stands to gain from better patient engagement.

Consequently, the Academic Section of the Canadian Association of Emergency Physicians (CAEP) convened a group of experts, including an experienced patient

partner to make pragmatic recommendations on current best practices for the meaningful engagement of patients in EM research in Canada.

## METHODS

We used mixed methods consisting of 1) a qualitative narrative review, 2) an online survey, 3) qualitative interviews, and 4) a face-to-face meeting to gather feedback and refine our recommendations.

### **Literature review**

We conducted a narrative review based on the recommendations of the Centre of Excellence for Partnership with Patients and the Public (Montreal, QC). They identified two existing systematic reviews about patient engagement in research<sup>8,9</sup> and the adapted framework by Wright for patient engagement in EM research.<sup>7</sup> In addition, we also reviewed all of the referenced papers included in these three publications to determine whether 1) they were relevant to EM, 2) they involved patients recruited from the ED, or 3) their conclusions would help us generate recommendations about patient engagement in EM research. Team members (PMA, KND, SLM, JSL, CV) each reviewed a subset of titles and determined whether a full-text review was needed based on the three inclusion criteria stated previously. For this qualitative narrative review, we did not perform any double extraction or intra-rater reliability testing.

This review allowed us to identify four additional patient engagement frameworks: Patient-Centered Outcomes Research Institute (PCORI),<sup>10,11</sup> INVOLVE,<sup>10</sup> National Health and Medical Research Council,<sup>12</sup> and the CIHR SPOR framework.<sup>13</sup> Three authors (PMA, CM, and CV) reviewed these frameworks to

identify elements that would guide the structure of our recommendations. After identifying the most relevant papers to review, we conducted a narrative summary of the evidence concerning current best practices, impact, barriers, and facilitators to engage patients in EM research.

### Online survey

We adapted a questionnaire developed by Boivin et al.<sup>14</sup> to question Canadian EM researchers about their experiences and beliefs about patient engagement. Our questionnaire contained 12 items about experience with previous patient engagement activities, types of patients engaged, strategies used to recruit patient partners, roles played by patient partners, impact of patient engagement on previous research activities, unmet needs to support patient engagement, perceived barriers and benefits, and intention for future patient engagement (Appendix 1). These questions were based on the gaps in knowledge that we identified in our literature review. After content and face validity testing within our group and three other EM researchers not involved in this work, we reduced our questionnaire to include 17 items (including 5 sociodemographic questions and 1 question verifying interest in participating in future steps of our project).

We first administered our survey to all of the attendees at the Network of Canadian Emergency Researchers (NCER) meeting held in March 2017. This meeting brought together 26 EM researchers from across Canada. After obtaining consent from all of those present, our questionnaire was completed on site by all of the participants. We then used CAEP's listserv containing the names of 49 additional EM researchers. The survey was programmed into Survey Monkey and sent out via email, and a single reminder was sent 2 weeks later. Consent to participate was implied by way of completing the survey.

### Qualitative interviews

In May 2017, we conducted five interviews with EM researchers from across Canada who had previous experience with patient engagement. These key informants were purposefully selected by an experienced qualitative researcher (KND) from a list of volunteers who had provided their names during our online survey. The interview allowed us to get more in-depth information about what kind of patients to engage, how

and when to engage them, and generally what works and what does not work (Appendix 2). The same researcher then performed qualitative content analysis and identified common themes across key informants.

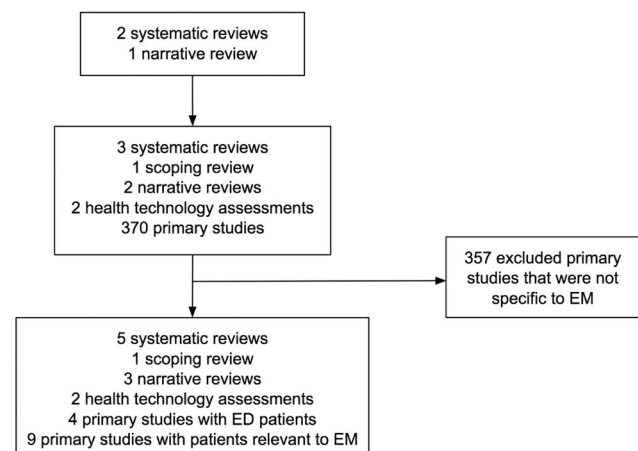
### Symposium presentation and feedback analysis

Our panel used an iterative consensus-based approach to formulate a set of preliminary recommendations. We presented our recommendations at the CAEP Academic Symposium held on June 3, 2017. During our presentation, notes were taken about the formulation of our recommendations, and written feedback was collected (Appendix 3). An online feedback form was created to solicit further feedback on each of our preliminary recommendations (Appendix 4). It was distributed using the same listserv used to gather feedback during our online survey and using Twitter to increase the likelihood of receiving feedback. After analysing this feedback, we formulated a final list of recommendations and knowledge gaps to address in future research about patient engagement in EM research.

## RESULTS

### Literature review

Based on our review of Domecq et al.,<sup>8</sup> Shippee et al.,<sup>9</sup> and Wright et al.,<sup>7</sup> we identified 3 systematic reviews,<sup>4,15,16</sup> 1 scoping review,<sup>17</sup> 2 narrative reviews,<sup>18,19</sup> 2 health technology assessments,<sup>2,20</sup> and 370 primary studies about patient engagement (Figure 1). We found four papers that included patients recruited from the ED<sup>21-24</sup> and



**Figure 1.** Flow of studies included in our review.

nine papers that included patients with health issues (e.g., coronary artery disease) that could be relevant for EM.<sup>25-33</sup> We then summarized our review results into the following themes relevant to EM research: 1) How to identify and engage patients, 2) What can patients do? 3) What are the observed benefits? 4) What are the harms? and 5) What are the barriers?

### *How to identify and engage patients in EM research*

There are no comparative effectiveness studies to support the most effective way of identifying or engaging patients for EM research.<sup>8</sup> To engage patients, researchers have used focus groups, interviews, surveys, study boards, and patient advisory councils.<sup>8,9,18,24</sup>

### *What can patients do?*

Previous EM studies have engaged patients to help with designing the consent process and developing information for patients participating in a trial.<sup>26,34-36</sup> Patients have also participated in selecting outcomes, determining the acceptability of data collection procedures, deciding on the ideal time to recruit participants, and deciding when to conduct follow-up.<sup>20</sup> Patients have also suggested changes to study design.<sup>24</sup>

### *What are the observed benefits?*

We found evidence that patient engagement improves 1) participant enrolment and decreases attrition in studies<sup>8</sup>; 2) selection of patient-centred outcomes<sup>8,17,18,25</sup>; 3) social acceptability of studies with waived or deferred consent<sup>4,34-36</sup>; 4) design of patient consent material<sup>4,35,36</sup>; and 5) content and design of knowledge translation material for patients and clinicians.<sup>37,38</sup>

### *What are the harms?*

We found evidence that patient engagement can 1) create frustration with the lengthy process of the research enterprise<sup>15</sup>; 2) create frustration with tokenistic patient engagement<sup>8</sup>; and 3) increase the scope of a project and undesirably change the focus of a project.<sup>8</sup>

### *What are the barriers?*

The main barriers to engaging patients in EM research are 1) the extra time needed to complete a research project<sup>15</sup>; 2) the time constraints of patients and researchers<sup>15</sup>; and 3) the lack of funding to support patient engagement.<sup>8</sup>

### *Online survey*

We sent survey invitations to 75 Canadian EM researchers and received 40 responses (26 NCER attendees and 14 other CAEP EM researchers), which represent a 53% response rate. Our participants were mostly male (75%) and mean (standard deviation) work experience was 14 (12) years. Our respondents came from five provinces across Canada (Table 1). Most respondents (n = 33; 83%) intended to engage patients as partners in the next few years. More than half of our participants (58%) had previously engaged patients in EM research: 78% had engaged individual patients; 52% had engaged patient representatives (associations, community organizations); 35% had engaged caregivers; and 17% had engaged other stakeholders (cardiopulmonary resuscitation [CPR] providers). The activities where patients were engaged and the roles that patients played are presented in Table 1. Almost all respondents (95%) stated that they would need support to engage patients in EM research. Table 1 also presents the type of support that would be needed, the perceived benefits, and the barriers. The different strategies used by Canadian EM researchers to recruit patient partners are found in Appendix 5.

### *Qualitative interviews*

All respondents were very positive about including patients in their research going forward but had very little experience. Participants all highlighted the need for help identifying and approaching patients. Other needs were expressed such as 1) guidelines for the conduct of both researchers and patient partners, 2) examples from successful research programs, and 3) training and funding opportunities through groups like CAEP and NCER. Respondents also had concerns and questions about patient engagement such as 1) risk of exposing researchers' vulnerabilities, 2) project scope creep and change of direction, 3) determining obligations if there is discord, 4) when to use patients given the strong desire to not waste people's time, and 5) the best patient characteristics (i.e., identifying the level of healthcare knowledge or aptitude that is important, Are patients willing to be educated about the research process? How does one ensure diversity in experience and culture? How does one distinguish between a patient care advocate and a patient research partner?).

**Table 1. Main results from the online survey**

	Percentage
<i>Distribution of province of respondents</i>	
Ontario	53
Quebec	30
Alberta	7.5
British Columbia	7.5
Saskatchewan	2.5
<i>Activities where patients were engaged</i>	
Research design	45
Knowledge translation	39
Project governance	39
Grant/protocol development	35
Outcome selection	31
Data collection	26
Research priorities	26
Recruitment	22
Ethical considerations	22
Intervention development	17
Intervention implementation	14
Research fundraising	4
Interpretation/analysis of results	0
<i>Role of patient partners in emergency medicine research</i>	
Collaborator	52
Research participant	44
Knowledge user	44
Member of a research committee	35
Co-investigator	17
Co-author of a scientific article	4
<i>Type of support needed expressed by respondents</i>	
Recruitment of patient partners	69
Training for public partners	66
Training for researchers	63
Guidelines on patient engagement	58
Logistical	55
Financial	55
Coordinator and facilitation of engagement activities	55
Evaluation of patient engagement	45
Access to literature on best practices	37
<i>Benefits to patient engagement in emergency medicine research</i>	
Better identify patient-important outcomes	73
Different perspective from the research team	58
Helps with patient buy-in/consent/recruitment	35
Helps improve chance of getting grant funding	30
<i>Barriers to patient engagement in emergency medicine research</i>	
How to identify/recruit/engage patients	73
Patient's knowledge/understanding of research	47
How to fund/reimburse patient participants	35
Time-consuming to engage patients	33

### Academic Symposium

During the Academic Symposium, two members (PMA and CM) presented a summary of our methodology, results, and a set of preliminary recommendations. These slides are available on Slideshare™ (Sunnyvale, CA, USA).<sup>39</sup> During the symposium, comments about our recommendations were mainly positive and concerned slight wording changes. We also received online feedback from four emergency physicians and one researcher. Feedback was also mostly positive, and one respondent suggested that we go further in our recommendations. In contrast, disagreement came from one online respondent who stated that funding for patient engagement should be built into public research funding, rather than depend on a national emergency physician specialty society.

### DISCUSSION

We grouped recommendations into three categories: 1) general recommendations (Box 1); 2) recommendations about CAEP policy (Box 2); and 3) recommendations for best practices at each phase of a research project (Box 3). For our general and policy-level recommendations, we chose to endorse the CIHR SPOR strategy<sup>40</sup> because of its applicability to the Canadian context and because it could help EM researchers better work in collaboration with the provincial SPOR SUPPORT Units. However, we used the U.S. PCORI framework<sup>9</sup> to structure and situate our recommendations because it represented well the familiar phases of research where patients could be engaged. Although we have formulated our recommendations based on current evidence, there remain knowledge gaps (Appendix 6) that need more research to inform future revisions of our recommendations.

#### Box 1. General recommendations

EM researchers in Canada should adopt and endorse the CIHR SPOR strategy for patient engagement in research to:

1. Improve the relevance of their research
2. Improve its translation into policy and practice
3. Contribute to more effective health services and products
4. Improve the quality of life of Canadians and result in a strengthened Canadian healthcare system

**Box 2. Recommendations about CAEP policy**

In order to foster patient engagement in EM research, CAEP should:

1. Create a National Patient Council as a partnership between a *diverse* group of patients and EM researchers (Note: Diverse means including members from First Nations, minority communities, vulnerable populations, and a lower literacy population.)
  - a. Explore a collaboration between organizations such as CAEP and CIHR to support this council.
  - b. Recruit continuously to support research projects and maintain a broad representation of patients and new ideas.
2. Adopt, adapt, and develop training material, guidelines, and tools for patient engagement for the context of EM research.
  - a. This would include, for example, how to provide the necessary emotional support for patients and to researchers engaging patients in their research.
  - b. Create better links and partnerships with provincial SPOR SUPPORT Units who have existing training material, guidelines, and tools for patient engagement.
3. Create a space on the CAEP website to disseminate resources that exist and foster interaction among CAEP EM researchers for patient engagement in research.
4. Make expenses related to engaging patients eligible for CAEP-funded projects.
5. Include patients as reviewers on grant competitions if applicable and relevant.
6. CAEP grant applicants should indicate whether or not and how they engaged patients in their research proposals or their rationale for not doing so.
7. CAEP should consider giving additional merit to projects that engage patients if applicable and relevant.

**Box 3. Recommendations for best practices at each phase of a research project**

1. Preparatory phase
  - a. Seek guidance from provincial SPOR SUPPORT Units.
  - b. Seek guidance about using a framework to help define your approach and situate where patients will be involved in your research (e.g., SPOR, PCORI, INVOLVE).
  - c. Engage patients as early as possible in designing a research project (e.g., target research questions that align with patient priorities).
  - d. Establish trust between researcher and patient partners and acknowledge each of their concerns.
  - e. Plan a budget to recruit patient partners and reimburse their expenses and those of researchers who engage in additional patient engagement activities.
2. Execution phase
  - a. Patients should be engaged throughout the research execution phase in tasks such as:
    - i. Deciding on most relevant patient-centred outcomes
    - ii. Patient recruitment strategies
    - iii. Guiding the creation of consent forms
    - vi. Interpreting results
3. Translational phase
  - a. Encourage and support patients to mobilize knowledge into practice.
  - b. Work with patients to identify where and how dissemination is most effective for knowledge users (patients, clinicians, policy-makers, and administrators).
  - c. Work with patients to ensure that language used to communicate results is understandable by knowledge users who will then be empowered to make better decisions.

**LIMITATIONS**

Our recommendations are limited by the current state of evidence and the complex nature of the intervention.<sup>41</sup> Nevertheless, there is evidence from recent studies in EM<sup>37,38,42,43</sup> that engaging patients can lead to the production of more relevant and socially acceptable research. Our recommendations are limited by the design of our literature review. A more in-depth future systematic review will be necessary. Although we did involve an experienced patient partner as a member of our team (CM), we did not interview other patients with experience in EM. Finally, in formulating our recommendations, we did not conduct a formal consensus building process and we did not use a methodology such as GRADE<sup>44</sup> because of time constraints and resource limitations. More work will be needed to engage with Canadian EM researchers, policy-makers

and patients to reach a wider consensus and grade the strength of our recommendations.

**CONCLUSION**

Patient engagement has the potential to improve EM research in Canada by helping researchers select outcomes that matter to patients, increase social acceptability of studies, and design knowledge translation strategies that better target patient's needs. Our panel made policy-level recommendations to help CAEP support patient engagement in research and pragmatic recommendations to help Canadian EM researchers better engage patients and address some of the barriers to engaging patients in their research.

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which allowed CM to attend and present our panel's recommendations on June 3, 2017, in Whistler, BC. We also thank Carrie Anna McGinn, Kelly Wyatt, Shanna Scarrow, Cameron Thompson, and Corinne Hohl for their coordination and/or support during this project. Finally, we thank all of the CAEP Academic Section members, Academic Symposium attendees, and online survey participants for their feedback and suggestions about our recommendations.

PMA was the panel lead. He contributed to developing the protocol, extracting data from reviewed literature, collecting data, analysing the results, and drafting the recommendations and the manuscript. He co-presented the panel's recommendations at CAEP's Academic Section in Whistler, British Columbia. CM was the patient partner on our panel; she contributed to developing the protocol, collecting data, analysing the results, and drafting the recommendations and the manuscript. She co-presented the panel's recommendations at CAEP's Academic Section in Whistler, British Columbia. KND was a panel member; she participated in developing the protocol, extracting data from reviewed literature, conducting the qualitative interviews, analysing the results, drafting the recommendations, and reviewing the manuscript. SLM was a panel member; she participated in developing the protocol, extracting data from reviewed literature, collecting survey results and feedback during the symposium, analysing results, drafting the recommendations, and reviewing the manuscript. CV was a panel member; he participated in developing the protocol, extracting data from reviewed literature, collecting feedback during the symposium, analysing the results, drafting the recommendations, and reviewing the manuscript. JSL was a panel member; he participated in developing the protocol, extracting data from reviewed literature, analysing the results, drafting the recommendations, and reviewing the manuscript. JJP was a panel member and the Academic Symposium Chair; he participated in developing the protocol, drafting the recommendations, and reviewing the manuscript. FPG was a panel member; he participated in developing the protocol and reviewing the manuscript. AB was a panel member; he participated in developing the protocol, analysing the results, drafting the recommendations, and reviewing the manuscript.

**Competing interests:** None declared.

### **SUPPLEMENTARY MATERIAL**

To view supplementary material for this article, please visit <https://doi.org/10.1017/cem.2018.370>

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