

PATIENT-CENTERED CARE FOR PULMONARY  
EMBOLISM TESTING IN THE EMERGENCY  
DEPARTMENT

ACHIEVING A PATIENT-CENTERED APPROACH  
TO THE TESTING OF PULMONARY EMBOLISM IN  
THE EMERGENCY DEPARTMENT

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## **Forward**

Pulmonary embolism occurs when blood clots form in veins of the legs, and travel to the lungs, causing chest pain and shortness of breath. There are well-established, evidence-based guidelines on how to diagnose pulmonary embolism. Diagnostic tools such as the Wells score and D-dimer have been proven to be safe and effective in ruling out pulmonary embolism in low risk patients preventing the need for a CT scan. However, CT scans are still being overused to diagnose pulmonary embolism in low risk patients. Unnecessary testing in the emergency department (ED) exposes patients to the harms associated with CT scanning: such as increased risk of cancer, and diagnosing blood clots that are not actually there, resulting in unnecessary treatment. It is possible that the answer behind the over-testing of PE in the ED lies within the physician-patient relationship. This three-part study first reviewed all prior studies on shared decision-making strategies, which are techniques used to help physician align medical decisions with patient-specific values, in the ED. Second, we employed qualitative methods to identify patient-specific values and preferences on PE testing in the ED. Finally, both of these aims informed the development of a patient-centered shared information tool to overcome barriers to patient-centered care. Ultimately, the goal of this study is to achieve a patient-centered approach to the testing of pulmonary embolism in the ED.

## Abstract

**Background:** There is an evidence-practice gap between guidelines for diagnosing pulmonary embolism (PE) and emergency physician practice. This is concerning because computed tomography (CT) scanning is being overused to exclude PE in the emergency department (ED). It is possible that the answer behind this lies within the physician-patient relationship. Past research on shared decision-making strategies have shown to decrease use of hospital resources, and improve patient outcomes.

**Objective:** The aim of this three-part MSc thesis was to achieve a patient-centered approach to the testing of PE in the ED.

**Method:** 1) A systematic review on existing shared decision-making models used for testing and/or treatment of medical decisions in the ED was conducted. 2) Qualitative interviews with ED patients being tested for PE identified patient-specific values and preferences which may present as barriers to patient-centered care in the ED. 3) Both the systematic review and patient interviews informed the development of a new shared information tool to be used in the ED.

**Results:** The systematic review found that shared decision-making interventions in ED patients tested for acute coronary syndrome and clinically-important traumatic brain injuries can potentially reduce hospital admissions and increase discharge rates without negatively affecting health outcomes. The qualitative interviews highlighted four major themes: 1) patient satisfaction comes from addressing their primary concern; 2) preference for imaging over clinical examination; 3) patients expect 100% certainty when given a diagnosis; and 4) patients expect individualized care throughout their entire ED visit. This data led to the formation of a shared information sheet which ensures that testing decisions for low-risk PE patients align with patient-specific values.

**Conclusion:** By placing the focus on patient-centered care, this study incorporates evidence-based medicine with patient priorities in order to improve patient outcomes in the ED.

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I am very thankful to the entire EMeRGE Research Group for creating such a helpful and friendly environment. Their diligence and commitment to conducting high-quality research motivated me to do the same, and greatly expanded my knowledge on clinical research. Working with this team made my experience as a graduate student very memorable.

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## Abbreviations

ACS	Acute coronary syndrome
CanVECTOR	Canadian Venous Thromboembolism Clinical Trials and Outcomes Research
CCTA	Coronary computed tomography angiography
CI	Confidence interval
ciTBI	Clinically-important traumatic brain injury
CT	Computed tomography
DVT	Deep vein thrombosis
EBCD	Experience-based co-design
ECG	Electrocardiogram
ED	Emergency department
GCS	Glasgow coma scale
ICD	International classification of disease
IPDAS	International Patient Decision Aids Standard
IQR	Interquartile range
MACE	Major adverse cardiac events
(N)STEMI	(Non-) ST-elevation myocardial infarction
PE	Pulmonary embolism
PECARN	Pediatric emergency care applied research network
PERC	Pulmonary embolism rule-out criteria
PRISMA	Preferred Reported Items for Systematic Reviews and Meta-Analyses
P(T)CI	Percutaneous (transluminal) coronary intervention
SDM	Shared decision-making

## **Declaration of Academic Achievement**

Vidushi Swarup (VS) and Dr. Kerstin de Wit (KdW) contributed to the conception and design of this study and interpretation of the results. Graduate student, Asfia Soomro (AS), and post-graduate student, Solen Abdulla (SA), from McMaster University contributed to the screening and data extraction processes of the systematic review, and assisted with the coding process for analysis of qualitative interviews. Over the past two years, the following supervisory members guided and evaluated this project: Dr. Teresa Chan, Dr. Lori-Ann Linkins, and Dr. Mathew Mercuri. All patients in the qualitative interviews were from either Hamilton General Hospital or Juravinski Hospital in Hamilton. This study was approved by the Hamilton Research Ethics Board and written informed consent was obtained from all participants.



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# **1. INTRODUCTION**

## **1.1 Patient-centered care in the ED**

Patient-centered care in medical practice stresses the importance of addressing a patient's individual needs throughout their entire treatment process<sup>1</sup>. The goal of a patient-centered approach is to help physicians provide care that is concordant with patient values and preferences<sup>1,2</sup>. During medical decision-making processes, patient engagement has been proven to lead to better outcomes such as patient satisfaction and patient safety<sup>1</sup>. For example, in family medicine, patient engagement can help physicians individualize antibiotic treatment for urinary tract infections depending on which side effects their patient feels are more reasonable to endure<sup>3</sup>. Creating a patient-centered environment requires a few key aspects: an adequate level of patient knowledge and engagement in the medical decision; physician awareness of patient preference and values; and open communication between the physician and patient whereby this information can be shared in an unbiased and non-judgemental manner<sup>1</sup>.

The majority of patient-centered approaches to medical practice have been implemented in health care settings where patients have time and privacy with their primary care physician to discuss the medical decision being made<sup>1</sup>. For example, studies that have successfully implemented patient-centered care range from hospitalized patients with chronic conditions, to outpatients visiting their family doctor with whom they have built a trusted, personal relationship<sup>1</sup>. However, implementing patient-centered care in a rapid outpatient setting such as the emergency department (ED) has only recently been studied and analyzed. This is due to several contextual barriers: the ED is a fast-paced environment where diagnostic and treatment decisions must be made in a matter of seconds or minutes at the patient's bedside; patients generally have acute conditions and are in a great deal of discomfort with respect to pain, anxiety

and fear which may affect their decision-making ability; and patients have interactions with several health care professionals which may make the timing of a patient-centered intervention rather challenging<sup>4</sup>. For example, in a study conducted in Boston, ED patients were asked about their risk tolerance in a low-risk chest pain scenario. They found that 43% of patients preferred discharge, whereas only 3% of emergency physicians would have discharged the patient<sup>5</sup>. This emphasizes that there is little research on patient values and preferences in the ED, and a poor physician understanding of patient-specific treatment goals. A popular method used to improve and implement patient-centered care is to employ a shared decision-making technique<sup>6</sup>.

## **1.2 Shared decision-making in the ED**

Shared decision-making (SDM) has often been referred to as the “pinnacle of patient-centered care” in medical practice<sup>6</sup>. It is a process where both physician and patient work together to determine the optimal testing or treatment option for a medical decision in cases where there is clinical equipoise<sup>6-8</sup>. Physicians provide information on the illness, testing and/or treatment options, and their associated risks and benefits. Patients share their preferences on each option depending on what they value. From this, the physician can take each individual patient’s preferences into account to guide the decision-making process, and a mutually beneficial decision is made. By this method, patients feel autonomous and more in-control of their health care, and physicians are aware that the option chosen provides the best possible care for their patient<sup>6</sup>. A review was conducted on studies using SDM interventions in all areas of health care, and researchers found that patients who received an SDM intervention had: increased knowledge, increased accuracy of risk perception, decreased decisional conflict, and were equally or more satisfied with the medical decision<sup>2</sup>. This demonstrates that patient input can

impact medical decisions when there is effective communication and information sharing between physician and patient.

In a 2016 breakout session at the *Academic Emergency Medicine* consensus conference, shared decision-making in the ED was deliberated. They concluded that even in the time-sensitive environment of an ED, patients were still able to complete a fully informed consent process. Patients were able to decide to enrol in clinical trials where medication administration was required within minutes (i.e. stroke, acute myocardial infarction), proving that ED patients with acute conditions are still able and willing to make time-sensitive decisions<sup>9</sup>. In a review of patient-centered care in the ED, the level of information shared at discharge was evaluated, and the following information was found to be discussed less than 65% of the time: information about diagnosis, expected course of illness, self-care, use of medications, time-specified follow-up, and symptoms that should prompt return to the ED<sup>5</sup>. This highlights a clear communication gap between emergency physicians and their patients, and presents an opportunity for improving patient-centered care in the ED.

In order to facilitate and standardize physician-patient communication, SDM techniques use decision aids<sup>2</sup>. These are paper-based or computerized educational tools that provide personalized information to patients. According to the International Patient Decision Aids Standard (IPDAS), decision aids must explicitly state the medical decision being made, provide evidence-based information on the potential risks and benefits associated with the health care options, and help patients recognize that their values are important for the given medical decision<sup>2,10</sup>. The use of decision aids in SDM techniques has been proven to be an effective



method at implementing patient-centered care in a clinical setting, and impacting medical decisions<sup>2,9</sup>. For example, a study conducted on individuals with schizophrenia showed a statistically significant increase in the uptake of psycho-educational interventions in those who received an SDM intervention using a decision aid<sup>2</sup>. Decision aids have been used and studied in clinical settings for over a decade, however little research has focussed on their effects in the ED<sup>2</sup>.

### **1.3 Pulmonary embolism diagnosis in the ED**

Evidence-based guidelines for the testing for pulmonary embolism (PE) in the ED are seldom followed<sup>9,11</sup>. More specifically, a large number of patients who are at low risk of PE are receiving chest computed tomography (CT) scans, despite PE being safely excluded by well-established clinical decision rules, such as the Well's score with a D-dimer blood test, and Pulmonary Exclusion Rule-out Criteria (PERC) rule<sup>11</sup>. In a study conducted in Boston, it was found that only 10% of the CT PE scans ordered in the ED were positive for PE between 2003-2007<sup>12</sup>. This poses the problem of unnecessary testing in the health care system which has several negative ramifications. Most notably, it exposes patients to radiation increasing their risk of cancer, it has the potential to induce an allergic reaction due to the contrast dye, and it increases the rate of false positive PE diagnoses resulting in unnecessary treatment. Consequently, the overuse of CT scans increases the cost and resources used by hospital facilities<sup>11</sup>.

It is possible that the answer behind the lack of adherence to evidence-based guidelines lies in improving the information shared between the physician and patient<sup>9</sup>. Thus, PE testing in the ED

may be an opportunity to evaluate whether patient-centered care in the ED will help alleviate this problem. A discussion on the medical appropriateness of a test given a patient-specific pretest probability, may help patients understand their risk of having that condition, and may help physicians feel more comfortable with the medical decision made as it aligns with their patient's values<sup>9</sup>. A previous study conducted by Geyer et al. in 2014 evaluated patient preferences on the use of SDM for CT PE scanning in the ED. All ED patients who presented with chest pain and dyspnea were included, and researchers presented patients with visual aids to depict the risks and benefits of CT PE scanning. Then, they went through hypothetical decision-making scenarios discussing the decision to order a CT PE scan for a low risk patient. Out of the 203 patients that were included, more than one-third of the patients declining CT PE scanning<sup>13</sup>. However, due to the limited research available on this topic, it is still uncertain whether SDM interventions can facilitate patient-centered care in the ED, and its impact on medical decisions.

#### **1.4 Experience-based co-design**

In order to properly implement a patient-centered approach to medical decisions, patients must be able to understand the decision being made<sup>7</sup>. The level of knowledge that a patient may have on a particular condition or test may be difficult for an emergency physician to gauge in such a short amount of time<sup>9</sup>. Experience-based co-design (EBCD) is an approach created by the *National Health Service* that gathers information and experiences from physicians and patients to develop solutions that improve the quality of care<sup>14,15</sup>. This qualitative research approach gathers rich insights into patient experiences and can potentially identify previously unknown patient-specific priorities. EBCD consists of interviews and focus groups with physicians and patients to identify barriers to care, brainstorm possible solutions, and ultimately create a solution that

improves patient outcomes and is feasible in medical practice<sup>14</sup>. An example of the successful use of EBCD was in the development of a support package given to carers of patients undergoing chemotherapy. The package included a DVD of past carer interviews, a leaflet, and a nurse-led group session. Not only did the package prove to be helpful to carers, but it was also easy for physicians to integrate into their medical practice<sup>14</sup>. EBCD use in the ED has been studied in the context of improving palliative care patients' experiences in the ED. The approach was successful in creating a DVD package, and was able to encourage collaboration between patients and physicians in the ED<sup>15</sup>. However, due to the limited research available on this topic, its impact on achieving patient-centered care is not well known<sup>14,15</sup>.

## **1.5 MSc Thesis Aims**

The first aim of this thesis will be to summarize current evidence on the effectiveness of shared decision-making in the ED by conducting a systematic review. The second aim is to identify patient expectations, values and preferences regarding the testing of PE in the ED. Lastly, both patient and physician input will be used to develop shared information tools for a future patient-centered PE diagnostic model. Overall, this thesis will help the ED achieve a more patient-centered approach to PE testing.

## **2. METHODS**

## **2.1 Systematic review**

To elucidate information on the effectiveness of SDM in the ED, a systematic review was conducted on the use of SDM for the testing and treatment of any condition in the ED. This will help inform whether an SDM approach could be appropriate to use in patients tested for PE in the ED.

### *2.1.1 PROSPERO Registration*

Before data collection, the study protocol is registered on PROSPERO, and can be accessed at: CRD42019079879. This systematic review adhered to Preferred Reported Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines.

### *2.1.2 Search strategy and study selection:*

The OVID MEDLINE and Google Scholar databases were systematically searched from January 1974 to March 2019. The search strategy used was:

(shared decision making.mp. or exp Decision Making/ or patient preferences.mp. or exp Patient Preference/ or patient choice.mp. or (values and preferences).mp. or exp Patient-Centered Care/ or patient centred.mp.)

AND

(emergency department.mp. or exp Emergency Service, Hospital/ or emergency care.mp. or exp Emergency Medical Services/).

The inclusion criteria for eligible studies were the following: i) must be conducted on emergency department patients in an emergency department setting; ii) focussed on testing- or treatment-related medical decisions between the patient and their medical team; iii) used a shared decision-making technique; iv) reported the decision results in terms of clinical outcomes.

### *2.1.3 Data extraction and quality assessment*

A minimum of two out of three reviewers (VS, AS and SA) independently conducted title and abstract screening for possible inclusion. Full-text versions of these studies were obtained to further assess eligibility, and all full papers were reviewed by three people (VS, AS and KdW) who agreed on the final inclusion or exclusion of each study. Conflicts were resolved by consensus. Data were extracted based on the following criteria: 1) general information (author, year of publication, country); 2) study characteristics (medical decision, study design); 3) sample population (patient age, and sample size); 4) effect of shared decision-making technique on medical decision; 5) occurrence of adverse events during a follow-up period. We used the Cochrane Risk of Bias Tool to assess bias in all included articles as either low, unclear, or high risk of bias.

## **2.2 Qualitative patient interview method**

To investigate patient preferences and expectations on PE testing in the ED, semi-structured qualitative interviews with ED patients were conducted and analyzed.

### *2.2.1 Interview Process*

We conducted 30 semi-structured interviews on ED patients from two Hamilton hospitals over the course of 2 years. ED patients were screened using the hospital's patient tracker system. If the patient was being tested for PE (i.e. the ED physician had ordered a D-dimer blood test and/or a CT PE scan), they were approached and consented by a researcher to take part in a 30-minute audio-recorded interview. In order to be included, they had to be fluent in English, age 18 or over, and willing to spend 30 minutes in an interview. Patients who had cognitive impairments, were hemodynamically unstable, or too unwell to focus on conversation were excluded. The interview took place at the patient's bedside while the patient waited for the results of their tests. If the patient was alert, oriented and consent was obtained, they were interviewed on the following topics of interest: expectations of their ED experience, personal preferences and values associated with the ED environment and their health care providers, understanding of PE and treatment, confidence in ED testing, and overall patient satisfaction (see Appendix A1, page 59 for interview transcript). Each interview was transcribed verbatim.

After each patient was interviewed, the following demographic data were also obtained: age, sex, weight, highest level of education, vital signs (body temperature, blood pressure, heart rate, breathing rate, and blood oxygen level), past medical history (diabetes, hypertension, stroke, cancer, chronic obstructive pulmonary disorder, coronary artery disease, past PE diagnosis, and

past deep vein thrombosis diagnosis), and previous or current administration of anticoagulants. Their PERC rule, Wells score, D-dimer blood test, CT PE scan results, and final PE diagnosis were also recorded.

### *2.2.2 Thematic Analysis*

The interviews were analyzed using constructivist grounded theory. This method was chosen to allow issues of importance to be co-constructed between the researcher and patients that were interviewed. The researcher determined points of interest (PE testing in the ED), and recorded qualitative data on patient opinions, values and expectations. Grounded theory provides guidelines to systematically analyze the qualitative data to construct multiple major themes<sup>16</sup>. Four researchers (VS, AS, KdW, and SA) independently analyzed each interview transcript using constant comparative coding, and met to review and agree on common codes. The codes were grouped into themes, and the interview script was modified in order to maximize information on developing themes. From this, major themes with associated subthemes were derived – each representing an opportunity, barrier or value which must be addressed in the new shared information tools.



## **2.3 Development of shared information tools using an experience-based co-design method**

For the development of shared information tools, a process called Experience-based co-design (EBCD) was used. The EBCD approach gathered patient and physician experiences regarding the testing of PE in the ED. Physicians and patients met in focus groups to discuss and identify barriers specific to PE testing in the ED, and created a list of key topics to be included in a shared information tool. This will help physicians and patients understand each other's perspective, fill in gaps between the physician-patient relationship, and ultimately create a tool that has the potential to improve patient outcomes in future PE testing practices.

### *2.3.1 Patient and physician focus groups*

The patient meeting was held on October 25<sup>th</sup>, 2018 at the 3<sup>rd</sup> Annual Canadian Venous Thromboembolism Clinical Trials and Outcomes Research (CanVECTOR) conference in Montreal, and the physician meeting was held on December 17<sup>th</sup>, 2018 at Hamilton General Hospital. The patient focus group included patients who had been previously tested for PE in the ED. Each patient was given an information sheet which had a brief summary of the study, a list of the key themes collected from the patient interviews, and a list of key themes collected from previously conducted physician interviews on PE testing in the ED. Then, the PE testing decision aids identified in the systematic review were presented to the patients, and feedback on the effectiveness of each aid was obtained. Each decision aid was presented, and patients were asked to comment on: their first impressions, what was helpful about the tool, and what they felt was missing. The same information was presented to emergency physicians and feedback on the effectiveness of each aid, as well as the feasibility of decision aids in the ED was obtained (see

Appendix A2, page 67 for the Patient/Physician Information Sheet). Feedback from both sessions informed the development of a shared information tool, to be handed out to patients who are being tested for PE in the ED.

# **3. RESULTS**

### 3.1 Systematic review

#### 3.1.1 Study characteristics

The search strategy identified 3436 citations for review, and three articles were found by an additional Google Scholar search. After the removal of 20 duplicates, and completion of the title/abstract screening process, 111 articles were selected for full-text screening. A total of four studies met all of the eligibility criteria, and were included in the narrative synthesis (see Figure 1 for PRISMA chart below).

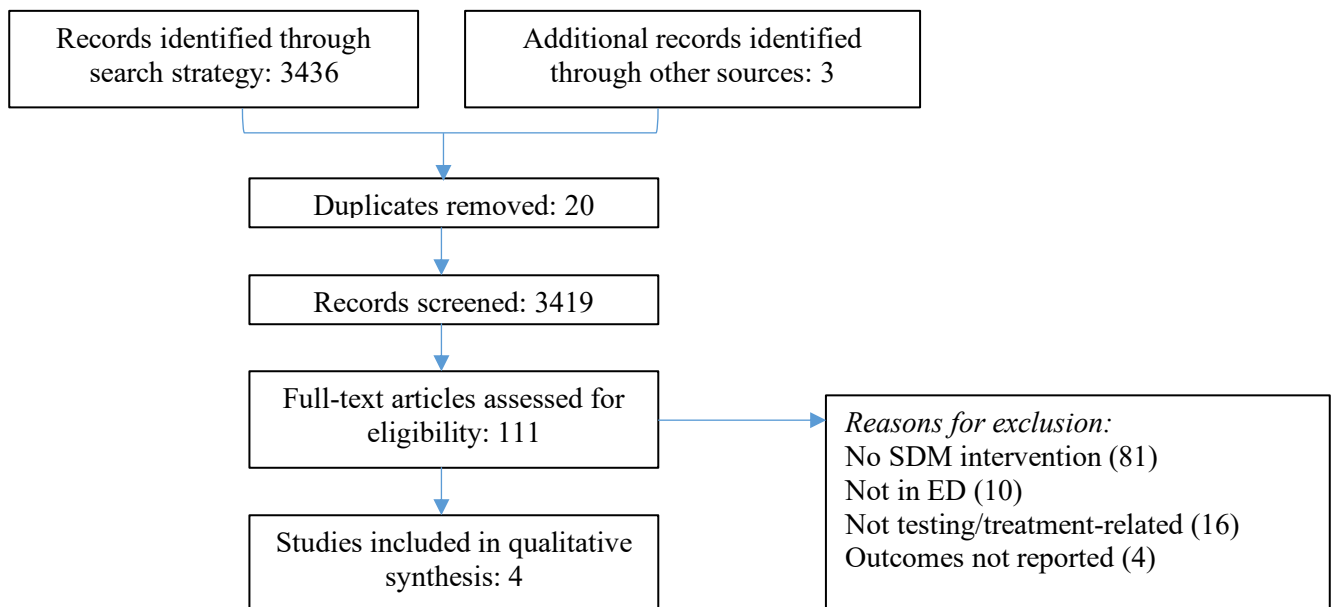


Figure 1: Preferred Reported Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of included and excluded studies.

Three of the four included articles focussed on the disposition of adult patients (>17 years old) with low risk chest pain and possible acute coronary syndrome (ACS)<sup>17-19</sup>. The fourth study was conducted on pediatric patients (age ≤17 years) with possible clinically-important traumatic brain injuries (ciTBI), where the medical decision was to order a head CT scan in the ED, or opt for at-home observation<sup>20</sup>. All studies had a generally low risk of bias. Full results of the study

characteristics are presented in Table 1.1, along with a risk of bias assessment presented in Table 1.2 below:

**Table 1.1: Characteristics of included studies**

Author, Year, Country	Medical Decision	Study Design	Sample Population	Sample Size		
				Control	Intervention	Total
<b>Kline et al., 2009,<sup>17</sup> USA</b>	Disposition for chest pain patients with possible ACS	Randomized controlled trial	Adult ED patients with a chief complaint of chest pain as identified by a triage nurse; an ECG was performed with no evidence of ischemia or infarction; a troponin test was done or ordered; the treating clinician did not have a definite plan to admit the patient	185	184	369
<b>Hess et al., 2016,<sup>18</sup> USA</b>	Disposition for chest pain patients with possible ACS	Randomized controlled trial	Adult ED patients (>17 years) with a chief complaint of chest pain; considered by treating physician to be admitted to the observation unit for cardiac stress testing or CCTA. Patients were excluded if they had ischemic changes on their initial ECG, and/or an initial cardiac troponin level more than the 99 <sup>th</sup> percentile	447	451	898
<b>Gafni-Pappas et al., 2018,<sup>19</sup> USA</b>	Disposition for chest pain patients with possible ACS	Prospective cohort study with historical controls	Adult ED patients (≥21 years) with a primary complaint of chest pain concerning for ACS in 2016 (verified by ICD-10 diagnosis codes); underwent troponin testing. In historical controls from 2014: ICD-9 diagnosis codes were used.	7657	5788	13455
<b>Hess et al., 2018,<sup>20</sup> USA</b>	Head CT scan for pediatric patients with ciTBI	Cluster randomized controlled trial	Pediatric ED patients (<18 years) with 1 or 2 PECARN non-high-risk factors for ciTBI within 24 hours of minor head trauma, defined by a GCS score of 15 after a non-negligible traumatic mechanism	478	493	971

Abbreviations: ACS = acute coronary syndrome; ED = emergency department; ECG = electrocardiogram; CCTA = coronary computed tomography angiography; ICD = International classification of diseases; ciTBI = clinically important traumatic brain injury; CT = computed tomography; PECARN = pediatric emergency care applied research network; GCS = glasgow coma scale

**Table 1.2: Risk of bias of included studies:**

<b>Author (Year)</b>	<b>Kline et al. (2009)</b>	<b>Hess et al. (2016)</b>	<b>Gafni-Pappas et al. (2018)</b>	<b>Hess et al. (2018)</b>
Random sequence generation	+	+	-	+
Allocation concealment	+	-	+	+
Blinding of participants and personnel	-	-	-	-
Blinding of outcome assessment	-	+	-	-
Incomplete outcome data (attrition bias)	+	+	+	+
Selective outcome reporting	-	+	+	+
Other sources of potential bias	+	+	+	+

### *3.1.2 Characteristics of decision aids*

All four studies used paper-based decision aids which were presented to patients by ED physicians, to discuss the medical decision<sup>17-20</sup>. Some common features that were present in all four decision aids include: each patient’s personalized risk score of having ACS or ciTBI respectively; a visual representation of the patient’s risk using a frequency chart; and checkboxes for each option for the physician and patient to check off together. The Hess et al. (2016), Hess et al. (2018) and Gafni-Pappas et al. studies also included information on the condition, outcomes associated with discharge, and follow-up information.

In the three studies focussing on low-risk ACS patients, the decision aids included tests that had been conducted in the ED: Hess et al. (2016) and Gafni-Pappas et al. included ECG and blood test results (which had to be negative for inclusion); and the Kline et al. study discussed the results of the ECG scan. These three studies also included a list of factors that were used to determine risk, the common ones being: age and patient history<sup>17-19</sup>. The Kline et al. and Hess et al. (2016) studies used a computer-generated tool called “Pretest Consult: ACS Pretest Probability Assessment” to calculate each individual patient’s 45-day probability of having ACS, whereas Gafni-Pappas et. al used the HEART score which predicts the risk of having a major adverse cardiac event within 30 days. Hess et. al (2016) and Gafni-Pappas et al. labelled their decision aids as “Chest Pain Choice” and “HAS-Choice”, respectively. All three studies focussed on the decision to be admitted to an ED observation unit, or else to be discharged home. The Hess et al (2016) study did not include inpatient admission as an option, unlike the other two studies, but further specified their discharge options into follow-up with a cardiologist or with a primary care physician. This study also included the option to let the emergency physician decide the outcome.

### *3.1.3 Effect of SDM technique on medical decisions*

Only two of the four studies reported statistically significant differences between the usual care and intervention groups<sup>18,19</sup>. Hess et al. (2016) and Gafni-Pappas et al. reported decreased rates of admissions to the ED for further cardiac testing, and increased rates of discharge in patients who received the SDM intervention. Hess et al. (2016) also found that a significantly lower number of patients in the intervention group wanted their emergency physician to decide their disposition. Gafni-Pappas et al. found that a significantly lower number of patients in the

intervention group opted for inpatient admission. The Kline et al. and Hess et al. (2018) studies did not find any statistically significant differences between groups<sup>17,20</sup>. For full results, see

Table 1.3 below:

**Table 1.3: Effect of shared decision-making interventions on medical decisions made in the ED**

Author, Year, Country	Medical Decision	Primary outcome			
		Usual Care (% n)	Intervention (% n)	P value <sup>a</sup>	
Kline et al., 2009, <sup>17</sup> USA	Disposition for chest pain patients with possible ACS	Discharged	32	31	0.795
		Observation in ED	38	45	0.263
		Inpatient admission	11	5	0.059
Hess et al., 2016, <sup>18</sup> USA	Disposition for chest pain patients with possible ACS	Observation in ED*	52	37	<0.001
		Follow-up with cardiologist*	12	23	<0.001
		Follow-up with primary care physician*	23	31	<0.001
		ERP decides disposition*	13	9	<0.001
Gafni-Pappas et al., 2018, <sup>19</sup> USA	Disposition for chest pain patients with possible ACS	Discharged*	44	54	<0.001
		Observation in ED*	49	42	<0.001
		Inpatient admission*	7	5	<0.001
Hess et al., 2018, <sup>20</sup> USA	Head CT scan for pediatric patients with ciTBI	Cranial CT performed	24	22	0.35
		1 PECARN risk factor	19	19	0.88
		2 PECARN risk factors	44	34	0.15

\*these options show statistical significance (p<0.05) between groups

<sup>a</sup>the p-values in this study were only reported on patients who did not have a significant cardiovascular diagnosis during a 45-day follow up period

<sup>b</sup>the usual care group represents historical controls which has been compared to an intervention group

<sup>c</sup>This odds ratio represents the association between intervention and disposition or testing outcomes, respectively.

Abbreviations: ACS = acute coronary syndrome; ciTBI = clinically important traumatic brain injury; CI = confidence interval; CT = computed tomography; PECARN = pediatric emergency care applied research network



### *3.1.4 Safety of shared decision-making interventions on health outcomes*

All four studies reported either a statistically significant reduction in the utilization of tests during a follow-up period, or reported no differences between the groups<sup>17-20</sup>. The Kline et al. study reported a significantly lower number of patients who received an ACS test requiring ionizing radiation with a negative test result within a 45-day period. Hess et al. (2016) reported a significantly lower proportion of patients in the intervention group who underwent cardiac stress testing within 30 days. Of the patients who underwent cardiac stress testing, a greater proportion of patients from the intervention group had the testing done in an outpatient setting. Hess et al (2018) reported no difference in the rate of CT scanning within a 7 day follow up period. Gafni-Pappas et al. did not report the testing that was done during a follow-up period.

There were no differences in the rate of deaths between the intervention and usual care groups, with the exception of the Gafni-Pappas et al. study. They found that patients in the usual care group had significantly more deaths than the intervention group. In the ACS studies, there were no differences in the rate of major adverse cardiac events in either group. In the Hess et al. (2018) study, there were no missed ciTBIs in either group.

The length of the ED visit was measured by all studies except for the Gafni-Pappas et al. study. The Hess et al. (2018) study was the only study to report a statistically significant difference where the length of stay was shorter in the intervention group. All studies measured the number of repeat ED visits within their respective follow-up periods. Only the Kline et al. study found a statistically significant difference where patients in the usual care group were more likely to return to the ED. For full results, see Table 3 below:

**Table 1.4: Occurrence of adverse events during a follow-up period**

Author, Year, Country	Medical Decision	Follow Up Period	Adverse Outcomes			
			Usual care (n=185, %)	Intervention (n=184, %)	P value	
Kline et al., 2009, <sup>17</sup> USA	Disposition for chest pain patients with possible ACS	45 days	Acute coronary syndrome diagnosis during follow-up	3 (1.6)	5 (2.7)	
			Missed/delayed ACS diagnosis	1 (0.01)	0 (0.0)	
			Rate of hospital admission in patients who had no significant cardiovascular diagnosis	20 (11)	10 (5)	0.059
			Rate of ACS testing using ionizing radiation	47 (25.5)	31 (16.8)	
			Negative result*	36 (19.6)	16 (8.6)	0.004
			Median length of stay in hospital	11.4 hours	9.2 hours	0.36
			ED return visit within 7 d*	20 (11)	6 (4)	0.001
			Acute coronary syndrome-defining events			
			Myocardial infarction	2	4	
			Coronary artery bypass graft surgery	0	1	
			Intracoronary stenting	2	4	
			Stenosis diagnosed with new medication	1	0	
			Other diagnoses			
			Pneumothorax	0	0	
			Aortic dissection	0	0	
			Pulmonary embolism	1	0	
			Congestive heart failure	3	1	
			Pneumonia	3	2	
			Asthma	2	0	
			Hypertension/hypertensive urgency	17	24	
			No significant cardiovascular diagnosis	156	152	
			Death	0	0	
			Hess et al., 2016, <sup>18</sup> USA	Disposition for chest pain patients with possible ACS	30 days	Cardiac stress test performed within 30 days*
Outpatient stress testing*	35 (17.2)	52 (30.2)				0.001
Exercise treadmill testing	65 (31.9)	44 (25.6)				0.779
Stress echocardiography	86 (42.2)	81 (47.1)				
Nuclear perfusion testing	39 (19.1)	37 (21.5)				
Other	14 (6.9)	10 (5.8)				
CCTA performed within 30 days	80 (17.9)	63 (14.0)				0.111
Coronary Revascularization	4 (0.9)	7 (1.6)				0.366
Percutaneous coronary intervention	3 (75.0)	6 (85.7)				
Coronary artery bypass grafting	1 (25.0)	1 (14.3)				
Admitted to hospital from ED observation unit	22 (4.9)	22 (4.9)				0.990
Repeat ED visit	39 (9.3)	52 (12.5)				0.156
Readmission to hospital	19 (4.5)	20 (4.8)				0.884
Outpatient clinic visit	259 (62.0)	266 (64.1)				0.568
Cardiac Events						
Acute myocardial infarction	1 (0.2)	4 (0.9)				0.215
Death of cardiac or unknown cause	0 (0.0)	0 (0)				1
MACE within 30 days	0 (0.0)	1 (0.2)	0.998			

			Usual care <sup>a</sup> (n=7657, %)	Intervention (n=5788, %)	P value			
<b>Gafni-Pappas et al., 2018,<sup>19</sup> USA</b>	Disposition for chest pain patients with possible ACS	30 days	All-cause ED bounce back	1044 (13.63)	883 (15.26)	0.76		
			Adverse Events within 30 days of index ED visit					
			NSTEMI or STEMI	4 (0.05)	7 (0.12)			
			PTCI/PCI	3 (0.04)	6 (0.10)			
			Cardiac arrest	3 (0.04)	0 (0)			
			Death*	43 (0.56)	13 (0.22)	0.02		
Any adverse event			49 (0.64)	22 (0.38)	0.10			
			Usual Care (n=478, %)	Intervention (n=493)	P value			
<b>Hess et. al, 2018,<sup>20</sup> USA</b>	Head CT scan for pediatric patients with ciTBI	7 days	Missed ciTBI diagnosis	0 (0)	0 (0)			
			Cranial CT obtained within 7 d (including index ED visit)			125 (26)	116 (24)	0.39
			ED length of stay in minutes, mean (SD)*	199 min (162)	176 min (135)	0.02		
			Admitted to the hospital	9 (2)	9 (2)	0.94		
			ED return visit within 7 d	18 (4)	10 (2)	0.15		
			Clinically important traumatic brain injury at 7 d	1 (0.2)	0	NA		

\*these rows show statistical significance (p<0.05) between groups

<sup>a</sup>the usual care group represents historical controls which has been compared to an intervention

Abbreviations: ACS = acute coronary syndrome; ED = emergency department; CCTA = coronary computed tomography angiography; MACE = major adverse cardiac events; (N)STEMI = (Non-)ST-elevation myocardial infarction; P(T)CI = percutaneous (transluminal) coronary intervention; ciTBI = clinically important traumatic brain injury; CT = computed tomography

### 3.1.5 Effect of shared decision-making technique on patient knowledge and experience

Only two out of the four studies, Hess et al. (2016) and Hess et al. (2018), measured patient knowledge and experience<sup>18,20</sup>. They used post-visit surveys which were given to ACS patients, or parents/caregivers of pediatric patients with ciTBI, respectively. Both studies found that participants in the intervention group reported significantly greater knowledge on their risk of having ACS or ciTBI, and their options for care when compared to the usual care group. Both studies also reported that participants in the intervention group had higher rates of satisfaction with their overall ED visit, and less decisional conflict. Hess et al. (2018) also found that parents in the intervention group had significantly greater trust in their physician, and were more

satisfied with the medical decision made. Hess et al. (2016) did not find a significant impact on trust in the physician.

***Summary: This systematic review found that SDM interventions in ED patients tested for ACS and ciTBI have the potential to reduce hospital admissions, and increase discharge rates without negatively affecting health outcomes, while simultaneously improving patient experience.***

## 3.2 Qualitative patient interviews

In order to identify patient-specific values and preferences on PE testing in the ED, qualitative semi-structured interviews were conducted. These were done at the patient bedside to capture their real-time opinions and expectations from patients while waiting for D-dimer or CT PE scan results.

### 3.2.1 Thematic sufficiency and patient demographics

Thematic sufficiency occurred after interviewing 30 ED patients (see Table 4 below for

demographic data). The first interview was conducted on October 24<sup>th</sup>, 2017 and the last interview was conducted on April 17<sup>th</sup>, 2019. For the first 10 interviews, four researchers (VS, AS, KdW, and SA) met to analyze the data, and compare common codes. For the remaining 20 interviews, three researchers analyzed the data (VS, AS, and KdW). An average of three interviews were analyzed per meeting, and a total of 11 meetings were held. The interview script was modified after the 10<sup>th</sup> and 23<sup>rd</sup> interview to expand on emerging themes. After the 26<sup>th</sup> interview, no new themes were found.

The average length of the interviews was 19 minutes (interquartile range = 3 min).

**Table 2.1: Patient characteristics**

Characteristic	No. (n=30)
Median age	59.5 (IQR* = 17)
Sex	
Female	14
Male	16
Highest education level	
Elementary school	2
High school	12
University/College	13
Post-graduate studies	3
Median weight (kg)	86 (IQR* = 31)
Past Medical History	
Diabetes	6
Hypertension	12
Stroke	5
Cancer	4
Chronic obstructive pulmonary disorder	2
Coronary artery disease	4
Past DVT** diagnosis	2
Past PE diagnosis	2
PERC $\geq$ 1	26
Wells' Score $\geq$ 4	12
D-dimer $\geq$ 500	17
Chest CT scan performed during initial ED visit	19
PE diagnosis in the ED	7

\*IQR = interquartile range

\*\*DVT = deep vein thrombosis

### 3.2.2 Thematic analysis

Through the method of constant comparative coding, four major themes with associated subthemes were identified. A conceptual model was created to illustrate the findings (Figure 2 below) and has been broken down to highlight how each theme related to each stage of an ED visit where a patient is being tested for PE:

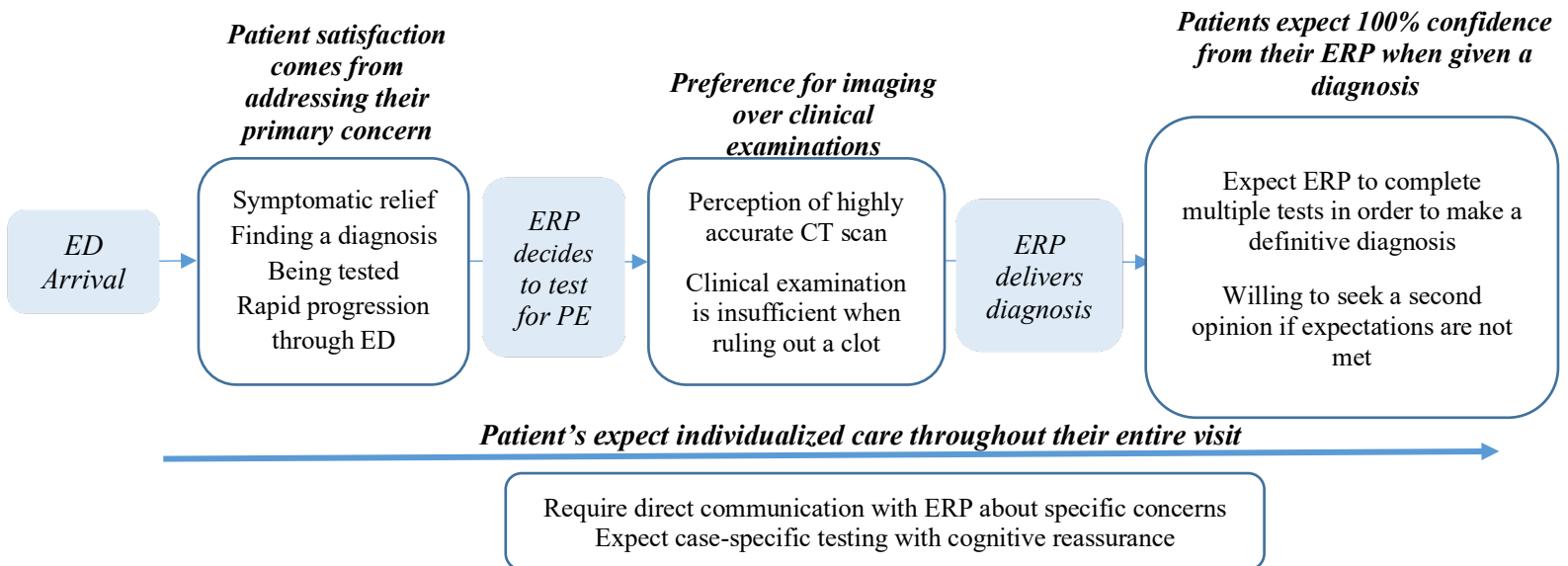
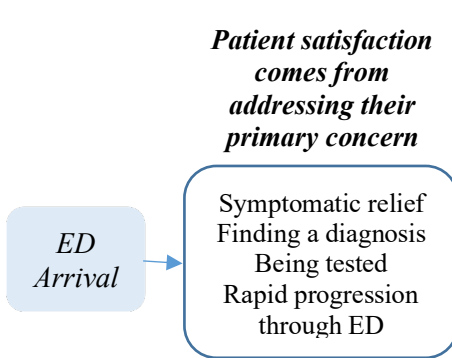


Figure 2: Conceptual model illustrating patient-specific values and expectations when tested for pulmonary embolism in the ED. Major themes are listed in bold, and their associated subthemes are listed in the boxes below.

Abbreviations: ED = emergency department; ERP = emergency room physician; CT = computed tomography

***Theme 1: Patient satisfaction comes from addressing their primary concern***



Upon ED arrival, patients came in with four main concerns which are listed as subthemes below. If any of these concerns were not addressed by their physician, patients expressed dissatisfaction with their ED visit.

***Subtheme 1: Symptomatic relief***

Chest pain and shortness of breath were two of the most concerning symptoms that patients expected to be addressed during their ED visit, with pain being the most common. Symptomatic relief was mentioned as a priority when patients were asked what the main goal of their ED visit was. One patient said: “relieving the symptoms, of course, is right at the top of the list” (patient 23). Symptomatic relief was also mentioned when patients were asked about the most unsatisfactory part of their ED visit. One patient said: “normally waiting wouldn’t bother me, except [I] can’t breathe because it is too painful, so waiting is hard” (patient 20). In this example, the persistence of symptoms while waiting in the ED led to dissatisfaction. Patients also expressed frustration when they did not know when their symptoms would be addressed by a physician. One patient said: “I waited here for over an hour and a half in pain and agony with my IV empty. I know they are busy and understaffed, but I asked if I could get an answer and they keep saying ‘Oh someone’s coming, someone’s coming’” (patient 9).

### Subtheme 2: Finding a diagnosis

Many patients expressed that their physician's main role was to find a diagnosis. One patient said that their main goal was: "to get checked out and find out what's going on...what's the reason for the shortness of breath and the pain" (patient 11). In these patients, finding a diagnosis was seen to be more important than symptomatic relief. Other patients said that finding a diagnosis was the reason why they came to the ED compared to other health care facilities: "I find [that] my family doctor is there to get you in and get you out as quick as possible and doesn't care. At least [the ED doctor] is gonna get down to what's going on" (patient 13). This quote emphasizes the fact that patients seek care in the ED specifically to get a diagnosis. Many patients believed that there must be a clinically-important reason behind their symptoms, and would not be satisfied with receiving no diagnosis: "If I don't [have] pain from [a] blood clot, find another reason" (patient 8). In these cases, patients are satisfied when they receive a diagnosis that justifies their symptoms.

### Subtheme 3: Being tested

Increased testing in the ED made patients feel prioritized. In other words, multiple tests made them feel like their emergency physician was "doing something" about their case. One patient said that the most satisfactory part of their ED visit was: "that [their ED physician] acknowledged that there was something. No matter how big or how small, they still ran the tests. They made sure that there was something and validated that I wasn't losing my mind" (patient 18). In these cases, patients felt that receiving multiple tests justified their ED visit because it meant that the symptoms that the patient perceived to be serious, were legitimate. There were a few patients who were most concerned with receiving tests due to a previous heart-related issue.

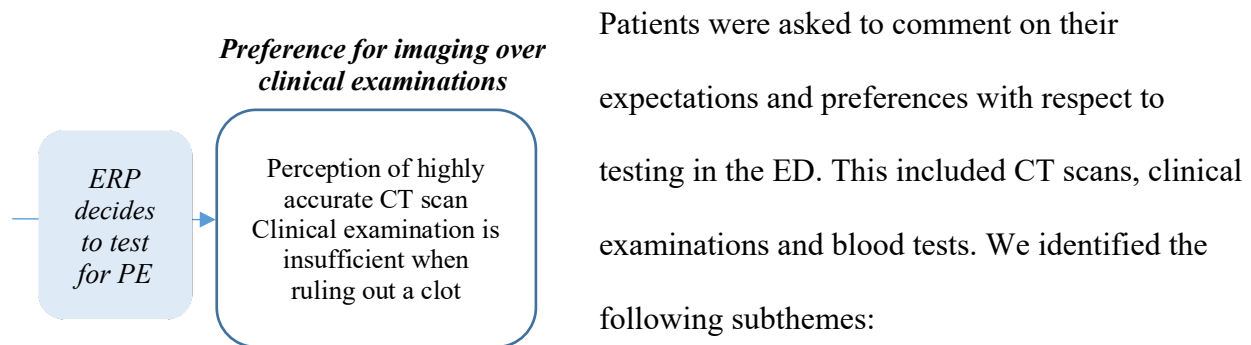


Specifically, many of them stated that they would only be satisfied with their visit as long as their heart was tested. When PE was described by the researcher to a patient with a previous heart condition, the patient said “I’m not too concerned about my lungs...as long as my heart is checked out, I’ll be okay” (patient 14). Here, the testing-related goal was specific to patients’ past medical history.

#### *Subtheme 4: Rapid progression through the ED*

Rapid progression included the quick admission from the waiting room to a hospital bed, short waiting times between visits by a physician or nurse, and short waiting times between subsequent tests. Many patients mentioned that the rapidity of their ED visit was the most satisfactory part of their ED visit: “They got at me right away. I didn’t have to wait at all...Time is a good thing” (patient 7). Conversely, patients who were dissatisfied due to long wait times (ex. overnight or over 24 hours) also expressed this as a primary concern. In one case, a patient said that her physician made her wait too long, which meant that her physician “[didn’t] seem to take [her case] too seriously, they seem to take it too lightly” (patient 27). These patients correlated long wait times to not being taken seriously by their physician.

## ***Theme 2: Preference for imaging over clinical examinations***



### ***Subtheme 1: Perception of highly accurate CT scans***

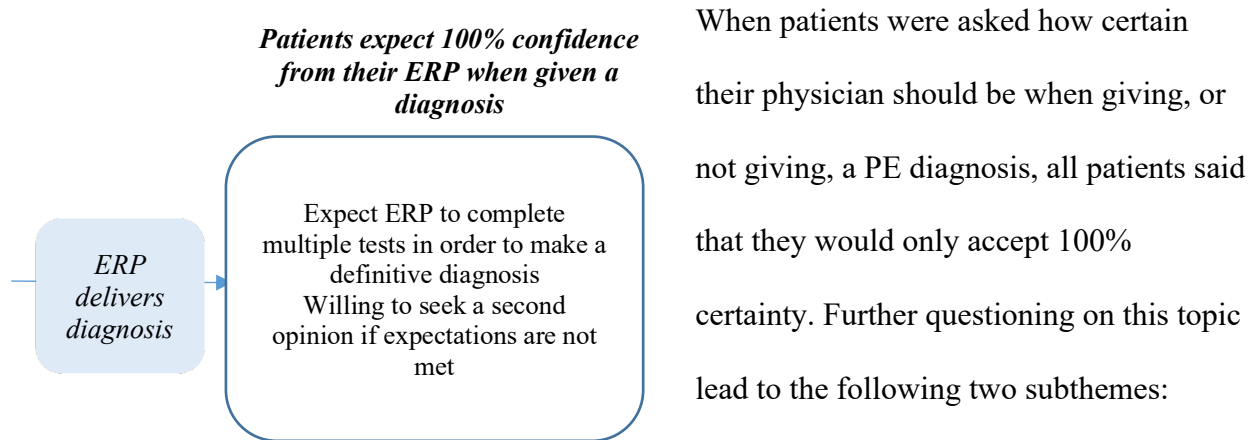
Patients were asked if they would accept clinical examination and blood testing to rule out a PE diagnosis, or if they should receive a CT scan. Almost all of the patients said that they would prefer a CT scan over clinical examination and blood testing, even if the latter option could rule out PE with 99% certainty. This was largely because the majority of patients felt that CT scans were 100% accurate in confirming a PE diagnosis. They felt that a CT scan would be able to “show” a clot, whereas a clinical examination and a blood test would not. One patient said: “All I [can] tell you is ‘*I have pain here, and I have pain here*’, but [the ED physician doesn’t] know exactly where I have pain because there is too much inside. There is a kidney and everything is inside. Only [a] CT scan can see what exactly is the problem” (patient 8).

### ***Subtheme 2: Clinical examination is insufficient when ruling out a clot***

Patients also felt that clinical examinations were more inaccurate than imaging tests. One patient mentioned: “I’d want the CT...to avoid human error” (patient 3). In addition, patients felt that further testing was needed in order to make a more definitive diagnosis: “I think [a clinical

examination and a blood test] is effective...but go further so [the ED physician can] pinpoint where [the blood clot] is... and the CT scan can define where it is” (patient 10).

***Theme 3: Patients expect 100% confidence from their emergency physician when given a diagnosis***



***Subtheme 1: Patients expect their ED physician to conduct multiple tests for a definitive diagnosis***

Receiving multiple tests in the ED was described as the most satisfying part of an ED visit because it meant that their examination was thorough. When one of the patients was asked how the physician can be 100% certain, they said that it was because of “the level of tests that the [doctor] put me through...It wasn’t just one test he did, [he did] the scan, the ultrasound, chest X ray, blood work” (patient 12). Multiple tests indicated to patients that their physician had checked everything. We also found a contradiction in that patients were aware that CT scans were not 100% accurate, but still expected 100% accuracy from their physician when given a

diagnosis. When they were further questioned on this contradiction, a patient had said that “the doctor would need more tests [in addition to a CT] in order to be [100%] accurate, they cannot rely on just one” (patient 17).

*Subtheme 2: Willing to seek a second opinion if expectations are not met*

Some patients expressed that they would be unsatisfied with their diagnosis if their physician did not order enough tests, or if they felt that their physician could not be 100% confident in their diagnosis. In these cases, patients sought a second opinion. When one patient was asked what they would do if they received no diagnosis, they said: “I would get a second opinion to be sure” (patient 26), and the second opinion was specified to be from another ED physician.

***Theme 4: Patients expect individualized care throughout their entire ED visit***

Throughout all stages of the ED visit, patients unanimously expected care to be specifically tailored to their needs and circumstances. This was outlined by the two subthemes below:

***Patient’s expect individualized care throughout their entire visit*** 

Require direct communication with ERP about specific concerns  
Expect case-specific testing

*Subtheme 1: Direct physician communication*

All patients emphasized the need to communicate with their physician throughout their ED visit. Specifically, many patients mentioned how a discussion with their doctor was the only way to guarantee that the physician had accurate information on their past medical history. For example, one patient had said “[I have] a recent history of a stroke, of PFO, and each time [I] come to the emergency it is like nobody knows anything about that, so there is a bit of a disconnect” (patient

10). A discussion with the physician verifies that their physician has all of the required information.

*Subtheme 2: Expect case-specific testing with cognitive reassurance*

Patients generally did not accept the idea of standardized testing – where other patients with similar signs and symptoms would receive the same tests and treatment. The majority of patients felt that they were different, or an “exception to the rule” (patient 21) where standardized tests may not apply. For example, one patients said that: “[Testing should be] different, because I’m different” (patient 13). Cognitive reassurance, or explanations and education from the physician, was needed in order to verify that the testing had been case-specific. These explanations were heavily valued by all patients as it made patients feel like their physician critically thought through their specific case. When asked what they would do if their doctor disagreed with their testing expectations, one patient said: “Well the thing is, if the doctor explained to me why [a test] wasn’t needed, then I would be fine” The explanation assures the patient that the physician’s decision to not order a test was specific to their case.

***Summary: The patient-specific values, preferences, and expectations for PE testing in these qualitative interviews highlight communication and expectation gaps in the physician-patient relationship which present as barriers to patient-centered care for PE testing in the ED.***

### **3.3 Shared information tool**

Our initial plan for patient-centered approach to PE testing in the ED was to implement an SDM intervention. However, based on the results from the systematic review, patient interviews, and EBCD focus group sessions (results listed in section 3.3.1 below), we discovered that an SDM approach may not be suitable. Since low-risk PE patients should not receive CT scans, this decision does not need to be shared. However, the themes discovered from the patient interviews emphasized the need for better, more effective communication between physicians and their patients. In effort to solve this issue, we created a shared information tool. The goals of this tools are to: inform patients on testing decisions, alleviate knowledge gaps found through the patient interviews, and facilitate a physician-patient conversation in the ED.

#### *3.3.1 Feedback from the patient focus group*

The patient portion of the EBCD meeting was held on October 25<sup>th</sup>, 2018 at the 3<sup>rd</sup> annual CanVECTOR conference held in Montreal. The patient focus group included six patients who had been previously tested for PE in the ED. It should be acknowledged that these participants are CanVECTOR patient partners attending a medical conference, and thus may not represent the average patient population. Each patient was given an information sheet which had a brief summary of the study, a list of the key themes collected from the patient and physician interviews on PE testing in the ED (see Appendix A2, page 67).

ED shared decision making aids were identified in the systematic review, and were presented at the meeting<sup>18,19</sup>. Each decision aid was presented, and patients were asked to comment on: their first impressions, what was helpful about the tool, and what they felt was missing. The decision

aids included: an information sheet on PE testing in the ED from Choosing Wisely<sup>21</sup>, the Chest Pain Choice and HAS-Choice decision aids from the studies included in the systematic review<sup>18,19</sup>, a tablet-based decision on the decision to order a head CT scan for TBIs<sup>22</sup>, and an opioid pain management decision aid<sup>23</sup> (see Appendix 3, page 68 for decisions aids).

### ***Key points from the patient focus group***

After discussion, the patients rated the following decision aid features as important in the development of a new tool for sharing information:

- 1) **Visually appealing:** Patients were most attracted to decision aids that were short, and colourful. This made decision aids seem less intimidating, and easier to follow.
- 2) **Inclusion of clinical prediction rules and past testing in the ED:** Patients valued decision aids that presented clinical prediction rules and past test results in the ED. This provided patients with insight into the physician's thought process and made them feel like their physician carefully considered their case, and rather than "doing nothing". They felt that this would also provide patients with the opportunity to ask about whether specific aspects of their medical history were considered during the decision-making process.
- 3) **Frequency charts:** Patients felt that frequency charts were not the best way of communicating risk, as patients may not be able to grasp the concept due to limited time with their emergency physician, and because they are in a stressful environment. The idea of using day-to-day analogies was deliberated (for example, relating the chances of having a PE as a low risk patient to the chances of winning the lottery), however there remained concern whether patients from all educational backgrounds will be able to

understand their individual risk. It was concluded that saying that a patient is safe to be discharged home, with advice about certain signs and symptoms warranting return to the ED was preferable to explaining the absolute (low) risk of having PE. This informs the patient that there is a possibility for the symptoms to persist or the condition to be present even when the tests are negative, and it also provides patients with “doctor-approved”, clearly explained discharge instructions.

- 4) **Checkboxes:** Patients felt that the use of checkboxes was empowering as they felt more involved with the medical decision being made. Checkboxes also gave a clear description of all possible outcomes, making them feel more equipped to make a decision as they had more knowledge on their condition. Checkboxes also helped facilitate a conversation between the patient and their physician, which reduces the frustration of not knowing what to ask a physician when given the opportunity.

Overall, the Choosing Wisely paper-based information sheet (Appendix 3.1, page 68) was thought to be easily discarded by patients, as they can find this information online. Patients valued decision aids that encouraged physician-patient interactions.



### *3.3.2 Feedback from the ED physician focus group*

The physician meeting was held on December 17<sup>th</sup>, 2018 at the Hamilton General Hospital. The attendees included six emergency physicians. The same information presented at the patient meeting was given to the ED physicians (see Appendix 2 for information sheet; see Appendix 3 for decision aids). Feedback on first impressions, effectiveness of each aid, and feasibility of decision aids in the ED was obtained. The feedback received from the patient meeting was also discussed during this session.

#### *Key points from ED physician focus group*

The following is a list of main points collected from the physician meeting:

- 1) **Improve patient knowledge:** After learning about the themes collected from the patient interviews, the physicians' main concern was lack of patient knowledge on the importance of clinical examinations and blood test results. In order to ensure patients that their physician had individualized their testing, physicians suggested emphasizing the relevance of the D-dimer blood test to the decision to order a CT scan. This would also encourage physicians to communicate which patient-specific factors (such as those included in a clinical decision rule) were involved when making this decision.
- 2) **Decision to order a CT scan:** Physician's did not agree with allowing patients to decide whether a CT scan should be ordered in low risk PE patients, as they would not normally order a CT scan for a low risk PE patient. Rather than employing an SDM model, a mode of educating patients on ED testing decisions should help alleviate gaps in the physician-patient relationship.

- 3) **Ease of implementation:** The decision aids presented were either tablet-based or paper-based. Physicians preferred paper-based decision aids because they would be easier to integrate into their natural ED workflow, as tablets are not integrated into the current testing and diagnostic processes in both hospitals.

### *3.3.3 Final design of the shared information tool*

The EBCD focus group meetings, along with the themes collected from the qualitative interviews, identified crucial components that needed to be addressed in the shared information tool. Briefly, these include: language to indicate individualized testing; information on PE and PE-related testing; importance of D-dimer test results; proper communication of low-risk scenarios; and the opportunity for patients to ask questions. For a full description of how these were integrated into the shared information tool, see Figure 3 below.

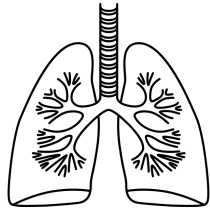
This information sheet will be given to the patient when their physician decides to test for PE. The patient can read the information while waiting for their D-dimer blood test result. When the physician returns, they will check off whether the test was positive or negative, and will explain and check off the appropriate next step.

***Summary: This shared information sheet will help standardize information presented to patients, and ensure that physicians are addressing patient-specific values and expectations during their ED visit.***

PATIENT STICKER HERE

**Your test results...**

Language such as “your” indicates to the patient that the medical decisions made have been individualized (**theme 4: patients expect individualized care**)



Based on your signs and symptoms, we have tested you for a condition called **pulmonary embolism** (blood clots in the lungs). One of the ways that we can test for this is to look at your blood for blood clotting (D-dimer test). The results of this blood test will tell us if you do not have blood clots.  
**The result from your D-dimer blood test is...**

Brief description of PE, and PE-related testing to improve patient knowledge, and communicate the importance and purpose of D-dimer blood test (**theme 2, subtheme 2: clinical examination and blood test is insufficient when ruling out PE; theme 4, subtheme 2: patients expect case-specific testing**)

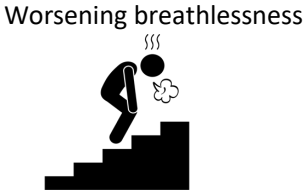
- Positive** this means we need a **chest scan** to rule out blood clots in the lungs
- Negative** this means that you do not have blood clots in the lungs, but we are testing you for other conditions.

Use of checkboxes to encourage patient involvement, and explain possible outcomes

**Your next step...**

- The tests were **negative** for blood clots and we have discussed your other test results.
- It is **safe for you to be discharged home** because the blood test was **negative** for blood clots. **Come back to the emergency department** if you feel any of the following symptoms:

Communication of low-risk scenarios as “safe to be discharged”, and information on when to return



Providing patients with the opportunity to discuss primary concerns with their physician (**theme 1: patient satisfaction comes from addressing their primary concern; theme 4, subtheme 1: patients value direct communication with physician**)

**Do you have any questions for your doctor?**

---



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Figure 3: Shared information tool for the testing of pulmonary embolism in the ED. Note: the information sheet has been modified to show relevancy of the findings collected from the qualitative patient interviews and EBCD focus group meetings to the shared information tool. Themes collected from the qualitative patient interviews are listed in bold.

# **4. DISCUSSION**

In this 3-part thesis project, I used the findings of the systematic review and patient interviews to develop a shared information tool for ED patients tested for PE.

## **4.1 Impact of shared decision-making on the ED**

### *4.1.1 Evidence for shared decision-making on medical decisions made in the ED*

Overall, there have been few studies evaluating SDM in the ED. The results of our systematic review were specific to two medical decisions – disposition of low risk chest pain patients with suspected ACS, and head CT scanning for pediatric patients who are at intermediate risk for ciTBI. The engagement of patients in their medical decisions resulted in fewer patients with chest pain being admitted for observation compared to a standard approach, and did not affect testing outcomes in pediatric patients with ciTBI. A significant decrease in hospital admissions, testing, and repeat ED visits was found in three of the included studies<sup>17-19</sup>. This has important clinical implications as it can potentially reduce testing performed in the ED, thereby decreasing the use of hospital resources, and shortening lengths of stay in the ED. Similar to the systematic review conducted, a Cochrane review published in 2017 also found no differences in adverse outcomes between intervention and usual care groups<sup>2</sup>. This is expected since each medical option presented in the decision aid has no clear health outcome advantage compared to the other options, which is why there is clinical equipoise between the disposition or testing outcomes.

ED SDM interventions have also improved the following patient-reported outcomes: increased patient knowledge, increased patient satisfaction, and decreased decisional conflict<sup>18,20,24</sup>. A previous systematic review on ED use of SDM published in 2012 also included the Kline et al.

study along with three other studies focussing on SDM use for treatment decisions in pediatric patients<sup>24</sup>. Our systematic review did not include these three studies because they did not report clinical outcomes<sup>25-27</sup>. They found patients in the intervention group had greater knowledge on their condition and associated risks with each treatment option. The decision aids used a computerized method to generate outcome probabilities for each individual patient. This addresses one of our four major themes from our patient interviews – **patients expect individualized care throughout their ED visit (theme 4)**. Providing patients with a list of patient-specific factors, may help them understand that their physician has carefully considered their case.

#### 4.1.2 Limitations

Due to the heterogeneity of outcomes, a meta-analysis or quantitative synthesis on study outcomes could not be conducted. A standard list of adverse health outcomes with a distinct follow-up period should be determined in order to standardize and validate the safety of SDM interventions in the ED. All four of the studies included in the systematic review were conducted in the USA<sup>17-20</sup>. Due to the fact that proper implementation of SDM in ED sites requires site-specific research to gauge physician and patient involvement, the results presented in these studies may not be generalizable. However, the positive findings on improved patient-reported outcomes, such as knowledge, satisfaction, and decisional conflict, show promise that SDM techniques may be used as a method of achieving patient-centered care in the ED for certain clinical scenarios.

### 4.1.3 Summary of our systematic review findings

Physicians can use high-quality evidence-based guidelines to stratify patients into low- or intermediate-risk categories, however the optimal management strategy for patients in each risk category can be debated<sup>9</sup>. Insight into patient preferences helps to ensure medical decisions are congruent with individual patient values<sup>2</sup>. This systematic review showed that there is potential for ED patients in low- and intermediate- risk clinical situations to share their values and be involved in medical decisions without negatively affecting health outcomes. We did not find any data supporting SDM use for patients being tested for PE in a low risk group as no study has been conducted. This systematic review provides indirect data supporting that educating patients being tested for PE on risk, diagnoses, and outcomes associated with testing decisions may lead to better management and patient satisfaction.

## **4.2 Patient preferences and values on PE testing in the ED**

### ***4.2.1 Inferences from qualitative patient interviews***

To our knowledge, this is the first qualitative study focussing specifically on ED patients who are being tested for PE. Adopting a post-positivist approach allowed for the development of multiple themes that ED patients have when being tested for PE. Four common themes were constructed from qualitative analysis: 1) patient satisfaction comes from addressing their primary concern; 2) patients prefer imaging over clinical evaluations; 3) patients expect 100% confidence from their physician when given a diagnosis; and 4) patients expect individualized care throughout their ED visit. These themes can be conceptualized throughout the course of a patient's ED visit while they are being tested for PE, as shown in the model above (Figure 2, page 26). In recent years, other studies have explored patient values and preferences in the ED in relation to other medical conditions.

### **Patients seek symptomatic relief**

A study conducted by Vaillancourt et al. interviewed ED patients post-discharge to define patient-reported outcomes<sup>28</sup>. One major theme was that patients seek symptomatic relief, where the most common symptom was pain. This is synonymous to the subtheme collected in our study, where patients wanted their physician to address and provide relief for their symptoms, the most common one being pain. The congruence between these two studies highlights the fact that patients put high value on symptomatic relief, especially if that symptom is pain. In addition, pain relief is not specific to patients being tested for PE; it extends across a wide range of patients who have come to the ED for various reasons<sup>28</sup>.



### **Patients seek a diagnosis**

Patients wanted to find a cause for their symptoms, or in other words, find a diagnosis. Several studies have found diagnosis-seeking to be the main reason why patients come to the ED<sup>28-30</sup>. A diagnosis helped patients understand the course of their symptoms: why they arose, management of symptoms if they persist, and when they will resolve<sup>28,30</sup>. In the case where patients are not given a diagnosis, they were satisfied if the physician gave a proper explanation for the symptoms, and why there was no diagnosis. In prior physician interviews conducted in our facility (de Wit et al., unpublished communication), ED physicians focused on ruling out all “deadly” diagnoses, one of them being PE. When patients do not have a deadly diagnosis, they want to know more about why they have symptoms. Patients may value knowing what is causing their symptoms, even when it is not a serious condition.

### **Patients prefer imaging over clinical evaluation**

In our study, many patients believed that a CT scan was 100% accurate in diagnosing PE. The main reason behind this is patients feel that imaging is “tangible”, meaning that a clot can be seen. The same was also seen in ED patients expecting a head CT scan after a minor TBI thinking that it would diagnose a concussion, which is also incorrect<sup>31</sup>. ED physicians can access high quality imaging technology quite easily, which could encourage the perception that imaging is the best test for patients. Imaging tests also indicate to patients that their ED physician is “doing something”, making patients feel like their case is important, and of high priority. More testing procedures may give the illusion that their physician is taking them seriously, and differentiating their case from other patients. One way to combat this could be to inform patients

of the importance of clinical examination and the D-dimer blood test prior to the decision to order a CT PE scan. This might help patients feel important and prioritized even if they are not given a CT scan.

### **Patients expect 100% confidence from their physician when given a diagnosis**

Patients felt that their physician should be 100% accurate when communicating a diagnosis because this was perceived to be the main role of the ED physician. Patients come to the ED to seek a diagnosis. This is the most common theme seen across studies, and it is evident that patients place a very high value on receiving a diagnosis in the ED. The only person who can give them this answer is their emergency physician<sup>28-30</sup>.

When asked how physicians will come to their diagnosis, many patients believed that it was because their physician conducted multiple tests. From the patient's perspective, it makes sense to believe that a physician will use multiple tests in order to confirm or deny a diagnosis. Conducting only one test might be open to error inherent in that test. This is demonstrated when patients will seek a second opinion if they feel they did not receive the testing that they deserve. A careful explanations from their physician about how PE is tested might help patients feel more comfortable and understand why a CT PE scan was not ordered during their ED visit.

### **Patients expect individualized care**

Patients expected their physician to provide individual care for them. Lin et al. found that the most popular patient-rated ED physician phrase was "I have carefully considered what you told me and what brought you here today"<sup>30</sup>. Patients want reassurance because they may feel

forgotten while waiting for test results, or that their case is not being taken seriously due to long wait times and limited interactions with their physician. Patients feel assured that their physician has carefully considered their specific case when they have the opportunity for direct discussion. Computer generated print-outs of their individualized risk scores (as used in the SDM practices discussed in section 4.1, page 42), may help assure patients that their testing was case-specific. They may feel that their long wait time or lack of a certain test is justified because their physician has come to this conclusion after reviewing their case details.

ED patients often have high acuity illness and short interactions with their physician which means that they have limited time to gather information and make decisions quickly<sup>33</sup>. Patients require explanations to help them understand why a certain medical decision was made, such as the decision to not order a specific test.

#### 4.2.2 Limitations

Our study included 30 patients of different ages, genders, time of day and experiences with PE testing. Although we reached theme saturation, the sample is small and other patients not included in the interviews may have different values and preferences to the ones we recorded. Theme generation was subjective to the researchers analyzing the data, which may have led to confirmation bias. We strived to incorporate researchers from different levels of medical knowledge. The researchers involved in analyzing the data consisted of: an emergency and thrombosis physician, myself, and two other students (one graduate and one postgraduate student from McMaster University). Since the interview was semi-structured, patients were at liberty to talk about what they wished to discuss in the interview, and were given the option to not

comment on a particular topic if they wished to do so. In addition, the patients and physicians in the focus groups represent a select population who are engaged in improving patient and physician interaction. There may be some physicians who are not willing to involve patients in this decision, and patients who will divert the responsibility of care to their physician.

## **4.3 Developing a shared information tool**

### ***4.3.1 Is shared decision-making appropriate for the testing of PE in the ED?***

There is potential to use and implement SDM in the ED as it seems plausible and may improve patient outcomes. However, SDM may not be applicable to every clinical scenario, one of them being PE testing. Our physician focus group determined that clinical equipoise does not exist in this situation. If a patient is low-risk, clinical guidelines state that they should not receive a CT scan in order to test for PE; PE can be safely excluded as a diagnosis. However, this does not mean that patient-centered care cannot be achieved for PE testing in the ED. By employing techniques that are similar to SDM, such as developing shared information tools, patients can be informed on their testing and treatment processes. Patients should have the opportunity to ask questions in a stressful clinical environment such as the ED. Thus, SDM techniques can be used as a guide to develop patient-centered ED tools, such as a shared information tool. These tools could facilitate patient-physician communication, and can be easily integrated into the natural ED workflow.

### ***4.3.2 Development of the shared information tool***

This shared information tool facilitates the involvement of patients in their testing decisions. It addresses patient-specific outcomes of importance as determined by the patient interviews: it individualizes care; allows direct communication with physicians; and strives to increase patient understanding of low-risk scenarios. Patients will be given the opportunity to work through the material before meeting with their physician, which allows patients to critically think about their concerns so that their physician can address them in the ED, rather than holding in their concerns and seeking a second opinion post-discharge. The shared information tool also provides patients

with practical information to effectively communicate a low-risk scenario in an ED setting – we link a low-risk situation to the idea that PE cannot be ruled out with 100% certainty, but it is safe for them to be discharged. From the physician’s perspective, the shared information tool standardizes the information given to patients. Since it is paper-based, it is easy to use and implement. Physicians can also ensure that the information presented to the patient is understood, and aligns with each patient’s values.

Although this shared information tool does allow patient input, it is not an SDM intervention; the only person responsible for making the medical decision is the physician. The main goal of the shared information tool is to enable patients to communicate their concerns with respect to the medical decision made, so that the physician can address them in the ED. In addition, this tool may be challenging to apply to patients with language barriers, dementia, or those who are unwilling to participate.

#### 4.3.3 Future research

The next step of this study would be to test the shared information tool by measuring: patient and physician engagement; physician uptake; patient satisfaction; and patient knowledge on their condition, testing and its associated risks during an ED visit. Patient-reported outcome measures (PROMs), as described by Vaillancourt et al., can be used to evaluate symptom relief and patient understanding of their care during the post-discharge period<sup>28</sup>. The impact of the shared information tool could be measured by: the ED length of stay, hospital resource use, frequency of repeat ED visits, and occurrence of adverse outcomes. These outcomes will help determine

whether the shared information tool is effective and safe to use on patients who are being tested for PE in the ED.

# **5. CONCLUSION**



Patient-centered care is commonly used in health care settings where patients and physicians are have time and privacy to engage in medical decisions. Contextual barriers in the ED, such as the fast-pace nature and lack of privacy, may pose barriers to SDM implementation. The systematic review informed us that shared decision-making is possible in the ED, and patients are willing to participate in their medical decisions despite these contextual barriers. Our patient interview analysis identified areas of importance for ED patients being tested for PE. We addressed these areas of importance in our shared information tool. The effectiveness of our shared information tool in the management of low-risk PE patients is yet to be determined. Overall, we believe that patient-centered care can be achieved in an ED setting.

# **6. REFERENCES**

1. What is patient-centered care?. *NEJM Catalyst* (2019). at <<https://catalyst.nejm.org/what-is-patient-centered-care/>>
2. Stacey, D. et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* (2017). doi:10.1002/14651858.cd001431.pub5
3. Epstein, R. The Science of Patient-Centered Care. *Journal of Family Practice* 49, 805 (2000).
4. Kanzaria, H. et al. Emergency Physician Perceptions of Shared Decision-making. *Academic Emergency Medicine* 22, 399-405 (2015).
5. Pham, J. et al. Interventions to Improve Patient-centered Care During Times of Emergency Department Crowding. *Academic Emergency Medicine* 18, 1289-1294 (2011).
6. Barry, M. & Edgman-Levitan, S. Shared Decision Making — The Pinnacle of Patient-Centered Care. *New England Journal of Medicine* 366, 780-781 (2012).
7. Charles, C., Gafni, A. & Whelan, T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine* 44, 681-692 (1997).
8. Fried, T. Shared Decision Making — Finding the Sweet Spot. *New England Journal of Medicine* 374, 104-106 (2016).
9. Barrett, T. et al. The 2016 Academic Emergency Medicine Consensus Conference, “Shared Decision Making in the Emergency Department: Development of a Policy-relevant Patient-centered Research Agenda” Diagnostic Testing Breakout Session Report. *Academic Emergency Medicine* 23, 1354-1361 (2016).
10. Stacey, D. & Volk, R. International Patient Decision Aids Standards (IPDAS) Collaboration. *Ipdas.ohri.ca* (2019). at <<http://ipdas.ohri.ca/>>
11. Tan, S. & Haramati, L. Are We Overdiagnosing Pulmonary Embolism? Yes!. *Journal of Thoracic Imaging* 33, 346 (2018).
12. Raja, A. et al. Effect of Computerized Clinical Decision Support on the Use and Yield of CT Pulmonary Angiography in the Emergency Department. *Radiology* 262, 468-474 (2012).
13. Geyer, B., Xu, M. & Kabrhel, C. Patient preferences for testing for pulmonary embolism in the ED using a shared decision-making model. *The American Journal of Emergency Medicine* 32, 233-236 (2014).
14. What is Experience-based co-design? | Point of Care Foundation. *Point of Care Foundation* (2019). at <<https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/1-experience-based-co-design/>>

15. Blackwell, R., Lowton, K., Robert, G., Grudzen, C. & Grocott, P. Using Experience-based Co-design with older patients, their families and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process and outcomes. *International Journal of Nursing Studies* 68, 83-94 (2017).
16. Mills, J., Bonner, A. & Francis, K. The Development of Constructivist Grounded Theory. *International Journal of Qualitative Methods* 5, 25-35 (2006).
17. Kline, J., Zeitouni, R., Hernandez-Nino, J. & Jones, A. Randomized Trial of Computerized Quantitative Pretest Probability in Low-Risk Chest Pain Patients: Effect on Safety and Resource Use. *Annals of Emergency Medicine* 53, 727-735.e1 (2009).
18. Hess, E. et al. Shared decision making in patients with low risk chest pain: prospective randomized pragmatic trial. *BMJ* i6165 (2016). doi:10.1136/bmj.i6165
19. Gafni-Pappas, G. et al. The HAS-Choice study: Utilizing the HEART score, an ADP, and shared decision-making to decrease admissions in chest pain patients. *The American Journal of Emergency Medicine* 36, 1825-1831 (2018).
20. Hess, E. et al. Effect of the Head Computed Tomography Choice Decision Aid in Parents of Children With Minor Head Trauma. *JAMA Network Open* 1, e182430 (2018).
21. CT Scans to Find a Blood Clot in the Lungs: When you need one and when you don't. *Choosing Wisely Canada* (2019). at <<https://choosingwiselycanada.org/ct-scans-find-blood-clot-lungs-need-one-dont/>>
22. Singh, N. et al. Tablet-Based Patient-Centered Decision Support for Minor Head Injury in the Emergency Department: Pilot Study. *JMIR mHealth and uHealth* 5, e144 (2017).
23. Omaki, E. et al. Using m-health tools to reduce the misuse of opioid pain relievers. *Injury Prevention* 25, 334-339 (2017).
24. Flynn, D. et al. Engaging Patients in Health Care Decisions in the Emergency Department Through Shared Decision-making: A Systematic Review. *Academic Emergency Medicine* 19, 959-967 (2012).
25. Yamamoto, L. Application of informed consent principles in the emergency department evaluation of febrile children at risk for occult bacteremia. *Hawaii Med J.* 56, 313-7, 320-2 (1997).

26 Yamamoto, L., Young, L. & Roberts, J. Informed consent and parental choice of anesthesia and sedation for the repair of small lacerations in children. *The American Journal of Emergency Medicine* 15, 285-289 (1997).

27 Karpas, A., Finkelstein, M. & Reid, S. Parental Preference for Rehydration Method for Children in the Emergency Department. *Pediatric Emergency Care* 25, 301-306 (2009).

28 Vaillancourt, S. et al. Patients' Perspectives on Outcomes of Care After Discharge From the Emergency Department: A Qualitative Study. *Annals of Emergency Medicine* 70, 648-658.e2 (2017).

29 Bhise, V. et al. Patient perspectives on how physicians communicate diagnostic uncertainty: An experimental vignette study†. *International Journal for Quality in Health Care* 30, 2-8 (2018).

30 Lin, M. et al. Improving perceptions of empathy in patients undergoing low-yield computerized tomographic imaging in the emergency department. *Patient Education and Counseling* 101, 717-722 (2018).

31 Melnick, E. et al. Understanding Overuse of Computed Tomography for Minor Head Injury in the Emergency Department: A Triangulated Qualitative Study. *Academic Emergency Medicine* 22, 1474-1483 (2015).

32 Hess, E., Grudzen, C., Thomson, R., Raja, A. & Carpenter, C. Shared Decision-making in the Emergency Department: Respecting Patient Autonomy When Seconds Count. *Academic Emergency Medicine* 22, 856-864 (2015).

# **7. APPENDICES**

## **A1: Interview script**

Hello [patient's name], my name is [research assistant's name] and I am a research assistant. I am here today because I was wondering if you would like to take part in a short interview about your thoughts on blood clot testing in the emergency department.

We are interviewing people who are having tests for blood clots in the lungs.

The interview will take 30 minutes. You are free to take a break or choose not to answer a question at any time. You may also withdraw yourself from the interview at any time. I will record your voice during the interview.

Everything you say will be confidential. Only the research team will hear what you say. What you say will have no effect on your treatment today.

You will not benefit directly from participating in this study, but your thoughts will help improve the treatment we give future patients. As a token of our appreciation, we will give you a \$10 voucher for Tim Hortons.

ENSURE CONSENT FORM IS SIGNED AND COPY GIVEN TO THE PATIENT.

### **Expectations of ED experience:**

---

Can you tell me what brought you in to the ED today?

Pt:

And how did you make the decision to come in to the ED?

Pt:

What is your primary concern?

Pt:

Is there anything specific that you would like to be addressed by your visit today?

Pt:

Are you most concerned with getting symptomatic relief, a diagnosis, or something else?

Pt:

How were your expectations of your emergency department visit influenced, for example did your family doctor tell you what would happen, or a family member?

Pt:

If you decided to come in on your own, what made you decide that it was an emergency?

Pt:

Have you or a family member ever come to the emergency department before?

Pt:

How does your past experience compare to today's visit?

Pt:

What is most important when you are tested for blood clots? Please can you line these cards up in order of most important to least important.

‘My opinion and satisfaction’

‘My family / friend / carers opinion’

‘My doctor’s opinion’

‘My nurse’s opinion’

‘My family practitioner’s opinion’

Can you explain your answer to me?

**Perceived role of self:**

---

Do you feel that your opinions matter here in the emergency department?

Pt:

Do you feel listened to here in the emergency department?

Pt:

Who do you think is responsible to addressing your concerns?

Pt:

Can you give me an example of a time where you did/did not feel listened to?

Pt:

What’s the most troubling thing in the ED? Has anything made it worse?

Pt:

V: And the most satisfactory thing, anything that has made you feel better?

Pt:

Did you have an idea of what your diagnosis might be before coming in? How did you come up with that?

Pt:

How likely do you think it is that you will get no diagnosis?

Pt:

How would you feel if your doctor said that you had no diagnosis?

Pt:

Did you have an idea of what tests might be ordered?

Pt:

Did you have any questions about the testing being done today?

Pt:



Was there anything that you wanted to get a test for today? Did you tell your doctor about it?

Pt:

Do you think that you should have a test if you really felt that you needed it? Is this your right?

Pt:

What if your doctor disagreed that you need that test?

Pt:

What do you think your doctor should consider when ordering tests today?

Pt:

**Perceived role of the physician:**

---

How do you see the role of your emergency department doctor in treating you today?

Pt:

Do you think your doctor should follow national guidelines when ordering tests?

Pt:

Do you think your doctor should use evidence from medical research studies to guide them on what tests they order?

Pt:

Should your doctor approach testing for each patient differently or the same? Why?

If someone came in with the same signs and symptoms as you, should your ED dr approach the patient the same way or different?

Pt:

If different - What makes you different from other patients?

Pt:

If personal history is mentioned – Do you think your doctor considered that when ordering your tests today?

Pt:

How do you think your doctor is treating you? The same or different from other patients?

Pt:

What would you say are good attributes of an emergency department doctor?

Pt:

What questions did you ask your doctor today? Did he/she answer all of them for you?

Pt:

**Perceived role of nurses:**

---

What is the role of the emergency nurse who is treating you?

Pt:

**Understanding of the condition:**

---

Your doctor is testing you for blood clots in your lungs today. Can you tell me what you know about blood clots in the lungs?

Pt:

[Give patient the opportunity to ask questions about what blood clots are. Supply simple, reassuring answers: ‘One in 20 people are diagnosed with blood clots at some point in their life. Blood clots can develop in the veins in the leg. They move with the blood flow into the lungs. Blood clots can’t pass through the lungs as the lungs act like a filter. They can cause the feeling of breathlessness or chest pain. Blood clots are treated with “blood thinner” medications’.]

What do you know about the treatment for blood clots in the lungs?

Pt:

[Supply reassuring answers – ‘Most people with blood clots are started on tablet blood thinners and treated at home. They are seen in clinic in a few days time. Sometimes people with blood clots in the lungs need to be admitted to hospital. In this case they may be given an infusion of blood thinners, or else injections of blood thinners’.]

Do you have an idea of whether you have a blood clot or not?

Pt:

Do you know how likely it is that you have blood clots in your lungs? Please choose the statement that is most applicable to you.

- ‘It is certain that I have blood clots in my lungs’
- ‘It is more likely than not that I have blood clots in my lungs’
- ‘It is less likely that I have blood clots in my lungs’
- ‘It is very unlikely that I have blood clots in my lungs’
- ‘I don’t really know’

Can you tell me why you think that?

Pt:

[Education: ‘Sometimes CT scans will diagnose blood clots when they are not there. One in 20 positive scans give a false positive result.’]

Please show me the statement that you think best describes the seriousness of this condition.

- ‘Blood clots are a grave and serious diagnosis.’
- ‘Blood clots are a serious but treatable condition.’
- ‘Blood clots are an illness that is easily treated.’
- ‘Blood clots are a mild condition with simple treatment.’

[If the patient does not choose one statement, ask what would be a better description of seriousness of the diagnosis.]

**Confidence in the emergency department testing:**

---

How much do you trust that your doctor will find out whether you have blood clots or not?

Pt:

What attributes about your doctor makes you trust him/her?

Pt:

Which would you say are the best tests for blood clots?

CT scan

Questions from you doctor and an examination

Blood testing

Why do you think \_\_\_\_\_ is the best test?

Pt:

Which tests would you like your doctor to use for a condition like PE?

Pt:

Do you think that your examination has been thorough? What would make you feel like the doctor has completed a thorough examination?

Pt:

On the whole in the emergency department, doctors test to RULE OUT blood clots. Only one in 20 people who are tested for blood clots in this department are ever diagnosed with them.

If your doctor tells you that you **don't** have a blood clot, how certain do you think they should be that there is no blood clot?

Do you think they should be 100% certain that you do not have a blood clot?

Would you accept if they were 99% or 98% certain?

Could you tell me how certain you would like your doctor to be? You have these options:

- 100%
- 99%
- 98%
- 97%
- 96%
- 95%
- 94%
- 93%
- 92%
- 91%
- 90%
- 89%
- 88%
- 87%
- 86%

- 85%
- ‘I don’t really know’

Pt:

If your doctor tells you that you have blood clots, how certain should they be that you actually have blood clots?

Would you accept if they were 99% or 98% certain?

Could you tell me how certain you would like your doctor to be? You have these options:

- 100%
- 99%
- 98%
- 97%
- 96%
- 95%
- 94%
- 93%
- 92%
- 91%
- 90%
- 89%
- 88%
- 87%
- 86%
- 85%
- ‘I don’t really know’

Pt:

There are several steps in testing for blood clots. Initially the doctor talks to you and examines you. The next step involves blood testing. Some people can have blood clots RULED OUT by the blood test.

How effective do you think it is to rule out blood clots using the blood test and examination? Can you tell me why you think that?

Pt:

[Education: ‘The blood test and examination findings can exclude blood clots with 99% certainty’.]

If your doctor cannot rule out blood clots with a blood test, they may order a CT scan.

Do you know how good CT scans are at diagnosing blood clots? Which would you say is true?

- ‘CT scans diagnose and exclude clots with 100% accuracy.’
  - Why do you think they are 100% accurate? Pt:
- ‘CT scans sometimes diagnose clots in people who don’t have them.’

- If contradiction - Previously you mentioned that your doctor should be 100% certain in your diagnosis, what do you think they need besides a CT scan that will give them 100% certainty? Pt:
- ‘CT scans are not accurate tests for blood clots.’

Do you know anything about the pros and cons of having a CT scan in the emergency department?

Pt:

[Education: ‘CT scanning uses radiation. We are exposed to small amounts of radiation throughout our life and CT scanning adds to that. A CT scan may increase your risk of radiation-induced cancer later in life.

CT scans sometimes see other things like lung nodules. We don’t understand if these are significant. Lung nodules are followed with repeat CT scans, which increases your radiation exposure. Sometimes there is even a biopsy. More often than not, the nodules turn out to be nothing.

CT scans use dye which can temporarily harm your kidneys.

The delay from ordering a CT scan to getting the results is 6-8 hours in this department.]

How were the risks communicated with you today?

Pt:

**Patient satisfaction:**

---

How satisfied are you with your emergency department visit today?

I am dissatisfied.

I am a little unsatisfied.

I am quite satisfied.

I am very satisfied.

How satisfied are you with the testing you are having for blood clots today?

I am dissatisfied.

I am a little unsatisfied.

I am quite satisfied.

I am very satisfied.

Can you explain your answer to me?

Pt:

**Development of visual aids to convey risk**

---

We are developing ways of explaining to emergency department patients about the risks and benefits of having blood testing and CT scans for blood clots.

Would you mind giving me some feedback on our pictures? These are still in development and we appreciate your opinion on whether they are simple to understand and whether they convey the message we want.

Pt:

Could you explain to me what this image shows?

Pt:

On a scale of 1-10, how easy is it to understand this image/risk?

Pt:

[Explain each image to the patient]

[Hypothetical decision-making scenario]

If you and your doctor were deciding whether or not to order a CT scan, would this make it easier or difficult?

Pt:

Which option would make the decision of CT testing easier?

Explanation of the risks/benefits from the doctor only

Visual aids on the iPad only

Explanation of the risks/benefits from the doctor + visual aids on the iPad

Video on the iPad

Interactive app on the iPad

One-page information sheet

## **Closing**

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Thank you for your time, honesty and help. We appreciate your participation. You have helped us improve the way we run testing for blood clots in the emergency department.

## A2: Patient/Physician Information Sheet

### ESCAPE Study – Patient Partner/Emergency Physician Meeting

#### Emergency SCAnning for Pulmonary Embolism

This study is focused on tailoring the diagnostic protocol for pulmonary embolism (PE) to the emergency department (ED). In order to increase adherence to evidence-based guidelines for PE diagnosis, we are creating a patient-centered approach that is also easy for emergency physicians to use. In order to do this, we interviewed both emergency physicians, and ED patients being tested for PE to identify their values and preferences with respect to PE testing:

#### Key Themes from Patient Interviews

##### **Patient satisfaction comes from addressing their primary concern**

- Providing symptomatic relief
- Finding a diagnosis
- Getting tested
- Getting rapid treatment

##### **Patients expect individualized care in the ED**

- Patient satisfaction comes from directly communicating with their ED physician
- Patients expect testing/treatment to be case-specific

##### **Patients prefer imaging over clinical examination when testing for PE**

- Patient -perception on CT scan accuracy for PE testing
- Clinical examination is insufficient when ruling out a clot

##### **Patients expect 100% confidence from physician when given a diagnosis**

- Patients expect absolute certainty when given diagnosis/no diagnosis
- Willing to seek a second opinion if expectations are not met

#### Key Themes from Physician Interviews

##### **Pulmonary embolism is a “mythical and deadly beast”**

- PE can be deadly, and can disguise as a different condition
- ED physicians feel that it is their job to rule-out all deadly diagnoses
- ED physicians look for PE everywhere (i.e. symptoms are unexplained, failure to improve)

##### **CT scans relieve anxiety and is accessible**

- Some clinical decision rules do not relieve physician anxiety around ruling out PE
- CT scans are inevitable and will give a definitive answer

##### **ED culture supports over-testing of PE**

- Physicians praise other physicians for being astute if they order a CT scan, even if the patient’s risk is low
- Some hospitals have blame culture if a physician misses a PE diagnosis

## A3: EBCD meeting decision aids

### A3.1 Choosing Wisely (information sheet)

#### CT Scans to Find a Blood Clot in the Lungs: When you need one—and when you don't



A pulmonary embolism (PE) is a blood clot in the lungs that has traveled from the deep veins of the leg or pelvis and causes a blockage in blood flow. A PE can be life threatening if not diagnosed and treated. Luckily, health care providers have many good methods available to test for PE.

A commonly used test to diagnose PE is a CT pulmonary angiogram (CTPA). But a CTPA is not always necessary. Here's why:

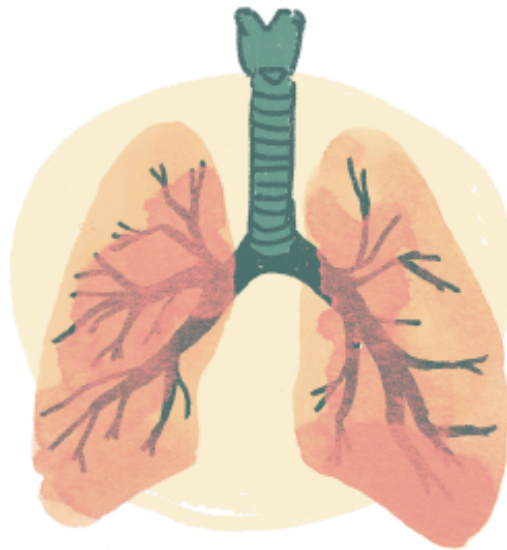
#### **CT scans are not risk-free.**

A CT (computerized tomography) scan is a machine that uses many X-rays to take pictures of bone, organs or soft tissues. CT scans usually result in exposure to large doses of radiation, which can increase the risk of cancer over your lifetime. CT scans looking for blood clots also use dye that can damage the kidneys or cause an allergic reaction.

For these reasons, if your risk of having a PE is low then the potential risks of a CT scan can outweigh the benefits. Your health care provider will use a CT scan only when necessary. In addition, there are other tests that can be used to search for a PE, such as a ventilation/perfusion lung scan ("VQ scan").

#### **How do health care providers know when a CT scan is necessary?**

Health care providers use guidelines based on research in patients just like you to decide what a patient's risk is for a PE, and which patients



need further testing. If your health care provider thinks you might have a PE, the following testing is recommended:

- For very low risk patients, a list of questions called the Pulmonary Embolism Rule-out Criteria (PERC) can safely rule out a PE without additional testing.
- For low and medium risk patients, a blood test called the D-dimer in conjunction with clinical decision rules can safely rule out a PE if the test is normal.
- For high risk patients and/or for those with an abnormal D-dimer blood test, imaging tests such as a CT scan or VQ scan are recommended to rule out a blood clot.



## A3.2: Chest Pain Choice

**What's Next?**

Prepared for: \_\_\_\_\_

**1 Your Chest Pain Diagnosis**

Your initial test results are **NEGATIVE** for a heart attack. These included:

- Blood tests to look for an enzyme called troponin that is released when the heart muscle is damaged. Additional troponin tests may be done to monitor you for heart attack during your emergency visit.
- An electrocardiogram to check whether your heart is getting enough oxygen and blood.

However, the chest pain you are experiencing today may be a warning sign for a future heart attack.

**2 What You Can Do**

A **STRESS TEST**, which views blood flow to your heart at rest and under stress may be needed.

Examining your risk will help you and your clinician decide together whether or not you should have additional heart testing.

<sup>1</sup>Stress test options include nuclear stress testing, ultrasound stress testing, or exercise ECG (electrocardiogram) stress testing. Nuclear stress testing involves exposure to radiation which has been shown to be related to increased cancer risk over a lifetime. Your doctor can help you explore which option may be best for you.

**3 Your Personal Risk Evaluation**

Your risk of having a heart or pre-heart attack within the next 45 days can be determined by comparing you to people with similar factors<sup>2</sup> who also came to the Emergency Department with chest pain.

**4 Would you prefer to have a stress test during this emergency visit or decide later during an outpatient appointment?**

I would like to have a stress test during my emergency visit. I realize that this may increase the cost of my care and/or lengthen my stay.

I would like to be seen by a heart doctor within 24-72 hours and would like assistance in scheduling this appointment.

I would like to schedule an appointment on my own to consult with my primary care physician.

I would like my Emergency Department doctor to make this decision for me.

<sup>2</sup> • Age  
• Gender  
• Race  
• if chest pain is made worse when manual pressure is applied to the chest area  
• if there is a history of coronary artery disease  
• if the chest pain causes perspiration  
• Findings on electrocardiograms (electronic tracings of the heart)  
• Initial cardiac troponin result

Of every 100 people like you who came to the Emergency Department with chest pain...

**3** had a heart or a pre-heart attack within 45 days of their Emergency Department visit, **97** did not.

## A3.3 HAS-Choice

### Low Risk Chest Pain Patients

**1 Your Chest Pain Diagnosis**

Our testing so far has **NOT** shown any evidence of a heart attack. This is based on a blood test, an electrocardiogram (ECG), your exam, and your risk factors<sup>1</sup>. It is recommended that a repeat blood test and ECG be performed during your emergency department visit to further rule out a heart attack.

However, even if everything today is normal, your chest pain may be an early warning sign of possible **FUTURE** heart attack or heart complication.

**2 Further Evaluation**

Further evaluation and testing will help check if your heart is working correctly. Understanding your risk of having a heart attack or heart complication can help decide how to best proceed with your care in the Emergency Department.

<sup>1</sup> Factors used to determine your risk:  
• History  
• ECG  
• Age  
• Risk Factor for heart disease

**3 Your Personal Risk Evaluation**

If your repeat blood test is negative, your risk of having a heart attack or heart complication within the next 30 days can be determined by comparing you to people with similar factors who also came to the Emergency Department with chest pain.

**4 The Next Step**

We feel it is safe for you to be discharged home and follow-up with your doctor in 3-5 days. If you do not have a doctor, please inform your emergency provider before discharge.

Although your risk is low, we recommend you stay for observation and further testing. This will increase your length of stay in the Emergency Department and/or Hospital.

Of every **100** people with your factors like yours who came to the Emergency Department with chest pain...

**One** had a heart attack or a heart complication within 30 days of their Emergency Department visit, **99** did not.

I was explained and understand my Personal Risk Evaluation as well as the importance of follow up. If my symptoms worsen or I am unable to get follow up within 1 week, I will return to the ED.

Patient/Caregiver Signature	Date	Time
Provider Signature	Date	Time

### A3.4 Head CT scan for possible ciTBI

CONCUSSION OR BRAIN BLEED? INJURY EVALUATOR **RISK VISUALIZATION** RISK DISCUSSION CONSIDERATIONS

**YOUR INJURY IS LOW RISK.**  
This means that the current risk of finding a brain bleed on CT scan for 100 people like you is...

- 97** people will not have a finding of brain bleed on CT scan
- 3** people will have a brain injury seen on CT scan which may or may not be a brain bleed
- 1** person would have their care plan changed (e.g. staying in the hospital longer)
- 0** people will have a finding that requires surgery or some other invasive procedure

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### A3.5 Opioid pain management

Which of these two factors is more important TO YOU?

Avoid addiction or overdose for myself (80% important) vs Relieve pain (20% important)

Which of these two factors is more important TO YOU?

Avoid side effects (40% important) vs Avoid addiction or overdose for others (60% important)

Please share this with your doctor. After your visit, ask the research assistant to help you proceed to the next section

**My Healthy Choices Report**

**Your priorities for a pain treatment option**

- 36% - Avoid addiction or overdose for others
- 29% - Avoid addiction or overdose for myself
- 21% - Relieve pain
- 14% - Avoid side effects

**Your medication options**

- 50% - Non-opioid
- 33% - Opioid
- 17% - No medication

**Your risks and what to do**

- Fall Risks
- Operating a Vehicle or Machinery
- Breathing Problems
- General Safety
- Take as Directed
- Store Safely and Don't Share