Thank you for listening: Assessing the Feasibility and Accessibility of Collecting Patient Reported Outcomes on Anxiety and Hospital Experience among Inpatients on an Internal Medicine Floor

Gregory D. Gooding, B.A

Department of Experimental Medicine

McGill University, Montreal

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LIST OF ABBREVIATIONS

PROMS – Patient-Reported Outcomes Measures
PROMIS - Patient-Reported Outcomes Measures Information System
CIHI - Canadian Institute of Health Information
PROMIS Anxiety 8a – PROMIS Anxiety 8a Short Form
RA – Research Assistant
IRT – Item Response Theory
CAT – Computer Adaptive Testing
ISOQOL - International Society for Quality of Life Research
CPES-IC - Canadian Patient Experience Survey -Inpatient Care
ED – Emergency Department
RN – Registered Nurse
SIG – Special Interest Group
MUHC - McGill University Health Centre
RVH – Royal Victoria Hospital

Abstract

Rational

Patient Reported Outcomes Measures (PROMs) are increasingly collected in healthcare settings to capture patient experiences and outcomes. However, few studies have assessed the feasibility of PROM collection among hospitalized Canadians.

Aim

To evaluate the feasibility and acceptability of collecting PROMs in an urban Canadian inpatient setting.

Methods

The project was conducted in 3 phases. The first phase involved an analysis of a survey of Canadian PROM researchers and an environmental scan of PROMs in use within Canada. In the second phase, input was gathered from a relevant stakeholder including floor nurses to prioritize PROMs and discuss opportunities and barriers for PROM implementation.

Participants were a convenience sample of adults hospitalized between October 2023 and March 2024 on the Internal Medicine floors of the Royal Victoria Hospital, McGill University Health Centre.

Participants completed a sociodemographic questionnaire, PROMIS Anxiety 8a and a modified version of the Canadian Patient Experience Survey-Inpatient Care (CPES-IC). Hospitalization information was abstracted from patient charts. Anxiety was classified as normal, moderate or severe. CPES-IC scored were recoded into “Middle/Bottom Box” vs. “Top Box” scores. Feasibility and acceptability were assessed by number of eligible patients; recruitment time, rate, refusal, and retention; and questionnaire completion rate and time. Acceptability among nurses was assessed by their willingness and availability to identify suitable patients; among patients it was assessed by informal comments about completing the surveys. Sociodemographic and questionnaire results were summarized, and groups were compared by anxiety status on using Mann-Whitney U test. Spearman correlations were calculated to evaluate the association between anxiety and CPES-IC domain scores. Logistic regression was used to evaluate the relationship between anxiety and selected patient experience domains, controlling for patient sex and age.

Results

The researcher survey indicated that PROMs were mainly collected for research, with the most common domains being those assessing mental health (56%), physical health (28%) and disease-specific measures (16%). Stakeholders identified the Internal Medicine floor as optimal for the study; nursing staff identified anxiety as an important but unmeasured symptom. Of 360 inpatients assessed for eligibility, 245 were excluded and 15 refused with

100 completing the surveys. The mean age of patients was 59 years, the majority of patients were male (60%), white (67%), college educated (64%), had at least five comorbidities (42%), and were on the floor for 5 days. Two-thirds (68%) of inpatients had at least mild anxiety. Anxiety was associated with significantly lower satisfaction with *Communication with Nurses and Doctors; Pain Control; Involvement in Decision-Making and Treatment Options; and Emotional Support*.

Conclusion

A dedicated research assistant could reliably collect information PROMs and PREMs in a subset of hospitalized adults on the Internal Medicine Service of a major academic hospital. Anxiety was common and was associated with reduced satisfaction with a range of patient experience outcomes.

Rationnel

Les mesures des résultats rapportés par les patients (MRRP) sont de plus en plus souvent recueillies dans les établissements de soins de santé afin d'évaluer les expériences et les résultats des patients. Cependant, peu d'études ont évalué la faisabilité de la collecte des PROM chez les Canadiens hospitalisés.

Objectif

Évaluer la faisabilité et l'acceptabilité de la collecte de MRRP dans un milieu hospitalier urbain canadien.

Méthodes

Le projet s'est déroulé en trois phases. La première phase comprenait une analyse d'une enquête auprès des chercheurs canadiens sur les MRRP et une analyse de l'environnement des MRRP utilisés au Canada. Au cours de la deuxième phase, des commentaires ont été recueillis auprès d'une partie prenante pertinente, notamment des infirmières d'étage, afin de hiérarchiser les MRRP et de discuter des possibilités et des obstacles à la mise en œuvre des MRRP.

Les participants étaient un échantillon de commodité d'adultes hospitalisés entre octobre 2023 et mars 2024 dans les étages de médecine interne de l'hôpital Royal Victoria (HRV), Centre universitaire de santé McGill.

Les participants ont rempli un questionnaire sociodémographique, PROMIS Anxiété 8a et une version modifiée de l'Enquête sur l'expérience des patients canadiens - soins aux patients hospitalisés (CPES-IC). Les informations relatives à l'hospitalisation ont été extraites des dossiers des patients. L'anxiété a été classée comme normale, modérée ou sévère. Les scores du CPES-IC ont été recodés en scores « Middle/Bottom Box » par rapport aux scores « Top Box ». La faisabilité et l'acceptabilité ont été évaluées en fonction du nombre de patients éligibles, du temps de recrutement, du taux, du refus et de la rétention, ainsi que du taux et du temps de remplissage du questionnaire. L'acceptabilité par les infirmières a été évaluée en fonction de leur volonté et de leur disponibilité à identifier les patients adéquats ; chez les patients, elle a été évaluée en fonction des commentaires informels sur le fait de remplir les questionnaires. Les résultats sociodémographiques et les résultats des questionnaires ont été résumés et les groupes ont été comparés en fonction de l'état d'anxiété à l'aide du test U de Mann-Whitney. Des corrélations de Spearman ont été calculées pour évaluer l'association entre l'anxiété et les scores du domaine CPES-IC. La régression logistique a été utilisée pour évaluer la relation entre l'anxiété et certains domaines de l'expérience du patient, en tenant compte du sexe et de l'âge du patient.

Résultats

L'enquête menée auprès des chercheurs a montré que les MRRP étaient principalement collectés à des fins de recherche, les domaines les plus courants étant ceux qui évaluent la santé mentale (56 %), la santé physique (28 %) et les mesures spécifiques à une maladie (16 %). Les parties prenantes ont identifié l'étage de médecine interne comme optimal pour l'étude ; le personnel infirmier a identifié l'anxiété comme un symptôme important mais non mesuré. Sur 360 patients hospitalisés, 245 ont été exclus, 15 ont refusé et 100 ont répondu à l'enquête. L'âge moyen des patients était de 59 ans, la majorité d'entre eux étaient des hommes (60 %), blancs (67 %), ayant fait des études supérieures (64 %), présentant au moins cinq comorbidités (42 %) et séjournant à l'étage depuis 5 jours. Les deux tiers (68 %) des patients hospitalisés souffraient d'une anxiété au moins légère. L'anxiété était associée à une satisfaction significativement plus faible en ce qui concerne la communication avec les infirmières et les médecins, le contrôle de la douleur, l'implication dans la prise de décision et les options de traitement, et le soutien émotionnel.

Conclusion

Un assistant de recherche spécialisé a pu collecter de manière fiable des informations MRRP dans un sous-ensemble d'adultes hospitalisés dans le service de médecine interne d'un grand hôpital universitaire. L'anxiété était fréquente et associée à une baisse de la satisfaction à l'égard d'une série de résultats liés à l'expérience du patient.

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Contribution of Authors

The study was designed by Drs. Susan Bartlett and Sara Ahmed and supported in part by funding for a pilot project from the McGill Department of Medicine. The study design and protocol were developed by Dr. Susan Bartlett. Gregory Gooding conducted the literature review, analyzed the foundational surveys, organized stakeholder meetings, recruited and consented hospitalized participants, and collected data for the pilot study. Data were analyzed and interpreted by Gregory Gooding and Dr. Bartlett. Gregory Gooding wrote this thesis.

1.0 Introduction

The Organisation for Economic Co-operation and Development (OECD) is an intergovernmental organization comprising 38 member countries, including Canada. Their mandate is to promote policies that enhance global economic and social well-being. In 2017, they convened to discuss the next generation of healthcare reforms. The two main conclusions of those discussions were that: 1) health systems need to become more people-centred and pay greater attention to what matters to patients; and 2) this could be achieved through widespread implementation of patient-reported outcome measures (PROMs)(1).

Newsweek is a weekly newsmagazine based in New York City that publishes an annual list of the “World’s Best Hospitals”. The top global hospitals were mainly determined based on the number of expert peer recommendations at the national and international levels. In 2023, they decided to add a new pillar to their scoring model-- the implementation and use of PROMs. In the following year, they added quality metric excellence and patient satisfaction excellence to the equation. In the 2024 "World Top 10 Hospitals" list, it is noteworthy that the Toronto General Hospital (ranked #3), was the only Canadian hospital to break into the top 25, largely due to PROM implementation (2,3).

These examples emphasize the global shift from a traditional medical model to a patient-centred care model and illustrate the role that PROMs play in driving this change. As we move towards a patient-centred approach to healthcare, capturing the input and feedback of patients on the achievement of outcomes that matter to them, along with their experience of care, has become essential.

Patient-Reported Outcomes (PROs) can be defined as “any report of the status of a patient’s health condition that comes directly from the patient without interpretation of the patient’s response by a clinician or anyone else” (4). PROMs are the tools used to capture symptoms, function, mental health, and well-being and are usually administered to patients in the form of a survey (5–7). When implemented in routine care, they can help personalize treatment by identifying patients who may benefit from additional psychological, social, or pharmacological support (8,9).

On a national scale, the systematic collection of PROMs can be leveraged in innovative ways to assess health outcomes across diverse patient populations and better ensure the quality of care. In the United States (US), for instance, PROMs are routinely collected in many settings to enhance population health, improve patient care experience, and reduce capita healthcare costs(10). This is achieved, in part, by tying reimbursement from private insurers, Medicare, and Medicaid to treatment as well as patient satisfaction scores, utilizing payment as a mechanism to instill accountability within healthcare organizations(11). In the United Kingdom (UK), a growing number of health care organizations and government agencies routinely collect PROMS to evaluate, monitor, and compare healthcare providers and organizations, providing crucial feedback to clinicians. This is facilitated by comparing pre- and post-treatment scores thereby offering the opportunity to support continuous quality improvement within healthcare facilities(10). Despite the proven benefits of collecting PROMs to improve the quality of care and patient outcomes worldwide, provinces in Canada have yet to implement a systematic approach to PROMs collection.

Currently, three provinces have initiatives to collect PROMs routinely in certain hospitals as part of regular care. In British Columbia, PROMs are collected for a sample of inpatient and emergency department patients, to evaluate patient experience (10). In Alberta, they are collected to develop population norms for certain conditions; Ontario collects PROMs to report symptoms in cancer patients (10,12). In the province of Quebec, applications are limited and typically focus on assessing conditions in cancer patients and palliative care (10,13).

PROMs also are increasingly used in clinical trials, regulatory applications, comparative research studies, and to increase scientific knowledge about diseases and their treatments. The Canadian Institute of Health Information (CIHI), an independent agency, notes that the collection, standardization, and reporting of PROMs are essential to inform future health system policies (12,14). However, the routine collection and use of PROM collections is a complex and costly process. There is no one-size-fits-all model for routine collection; although processes may share similarities, there is a need for a nuanced assessment of barriers at patient, clinician, and health system levels, acknowledging potential variations across different settings (9,15).

The goal of this thesis was to gather initial information about the feasibility and acceptability of implementing PROMs collection in a busy urban adult hospital. This research was conducted in three phases. This process was iterative, with each phase informing subsequent activities.

The first phase included an environmental scan of PROMs in use within Canadian settings in addition to analyzing survey data collected by Drs. Bartlett and Ahmed for the Canadian Special Interest Group (SIG) of the International Society for Quality-of-Life Research (ISOQOL). ISOQOL is a group of researchers, clinicians, healthcare professionals, industry professionals, consultants, and patient research partners whose aim is to advance the science of quality of life research and patient-centred outcomes (16). The survey was developed to gather information about the use of ongoing PROMs in the Canadian healthcare landscape. The respondents were a convenience sample of clinicians, researchers, and administrators and their associates throughout Canada known to SIG members.

The second phase involved bringing together a hospital stakeholder advisory committee at the Royal Victoria Hospital (RVH), part of the McGill University Health Centre (MUHC), Montreal, Canada and meeting with the nursing staff to assess current needs and opportunities to administer one or more PROMs to patients that could inform care. The stakeholder committee was comprised of clinical staff, researchers, and hospital administrators. The committee identified potential outcomes of interest that were not currently being systematically collected at the MUHC. The nursing staff was drawn from the General Internal Medicine units of the RVH.

In the third phase, a pilot study was conducted onsite in the General Internal Medicine units of the Royal Victoria Hospital to assess the feasibility and acceptability of collecting PROMs in hospitalized patients.

2.0 Literature Review

2.1 Patient-Centred Care

Patient-centred care is an approach that emphasizes a holistic approach to health care. The notion of patient-centred care was formalized by the US Picker Institute in 1986; the institute's primary objective is promoting "care as seen through the patient's eyes" (17). This paradigm emerged as a response to the traditional medical model of healthcare. In the traditional (medical) model, physicians base their diagnosis on symptoms and deficits in the function they observe, and treatment decisions largely on their perceptions of symptoms, observed patient behaviours and physician judgement; typically, this is done with minimal input from the patient themselves and based on medical staff schedules and convenience (18,19). An assessment of the quality of care received is primarily based on the extent to which it meets professional and guideline-based treatment standards. The medical model has been criticized for its reductionist approach to patient care, focusing on disease pathology and functional deficits while neglecting the sociocultural and humanistic aspects of patient care (20,21). In 2001, the US Institute of Medicine's (IOM) Quality of Health Care Committee acknowledged the patient-centred care approach as one of the six domains of quality of care, encompassing safe, effective, timely, efficient, and equitable care (22).

As defined by the IOM, patient-centred care encompasses “care that is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions” (22). Patient-centred care can be categorized into eight distinct categories: Patient Preferences, Emotional Support, Physical comfort, Information and Education, Continuity and Transition, Coordination of Care, Access to Care, and Family and Friends (22).

The potential advantages of patient-centred care for patients and healthcare providers have been examined extensively. The benefits of patient-centred care for patients are not limited to any specific condition, age group, or gender (23). Patients demonstrated improved satisfaction, experience in overall hospital experience, self-management, medication adherence, communication, and reduced fall rates when receiving patient-centred care (23–26). Moreover, patient-centred care has the potential to enhance the job satisfaction of healthcare providers, streamline care processes, improve biophysical markers of patients, decrease emergency department (ED) utilization, improve the perception of healthcare providers by patients, optimize resource allocation, and promote professional collaboration (23–25).

Patient-centred care endeavours to empower patients by disseminating information and providing them with the autonomy to participate in their treatment and care as they see fit (23,27). The active involvement of patients in their healthcare is vital and has been shown to have a positive impact on the overall healthcare experience, improve healthcare delivery, reduce medical errors, and promote shared decision-making (SDM), culminating in enhanced health outcomes and improved quality of care (27–29).

2.2 Patient Reported Outcomes Measures

PROMs are standardized self-reported measures that typically capture physical, emotional, social function and well-being (5–7). PROMs offer additional insight into patient outcomes, providing a more holistic and comprehensive assessment of how they feel and function (30,31).

Multiple studies have shown that physicians frequently overlook symptoms reported by patients, which can potentially lead to serious complications (32,33). By providing a direct and unfiltered account of the patient's perception of their health, PROMs can aid in resolving this issue (34,35). PROMs influence patient-clinician communication by increasing symptom awareness, prompting discussions, streamlining consultations, and facilitating shared decision-making, resulting in fewer ER visits, fewer hospitalizations and superior quality-adjusted survival rates (36–38). They can facilitate communication without adding consultation time, and when integrated efficiently, they may alter the workflow without substantially increasing the workload (13,37,39,40). PROMs can also trigger alerts to the medical team when a predetermined threshold is reached, thereby indicating when a treatment re-evaluation or referral to a specialist may be needed (35,41,42). Finally, they help to identify gaps within a healthcare system. Thus, there is growing interesting in the routine collection and use of PROMs in health care settings, along with specific strategies to ensure care pathways are indeed patient-centred (13,33,41,42).

Decision-makers are increasingly utilizing PROMs to inform healthcare policy, monitor and enhance patient safety, and improve the quality of care. In the US, PROMs are collected on a national scale to compare health plans and inform reimbursements (11,43). PROMs are required as part of approval by the Food and Drug Administration (FDA) (44). In the UK, the National Health Service (NHS) mandates the collection of data related to specific surgeries, including hip replacement and knee replacement. This information is also utilized to shape healthcare policies (45,46). In Sweden, over 100 registries collect information from patients throughout their lifetime, which is then used for quality improvement (47,48). In Canada, PROMs are primarily utilized by independent researchers or scaled down with minimal support from institutions or the government (10). As a result, in 2024, they are not routinely utilized in Canadian healthcare settings. Notable exceptions include the Canadian Joint Replacement Registry and PROMs collected form cancer patients in Alberta, Saskatchewan, and Ontario patients (10,49–52).

2.3 PROMIS: The Patient-Reported Outcomes Measures Information System

The process of selecting a suitable measure from the growing number of available PROMs has become a significant challenge in recent years. Not all PROMs perform equally well, and some have limited evidence regarding their psychometric properties. PROMs should also have strong evidence of validity, reliability, and responsiveness to change (53–55). There are other considerations of importance, including burden on participants, use of disease-specific vs. generic PROMs, mode of delivery, availability of translations, whether the measure has been validated in the specific patient population, and training to administer and interpret results, among others (56–58). PROMIS Adult Health Profiles were created by identifying seven core health-related quality of life (HRQL) domains widely applicable across chronic diseases. HRQL is a composite construct that encompasses physical, psychological, and social functions and should not be confused with the broader construct of quality of life, which encompasses all aspects of an individual's life (59,60).

In 2002, the US National Institutes of Health (NIH) developed a Roadmap for Medical Research. Part of this goal focused on creating technology to enhance clinical outcomes assessment by increasing access to valid, reliable, and generalizable self-report measures of outcomes that mattered to patients. One initiative of the Roadmap was PROMIS: The Patient-Reported Outcomes Measurement Information System (PROMIS™). Groups of investigators developed and tested new measures that can be applied across a broad range of chronic diseases (61–63). The process for each measure involved collating a bank of items from existing PROs that could be administered using computerized adaptive testing (CAT) (61–63). The development process involved pooling literature reviews, qualitative item reviews from experts and patients, analyzing item-response theory (IRT) data to inform item selection, and modified Delphi rounds to achieve consensus.

Another feature of PROMIS is that measures are created using IRT-calibrated item banks. Item banks are a collection of questions about a symptom or functional problem comprised of calibrated questions that define and quantify a common concept, thus operationalizing a symptom such as anxiety or pain (64,65). The creation of the PROMIS item bank involved six phases of development to ensure face validity and avoid redundancy. An item library with over 10,000 entries was constructed by gathering items from existing PROs, and all items were classified according to content, with 1,100 selected for review (61,64,66,67). The reviewed items were subsequently revised, and focus groups were conducted with groups of patients across multiple disease populations to evaluate the comprehensiveness and domain coverage of the item bank. Cognitive interviews with patient populations were conducted with individual items, and the final items were revised for clarity, precision, readability, translatability, and compatibility with a computer-adapted tests (CAT) framework (61,64,66,67). Calibrated using IRT, these item banks can be administered using both CATs and short forms (68). PROMIS can also be administered in a fixed-length short-form format, which consists of four, six, or eight items per domain and is available in both electronic and paper formats.

Domains are measured and standardized to a T-score metric with a mean of 50 and a standard deviation of 10 in the reference population (69). Higher scores equal more of the concept being measured. Thus, a score of 60 is one standard deviation above the average referenced population which could be a desirable or undesirable outcome depending on the concept being measured (70). The common metric that allows the easy interpretation of results with results calibrated to established severity thresholds (e.g., anxiety scores can be categorized as none, mild, moderate, or severe) (37,71,72). PROMIS T-scores have been used to create a map that displays the most likely responses for a subset of items for a given score, and to link scores into language used by patients to describe their degree of severity or impairment in a given symptom or function (72).

The seven core domains of the PROMIS-29 Adult Health Profile are depression, anxiety, physical function, pain interference, fatigue, sleep disturbance and the ability to participate in social roles and activities. The Adult Health Profiles have demonstrated good validity, reliability and responsiveness in a range of populations with chronic conditions such as chronic obstructive pulmonary disease, back pain, major depressive disorder, and rheumatoid arthritis, among others (73–75).

2.4 Understanding Patient Experiences

The paradigm shift towards a patient-centred care model was not simply a novel way of thinking about the patient's role in the healthcare system; it also brought about the need to measure patient experiences with care in hospitals. Initially, there were fragmented efforts in different hospitals in the US to collect information on patient satisfaction with care, but there were no standards regarding instruments or methodologies that would allow valid comparisons to be made. In the U.S., this led the Centers for Medicaid & Medicaid Services to partner with the Agency for Healthcare Research and Quality to develop the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey in 2018 (76,77).

The HCAHPS survey had three primary objectives. First, the survey focused on patient perspectives of care they received during hospitalization, enabling comparisons among hospitals in domains that are important to patients (77). Second, the survey results were made public by hospitals to create incentives to enhance the quality of care they provide (77). Finally, by making the reports publicly available, the survey would make hospitals more accountable, given that the quality of hospital care will lead to additional investment (77). As of 2012, hospital reimbursements could be withheld or reduced in the US based on the patient satisfaction scores measured using the HCAHPS. The HCAHPS survey has been translated into Spanish, Chinese, Russian, Vietnamese, Portuguese, German, Tagalog, and Arabic. As of 2023, it was being utilized by more than 4,000 hospitals across the United States, with over 3 million patients participating in the survey annually (78,79).

The survey uptake has led to promising results. A systematic review of the relationship between the HCAHPS and clinical and quality outcomes revealed multiple associations among the three factors. Better patient-provided communication has been associated with fewer emergency room visits, fewer inpatient hospital stays, lower odds of prolonged hospitalization, and an increased likelihood of being prescribed the appropriate medication (80). Regarding the quality of care, improved care coordination has been associated with getting care more efficiently, getting needed care, and more comprehensive examinations (80). Better patient-provider communication has been associated with better self-reported physical and mental health scores, improved pain management, better medication adherence, higher care facility ratings, and high global physician ratings (80).

A better patient experience has also been linked to lower mortality rates, fewer surgical complications, and higher medical guideline adherence (81–84). Price et al. suggest that some of these effects may reflect increased attention to older, sicker, or near-death patients (81). Conversely, poor patient experiences may contribute to a later diagnosis of breast cancer due to non-adherence to screening guidelines and delays in diagnosis after abnormal screenings (85). These results suggest that understanding the patient experience may help to identify hospital practices that may independently influence perceptions of care, health behaviours, and health outcomes.

2.5 Assessing patient experience in Canadian healthcare settings.

CIHI is an independent agency that “provides comparable and actionable data and information that are used to accelerate improvements in health care, health system performance and population health across Canada” (86). In 2011, CIHI recognized the need for standardized data collection of health and comparative information on health system performance indicators within Canada. This led to the development of the first Canadian PREM (patient reported experience measure), the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC), also known as CPES (87). Across Canadian hospitals, this is the primary method used to assess patient experiences.

The CPES-IC was designed using the HCAHPS as the base for its development owing to its rigorous testing and validation process and years of reference data that allowed for international benchmarking (87). The development of the CPES-IC involved multiple stages including examining important dimensions of the health care experience for patients, cognitive testing with patients, expert panel reviews, and pilot testing in 13 hospitals within the provinces of Alberta, British Columbia, and Ontario to evaluate validity and reliability (87). The HCAPHPS has been translated into French and validated in patients at the New Brunswick Health Council and the MUHC.

The CPES-IC contains all 22 original HCAHPS questions along with 19 additional questions relevant to the Canadian context (88). The CPES-IC contains an “About You” section that asks for sociodemographic information such as education, sex, ethnicity and, a section where participants rate their overall physical and mental health (88) The CPES-IC builds on the HCAHPS' six composite scores: *Communication with Nurses, Communication with Doctors, Responsiveness of Hospital Staff, Communication about Medicines, Discharge Information, and Pain Management* (78). The original HCAHPS questions use the following response scale: Never, Sometimes, Usually, Always. The four additional categories in the CPES-IC *are Information and Understanding when Leaving the Hospital*, *Information Shared with Patients in the ED, Internal Coordination of Care*, and *Involvement in Decision-Making and Treatment Options* (88,89). The CPES-IC also contains an additional response scale for certain items with the following options: Not at all, Partly, Quite a bit, and Completely (87). The survey is available in English and French (88) (see Appendix A: Supplementary table 1).

The administration is similar to that used for HCAHPS, but Canadian hospitals can choose to send the survey to patients via email. However, there are no options for active, interactive voice responses or mixed-method surveys (88).

PREMs like the HCAPHS and CPES-IC can help ensure care is more patient-centred when implemented broadly and consistently and information is readily available to the public. In other countries, such as the US and UK, patients may elect to choose providers and hospitals with higher ratings (90,91). However, in Canada, collecting CPES-IC surveys remains voluntary and even when information is available, only some of the results from a limited number of provinces are available to the public (92,93).

CPES-IC and HCAHPS results have repeatedly shown that not only does communication play an important role in the overall patient experience, however, *Communication with Nurses and Doctors* are the two biggest predictors of overall patient experience (87,94–97). This suggests that linking the results of both surveys can serve as an effective strategy for measuring the desired outcome. By employing PREMs and PROMs, the evaluation places more emphasis on the patient's perspective, thus employing a patient centred care approach.

The use of PROMs and PREMs within the Canadian landscape is fragmented. The provinces of Alberta, Saskatchewan and Ontario routinely collect the Edmonton Symptom Assessment System-revised on a provincial scale for cancer patients (10,49–51). In British Columbia, the Patient-Centred Measurement Working Group, which includes representation of the Ministry of Health and all seven of its health authorities, has implemented PROMs and PREMs into their healthcare system resulting in province-wide collections of PROMs in addition to the CPES-IC in various settings, such as ED, long-term residential care, short stay mental health sectors, and more (10,98). In the province of Quebec, applications are limited and typically focus on assessing conditions in cancer patients and palliative care (10,13). Overall, PROMs in Canada appear to be primarily utilized for independent research or are scaled down with minimal support from institutions or the government (10). However, researchers have demonstrated the feasibility and benefits for healthcare providers and patients of integrating PROMs and PREMs into standard medical practice for diverse remote, rural, and urban areas within Canada (13,99–102)

2.6 Factors impacting hospital experience

Over the years, multiple studies have investigated the different factors that impact patient satisfaction with their hospital experience. There is mixed evidence for factors such as age, ethnicity, sex, and hospital readmission status (103–107). Communication with staff, specifically nurses and doctors has been shown to have the strongest impact on satisfaction (108–110). Another important factor is pain management. In addition to being associated with higher Charlson Comorbidity Index scores, age, and sex have been shown to have a strong association with overall satisfaction (111–113). *Emotional support*, although rarely included, is considered an important factor (104).

Anxiety may also play an important role in satisfaction with the care (114,115). Among 31 chronic conditions, including diabetes, lung disease, and rheumatoid arthritis showed that patients experienced worse pain (116). Research shows that anxiety is prevalent among hospital inpatients regardless of comorbidity and is associated with patient age and sex (107,117,118). In an analysis of 32 studies on general hospital inpatients the prevalence of anxiety in hospitalized patients averaged 28% (range 11% to 62%) highlighting potential variation based on a variety of factors such as setting and healthcare system (119). It is of note that the meta-analyses did not include patients in Canadian hospitals. Additionally, a large limitation was their inability to investigate the potential sources of heterogeneity because of reported information in the selected studies. Thus, investigating factors that play a role in patient anxiety has the potential to address an important gap within the literature. That is, understanding the relationship between patient anxiety and potential mediating factors that play a role in the relationship. These discrepancies could occur for a variety of reasons such as differences in hospital systems, how long patients have been hospitalized, different measures being used to measure anxiety, or the time when patients answered the surveys. High levels of distress have been associated with prolonged hospital stays and higher readmission rates (120). Furthermore, there's a strong link between pain intensity and anxiety and depression (118)

3.0 Study Objective

The primary aim of this project was to evaluate the feasibility and acceptability of collecting relevant PROMs that could guide care and discharge planning in patients hospitalized in a large academic hospital in a large Canadian city. A secondary objective was to explore potential associations between anxiety and hospitalization experiences.

4.0 Methods

4.1.0 Phase 1

In the first phase we conducted an environmental scan of PROMs in use within Canadian settings in addition to analyzing survey data collected by the ISOQOL Canada SIG.

4.1.1 Survey of Canadian PROM Researchers

A survey was developed by the leaders (S. Bartlett, S. Ahmed, N. Fayed, A, Kuspinar, A. Moga) of the Canadian Special Interest Group of the International Society of Quality of Life Research (ISOQOL). ISOQOL is a group of international researchers and clinicians interested in health measurement and quality of life research. The goal of the survey was to gain a better understanding of the current use of PROMs in the Canadian healthcare landscape. The survey included questions about roles, affiliations, PROMs, collection methods and language, data linkage, target users, uses, common barriers, and potential facilitators to implementation. The survey was emailed to 120 clinicians, researchers, patient advocates, and administrators across Canada who were ISOQOL Canada SIG members or associates of members (i.e., snowball sampling) between July and December 2022.

4.1.2 Environmental Scan

To gain a broader understanding of how PROMs were being used in Canadian patients, we conducted an environmental scan of the literature in January 2023. An environmental scan is a concept taken from the business sector, the goal is the gather information and direct organizational change (121). The process entails seeking, gathering, interpreting and using information to inform strategic decision-making and future action (122). This approach has been employed in the healthcare sector because of its relevance in information decision-making and strategic planning within complex systems (121,122). Environmental scans help organizations and policy makers foresee, understand and prepare to address complex issues within complex healthcare system (121,122). such as patient safety, identify gaps in services and guide quality improvement initiatives (121,122).

Our search was conducted using Google, and the keywords: “toolkits,” “implementation,” “Canada,” “PROMs,” and “PREMs.” Information on stakeholders, infrastructure, workflow, facilitators, and barriers were collected and compiled. The search was extended to identify articles that described the successful implementation of PROMs in Canadian clinics and hospitals using PubMed, APA PsycNet, and Google Scholar databases. The keywords included “Canada”, “PROMs”, “pilot”, “routine collection”, “implementation”, “clinic”, and “hospital”. Information about the collection methods, target users, goals, selected PROMs, clinical specialty, and feasibility were collected and compiled.

Both searches used the Setting, Perspective, Intervention, Comparison, Evaluation (SPICE) framework for article selection (123–125). The setting was Canada, the perspective was inpatient clinics or hospitals, the intervention was PROM or PREM implementation, the comparison was the status quo, and the evaluation was feasible implementation.

Together, the information collected from the survey and environmental scan informed the discussion of a potential range of candidate domains that were presented to the Stakeholder Advisory Committee.

4.2.0 Phase 2

In Phase 2, we brought together and conducted interviews with the stakeholder advisory committee as well ass nursing staff on the floor to assess current needs and opportunities to administer PROMs to patients that could inform care.

4.2.1 Stakeholder Advisory Committee

A stakeholder advisory committee of clinicians, researchers, and hospital administrators was brought together to discuss a pilot trial to evaluate the feasibility and acceptability of collecting PROMs in patients hospitalized in a General Internal Medicine unit at the MUHC in Montreal, Canada. The meetings took place on March 14th and 30th 2023. The advisory committee was composed of seven members including the Executive Associate Physician-in-Chief, Dr. Joyce Pickering; the Associate Director of Nursing, Lucy Wardell; the Director of Quality, Evaluation, Performance and Ethics, Dr. Emily McDonald; the Associate Chair of Quality and Safety, Keith Woolrich, a Post-Doctoral student in Health Services Research, Mohammed Al Khaldi, and the supervisor and faculty serving on the master's students supervisory committee with expertise in the field of PROMs and PREMs.

Stakeholders viewed a presentation informing them about the results of the environmental scans and ISOQOL surveys and provided feedback on ways to optimize the implementation of the PROMs collection as well as on what domains would be relevant to collect.

4.2.2 Nursing Staff Interviews

Mr. Gooding first approached the nurse manager, Aparna Bhattacharjee, to review project requirements and request permission to interview nurses. In April 2023, Mr. Gooding met with 31 nurses over two sessions of 20 minutes (a total of 40 minutes) to describe the proposed project and seek their input. A brief presentation on PROMs, PREMs, and the rationale for the project was presented. Nurses were asked if there are any ongoing issues that could be addressed by collecting PROMs and if there are any potential barriers related to implementation that the research team should consider.

4.3.0 Phase 3

In phase 3, we conducted a pilot study to assess the feasibility and acceptability of implementing PROM collection of information about the level of anxiety and inpatient experiences among adult hospitalized on an internal medicine unit of a major urban hospital.

4.3.1 Research Design

A cross-sectional survey was planned for hospitalized adults who were receiving treatment in two wings of the Royal Victoria Hospital of the MUHC Glen site in Montreal. The RVH is a major academic hospital affiliated with McGill University in Montreal, with a total of 50 beds and a ratio of approximately two registered nurses (RNs) per 13 beds. Nurses identified potential participants to Mr. Gooding each morning that he was on the unit, Mr. Gooding confirmed their eligibility, described the project and assessed their interest in participating in this initiative. The MUHC Research Ethics Board affirmed that written informed consent was not required from participants as the project was considered a quality improvement initiative; after being briefed on the goals and requirements of the study by Mr. Gooding, all participants were asked to provide their verbal consent to participate.

The project aimed to recruit 100 participants. As this is a feasibility study, no formal sample size calculation was performed; however, the sample size was the estimated number that would be feasible to assess eligibility, feasibility, and acceptability in a diverse group of hospitalized patients and an initial exploration of study outcomes.

4.3.2 Funding

This research was supported in part by a quality project grant from the McGill University Department of Medicine that had been awarded to principal investigators Drs. Susan Bartlett and Sara Ahmed to pilot test the implementation of PROMs in the McGill University Health Center.

4.3.3 Participants

Participants were drawn from the pool of adults who were hospitalized between September 8, 2023, and March 22, 2024, in the C9 and D9 sections of the General Internal Medicine unit at the RVH. Inclusion criteria included adults aged 18+ who had been hospitalized for at least one night and were fluent in English or French. Exclusion criteria were having significant cognitive impairment, receiving palliative care, and patients not recommended for participation (e.g., too sick, confused) as identified by the nursing staff or Mr. Gooding once he approached them directly. Nurses confirmed that patients were fluent in English or French, alert and oriented to their person, time, and place, and healthy enough to hold a conversation for 10 minutes.

4.3.4 Outcomes

Sociodemographic characteristics. Sociodemographic information including sex, ethnicity, and educational level were self-reported as part of the CPES-IC. The Charlson Comorbidity Index (CCI) was retrieved from hospital records and classified into three grades: mild (CCI scores of 1-2), moderate (CCI scores of 3-4), and severe (CCI scores ≥5) (126,127). Other characteristics such as age and sex were retrieved from hospital records (see Appendix B: Supplementary table 2).

Hospitalization information. Time spent in the emergency department (days), when applicable, and length of stay (days) on the unit at the time of assessment, the reason for admission as well as discharge date were retrieved from the patient chart (see Appendix B: Supplementary table 2). Hospital readmission was retrieved from hospital records and defined as returning within 30 days of discharge for the same or related care (128,129).

Overall Physical and Mental health. As part of the CPES-IC, participants were asked, “In general, how would you rate your overall physical health?” and “In general, how would you rate your overall mental or emotional health?”. Response options included: “Excellent”, “Very good”, “Good”, “Fair”, or “Poor”.

Anxiety. The PROMIS Anxiety 8a Short Form measures anxiety symptoms (5). The tool is comprised of eight items that assess anxiety symptoms and impacts over the past seven days. Participants responded on a 5-point scale (“never, rarely, sometimes, often, always”) to questions about the frequency of symptoms such as “I felt anxious” and “My worries overwhelmed me” (see Appendix C: Supplementary table 3) (130).

The PROMIS Anxiety 8a has shown adequate convergent validity with legacy measures such as the Hospital Anxiety and Depression Scale-Anxiety (HADS-A) and Generalised Anxiety Disorder-7 (GAD-7) with r=0.82 and 0.76, respectively (131,132). It has been shown to be acceptable and relevant in populations including oncology, heart failure, inflammatory bowel disease, multiple sclerosis, and inflammatory arthritis (131,133–136). Reliability is adequate with a mean adjusted item-total correlation of 0.79 and an alpha coefficient of 0.93 (130)good test-retest reliability (r= 0.79) (133). It is sensitive to change and can discriminate between anxious and non-anxious individuals (137–139). It has been used to evaluate anxiety in a variety of inpatient populations including oncology and orthopedics (140–142).

The PROMIS Anxiety 8a is scored by adding the 8-item scores together to obtain a raw score, which is then transformed into a T-score using the recommended IRT calibrations. This T score has a mean of 50 and a standard deviation of 10, with higher scores representing higher levels of anxiety (143,144). Scores were categorized according to PROMIS recommended cut-points as follows: <55 normal; 55 - 59.9 mild; 60 – 69.9 moderate; 70+ severe levels of anxiety (69).

Patient Experience. The CPES-IC was selected to assess patient experience because it was designed specifically for adults who had been hospitalized in Canadian hospitals, is routinely collected across Canada in subsets of patients' post-hospitalization and has strong psychometric properties (87). CPES-IC domain scores for *Communication with Nurses, Communication with Doctors, Pain Controlled, Involvement in Decision-Making and Treatment Options,* and *Emotional Support* are publicly reported (see Appendix

D: Supplementary table 4). Given the literature, we anticipated these domains would likely be affected by anxiety; additionally, they have been identified as being important to patients (87,94–97). The CPES-IC is usually sent to patients after they have been discharged from the hospital; thus, it was modified for this study (145). Specifically, we modified questions to reflect the fact that patients were currently in the hospital when completing the questionnaire. We added the question, “Is there anyone at home that can help you with your care?” with the response options “Yes” or “No” to help answer the questions raised by nurses about whether this contributed to patient anxiety during hospitalization. To reduce patient burden, questions regarding their overall hospital experience and intent to recommend the hospital were removed (see Appendix A: Supplementary table 1). Discharge plans in the hospital were not collated given that they had not yet been developed for many of the patients.

There is limited information available about the psychometric properties of the CPES-IC(87,88). However, it is based on the US HCAHPS survey that has been extensively studied (87,146). A 2023 report of the HCAHPs outcomes by the Center for Medicare and Medicaid Services (CMS) found good internal consistency (e.g., 0.45 to 0.80) (see Appendix A: Supplementary table 1) (147). The HCAHPS’s criterion validity measures range from 0.32 to 0.68, which is just below the recommended 0.70 threshold for clinical trials and is reliable over a 12-month period (r’s 0.86 to 0.94) (147–149).

Pain. Patient pain level (0-10) was retrieved from the patient’s medical records for the day the interview took place; if not available, Mr. Gooding recorded the pain level at the closest time to the interview.

Feasibility and Acceptability. Mr. Gooding collected information that speaks to the feasibility and acceptability of the project. This included the number of patients that completed the questionnaires, the number of patients that were eligible, enrolled and those that refused participation, the amount of time it took for patients to complete the questionnaire, and the number of total days spent recruiting patients. Acceptability for staff was determined by the willingness and availability of nurses to help Mr. Gooding identify suitable patients as well as the interest nurses had about the project. Acceptability for patients was determined by how they informally commented about the experience.

4.3.5 Procedures

Patients were approached 3 days a week (Monday, Wednesday and Friday) over 4 months (October and November 2023; January and February 2024), and 5 days/week during the first week of March 2024 (total 53 days and 13 weeks). On each collection day, Mr. Gooding met with the RNs in charge of the two units to identify potential participants. Nurse recommendations regarding the exclusion of patients were systematically recorded, along with patient refusal to participate and reasons for refusal.

Next, Mr. Gooding approached patients directly to confirm their interest and willingness to participate and evaluated their ability to answer questions on a tablet computer with minimal assistance. Following the recommended hospital protocol, before entering a patient’s room Mr. Gooding donned personal protective equipment (PPE) when entering rooms where there was a concern of infection. Upon exiting he would doff the PPE and disinfect the tablet before meeting the next patient. Eligible patients completed the

PROMIS Anxiety 8a followed by sociodemographic information, the general mental and physical health questions and selected domains in the CPES-IC. Questionnaires were available in both English and French and administered according to the participant's language preference. Throughout the survey completion process, Mr. Gooding offered guidance and addressed questions.

4.3.6 Statistical Analysis

Phase 1. Data from the survey of Canadian PROM researchers as well as the data from the environmental scan were grouped into relevant categories. The frequency of each category was then calculated and converted into percentages.

Phase 2. Information from Stakeholder Advisory Committees and Nursing interviews were noted and summarized.

Phase 3. Data from the implementation study were initially reviewed for missing values and outliers. The distribution of all variables was examined using plots and other statistical indicators. Anxiety was classified into categories based as follows: <55 normal; 55 - 59.9 mild; 60 – 69.9 moderate; 70+ for severe levels of anxiety (69). Descriptive statistics were calculated for the full group and were compared by anxiety status (<55 vs. 55+) using chi-square tests and independent sample t-tests.

CPES-IC domain scores were recoded into "Middle/Bottom Box" vs. "Top Box" scores. (*Note: CIHI generally reported "Top-Box" scores reflecting patient satisfaction when publishing public information (150)). Because we were interested in predicting patient dissatisfaction, we used "Middle/Bottom Box" scores which represent the average percentage of respondents that choose the unfavourable response choice (i.e., “Never” or “Sometimes”); (150,151). Point-biserial correlations were used in continuous and dichotomous variables to examine the strength and direction of the association between sociodemographic characteristics and CPES-IC domain scores. (see Appendix D: Supplementary table 4).

Given that the data were not normally distributed, the Mann-Whitney U test was used to compare groups by anxiety status based on people answering never, sometimes, or usually in CPES-IC questions. Spearman rank correlations were calculated to evaluate the strength of the association between Anxiety scores and the CPES-IC domain (see Appendix E: Supplementary table 5). Unadjusted and adjusted logistic regression models were used to assess the association between CPES-IC domains and anxiety expressed as odds ratios. Confounders and covariates were initially considered for inclusion based on empirical evidence and point-biserial correlations >0.3 between anxiety and socio-demographic information and hospital characteristics. Statistical analyses were conducted using IBM SPSS version 29.0.

5.0 Results

5.1 Phase 1

5.1.1 ISOQOL Survey Results

Of the 120 clinical researchers who were contacted to fill out the survey, 6 refused (5%), 26 did not respond (22%), and 88 consented (73%). Of the 88 individuals who consented, 57 completed the survey (65%), and 31 were incomplete (35%). Respondents were mostly from Quebec (36%), British Columbia (25%), and Ontario (21%). Over half (53%) of respondents administered PROMs and PREMs in English; (41%) offered bilingual versions (English and French), and (6%) collected in French.

More than half (56%) of respondents had roles in research (i.e. Clinician-scientist, academic researcher, trainee, or research coordinator), 13% were clinicians, and 4% were patient advocates; the rest (27%) were a balance of policy makers, administrators, quality agency workers, etc. The most common primary affiliations were universities (48%), health care organizations (33%) and a provincial government (10%). The five most widely used PROMs and PREMs were the EuroQoL-5D (EQ-5D; 18%), Short Form Health Survey (SF-36 or SF-12; 16%), Edmonton Symptom Assessment System (ESAS; 12%), Patient Health Questionnaire (PHQ - 9, PHQ - 8, PHQ - 2;10%), and the Generalized Anxiety Disorder Questionnaire or Screener (GAD – 7, GAD – 2; 8%). Most (70%) respondents collected PROMs and PREMs from adults and seniors, whereas (30%) were collected from children, their parents, or their caregivers.

PROMs and PREMS were most often linked to other self-reported data (29%), data collected by clinicians (27%), and administrative and registry data (tied at 14% each). The majority identified clinicians as the primary users of the data (50%), followed by researchers (17%) and administrators (14%). Results were generally used to evaluate outcomes associated with programs or services (19%), treatment decision-making (16%), and to develop new measurement tools or evaluate measurement properties (14%). Respondents indicated findings were being generally used as intended by target users “to a great extent” (16%) and “somewhat” (41%). Finally, the most important challenges to implementing and using PROMs and PREMs were related to integrating measures into existing systems (22%), lack of dedicated resources (19%), and identifying which measures to use (16%). We used these results to understand how and where PROMs were being used in Canada in addition to identifying the most commonly used domains and tools. This helped to inform the initial candidate domains that were presented to the stakeholder advisory group and the nurses.

5.1.2 Environmental Scan of PROM/PREM Use in Canada

During our search of Canadian PROMs in use and related toolkits to assist with implementation, we identified four toolkits (152–155). The search for successful PROM implementation in Canadian ambulatory clinics and inpatient settings resulted in 12 articles (13,99,100,102,156–163). Two studies took place in an inpatient setting in Ontario (50%) and British Columbia (50%). Data collection ranged between 1 and 13 months; both studies collected data for research purposes and took place in hospitalized patients recovering from surgery. The data was collected via tablet (50%) or mail (50%). The target users were clinicians (50%) and researchers (50%). The main goals for implementing PROMs were for quality (50%) and research (50%) purposes. Both studies took place in a surgical setting (100%). Finally, the most commonly used PROMs in this setting were PHQ-9 (25%), EQ-5D (25%), SF36 (25%), and Pain Intensity (P), Interference with Enjoyment of Life (E), and Interference with General Activity (G) (25%), also known as the PEG(159,163).

A total of 10 studies took place in outpatient settings in the provinces of Ontario (80%), Alberta (20%) and Quebec (10%) (13,99,100,102,156–158,160–162). The most popular collection methods were tablet (54%), paper (27%), kiosk (9%) and, mobile (9%). Data collection ranged between 3 and 23 months and took place in 9 hospitals and 16 clinics. The primary target users were clinicians (26%), nurses (26%), allied health professionals (22%), patients (13%) and researchers (13%). The main goals for implementing PROMs were for quality (90%) and research (10%) purposes. The most commonly used tools were related to mental health (56 %), physical health (28%) or disease-specific measures (16%). Most common settings tools were administered were Oncology (30%), Infectious diseases (20%), Nephrology (20%), General Medicine (10%), Diabetes (10%) and Cardiology (10%). Studies also mentioned benefits to staff and patients, such as reducing anxiety in patients, improving the patient experience, improving the quality of clinical care encounters, improving patient-clinician communication, and increasing the amount of complex health and behavioural issues identified by physicians.

Table 1: *Selected characteristics of studies included in the Environmental Scan (n=12)*

Characteristic	N
Province	
Ontario	9 (69%)
Alberta	2 (15%)
Quebec	1 (8%)
British Columbia	1(8%)
Collection Method	
Tablet	7 (53%)
Paper	3 (23%)
Kiosk	1 (8%)
Mobile	1 (8%)
Mail	1 (8%)
Users	
Clinician	6 (25%)
Nurse	5 (21%)
Allied health professional	5 (21%)
Research	5 (21%)
Patient	3 (12%)
Goal	
Quality	10 (83%)
Research	2 (7%)
Setting	
Oncology	3 (25%)
Infectious Diseases	2 (17%)
Nephrology	2 (17%)
Surgery	2 (17%)
General Medicine	1 (8%)
Diabetes	1 (8%)
Cardiology	1 (8%)

The primary obstacles preventing their widespread adoption were implementation-related challenges such as resistance from staff due to concerns about potential increases in workloads (31,42,46,164,165).

The toolkits provided information on best practices for implementation within a Canadian context. The information taken from the implementation toolkits can be divided into three categories: 1) understanding the environment; 2) identifying stakeholders; and 3) attention to workflow. In order to increase the chances of successfully implementing PROMs and PREMs, toolkits generally stressed the importance of understanding environmental factors that served as potential barriers and facilitators to implementation that are unique to specific settings. An example would be to verify if the setting had the appropriate technological infrastructure to implement the desired PROMs into an existing electronic health record and to identify alternatives if this is not the case (152–155). Another example would be to capitalize on local resources by identifying a “champion” who can interact with all levels of stakeholders (152,153,155). This person can provide long-term implementation support such as training, gathering resources, or provide support to staff members or patients using PROMs. Champions often play an important role in helping stakeholders accept implementation (152,153,155).

A second factor identified that increased implementation success is to engage stakeholders (152–155). There are various methods through which this may be achieved; it can be done by increasing the knowledge of PROMs and PREMs by giving demonstrations (152–154). It is also important to have stakeholder buy-in on multiple levels (i.e. physicians, directors, administrators, nurses, clerks) (152–155). Moreover, involving the care team in the decision-making process helps to identify their preferences and needs which will facilitate the selection process for PROMs (152–155).

The third category of recommendations was on the topic of workflow. When implementing PROMs, it is best to have a clear plan and, when possible, to anticipate days when clinics are less busy or when there are downtimes to collect data (152,153,155). Increased workloads are a universal stakeholder concern; therefore, it is necessary to implement PROMs in a manner that causes minimal workflow disruption (152,153,155). Furthermore, individuals looking to implement PROMs should be prepared to address concerns from stakeholders (152–155). Ideally, computerized collection methods should be employed when possible because they require less attention than paper surveys (152,153). Finally, it is important to have a plan and to remain flexible (153,155). We noted that implementation strategies offered in the toolkits did not differentiate between inpatient and outpatient settings.

The information obtained from the environmental scan informed various aspects of the pilot study. We opted to use a tablet to collect data given that it has been shown to be acceptable and less burdensome to patients and administrators (99,152,153). Similar to the results obtained in the ISOQOL survey, PROMs were primarily used to assess physical function and emotional status. In addition, results highlighted that the implementation of PROMs has been successful in various environments across Canada and how they have been leveraged to reduce anxiety in patients, improve-clinician communication, and improve the patient experience (13,50,99,100,102,156–163). Toolkits emphasized the importance of engaging with stakeholders (152–155). This prompted us to include physicians, nurses, researchers, and hospital administrators in our stakeholder committee. It also led to consulting with nurses and asking about their specific needs and how results could benefit them and the patients for whom they provided care. Finally, the scan highlighted the importance of understanding the environment; this led to assessing the workflow and consulting with nurses to identify days and times of the floor where collection would be less disruptive (152,153,155).

5.2 Feedback from Scientific Advisory Committee and Nurses SAC

The advisory group discussed whether any similar ongoing projects existed and identified what data were already being collected, as well as the potential value of different PROMs and PREMs to potentially improve the quality of care. Discussions also addressed the ongoing clinical staff shortages within the Quebec health system and how it would affect the pilot project (166–168). It was agreed that the General Internal Medicine inpatient floors that are serviced by the Division of Internal Medicine of the Royal Victoria Hospital (MUHC Glen Site) were an appropriate setting for the project. Candidate domains to measure were discussed based on the results of the first two phases of the project.

In General Internal Medicine, the physician staff rotates through the unit, generally providing services for two weeks while the nursing staff is relatively permanent. To ensure the success of the pilot project, it was agreed that the nursing staff would be consulted to identify how the project could potentially benefit patient care, impact workflow, and the optimal domains to measure from a nursing perspective. Thus, informal interviews were conducted with the nurse manager and some of the nursing staff on the units to identify the needs of the team.

Nurses expressed a desire to learn more about patient symptoms and experiences including sleep, perceptions of overall care, communication, and concerns about discharge. Several PRO domains were proposed including physical function, anxiety and depression. However, during consultations with the nursing staff, it was unanimously agreed that high levels of anxiety in patients were an area of concern. More specifically, they felt that some patients were less able to comprehend the education and treatment information given to them by the medical, nursing, and other clinical staff, and would often deny that information had been shared with them. Many nurses believed that patients who did not get enough sleep and those being discharged home with nobody to help them with their care also tended to be more anxious. There was widespread agreement among the nursing staff that anxiety would be an important outcome to capture, as there was no systematic effort at present to assess this in patients.

Potential barriers to assessing anxiety using PROMs were also discussed. Nurses noted that patients often arrived on the floor with high levels of acuity, multiple comorbidities, and cognitive impairment. Several noted that some patients would likely be too sick to participate in the project. Given the pressures associated with chronic staff shortages, they also indicated that it would be necessary to limit nurse involvement. Hence, it was agreed that nurses would identify patients who they felt were potentially able to participate in the project each morning, and Mr. Gooding would confirm eligibility and approach patients directly about participating in the project to answer questions and obtain verbal consent.

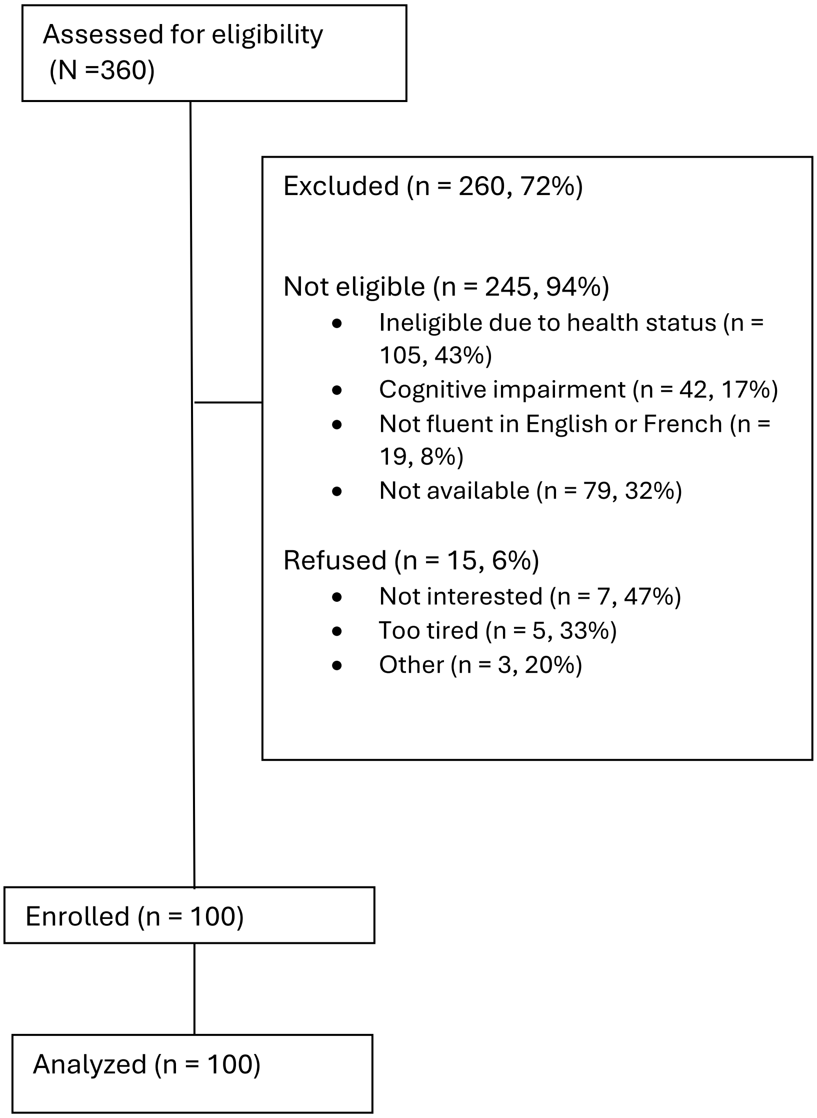
5.2.0 Phase 3

5.2.1 Data Collection

From September 2023 to March 2024, data were collected from patients on the two units over 57 days. A total of 360 patients on the floor were assessed for eligibility; 245

(68%) patients were not eligible for the following reasons: 1) current health status (e.g., unconscious, too sick to hold a conversation) (n=105 ; 43%); 2) not available (e.g., off unit, sleeping, receiving care, etc.) (n= 79; 32%); 3) cognitively impaired (n= 42; 17%); and 4) not fluent in English or French (n=19; 8%). Of the 115 patients that were approached, 15 refused to participate (13%). Reasons for refusal were: 1) not interested (n=7; 47%); 2) too tired (n=5; 33%); and other (n=3; 20%). The other category included: breathing difficulties (n=1; 33%), concerns about confidentiality (n=1; 33%) and feeling overwhelmed (n=1; 33%). Thus, 100 participants were enrolled and all completed the questionnaires (see Figure 1).

Figure 1. *Flow of Participants*



The mean age of patients was 59 years (standard deviation (SD):16), with a range from 18-93 years. Median completion time was 15 minutes (IQR:10-20). Participants were primarily white (n= 67; 67%), men (n= 60; 60%) who spoke English (n= 60; 60%) and were well educated (n= 64; 64%). Very few (5%) had been readmitted, and the majority (93%) arrived on the floor through the ED. The average length of stay within the emergency department was three days (SD = 1.9) with a range of 0-10 days, and the median length of stay of patients on the floor before being approached was five days (IQR:3-10) with a range of 1-213 days. The median pain level of patients was 0.0 (IQR:0.0; scale 0-9), and most (n= 69; 69%) patients had a Charlson comorbidity index ≥3. Most (n= 92; 92%) anticipated being discharged directly home, with the majority (n= 74; 80%) having someone at home who can help with their care. As shown in Table 1, participant characteristics did not differ significantly (i.e., p<.05) by anxiety status on any of the sociodemographic and hospitalization characteristics we evaluated.

Table 2. *Patient characteristics by anxiety status.*

Variable	All (N=100)	Anxiety (n= 68)	No-Anxiety (n= 32)	P value
Men	60 (60%)	40 (59%)	20 (63%)	0.73
Age (18 – 93)				
Mean, SD	59 (16.2)	58 (17.4)	60 (13.7)	0.71
18-29	6 (6%)	5 (7%)	1 (3%)	0.40
30-39	6 (6%)	4 (6%)	2 (6%)	
40-49	17 (17%)	14 (21%)	3 (9%)	
50-59	18 (18%)	9 (13%)	9 (28%)	
60-69	28 (28%)	19 (28%)	9 (28%)	
70-79	17 (17%)	10 (15%)	7 (22%)	
80+	8 (8%)	7 (10%)	1 (3%)	
Education				
Less than High School	18 (18%)	13 (19%)	5 (16%)	0.68
High School	18 (18%)	14 (21%)	4 (13%)	
College/CEGEP	32 (32%)	20 (30%)	12 (38%)	
Undergraduate	23 (23%)	14 (20%)	9 (28%)	
Post-Graduate	9 (9%)	7 (10%)	2 (6%)	

Race/Ethnicity				
White	67 (67%)	48 (71%)	19 (60%)	0.85
Black	10 (10%)	6 (9%)	5 (10%)	
Filipino	6 (6%)	3 (4%)	4 (13%)	
Latin American	5 (5%)	3 (4%)	3 (9%)	
Arab	4 (4%)	2 (3%)	2 (6%)	
South Asian	3 (3%)	2 (3%)	1 (3%)	
Indigenous	2 (2%)	2 (3%)	0 (0%)	
Chinese	2 (2%)	1 (2%)	1 (3%)	
South-East Asian	1 (1%)	1 (2%)	1 (1%)	
Language				
English	60 (60%)	39 (58%)	21 (66%)	0.43
French	40 (40%)	29 (42%)	11 (34%)	
Pain (0-10)				
Pain (Median, IQR)	0 (0)	0 (0)	0 (0)	0.69
Charlson Comorbidity Index				
Charlson Comorbidity Index (Median, IQR)	4 (2-5)	4 (2-5)	4 (2-5)	
0	14 (14%)	10 (15%)	4 (13%)	0.87
1-2 (mild)	17 (17%)	11 (16%)	6 (19%)	
3-4 (moderate)	27 (27%)	17 (25%)	10 (31%)	
5+ (severe)	42 (42%)	30 (44%)	12 (37%)	
Length of Stay on Floor at Interview (Days)				
Length of Stay on Floor at Interview (Median, IQR)	5 (3-10)	6 (3-10)	5 (2-10)	
1-3	37 (39%)	25 (37%)	12 (40%)	0.96
4-7	30 (31%)	21 (32%)	9 (30%)	
8-14	18 (19%)	13 (20%)	5 (17%)	
15+	11 (11%)	7 (10%)	4 (13%)	
Length of Stay in the Emergency Department (Days)				
(Mean, SD)	3 (1.9)	3 (2.0)	3 (1.5)	0.35
0-3	63 (68%)	43 (67%)	20 (69%)	0.20
4-5	24 (26%)	15 (23%)	9 (31%)	
6+	6 (6%)	6 (10%)	0 (0%)	
Admitted through ED	93 (93%)	62 (91%)	31 (97%)	0.30
Readmission	5 (5%)	4 (6%)	1 (3%)	0.55

5.2.2 Anxiety, Physical, and Mental Health

Two-thirds (n= 68; 68%) of participants had at least mild levels of anxiety; 30% scored in the moderate to severe range (Table 2). In the self-rated General Physical Health category, a little over half (n= 54; 54%) of participants rated their health as Good, Very Good, or Excellent. For General Mental Health, the majority (n= 77; 77%) of participants rated their health as Good, Very Good, or Excellent (Table 2). There were no significant differences between general physical or mental health when comparing the anxious and non-anxious groups. The full set of the CPES-IC responses are available in the appendix (see Appendix F: Supplementary table 6).

Table 3. *PROMIS Anxiety scores and CPES-IC self-rated physical and mental health by anxiety status.*

Variables	All (N=100)	Anxiety (55+) (n= 68)	No-Anxiety (<55) (n= 32)	P value
PROMIS Anxiety 8a				
<55 (Normal)	32 (32%)	-------	32 (100%)	<0.001
55.0 – 59.9 (Mild)	38 (38%)	38 (38%)	-------	
60 - 69.9 (Moderate)	23(23%)	23(23%)	-------	
70+ (Severe)	7 (7%)	7 (7%)	-------	
Self-Rated General Physical Health				
Excellent	4 (4%)	2 (3%)	2 (6%)	0.14
Very Good	12 (12%)	6 (9%)	6 (19%)	
Good	38 (38%)	23 (34%)	15 (47%)	
Fair	34 (34%)	28 (41%)	6 (19%)	
Poor	12 (12%)	9 (13%)	3 (9%)	
Self-Rated General Mental Health				
Excellent	12 (12%)	9 (13%)	3 (9%)	0.29
Very Good	31 (31%)	21 (31%)	10 (31%)	

Good	34 (34%)	19 (28%)	15 (47%)
Fair	19 (19%)	16 (24%)	3 (9%)
Poor	4 (4%)	3 (4%)	1 (3%)

5.2.3 Patient Satisfaction

Sociodemographic and hospital factors. We first examined the extent to which patient satisfaction domains were associated with sociodemographic and hospital characteristics. This resulted in weak correlations between the language spoken and dissatisfaction in *Communication with Nurses* (r= -0.21) and *Communication with Doctors* (r= -0.24). The *Involvement in decision making and treatment options* domain had a moderate correlation with being discharged home (r= -0.47), having someone at home to help with care (r= -0.36), and Pain level reported by patients (r= -0.33). Pain level was also moderately correlating with the *Pain Controlled* domain (r= -0.34) and had a weak correlation with *Communication with Doctors* domain (r= -0.21) (Appendix D: Supplementary table 4).

Dissatisfaction among CPES-IC domains. The following table shows the aggregated results of patients that selected *reported never, usually, or sometimes* according to CPES-IC domains. On average patients reported low to moderate level dissatisfaction with their care in various CPES-IC domains. Additionally, the following domains resulted in significant differences in responses between the anxiety and non-anxiety groups: *Communication with Nurses, Communication with Doctors, Pain Controlled, Emotional support, Information Shared with Patients in the Emergency Department, in Decision-Making and Treatment Options, Internal Coordination of Care* and

Cleanliness. The majority of surveyed CPES-IC questions resulted in differences between anxious and non-anxious patients with higher dissatisfaction among patients with anxiety. For the full set of responses see (Appendix E: Supplementary table 5).

Table 4. *The proportion of patients reported never, usually, or sometimes according to CPES-IC domains.*

CPES-IC Domain	All N
Communication With Nurses	26 (26%)
Communication With Doctors	24 (24%)
Pain Controlled	33 (33%)
Emotional Support	32 (32%)
Involvement in Decision-Making and Treatment Options	27 (27%)
Internal Coordination of Care	32 (32%)
Cleanliness	18 (18%)
Coordination of Tests and Procedures	25 (25%)
Received Information About Condition and Treatment	29 (29%)
Transfer From ED to Hospital Bed Organized (Admission Through ED)	5 (6%)

The next series of tables show the results of unadjusted and adjusted multivariable logistic regression models that assess the association between anxiety and patient dissatisfaction for each CPES-IC domain. Because age and sex are often associated with anxiety in other studies, and given that CIHI employs these factors in analyses, we included these as covariates in our models (107,151,169–171).

Communication with Nurses. Table 3 presents the univariable and adjusted multivariable logistic regression showing anxiety levels and dissatisfaction with Communication with Nurses by anxiety level. The odds of dissatisfaction (i.e., CPES-IC bottom/middle box scores) increased significantly in patients with moderate and severe anxiety in a dose response fashion. Adjustment for age and sex yielded similar results, though moderate anxiety was associated with even greater dissatisfaction.

Table 5: The odds of patient dissatisfaction with *Communication with Nurses* by anxiety level among hospitalized patients *(N=100)*.

Anxiety level	Unadjusted (OR, 95%CI)	Adjusted[1] (OR, 95%CI)
No Anxiety (reference)	1.0	1.0
Mild Anxiety (55-59.9)	4.0 (0.8, 20.4)	3.9 (0.7, 20.3)
Moderate Anxiety (60-69.9)	16.4 (3.1, 85.1)	19.3 (3.4, 54.1)
Anxiety Severe (70+)	20.0 (2.5, 158.7)	20.3 (2.1, 111.6)

[1] Adjusted for age and sex

OR = odds ratio, CI = Confidence interval

Communication with Doctors. Table 4 presents the unadjusted and adjusted multivariable logistic regression results between dissatisfaction with Communication with Doctors and anxiety levels. The odds of dissatisfaction increased significantly in patients with anxiety with mild, moderate and severe anxiety, with the highest odds in those with moderate anxiety. Similarly, in the adjusted model, there is a slight increase in the moderate anxiety category and a decrease in the odds of patient dissatisfaction in the severe anxiety category.

Table 6: The odds of patient dissatisfaction with *Communication with Doctors by anxiety level among hospitalized patients (N=100).*

Anxiety level	Unadjusted (OR, 95%CI)	Adjusted[1] (OR, 95%CI)
No Anxiety (reference)	1.00	1.00
Anxiety Mild (55-59.9)	9.6 (1.2, 80.7)	9.5 (1.1, 80.2)
Anxiety Moderate (60-69.9)	28.4 (3.3, 244.7)	30.1 (3.5, 261.7)
Anxiety Severe (70+)	23.3 (1.9, 280.8)	22.7 (1.9, 276.7)

[1]Adjusted for age and sex

OR = odds ratio, CI = Confidence interval

Support to deal with Anxiety/Fears/Worry. Table 5 presents the unadjusted and adjusted results between dissatisfaction with Emotional Support (i.e., to deal with anxieties, fears and worries) by anxiety level. Notably, all patients reporting no anxiety were satisfied with the emotional support they received. Consequently, we used mild anxiety as the reference group to see if increasing anxiety was associated with greater dissatisfaction. The odds of dissatisfaction increased with higher levels of anxiety in both unadjusted and adjusted models.

Table 7: The odds of patient dissatisfaction with *Emotional Support to deal with worries, fears, and anxieties* by anxiety level among hospitalized patients *(N=100)*.

Anxiety level	Unadjusted (OR, 95%CI)	Adjusted[1] (OR, 95%CI)
Mild Anxiety (reference)	1.00	1.00
Anxiety Moderate (60-69.9)	4.1 (1.4, 12.2)	4.8 (1.5, 15.5)
Anxiety Severe (70+)	5.4 (0.9, 32.0)	5.5 (0.9, 33.6)

[1]Adjusted for age and sex

OR = odds ratio, CI = Confidence interval

Pain Control. Table 6 presents the unadjusted and adjusted results between dissatisfaction with Pain Control by anxiety level. The odds of dissatisfaction increased significantly in patients with moderate and severe anxiety. The adjusted model produced similar results.

Table 8: The odds of patient dissatisfaction with Pain *Control* by anxiety level among hospitalized patients *(N=100)*.

Anxiety level	Unadjusted (OR, 95%CI)	Adjusted[1] (OR, 95%CI)
No Anxiety (reference)	1.0	1.0
Anxiety Mild (55-59.9)	2.2 (0.7, 7.2)	2.2 (0.7. 7.4)
Anxiety Moderate (60-69.9)	7.0 (2.0, 24.8)	7.1 (2.0, 25.0)
Anxiety Severe (70+)	7.2 (1.2, 42.5)	7.2 (1.2, 42.7)

[1] Adjusted for age and sex

OR = odds ratio, CI = Confidence interval

Involvement in Decision-Making and Treatment Options. Table 7 presents the unadjusted and adjusted results between dissatisfaction with Involvement in Decision-Making and Treatment Options by anxiety level. The odds of dissatisfaction increased significantly in patients with moderate anxiety only; though the odds were numerically higher for mild and severe categories, results were not statistically significant. Results were similar with adjustments for age and sex.

Table 9: The odds of patient dissatisfaction with Involvement *in Decision-Making and Treatment Options* by anxiety level among hospitalized patients *(N=100)*.

Anxiety level	Unadjusted (OR, 95%CI)	Adjusted[1] (OR, 95%CI)
No Anxiety (reference)	1.00	1.00
Anxiety Mild (55-59.9)	1.4 (0.4, 4.9)	1.4 (0.4, 5.2)
Anxiety Moderate (60-69.9)	5.0 (1.4, 17.4)	6.3 (1.6, 24.3)
Anxiety Severe (70+)	4.0 (0.7, 23.9)	4.0 (0.6, 25.2)

[1] Adjusted for age and sex

OR = odds ratio, CI = Confidence interval

5.2.4 Other Factors Impacting Anxiety

Nurses wanted to know whether anxiety in patients also may be related to having someone at home to help with their care post-discharge. They hypothesized that some patients were anxious because they had to return home alone with no one available to help them.

Almost all patients (92%) were being discharged to their homes with no significant differences between anxiety groups. Most patients (82%) in the group reporting at least mild anxiety had someone to help with care compared to 77% of patients in the normal anxiety group (p=.53).

Nurses also wanted to know if the amount of sleep patients were getting was affecting their anxiety levels; while we were not able to directly assess this, results from Supplementary Table 5 indicate that most patients in the anxiety group (71%) as well in the no-anxiety group (84%) responded always to the area around the room at night was quiet. Additionally, we observed no significant difference between anxiety and no-anxiety groups (p = 0.14), and this variable had a weak correlation with anxiety (r = -0.12) (Supplementary Table 5).

6.0 Discussion

This thesis presents the results of several investigations providing new information about the use of PROMs in Canada including: 1) new results of a survey of Canadian researchers; 2) an environmental scan of existing literature on PROMs uses and implementation strategies within Canadian health care settings; and 3) a pilot study to evaluate the feasibility and acceptability of collecting PROMs in patients hospitalized in a large academic hospital. We also explored potential associations between anxiety levels and dissatisfaction with different aspects of the patient's hospitalization experience. Overall, we found that PROMs use remains limited largely to research applications and quality initiatives in Canada and is largely focused on assessing patient perceptions of physical function and emotional health in outpatient settings. Our pilot study suggested that up to two-thirds of patients on a general medicine floor had at least mild anxiety, with 30% experiencing moderate to severe symptoms, and that worsening anxiety was also associated with greater dissatisfaction with communication with the professional staff, worse perceived pain control, and lower emotional support.

A primary goal of PROMs collection is to promote care that is patient-centred, to improve patient satisfaction and patient experience of care, and facilitate shared decision-making (172). The results of our survey of Canadian researchers and the environment scan, provided insights into the current landscape of PROMs use in Canada. First, we noted that in Quebec, few initiatives are systematically collecting, reporting, or using PROMs (10,49–51). Second, we found that the domains most frequently collected in Canada were mostly limited to physical function and mental health, with the exception of oncology patients in Ontario and BC. Lastly, PROMs collection appears to be mainly limited to isolated (and funded) research (10,49–51). Conversely, in the US PROMs, are collected at scale across most settings to optimize reimbursement, allow patients to compare health plans and providers, and as part of larger initiatives to increase the value of care provided. In the UK, the collection of PROMs focuses on specific surgeries and is utilized to allocate resources within the NHS, compare outcomes at different surgical centres, and shape healthcare policies (11,43,45,46). Thus, PROMS data that is collected in the US and UK tends to be harmonized, mandated (by payers or the national health service) and utilized on a national scale by multiple stakeholders including patients, clinicians, payers, hospital administrators, and decision-makers (172). In Canada, there is evidence that we are moving in a similar direction, but on a much more limited scale, and without incentives in place to boost adoption. For example, in the UK the EQ-5D and the Oxford Hip/Knee Score are collected for all patients who undergo total hip or knee replacement surgery; currently, the same measures are collected voluntarily by hospitals for Canadian patients in Ontario, Manitoba and Alberta (173,174). This is likely because when Canadian health leaders discussed what PROMs to implement, they brought in experts from the UK and the US for consultation (175).

The results of the environmental scan of toolkits highlighted specific examples of successful PROM implementation in inpatient and outpatient settings in Canada. Factors that enhanced PROM adoption and use include involving the care team in selecting domains to measure, engaging stakeholders on multiple levels, evaluating workflow, and using computerized collection methods to decrease burden (152–155). However, only a small number of studies have been conducted in inpatient settings, and it is unclear if different or additional strategies are needed to successfully implement PROMs in hospitalized patients. When designing our pilot study, we established a stakeholder committee that included researchers, clinicians, and hospital administrators, consulted with floor nursing staff about their needs and preferences, evaluated the workflow on the floor, and provided a research assistant to collect PROMs directly from patients using a tablet to minimize the burden on floor staff. This approach acknowledged the importance of developing a strategy within the constraints of busy hospital settings with inadequate staffing and limited resources as is currently seen in hospitals in Quebec and Canada (166–168). We found that on two general medical units, only about 1 in 3 were appropriate or available to complete PROMs despite having research staff onsite most days over several months. Given there are neither payer nor governmental incentives to collect PROMs from inpatients, these findings raise important questions about the feasibility of collecting PROMs in times when clinical staff shortages are impacting access to and the quality of care received in Canadian hospitals.

Our results suggest that among patients hospitalized on a general medicine floor, 2 in 3 patients were experiencing at least mild anxiety symptoms with 30% reporting moderate to severe anxiety according to DSM-5 diagnostic criteria (176). The prevalence of anxiety in our sample is substantially higher than the 28% (95% CI 19% to 38%) reported in a 2021 meta-analysis of 32 studies examining anxiety among general hospital inpatients (119). This meta-analysis included studies with sample sizes that ranged from 45 to 2009 hospitalized patients in settings ranging from internal and geriatric medicine to subspecialty units (e.g., surgical oncology, transplant, burn unit). The meta-analysis also generally excluded patients with cognitive impairments, were physically unwell, or had a known psychiatric history. We did not find any of the sociodemographic factors we included were systematically associated with anxiety. Similarly, the investigators conducting the meta- analysis found no evidence that age, female sex, or publication year were associated with anxiety symptoms. However, the investigators noted considerable statistical heterogeneity in prevalence due to the ascertainment method (i.e., use of DSM criteria and/or rating scales), country and type of hospital unit, and timing of the assessment after admission.

In contrast, some researchers have reported that hospitalized women are more likely to be anxious compared to men (107,169–171). The American Psychological Association notes that women are more likely than men to report anxiety (177). Additionally, sociodemographic factors were not associated with any of the selected hospital characteristics in our study, which is consistent with another Canadian sample (94,117). Given that the prevalence of anxiety in the non-hospitalized population is estimated to be 5.2% in 2022 in Canada, these findings highlight that being hospitalized is associated with anxiety, likely from multiple factors (178,179). More research is needed to better understand potential sociodemographic contributors that may help identify individuals at risk for higher anxiety in hospitalized Canadians.

We also found that patients with anxiety had greater odds of being dissatisfied with four aspects of the patient experience we examined using the CPES-IC -- *Communication with Nurses and Doctors, Emotional Support, Pain Control, Involvement in Decision-Making and Treatment Options*. Anxiety had the largest impact on dissatisfaction with communication with both doctors and nurses, and the least impact on dissatisfaction with shared decision-making. The dose response relationships observed in several of these predictors with increasing anxiety resulting in a greater odd of dissatisfaction increases confidence in the strength of the association. Patients with severe anxiety had ≥20 times the odds of being dissatisfied with communication with their doctors and nurses.

Others have also noted that patients with anxiety report lower patient satisfaction (114,115). We also observed significant differences between the anxiety and no-anxiety groups; patients with anxiety were less satisfied with receiving explanations about medications, feeling that there was good communication about their care between hospital staff, and receiving all the information needed about their condition and treatment. These factors play a role in how patients communicate with nurses during their hospital stay (180). These associations might be part of why patients with anxiety report poor communication with medical staff.

There are compelling reasons to focus on patient experience and symptoms during hospitalization. Heightened anxiety in inpatients is not only associated with greater fatigue, pain, and disability but also has been linked to negative thinking and challenging behavioural manifestations (181–183). Conversely, better patient experiences are linked to lower mortality rates and higher medical guideline adherence (81–84). Better patient-provider communication is associated with higher physical and mental health, shorter hospitalizations, improved pain management, better medication adherence, and higher care facility ratings (80). Although this study was conducted during the COVID-19 pandemic, emerging evidence suggests the pandemic has not substantially impacted CPES-IC scores (184). A comparative cross-sectional study in Canada found that patients hospitalized during COVID-19 had higher odds of reporting high patient satisfaction on 17 of 39 questions with lower odds on only two questions (information about admission, inclusion of family/friends in care decisions); the remaining 20 questions showed no significant difference with respect to levels of patient satisfaction during hospitalization (184).

Patients with moderate anxiety had the highest odds of being dissatisfied with their *Involvement in Decision-Making and Treatment Options*. Two items make up this domain, fair patient involvement (r = 0.38) and poor involvement of family (r = 0.26) and are correlated with the overall rating of hospital satisfaction (95). It is of note that during the development process of the CPES-IC, this domain did not have strong associations with the global hospital experience questions, however, the creators opted to retain it given it has one of the highest response rates suggesting that it is a topic that was important to Canadian patients (87). More research in needed on this topic to explore its role in the patient experience.

All participants reporting expected levels of anxiety (i.e., PROMIS <55) reported being satisfied with the level of emotional support they received during their stay. This category had the fourth strongest association with global hospital experience among the 11 new Canadian-specific questions added to the CPES-IC (87).

Pain is among the factors that likely impact the level of anxiety patients experience during hospitalization and is directly associated with overall satisfaction (111–113,117,120). Our patients with anxiety were more likely to indicate that their pain was not well controlled or that hospital staff was doing everything they could to help them with their pain. Pain control is important for patient comfort, experience and outcomes, as seen in patients with chronic illnesses (116). However, we noted a major discrepancy between the patient's reported pain level and the patient's reported Pain Controlled score. Chart records revealed that most patients (81%) had a pain score of 0 (out of 10) even though (29%) of patients reported their pain was not well controlled on the CPES-IC. Pain is regularly recorded by the nurses in the patients’ charts; our results suggest the validity and reliability of this chart rating is unclear. Others have found inconsistent relationships between pain intensity and pain management (185–187). For example, one small study of 88 patients found that there was only a weak inverse relationship between pain intensity and patient satisfaction with overall pain management (r = -0.31) (185). Another study found that six predictors explained 79% of the variance in patient perceptions of pain control in the HCAHPS: 1) not receiving help as soon as they wanted; 2) poor nurse communication; 3) poor medication education; 4) receiving care in a teaching hospital; 5) higher numbers of nursing staff; and 6) receiving care in a nonprofit hospital (187). This suggests that patient perceptions of the adequacy of pain control is influenced by multiple factors, including the level of anxiety patients are experiencing.

A large U.S. study of hospitalized patients who completed patient experience surveys revealed a strong correlation between nurse and doctor communication and overall hospital rating, with nurse communication emerging as the most influential predictor (96). Researchers examined the results of surveys from 4898 patients receiving medical or surgical care in a university-affiliated inner-city hospital. Overall hospital rating was moderately correlated with doctor communication for medical (r=0.54) patients and for surgical (r=0.57) patients. Additionally, the correlation between overall hospital rating and nurse communication was 0.59 for medical patients and 0.64 for surgical patients (96).

Similarly, a large study in Alberta, analyzed the results of 27 369 inpatient experience surveys collected over 3 years to see how HCAHPS domains correlated with overall inpatient hospital experience in Canada. They identified communication with nurses as having the most robust correlations (r=0.60) with the overall hospital experience and care ratings (95). Other factors that had a moderate correlation with overall hospital experience included *Responsiveness of Hospital Staff* (r = 0.49); *Pain Management* (r = 0.48), *Communication with Doctors* (r = 0.43) and *Communication about Medicines* (r = 0.42). In other words, the patient's perception of how well they can communicate with their medical team, especially nurses, plays an important role in determining their overall perceptions of hospital care (95). Our results are consistent with the growing number of studies suggesting that anxiety is an important mediator of perceived communication and overall experience.

Input from nurses when designing this study also lends additional support to the confidence of our findings that anxiety is common among inpatients. Nurses stated that they believed that they were communicating effectively with patients, but patients who were anxious were not able to comprehend or retain the information given to them. We found that patients with severe anxiety had up to 20 times the odds of being dissatisfied when asked bout their communicating with nurses. Other qualitative studies have reported that anxiety can serve as an important barrier to communication with healthcare workers (188–190). One study noted that low levels of anxiety (i.e., when patients are not overwhelmed) do not result in poorer communication, whereas when patients are anxious, some withhold important information such as a new symptom (188). Notably, anxious patients often cannot take in novel information and will frequently repeat the same questions (186). In another study investigating barriers to nursing communication, anxiety and pain were identified as the most important barriers to effective communication with patients (189). Furthermore, a study investigating communication barriers from the perspectives of nurses found that nurses ranked patient anxiety as the third most important barrier to communication after a lack of awareness of nurse duties and family interference. Whereas patients ranked their anxiety as the most important barrier to communication (190).

Our nurses hypothesized that anxiety in patients may be higher when they are when there is no one to help them with their care at home post-discharge. However, we found similar anxiety levels in patients irrespective of their discharge disposition. Furthermore, nurses wanted to know if sleep duration impacted patient anxiety. While we did not directly assess this, we found that most patients (71% in the anxiety group and 84% in the no-anxiety group) reported that the area around their room at night was always quiet. Others have also noted the *Quietness of Hospital* domain of the CPES-IC is only weakly associated (r= 0.30) with overall hospital satisfaction rating noise levels around a patient's room do not appear to significantly impact overall satisfaction (95,115,191).

Given the central role that patient satisfaction plays in communication with nurses, researchers are searching for ways to improve patient experience (192). Studies have found that training nurses on non-verbal skills such as making eye contact, smiling and nodding during engagements, informing patients about what to expect during their stay, using plain language, teaching patients how self-care skills before discharge and checking in on patients (who are not asleep) during the night improve the likelihood of positive patient experiences (193,194). One study that offered brief communication training to nurses and residents found that sessions as brief as 1-2 hours improved communication (194). It is unclear if specific skills are needed to improve communication between medical staff and patients who have moderate to high levels of anxiety.

Taken together, these findings highlight inter-relationships between patient anxiety, patient perceptions of communication with doctors and nurses, how well their pain is controlled, perceived support, and how involved they are in shared decision-making. Identifying and addressing anxiety can serve as an opportunity for targeted interventions. Providing high-quality care that optimizes the physical and psychological health of patients ultimately contributes to a more holistic and patient-centred approach. Providing clinicians with training in these skills has resulted in reduced stress and anxiety levels in patients (195,196). A study assessing the effects of physician communication style of patient's affective state and outcomes found that when a physician was trained to be warm and empathic in their communication it raised positive expectations which reduces patient's anxiety (196). Another study examined the feasibility, acceptability and effect of a communication quality-improvement intervention on patient outcomes in an oncology outpatient setting. They found a (10%) reduction in depression symptoms and a (5%) reduction in anxiety symptoms in patients with moderate to severe anxiety. The anxiety reduction was sustained at 24 weeks (195).

It is also likely that collecting PROMS also can impact overall communication with the medical team. A systematic review of the impact of PROs on patient-clinician communication in oncology found that PROMs may help relieve patient anxiety by giving the staff an opportunity to discuss symptoms and normalize for them that their side effects are common among other patients receiving the same therapy (36). Additionally, PROMs provided patients and clinicians with a similar and shared understanding of patient symptoms (38). In a 2020 multi-site Canadian study involving 6000 patients at three hospitals in Ontario and three in Quebec (including the MUHC), researchers evaluated the effects of implementing e-PRO collection on the patient experience as part of a quality improvement initiative (13). e-PROs were collected from 51%-91% of the population and were judged acceptable for communicating symptoms by 76% of patients and for treatment planning by 80% of clinicians. Patient experience was better than provincial averages, and statistically significant reductions in mean GAD-7 change slopes between baseline and treatment ranging from 0.15 and 0.48 were evident in Ontario sites. They hypothesized that monitoring of symptoms through the use of e-PROs helped patients feel more confident that their symptoms would be addressed by clinicians. Additionally, higher levels of patient activation (a measure of knowledge, skills, and confidence for self-management in patients) from baseline to the endpoint (6 months) were seen in the Ontario (but not Quebec) sites. They hypothesized that this might be due, in part, to the fact that in Ontario, the Edmonton Symptom Assessment System has been routinely collected at every visit in Ontario cancer clinics for several years, and staff and clinicians are already familiar with using PROMs data at visits to guide care. Conversely, Quebec sites were impacted by concurrent restructuring of the health care system while the study was collecting data. Furthermore, they found a 3.2% reduction in hospitalization rates and a 2% reduction in emergency department visit rates. They hypothesized that e-PROs may lead to earlier identification and management of symptoms and emotional distress which may improve patient experience and activation and reduce healthcare utilization (13).

Although PROMs have benefits, there may be unintended consequences. In addition to the implementation challenges previously discussed, there are other issues associated with their use. Reports indicate that individuals have employed PROMs in ways that creators have not approved, such as using them for different patient populations or mixing different versions of PROMs (197). A systematic review of PROMs studies found that some issues are consistent across diverse health conditions and clinical settings (198). They found that patients have reported a reduction in quality of care by inaccurately estimating symptoms and raising expectations for care that exceed clinicians' resources. Others have found that some PROMs lacked clinically meaningly information and were not considered suitable for all patients. Additionally, some clinicians reported that PROMs provided redundant information and negatively impacted the focus of consultations (198). It is important to mention that groups such as ISOQOL have developed guidelines that address common issues and emphasize the importance of choosing appropriate PROMs for specific patient groups and clinical contexts (15).

Our pilot study demonstrated it is possible to routinely collect PROMs in inpatient settings as part of a research initiative that provided a person dedicated to this activity. Overall, our refusal rate among eligible patients was low (15%) which is comparable to other Canadian studies in similar settings that have (28%) and (7%) (99,100). Overall, we found that eligible patients seemed interested in completing the PROM as have others (99). Interruptions from physicians or nurses during the process were rare, likely because the research assistant timed interactions with patients around clinical workflow. For example, if one patient was being seen by the medical staff, the recruiter could speak to other patients. On average, it took patients about 15 minutes to answer 43 questions to complete the survey, which is comparable to 26 minutes (36 questions) and 12 minutes (51 questions) in similar Canadian studies with patients of similar age groups (100,160). The largest obstacle we faced was waiting for the RN on the floor to provide information on the patient's eligibility. Although information received from nurses was crucial in this process, a possible solution would be to seek information from other members of the clinical staff who may be able to speak to a patient's status (e.g., licensed professional nurses (LPN) on the unit). On multiple occasions, the RN we spoke with would refer to the LPN to confirm information about a patient. Having clinical staff indicate the potential suitability of a patient for PROM collection on the patient chart also could streamline the approach to identifying appropriate patients for PROM collection.

Overall, we found that the nurses were interested and engaged in this project. They would often volunteer information on a patient's status. Patients also found the process acceptable. Most patients appreciated being asked questions about their experience and used questions as an opportunity to start a broader conversation about their hospital experience. They would pause and reflect on their experience to answer questions. Many patients ended the conversation by thanking Mr. Gooding for listening to them.

6.1 Strengths and Limitations

This project has several strengths. We included multiple Canadian stakeholders to inform and help interpret the results of the foundational work (i.e., the ISOQOL survey and environmental scan). We also incorporated existing recommendations from PROM implementation toolkits to offer insights into best practices for implementation in Canada and increase the likelihood of successful adoption of PROMs in our pilot study. Involving nurses from the units allowed us to identify a PROM domain that would address a clinical gap and could potentially help inform care. We used a brief measure of anxiety that has been validated in this population and can yield precise measures of anxiety linked directly to DSM-5 diagnostic criteria. Administering the questionnaires via a tablet computer improved efficiency and reduced patient and administrator burden. It is worth noting that generally, patients did not require assistance when completing the questionnaires on the tablet.

Although this study was conducted during the COVID-19 pandemic, emerging evidence suggests the pandemic has not substantially impacted CPES-IC scores (184). A comparative cross-sectional study in Canada found that patients hospitalized during COVID-19 had higher odds of reporting high patient satisfaction on 17 of 39 questions with lower odds on only two questions (information about admission, inclusion of family/friends in care decisions); the remaining 20 questions showed no significant difference with respect to levels of patient satisfaction during hospitalization (184).

There are also limitations. We used a convenience sample of participants on the floor of a large urban hospital in Montreal who were deemed able by nursing staff to participate. Eligible participants represented about 32% of the patients hospitalized on these floors and who were available when the research assistant was on site. We excluded patients who were not physically well, were not fluent in English or French, receiving palliative care, and/or had significant cognitive impairments. The generalizability of these results to other floors in the hospital is unclear. However, others have noted that trends of higher anxiety levels tend to be consistent across floors in a hospital suggesting that we could expect similar results from different departments within the hospital (199,200). PROMs collection was feasible because this initiative provided a research assistant who determined eligibility and met with patients to collect the PROMs. Results were not communicated to the clinical staff and hence were not incorporated into care. The need to use PPE with many patients and decontaminate the tablet between patients also added an additional 2 to 5 minutes per patient to our protocol to collect data.

The mode of survey administration can significantly influence respondents' answers with evidence indicating that healthcare evaluations tend to be more positive when conducted by phone as opposed to mail (201). Thus, some patients may have been reluctant to acknowledge dissatisfaction with the provider or hospital services given the research assistant was in the room when they completed the survey and they would remain in the hospital, often for an unknown duration at the time the questionnaires were completed. We note too that the Emotional Support question asks if the person felt they got support needed to help with any anxieties, fears or worries during their hospital stay, but does not specifically query support received from the hospital staff. There is a possibility that some patients may have interpreted this question as asking about support from family members and friends. We used odds ratios to quantify associations. Odds ratios are known to inflate the size of the effect as compared with relative risks, particularly when the frequency (i.e., dissatisfaction) of an outcome is high (202). However, while the magnitude of the risk may be overestimated, there is little doubt that anxiety plays a major role in patient dissatisfaction. Finally, we assessed anxiety at a single time point; it is unclear how representative this timepoint may be given that some patients had already been in the hospital for an extended period of time (e.g., 40 days). Additionally, we did not investigate why patients were feeling anxious. Future research should monitor anxiety over time to identify patterns as well as investigate what is making patients anxious. This will enable us to better understand patient anxiety by observing potential determinants and fluctuations throughout their hospital stay. There is potential to target interventions at times when patients are expected to experience higher or lower anxiety. Finally, although we collected 100 participants, we did not calculate a sample size which may have limited our ability to determine the power of our study.

7.0 Conclusion

In conclusion, our results provide additional support to the feasibility, acceptability and relevance of collecting PROMs by a dedicated research assistant in selected patients hospitalized on a large, urban internal medicine floor. Our findings highlight that most participants (68%) were experiencing at least mild anxiety with 30% experiencing moderate to severe symptoms (which may benefit from clinical intervention). Anxiety was not related to individual patient characteristics that we investigated but was an important determinant of the patient experience including communication with the medical staff, perceptions of their involvement in shared decision-making, pain control and emotional support received. The largest impact of anxiety was on the communication with nurses and doctors, with evidence of a dose response relationship. Hence, recognizing and addressing anxiety in patients may be an important avenue to optimizing communication with the medical team. Finally, our results suggest that up to 30% of patients with moderate to severe anxiety may benefit from targeted interventions to specifically the consequences of increased anxiety (i.e., reduced worrying, fears, ruminations, etc). The benefits of talking directly with patients about their anxiety may serve to reduce overall levels of anxiety, as has been seen in outpatient cancer settings.

Identifying and potentially addressing anxiety in hospitalized patients has the potential to increase not only patient satisfaction but also result in better clinical outcomes. The benefits of talking directly with patients about their anxiety may serve to reduce overall levels of anxiety, as has been seen in outpatient cancer settings. Further, reduced patient anxiety can also benefit families and even clinical staff. Identifying and addressing increased anxiety may help allow clinical staff to communicate with patients based on their individual needs. Collecting PROMs and PREMs captures the patient's perspective of how they are feeling and can function, and their hospital experience. This is important in our continued effort to move towards a patient centred medical model. The systematic collection of PROMs can be a powerful tool as it contributes to a more holistic and patient-centred approach by providing opportunities to provide care that is safe, effective, patient-centered, timely, efficient and equitable.

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9.0 Appendix:

Appendix A

Supplementary table 1: *Domains within HCAHPS, CPES-IC and new domains included*

HCAPHS	CPES-IC (2022)**	Modified CPES-IC changes
Care from nurses* (α=0.78) Care from doctors* (α=0.80) Cleanliness of hospital Quietness of hospital Staff responsiveness* (α=0.68) Pain control* (α=0.83) Communication about medicines* (α=0.63) Discharge information* (α=0.45) Overall hospital rating	Pain controlled* (Response options: Never, Sometimes, Usually, Always) Explanation about Medications* (Response options: Never, Sometimes, Usually, Always) Discharge planning* (Response options: Yes, No) Hospital rating (0-10) (Response options: 0 worst hospital to 10 best hospital) Emotional support (Response options: Never, Sometimes, Usually, Always) Involvement in decision-making and treatment options* (Response options: Never, Sometimes, Usually, Always, I did not want them to be involved, I did not have family or friends to be involved) Coordination of tests and procedures (Response options: Never, Sometimes, Usually, Always) Received info about condition and treatment	Hospital rating (0-10) Removed Hospital stay helpful Removed Information and understanding when leaving the hospital Removed Intent to recommend hospital to family and friends Removed Overall hospital experience Removed Help at home: Is there anyone at home that can help you with your care? (Response options: Yes, No) Added

(Response options: Never, Sometimes, Usually, Always)

Information shared with patients in the ED (Admission through ED)

(Response options: Not at all, Partly, Quite a bit, Completely)

Transfer from ED to hospital bed (Admission through ED)

(Response options: Not at all, Partly, Quite a bit, Completely)

Waited too long in ED for bed (Admission through ED)

(Response options: Yes, No)

Internal coordination of care*

(Response options: Never, Sometimes, Usually, Always)

Enough info given about admission process prior to arrival (Direct admission)

(Response options: Not at all, Partly, Quite a bit, Completely)

Admission into hospital organized (Direct admission)

(Response options: Not at all, Partly, Quite a bit, Completely)

Hospital stay helpful

(Response options: 0 not helped at all to 10 helped completely)

Information and understanding when leaving the hospital*

(Response options: Not at all, Partly, Quite a bit, Completely)

Intent to recommend hospital to family and friends

	(Response options: Definitely no, Probably no, Probably yes, Definitely yes) Overall hospital experience (Response options: 0 very poor experience to 10 very good experience)

*Composite (multi-item) measure

**Canadian Institute for Health Information. Canadian Patient Experiences Survey —

Inpatient Care: Patient-Reported Experience Measures. Ottawa, ON: CIHI; 2022.[1]

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[1] The Canadian Institute for Health Information (CIHI: May 2022) has 23 patient-reported experience measures (10 multi-question [composite], 9 single and 4 overall hospital experience measures). This table describes the measures and the survey questions from CIHI's Canadian Patient Experiences Survey — Inpatient Care (CPES-IC) that are used to calculate them. The composite measures use a combination of survey questions with similar concepts. The single measures use 1 survey question that measures a distinct concept.

Appendix B

Supplementary Table 2: *Information collected from participants medical records*

Variable	Response format
First name initial	A-Z
Last name initial	A-Z
Age	Year
Sex	Male / Female
Language	English / French
Readmission status	Yes / No
Length of stay in emergency department	Days
Length of stay on floor when approached	Days
Charlson comorbidity index	0-5
Pain	0-10
Reason for admission	As recorded in chart
Arrival date	YYY-MM-DD
Discharge date	YYY-MM-DD

Appendix C

Supplementary Table 3: *PROMIS Short Form 8 anxiety questions and responses*

Question	Response format
In the past 3 days	
I felt fearful I found it hard to focus on anything other than my anxiety	Never, Rarely, Sometimes, Often, Always

PROMIS Item Bank v1.0 – Emotional Distress – Anxiety – Short Form 8a. Available from

http://www.rehabmeasures.org/Lists/RehabMeasures/Attachments/1112/PROMIS SF v1.0 - ED-Anxiety-SF8a.pdf

Appendix D

Supplementary table 4: *Point-biserial correlation between socio-demographic and hospital characteristics*

Variable	Communication				
	Nurse	Doctor	Pain controlled	Involvement in decision making and treatment options	Emotional Support
Sex (Male)	0.16	0.04	-0.02	0.22	0.08
Age	0.12	0.05	-0.01	0.15	0.10
Language	-0.21	-0.24	-0.08	-0.10	-0.05
Discharged home	-0.08	-0.04	-0.20	-0.47	-0.19
Help with care post discharge	-0.03	-0.03	0.01	-0.36	-0.10
Education	-0.00	0.13	0.07	0.09	0.19
Ethnicity	-0.11	0.01	-0.01	-0.03	-0.00
Pain	0.10	-0.21	-0.34	-0.33	-0.03
Charlson Comorbidity Index	-0.01	-0.07	-0.09	-0.07	-0.09
Length of Stay on Floor Before Approach	0.13	0.09	-0.00	0.09	-0.11
Length of Stay in Emergency Department	-0.08	-0.09	-0.14	-0.02	-0.09
Readmission	0.18	0.02	0.10	0.09	0.24
General Physical Health	-0.12	-0.08	-0.29	-0.09	-0.13
General Mental Health	-.05	-0.08	-0.06	-0.04	-0.12

Appendix E

Supplementary table 5: *Number of people answering never, sometimes or usually (Bottom/ Middle-Box) by anxiety status and association with Short Form 8 anxiety scores*

Question	All N	Anxiety (N)	No-Anxiety (N)	Man-Whitney U	Spearman r
Communication With Nurses	26 (26%)	24 (36%)	2 (6%)	0.002	0.39
How often are the nurses treating you with courtesy and respect?	20 (20%)	20 (29%)	0 (0%)		0.41
How often are the nurses listening carefully to you?	36 (36%)	32 (48%)	4 (12%)		0.43
How often are the nurses explaining things in a way you could understand?	30 (30%)	26 (38%)	4 (12%)		0.32
Communication With Doctors	24 (24%)	23 (34%)	1 (3%)	<0.001	0.34
How often are the doctors treating you with courtesy and respect?	19 (19%)	19 (28%)	0 (0%)		0.35
How often are the doctors listening carefully to you?	30 (30%)	27(41%)	3 (9%)		0.38
How often are the doctors explaining things in a way you could understand?	27 (27%)	25 (37%)	2 (6%)		0.38
Pain Controlled	33 (33%)	28 (41%)	5 (16%)	0.012	0.33
How often is your pain well controlled?	29 (29%)	24 (36%)	5 (16%)		0.28
How often does the hospital staff do everything they could to help you with your pain?	22 (22%)	21 (31%)	1 (3%)		0.44

Emotional Support					
Did you get the support you needed to help you with any anxieties, fears or worries you had during this hospital stay?	32 (32%)	32 (47%)	0 (0%)	<0.001	0.52
Explanation About Medications					
Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?	15 (27%)	14 (35%)	1 (6%)		0.35
Before giving you any new medicine, how often does the hospital staff describe possible side effects in a way you could understand?	42 (42%)	27 (40%)	15 (47%)		0.30
Information Shared with Patients in the Emergency Department (Admission Through ED)					
When you were in the emergency department, did you get enough information about your condition and treatment?	58 (66%)	44 (75%)	14 (47%)	0.006	0.34
Were you given enough information about what was going to happen during your admission to the hospital?	58 (65%)	41 (69%)	17 (43%)	0.02	0.38
Involvement in Decision-Making and Treatment Options	27 (27%)	22 (33%)	5 (16%)	0.08	0.16
Are you involved as much as you want to be in decisions about your care and treatment?	26 (26%)	22 (33%)	4 (12%)		0.27
Are your family or friends involved as much as you wanted in decisions about your care and treatment?	7 (10%)	6 (12%)	1 (5%)		0.07

Staff Responsiveness					
After you pressed the call button, how often did you get help as soon as you wanted it?	51 (51%)	42 (62%)	9 (28%)		0.34
How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted?	9 (45%)	9 (50%)	0 (0%)		0.51
Internal Coordination of Care					
Do you feel that there is good communication about your care between doctors, nurses and other hospital staff?	32 (32%)	29 (43%)	3 (9%)	<0.001	0.40
Cleanliness					
How often are your room and bathroom kept clean?	18 (18%)	16 (23%)	2 (6%)	0.04	0.25
Coordination of Tests and Procedures					
How often were tests and procedures done when you were told they would be done?	41(41%)	35 (51%)	6 (19%)	0.002	0.31
Quietness					
How often is the area around your room quiet at night?	25 (25%)	20 (29%)	5 (16%)	0.14	0.12
Received Information About Condition and Treatment					
Did you get all the information you needed about your condition and treatment?	29 (29%)	25 (37%)	4 (12%)	0.01	0.28
Transfer From ED to Hospital Bed Organized (Admission Through ED)					
Was your transfer from the emergency department into a hospital bed organized?	5 (6%)	5 (8%)	0 (0%)	0.1	0.22

Appendix F

Supplementary table 6: *Full CPES-IC responses*

Question	All N (%)	Anxiety (N)	No-Anxiety (N)
Communication With Nurses			
How often are the nurses treating you with courtesy and respect?	Never = 0 (0%)	Never = 0 (0%)	Never = 0 (0%)
	Sometimes = 4 (4%)	Sometimes = 4 (6%)	Sometimes = 1 (0%)
	Usually = 16 (16%)	Usually = 16 (24%)	Usually = 0 (0%)
	Always = 80 (80%)	Always = 48 (70%)	Always = 32 (100%)
How often are the nurses listening carefully to you?	Never = 2 (2%)	Never = 2 (3%)	Never = 0 (0%)
	Sometimes = 11 (11%)	Sometimes = 10 (14%)	Sometimes = 1 (3%)
	Usually = 23 (23%)	Usually = 21 (31%)	Usually = 2 (6%)
	Always = 64(64%)	Always = 35 (52%)	Always = 29 (91%)
How often are the nurses explaining things in a way you could understand?	Never = 2 (2%)	Never = 1 (1%)	Never = 1 (3%)
	Sometimes = 7 (7%)	Sometimes = 7 (10%)	Sometimes = 0 (0%)
	Usually = 21 (21%)	Usually = 18 (27%)	Usually = 3 (9%)
	Always = 70 (70%)	Always = 42 (62%)	Always = 28 (88%)
Communication With Doctors			

How often are the doctors treating you with courtesy and respect?	Never = 1 (1%) Sometimes = 7 (7%) Usually = 11 (11%) Always = 81 (81%)	Never = 1 (1%) Sometimes = 7 (10%) Usually = 11 (16%) Always = 49 (72%)	Never = 0 (0%) Sometimes = 0 (0%) Usually = 0 (0%) Always = 32 (100%)
How often are the doctors listening carefully to you?	Never = 3 (3%) Sometimes = 12 (12%) Usually = 16 (16%) Always = 69 (69%)	Never = 3(4%) Sometimes = 11 (16%) Usually = 14 (21%) Always = 40 (59%)	Never = 0(0%) Sometimes = 1 (3%) Usually = 2 (6%) Always = 29 (91%)
How often are the doctors explaining things in a way you could understand?	Never = 1(1%) Sometimes = 4(4%) Usually = 22(22%) Always = 73(73%)	Never = 1 (2%) Sometimes = 4 (6%) Usually = 20 (29%) Always = 43 (63%)	Never = 0 (0%) Sometimes = 0 (0%) Usually = 2 (6%) Always = 30 (94%)
Pain Controlled			
How often is your pain well controlled?	Never = 2 (2%) Sometimes = 11 (11%) Usually = 16 (16%) Always = 71 (71%)	Never = 2 (3%) Sometimes = 10 (15%) Usually = 12 (18%) Always = 44 (64%)	Never = 0 (0%) Sometimes = 1 (3%) Usually = 4 (13%) Always = 27 (84%)
How often does the hospital staff do everything they could to help you with your pain?	Never = 2 (2%) Sometimes = 9 (9%) Usually = 11 (11%)	Never = 2 (3%) Sometimes = 8 (12%) Usually = 11 (16%)	Never = 0 (0%) Sometimes = 1 (3%) Usually = 0 (0%)

	Always = 78 (78%)	Always = 47 (69%)	Always = 31 (97%)
Emotional Support			
Did you get the support you needed to help you with any anxieties, fears or worries you had during this hospital stay?	Never = 4 (4%) Sometimes = 13 (13%) Usually = 15 (15%) Always = 68 (68%)	Never = 4 (6%) Sometimes = 13 (19%) Usually = 15 (22%) Always = 36 (53%)	Never = 0 (0%) Sometimes = 0 (0%) Usually = 0 (0%) Always = 32 (100%)
Explanation About Medications			
Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?	Never = 5 (8%) Sometimes = 7 (15%) Usually = 4 (7%) Always = 43 (73%)	Never = 4 (9%) Sometimes = 7 (16%) Usually = 4 (9%) Always = 28 (65%)	Never = 1 (6%) Sometimes = 0 (0%) Usually = 0 (0%) Always = 15 (94%)
Before giving you any new medicine, how often does the hospital staff describe possible side effects in a way you could understand?	Never = 15(26%) Sometimes = 5(9%) Usually = 2(3%) Always = 36(62%)	Never = 13 (32%) Sometimes = 5 (12%) Usually = 1 (2%) Always = 22 (54%)	Never = 2 (12%) Sometimes = 0 (0%) Usually = 1 (6%) Always = 14 (82%)
Information Shared with Patients in the Emergency Department (Admission Through ED)			
When you were in the emergency department, did you get enough information about your condition and treatment?	Not at all = 10 (11%) Partly = 20 (23%)	Not at all = 10 (17%) Partly = 13 (22%)	Not at all = 0 (0%) Partly = 7 (23%)

	Quite a bit = 28 (32%)	Quite a bit = 21 (36%)	Quite a bit = 7 (23%)
	Completely = 30 (34%)	Completely = 14 (24%)	Completely = 16 (53%)
Were you given enough information about what was going to happen during your admission to the hospital?	Never = 20 (22%)	Never = 16 (27%)	Never = 4 (13%)
	Sometimes = 20 (22%)	Sometimes = 15 (25%)	Sometimes = 5 (17%)
	Usually = 14 (16%)	Usually = 10 (17%)	Usually = 4 (13%)
	Always = 35 (39%)	Always = 18 (31%)	Always = 17 (57%)
Involvement in Decision-Making and Treatment Options			
Are you involved as much as you want to be in decisions about your care and treatment?	Never = 2 (2%)	Never = 2 (3%)	Never = 0 (0%)
	Sometimes = 12 (12%)	Sometimes = 10 (15%)	Sometimes = 2 (6%)
	Usually = 12 (12%)	Usually = 10 (15%)	Usually = 2 (6%)
	Always = 74 (74%)	Always = 46 (67%)	Always = 28 (88%)
Are your family or friends involved as much as you wanted in decisions about your care and treatment?	Never = 0 (0%)	Never = 0 (0%)	Never = 0 (0%)
	Sometimes = 2 (2%)	Sometimes = 2 (3%)	Sometimes = 0 (0%)
	Usually = 5 (5%)	Usually = 4 (6%)	Usually = 1 (3%)
	Always = 62 (62%)	Always =41 (60%)	Always =21 (66%)
	I did not want them to be involved = 26 (26%)	I did not want them to be involved = 18 (27%)	I did not want them to be involved = 8 (25%)
	I did not have family or friends to be involved = 5 (5%)	I did not have family or friends to be involved = 3 (4%)	I did not have family or friends to be involved = 2 (6%)
Staff Responsiveness			

After you pressed the call button, how often did you get help as soon as you wanted it?	Never = 6 (6%)	Never = 5 (7%)	Never = 1 (3%)
	Sometimes = 22 (22%)	Sometimes = 19 (28%)	Sometimes = 3 (9%)
	Usually = 20 (20%)	Usually = 17 (25%)	Usually = 3 (9%)
	Always = 49 (49%)	Always = 26 (38%)	Always = 23 (72%)
	Never pressed = 3 (3%)	Never pressed = 1 (2%)	Never pressed = 2 (6%)
How often did you get help in getting to the bathroom or in using a bedpan as soon as you wanted?	Never = 1 (5%)	Never = 1 (6%)	Never = 0 (0%)
	Sometimes = 4 (20%)	Sometimes = 4 (22%)	Sometimes =0 (0%)
	Usually = 4 (20)	Usually = 4 (22%)	Usually = (0%)
	Always = 11 (55)	Always = 9 (50%)	Always = 2 (100%)
Internal Coordination of Care			
Do you feel that there is good communication about your care between doctors, nurses and other hospital staff?	Never = 5 (5)	Never = 5 (7%)	Never = 0 (0%)
	Sometimes = 13 (13)	Sometimes = 10 (15%)	Sometimes = 3 (9%)
	Usually = 14 (14)	Usually = 14 (21%)	Usually = 0 (0%)
	Always = 68 (68)	Always = 39 (57%)	Always = 29 (91%)
Cleanliness			
How often are your room and bathroom kept clean?	Never = 1 (1%)	Never = 1 (1%)	Never = 0 (0%)
	Sometimes = 6 (6%)	Sometimes = 5 (7%)	Sometimes = 1 (3%)
	Usually = 11 (11%)	Usually = 10 (15%)	Usually = 1 (3%)
	Always = 82 (82%)	Always = 52 (77%)	Always = 30 (94%)

Discharge Planning			
During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?	No = 2 (15%)	No = 2 (18%)	No = 0 (0%)
	Yes = 11 (85%)	Yes = 9 (82%)	Yes = 2 (100%)
During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?	No = 2 (15%)	No = 2 (18%)	No = 0 (0%)
	Yes = 11 (85%)	Yes = 9 (82%)	Yes = 2 (100%)
Admission Into the Hospital Organized (Direct Admission)			
Was your admission into the hospital organized?	Not at all = 0 (0%)	Not at all = 0 (0%)	Not at all = 0 (0%)
	Partly =2 (29%)	Partly = 2 (33%)	Partly = 0 (0%)
	Quite a bit = 0 (0%)	Quite a bit = 0 (0%)	Quite a bit = 0 (0%)
	Completely = 5 (71%)	Completely = 4 (67%)	Completely = 1 (100%)
Coordination of Tests and Procedures			
How often were tests and procedures done when you were told they would be done?	Never = 6 (6%)	Never = 5 (7%)	Never = 1 (3%)
	Sometimes = 16 (16%)	Sometimes = 13 (19%)	Sometimes = 3 (9%)
	Usually = 19 (19%)	Usually = 17 (25%)	Usually = 2 (6%)
	Always = 59 (59%)	Always = 33 (49%)	Always = 26 (81%)
Quietness			
How often is the area around your room quiet at night?	Never = 3 (3%)	Never = 3 (4%)	Never = 0 (0%)
	Sometimes = 7 (7%)	Sometimes = 5 (7%)	Sometimes = 2 (6%)
	Usually = 15 (15%)	Usually = 12 (18%)	Usually = 3 (9%)
	Always = 75 (75%)	Always = 48 (71%)	Always = 27 (84%)

Received Information About Condition and Treatment			
Did you get all the information you needed about your condition and treatment?	Never = 2 (2%)	Never = 2 (3%)	Never = 0 (0%)
	Sometimes = 9 (9%)	Sometimes = 7 (10%)	Sometimes = 2 (6%)
	Usually = 18 (18%)	Usually = 16 (24%)	Usually = 2 (6%)
	Always = 71 (71%)	Always = 43 (63%)	Always = 28 (88%)
Transfer From ED to Hospital Bed Organized (Admission Through ED)			
Was your transfer from the emergency department into a hospital bed organized?	Not at all = 1 (1%)	Not at all = 1 (2%)	Not at all = 0 (0%)
	Partly = 1 (1%)	Partly = 1 (2%)	Partly = 0 (0%)
	Quite a bit = 3 (3%)	Quite a bit = 3 (5%)	Quite a bit = 0 (0%)
	Completely = 84 (94%)	Completely = 54 (91%)	Completely = 30 (100%)
Waiting Too Long in the ED for a Hospital Bed (Admission Through ED)			
After you knew that you needed to be admitted to a hospital bed, did you have to wait too long before getting there?	No = 44 (51%)	No = 29 (50%)	No = 15 (52%)
	Yes = 43 (49%)	Yes = 29 (50%)	Yes = 14 (48%)
Enough Information Given About Admission Process, Prior to Arrival (Direct Admission)			
Before coming to the hospital, did you have enough information about what was going to happen during the admission process?	Not at all = 1 (14%)	Not at all = 1 (17%)	Not at all = 0 (0%)
	Partly = 1 (14%)	Partly = 1 (17%)	Partly = 0 (0%)
	Quite a bit = 1 (14%)	Quite a bit = 1 (17%)	Quite a bit = 0 (0%)
	Completely = 4 (57%)	Completely = 3 (50%)	Completely = 1 (100%)