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Implementing a Patient Reported Outcome Measure for Patient with Anemia of Chronic Kidney Disease (CKD) in the Outpatient Setting

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Implementing a Patient Reported Outcome Measure for Patient with Anemia of Chronic Kidney Disease (CKD) in the Outpatient Setting

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A DNP project submitted in partial fulfillment of the requirements for
the degree of Doctor of Nursing Practice

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This is to certify that the DNP Project Final Report by

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has been approved by the DNP Project Team on

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Abstract

Title: Implementing a Patient Reported Outcome Measure for Patient with Anemia of Chronic Kidney Disease (CKD) in the Outpatient Setting.

Introduction: Chronic kidney disease (CKD) is a growing public health concern in the United States. People with CKD suffer from many symptoms that cause distress and low quality of life (QoL). Research has found an association between symptom burden in patients with CKD and the disease's worsening progression. There is little data on ways to monitor and address CKD symptoms routinely.

Purpose: The purpose of this project was to identify symptoms related to advancing kidney disease using patient-reported outcome measures (PROMs) through IPOS-Renal survey and implement a nurse-driven protocol to manage patient reported symptoms.

Interventions/Setting: Over a three-month period at the outpatient nephrology clinic in Boston, Massachusetts, patients completed the IPOS-Renal survey before their appointment with the renal nurse to assess uremic symptoms. Once the IPOS-Renal survey was conducted, the nurse evaluated the survey and implemented the agreed-upon interventions. The patients were then asked to fill out another IPOS-Renal survey before their next visit to see if the interventions were effective and whether they had new symptoms that needed to be addressed.

Evaluation: A total of 23 patients were eligible for the QI project. The final analysis included survey data from nine patients who completed both IPOS-Renal surveys. 50% of patients who reported pain, SOB, nausea, poor appetite, constipation, and, itching had full resolution of symptoms after interventions. Patients with weakness/lack of energy had 40% complete resolution and 20% had symptom improvement. Patients who reported drowsiness, 75% reported complete resolution their symptoms. 40% of paints reported improvement of difficulty sleeping.

100% of patients who reported restless leg syndrome and diarrhea reported resolution of symptoms after interventions.

Discussion: Implementing PROMs is allows for a standardized way to assess, treat, and monitor symptoms associated with CKD and ESRD. The results showed benefits to having a consistent way to evaluate, manage, and monitor symptoms of CKD. This protocol also has the potential to be used as a metric on whether the patient needs to start dialysis.

Problem Identification, Development of Clinical Question, and Evidence Review

Background and Significance of Problem

Chronic kidney disease (CKD) and end-stage renal disease (ESRD) are a growing public health concern in the United States. The Centers for Disease Control (CDC) estimates that 37 million US adults have CKD. It is the ninth leading cause of death. Not only is the number of patients affected by this disease growing, but so is the cost to manage this disease. Medicare spends $84 billion on CKD management and $36 billion on ESRD (Leventhal, 2021). Decreasing the number of patients who progress to ESRD and improving outcomes for people living with CKD can reduce this cost by reducing hospital admissions.

People with CKD and ESRD suffer from many symptoms that cause distress and low quality of life (QoL). These symptoms include fatigue, shortness of breath, pruritus, loss of appetite, sleep disturbances, nausea, vomiting, constipation, low mobility, and lack of energy. According to Brown et al. (2017), there is an association between symptom burden in patients with CKD stages 1-5 and the disease's worsening progression. It is essential to recognize and understand the factors that impact these patients' QoL in treating CKD because interventions could reduce their symptom burden and increase their QoL (Krishnan et al., 2020).

Description of Local Problem

Many patients at a local, non-profit hospital with advanced chronic kidney disease develop anemia due to the lack of production of a hormone called erythropoietin, or EPO. EPO is a hormone released by the kidney that signals the bone marrow to make red blood cells (RBCs) (NIDDK, 2020). After a failed trial with iron supplements, patients with anemia are referred to the renal nurse to receive an erythropoietin-stimulating agent (ESA).

During the ESA appointments, the renal nurses are supposed to assess for uremic and anemia symptoms to monitor their CKD progression. At a local, non-profit hospital, there is no process for the renal nurse to monitor and manage the patient's reported symptoms independently. This leads to inaccuracies in the assessment of those symptoms.

Organization Priority:

This project has the support of the Renal Clinic Director, and Chief of Ambulatory Nephrology. The Medical Specialities director, also supports this initiative. The clinic nephrologists also supported this initiative.

Focused Search Question

In patients with advanced chronic kidney disease (P), how does the use of patient-reported outcome measures through the IPOS-Renal survey (I), compared to not utilizing standardized assessments (C), affect symptom burden and quality of life (O)? This type of PICO question used for this project is intervention. Randomized controlled trials (RCT) and systematic reviews of a single RCT are appropriate for consideration in answering this type of question. Though, given the lack of abundant evidence at this level, lower levels of evidence were used. This evidence consisted of observational studies.

Evidence Search

External Evidence. CINAHL and Medline databases were searched. The keywords searched were chronic kidney disease or chronic renal failure or CKD or ESRD, chronic kidney disease and education, chronic kidney disease and emergent dialysis, chronic kidney disease or chronic renal failure or CKD or ESRD and education, chronic renal failure, or CKD or ESRD and renal replacement therapy, chronic renal failure, or CKD or ESRD and renal replacement therapy and education, and chronic renal failure or CKD or ESRD and patient satisfaction.

Limits and filters for all searches included the English language full-text articles published between 2015 and 2021. See Appendix I; Tables 1 and 2 displace the database, search terms, and research results.

Internal Evidence. The outpatient renal and float nurses were surveyed for their current practices to evaluate their assessment and management of advanced chronic kidney disease and anemia symptoms. It was found that there was no process or procedure in place for the nurse to ask patients about their uremic symptoms. Since there was no process in place, nurses would often forget to ask about each of the uremic symptoms. There was also no system or protocol for the nurses to evaluate, treat, and monitor individual patients' symptoms. The management of the patient's symptoms relied entirely on the physician. These responses from the nurses suggested the need for a standardized nurse-driven protocol to make autonomous care decisions and foster efficiency in care delivery.

Evidence Appraisal, Summary, and Recommendations

Five articles focusing on utilizing patient-reported outcome measures (PROMs) to improve patient outcomes were reviewed. The level of evidence for the five studies was a mix of level one, systematic review or meta-analysis, and level five, cohort studies, see Appendix II for evidence summary. The studies found that PROMs assessments were associated with improved patient satisfaction, increased self-management of chronic disease, decreased symptom burden, enhanced health literacy, and improved quality of life. Additionally, studies found having nurse-led disease management programs in CKD may improve some quality-of-life parameters. The IPOS-Renal survey was chosen as the PROMs tool for this project because it was found to have good test-retest reliability, internal consistency, and construct validity in patients with CKD (Raj et al., 2018), see Appendix XII. Based on this evidence, the recommendation is to implement IPOS-Renal assessment in the outpatient CKD clinic to improve patient care and outcomes.

Project Plan

Project Objectives

1. Reduce symptom burden in patients with CKD stage 4/5 on EPO
2. Improve patient satisfaction with their care
3. Improve patient-provider communication
4. Increase hospital revenue through reimbursements from Medicare and Medicaid

Project Goals

1. Identify symptoms related to advancing kidney disease using PROMs through IPOS-Renal.
2. Implement a nurse-driven protocol to manage patient-reported symptoms.

Context

This non-profit hospital is part of an integrated healthcare system with several nephrology departments. The setting of this quality improvement project would be in an outpatient renal medicine department. Participants will include adult patients with CKD stage IV/V defined as GFR <30 receiving EPO from the renal nurse.

Key Stakeholders

Director of KidneyPal Outpatient Program; Clinical Chief of Renal Division; director of Renal Division; nephrologists of patients receiving EPO. Renal nurse and Float Renal Nurses.

Framework

The Plan-Do-Study-Act cycle is the recommended tool of the Institute for Healthcare Improvement when testing a real work environment change. The PDSA allows for the development of a plan to test the change (Plan), execution of the plan (Do), observations and learnings from the results (Study), and modifications to make the plan more efficient (Act) (IHI, n.d.). As discussed, this project aims to decrease the symptom burden of patients with advanced CKD receiving EPO. The PDSA cycle for this QI project is outlined below (see Appendix III).

Plan Phase. The DNP student met with one of the nephrologist to create a protocol to monitor and manage advancing CKD and anemia symptoms utilizing provider input and approval. The interventions were also sent to the Chief of Ambulatory Nephrology, and the Director of Ambulatory Nephrology. A Smart Phrase was designed in order to standardize documentation for each nurse (Appendix VI). The PROMs, IPOS-Renal, survey was integrated into an electronic version that can be sent to patients via their patient portal. Project goals #1 and #2 will be addressed in this phase.

Do Phase. In this phase, the clinic and float nurses were introduced to the plan and educated on how to use the Smart Phrase, what the plan of care is for each symptom reported, and how to send the survey on the patients' Patient Gateway (PGW) portal by the DNP student. The IPOS-Renal survey will be sent to the PGW portal to fill out prior to their EPO injection appointment. The nurses will review the survey and have an individualized plan of care in place for the patients to review during their EPO appointment. Verbal feedback will be gathered by the DNP student from the renal nurses, providers, and patients on the updated nurse-led protocol.

Study Phase. Process measures include analyzing the IPOS-Renal surveys to compare symptom burden pre- and post-interventions. During the study phase, the DNP student also adjusted the symptom management and clinic processes based on patient and staff feedback.

Act Phase. In this phase, the recommendations would be modified as needed to decrease symptom burden based on provider and patient input. There would also be an adjustment to how the surveys are sent out and interpreted based on nurse and patient feedback.

Barriers to Implementation/Sustainability

Barriers to implementation include increasing appointment time for the patients. This is due to the nurse having the patient complete it during their appointment, assessing the survey, and discussing the treatment modalities with the patient. This also increases the workflow for the nurse, which is not ideal. There is only one full-time nurse in the renal department who also has to triage and answer portal messages. Additional barriers may include training the float nurses to assess the survey results and utilize the Smart Phrases when the regular renal nurse is not there. Another impediment to implementation is that the providers may be unwilling to support a nurse-driven protocol to manage patient symptoms. Providers may also feel under scrutiny for not effectively managing their patients' symptoms (Zhang et al., 2019). Additional implementation challenges include patients' inability to complete the electronic IPOS-Renal survey due to age, computer literacy, access to the internet, and the burden of completing the survey multiple times (Elliot et al., 2019).

Plans to address these deterrents involve creating a paper survey if a patient meets the criteria but does not have Patient Gateway. There were also be plans to educate providers that PROMs individualize patient care and allow for the close monitoring of symptom burden and have been successful in enhancing provider-patient communication and patient satisfaction with care. Furthermore, providers will be reassured they are the individuals who approve the interventions on a patient-to-patient basis. Another way to address these limitations is to assure providers that this will not increase their workload since it is a nurse-driven protocol. Lastly, the float nurses and new renal nurses will be educated on the significance of individualizing patient care and improving patient outcomes, so they are willing to participate in this initiative.

Dissemination

There are many nephrology departments within the integrated healthcare system. Internal and external dissemination of PROMs use in decreasing symptom burden efforts is crucial in facilitating the transfer of the findings from this QI initiative (Melnyk et al., 2019). Every Tuesday and Thursday at MGB, there are Renal Grand Rounds with invited international speakers who discuss current clinical research in nephrology (BWH, n.d.). During the Grand Rounds, an EBP presentation demonstrating the effects and outcomes of utilizing PROMs to monitor symptom burden and implement modalities based on results would be highlighted (Cullen et al., 2017). The presentation of these findings on a platform as wide-reaching as the Renal Grand Rounds would disseminate the information and provide others with resources to utilize and implement this practice in their organization.

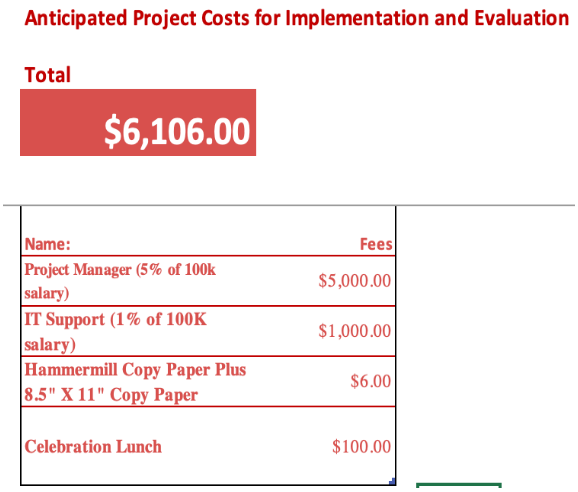
MGB's weekly newsletters will also serve an essential role in conveying the findings to other departments. A brief summary of project findings will be mentioned in this newsletter to report the QI initiative's pilot results to help gain other units' interest (Cullen et al., 2017). Increased visibility would allow every employee to monitor the initiative's effectiveness in the outpatient CKD clinic. At the end of the newsletter, the project leader and supervisor's contact information would be listed for employees to reach out for more details.

Estimated Timeline

The project timeline begins with completing the project proposal draft, completing the DNP project proposal to present to stakeholders, obtaining their approval to implement the project, implementing the project in the renal clinic, adjusting the project based on the PDSA cycle, tracking outcome measures, and ends with presenting and submitting the final DNP project, see Appendix IV for estimated dates.

Resources

Table III describes the anticipated costs of project implementation and evaluation. The Project Manager will spend approximately 5% of time managing the entire project over four months, about 24 hours per month. The duties fulfilled by the Project Manager include implementation of the project, creation of a plan of care document, data collection, creating a Red Cap survey to track data, training of nurses, and evaluating survey responses. The IT support will spend 1% of time helping to guide DNP students through making Smart Phrases for documentation, survey support, and Red Cap support. Additional support includes printing the IPOS-Renal surveys for patients who meet the criteria but do not have a patient portal activated to complete surveys.



Anticipated Project Costs for Implementation and Evaluation

Total

$6,106.00

Name:	Fees
Project Manager (5% of 100k salary)	$5,000.00
IT Support (1% of 100K salary)	$1,000.00
Hammermill Copy Paper Plus 8.5" X 11" Copy Paper	$6.00
Celebration Lunch	$100.00

Review for Ethical Consideration

Quality improvement projects are not required to obtain IRB (Institutional Review Board) review by the hospital, per their Clinical Quality Improvement/Measurement Checklist, see Appendix V. This project was deemed as a QI project buy the Ambulatory Nursing Director, Rossana Encalada, DNP, RN, NEA-BC.

Project Implementation

Create Awareness and Interest

In phase I of the implementation strategy, it is essential to highlight the advantages and anticipated impact of the quality improvement initiative (Cullen et al., 2017). Currently, at the hospital, the renal nurse monitors the progression of the patients' chronic kidney disease and anemia symptoms by asking them questions at every appointment. However, the renal nurse cannot provide treatment modalities to help alleviate those symptoms. Additionally, the providers at the hospital are only in the clinic 1-2 days a week, so non-emergent messages may take up to 72 hours to receive a response. The potential stakeholders would be made aware of this fact during the presentation. The positive aspects of implementing a nurse-based protocol to handing CKD symptoms would be brought to the stakeholders' attention. Some favorable aspects would be having the nurse monitor the patient's symptoms at every EPO appointment to implement care that would help alleviate the patient's symptoms, which will increase the patient's satisfaction with their care.

Highlighting the anticipated impact of increased patient satisfaction will increase profitability through reimbursements from Medicare and Medicaid. This incentivizes greater buy-in from hospital administration (Richter & Muhlestein, 2017). Medicare and Medicaid have moved to value-based programs and reimburse providers for providing quality care to patients (CMS, 2020). One metric that Medicare and Medicaid use to measure health care quality is patient satisfaction, which would relate to this quality improvement initiative.

Build Knowledge and Commitment

Phase II of the implementation strategy builds knowledge and commitment through education and links the project to stakeholder priorities (Finger, 2020). During monthly nursing huddles, the float nurses would be educated on the importance of evaluating the IPOS-Renal survey and using the Smart Sets to help manage their patients' symptoms. This discussion would identify gaps in the current practices and highlight the float nurses' roles in this process (Cullen, 2015).

Along with providing the education, there would also be face-to-face training for the float nurses to review the new material and provide feedback to the primary renal nurse. Including all the nurses in the project refinement process will increase ownership and engagement in this initiative. According to Mathieson, Grande, and Luker (2018), when nurses deem evidence-based practice beneficial and can envision a positive impact on the patient, they are more likely to support the implementation.

Linking the project to stakeholder priorities allows for a sense of importance in implementing the practice change (Cullen et al., 2017). Part of the mission statement at this hospital is to improve patient satisfaction scores and patient experience through leadership in compassionate care, scientific discovery, and education (BWH, n.d.). This movement would directly correlate with the quality improvement initiative to improve patient satisfaction through the standardization of education provided to the patient. Recently, the renal clinic employed a renal palliative provider. This provider has expressed interest in updating and improving practices within the renal clinic to add another layer of support to patients by destigmatizing the word "palliative." For example, as CKD progresses, many of the patients receiving EPO report a wide variety of symptoms they are struggling with. However, patients do not want a referral to palliative care because they associate that word with dying. Part of the protocol would include referrals to palliative care, and the patients would be educated on why the referral was being made and the benefits of having this extra layer of support.

Promote Action and Adoption

Reporting progress directly to colleagues and implementing leadership rounds will help aid Phase III's implementation strategy by creating incentives and enthusiasm for adopting the initiative (Cullen et al., 2017). Sending a monthly email to the stakeholders would provide transparency on the impact of this project. The email would include the number of patients who completed the IPOS-Renal survey, their scores, and the scores of the repeat IPOS-Renal survey that would show whether the implementations were leading to a decrease in patient symptom burden.

Utilizing leadership rounds would allow the providers to implement the new practice change, troubleshoot, and reinforce the recent practice change (Cullen et al., 2017). The lead renal nurse and project manager would conduct rounds to assess the float nurses' competency in implementing the new initiative. All questions would be answered, and additional training and direction would be provided if needed. This would support the nurses during the implementation of the quality initiative.

Pursue Integration and Sustained Use

The final phase of the implementation strategy is to pursue integration and sustained use of the practice change (Cullen et al., 2017). Trended results are one way that would be utilized to encourage shared accountability and provide transparency of results (Cullen et al.). Pre/post data would help show the patient symptom burden trends throughout the implementation process. The reports would continue monthly, and stakeholders would be encouraged to provide feedback on the project.

Celebrating progress is one strategy to encourage clinicians to maintain the practice change. It allows the staff involved with the achievement to acknowledge that they partook in making a positive change (AAFP, n.d.). After observing a decrease in symptom burden and improved patient satisfaction, employees would be rewarded with a celebratory luncheon. Food and soft beverages will be provided for the staff who can attend catered by a local restaurant. All stakeholders will be invited to join the celebration.

Evaluation

Process Measures

The process measures include data collected from the electronic medical record (EHR (Electronic Health Record)) to describe the patient population, including eGFR, and whether they are receiving erythropoietin stimulating agent (ESA) for chronic kidney disease. The eligible patients for this QI project included patients 18 years or older, having chronic kidney disease, being seen by the renal nurse for ESA shots that had an eGFR <30 in the outpatient renal medicine clinic. Out of 23 eligible patients, 14 patients completed the pre-IPOS-Renal survey. Out of those 14 patients, nine patients completed the post-IPOS-Renal survey. For the results to be accurate, five pre-surveys were discarded because there would be no data to from the post-intervention IPOS-Renal survey to compare against.

Outcome Measures

According to the IHI (n.d.), the process measures are used to indicate how well an intervention is functioning and adhering to the model that it is based on. For this quality improvement project, the process measures are the IPOS-Renal survey before the interventions are incorporated into the patients' care plan compared to the post-IPOS-Renal survey. The renal nurse evaluated both surveys to assess whether there were improvements in the patients' symptom burden based on the interventions implemented by the nurse. In the pre-intervention survey, the most reported symptoms were weakness/lack of energy and difficulty sleeping (n=5). In the post-survey, the most reported symptom was weakness/lack of energy (n=5). Of the write-in area of the IPOS-Renal survey (n=18), there were 61.1% of missing answers, see Appendix VIII. 83.3% of patients reported they have had as much information as they wanted, 11.1% of patients wrote sometimes they have as much information as they wanted, and 5.6% of patients reported not at all that they had as much information as they wanted.

When looking at individual symptoms and patient improvement, patients reported pain (n=4) in the pre-intervention 50% of patients reported an improvement in their pain after interventions; see appendix VI for interventions applied to the patients. The other 50% report they had complete resolution of their pain at the next visit when comparing pain to their first visit.

Looking at the shortness of breath (n=4), 50% of patients had improvement when comparing their pre-intervention survey to post-intervention survey. 25% of patients reported going from moderately affecting them to slighting affecting them. 25% of patients improved from slightly affecting them to not at all. 50% of patients were unchanged in how much shortness of breath influenced them.

Five patients reported weakness/lack of energy during the pre-intervention survey. Of those five patients, 40% reported weakness/lack of energy was not affecting them anymore. 20% had improvement in their weakness/lack of energy reporting on the pre-intervention survey severely affecting them, and on the post-intervention survey, it was moderately affecting them. 40% of patients reported their weakness/lack of energy worsened, going from slightly to moderately.

Of the patients who reported nausea (n=2), 50% conveyed that their nausea was entirely resolved, and 50% reported their nausea stayed consistent. The patient that reported their nausea remained unchanged had other comorbidities affecting it, which may have played a role. One patient also reported vomiting was affecting them slightly in the pre-intervention survey, but there was no improvement in the post-intervention survey. For poor appetite (n=2), 50% of patients reported no change and 50% reported complete resolution. Constipation (n=2), 50% reported full resolution and 50% remained consistent. Patients who reported diarrhea (n=1) on the pre-intervention survey had a complete resolution on the post-intervention survey.

The patient who reported on the pre-intervention survey that they were experiencing dry mouth (n=1) was slightly affecting them over the last week reported it was not at all affecting them on the post-intervention survey. However, two patients in the post-intervention survey reported that they were now experiencing sore/dry mouths.

Of patients who reported drowsiness (n=4), 75% of them reported complete resolution of their symptoms. 25% reported that their drowsiness remained the same after the interventions. Of poor mobility (n=4), 50% reported improvement in their symptoms after interventions. 25% reported worsening symptoms, reporting poor mobility was moderately affecting them over the past week to severely affecting them over the past week. 25% reported no change in mobility. On the post-intervention survey, a patient who reported mobility was not affecting them now reported it was affecting them moderately.

Four patients reported that itching was affecting them. Of those four patients, 50% had resolution of symptoms after interventions. 50% of patients reported no change in their symptoms after interventions. Patients who reported changes in their skin (n=1) reported resolution of symptoms on the post-survey.

Of patients who reported difficulty sleeping (n=5), 40% of patients reported improved symptoms after interventions were applied. 40% of the patients report worsening symptoms, both going from slightly to moderately. 20% of those five patients reported that their symptoms affected them moderately both before and after interventions were applied.

Restless leg syndrome (n=1) reported complete resolution of their restless leg syndrome after interventions were applied. Two patients who reported no restless leg syndrome on the first survey reported it on the follow-up survey.

Table 2.

Symptoms	**Pre-Intervention Survey (n=9)**	**Post-Intervention Survey (n=9)**
Pain	4	2
Shortness of Breath (SOB)	4	3
Weakness/Lack of Energy	5	5
Nausea	2	1
Vomiting	1	1
Poor Appetite	2	1
Constipation	2	1
Sore/Dry Mouth	1	2
Drowsiness	4	1
Poor Mobility	5	4
Itching	4	3
Difficulty Sleeping	5	4
Restless Leg Syndrome	1	2
Changes in Skin	1	0
Diarrhea	1	0

Return of Investment

This project focused on a protocol set to manage patients' CKD and anemia. Overseeing these symptoms as they arise allowed patients to avoid emergency room (ER) visits. After the completion of a chart review, it was found that on average four interventions were applied for each patient who reported a symptom that was bothering them. These interventions included further labs to evaluate their symptoms, additional assessments, non-pharmacologic interventions, or over-the-counter medication recommendations.

Additionally, the average ER visit in the state of Massachusetts costs approximately \$1,000 (Benedict et al., 2021). Suppose all nine patient's symptoms worsened and necessitated a visit to the ER, that would cost the hospital approximately \$9,000. By providing interventions to avoid the ER, after subtracting costs of implementing this project, the hospital would net \$2,893.01 in profits. Positive patient experiences can also lead to a better reputation. If patients are satisfied with the care they are receiving, they are more likely to recommend the hospital to friends and family. This would increase appointments made at this hospital in Boston due to personal referral.

Barriers Encountered During Implementation

One barrier faced was how the patients were completing the survey. The IPOS-Renal survey was meant to be completed electronically before patients' appointments. However, there were barriers to achieving this, such as lack of computer literacy, language barriers, and no patient portal activation. Approximately 29% of patients completed the pre-survey electronically before their appointment, see Table 3. Of the patients who completed the pre-survey, only 11% finished the post-survey. To account for this, if the patient had not filled out their survey prior to their appointment, the nurse would provide them with the survey and offer to complete it with them. This was very time-consuming because the nurse would evaluate the responses then implement the care plan. This increased appointment times by 33%.

Another significant barrier that was experienced in this project was survey fatigue. It was meant to have a survey to re-evaluate patients' symptoms at every visit. However, the patient did not want to keep completing surveys. If the patient had completed more than two surveys, there would have been a better understanding of the effectiveness of the interventions applied to the symptoms. It also caused a small sample size because not all the patients who were eligible completed the survey.

Staffing was also a hurdle during implementation. One primary renal registered nurse ran the project due to the lack of staff in the outpatient renal clinic. The three ambulatory float nurses did not cover the renal clinic during this time. One renal/GI float nurse was hired during this project but felt it was too complex to contribute to before she felt comfortable in the clinic. This limited the amount of support during the project. It also skewed whether this would have been a sustainable project.

Table 3.

How the IPOS-Survey Was Completed

	Pre-IPOS Renal Survey (n=14)	Post-IPOS Renal Survey (n=9)
Assistance from Nurse	4	4
Independent in Clinic Prior to Appt	6	4
Electronically Prior to Appt.	4	1

Dissemination

Implications of Project Results to Organization and Practice

The results demonstrated the benefits of having a nurse-driven protocol to manage chronic kidney disease and anemia symptoms for most symptoms. The surveys help to manage the patients' most bothersome symptoms and assist the provider in knowing when the patient is approaching the need for dialysis. For the initiation of dialysis, nephrologists look at the patients' eGFR and their subjective symptoms. Patients with severe chronic kidney disease show an increase in their subjective symptoms such as SOB, fatigue, muscle cramps, nausea, vomiting, etc. The provider can use that information as rationale data to initiate dialysis.

Sustainability plan

Plans to sustain this QI project include shortening the survey and incorporating this project in the nurse onboarding process. There will be an increase in staffing for the outpatient renal department, so if a new hire is taught this as protocol and procedure, it will be part of their routine. This is very specific to the renal medicine department because there are plans to hire more renal nurses to account for the growing department. Another way to sustain this change would be to complete chart reviews and provide data on how many patients were initiated on dialysis from their IPOS-Renal survey scoring.

Conclusion

Implementing a PROM survey for patients in the renal department has many benefits, such as close monitoring of uremic symptoms to indicate that the start of dialysis is near. Early management of those symptoms to increase patient satisfaction and communication with their providers. Increased revenue from reimbursement of insurance and referrals from increase in satisfied patients with their care.

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Appendix I: Evidence Search

Table 1.
CINAHL Complete Search Terms and Search Results

Search Terms	Number of hits	Number of title & abstract reviewed	Number of full-text articles reviewed	Number of articles selected for this review without duplicates
Chronic kidney disease or chronic renal failure or ckd or esrd	33,379			
Chronic Kidney Disease and Education	395			
Chronic Kidney Disease and Emergent Dialysis	4			
Chronic kidney disease or chronic renal failure or ckd or esrd and education	420			
Chronic kidney disease or chronic renal failure or ckd or esrd and renal replacement therapy	279	50	8	4
Chronic kidney disease or chronic renal failure or ckd or esrd and renal replacement therapy and education	144	60	15	11
chronic kidney disease or chronic renal failure or ckd or esrd and education and patient satisfaction	80	40	10	3

Table 2.

Medline Complete Search Terms and Search Results

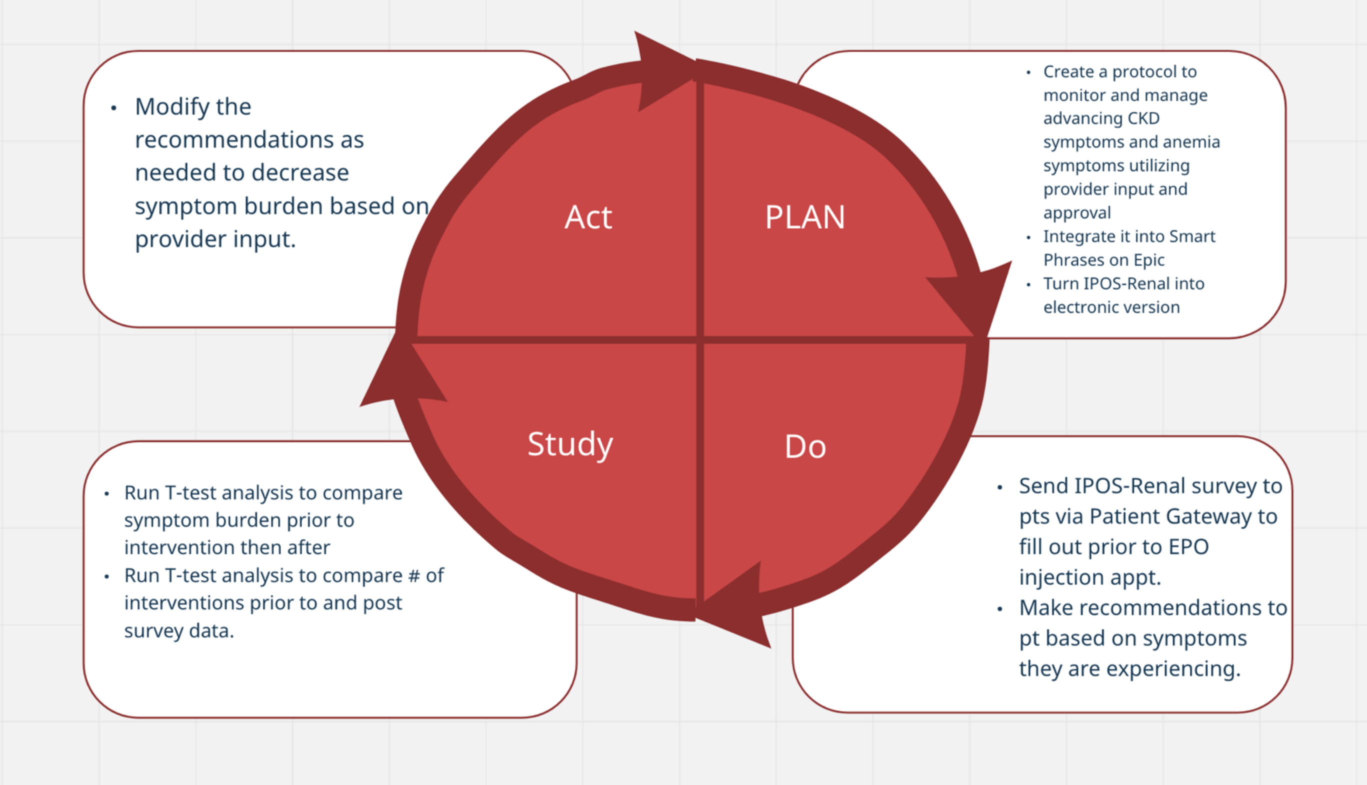
Search Terms	Number of hits	Number of title & abstract reviewed	Number of full-text articles reviewed	Number of articles selected for this review without duplicates
chronic kidney disease or chronic renal failure or CKD or ESRD	137,265			
Chronic Kidney Disease and Education	4,934			
Chronic Kidney Disease and Emergent Dialysis	21	21	4	4
Chronic kidney disease or chronic renal failure or CKD or ESRD and education	2,322	30	5	1
Chronic kidney disease or chronic renal failure or CKD or ESRD and renal replacement therapy	1,793	40	4	2
Chronic kidney disease or chronic renal failure or CKD or ESRD and renal replacement therapy and education	148	60	6	4
chronic kidney disease or chronic renal failure or CKD or ESRD and education and patient satisfaction	31	31	4	2

Appendix II: Evidence Summary

First Author (Year)	Purpose	Level of Evidence/Type of Evidence	Sample/Setting	Major Variables	How Variables were Measured	Findings	Worth t Practic
Article 1:							
Ducharlet (2019)	To examine relationships between symptom burden, QOL (quality of life) and functional status and associations of symptoms and mortality risk	Level 5 A multisite longitudinal cohort analysis	CKD stage 4/5 (no dialysis) and dialysis patients	Symptom burden, QOL, functional status, association of symptoms, and mortality risk	Wilcoxon rank-sum test, Spearman's rank correlation coefficient, Univariate Cox Proportional Hazards, POS-S Renal	Patients with advanced CKD (Including dialysis, patients managed conservatively without dialysis or pre-dialysis) have significant symptom burden associated with reduced self-reported QO	There is reduced sel reporting o symptom burden, so i there were t in place to assess symp burden and QOL, it cou help improv patient satisfaction.
Article 2:							
Aiyegbusi (2017)	To evaluate studies that assessed the measurement properties of PROMs in adults with CKD to see if they are suitable for use in research or clinical practice.	Level 1 Systemic review with or without meta-analysis of randomized control trials	66 articles were used in the final analysis that met the criteria.	Type or PROMs being utilized, the population (dialysis, pre-dialysis, and renal transplant)	COSMIN checklist, Cohen's Kappa Statistic	KDQOL-36 for use in pre-dialysis patients; the KDQOL-SF or KDQOL-36 for dialysis patients and the ESRD-SCLTM for use in transplant recipients.	This is goo know, so if want to sta utilizing PROMs in practice, th provider sh utilize the specific PROMs to match the population.
Article 3:							
Havas (2017)	To evaluate the benefits of patient-centered care in CKD patients	Level 5 Cross-sectional	Patients with CKD Cross-sectional survey identified 10 areas that those with CKD believe require additional support. Descriptive data were generated, and Mann-Whitney U tests were performed	CKD, patient reported symptoms, desire for	SPSS version 22. Continuous data are presented as median (interquartile range; IQR). As data failed assumptions of t-tests, non-parametric	Participants reported desiring more support with all 10 aspects of self-management, with the most would like self-management of developing and sustaining a positive	This article showed tha CKD pts require additional support acr the self-managemen spectrum, s providers should try a include/eng the patient become act

			to compare the desires of diverse groups of participants.		Mann-Whitney U tests were used.	attitude and caring for mental and physical wellbeing.	parts of thei healthcare t while empowering them with t knowledge do so.
Article 4:							
Örsal (2019)	To examine the relationships between health literacy, primary care satisfaction levels and health awareness of the patients who were admitted to primary care centers	Level 5 Cross-sectional	cross-sectional study conducted on individuals who were admitted to Family Health Centers	Health awareness and satisfaction, health literacy	Turkish Health Literacy Scale (HLS-TR), Index score calculation for matrix components, Cronbach Alpha coefficient	The patients with an elevated level of satisfaction from physicians, healthcare and health centers have a higher health literacy level than those who have a lower level of satisfaction.	This is an important finding beca providers should be trying to improve patients' he literacy to h encourage t to be active partners in t healthcare team. Also, Medicare ar Medicaid moved to a value-based reimbursem so improvin health litera will also improve pat satisfaction scores.
Article 5:							
Peng (2019)	To investigate whether self-management intervention improves renoprotection for non-dialysis chronic kidney disease	Level 1 Systematic review with meta-analysis of RCT	19 studies with a total of 2540 CKD patients and a mean follow-up of 13.44 months.	Self-management intervention (lifestyle modifications, medical-behavior modifications, and multi-factorial modifications and CKD progression.	Cochrane Q statistic and an I^2 test, funnel plot, Egger's linear regression test for dichotomous data or Harbord's test for continuous data.	Self-management intervention was beneficial for changing modifiable risk factors (e.g., proteinuria, blood pressure level, blood glucose level, exercise capacity) for the progression of CKD	Providers ca utilize this article to he educate pat on modifiab risk factors help slow th progression CKD.

Appendix III: PDSA Cycle



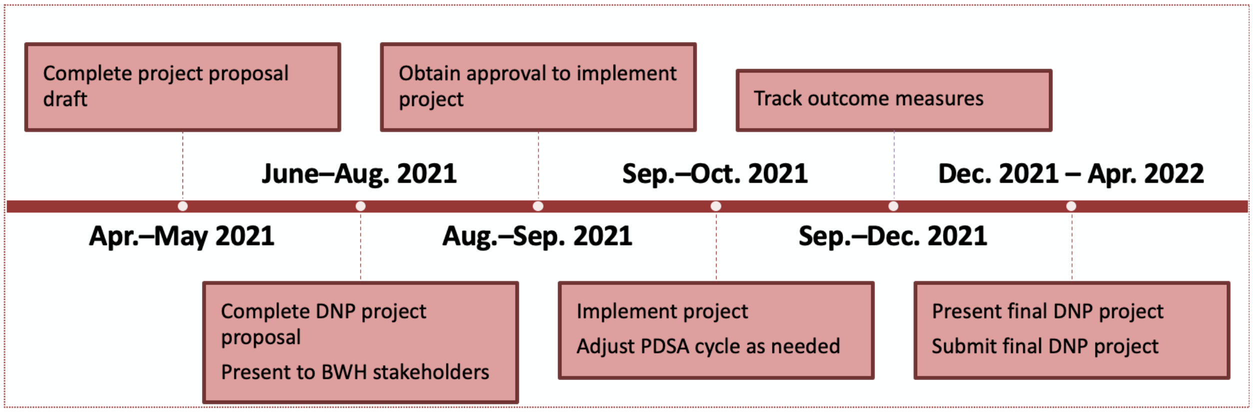
- Create a protocol to monitor and manage advancing CKD symptoms and anemia symptoms utilizing provider input and approval
- Integrate it into Smart Phrases on Epic
- Turn IPOS-Renal into electronic version

- Send IPOS-Renal survey to pts via Patient Gateway to fill out prior to EPO injection appt.
- Make recommendations to pt based on symptoms they are experiencing.

- Run T-test analysis to compare symptom burden prior to intervention then after
- Run T-test analysis to compare # of interventions prior to and post survey data.

- Modify the recommendations as needed to decrease symptom burden based on provider input.

Appendix IV: Project Timeline



Apr.–May 2021

Complete project proposal draft

June–Aug. 2021

Complete DNP project proposal

Present to BWH stakeholders

Aug.–Sep. 2021

Obtain approval to implement project

Sep.–Oct. 2021

Implement project

Adjust PDSA cycle as needed

Sep.–Dec. 2021

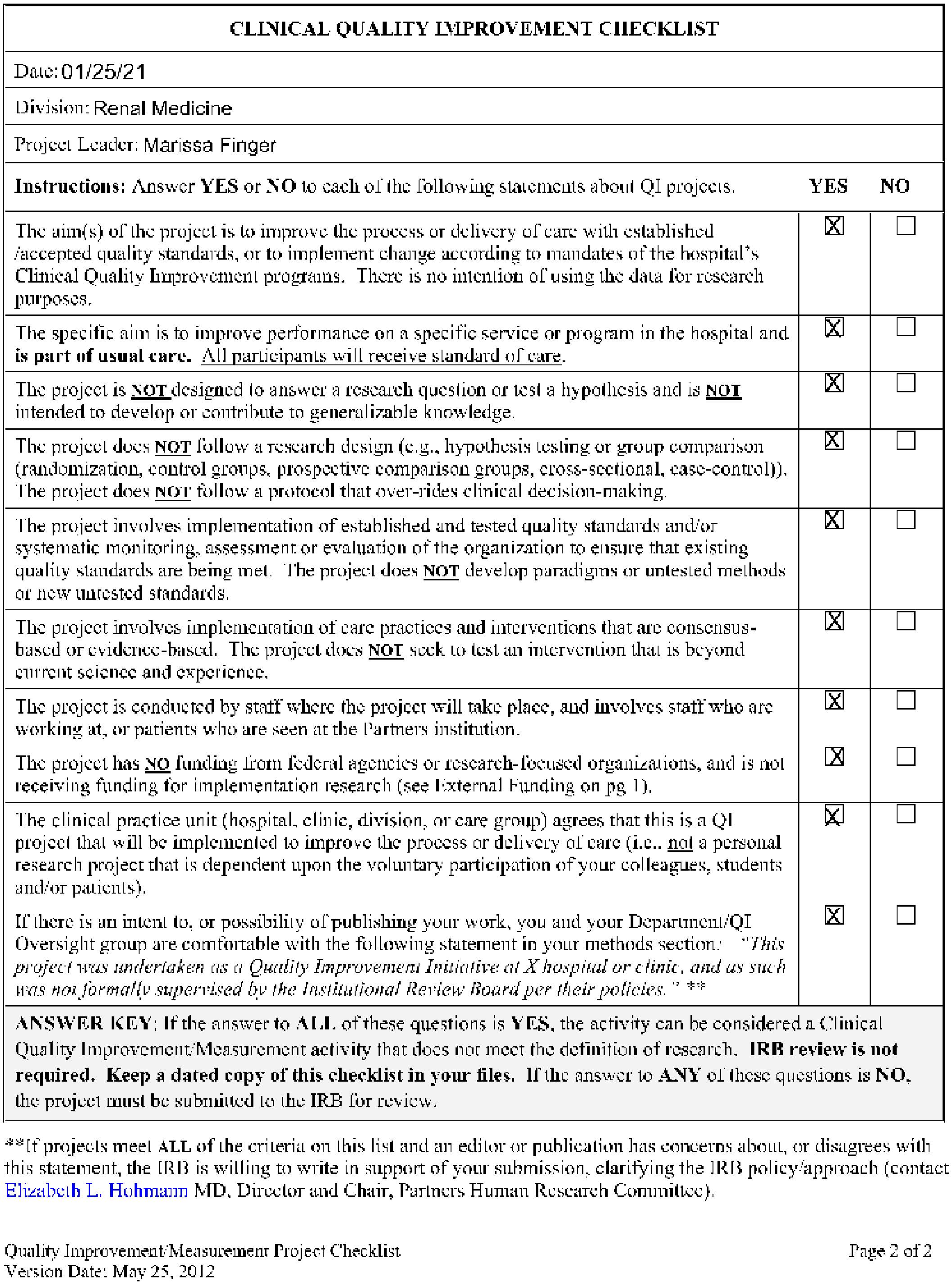
Track outcome measures

Dec. 2021 – Apr. 2022

Present final DNP project

Submit final DNP project

Appendix V: Clinical QI Checklist



CLINICAL QUALITY IMPROVEMENT CHECKLIST

Date: 01/25/21

Division: Renal Medicine

Project Leader: Marissa Finger

Instructions: Answer **YES** or **NO** to each of the following statements about QI projects.	**YES**	**NO**
The aim(s) of the project is to improve the process or delivery of care with established /accepted quality standards, or to implement change according to mandates of the hospital's Clinical Quality Improvement programs. There is no intention of using the data for research purposes.	☒	☐
The specific aim is to improve performance on a specific service or program in the hospital and **is part of usual care.** All participants will receive standard of care.	☒	☐
The project is **NOT** designed to answer a research question or test a hypothesis and is **NOT** intended to develop or contribute to generalizable knowledge.	☒	☐
The project does **NOT** follow a research design (e.g., hypothesis testing or group comparison (randomization, control groups, prospective comparison groups, cross-sectional, case-control)). The project does **NOT** follow a protocol that over-rides clinical decision-making.	☒	☐
The project involves implementation of established and tested quality standards and/or systematic monitoring, assessment or evaluation of the organization to ensure that existing quality standards are being met. The project does **NOT** develop paradigms or untested methods or new untested standards.	☒	☐
The project involves implementation of care practices and interventions that are consensus-based or evidence-based. The project does **NOT** seek to test an intervention that is beyond current science and experience.	☒	☐
The project is conducted by staff where the project will take place, and involves staff who are working at, or patients who are seen at the Partners institution.	☒	☐
The project has **NO** funding from federal agencies or research-focused organizations, and is not receiving funding for implementation research (see External Funding on pg 1).	☒	☐
The clinical practice unit (hospital, clinic, division, or care group) agrees that this is a QI project that will be implemented to improve the process or delivery of care (i.e., not a personal research project that is dependent upon the voluntary participation of your colleagues, students and/or patients).	☒	☐
If there is an intent to, or possibility of publishing your work, you and your Department/QI Oversight group are comfortable with the following statement in your methods section: *"This project was undertaken as a Quality Improvement Initiative at X hospital or clinic, and as such was not formally supervised by the Institutional Review Board per their policies."* **	☒	☐

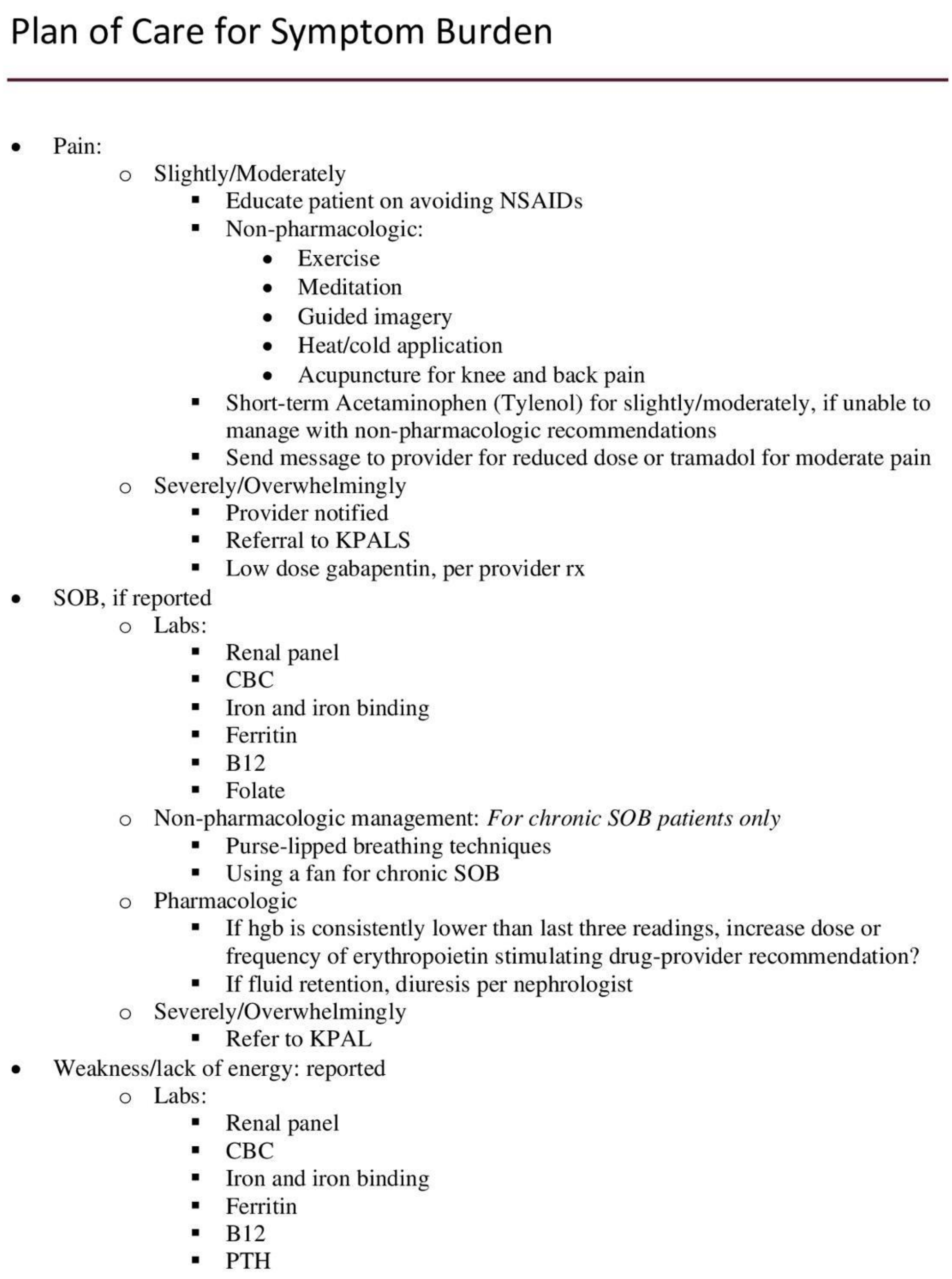
ANSWER KEY: If the answer to **ALL** of these questions is **YES**, the activity can be considered a Clinical Quality Improvement/Measurement activity that does not meet the definition of research. **IRB review is not required. Keep a dated copy of this checklist in your files.** If the answer to **ANY** of these questions is **NO**, the project must be submitted to the IRB for review.

If projects meet **ALL of the criteria on this list and an editor or publication has concerns about, or disagrees with this statement, the IRB is willing to write in support of your submission, clarifying the IRB policy/approach (contact Elizabeth L. Hohmann MD, Director and Chair, Partners Human Research Committee).

Quality Improvement/Measurement Project Checklist
Version Date: May 25, 2012

Page 2 of 2

Appendix VI: Plan of Care for Symptom Burden



Plan of Care for Symptom Burden

- Pain:
  - Slightly/Moderately
    - Educate patient on avoiding NSAIDs
    - Non-pharmacologic:
      - Exercise
      - Meditation
      - Guided imagery
      - Heat/cold application
      - Acupuncture for knee and back pain
    - Short-term Acetaminophen (Tylenol) for slightly/moderately, if unable to manage with non-pharmacologic recommendations
    - Send message to provider for reduced dose or tramadol for moderate pain
  - Severely/Overwhelmingly
    - Provider notified
    - Referral to KPALS
    - Low dose gabapentin, per provider rx
- SOB, if reported
  - Labs:
    - Renal panel
    - CBC
    - Iron and iron binding
    - Ferritin
    - B12
    - Folate
  - Non-pharmacologic management: *For chronic SOB patients only*
    - Purse-lipped breathing techniques
    - Using a fan for chronic SOB
  - Pharmacologic
    - If hgb is consistently lower than last three readings, increase dose or frequency of erythropoietin stimulating drug-provider recommendation?
    - If fluid retention, diuresis per nephrologist
  - Severely/Overwhelmingly
    - Refer to KPAL
- Weakness/lack of energy: reported
  - Labs:
    - Renal panel
    - CBC
    - Iron and iron binding
    - Ferritin
    - B12
    - PTH

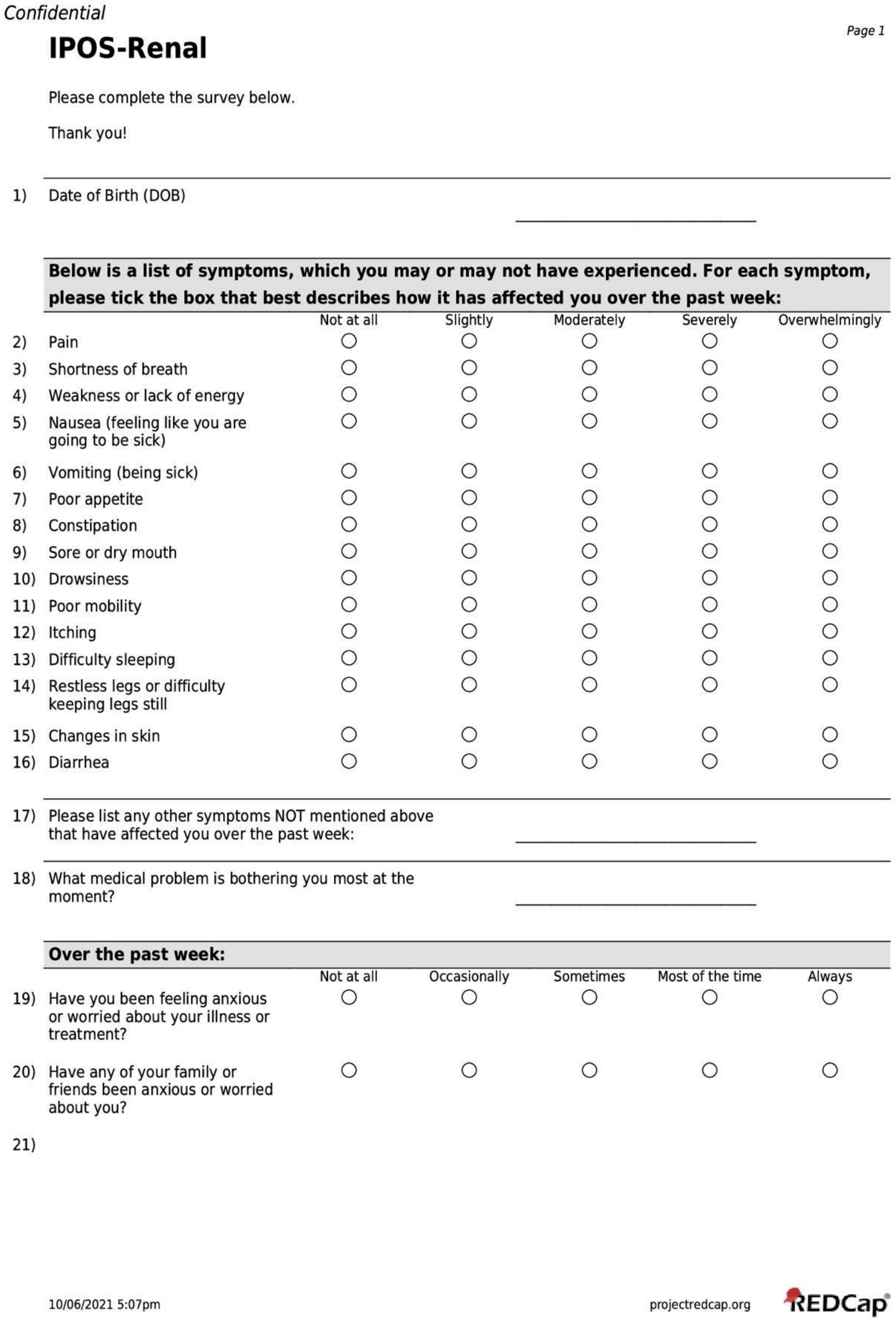
    - CRP
  - Assessment:
    - S/S of depression
      - Screen using PHQ-2 (if yes) then PHQ-9
        - If they score, instant referral to KPAL?
      - Exercise, relaxation techniques, massage, cognitive behavioral therapy
    - Sleep patterns
    - Dietary intake
  - Non-pharmacologic management:
    - Refer to dietician for a renal meal plan
    - Educate on proper sleep hygiene
      - Following a sleep schedule
      - Unplug electronic 30-60 minutes prior to bedtime
      - 30-minute wind down prior to bed
      - Regular exercise
      - Avoid smoking/afternoon caffeine/alcohol
    - Regular exercise
- Nausea/Vomiting
  - Non-pharmacological strategies
    - Reduce or eliminate potentially nauseating stimuli (e.g., spicy, strong-smelling and high fat foods)
    - Encourage a trial of cold, bland foods instead.
    - Try using ginger products (e.g., tea, tablet, ginger ale, cookies, candied ginger).
    - Eat frequent small, high calorie meals and snacks – hunger can make feelings of nausea stronger.
    - Sit upright or recline with head elevated for 30-60 min after meals.
    - Good oral hygiene – can help reduce unpleasant mouth taste contributing to nausea.
    - Wear loose clothing.
    - Apply a cool damp cloth on neck or forehead if very nauseous.
    - Consider relaxation, imagery, acupressure, acupuncture.
  - Pharmacologic if severe/overwhelmed:
    - Referral to KPAL
    - Ondansetron, per provider rx
- Poor appetite
  - Non-pharmacologic management:
    - Try to eat meals even if you are not hungry.
    - Consume four to six small meals or snacks every day.
    - Cool or cold foods might taste better than hot or warm ones.
    - For adequate protein intake, eat high-protein foods (eggs, meat, fish, poultry) first.
    - Use calorie and protein supplements if needed.
      - Nephro shakes

  - Pharmacologic:

- Constipation:
    - Assessment
        - Complete med rec to look for medications that may be aiding in constipation
    - Non-pharmacologic:
        - Increase hydration-2L to avoid dehydration
        - Increase dietary fiber/supplements
            - fiber supplementation significantly increased stool frequency from 1.4 ± 0.2 to 1.9 ± 0.3 times/day
        - Increase physical activity
        - A meta-analysis by Dimidi et al. revealed that probiotics reduced the whole-gut transit time in non-CKD patients by 12 hours and increased stool frequency by 1.3 times/week
    - Pharmacologic
        - Osmotic laxatives-Reduced dose of MiraLAX
- Dry or Sore Mouth
    - Assessment:
        - Oral assessment to look for lesions
    - Non-pharmacologic
        - Saline spray
        - Ice
        - Chewing gum, if appropriate.
        - Sugar-free hard candies
        - Proper dental hygiene
        - Dental cleaning q 4-6 months
- Drowsiness
- Poor Mobility
    - Assessment
        - ‘Get Up and Go’
    - Non-pharmacological Management:
        - Exercises
        - SMART Goals for exercise
        - Referral to PT
- Pruritus
    - Labs:
        - PTH
        - Calcium
        - Phos
        - Renal function
    - Non-pharmacological Management:
        - Showering every other day
        - Applying Sarna lotion
        - Low phos diet-if phos is elevated
    - Severely/overwhelmingly:
        - Pharmacologic
            - Refer to KPAL
            - 1-week trial with antihistamines

            - Hydroxyzine 25 mg po TID or diphenhydramine 25 mg po TID
                - Sedating
            - Less sedating option: Loratadine during the day then sedating at night
        - Low dose gabapentin with failed one-week trial
        - Sertraline 35 mg (Kobrin, 2019)
- Difficulty sleeping
    - Non-pharmacologic Management:
        - Educate on proper sleep hygiene
            - Following a sleep schedule
            - Unplug electronic 30-60 minutes prior to bedtime
            - 30-minute wind down prior to bed
            - Regular exercise
            - Avoid smoking/afternoon caffeine/alcohol
            - Limit daytime napping
            - Take diuretics in the AM
    - Pharmacologic:
        - OTC melatonin 3 mg (Maung et al., 2016).
    - Referral:
        - Possibly a referral for a sleep study to be eval for sleep apnea
        - Possibly refer for CBT
- Restless Leg Syndrome (RLS)
    - Labs:
        - CBC
        - Iron and iron binding
        - Ferritin
    - Non-pharmacologic:
        - Aerobic exercise and resistance training
    - Pharmacologic
        - Correcting iron deficiency
        - Referral to KPAL
            - Gabapentin
- Diarrhea:
    - Labs:
        - BMP
        - Mag
    - Non-pharmacologic:
        - Bland diet
        - Hydration

Appendix XII: IPOS-Renal Survey



Confidential

Page 1

IPOS-Renal

Please complete the survey below.

Thank you!

1) Date of Birth (DOB) ____________________________

Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week:

		Not at all	Slightly	Moderately	Severely	Overwhelmingly
2)	Pain	○	○	○	○	○
3)	Shortness of breath	○	○	○	○	○
4)	Weakness or lack of energy	○	○	○	○	○
5)	Nausea (feeling like you are going to be sick)	○	○	○	○	○
6)	Vomiting (being sick)	○	○	○	○	○
7)	Poor appetite	○	○	○	○	○
8)	Constipation	○	○	○	○	○
9)	Sore or dry mouth	○	○	○	○	○
10)	Drowsiness	○	○	○	○	○
11)	Poor mobility	○	○	○	○	○
12)	Itching	○	○	○	○	○
13)	Difficulty sleeping	○	○	○	○	○
14)	Restless legs or difficulty keeping legs still	○	○	○	○	○
15)	Changes in skin	○	○	○	○	○
16)	Diarrhea	○	○	○	○	○

17) Please list any other symptoms NOT mentioned above that have affected you over the past week: ____________________________

18) What medical problem is bothering you most at the moment? ____________________________

Over the past week:

		Not at all	Occasionally	Sometimes	Most of the time	Always
19)	Have you been feeling anxious or worried about your illness or treatment?	○	○	○	○	○
20)	Have any of your family or friends been anxious or worried about you?	○	○	○	○	○

21)

10/06/2021 5:07pm

projectredcap.org REDCap®

	Have you been feeling depressed?	○	○	○	○	○
		Always	Most of the time	Sometimes	Occasionally	Not at all
22)	Have you felt at peace?	○	○	○	○	○
23)	Have you been able to share how you are feeling with your family or friends as much as you want?	○	○	○	○	○
24)	Have you had as much information as you wanted?	○	○	○	○	○

		Problems addressed/no problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
25)	Have any practical problems resulting from your illness been addressed (financial/personal)	○	○	○	○	○

		None at all	Up to half a day wasted	More than half a day wasted
26)	How much time do you feel had been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests?	○	○	○

27) Are you able to do everything that you would like to do or is your disease limiting you in some way? ______________________________

		On my own	With help from a friend or relative	With help from a member of staff
28)	How did you complete this questionnaire?	○	○	○

Appendix XIII: All Data with No Distinction Between Pre/Post Survey

Data Exports, Reports, and Stats

All data (all records and fields)

Name: *(name)*

Total Count (N)	Missing*
18	0 (0.0%)

Date of Birth (DOB) *(dob)*

Total Count (N)	Missing*
18	0 (0.0%)

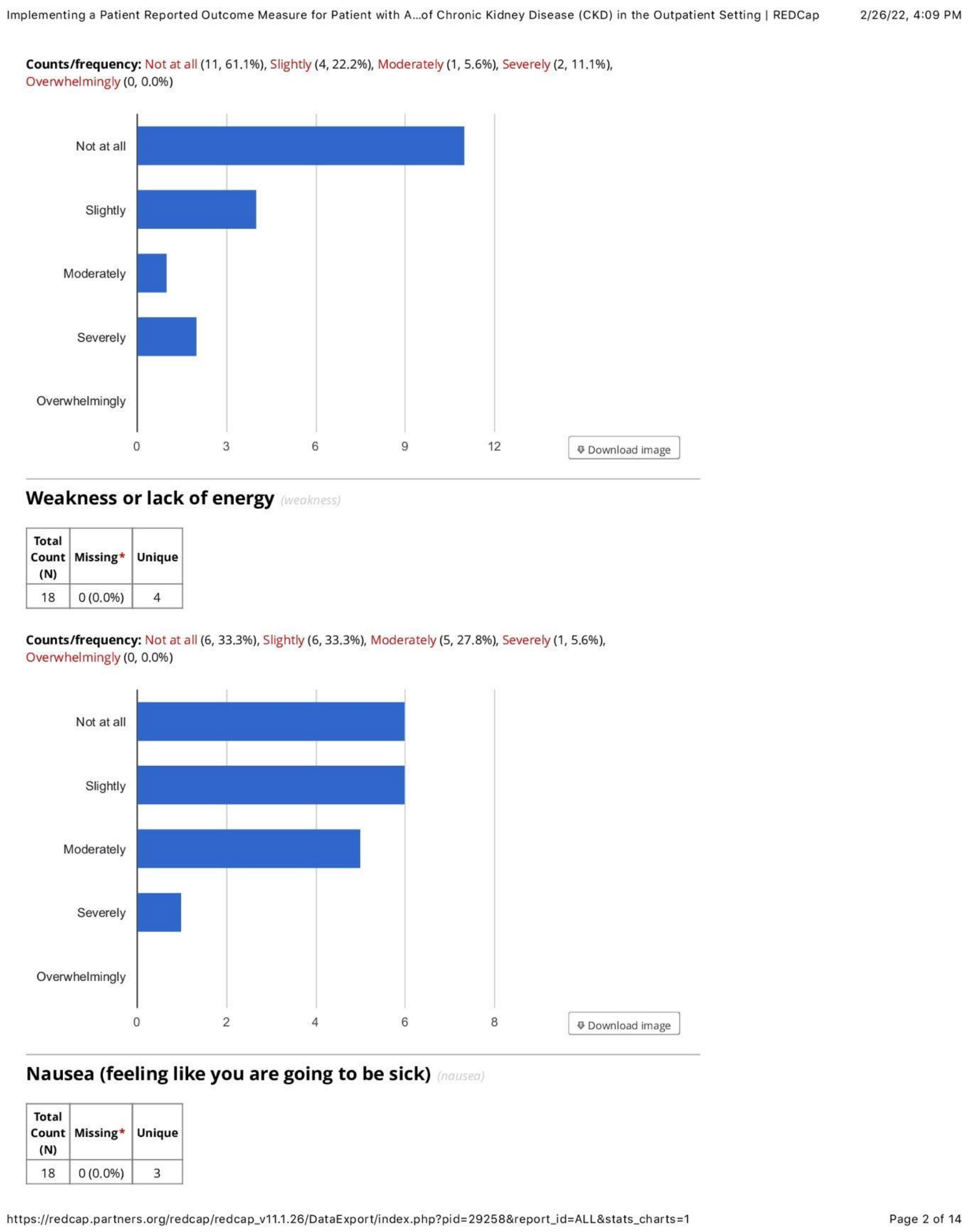
Pain *(pain)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	3

Counts/frequency: Not at all (12, 66.7%), Slightly (4, 22.2%), Moderately (0, 0.0%), Severely (2, 11.1%), Overwhelmingly (0, 0.0%)

Shortness of breath *(sob)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	4



Counts/frequency: Not at all (11, 61.1%), Slightly (4, 22.2%), Moderately (1, 5.6%), Severely (2, 11.1%), Overwhelmingly (0, 0.0%)

Weakness or lack of energy *(weakness)*

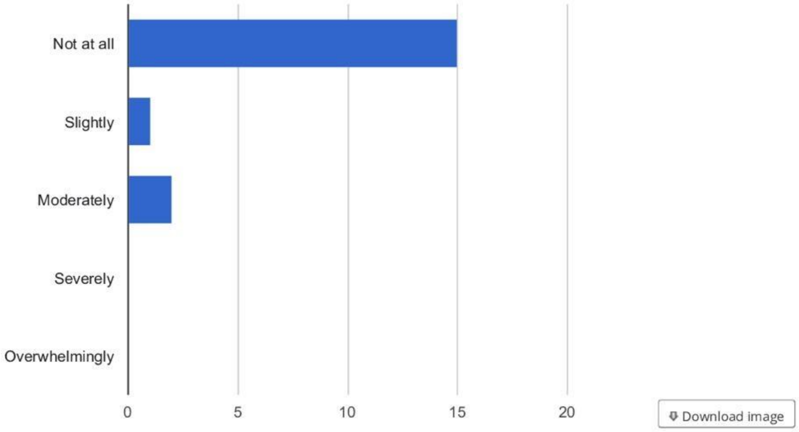
Total Count (N)	Missing*	Unique
18	0 (0.0%)	4

Counts/frequency: Not at all (6, 33.3%), Slightly (6, 33.3%), Moderately (5, 27.8%), Severely (1, 5.6%), Overwhelmingly (0, 0.0%)

Nausea (feeling like you are going to be sick) *(nausea)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	3

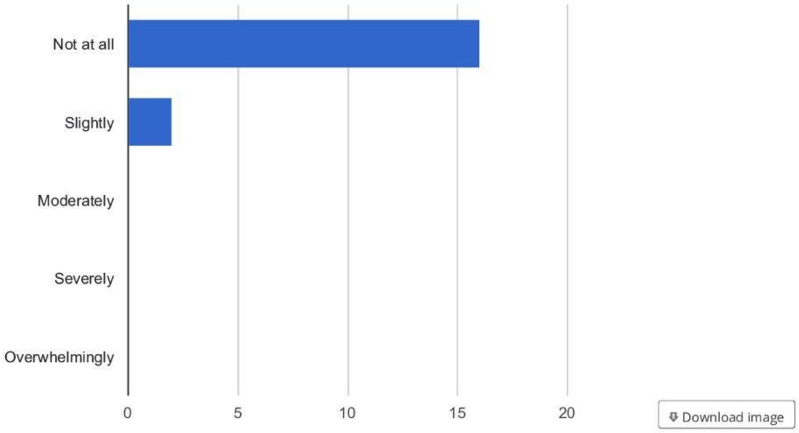
Counts/frequency: Not at all (15, 83.3%), Slightly (1, 5.6%), Moderately (2, 11.1%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



Vomiting (being sick) *(vomiting)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	2

Counts/frequency: Not at all (16, 88.9%), Slightly (2, 11.1%), Moderately (0, 0.0%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)

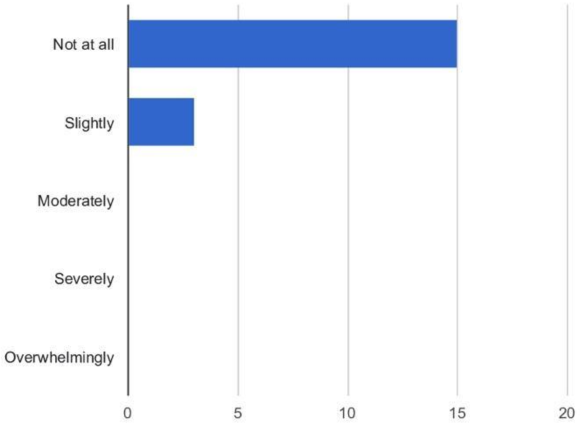


Poor appetite *(poor_app)*

Total Count (N)	Missing*	Unique

18	0 (0.0%)	2

Counts/frequency: Not at all (15, 83.3%), Slightly (3, 16.7%), Moderately (0, 0.0%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



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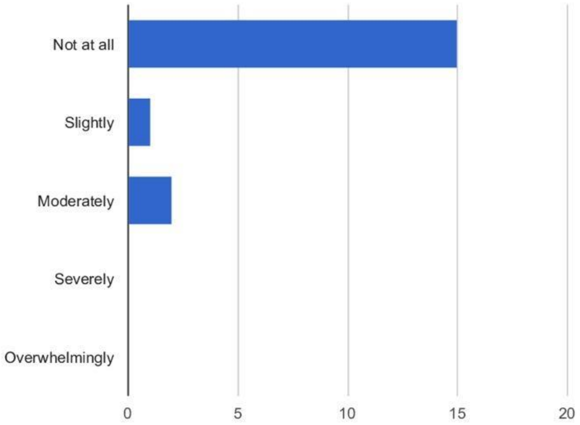
Constipation *(constipation)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	3

Counts/frequency: Not at all (15, 83.3%), Slightly (1, 5.6%), Moderately (2, 11.1%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



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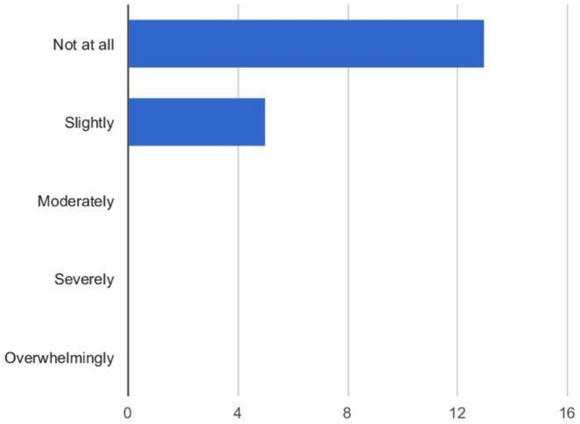
Sore or dry mouth *(mouth)*

Total Count	Missing*	Unique

(N)		
18	0 (0.0%)	2

Counts/frequency: Not at all (13, 72.2%), Slightly (5, 27.8%), Moderately (0, 0.0%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



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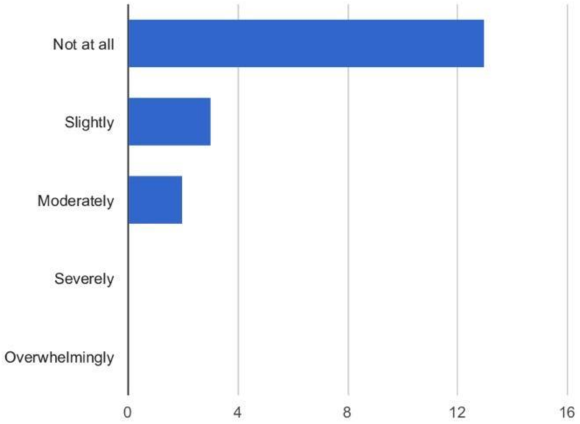
Drowsiness *(drowsiness)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	3

Counts/frequency: Not at all (13, 72.2%), Slightly (3, 16.7%), Moderately (2, 11.1%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



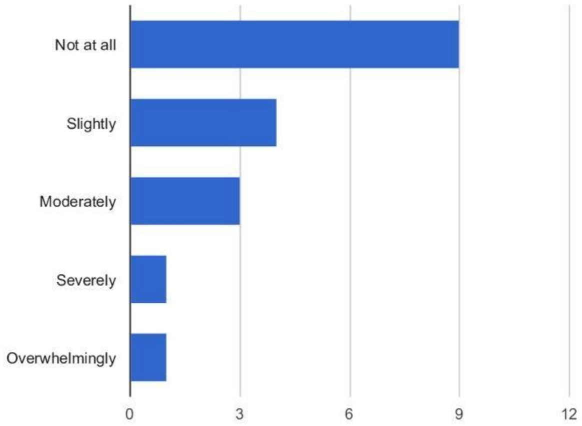
Download image

Poor mobility *(mobility)*

Total		

Count (N)	Missing*	Unique
18	0 (0.0%)	5

Counts/frequency: Not at all (9, 50.0%), Slightly (4, 22.2%), Moderately (3, 16.7%), Severely (1, 5.6%), Overwhelmingly (1, 5.6%)

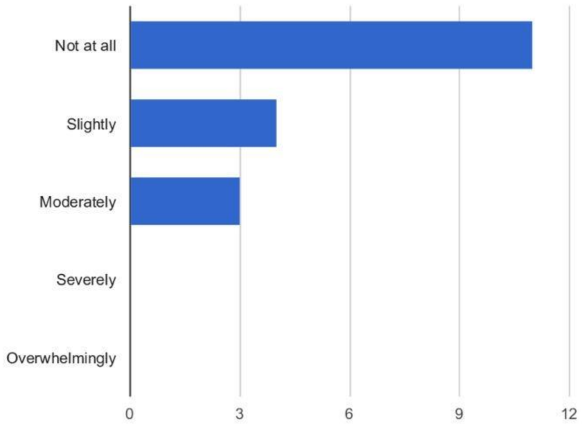


Download image

Itching *(pruritus)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	3

Counts/frequency: Not at all (11, 61.1%), Slightly (4, 22.2%), Moderately (3, 16.7%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



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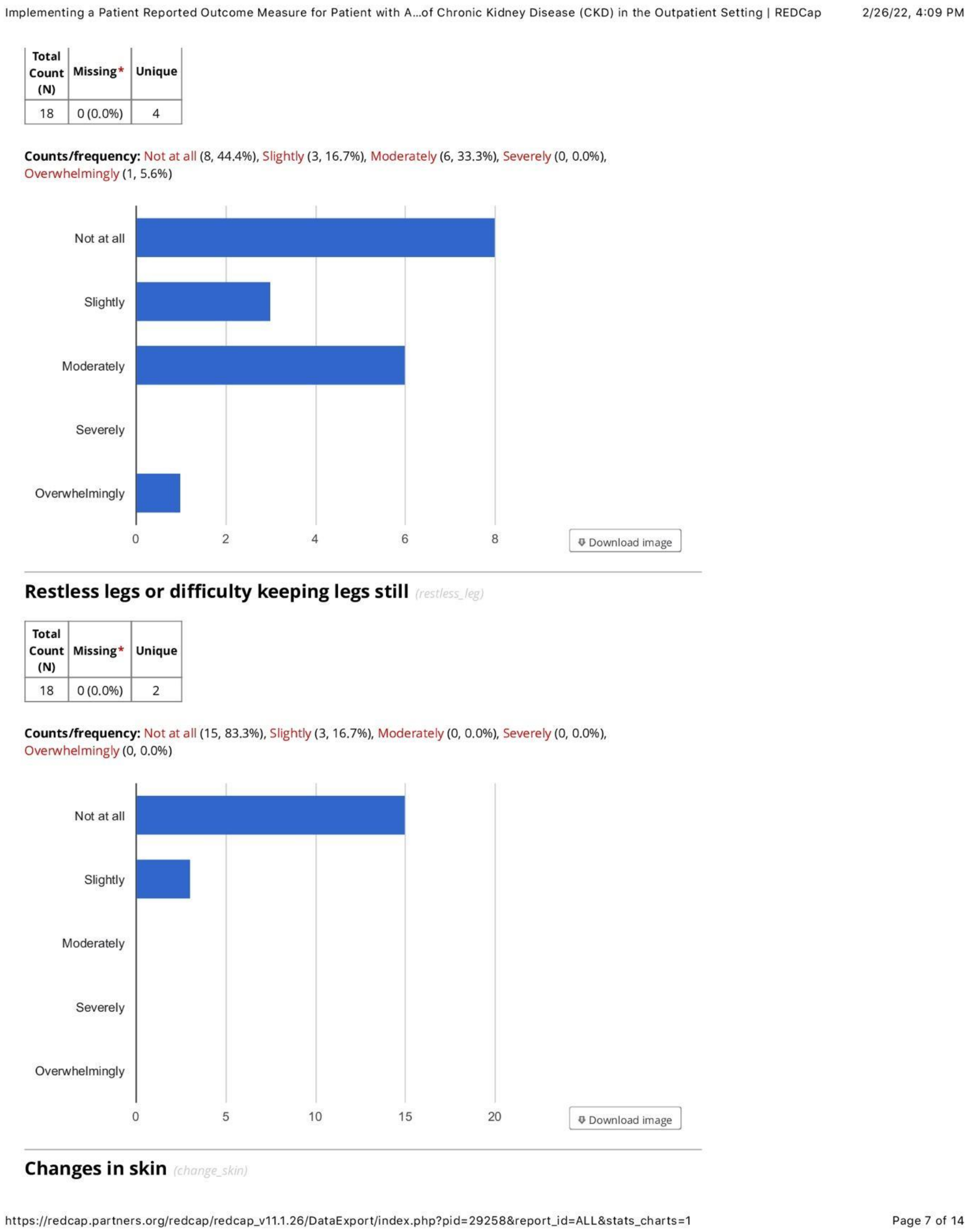
Difficulty sleeping *(sleep)*



Total Count (N)	Missing*	Unique
18	0 (0.0%)	4

Counts/frequency: Not at all (8, 44.4%), Slightly (3, 16.7%), Moderately (6, 33.3%), Severely (0, 0.0%), Overwhelmingly (1, 5.6%)

Restless legs or difficulty keeping legs still *(restless_leg)*

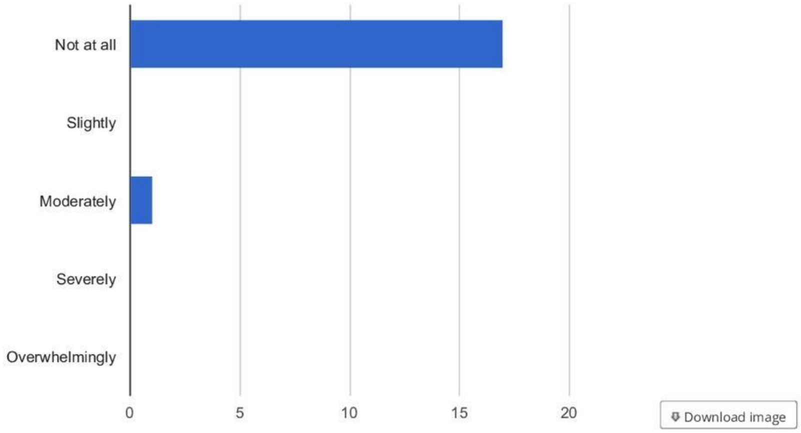
Total Count (N)	Missing*	Unique
18	0 (0.0%)	2

Counts/frequency: Not at all (15, 83.3%), Slightly (3, 16.7%), Moderately (0, 0.0%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)

Changes in skin *(change_skin)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	2

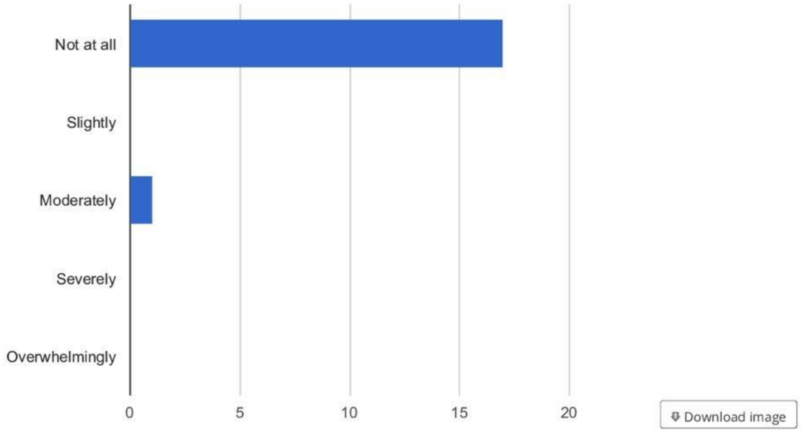
Counts/frequency: Not at all (17, 94.4%), Slightly (0, 0.0%), Moderately (1, 5.6%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



Diarrhea *(diarrhea)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	2

Counts/frequency: Not at all (17, 94.4%), Slightly (0, 0.0%), Moderately (1, 5.6%), Severely (0, 0.0%), Overwhelmingly (0, 0.0%)



Please list any other symptoms NOT mentioned above that have affected you over the past week: *(additional_symptoms)*

Total Count (N)	Missing*
7	11 (61.1%)

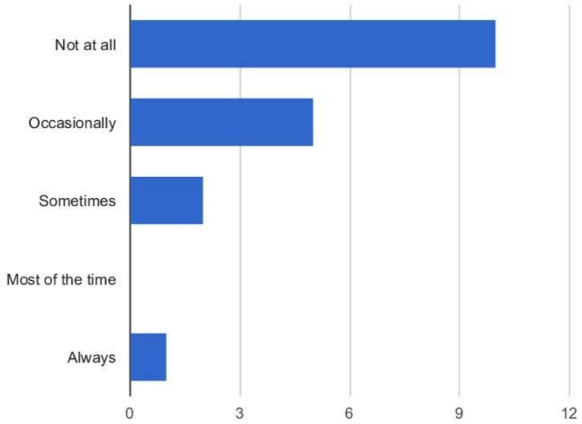
What medical problem is bothering you most at the moment? *(bothersome)*

Total Count (N)	Missing*
9	9 (50.0%)

Have you been feeling anxious or worried about your illness or treatment? *(anxious)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	4

Counts/frequency: Not at all (10, 55.6%), Occasionally (5, 27.8%), Sometimes (2, 11.1%), Most of the time (0, 0.0%), Always (1, 5.6%)



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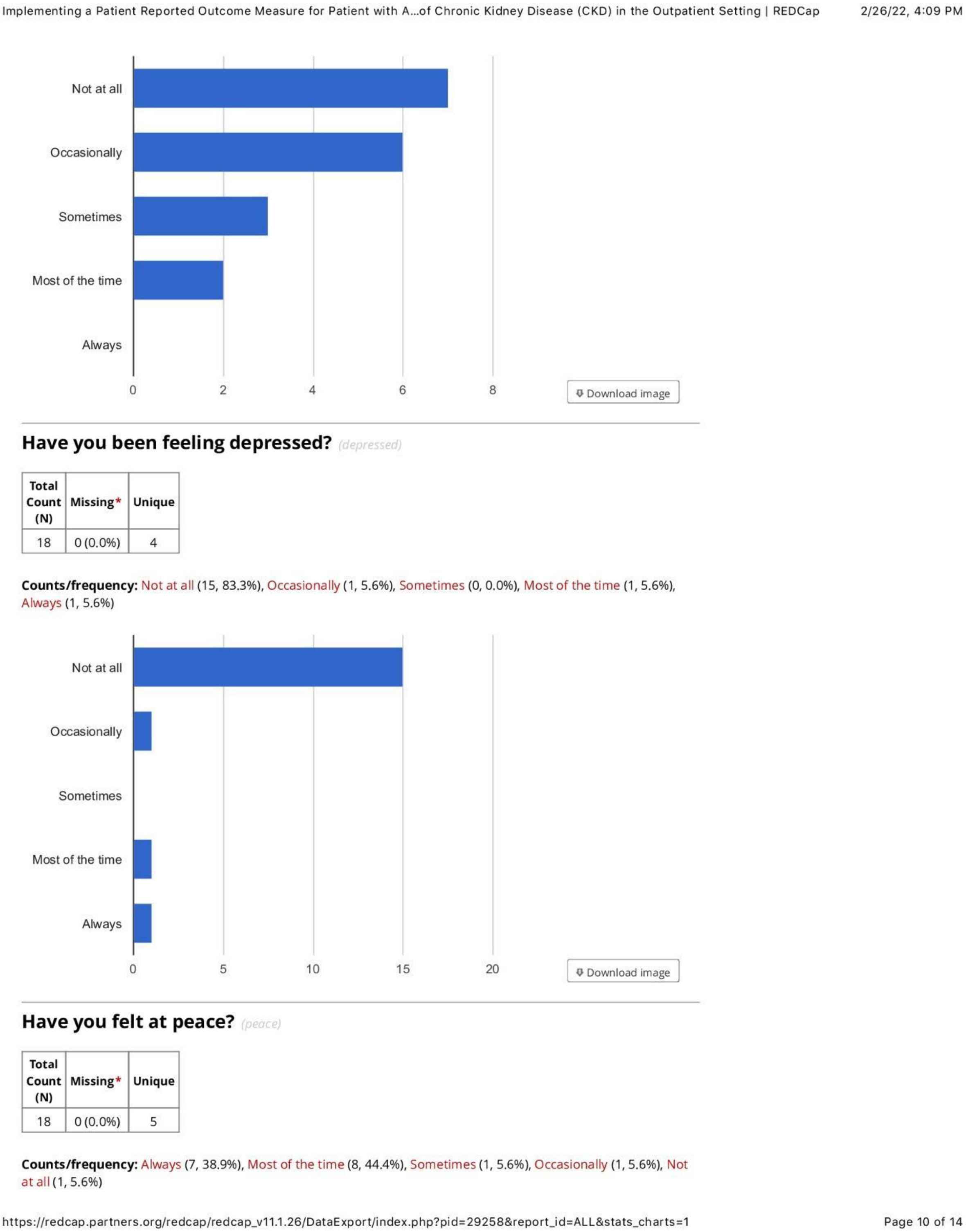
Have any of your family or friends been anxious or worried about you? *(worried)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	4

Counts/frequency: Not at all (7, 38.9%), Occasionally (6, 33.3%), Sometimes (3, 16.7%), Most of the time (2, 11.1%), Always (0, 0.0%)



Have you been feeling depressed? *(depressed)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	4

Counts/frequency: Not at all (15, 83.3%), Occasionally (1, 5.6%), Sometimes (0, 0.0%), Most of the time (1, 5.6%), Always (1, 5.6%)

Have you felt at peace? *(peace)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	5

Counts/frequency: Always (7, 38.9%), Most of the time (8, 44.4%), Sometimes (1, 5.6%), Occasionally (1, 5.6%), Not at all (1, 5.6%)

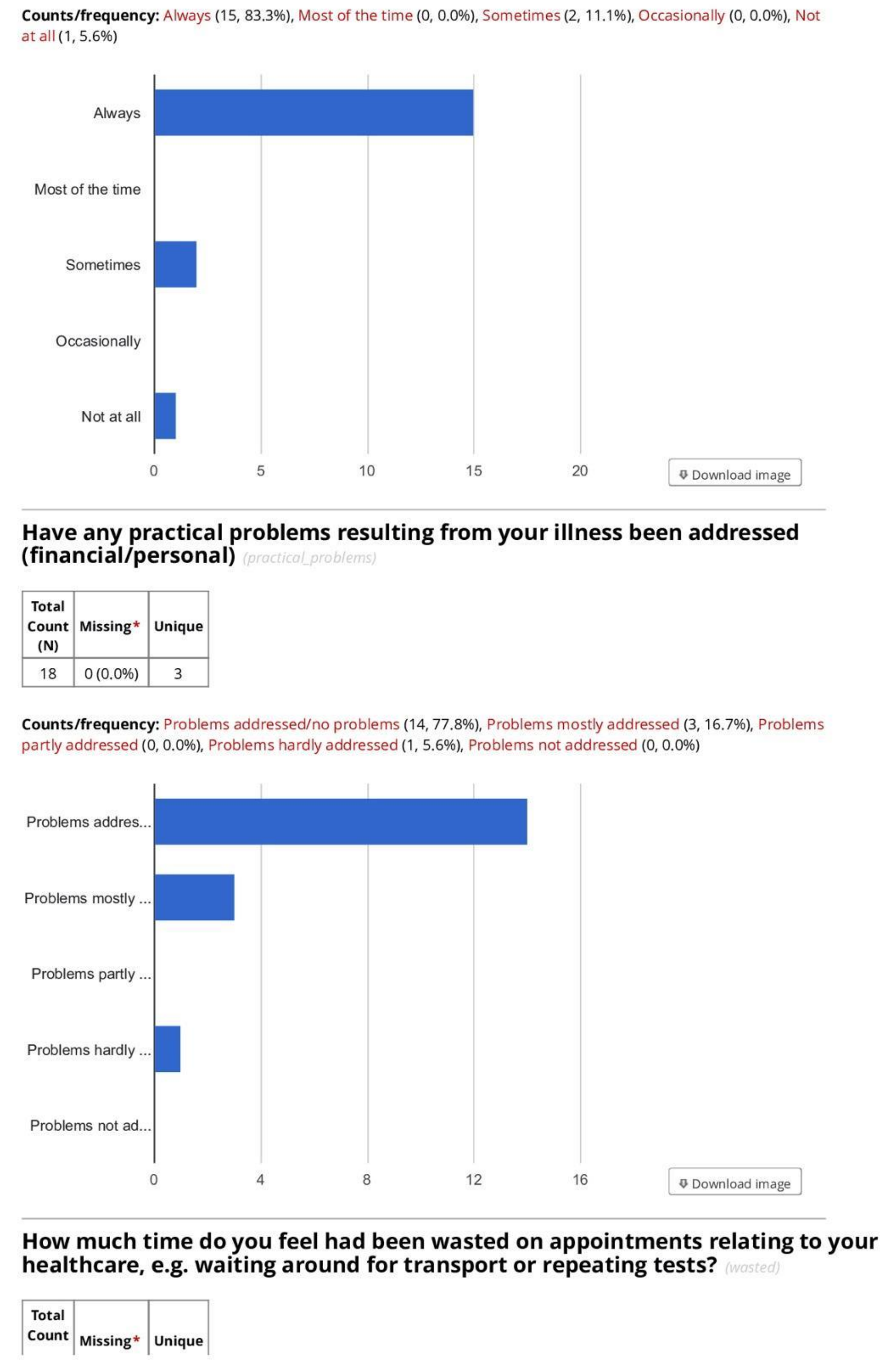
Have you been able to share how you are feeling with your family or friends as much as you want? *(sharing)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	5

Counts/frequency: Always (9, 50.0%), Most of the time (3, 16.7%), Sometimes (2, 11.1%), Occasionally (1, 5.6%), Not at all (3, 16.7%)

Have you had as much information as you wanted? *(information)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	3



Counts/frequency: Always (15, 83.3%), Most of the time (0, 0.0%), Sometimes (2, 11.1%), Occasionally (0, 0.0%), Not at all (1, 5.6%)

Have any practical problems resulting from your illness been addressed (financial/personal) *(practical_problems)*

Total Count (N)	Missing*	Unique
18	0 (0.0%)	3

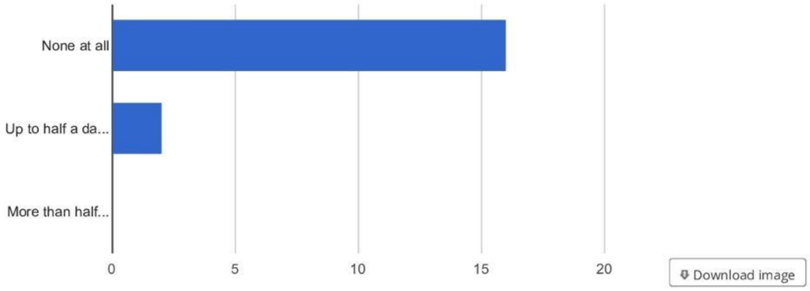
Counts/frequency: Problems addressed/no problems (14, 77.8%), Problems mostly addressed (3, 16.7%), Problems partly addressed (0, 0.0%), Problems hardly addressed (1, 5.6%), Problems not addressed (0, 0.0%)

How much time do you feel had been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests? *(wasted)*

Total Count	Missing*	Unique

(N)		
18	0 (0.0%)	2

Counts/frequency: None at all (16, 88.9%), Up to half a day wasted (2, 11.1%), More than half a day wasted (0, 0.0%)



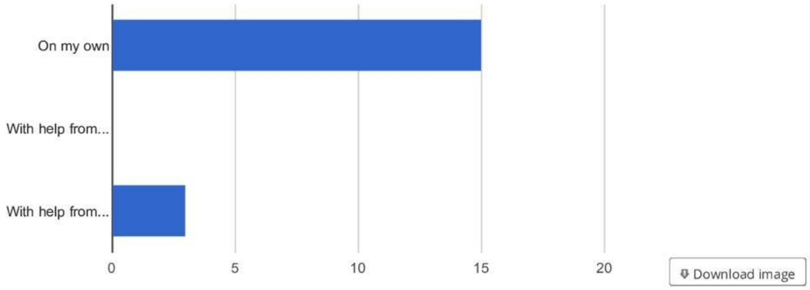
Are you able to do everything that you would like to do or is your disease limiting you in some way? *(limiting)*

Total Count (N)	Missing*
9	9 (50.0%)

How did you complete this questionnaire? *(questionnaire)*

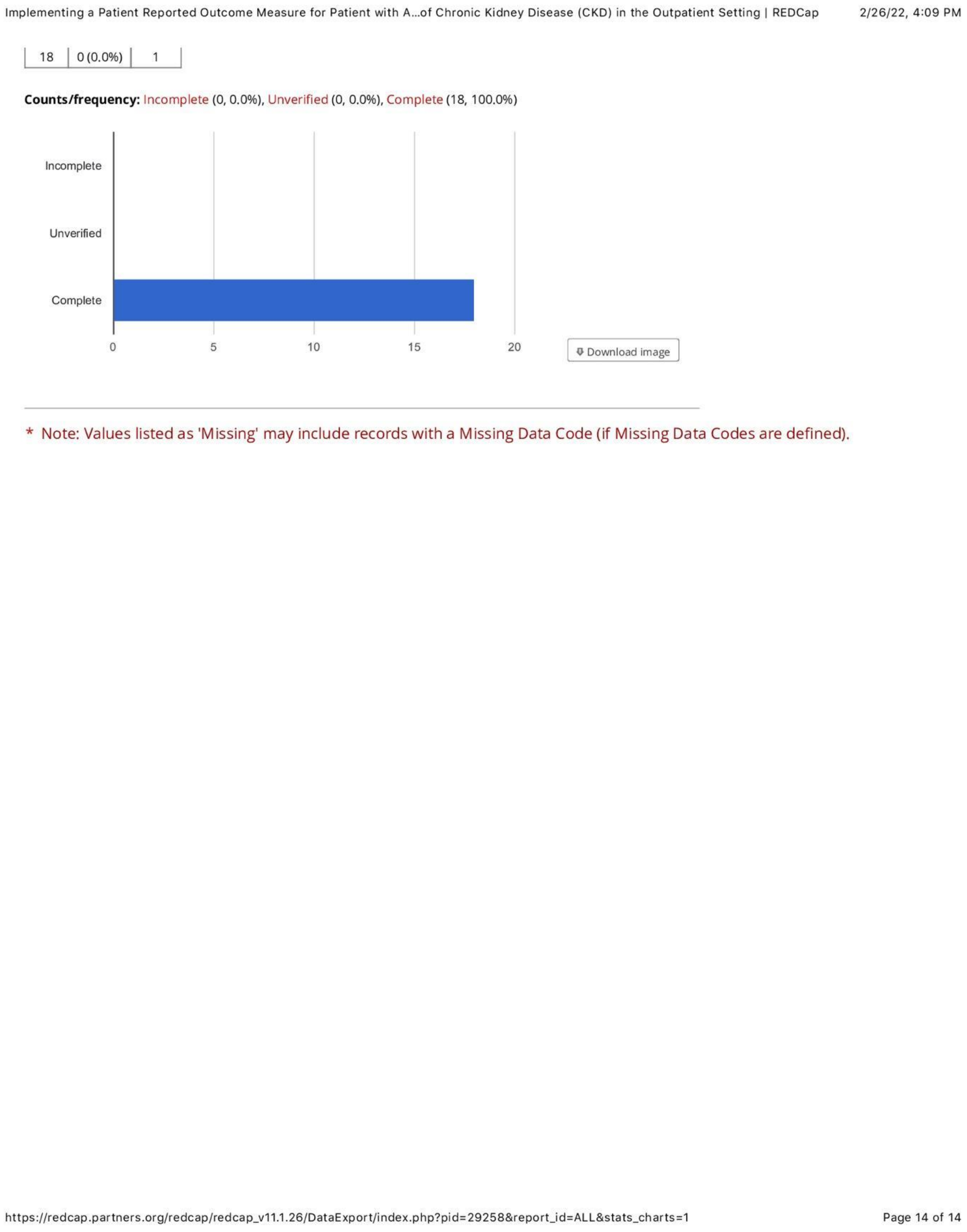
Total Count (N)	Missing*	Unique
18	0 (0.0%)	2

Counts/frequency: On my own (15, 83.3%), With help from a friend or relative (0, 0.0%), With help from a member of staff (3, 16.7%)



Complete? *(iposrenal_complete)*

Total Count (N)	Missing*	Unique



Implementing a Patient Reported Outcome Measure for Patient with A...of Chronic Kidney Disease (CKD) in the Outpatient Setting | REDCap 2/26/22, 4:09 PM

18	0 (0.0%)	1

Counts/frequency: Incomplete (0, 0.0%), Unverified (0, 0.0%), Complete (18, 100.0%)

* Note: Values listed as 'Missing' may include records with a Missing Data Code (if Missing Data Codes are defined).

https://redcap.partners.org/redcap/redcap_v11.1.26/DataExport/index.php?pid=29258&report_id=ALL&stats_charts=1 Page 14 of 14