2022-08-24

Evaluating key performance indicators of the process of care in juvenile idiopathic arthritis

Cooper, Sarah M

UNIVERSITY OF CALGARY

Evaluating key performance indicators of the process of care in juvenile idiopathic arthritis

by

Sarah Marie Cooper

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE

DEGREE OF MASTER OF SCIENCE

GRADUATE PROGRAM IN COMMUNITY HEALTH SCIENCES

CALGARY, ALBERTA

AUGUST, 2022

Abstract

Objective

To determine whether and how often the required information to measure a set of previously developed key performance indicators (KPIs) was documented in data routinely collected in a Pediatric Rheumatology Clinic.

Methods

A retrospective electronic chart review and administrative data analysis was conducted for a cohort of 140 patients with juvenile idiopathic arthritis (JIA) at a tertiary Pediatric Rheumatology Clinic between 2016-2020. Data was assessed as a binary variable indicating whether the required information was found. Documentation frequency for each KPI was assessed with counts and percentages of the number of times the required information was documented for each clinic visit. Compliance with the safety KPI definitions was assessed using administrative databases.

Results

Although data for each KPI were found in the cohort, documentation varied in frequency and consistency. Access to care and safety KPIs were documented more frequently than patient outcome KPIs. A joint assessment was documented at every visit for 95% of patients, 46% for an assessment of pain, and none for a physician's global assessment of disease activity, an assessment of functional ability, or a composite disease activity measurement. Of the patients with documentation for waiting time for pediatric rheumatologist referral visit, 75% (n=24) had an eligible date documented. All of the patients who had a visit following their diagnosis date, had a visit within the first year of diagnosis and 78% of patients saw their rheumatologist at least once every year over their follow-up period. Tuberculosis screening was documented in 96% of

the biologic patients. The first two years of eligible intervals documentation of laboratory monitoring for patients receiving methotrexate and leflunomide ranged from 76% to 90% after the first month.

Conclusion

Although the KPIs are feasible to measure in routinely collected data, there is an opportunity for improving the consistency of documentation. Having an active system of monitoring KPIs and tools to simplify measurement is a key step in the process toward improving patient outcomes. Streamlining the collection of KPI data can increase the likelihood of compliance. Next steps should involve replicating this study in various centres.

Keywords

Juvenile idiopathic arthritis, key performance indicators, quality of care

Preface

This is a manuscript-based thesis. Chapter 5 is a manuscript that has been prepared for submission to the "ACR Open Rheumatology" journal.

Chapter Five

Cooper SM, Currie GR, Kromm S, Twilt M, Marshall DA. Evaluating key performance indicators of the process of care in juvenile idiopathic arthritis. *ACR Open Rheumatology*. Submitted 15 July 2022.

Author Contributions

GC and DM designed the study with input from SC. SC completed the electronic chart review. SC analyzed and interpreted the data with input from GC and DM, and feedback from SK and MT. SC drafted the manuscript and all authors provided feedback and approved the submitted version.

Acknowledgements

I would like to thank all the individuals who supported me throughout my master's thesis, it truly took a village of dedicated professionals. I appreciate the guidance, encouragement, patience, and time that the following individuals provided: Dr. Gillian Currie, Dr. Deborah Marshall, Dr. Seija Kromm, Dr. Marinka Twilt, and Dr. Luiza Grazziotin. I am so honoured to have been granted the opportunity to work with each of you.

Thank you to Trevor Seeger and Shakib Rahman for your patience and guidance through my coding and conceptual roadblocks. Thank you to Darren Mazzei and Bryanne Kennedy for your patience and support as I transitioned to graduate school during a global pandemic.

I would like to acknowledge funding support from the Understanding Childhood Arthritis Network (UCAN) CURE: Precision Decision for Childhood Arthritis. In addition, I would like to acknowledge Alberta Health Services for providing the data for the study.

Table of Contents

Abstract....ii
Preface....iv
Acknowledgements....v
Table of Contents....vi
List of Tables....viii
List of Figures and Illustrations....x
List of Symbols, Abbreviations and Nomenclature....xi

CHAPTER ONE: INTRODUCTION....1
1.1 Overview....1
1.1.1 Juvenile Idiopathic Arthritis....3
1.1.2 Key Performance Indicators and Quality Improvements....3
1.1.3 Definitions....4
1.2 Purpose....9
1.3 Objectives and Research Questions/Hypotheses....10
1.4 Thesis Outline....11
1.5 Literature Review....11
1.5.1 Performance Measurement....11
1.5.2 Quality Measures in Health Care....13
1.5.3 Benchmarks for JIA....15
1.5.4 KPI Evaluation of Feasibility....16
1.5.5 KPI Reporting....17
1.5.6 KPIs in Practice....20
1.5.7 JIA KPI Development....21

CHAPTER TWO: METHODS....24
2.1 Research Design Overview....24
2.2 Cohort....25
2.3 Data Collection....26
2.3.1 Data Sources....29
2.3.2 Data Collection Guidelines/Standard for Chart Review....31
2.4 Analysis....34

CHAPTER THREE: RESULTS....37
3.1 Cohort Characteristics....37
3.2 Documentation of set of KPIs (Objective 1)....39
3.3 Documentation frequencies (Objective 2)....43
3.3.1 Measurement of Patient Outcomes KPIs....43
3.3.1.1 KPI #1: Rheumatological joint assessment....43
3.3.1.2 KPI #2: Physician's Global Assessment of disease activity....44
3.3.1.3 KPI #3: Assessment of functional ability....45
3.3.1.4 KPI #4: Composite disease activity measurement....46
3.3.1.5 KPI #5: Assessment of arthritis-related pain....47

3.3.2 Access to Care KPIs 48
3.3.2.1 KPI #6: Waiting times for rheumatologist consultation for patients with new onset JIA 48
3.3.2.2 KPI #7: Patients newly diagnosed with JIA with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis 50
3.3.2.3 KPI #8: Patients seen in yearly follow-up by a pediatric rheumatologist 51
3.3.3 Safety KPIs 53
3.3.3.1 KPI #9: Tuberculosis (TB) screening 53
3.3.3.2 KPI #10: Laboratory monitoring for DMARDs 56

CHAPTER FOUR: DISCUSSION AND CONCLUSION 59
4.1 Overview 59
4.2 Feasibility of the KPIs (Study Aim) 60
4.3 Implications 68
4.4 Strengths and Limitations 73
4.4.1 Strengths 73
4.4.2 Limitations 74
4.5 Conclusions 77

CHAPTER FIVE: EVALUATING KEY PERFORMANCE INDICATORS OF THE PROCESS OF CARE IN JUVENILE IDIOPATHIC ARTHRITIS 78
5.1 ABSTRACT 78
5.2 INTRODUCTION 79
5.3 PATIENTS AND METHODS 80
5.3.1 Cohort Selection 80
5.3.2 Data Sources 84
5.3.3 Analysis 85
5.4 RESULTS 85
5.4.1 Cohort Description 85
5.4.2 Documentation 86
5.4.3 Documentation Frequencies 88
5.5 DISCUSSION 94

REFERENCES 101

APPENDIX A: INTER-RATER RELIABILITY CALCULATION 107

List of Tables

Table 1: JIA KPI Definitions....7

Table 2: KPI Operational Definitions....8

Table 3: Initial JIA Proposed Benchmarks....15

Table 4: KPI Variables Collected....27

Table 5: JIA Cohort Clinical Characteristics....37

Table 6: JIA Cohort Patient Demographics....38

Table 7: JIA Cohort Visit Characteristics....38

Table 8: Is the data for the respective KPI documented in at least one visit in the cohort?....39

Table 9: If the required information was found documented in at least one visit for each patient....41

Table 10: Documentation frequency of KPI #1: rheumatological joint assessment being documented in SCM....43

Table 11: Documentation frequency of KPI #2: Physician's Global Assessment (PGA) of disease activity being documented in SCM....44

Table 12: Documentation frequency of KPI #3: CHAQ being documented in SCM....45

Table 13: Documentation frequency of KPI #4: the components for the cJADAS being documented in SCM....46

Table 14: Documentation frequency of KPI #5: an assessment of arthritis-related pain being documented in SCM....47

Table 15: Documentation frequency and performance of KPI #6: time between referral date and first visit with pediatric rheumatologist....49

Table 16: Compliance of KPI #7: patients newly diagnosed with at least 1 visit in the first 12 months of diagnosis....51

Table 17: Compliance of KPI #8: patients having annual follow-up visits with the pediatric rheumatologist (12 months)....52

Table 18: Documentation frequency and compliance of KPI #9: TB tests for patients on a biologic in SCM and in the administrative databases....54

Table 19: Documentation frequency of KPI #10: ordering and reporting laboratory tests for patients on methotrexate or leflunomide in SCM. 56

Table 20: Characteristics of patients on methotrexate or leflunomide requiring laboratory monitoring. 57

Table 21: Documentation frequency and compliance of KPI #10: proportion of patients on methotrexate or leflunomide receiving laboratory monitoring using the Consolidated Laboratory Repository. 58

Table 22: UCAN CURE JIA KPI Definitions and Operational Definitions.(1) 81

Table 23: Cohort demographics. 86

Table 24: Documentation of UCAN CURE KPIs in SCM and the administrative databases. 87

Table 25: Documentation frequency of measurement of patient outcomes KPIs found in SCM. 89

Table 26: Documentation frequency of access to care KPIs. 91

Table 27: Documentation frequency of safety KPIs in SCM and the administrative databases. ..92

List of Figures and Illustrations

Figure 1: Retrospective Chart Review Timeline 27

Figure 2: Duration of laboratory monitoring 36

List of Symbols, Abbreviations and Nomenclature

Symbol	Definition
ACH	Alberta Children's Hospital
ALT	Alanine aminotransferase
AST	Aspartate aminotransferase
CBC	Complete blood count
CCI	Canadian Classification of Health Interventions
CHAQ	Childhood Health Assessment Questionnaire
cJADAS	Clinical Juvenile Arthritis Disease Activity Score
COSI-PPC-EU	Core Set of Indicators for Primary Pediatric Care in Europe
DMARD	Disease-modifying anti-rheumatic drug
EAC	Early Arthritis Clinic
EMR	Electronic medical record
ER	Emergency room
GP	General practitioner
HIV	Human immunodeficiency virus
ICD	International Classification of Diseases
INR	International normalized ratio
IHI	Institute for Health Improvement
JIA	Juvenile Idiopathic Arthritis
KPI	Key performance indicator
MIPS	Merit-based Incentive Payment System
NACRS	National Ambulatory Care Reporting System
NQF	National Quality Forum
NSAID	Non-steroidal anti-inflammatory drugs
PGA	Physician's Global Assessment
PR	Pediatric rheumatologist
PR-COIN	Pediatric Rheumatology Care and Outcomes Improvement Network
PT	Physical therapist
PTT	Partial thromboplastin time
QCDR	Qualified Clinical Data Registry
RA	Rheumatoid Arthritis
RISE	Rheumatology Informatics System for Effectiveness
SCM	Sunrise Clinical Manager
SD	Standard deviation
TB	Tuberculosis
UCAN CURE	Understanding Childhood Arthritis Network CURE: Precision Decision for Childhood Arthritis

CHAPTER ONE: INTRODUCTION

1.1 Overview

Approximately 24,000 children or about 3 out of every 1,000 children in Canada have juvenile idiopathic arthritis (JIA).(1,2) Without early diagnoses and timely treatment, persistent joint pain, swelling, and stiffness caused by JIA can lead to permanent disfigurement and disability.(1–3) Such unfavourable outcomes create negative impacts and challenges to a patient's quality of life, which can include slow growth, osteoporosis, and in rare extreme cases kidney, heart, or endocrine system complications.(4)

Indicators are measurable parameters used to assess processes, structures, and outcomes (5) that reflect the quality of care that a patient receives. For example, monitoring waiting times and length of time to be seen for follow-up visits are process indicators for access to care. Indictors can be used to assess quality of patient care and identify opportunities for quality improvements in patient care and outcomes by providing data to initiate interventions to reduce "unwarranted variability" in practice and care.(1,6)

As part of the *Understanding Childhood Arthritis Network (UCAN) CURE: Precision Decision for Childhood Arthritis* project, a multicentre, international precision health program examining biology-based treatment strategies for JIA, a set of 10 process KPIs along the JIA care continuum were identified: 1) joint count; 2) physician's global assessment; 3) functional ability; 4) disease activity; 5) arthritis-related pain; 6) waiting times for pediatric rheumatologist consultation; 7) patients newly diagnosed with JIA with at least one visit to a pediatric rheumatologist in the first year of diagnosis; 8) patients seen in yearly follow-up by a pediatric rheumatologist; 9) tuberculosis screening; and 10) laboratory monitoring for disease-modifying anti-rheumatic drugs (DMARDs).(1) This research evaluated the set of 10 KPIs using a Calgary

JIA cohort. The KPIs were grouped into three categories: 1) measurement of patient outcomes KPIs (KPIs #1 to #5); 2) access to care KPIs (KPIs #6 to #8); and 3) safety KPIs (KPIs #9 and #10).

The population-based performance measures (access to care KPIs described in **Table 1**) were previously examined and gaps in JIA care were identified.(3,7,8) The two studies found that the median waiting times met the national benchmarks but there were delays in older patients (7) and that the first visit and follow-up visits with the pediatric rheumatologist were found to have "suboptimal access".(3) There is some evidence of the feasibility of the certain KPIs in the Manitoba administrative databases (3) the CATCH (Canadian Early Arthritis Cohort) dataset (8). To date, there have been no studies assessing the feasibility of measuring the full set of 10 JIA KPIs in Canada using routinely collected and readily available clinical data.

Evaluating the feasibility of measuring and reporting these KPIs will identify if these KPIs can be easily monitored using standard documentation in routine clinical visits. Having KPIs that are easily measured using readily collected data and then reported is a critical step toward transparency and accountability in delivering high quality patient care and improving patient outcomes.

For KPIs that are feasible and routinely captured in JIA clinical patient data, the actual values of these KPIs could later be used as a first step toward establishing benchmarks of care to guide improvements in the overall quality of JIA patient care. The study objectives were to assess the documentation of routine data for each of the 10 KPIs captured in Calgary's acute care electronic documentation system Sunrise Clinical Manager (SCM) and health system administrative data through the presence or absence of the relevant KPI data. The collected data were used to evaluate the feasibility of measuring each of the KPIs, and report on the current

levels of performance, documentation frequency, and for those that have a time component, whether the time component was met (which was defined as compliance) of these KPIs within the routinely collected and summarized JIA clinical data.

1.1.1 Juvenile Idiopathic Arthritis

JIA is one of the most common chronic childhood rheumatic diseases.(9) The American College of Rheumatology classifies JIA according to the following criteria: age at onset is 16 years or younger, arthritis in at least one joint, and duration of disease is at least 6 weeks.(9)

JIA management is primarily determined by the severity of the subtype and typically involves "pharmacological and nonpharmacological approaches."(10) The pharmacological approaches include the use of nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids, biologic and non-biologic DMARDs, with the most commonly prescribed DMARD being methotrexate.(10) The primary goal of treatment is to "achieve remission, prevent or halt joint damage, and foster normal growth and development."(9) JIA requires individual treatment plans and disease management is to be tailored toward the disease subtype, severity, "presence of poor prognostic indicators", and "response to medications" which also requires toxicity monitoring from medications.(9)

1.1.2 Key Performance Indicators and Quality Improvements

As W. E. Deming, the expert in "continual improvement of quality"(11), put so eloquently: "Best efforts are essential, but unfortunately, best efforts alone will not accomplish the purpose. Everyone is already doing his best. Efforts, to be effective, must move in the right direction. Without guidance, best efforts result in a random walk".(12) This guidance is the basis of performance measurement. W. E. Deming proposed three ways of improving quality: "through innovation in design of a product or service, through innovation in processes, and through

improvement of existing processes".(13) This thesis is focused on measuring and reporting on the set of KPIs as a step toward improving quality of care through existing processes. Berwick *et al*. identified two pathways for improvement: "improvement through selection" and "improvement through changes in care."(14) This allowed for the understanding of performance itself to change behaviours as it is conveyed to the individuals providing the care rather than just the leadership of an organization.(14) Measuring improvements for change can actually provide relevant information to those wishing and able to make improvements using the "improvements through selection" pathway as the information can contain both process and outcome-level data.(14) The purpose of improvement through selection was based on the consumer perspective where patients can "get better by choosing better care".(14) Improvement through changes in care had three approaches: 1) quality control, 2) quality improvement, and 3) quality design.(14) This research followed Berwick's improvement through "changes in care using the quality improvement approach with changes that improve processes and reducing their costs or increasing their performance to new levels".(14) Berwick *et al*. note that although measurement is necessary, it is not sufficient alone to measure performance because organizations and providers of care must also have the capacity to make improvements in quality of care through systematic change.(14) The results from this study are intended to be used in future studies to establish benchmarks for quality of care that will ultimately guide future treatment improvement actions.(1)

1.1.3 Definitions

Having clear definitions for the terms used in performance measurement is imperative for definitions to be understood and implemented. Performance measurement requires the

operationalization of various indicators aligned to their goal. Lawrence and Olesen defined an indicator as

> *"a measurable element of practice performance for which there is evidence or consensus that it can be used to assess the quality, and hence change in the quality, of care provided".(15)*

This was to be considered within the approaches by Donabedian of structure, process, and outcome indicators.(5) There are important specifications that differentiate the terms: quality indicators, quality measures, and key performance indicators. As defined by the Agency for Healthcare Research and Quality (AHRQ), quality indicators are

> *"standardized, evidence-based measures of health care quality that can be used with readily available hospital inpatient administrative data to measure and track clinical performance and outcomes".(16)*

The Centers for Medicare & Medicaid Services define quality measures as

> *"tools that help us measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality health care and/or relate to one or more quality goals for health care".(17)*

Quality indicators and measures are usually used interchangeably (18); however, the former indicates quality and the latter measures quality. Key performance indicators are used to measure the performance of an organization in particular areas that are considered critical to strategic goals.(19) KPIs differ from quality indicators and quality measures in that the focus is on an *organization's* performance rather than providing overall quality to an applicable population. A performance or quality measure are very similar, and these can become key performance

indicators if they are specifically chosen in alignment with strategic goals of an organization. The alignment with the strategic goals of an organization is the key distinguishing feature that separates performance or quality measures from key performance indicators. The term key performance indicator is sometimes also used in healthcare without the strategic goal alignment aspect of the definition (1,20–23). In this research, the indicators were previously developed and labelled as KPIs.(1) Given the definitions above, these indicators could be labelled as quality measures or quality indicators but for consistency with the original paper that published the KPIs, this research adopted the term KPIs. This thesis used the term KPIs were used to support JIA rheumatology programs and these KPIs are critical to achieving the goal of delivering high quality care to JIA patients.

For the purpose of this research, performance was defined as the percentage of patients with documentation that met or exceeded the specified benchmark of the respective KPI. Performance monitoring involves assessing "certain parameters while keeping the preestablished criteria and objectives as a benchmark".(24) A key step in assessing performance is "to prepare a *baseline* against which performance will be measured".(25) The baseline is considered the "chosen standard" which is a benchmark and will provide the initial set of values to compare against.(25) Adhering to best practices, ongoing measurement is an essential step in the process of continuous improvement.(26)

Documentation frequency was defined as the percentage of patients with documentation that met the KPI during the measurement period.(27) Compliance was defined as the proportion of patients whose charts reported the data for each KPI and "calculated as the number of eligible patients meeting the quality indicator divided by the total number of eligible patients" (28) during a specified time period.

The definitions for each KPI are summarized in **Table 1**. The operationalized definitions for each KPI (numerator and denominator) are provided in **Table 2**.

Table 1: JIA KPI Definitions

KPI	Definition
Measurement of Patient Outcomes KPIs	
1. Rheumatological joint count	Percentage of patients where a joint count was conducted on the first visit and each subsequent visit using a validated tool (1)
2. Physician's Global Assessment (PGA) of disease activity	Percentage of patients assessed for a PGA using any validated tool at the first visit and at each subsequent visit (1)
3. Assessment of functional ability	Percentage of patients assessed for functional ability using any validated tool at the first visit and at every routine clinic visit (1)
4. Composite disease activity measurement	Percentage of patients in the measurement period with an assessment of disease activity using the clinical juvenile arthritis disease activity score (cJADAS) at the first visit and at every routine clinic visit (1)
5. Assessment of arthritis-related pain	Percentage of patients assessed for pain at the first visit and each subsequent visit that occur at least 7 days apart using any validated age-appropriate tool to measure average pain (1)
Access to Care KPIs	
6. Waiting times for rheumatologist consultation for patients with new onset JIA	The 50th and 90th percentile waiting time for rheumatologic consultation (1)
7. Patients newly diagnosed with JIA with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis	Percentage of patients with new onset JIA (incident JIA) with at least one visit to a pediatric rheumatologist in the first year of diagnosis (1)
8. Patients seen in yearly follow-up by a pediatric rheumatologist	Percentage of patients with JIA seen by their pediatric rheumatologist at least once every year over (1)
Safety KPIs	
9. Tuberculosis (TB) screening	Percentage of patients screened for TB within 12 months prior to receiving a first course of therapy using a biologic DMARD (1)

10. Laboratory monitoring for disease-modifying anti-rheumatic drugs	Percentage of patients who received methotrexate and leflunomide and monitored for toxicity by clinical laboratory methods (1)

Table 2: KPI Operational Definitions

KPI	Operational Definition
Measurement of Patient Outcomes KPIs	
1. Rheumatological joint count	**Numerator:** the number of patients where a joint count was conducted on the first visit and each subsequent visit using any reliable tool in the measurement period **Denominator:** the total number of patients seen in the measurement period
2. Physician's Global Assessment (PGA) of disease activity	**Numerator:** the number of patients assessed for a PGA at the first visit and at each subsequent visit in the measurement period **Denominator:** the total number of patients seen in the measurement period
3. Assessment of functional ability	**Numerator:** the number of patients assessed for functional ability at the first visit and at each subsequent visit in the measurement period **Denominator:** the total number of patients seen in the measurement period
4. Composite disease activity measurement	**Numerator:** the number of patients with an assessment of disease activity using the cJADAS in the measurement period **Denominator:** the total number of patients seen in the measurement period
5. Assessment of arthritis-related pain	**Numerator:** the number of patients assessed for pain at the first visit and each subsequent visit using any validated, reliable, age-appropriate tool to measure average pain in the measurement period **Denominator:** the total number of patients seen in the measurement period
Access to Care KPIs	
6. Waiting times for rheumatologist consultation for patients with new onset JIA	**50th percentile:** the number of days that half the patients in the sample with new onset JIA saw a pediatric rheumatologist and half are still waiting (50th percentile) **90th percentile:** the number of days that 90% of the patients in the sample with new onset JIA saw a

	pediatric rheumatologist and 10% are still waiting (90th percentile)
7. Patients newly diagnosed with JIA with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis	**Numerator:** the number of patients with new onset JIA with at least one visit to a pediatric rheumatologist in the first year of diagnosis during the measurement period **Denominator:** the total number of patients with new onset JIA seen during the measurement period
8. Patients seen in yearly follow-up by a pediatric rheumatologist	**Numerator:** the number of patients with a diagnosis of JIA under the case of a pediatric rheumatologist seen in follow up by a pediatric rheumatologist at least once every year during the measurement period **Denominator:** the total number patients with a diagnosis of JIA patients under the care of a pediatric rheumatologist in the measurement period excluding patients who meet exclusions
Safety KPIs	
9. Tuberculosis (TB) screening	**Numerator:** the number of patients screened for TB within 12 months prior to start of any biologic therapy using a standard TB skin test/ blood test in the measurement period. **Denominator:** the total number of patients on a biologic therapy in the measurement period
10. Laboratory monitoring for disease-modifying anti-rheumatic drugs	**Numerator:** the number of patients who received methotrexate and leflunomide and monitored for toxicity 1 month after the start of therapy, and every 3-4 months after by clinical laboratory methods in the measurement period. **Denominator:** the total number of patients who received methotrexate and leflunomide in the measurement period

1.2 Purpose

The aim of this study was to determine whether the information was available to measure the JIA KPIs in routinely captured patient summary data from January 1st, 2016, to March 13th, 2020, at the Alberta Children's Hospital Pediatric Rheumatology Clinic. This study assessed the routinely collected JIA patient summary records to determine if the data for the identified set of KPIs was documented, including the current documentation frequencies. Data were used to

determine the feasibility of each KPI. This study represents the first step in the evaluation of processes to assess JIA quality of care and is critical for future work in establishing benchmarks for quality of care (1) to guide future treatment improvement initiatives.

1.3 Objectives and Research Questions/Hypotheses

The objectives of this study were to:

1. Assess the documentation of routine data captured in Calgary's electronic documentation storage system – the acute care electronic Sunrise Clinical Manager (SCM) and administrative data for each of the 10 KPIs through the presence and absence of data.
2. Report on the current levels of performance, documentation frequency and compliance within routine JIA patient summary data for each KPI.

The research questions for this study were:

1. Is the data for each KPI documented in the routinely collected data?
2. What is the current level of documentation frequency for each KPI captured in the routinely collected data?
3. Are the chosen data sources feasible and usable to measure each KPI and if not, what are other potential data sources that may contain this information?

The KPIs were selected through a modified Delphi panel comprised of pediatric rheumatologists, allied health professionals, and a parent of a child with JIA that were recruited from various centres across Canada.(1) The panelists were tasked to judge and assess the KPIs on the perceived feasibility of measuring (1) quality care. This research assessed the actual feasibility of measuring these indicators.

1.4 Thesis Outline

The remainder of this chapter provides background on quality indicators, performance measurements and KPI development. Chapter Two provides the methods used for this thesis to address the objectives stated above. Chapter Three reviews the cohort demographics and the results of each key performance indicator. Chapter Four provides a discussion of the results and a contextualization of the relevant data sources and conclusions. Chapter Five presents the manuscript which reports on the key findings of this work, discussion on the documentation of information within the relevant data sources.

1.5 Literature Review

1.5.1 Performance Measurement

The goal of performance measurement is to improve the quality of patient health, and this requires a method of measurement.(29) Evaluating health care can represent a complex and difficult task that is better accomplished when grounded in a logical and systematic process. Quality of care is difficult to define and as Donabedian points out, is dependent upon the professional judgement of the assessor.(30) The measure of quality care must rest on a conceptual and operationalized definition of what the "quality of medical care" means.(30) Although Donabedian's paper succeeds in bringing attention to evaluate quality of care, no single comprehensive criterion was identified that measures the quality of patient care.(30) Quality of care can be measured using process, structure, and outcome indicators. Process indicators are less likely to be influenced by external factors and are better controlled by the health care provider (31); structure indicators relate more to the attributes of the settings where patient care takes place (5); and outcome indicators "measure the impact of services on health" and can be influenced by external factors.(31) Although Adair *et al.* found that many writers

considered process indicators more practical, overall, they considered them to be "complementary to outcomes or results".(32) Donabedian's structure-process-outcome model "has set the framework for most contemporary quality measurement and improvement activities".(29) When structural and process measures have been linked to improvements in outcomes, they are "accepted and feasible" because they are easier to collect and report than outcome measures.(29)

Adair *et al*. provided tools to go beyond Donabedian by defining performance as "what is done and how well it is done to provide health care" and providing healthcare improvement activities such as benchmarking.(33) They define performance measurement as "the use of both outcomes and process measures to understand organizational performance and to effect positive change to improve care".(33) A performance measure is "a quantitative tool … that provides an indication of an organization's performance in relation to a specified process or outcome".(33) A process measure is "a change in status [that is] confidently attributable to antecedent care [intervention]".(33)

An important approach to performance measurement is having strong leadership and focusing on a positive and constructive approach to not place blame.(32) This research focused on the reporting of data as a whole rather than on individual clinician or provider performance. It is also important to understand that performance measurement is a "long-term endeavour" that requires organizations to "plan for performance management".(32) This means that organizations will need mechanisms to be in place in order to use the results of the performance measurement to enact system changes.(32)

Performance measurement can also serve to inform patients and hold health providers accountable which provides transparency and can build trust.(29) With patients having access to

performance data, they can be aware of the "expected professional standards of care" and "where they can go to receive it" (29) and how they can better advocate for themselves. Regulatory agencies can also use the performance data for "accreditation, maintenance of certification, and regionalization of care".(29) Performance measurement can also be used to incentivise through systems such as pay-for-performance or national rankings.(29)

1.5.2 Quality Measures in Health Care

There are three steps in achieving quality health care.(29) The first step is to define standards of care that are developed through the collaboration of health care industry experts and patients.(29) The next step is to "pinpoint where patient care falls short" which is done through measuring performance.(29) The final step involves caregivers examining this information and using it to make improvements.(29) In this study, the first step was previously completed through the development of the KPIs.

Improvement projects are increasingly being used to prevent and address issues by "deeply understanding the processes of care and operations".(34) The Institute for Healthcare Improvement (IHI) states that an element within a framework for safe, reliable and effective care is *measurement* over time.(34) IHI suggests a *Model for Improvement* to "redesign process[es] and achieve outcomes that matter to patients, families and staff."(34) This is accomplished by an improvement project answering three questions and developing a *Plan-Do-Study-Act* loop to assess whether potential changes will lead to the desired improvements.(34) The first question, "what are we trying to accomplish", will give the project team a clear vision of what they are striving to achieve.(34) The second question, "how will we know that a change is an improvement", is the measurement component of the model.(34) Finally, the third question, "what change can we make that will result in improvement", is the change component.(34) Once

the project team answers the three questions, the team will create a *Plan-Do-Study-Act* loop where the first step, the *Plan* stage, is to plan the test or observations including data collection generated from the answers to the question "what change can we make that will result in improvement".(34) After the *Plan* stage, the ideas are tested in a small-scale setting, the *Do* stage; the third step, the *Study* stage, is where the data and results are analyzed.(34) Lastly, in the *Act* stage, the ideas based on the conclusions drawn from the small-scale study are refined.(34)

For Cooper *et al*., the importance of quality measures lies in their ability to ensure that a consistent standard of high-quality care is being used population-wide.(35) To be an informative quality measure, quality measures must have "face/content validity, reproducibility, acceptability, feasibility, reliability, sensitivity to change, and predictive validity".(35) Others describe ideal indicators as representing the ideals of the institution and "being well defined, measurable, and reproducible".(36) Some of these would be defined during the development of the measures while others such as reproducibility, feasibility and reliability would be defined during the testing of the measures.(35) Cooper *et al*. noted that many studies only routinely reported some of these attributes in their systematic review and challenged researchers to assess validity and feasibility when developing these quality of care indicators.(35) When outcomes measures are influenced by more external factors (37) including clinical, treatment, patient and random factors, process measures are advantageous as they are more sensitive to detecting differences in quality of care than outcome measures.(37) An emerging focus of improvement in quality care that should be considered is patient activation – "a patient's engagement in their own health."(38)

Adult quality measures cannot simply be equated to pediatric care.(39) This is because children require special considerations:

1. Children have differential epidemiology as compared to adult care.(39)
2. Children are dependent on their parents or other adults which can impact financing, decision-making, and care.(39)
3. Children have a wide range of demographics that can make "risk adjustment potentially more complex".(39)
4. Children are "constantly changing physically, emotionally, and cognitively".(39)

Thus, "measures and their uses are best approached the same way we think about quality itself – through a continuous cycle of improvement".(39)

1.5.3 Benchmarks for JIA

Benchmarks are "calculated standards that represent the best performance".(29) When a specific quality measure has an assigned benchmark, "it can be used to compare performance between systems, groups, and individuals".(29) Benchmarks are the chosen standard used to set targets for improvements and can "stimulate the work of quality collaboratives".(29) Currently, Canadian guidelines stipulate the benchmarks for waiting times for a rheumatologist consultation is 7 days for systemic JIA and 4 weeks for the other JIA subtypes.(7,40) Lovell *et al.* proposed the remaining benchmarks for quality performance, but did not make a recommendation for follow-up visits on the basis that follow-up visits are "dependent on numerous factors".(41) Lovell *et al.* proposed the initial benchmarks based on what the working group "concluded were reasonable and feasible for most practices to achieve" but did not set ideal benchmarks as the purpose of "continuous quality improvement" is that the benchmarks are continually being improved and set to higher standards.(41) Initial benchmark goals for quality performance from other studies are defined in **Table 3**.

Table 3: Initial JIA Proposed Benchmarks

KPI	Initial Benchmark Proposed
Measurement of Patient Outcomes KPIs	
1. Rheumatological joint count	"≥ 80% of initial visits and 6-month interval visits included a joint count"(41)
2. Physician's Global Assessment (PGA) of disease activity	"80% of initial and subsequent visits include a PGA"(41)
3. Assessment of functional ability	"≥ 70% of initial and 6-month interval visits will include an assessment of functional ability"(41)
4. Composite disease activity measurement	Not available
5. Assessment of arthritis-related pain	"≥ 80% of patients receive an assessment of pain at the first visit and at each subsequent visit if at least 7 days apart"(41)
Access to Care KPIs	
6. Waiting times for rheumatologist consultation for patients with new onset JIA	7 days for systemic JIA and 4 weeks for other JIA categories(7,40)
7. Patients newly diagnosed with JIA with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis	Not available
8. Patients seen in yearly follow-up by a pediatric rheumatologist	Not available
Safety KPIs	
9. Tuberculosis (TB) screening	"100% of patients receive TB screening prior to start of any biologic therapy and yearly thereafter"(41)
10. Laboratory monitoring for disease-modifying anti-rheumatic drugs	"70% of patients receiving DMARDs undergo the recommended laboratory monitoring"(41)

1.5.4 KPI Evaluation of Feasibility

In the strategic framework for quality indicator development, Stelfox and Straus outline four criteria: 1) important, 2) scientifically sound, 3) feasible, and 4) usable.(42) The modified Delphi panel (1) used to establish the set of UCAN CURE KPIs, ensured the important and scientifically sound criteria were qualitatively met through the process of selecting and ranking the KPIs. Stelfox and Straus define the criterion of scientifically sound as "measure will produce consistent

and credible results".(42) Scientifically sound can be routinely re-evaluated qualitatively through "limited literature reviews … combined with expert input [and] may be equally effective to more comprehensive systematic reviews".(42) The criterion for feasibility, defined as the "quality indicator can be implemented" into patient care and is usable, indicating that the "target audience can understand the results and use them for decision making".(42) A key factor in the feasibility of measurement is having "the required information to measure performance available from relevant data sources".(43) Indicators are to be operationalized in order to assess feasibility.(44) The information needs to be clinically important and scientifically sound as a basis of assessing quality with respect to a specific patient's progress and ongoing health. This research quantitatively evaluated the feasibility of the established KPIs by reporting on the current levels of performance, documentation frequency, and compliance of these KPIs within routinely collected JIA patient data. Future research will be required to assess the usability of these KPIs for decision makers.

Although many of the 10 KPIs identified by the UCAN CURE project team were also identified by Lovell *et al*. (41), the UCAN CURE project team identified 10 KPIs that represented the most current objectively developed KPIs available for evaluation.(1) The results of this research will inform decision-makers and clinicians on improving JIA patient care and outcomes, and ultimately future studies to establish benchmarks of JIA patient care. Barber *et al*. noted that their selected KPIs are to be implemented and tested in future studies in order to "help assess strategies for care improvement".(1)

1.5.5 KPI Reporting

The first step in KPI reporting is to establish the operational definitions for each indicator. The operational definitions consist of a numerator and denominator where the numerator is the

unit of measurement that has data documented that meets the respective indicator, and the denominator is the total eligible unit of measurement in the measurement period. This operational definition was the number of patients with visits that report the required data at every visit divided by the total number of patients in the measurement period. Documentation frequency was operationalized as the number of visits that report the required data divided by the total number of visits in the measurement period. As they capture different things, both definitions were used in this research to achieve the broadest understanding of the distribution of documentation. Barber *et al*. (8) used many of the commonly proposed methods to report and record KPIs, specifically using descriptive statistics to calculate baseline characteristics and chi-square tests to "examine differences in performance over time". They also developed control charts "for the measures depicting performance over time compared to overall mean, and with upper and lower control limits set at 3 standard deviations (SDs) above and below the mean".(8) Another study (7) also used 1) descriptive statistics to calculate baseline characteristics for reported waiting times, 2) a non-parametric Kruskal-Wallis rank test to examine the difference in waiting times among the JIA categories, and 3) evaluated factors associated with waiting times by using cox proportional hazard modelling to estimate hazard ratios at the 95% confidence level.(7) Overall, the study found that "62% of JIA cases were seen [by a pediatric rheumatologist] within the established waiting times benchmarks".(7) In addition, Barber *et al*. (3) reported on JIA cases where patients saw a pediatric rheumatologist within the first year after their JIA diagnosis by recording the diagnosed JIA incident cases per fiscal year and the percentage of cases seen by a pediatric rheumatologist within a year. When reporting JIA follow-up visits with a pediatric rheumatologist using fixed 12-month intervals, they recorded the observed and expected number of follow-up visits in each fiscal year.(3)

Saliba *et al*. (45) looked at the feasibility of quality indicators for the management of geriatric syndromes in nursing home residents. Similar to Barber *et al*. (1), they used a modified Delphi process to evaluate potential quality indicators and ranked the indicators on the following criteria: 1) validity – process associated with improved outcomes; 2) feasibility of measurement – with charts or interviews; 3) feasibility of implementation – given staffing resources in average community nursing homes; and 4) importance – expected benefit and prevalence in nursing homes.(45) Both Barber *et al*. (1) and Saliba *et al*. (45) used a Likert scale; however, where Barber et al. rated each proposed KPI from 1 to 9 , Saliba *et al*. used the panel's median validity and importance ratings: scores rated from 0-3 were considered 'not feasible'; scores rated from 4-6 were 'variable'; and scores rated from 7-9 were 'clearly feasible'. Although Saliba *et al*. (45) followed the same qualitative method to create a final set of KPIs as Barber *et al*. (1), Barber *et al*. indicated that the next step should be a quantitative method that actually looks at what is currently reported in the clinical patient data to determine the actual versus perceived feasibility of each KPI. Accordingly, this study determined the feasibility of the JIA KPIs using a quantitative approach based on the performance, documentation frequency, and compliance levels of reporting for each KPI using routinely collected JIA patient clinical data.

There is a significant importance in measuring changes in adherence over time. Like the chi-square test, the Cochran-Armitage statistic can also be used to measure changes in adherence. To demonstrate the change in therapy adherence over time from the first follow-up to the last follow-up visit, Maqutu *et al*. used the Cochran-Armitage statistic to test for the "trend of optimal adherence over time" when exploring factors affecting antiretroviral therapy among HIV positive adults over three years.(46) As the Cochran-Armitage statistic method requires the presence of an ordinal variable which is more effective when studying drugs, (47) it was not

chosen to assess differences in reporting over time for this JIA study. This study also did not use the Cochran-Armitage test as the scope of this study was using descriptive statistics rather than inferential.

1.5.6 KPIs in Practice

The National Quality Forum (NQF), under a contract with the RAND Corporation, established a portfolio of quality and efficiency measures and then evaluated its uses "for the purposes of accountability".(48) Their evaluation found that public reporting was the most common use of the measures which were drawn from seven domains: 1) structure of care, 2) process of care, 3) outcome, 4) access, 5) safety, 6) costs, and 7) patient experience.(48) The report discovered that process of care measures were the most widely used.(48) The driving forces for the use of performance measures were to respond to local health issues, meet legislative requirements related to pay for performance and enable public reporting.(48)

The Rheumatology Informatics System for Effectiveness (RISE) is the largest rheumatology registry in the United States with over 1,000 rheumatologists and 2.4 million patients.(49) The registry was designed by the American College of Rheumatology to optimize patient outcomes, navigate reporting requirements, advance rheumatology, and demonstrate the value of rheumatology.(49) The registry helps clinicians monitor a patient's quality of care by having the ability to track performance at the patient-level on various measures as well as allow clinicians to compare themselves to their peers nationally.(50) The RISE registry is personalized to automatically collect data from electronic medical record systems at no extra cost to the providers.(50) Given that the measures in the registry for the Merit-based Incentive Payment System (MIPS) are reportable and the online dashboard is free, it is likely clinician uptake is higher among clinicians participating in the RISE registry.

Alberta's largest rheumatology registry is Rheum4U (51), though it does not currently include JIA. Currently, data must be entered directly into the Rheum4U platform as well as the provincial medical record system. This platform differs from that used in the RISE registry as it does not currently personalize to different electronic health record systems. Rheum4U is used to provide insight on KPI levels and patient care.(52) The registry collects information on patient-reported outcomes completed at their visits, medication history, joint assessments and disease activity.(53) Rheum4U also has the ability to be linked to administrative data to enable more in depth research.(53)

Established across Canada and the United States in 2011, the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) is focused on improving the outcomes of JIA patients.(54) The network uses its registry to inform areas of quality improvement.

1.5.7 JIA KPI Development

As the evaluation of quality of care in JIA is not part of current routine care in Canada, Barber *et al*. (1) developed a set of KPIs to measure the quality of care for JIA patients. The team used a panel of experts to develop and compile KPIs that were relevant and feasible to collect during JIA routine care. Many of the compiled KPIs were previously proposed by Lovell *et al.* (41). The first phase involved conducting systematic and grey literature searches on "existing KPIs, quality improvement efforts, and clinical practice guidelines".(1) Their second phase involved establishing a working group of JIA and measurement experts to determine the candidate list of KPIs (1). The third phase involved selecting the KPIs in the evaluation framework through a three round modified Delphi panel: round one involved the rating of each candidate KPI against three criteria 1) targeting an important gap in JIA care, 2) the likelihood of being measured, and 3) the overall priority; round two involved an in-person discussion on the

results; and, round three consisted of re-rating the candidate KPIs against the same criteria questions used in round one.(1)

Barber *et al*. (1) identified 37 candidate KPIs from the systematic review. The working group of experts reviewed the project methodology and draft KPIs to develop a short-list of 12 KPIs to be reviewed by the modified Delphi panel. Some of the 12 quality measures for the process of care in JIA that were proposed by Lovell *et al.* (41), did not meet the threshold for inclusion when rated by the panel. It should be noted that Barber *et al*. never dismissed the importance of any of the indicators that were evaluated in their study but rather reported that indicators were excluded because the panel provided a lower Likert rating. Barber *et al*. also acknowledged that those indicators excluded from the study should be further studied.(1) For example, Barber *et al*. (1) noted that the panelists excluded the parameter for documentation on eye examinations for uveitis, an inflammation in the eye that is associated with JIA, because it was seen as a challenge for many centres to document and could potentially result in the reporting of erroneously low levels.

Both Barber *et al.* and Lovell *et al.* acknowledged that their working groups viewed the driver for improvement to quality of care was a widely adopted use of a standardized set of quality measures.(1,41) Both studies (1,41) also allowed for the patient's professional evaluator to have flexibility in choosing the specific tools or instruments for their evaluation by using *any validated tool* to measure the respective KPIs. For example, the rheumatological joint count indicator is measured using a validated tool.(1) Barber *et al*. excluded patient satisfaction due to feasibility of measurement concerns.(1)

To be consistent with Canadian clinical practice, Barber *et al*. updated the interval periods to each and every visit, screening for tuberculosis to 12-months prior to the commencement of

biologic therapy, and laboratory monitoring for patients on methotrexate or leflunomide to every 3-4 months after the first month.(1)

Barber *et al*. included tuberculosis screening and laboratory monitoring to address safety concerns.(1) It is important that patients are screened for tuberculosis prior to commencing biologic therapy because the "most adverse effects of biological [DMARDs] is an increased risk of reactivation of latent tuberculosis infection".(55) As DMARDs can be associated with "increased cardio vascular risk, liver and hematologic toxicity, renal impairment, infection and bleeding", laboratory monitoring is a "critical part of patient care" because these risks are minimized through early identification of "abnormal laboratory values".(56) The laboratory monitoring of methotrexate and leflunomide was chosen to represent the most common DMARDs and the interval period of DMARDs is consistent with Canadian clinical practice.(1)

The clinical juvenile arthritis disease activity score (cJADAS) was selected as an indicator of quality care because it is a single indicator representing three components (physician's global assessment, joint count, and parent/patient well-being assessment). The cJADAS was also chosen because it would streamline data collection process across Canada (1) and eliminate the requirement of laboratory services to measure disease activity.(1) Rheumatological joint count, functional ability, physician's global assessment and pain were selected as KPIs to track affected joints and disease progression.

CHAPTER TWO: METHODS

2.1 Research Design Overview

This research is a quantitative, retrospective cohort study design that followed a positivist paradigm using a deductive approach.(57) This research is reporting on the frequency of the data required to measure the KPIs documented in the routinely collected data. The previously developed set of KPIs created the structure of what data was required for collection to measure the KPIs. This study does not evaluate which KPIs *should* be measured rather it evaluates the ability to measure the predetermined set of KPIs (previously established through a Modified Delphi Panel) based on the availability of data in the routinely collected data sources. Positivism is used when a single reality that can be measured and known, in this study that is whether the data is documented within the specified routinely collected data and what is the frequency of the data being documented.

Ontology refers to the nature of reality while epistemology is the nature of knowledge, how reality can be known.(57,58) The ontological assumption of positivism is that the truth is discoverable, and the epistemological assumption is that the research findings will lead to a better understanding of this truth (the feasibility of measuring the KPIs). The outcome of this study was to determine if the KPIs were feasible to measure based on the observations of data being present or absent, which is discoverable by evaluating the routinely collected data sources. The conclusions of this research are to determine if the data required to measure the KPIs are captured in the routinely collected data and their documentation frequencies. These results were used to suggest what data should be documented more consistently to accurately measure and monitor the KPIs. The findings and recommendations of this study can guide future research to

determine if changes/refinement to the KPIs are required. This is consistent with Ferrua *et al.*'s 'update' step in the development of quality indicators after the first test of feasibility.(59)

This research uses a deductive approach to explore whether the data for the specified KPIs are documented within the routinely collected data. The deductive approach begins with a theory or premise from the literature to then conduct research where the observations and results are used to inform the initial theory or premise.(57) As the KPI values can later guide target levels of reporting, a quantitative method was necessary to assess the feasibility of the KPIs. Since a performance measure is a *quantitative tool* (33), a quantitative approach to measurement was necessary to evaluate the feasibility of measuring the KPIs prior to implementation.(24) The value of the KPIs will lie in whether the "target audience can understand the results and use them for decision-making".(42)

2.2 Cohort

Patients were identified from the Alberta Children's Hospital (ACH) Pediatric Rheumatology Clinic, a tertiary practice and academic centre including seven pediatric rheumatologists (PR) providing care for pediatric JIA patients up to and including the age of 17.(60,61) The clinic provides multidisciplinary care; patients can access care from pharmacists, physiotherapists, registered nurses, rheumatologists, and social workers.(60)

This project leveraged a dataset collected in a previous research study (62,63), which identified a JIA cohort from the ACH using an administrative data algorithm (64) for JIA and confirmed diagnosis by cross-referencing JIA diagnosis in Calgary's acute care electronic storage system, Sunrise Clinical Manager (SCM). When the diagnosis was unclear, the research team consulted a pediatric rheumatologist and patients were excluded if their diagnosis was secondary to another disease. The previous study chose the highest sensitivity case ascertainment

algorithm to validate JIA diagnosis between 2011 and 2019. This two-step process was applied to increase the probability of all relevant patients being included in the cohort. The inclusion criteria, International Classification of Diseases (ICD) codes used for this algorithm and patient identification is further discussed in Grazziotin *et al.*(62) As one visit would not adequately reflect a pattern of care for routinely collected data, each patient required a minimum of two clinic visits for inclusion into the cohort. Data collected within SCM consists of a summary of the clinic visit: consultation notes, nursing notes and pharmacy notes. The complete paper chart for the clinic visit is not documented within SCM.

Of the 392 JIA patients at the ACH Pediatric Rheumatology Clinic, a subset of 140 patients met the inclusion criteria of having a JIA diagnosis and first visit with a pediatric rheumatologist at the clinic between January 1st, 2016, and December 31st, 2018. This period of diagnosis was chosen to provide the most recent KPI performance levels as well as sufficient time for a follow-up visit to capture patterns of reporting. This population size was justifiable for reporting the current levels of each KPI because it represents all the patients diagnosed at the Alberta Children's Hospital in that period.

2.3 Data Collection

Figure 1 shows the timeframes for this study. A subset of the cohort who were diagnosed between 2016 and 2018 were analyzed to capture the most recent KPI documentation frequencies. Data were collected from January 1st, 2016, to March 13th, 2020. To have a series of follow-up visits for the patient and to track the patterns of reporting, diagnosis was only up to 2018 inclusive. Additional data were collected to complete the information required for each KPI. To determine whether the KPI was met, data for the respective KPI description (e.g., if joint count was conducted) was collected for all KPIs through an SCM electronic chart review and

entered into a REDCap data collection form shown in **Table 4**. The REDCap form was created with input from a pediatric rheumatologist and members of the research team. The form included visits with the pediatric rheumatologist, physiotherapist, and nurse at the Alberta Children's Hospital Pediatric Rheumatology Clinic. For the safety KPIs (KPIs #9 and #10), administrative data for laboratory tests were extracted from the Practitioner Claims (KPI #9), NACRS (KPI #9) and the Consolidated Laboratory Data Repository (KPIs #9 and #10).

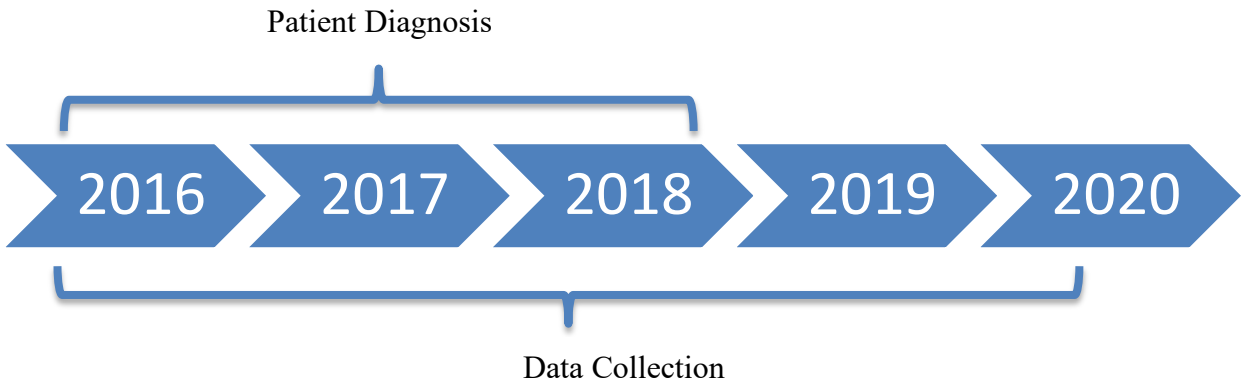

Figure 1: Retrospective Chart Review Timeline

Table 4: KPI Variables Collected

KPI	Variable Collected	How Variable Reported
Measurement of Patient Outcomes KPIs		
1. Rheumatological joint count	During this visit, was the joint evaluation recorded? (Either by counting the number of active joints, describing the affected joints, or describing that no joints were active)	Binary (yes/no)
2. Physician's Global Assessment of disease activity	During this visit, was the Physician global assessment recorded?	Binary (yes/no)

3. Assessment of functional ability	During this visit, was the CHAQ score recorded?	Binary (yes/no)
	Does the PR report the patient's functional ability during this visit using a validated tool other than the CHAQ?	Binary (yes/no)
4. Composite disease activity measurement	Was the cJADA score reported during the visit?	Binary (yes/no)
	During this visit, was the joint evaluation recorded? (Either by counting the number of active joints, describing the affected joints, or describing that no joints were active)	Binary (yes/no)
	During this visit, was the Physician global assessment recorded?	Binary (yes/no)
	During this visit, was the parent/patient well-being assessment recorded?	Binary (yes/no)
5. Assessment of arthritis-related pain	During this visit, does the clinician report about any assessment of arthritis-related pain?	Binary (yes/no)
Access to Care KPIs		
6. Waiting times for rheumatologist consultation for patients with new onset JIA	During this visit, was any information on referral date between GP and first visit to the PR recorded?	Binary (yes/no)
7. Patients newly diagnosed with JIA with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis	Date of JIA diagnosis confirmed.	Date (day/month/year)
	What is the date of the visit?	Date (day/month/year)
8. Patients seen in yearly follow-up by a pediatric rheumatologist	Date of first visit after JIA diagnosis confirmed.	Date (day/month/year)
	What is the date of the visit?	Date (day/month/year)
Safety KPIs		

9. Tuberculosis (TB) screening	If patient started a new biologic: Was the performance of the tuberculosis test recorded in the chart?	Binary (yes/no)
10. Laboratory monitoring for disease-modifying anti-rheumatic drugs	For patients on methotrexate or leflunomide: Did the chart report on tests ordered in that clinic visit?	Categorical Variable Option: • Specific lab tests were reported as ordered in that clinic visit • Lab tests ordered (tests not specified) in that clinic visit • It was reported that no lab tests ordered • No reported of ordering tests
	For patients on methotrexate or leflunomide: Did the chart report on test results reviewed in that clinic visit?	Categorical Variable Options: • Specific lab test results were reported in that clinic visit • Lab test results reported, but no specific tests • It was reported no lab tests were done since last visit • No reporting of test results reviewed • Results reported as pending for today/results not yet available/missing

2.3.1 Data Sources

Data for each KPI was extracted from AllScripts Sunrise Clinical Manager (SCM), a Calgary-wide electronic documentation storage system used for medical records. The system was chosen as the data source because it is currently used in Calgary and is a centrally accessible digitized summary of the in-clinic visits. SCM provides summary documents for each visit. SCM does not equate to the full paper chart found within clinics, but rather contains structured notes, transcribed documents and select flowsheets. Since it is not practical or feasible for decision-

makers to go to clinics for routine monitoring purposes, in-clinic paper charts were not used in this study.

Same day visits with the pediatric rheumatologist, nurse, and physical therapist having separate notes entered into SCM were treated as a single visit for the documentation analysis. As the data entered in SCM is not standardized between clinicians, the documentation patterns were measured to understand if there was sufficient data in SCM to measure the KPIs. By using the electronic SCM system to determine the feasibility of measuring the JIA KPIs, this study helped to identify areas of focus with respect to what data needs more consistent documentation and provided insight into how it can be recorded in the new province-wide electronic medical record (EMR) system, Epic.(65,66) The study results can direct recommendations on gaps in SCM data that should be addressed when transitioning to the new system Epic.

It is important to note that the absence of data in SCM does not necessarily mean that the data were not collected, it may be available in other clinic databases, paper charts, or researchers and decision-makers may not have access to the data as it may be restricted to clinicians only. As the purpose of this thesis was to assess the feasibility of measuring the KPIs using readily available data in the electronic repository, this study does not evaluate or infer the performance of the clinician. The results could demonstrate that the data contained in SCM is not sufficient to measure the KPIs. This is noted as a limitation of the data source and all findings reference this potential explanation for KPIs that exhibit lower levels of reporting.

Data for the measurement of patient outcomes and access to care KPIs (KPIs #1 to #8) were collected from SCM. For the purposes of this analysis, data from Clinibase, which contains the referral letters for patients in Calgary (KPI #6), was excluded as the electronic data was not available for the study duration. The Practitioner Claims database was not used for the visits in

the access to care KPIs (KPIs #7 and #8) as it does not specify the type of pediatrician that the patient saw, it only lists the identification number for each doctor.

In addition to that found in SCM, the safety KPIs (#9 and #10) required information on tuberculosis screening and laboratory monitoring. This data was obtained from the readily available administrative databases: Practitioner Claims, National Ambulatory Care Reporting System (NACRS) and the Consolidated Laboratory Repository. These three databases were used to determine whether documentation was present for these patients and if so, to record the dates of the relevant laboratory tests. In Alberta, ICD-9 codes (795.7 – *other nonspecific immunological findings* and V74 – *screening for pulmonary tuberculosis*) and Health Service Codes (98.8 – *Invasive diagnostic procedures on skin and subcutaneous tissue*) for Practitioner Claims; and ICD-10 codes (Z11.1 – *encounter for screening for respiratory tuberculosis*) and CCI intervention codes (2ZZ08MF – *Test, total body microorganisms [e.g., tuberculin] intracutaneous [intradermal] injection, immediate type reaction*) for NACRS were used to determine whether patients who were prescribed biologics, were screened for tuberculosis (KPI #9). The Consolidated Laboratory Repository database was used to identify if patients on biologics had a TB blood test (KPI #9) and if patients on methotrexate and leflunomide (KPI # 10) had the relevant laboratory tests.

Ethics approval was obtained from The Conjoint Health Research Ethics Board, University of Calgary (REB19-0471).

2.3.2 Data Collection Guidelines/Standard for Chart Review

Individuals that collected data through SCM received training in the documentation required for each input of the REDCap data collection form. To ensure consistency and quality assurance, 10% of a random sample of patients from the SCM charts were reviewed independently by two

members from the research team. Inter-rater reliability was assessed with Cohen's kappa (67) for each KPI question:

1. During this visit, was the joint evaluation recorded? (Either by counting the number of active joints, describing the affected joints, or describing that no joints were active.)
2. During this visit, was the Physician global assessment recorded?
3. During this visit, did the clinician report about any assessment of arthritis-related pain?
4. During this visit, was the Childhood Health Assessment Questionnaire (CHAQ) score recorded?
5. Does the PR report the patient's functional ability during the visit using a validated tool other than the CHAQ?
6. Was the clinical juvenile arthritis disease activity score (cJADAS) reported during the visit?
7. During this visit was the parent/patient well-being assessment recorded?
8. During this visit, was any information on referral date between general practitioner (GP) and first visit to pediatric rheumatologist (PR) recorded?
9. If the patient initiated biologic therapy, was a tuberculosis screening completed?
10. Is the patient on methotrexate or leflunomide?
    10.1 Did the chart report on tests ordered in that clinic visit?
    10.2 Did the chart report on test results reviewed in that clinic visit?

To ensure consistency and avoid systematic errors, the review was initiated early in the data collection period. Cohen's kappa was calculated by the observed percentage of agreement (P(a)) minus the probability of expected agreement due to chance (P(e) divided by 1 minus P(e)).(68) A

kappa statistic of 1 means perfect agreement, 0 means completely random agreement, and -1 means perfect disagreement.(67) There was perfect agreement for questions 1 to 9 above (a kappa value equal to 1). The kappa for question 10.1 was 0.93 and for question 10.2 it was 0.86.

In addition, each discrepancy was re-evaluated by each data extractor and then decisions were discussed and agreed upon. To minimize the risk of missed questions by the data extractor, the REDCap data collection form was constructed to require select questions to be answered. There were no missing data points. Observed outcomes were calculated as the frequency of reported KPIs in each visit in the measurement period and the expected compliance standards refers to the total number of eligible visits in the measurement period.

The previously collected data included: the date of the visit; type of visit; comorbidities reported; if a joint evaluation was reported; the number of active joints and which joints were active (active joints are considered to be swollen, tender, have fullness, with an effusion, with limited or decreased range of motion, active, affected, stiffness, with inflammation, and dactylitis); the physician global assessment; the parent/patient well-being/global assessment; the Childhood Health Assessment Questionnaire (CHAQ); disease status; and, for patients beginning a biologic treatment – if a tuberculosis test was completed.

The CHAQ was specifically listed as a variable because it measures physical function which is considered "one of the core outcome measures" in clinical trials of JIA and it is the "most widely used measure of function in childhood arthritis".(69) The additional data that was collected for this specific research study included: if the clinician reports any assessment of arthritis-related pain; if this was overall pain or joint specific; if a named tool was used; if no named tool was used then if the pain was recorded as a numerical scale, a categorical description, a dichotomous answer (no pain or pain), or other; if the clinician reports the patient's functional

ability using a named tool other than the CHAQ; if the clinician reports the cJADA score; and, if any information on referral date between the general practitioner and first visit to the pediatric rheumatologist was recorded.

Where KPI definitions required the use of a "validated tool", data was collected on the tool used and each named tool was verified or rejected based on literature.

2.4 Analysis

Data were first assessed and recorded as a binary (yes/no) variable based on the presence of data for each KPI being documented at least once in the cohort and then by the number of patients who had data for the respective KPI documented. The documentation frequencies were reported as percentages based on the operational definitions described in **Table 2**. Documentation frequencies reported the overall proportion of visits with documentation for the cohort, the number of first visits at the clinic with documentation, the average proportion per patient, and the KPI definition calculated based on the pre-defined KPI case definition for numerator and denominator specified in **Table 2**.(1) In addition to the previously defined operational definitions in **Table 2**, the documentation frequency was calculated for each KPI defined as the percentage of eligible visits where data for the KPI was documented divided by the total eligible visits in the measurement period. Descriptive statistics of proportions, means, standard deviations, and medians (interquartile range) were also used to report on current documentation levels for each KPI.(35) As patients had different lengths of follow-up time, a comparison between the mean number of visits with documentation of each measure of patient outcome KPI (KPIs #1 to #5) and the mean number of visits was conducted. The waiting times access to care KPI (KPI #6), was measured as 50^{th} and 90^{th} percentile waiting times as per the pre-defined case definition.(1) Results from visit notes by the pediatric rheumatologist, nurse,

and physical therapist that occurred at the same visit were reported together. The last visit at the clinic was defined as the earliest date when the patient either left the province, transitioned to adult care, or the March 13th, 2020, study cut-off date.

For the annual follow-up visits (KPI #8) the numerator for each year was the number of eligible patients who had a follow-up visit during the respective year. The denominator was the sum of the patients who had a follow-up visit and the number of patients who should have seen their pediatric rheumatologist but did not. The last eligible year for each patient was determined by the earliest date that the patient either transitioned to adult rheumatology, moved out of the province, or March 13, 2020, the study's cut-off date.

Data from the Consolidated Laboratory Repository was initiated in 2009 with limited data and full data from 2012 onward.(70) Practitioner Claims data were available from 1993 and the NACRS from 1997.(70) After isolating patients with the respective procedure and diagnoses codes, a variable representing the date of the first biologic being prescribed (taken from SCM) was used as the biologic start date to calculate the duration between the TB test and the biologic start date (KPI #9). In the case of patients with multiple TB tests, the test closest to the biologic start date was used. This represents patients who had a TB test regardless of their biologic start date. An additional calculation was conducted to represent the number of patients who had a TB test within the 12-months prior to the first biologic start date.

For the laboratory monitoring of patients on methotrexate or leflunomide (KPI #10), the lab tests were filtered to only include: 1) complete blood count (CBC); 2) aspartate aminotransferase (AST); 3) alanine aminotransferase (ALT); 4) international normalized ratio (INR); 5) partial thromboplastin time (PTT); 6) creatinine; and 7) albumin. The date that the patient was prescribed DMARD, methotrexate (oral or subcutaneous) or leflunomide, was used as the

DMARD start date. The DMARD stop date was either the stop date listed in SCM, the date the patient transitioned to adult care, left the province, or the study cut-off date, whichever came first. As per the KPI definition, a patient was considered to have *missed* an interval of laboratory testing if a test date from the Consolidated Laboratory Repository did not occur during each specified interval (initiation to first month, 4-8 months, 8-12 months, etc.) until the stop date. **Figure 2** demonstrates the intervals used to determine the duration a patient was on methotrexate or leflunomide. Each patients *start date* was determined as the clinic date where the pediatric rheumatologist prescribed methotrexate or leflunomide. A patient's *stop date* was determined by whichever event came first – either a stop date being documented in a subsequent clinic visit, if the patient transitioned to adult rheumatology or moved out of the province, or the cut-off date of March 13, 2020.

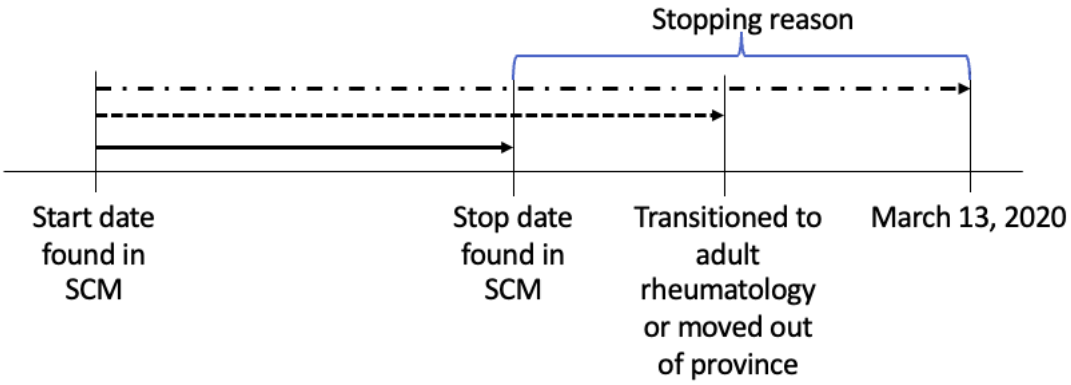

Figure 2: Duration of laboratory monitoring

CHAPTER THREE: RESULTS

3.1 Cohort Characteristics

As shown in **Table 5**, the median age at diagnosis in the JIA cohort was 11 years old. The median time between first visit with the pediatric rheumatologist and diagnosis date was 36 days. The shortest time between first pediatric rheumatologist visit and diagnosis date was 10 days prior to the first pediatric rheumatologist visit (in these two cases, the patients were diagnosed through hospital admissions before their first visit with the pediatric rheumatologist). The median time between symptom onset and first visit with the rheumatologist was four months. The average follow-up period was three years. This was the time between the first visit at the clinic and the last visit at the clinic.

Table 5: JIA Cohort Clinical Characteristics

Clinical Characteristics	Total Cohort (n=140)	
	Mean (SD)	**Median (Q1, Q3), [min, max]**
Age at diagnosis (years)	10 (5)	11 (6, 14), [1, 18]
Time between first pediatric rheumatologist visit and diagnosis date (days)	85 (126)	36 (0, 103), [-10, 596]
Symptom onset as time between initial symptoms and first visit with pediatric rheumatologist (months)	12 (18)	4 (2, 13), [0, 135]
Follow-up period as time between first visit at clinic and last visit at clinic (years)*	3 (1)	3 (2, 3), [0, 4]

Notes: No missing data points. Values are rounded to the nearest whole number.
*Last visit at clinic was defined as the end of follow-up which was the earliest date of either when the patient left the province, transitioned to adult care, or the March 13th, 2020, cut-off date.

As shown in **Table 6**, over half of the cohort was female (57%) and oligo-arthritis was the most frequent JIA subtype (41%). The results from **Table 5** and **Table 6** were similar to the larger cohort.(62,63)

Table 6: JIA Cohort Patient Demographics

Patient Characteristics	Total Cohort (n=140), n [%]
Sex	
Male	60 [43%]
Female	80 [57%]
JIA Subtype	
Systemic	5 [4%]
Oligo-arthritis (persistent, extended, not specified)	57 [41%]
Polyarticular arthritis	45 [32%]
Enthesitis-related arthritis	24 [17%]
Other (psoriatic, undifferentiated, unknown)	9 [6%]

Notes: No missing data points. Values are rounded to the nearest whole number.

As shown in **Table 7**, there were a total of 1360 visits for the cohort between 2016 and March 13th, 2020. Visits are defined as all patient visits to the early arthritis clinic with the pediatric rheumatologist, physical therapist, and nursing professional. The median number of visits per patient during the follow-up period was 11 visits and ranged from 2 to 29 visits.

Table 7: JIA Cohort Visit Characteristics

Visit Characteristics	Visit (PR, Nurse, PT)
Total number of visits for the cohort	1360
Mean number of visits per patient (SD)	11 (5)
Median number of visits per patient (Q1, Q3), [min, max]	11 (8, 14), [2, 29]

Notes: No missing data points. Values rounded to the nearest whole number.

The subsequent sections discuss the study objectives, specifically, presenting the results on the KPI data documentation in the routinely collected data and the level of documentation frequency for each KPI.

3.2 Documentation of set of KPIs (Objective 1)

All KPIs were documented in at least one visit in the cohort (**Table 8**). Of the measurement of patient outcomes KPIs, an assessment of functional ability besides the CHAQ was not found in SCM. The explicit cJADAS was also not found in SCM; however, the components required to calculate the cJADAS were found. For the presence of visit dates (KPI #7 and #8), there was an assumption that there were no missing visits from the data entered visits into SCM. As there are multiple methods of screening for tuberculosis, documentation was found in the Consolidated Laboratory Repository, Practitioner Claims, and NACRS for patients in the cohort who had a TB test. The safety KPIs were also documented in SCM.

Table 8: Is the data for the respective KPI documented in at least one visit in the cohort?

KPI	Visit (PR, Nurse, PT)
Measurement of Patient Outcomes KPIs	
1. Rheumatological Joint Assessment in SCM	Yes
2. Physician's Global Assessment (PGA) of Disease Activity in SCM	Yes
3. Assessment of Functional Ability	Yes
Assessment of Functional Ability using CHAQ in SCM	Yes
Other Functional Ability Assessment in SCM	No
4. Composite disease activity measurement	Yes
All Components of cJADAS present in SCM	Yes
cJADAS in electronic SCM	No
5. Assessment of arthritis-related pain in SCM	Yes
Access to Care KPIs	
6. Waiting time between referral date and first visit in SCM	Yes
7. Prescence of visit dates for first year of diagnosis in SCM	Yes
8. Prescence of visit dates for follow-up visits in SCM	Yes
Safety KPIs	

9. Tuberculosis Screening	Yes
Tuberculosis Screening in SCM	Yes
Tuberculosis Screening in Consolidated Laboratory Repository	Yes
Tuberculosis Screening in Practitioner Claims	Yes
Tuberculosis Screening in NACRS	Yes
10. Laboratory Monitoring for DMARDs	Yes
Labs Ordered in SCM	Yes
Lab Results in SCM	Yes
Laboratory Tests in Consolidated Laboratory Repository	Yes

Notes: 'Documented' – means data required for each KPI is found in at least one visit in the entire JIA cohort. If the data is found to be documented, this is shown in the table as 'Yes'. If data is not found, this is shown in the table as 'No'. If the KPI is not relevant to be reported separately for the respective visit type, it is shown in the table as N/A.

The safety KPIs were the most frequently captured electronically, followed by the access to care and then the measurement of patient outcomes KPIs (**Table 9**). For the measurement of patient outcomes KPIs, 56 (40%) patients had a Childhood Health Assessment Questionnaire (CHAQ) score documented in at least one visit. No other assessment of functional ability was found in the SCM records. The physician's global assessment (PGA) was documented in at least one visit for 66 (47%) of the patients and 58 (41%) patients had all the required components for the cJADAS (joint count, PGA, and parent/patient assessment of well-being) in at least one visit. The most documented of the five measurement of patient outcomes KPIs were the rheumatological joint assessment (100%) and assessment of arthritis-related pain (100%). No validated tools were specified for the joint or pain assessments.

For the three access to care KPIs, visit dates for first year diagnosis and for follow-up visits were the most frequently documented. Discussion of the time between a patient's referral and their first clinic visit was found in 24 (17%) patient charts. This ranged from either an explicit

date of the referral receipt, a date when the patient last saw their family doctor or an Emergency room (ER) doctor who referred them, a numerical description (i.e., the patient was referred two weeks ago), or a categorical description (i.e., the patient has waited a long time for this visit).

Of the two safety KPIs, laboratory monitoring for patients on the DMARDs methotrexate and leflunomide was documented in all patients. In all the data sources for TB screening, 96% patients had documentation of a TB test (53 patients in SCM, five patients in Consolidated Laboratory Repository, 18 in Practitioner Claims, and four in NACRS) with some having documentation in multiple databases. One patient had TB testing documentation in the administrative data and there was no TB testing documentation in SCM. All patients on methotrexate or leflunomide had documentation in either SCM or the Consolidated Laboratory Repository.

Table 9: If the required information was found documented in at least one visit for each patient.

KPI	Visit (PR, Nurse, PT)
Measurement of Patient Outcomes KPIs	
1. Rheumatological Joint Assessment found in SCM	140 (100%)
2. Physician's Global Assessment (PGA) of Disease Activity found in SCM	66 (47%)
3. Assessment of Functional Ability[1]	56 (40%)
Assessment of Functional Ability using CHAQ in SCM	56 (40%)
Other Functional Ability Assessment in SCM	0
4. Composite disease activity measurement[2]	58 (41%)
All Components of cJADAS present in SCM	58 (41%)
cJADAS in SCM	0
5. Assessment of arthritis-related pain found in SCM	140 (100%)
Access to Care KPIs	
6. Waiting time between referral date and first visit found in SCM	24 (17%)

7. Prescence of visit dates for first year of diagnosis found in SCM [n=137]*	137 (100%)
8. Prescence of visit dates for follow-up visit found in SCM [n=137]*	137 (100%)
Safety KPIs	
9. Tuberculosis Screening [n=56]**	54 (96%)
Tuberculosis Screening in SCM [n=56]**	53 (95%)
Tuberculosis Screening in Consolidated Laboratory Repository [n=56]**	5 (9%)
Tuberculosis Screening in Practitioner Claims [n=56]**	18 (32%)
Tuberculosis Screening in NACRS [n=56]**	4 (7%)
10. Laboratory Monitoring for DMARDs[3] [n=102]***	102 (100%)
Labs Ordered in SCM [n=99]****	91 (92%)
Lab Results in SCM [n=99]****	91 (92%)
Laboratory Tests in Consolidated Laboratory Repository [n=102]***	102 (100%)

Notes: No missing data points. A patient is included in the "documentation" count if the data required for the KPI was found in at least one visit for that patient. N/A is when data for that KPI would not be recorded in that type of visit. All values are rounded to the nearest whole number. N=140 unless otherwise stated.
*n=137 because 3 patients did not have a follow-up visit after diagnosis date.
**n=56 because this only applies to those prescribed biologics. Documentation of tuberculosis screening in any of the data sources used. One patient's screening was not documented in SCM but was documented in the Consolidated Laboratory Repository.
***n=102 because this is only applicable to those prescribed the DMARDs methotrexate and leflunomide.
****n=99 because this is only applicable to patients who had a visit after being prescribed the DMARDs methotrexate and leflunomide.
[1]The CHAQ was the only assessment of functional ability found.
[2]The cJADA score was never explicitly found, only the components required to calculate the cJADAS (joint count, physician's global assessment, parent/patient assessment of well-being).
[3]Disease modifying anti-rheumatic drugs (DMARDs)

3.3 Documentation frequencies (Objective 2)

3.3.1 Measurement of Patient Outcomes KPIs

3.3.1.1 KPI #1: Rheumatological joint assessment

The KPI description for a rheumatological joint assessment was that "a joint count should be done on all patients at the first visit and at every routine clinic visit".(1) To capture a broader scope of reporting, data was collected on rheumatological joint assessment conducted to account for both a specific count and/or a review of active joints. A rheumatological joint assessment was documented in 99% of visits. The mean number of visits with documentation of a joint assessment was 10 and the median number was 9 with a range from 2 to 28 visits with documentation (**Table 10**). These results were relatively close to the mean and median number of visits during the follow-up period (11) ranging from 2 to 29 (**Table 7**). On average, 99% of a patient's visits had a joint assessment documented in SCM. Of the 140 first visits at the clinic, 139 had documentation of a joint assessment. It was not just the most documented KPI, it was documented at almost every visit for every patient (95%) and was only missed in one patient chart at the first visit.

Table 10: Documentation frequency of KPI #1: rheumatological joint assessment being documented in SCM.

Measurement of Patient Outcomes KPI	
	Visit (PR, Nurse, PT)
Number of visits with rheumatological joint assessment documented [n=1360], n (%)	1351 (99%)
Mean number of visits with rheumatological joint assessment documented (SD)	10 (4)
Median number of visits with rheumatological joint assessment documented (Q1, Q3), [min, max]	9 (7, 12), [2, 28]
Average of the proportion of visits with rheumatological joint assessment documented per patient (95% CI)	99% (99-100)

Proportion of first visits with rheumatological joint assessment documented [n=140], n (%)	139 (99%)
Number of patients with rheumatological joint assessment documented at each and every visit [n=140], n (%)	133 (95%)

Notes: No missing data points. All values are rounded to nearest whole number.

3.3.1.2 KPI #2: Physician's Global Assessment of disease activity

The final description for KPI #2, a physician's global assessment of disease activity, was that "a PGA should be completed on all patients at the initial visit and at each subsequent visit".(1) **Table 11** reports the documentation frequency for a PGA. The mean number of visits with documentation of a PGA was one and the median number was zero with a range from 0 to 9 visits with documentation. These results were not close to the mean and median number of visits during the follow-up period (11) ranging from 2 to 29 (**Table 7**). On average, 7% of a patient's visits had a PGA documented in SCM. Of the 140 first visits at the clinic, one had a PGA documented. A PGA was documented in 15% of visits and no patients had documentation at every visit.

Table 11: Documentation frequency of KPI #2: Physician's Global Assessment (PGA) of disease activity being documented in SCM.

Measurement of Patient Outcomes KPI	
	Visit (PR, Nurse, PT)
Number of visits with PGA documented [n=1360], n (%)	205 (15%)
Mean number of visits with PGA documented (SD)	1 (2)
Median number of visits with PGA documented (Q1, Q3), [min, max]	0 (0, 3), [0, 9]
Average of the proportion of visits with PGA documented per patient (95% CI)	7% (6-8)
Proportion of first visits with PGA documented [n=140], n (%)	1 (1%)
Number of patients with PGA documented at each and every visit [n=140], n (%)	0

Notes: No missing data points. All values are rounded to nearest whole number.

3.3.1.3 KPI #3: Assessment of functional ability

The final description for KPI #3, assessment of functional ability, was that "all patients should receive an assessment of functional ability at the initial visit and at every routine clinic visit".(1) **Table 12** reports the documentation frequency for an assessment of functional ability, using the CHAQ specifically. The CHAQ was the only method of assessment for functional ability found in SCM and was documented in at least one visit for less than half the cohort. The CHAQ is a validated tool for childhood arthritis.(71) The mean number of visits with documentation of a CHAQ score was one and the median number was zero with a range from 0 to 9 visits with documentation. The results were not close to the mean and median number of visits during the follow-up period (11) ranging from 2 to 29 (**Table 7**). On average, 5% of a patient's visits had a CHAQ score documented in SCM and of the 140 first visits at the clinic, one had a PGA documented. A CHAQ score was documented in 11% of visits and no patients within the cohort met the KPI definition.

Table 12: Documentation frequency of KPI #3: CHAQ being documented in SCM.

Measurement of Patient Outcomes KPI	
	Visit (PR, Nurse, PT)
Number of visits with CHAQ documented [n=1360], n (%)	150 (11%)
Mean number of visits with CHAQ documented (SD)	1 (2)
Median number of visits with CHAQ documented (Q1, Q3), [min, max]	0 (0, 2), [0, 9]
Average of the proportion of visits with CHAQ documented per patient (95% CI)	5% (4-5)
Proportion of first visits with CHAQ documented [n=140], n (%)	1 (1%)

Number of patients with CHAQ documented at each and every visit [n=140], n (%)	0

Notes: No missing data points. All values are rounded to nearest whole number.

3.3.1.4 KPI #4: Composite disease activity measurement

The final description for KPI #4, composite disease activity measurement, was the "percentage of patients 16 years and younger with a diagnosis of JIA with an assessment of disease activity cJADAS at every routine clinic visit".(1) **Table 13** reports the documentation frequency of having all the cJADAS components present. The mean number of visits with all the cJADAS components documented was one and the median number was zero with a range from 0 to 9 visits with documentation. The results were not close to the mean and medium number of visits during the follow-up period (11) ranging from 2 to 29 (**Table 7**). On average, 5% of a patient's visits had all the cJADAS components documented in SCM and of the 140 first visits at the clinic, one visit had all the components documented. All the components for the cJADAS were found in 12% of visits and no patients within the cohort had documentation for every visit.

Table 13: Documentation frequency of KPI #4: the components for the cJADAS being documented in SCM.

Measurement of Patient Outcomes KPI	
	Visit (PR, Nurse, PT
Number of visits with all the cJADAS components documented [n=1360], n (%)	169 (12%)
Mean number of visits with all the cJADAS components documented (SD)	1 (2)
Median number of visits with all the cJADAS components documented (Q1, Q3), [min, max]	0 (0, 2), [0, 9]
Average of the proportion of visits with all the cJADAS components documented per patient (95% CI)	5% (4-6)
Proportion of first visits with all the cJADAS components documented [n=140], n (%)	1 (1%)

Number of patients with all the cJADAS components documented at each and every visit [n=140], n (%)	0

Notes: No missing data points. All values are rounded to nearest whole number.

3.3.1.5 KPI #5: Assessment of arthritis-related pain

The final description for KPI #5, an assessment of arthritis-related pain, was that "pain should be assessed in all patients at the first visit and at each subsequent visit that occur at least seven days apart" using a validated tool.(1) Documentation was included when the words "pain" or "arthralgia" were used and did not include pain when movement during the physical examination was described. **Table 14** reports the documentation frequency for this KPI. The mean and median number of visits with a pain assessment documented was 8 with a range from 1 to 28 visits with documentation. These values were close to the mean and median number of visits during the follow-up period (11) ranging from 2 to 29 (**Table 7**). On average, 82% of a patient's visits had a pain assessment documented in SCM and of the 140 first visits at the clinic, 124 had a pain assessment documented. An assessment of arthritis-related pain was documented in 87% of visits and 46% of the cohort met the KPI definition which was the number of patients with an assessment of arthritis-related pain documented at every visit. When looking at the nuance between having a pain assessment documented at every visit and having it documented at every visit if at least seven days apart, the number of patients was 64 and 65 respectively.

Table 14: Documentation frequency of KPI #5: an assessment of arthritis-related pain being documented in SCM.

Measurement of Patient Outcomes KPI	
	Visit (PR, Nurse, PT)
Number of visits with assessment of arthritis-related pain documented [n=1360], n (%)	1186 (87%)
Mean number of visits with assessment of arthritis-related pain documented (SD)	8 (4)

Median number of visits with assessment of arthritis-related pain documented (Q1, Q3), [min, max]	8 (6, 11), [1, 28]
Average of the proportion of visits with assessment of arthritis-related pain documented per patient (95% CI)	82% (80-84)
Proportion of first visits with assessment of arthritis-related pain documented [n=140], n (%)	124 (89%)
Number of patients with assessment of arthritis-related pain documented at each and every visit [n=140], n (%)	64 (46%)
Number of patients with assessment of arthritis-related pain documented at each and every visit if at least 7 days apart [n=140], n (%)	65 (46%)

Notes: No missing data points. All values are rounded to nearest whole number.

3.3.2 Access to Care KPIs

3.3.2.1 KPI #6: Waiting times for rheumatologist consultation for patients with new onset JIA

The final description for the access to care KPI waiting times for rheumatologist consultation for patients with new onset JIA was "the number of days that patients waited, between the date the initial referral was received and the date of consultation" with a pediatric rheumatologist.(1) This was reported as the 50th and 90th percentile waiting times for rheumatologic consultation.(1) **Table 15** represents the documentation frequency and performance for the waiting time between the referral date and the first visit with the pediatric rheumatologist. For 24 patients, the time from referral date to first visit at the clinic was mentioned in the documentation found in SCM either numerically or with a qualitative description where a date was not able to be determined or calculated. Of these patients, 18 had a quantitative timeframe mentioned and only one patient had an explicit referral date reported. For the remaining 17 patients, when the referral date was not explicit, references within the documentation were used to determine the date of referral and when only the month and not the day was reported, the 15th day of the month was used as the date of referral. The cohort size for

systemic JIA patients was too small to report independently. There were 14 systemic and non-systemic patients that met the respective benchmarks of seven days for systemic JIA and four weeks for the other JIA non-systemic subtypes. Of the patients with an eligible date of referral reported, the mean time from referral to first visit was 23 days and ranged from 1 to 50 days. The 50th and 90th percentiles were 24 days and 46 days respectively.

Table 15: Documentation frequency and performance of KPI #6: time between referral date and first visit with pediatric rheumatologist.

Access to Care KPI	
	Visit to PR
Number of patients with a mention of time from referral date to first visit at clinic [n=140], n (%)	24 (17%)
Of the patients with a mention of time from referral date to first visit at clinic [n=24]:	
Number of patients with an eligible date of referral reported, n (%)	18 (75%)
Number of patients with approximate date used for eligible date of referral reported (such as month or week duration specified), n (%)	17 (71%)
Number of patients with a complete date used for eligible date of referral reported, n (%)	1 (4%)
Number of patients without a documented eligible date of referral reported but discussion of waiting time, n (%)	6 (25%)
Number of patients that met benchmark of time from referral to first visit in days [n=18], n (%) **	14 (78%)
Mean time from referral to first visit in days for patients with eligible date of referral reported [n=18], (SD) *	23 (16)
Mean time from referral to first visit in days for non-systemic JIA patients with eligible date of referral reported [n=16], (SD) *	23 (14)
Median time from referral to first visit in days for patients with eligible date of referral reported [n=18], (Q1, Q3), [min, max] *	24 (11, 30), [1, 50]
Median time from referral to first visit in days for non-systemic JIA patients with eligible date of referral reported [n=16], (Q1, Q3), [min, max] *	24 (12, 29), [3, 48]

10th percentile (number of days that 10% of the patients saw a pediatric rheumatologist and 90% are still waiting), [n=18]	4
10th percentile for non-systemic JIA patients, [n=16]	6
50th percentile (number of days that 50% of the patients saw a pediatric rheumatologist and 50% are still waiting), [n=18]	24
50th percentile for non-systemic JIA patients, [n=16]	24
90th percentile (number of days that 90% of the patients saw a pediatric rheumatologist and 10% are still waiting), [n=18]	46
90th percentile for non-systemic JIA patients, [n=16]	45

Notes: All values rounded to the nearest whole number. No missing data points. All values include systemic and other types of JIA. ** Benchmark is 7 days for systemic JIA and 4 weeks for other types of JIA and denominator is n=140. *Includes approximate date used for eligible date of referral reported and complete date of referral reported. When no specific date was reported and only month/year, 15th of the month was used.

3.3.2.2 KPI #7: Patients newly diagnosed with JIA with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis

The final description for KPI #7, percentage of patients with JIA seen by a rheumatologist, was "the percentage of patients with new onset JIA with at least one visit to a pediatric rheumatologist in the first year of diagnosis".(1) The KPI for visits during the first year of diagnosis, defined as 12 months after diagnosis, had a sample size of 137 because three patients did not have a visit date after their date of diagnosis (two patients transitioned to adult care and one patient was lost to follow-up after diagnosis). Of these patients who had at least one visit after diagnosis, 100% saw the pediatric rheumatologist in the first 12 months after diagnosis. The median duration between the first visit at the clinic and diagnosis date was 36 days and ranged from 10 days prior to the first visit to 596 days after the first visit. The median duration between the diagnosis date and the next visit at the clinic was 70 days where the median number of visits in the first 12 months after diagnosis was 3 and ranged from 1 to 11 visits.

Table 16: Compliance of KPI #7: patients newly diagnosed with at least 1 visit in the first 12 months of diagnosis.

Access to Care KPI	
	Visit to PR
Total number of PR visits for cohort in first 12 months of diagnosis [n=1354], n (%)	514 (38%)
Mean duration between first visit at clinic and diagnosis date in days [n=140], (SD)	85 (126)
Median duration between first visit at clinic and diagnosis date in days [n=140], (Q1, Q3), [min, max]	36 (0, 103), [-10, 596]
Mean duration between diagnosis date and next visit in days [n=137], (SD)	74 (53)
Median duration between diagnosis date and next visit in days [n=137], (Q1, Q3), [min, max]	70 (38, 98), [1, 284]
Mean number of visits in first 12 months of diagnosis [n=137], (SD)	4 (2)
Median number of visits in first 12 months of diagnosis [n=137], (Q1, Q3), [min, max]	3 (2, 4), [1, 11]
Number of patients with visits in the first 12 months of diagnosis [n=137], n (%) **	137 (100%)

Notes: No missing data. First year is defined as within one year from date of diagnosis and is exclusive of diagnosis date. Number of patients with visits in the first year of diagnosis is according to KPI definition. All values are rounded to the nearest whole number. Any type of visit is inclusive of visits to nurse and physical therapist. 3 patients were diagnosed on their last recorded visit at clinic. Similar values between first 12 months of diagnosis and first 14 months of diagnosis. **Two patients transitioned to adult care, and one was lost to follow-up so three patient's last visit was date of diagnosis.

3.3.2.3 KPI #8: Patients seen in yearly follow-up by a pediatric rheumatologist

The final description for KPI #8, patients seen in yearly follow-up by a pediatric rheumatologist, was "the percentage of patients with a diagnosis of JIA under the care of a pediatric rheumatologist seen in follow-up by a pediatric rheumatologist at least once per year".(1) **Table 17** shows the patients having an annual follow-up visit with the pediatric rheumatologist. Patient-centric years were defined using the anniversary of the diagnosis date to calculate annual follow-up visits with the pediatric rheumatologist after the first 12-month

period. Over each patient's follow-up period, 77% (105 of the 137) patients had a visit during each eligible interval. To be included in the denominator, patients had to have visited a pediatric rheumatologist after their date of diagnosis. The first year of diagnosis was described in the previous KPI. In the 12- to 24-month and 24- to 36-month interval after date of diagnosis, 96% and 83% of patients respectively, had at least one follow-up visit. In the 36- to 48-month interval after diagnosis, 67% of patients had at least one visit with a rheumatologist. The lower performance of the 36- to 48-month interval after diagnosis is likely due to the 12-month window for some patients extending past the study's ultimate cut-off date of March 13th, 2020.

Table 17: Compliance of KPI #8: patients having annual follow-up visits with the pediatric rheumatologist (12 months).

Access to Care KPI					
Interval of follow-up after date of diagnosis	Number of patients who did not have a visit during interval but should have	Number of patients who had a follow-up visit during interval, n (%)	N	Number of patients whose last visit was in interval	Total number of visits for the cohort that year
Complete Duration after date of diagnosis					
Visit to PR	32	105 (77%)	137	137	1082
0 to 12-months after date of diagnosis					
Visit to PR	0	137 (100%)	137	9	514
12 to 24-months after date of diagnosis					
Visit to PR	5	123 (96%)	128	39	359
24 to 36-months after date of diagnosis					
Visit to PR	15	74 (83%)	89	53	165
36 to 48-months after date of diagnosis					
Visit to PR	12	24 (67%)	36	35	44

Notes: No missing data points. Follow-up year is defined from diagnosis date and exclusive of diagnosis date. All values are rounded to the nearest whole number. N represents the total number of eligible patients during the interval.

3.3.3 Safety KPIs

3.3.3.1 KPI #9: Tuberculosis (TB) screening

The final description for safety KPI, tuberculosis screening, was that "all patients with JIA, with a consideration of risk factors, will undergo TB screening within 12 months prior to receiving a first course of therapy using a biologic DMARD".(1) In the cohort, 56 patients were on a biologic with 71 biologic starts documented in SCM (**Table 18**). This variance was because some of the 56 patients on a biologic had taken multiple biologics over the course of their follow-up period, thus increasing the number of 'starts'. Documentation for TB testing in either SCM, the Consolidated Laboratory Repository, NACRS, or Practitioner Claims was found for 96% of the patients. The median number of biologic starts per patient was one and ranged from one to three biologics. Of the 56 patients, 53 patients had a documented TB test for a biologic start in SCM, while 52 patients had a TB test documented for a first course of a biologic start.

Screening for tuberculosis can take many different forms such as a blood test, a skin test, or a chest x-ray. In total, five patients had a TB blood test found in the Consolidated Laboratory Repository with a total of six biologic starts documented. Based on the start date of the biologic, determined as the visit date where the biologic was prescribed, the median days of the TB blood test was 11 days prior to the biologic start date. This value was skewed due to one patient having a TB screening over a year prior to starting a biologic. Of the five patients documented in the Consolidated Laboratory Repository, no patient had a TB blood test within 12-months prior to starting a first course of a biologic therapy (the KPI definition). One patient had a test reported in the Consolidated Laboratory Repository as well as the Practitioner Claims and did not have it documented in SCM.

The Practitioner Claims codes identified 18 patients in the dataset. The NACRS codes identified four patients. Four patients were found in two of the administrative datasets (two found in both the Consolidated Laboratory Repository and Practitioner Claims; two found in both Practitioner Claims and NACRS). In total, 23 patients were documented at least once in the administrative dataset as having had a TB test. A negative value for the duration between the biologic start date and TB test occurred if the date of the TB test occurred after the biologic start date. Overall, five patients met the tuberculosis screening KPI, three patients were found with documentation in the Practitioner Claims database and two patients were found with documentation in NACRS.

Table 18: Documentation frequency and compliance of KPI #9: TB tests for patients on a biologic in SCM and in the administrative databases.

Safety KPI	
	Patients on a Biologic
Number of patients on a biologic (n=140)	56 (40%)
Number of biologic starts	71
Median number of biologic starts per patient [n=56], (Q1, Q3), [min, max]	1 (1, 1), [1, 3]
Sunrise Clinical Manager (SCM)	
Number of patients with documentation of a TB test for a patient with a biologic start in SCM [n=56], n (%)*	53 (95%)
Number of patients with documentation of a TB test for a patient with a first course of a biologic start in SCM3 [n=56], n (%)	52 (93%)
Consolidated Laboratory Repository	
Number of biologic starts for patients with TB tests documented in consolidated laboratory repository [n=71]	6 (8%)
Number of patients with TB tests in consolidated laboratory repository [n=56], n (%)	5 (9%)
Median duration between start of first course of biologic therapy and TB blood test in days (Q1, Q3), [min, max], [n=5]	-11 (-21, -4), [-26, 425]

Number of patients with TB blood test no more than 12-months prior to starting a first course of biologic therapy [n=5], n (%)	0
Practitioner Claims	
Number of patients with TB test in Practitioner Claims [n=56], n (%)	18 (32%)
Number of biologic starts for patients with TB test in Practitioner Claims [n=71], n (%)	24 (34%)
Median duration between start of first course of biologic therapy and TB test in years (Q1, Q3), [min, max], [n=18]	-2 (0, 5), [-2, 11]
Number of patients with TB test no more than 12-months prior to starting a first course of biologic therapy [n=18], n (%)	3 (17%)
National Ambulatory Care Reporting System (NACRS)	
Number of patients with TB test in NACRS [n=56], n (%)	4 (7%)
Number of biologic starts for patients with TB test in NACRS [n=71], n (%)	4 (6%)
Median duration between start of first course of biologic therapy and TB test in days (Q1, Q3), [min, max], [n=4]	-2 (-6, 17), [-12, 68]
Number of patients TB test no more than 12-months prior to starting a first course of biologic therapy [n=4], n (%)	2 (50%)
Overall	
Total number of patients with documentation of a TB test for a patient with a biologic start in SCM, Consolidated Laboratory Repository, Practitioner Claims, or NACRS [n=56], n (%)	54 (96%)
Number of patients screened for TB within 12 months prior to receiving a first course of therapy using a biologic DMARD [n=56], n (%)	5 (9%)

Notes: No missing data points. Tuberculosis (TB). Biologic starts refers to each time the patient has a documented start of a biologic and can include a patient starting a subsequent biologic while they are currently on one. *Numerator is patients that had a TB test documented ever and does not account for multiple biologic starts. One patient had a TB test reported in consolidated laboratory repository and documentation in electronic SCM not found.

3.3.3.2 KPI #10: Laboratory monitoring for DMARDs

The final description for KPI #10, laboratory monitoring for DMARDs, was that "all JIA patients receiving methotrexate or leflunomide will be monitored for toxicity by clinical laboratory methods. The minimal frequency of laboratory monitoring [was] one month after the start of therapy, and every 3-4 months thereafter".(1) **Table 19** represents the documentation frequency for laboratory tests being found in SCM for patients on methotrexate and leflunomide. Documentation in SCM required the patient to have a visit during the follow-up period after being prescribed a DMARD, thus the sample size for documentation in SCM was 99 patients (**Table 19)** and was 102 patients in the Consolidated Laboratory Repository (**Table 20**). For the cohort, 50% of the total visits had a patient on methotrexate or leflunomide. A mention of a laboratory test being ordered, either ordering a specific test, non-specific tests, or that no tests were required was found in 63% of these visits. Of the patients on methotrexate or leflunomide, 63% of the visits had a mention of laboratory test results, either specific tests, non-specific tests, that the test results were pending or missing, or that no tests were completed. A mention of ordering laboratory tests at every visit that the patient was on methotrexate or leflunomide was achieved for 22% of the patients and 33% of the patients had a mention of laboratory test results at every visit the patient was one of the drugs.

Table 19: Documentation frequency of KPI #10: ordering and reporting laboratory tests for patients on methotrexate or leflunomide in SCM.

Safety KPI	
	Visit (PR, Nurse)
Number of patients on methotrexate or leflunomide (n=140), n (%) *	99 (71%)
Number of visits for patients on methotrexate or leflunomide [n=1360], n (%)	681 (50%)
Of the visits for patients on methotrexate or leflunomide [n=681]:	
Number of visits with mention of laboratory tests being ordered, n (%)	428 (63%)

Number of visits with mention of laboratory test results, n (%)	432 (63%)
Number of patients on methotrexate or leflunomide with mention of laboratory tests at each and every visit [n=99]:	
Mention of laboratory tests ordered, n (%)	22 (22%)
Mention of laboratory test results, n (%)	33 (33%)

Notes: No missing data points. All values are rounded to nearest whole number. *Does not include patients who began methotrexate or leflunomide at last visit and denominator is entire cohort. "Mention of laboratory tests ordered" includes documentation reporting specific tests, non-specific tests, and ordering no tests. "Mention of laboratory test results" includes documentation reporting specific tests, missing/pending/not yet available tests, non-specific tests, and documentation that no recent tests were completed.

Table 20 has 102 patients (73% of the cohort) on methotrexate or leflunomide because the administrative data were able to capture laboratory tests that occurred after the last reported visit in SCM and prior to the cut-off date of March 13, 2020. The median duration a patient was on methotrexate or leflunomide was 21 months and ranged between 1 to 47 months.

Table 20: Characteristics of patients on methotrexate or leflunomide requiring laboratory monitoring.

Characteristics	
Number of patients that started methotrexate or leflunomide [n=140], n (%)	102 (73%)
Mean duration a patient is on methotrexate or leflunomide in months (SD)	22 (12)
Median duration a patient is on methotrexate or leflunomide in months (Q1, Q3), [min, max]	21 (13, 30), [1, 47]

Table 21 In the cohort, 102 patients on methotrexate or leflunomide had a documented laboratory monitoring test. During the first month the patient received methotrexate or leflunomide, 59% of these patients were monitored for toxicity by clinical laboratory methods in the Consolidated Laboratory Repository (**Table 21**). Focusing on the first two-years of DMARD treatment, the percentages of patients who received methotrexate and leflunomide and were monitored for toxicity were high, ranging from 76% to 90% after the first month. The high level

of testing was in accordance with the mean duration a patient was on the drug (22 months). As the number of eligible patients on the DMARDs becomes too small to be meaningful, the subsequent intervals should not be the focus of the KPI's performance.

Table 21: Documentation frequency and compliance of KPI #10: proportion of patients on methotrexate or leflunomide receiving laboratory monitoring using the Consolidated Laboratory Repository.

Safety KPI			
Interval on DMARD	Number of patients with laboratory testing during interval, n (%)	Number of patients who did not have laboratory testing during interval but should have, n	Number of patients that stopped DMARD during interval, n
0-1 month [n=102]	60 (59%)	42	1
1-4 months [n=101]	85 (84%)	16	7
4-8 months [n=94]	85 (90%)	9	6
8-12 months [n=88]	77 (88%)	11	9
12-16 months [n=79]	70 (89%)	9	11
16-20 months [n=68]	53 (78%)	15	13
20-24 months [n=55]	42 (76%)	13	12
24-28 months [n=43]	33 (77%)	10	10
28-32 months [n=33]	28 (85%)	5	10
32-36 months [n=23]	16 (70%)	7	10
36-40 months [n=13]	11 (85%)	2	6
40-44 months [n=7]	4 (57%)	3	5
44-48 months [n=2]	2 (100%)	0	2
Every eligible interval [n=102]	29 (28%)	73	-

CHAPTER FOUR: DISCUSSION AND CONCLUSION

4.1 Overview

This study assessed the documentation and frequency of the required data to measure each of the 10 JIA KPIs. Objective One was to determine if the data required for each KPI was documented in the routinely captured data. Data for all KPIs were found at least once in the cohort. As the assessment of functional ability (KPI #3) was only found to use the CHAQ, it may provide more guidance to specify the CHAQ in the KPI definition. For the clinical disease activity measurement KPI (KPI #4), it was never found to be documented explicitly in SCM; however, the components required to calculate the cJADAS were found in SCM. This may imply a need for a clearer definition of the KPI, specifying if the documentation of the explicit score is required, if documenting the three components of the cJADAS is acceptable, and if a software that automatically calculates scores would be beneficial. For the waiting times KPI (KPI #6), an exact referral date was found only once but demonstrates that it is possible for it to be documented in SCM.

Objective Two was to report on the documentation frequencies of each KPI. The access to care and safety KPIs (KPIs #6 to #10) were documented more frequently than the measurement of patient outcomes KPIs (KPIs #1 to #5). In terms of overall documentation for the measurement of patient outcomes KPIs, joint count (KPI #1) and assessment of arthritis-related pain (KPI #5) were well documented in SCM for all visits in the cohort and can be easily used in future analyses. Waiting times for rheumatological consultations (KPI #6) were relatively timely given the small cohort size with eligible dates to be used for referrals. Visits during the first year of diagnosis (KPI #7) and annual follow-up visits (KPI #8) performed well. TB screening (KPI #9) was consistently documented in SCM although accuracy for timing between date of the test

and the start of the biologic can be improved. Laboratory monitoring for patients on methotrexate and leflunomide (KPI #10) had high compliance for individual intervals but not collectively, only 28% had laboratory monitoring completed in every interval.

This study found that although the data required to measure all the KPIs were documented, the measurement of patient outcomes KPIs were not consistently documented. Although the current documentation frequencies for each of the 10 JIA KPIs are sufficient to develop benchmarks of care, there is a significant opportunity for better clinical documentation and more consistent data collection for KPIs during clinical visits that align with current clinical guidelines for JIA management.(1)

4.2 Feasibility of the KPIs (Study Aim)

There are four data sources for performance measurement in health care: 1) administrative data, 2) chart review (paper or electronic documents), 3) surveys of patients/families/staff, and 4) data generated and extracted from electronic health records.(29) Measurement using administrative data necessitates the assumption that the diagnosis and procedure coding was accurate and medication that was prescribed matches the medication taken.(29) Chart reviews are very labour intensive and used to validate measures from administrative data and electronic health records.(29) The use of electronic health records provides an "opportunity to access patient-centric clinical data and the ability to efficiently measure quality performance outcomes measures".(29) Technological advances have enabled data extraction from both discrete or free-text fields in electronic health records.(29) Calgary's new system, Epic, has the potential to capture the required data from a variety of data locations and consolidate to a single electronic database system, increasing the ease of monitoring KPIs by physicians and decision makers.

A rheumatological joint assessment (KPI #1) was the most frequently documented KPI in this study. This KPI's documentation of 95% exceeded Lovell *et al.* (41) proposed benchmark of quality care which was at a reporting level of ≥80% of patients. The standardized layout of the SCM form, with physical examination having its own section, including a description of a joint assessment, could explain the high compliance of documenting a joint assessment. Consideration could be given to software that allows the clinician to select joints based on categories such as swollen or limited range of motion. These changes have the potential for increased accuracy in monitoring a patient's treatment pathway.

Documentation of a PGA at each and every visit (KPI #2) did not meet the proposed Lovell *et al.* (41) benchmark of 80%, as there were no patients with documentation of a PGA at every visit in SCM. Performance for an assessment of functional ability (KPI #3) had a proposed benchmark of 70% (41) and was similar to KPI #2 (PGA) where no patients met the criteria for each and every visit. Literature using the RISE registry for RA patients that required "functional status assessment was performed at least once during the measurement period" had performances of 53.6% (72) and 69.1% (73). One patient had documentation of a PGA, CHAQ, and components for the cJADAS documented at their first clinic visit in SCM. This patient was seen at the early arthritis clinic (EAC) at their first visit whereas patients are typically seen at the EAC after their first visit with the pediatric rheumatologist. This explains the difference in documentation at the first clinic visit. Notably, CHAQ and patient PGA are currently collected in the clinic's paper charts and moving to an electronic system incorporated in Epic should greatly increase the frequency of documented CHAQ and patient PGA values.

No previously proposed benchmark for an assessment of clinical disease activity using the cJADAS (KPI #4) was found in the literature and there were no patients that had documentation

of the cJADAS or cJADAS components for every visit. In a previous study on rheumatoid arthritis (RA), a disease activity performance measure was defined as the "percent of RA patients with ≥ 50% of total number of outpatient encounters per year with assessment of disease activity using a standardized measure", and 100% of the patients met this measure.(74) This contrasts dramatically to this study where only 12% of all JIA clinic visits documented the cJADAS in SCM. It is possible that the higher levels of reporting disease activity by any acceptable composite measure (such as Disease Activity 28 or the Clinical Disease Activity Index) in the previous RA study was due to the use of the data platform Rheum4U.(74) The Rheum4U platform was developed for inflammatory disease patients and was implemented in both clinics in the study to collect patient reported outcomes.(74) These higher levels could mean that the data is not routinely documented unless part of a specific RA registry where patient outcome data is explicitly recorded. A study using the RISE registry for RA a performance rate for disease activity of 55.2% (72) was found and a separate RISE study found a performance of 53.6% in a random sample of RA patients (73) with the same KPI definition of documentation in ≥ 50% of outpatient encounters per year.

The data for the measurement of patient outcomes KPIs for PGA, assessment of functional ability, and measurement of clinical disease activity (KPI #2 to #4) were minimally documented in SCM. Although minimal data for these KPIs was found in SCM, the data may be documented in the in-clinic paper charts. The documentation of these KPIs could be improved with a streamlined transition of data from the paper chart to the electronic note. Previous literature assessing the feasibility of the Core Set of Indicators for Paediatric Primary Care in Europe (COSI-PPC-EU) concluded that an "improvement of information technology" that calculated indicators automatically should be implemented and that the software should be designed for

"easier documentation and filter settings" for KPI measurement.(44) This is because a lack of time was considered a significant obstacle as the KPI measurement was an additional task for clinicians to complete on already busy schedules.(44) This could be facilitated through standardized headers for each clinician note, requiring data to be entered before the form can be completed and having the software automatically calculate scores for various assessments such as the cJADAS.

An assessment of arthritis-related pain (KPI #5) had a high documentation frequency for the total number of visits in the cohort but dropped in frequency for every visit for every patient. When compared against the proposed benchmark by Lovell *et al.* (41) which is "≥80% of patients receive an assessment of pain at the first visit and at each subsequent visit if at least 7 days apart", only 46% of patients met the benchmark. This could be due to the absence of a standard section for pain similar to the one for physical examination for a joint assessment. The assessment of pain is typically written at the start of the note where anything that has occurred since the last clinic visit is described and it is possible that the pain information does not always get transferred to SCM if the patient's pain was not significant in that visit. This could explain part of the 49% difference between the pain assessment and joint evaluation KPIs. A specific section for pain referencing severity in the SCM notes would be a step towards improved documentation. This could be accompanied in the software by clinicians being able to select which joints are painful and rate them on a numerical scale. Further clarification in the definition could also be provided to inform clinicians if pain refers to at the time of the clinic visit, during the interval history, during the musculoskeletal exam or any of the above.

Documentation for access to care KPIs was highly compliant except for the waiting times KPI. In SCM, the waiting times from referral was only mentioned in 17% of the cohort;

however, this could be due to the use of Clinibase in Calgary, a database that contains the referral letters for each patient and is separate from SCM. However, Clinibase was not used due to the availability of data occurring after the cohort's diagnoses time period. The waiting time for rheumatological consultation, was defined as the 50th and 90th percentiles and were 24 and 46 days, respectively. Of the patients with a documented eligible date of referral, 72% of patients were within 28 days. This was similar to a study (7) where 62% of patients met the waiting times benchmark. The percentage of patients newly diagnosed with JIA who saw a pediatric rheumatologist within the first year of their diagnosis (KPI #7) was higher than previously published studies. Such studies include Barber *et al.* who found that 78% to 81% of patients met the KPI between 2008 to 2014 and declined in 2014/2015 to 51%.(3) This suggests that Alberta's performance for this KPI has improved.

Annual follow-up visits (KPI #8) demonstrated that 77% of patients had visits during each eligible interval. Following the first year of diagnosis (after the first 12 months of diagnosis), compliance to follow-up visits ranged from 96% to 67%. This is consistent with other studies that declined over time from 100% to 85% over the eight-year follow-up period.(8) In a study on implementing and evaluating performance measures for RA using treat-to-target strategies found that 89% of all RA patients met the measure during the first year and 87% of the patients met the measure in the second year.(74) The trend that follow-up visits declined slightly over time was consistent with the results of this study. Visits during the first year of diagnosis (KPI #7) and annual visits (KPI #8) demonstrate strong compliance as all applicable patients had a visit during the first year after diagnosis and 77% of patients had annual follow-up visits; however, this hedges on the assumption that all visits were entered into SCM. It is possible that performance is

higher if some visits were not entered into SCM. A more nuanced approach to performance could be conducted looking at a range of time rather than a strict 12-month cut-off.

Of the two safety KPIs, TB screening was documented in SCM more consistently than the KPI for laboratory monitoring for DMARDs. SCM currently does not allow for accurate calculations of the KPI definition for TB screening (KPI #9) where a TB test was required within 12-months prior to starting a first course of biologic therapy. This was for two reasons, firstly, the exact start date of biologic therapy was considered as the visit the prescription was written. Typically, the actual start date would be after this as a result of conditions the patient must meet such as requiring TB screening, completion of vaccinations, or the insurance paperwork. The insurance paperwork should create a mechanism for ensuring TB screening was completed, however, this was not confirmed as part of this study. Patient input would be required to know the exact start date of medication. Secondly, the results of the TB screening that the clinic receives are documented in the form of a note with no test date provided. Thus, the KPI reporting may be higher than shown in **Table 18**. Patients who have documentation in SCM of a TB test for the first course of biologic therapy but with no documentation within the administrative databases, were deemed to have not met the KPI definition. This represents a limitation in the study in that we cannot confirm a TB test at this time. For RA patients in the RISE registry, a study determined that performance for this KPI was 55.2%.(72) The study attributed the low performance to a gap in quality and the low reliability of capturing TB screening.(72) Another study using the RISE registry for RA patients found that the performance of TB screening in a random sample was 72.8%.(73) The TB screening KPI (KPI #9) was documented in SCM for 95% of eligible patients. The Consolidated Laboratory Repository contained the test for patients who received a TB screening blood test. This was typically only done for patients who recently

had vaccinations or had prior TB exposure. This would explain the small number of patients who had this test reported in the Consolidated Laboratory Repository. The gold standard for TB screening is the TB skin test. NACRS and Practitioner Claims were used to identify TB screening; however, it has been consistently found that using ICD codes to identify TB screening and diagnoses has a relatively lower positive predictive value compared to other communicable diseases.(75) A TB skin test can also be performed in the Infectious Disease Clinic at the hospital which would not be found in the administrative data since claims from the hospital are not sent in. A more accurate method of identifying TB screening for KPI #9 should be a focus of future study.

Although the laboratory monitoring KPI for patients on methotrexate and leflunomide was well documented in SCM, the Consolidated Laboratory Repository contained more accurate data. Even so, this study was unable to determine the exact biologic start date without patient interaction documented. For laboratory monitoring of patients on methotrexate or leflunomide (KPI #10), when filtered for the number of intervals that a laboratory test was completed divided by the number of intervals given their duration on the drug, 28% of patients had a test at every interval, 100% compliance. This is below the proposed benchmark by Lovell *et al.* (41) which is 70% of patients meeting the recommended laboratory monitoring guidelines. Further analysis showed that within the cohort, 71% of the patients had compliance of 70% or better to the KPI. The laboratory monitoring KPI (KPI #10) for patients on methotrexate and leflunomide was shown to be well documented in SCM; however, the Consolidated Laboratory Repository contained more accurate data. Accuracy for start and stop dates could be improved by 1) using the Pharmaceutical Information Network (PIN) databases to track the date the prescription was dispensed, 2) patient feedback on their start and stop dates, or 3) having more explicit descriptive

headers in the clinic visit note. The lower compliance levels for laboratory testing demonstrates that there is an opportunity for improvement in the compliance and documentation of this KPI, but the KPI is feasible to measure. The KPI definition for laboratory monitoring could be expanded upon to include the specific tests that should be involved. The current study used the input from a pediatric rheumatologist to determine which laboratory tests should be documented.

Since all KPIs can be measured using software, the next step is to determine if this is feasible for clinicians. Having readily available KPI monitoring levels can help encourage behaviour amongst clinicians. Barber *et al.* looked at the implementation and evaluation of RA performance measures that analyzed the levels of reporting, how rheumatologists viewed the measures and what their predicted levels were for reporting.(74) This was the first time that the rheumatologists who participated in the study were able to see their performance levels compared to their peers.(74) The study found that rheumatologists valued the data and did not dispute the selected measures as best practices but thought that a change in their practice would be "unlikely to drive practice change as they believed they were in line with their peers in terms of patient outcomes".(74) Those who believed that they were not in line with their peers attributed these differences to possible contextual factors such as patient complexity or the number of patients as a function of the length of the physician's practice.(74) This could be combatted by having integrated software that would not increase the workload of clinicians. The literature demonstrates that implementing, designing, and incentivizing a system that allows for KPIs to be easily monitored should be the goal of quality improvement efforts. A previous literature review found that the success of quality improvement strategies was the use of structured data fields and modifications to the workflow of the clinic itself where medical

assistants took part in the intake process.(38) The key was to streamline the data collection process (38) and to minimize any time that would be required to complete the documentation.

The availability of data is a common theme that quality measures rely on. This was cited as both the greatest factor that facilitated or impeded the use of quality measures by the NQF report.(48) It referenced that data infrastructures need to be able to "talk to each other" and how current electronic health records are "not sufficiently robust at this stage to generate this information for measure construction".(48) Measures that were endorsed by the NQF or had widespread use had greater provider buy-in as well as physicians trusting national registries because they understood the "data being collected".(48) Having KPIs endorsed by the Canadian Rheumatology Association is an important step in ensuring the uptake of these KPIs.

4.3 Implications

Although there were commonalities within the structure of each clinician note, there were no clear guidelines determining what was or was not recorded in SCM. Physical therapist notes in SCM had clear free text fields for pain which was either filled with a numerical value or dichotomous text of "pain" or "no pain" for the respective joints. This was the only clinician note that had the standard header for pain. Every nurse note from the early arthritis clinic had specific headers for joint count, CHAQ, PGA, Parent/Patient Assessment of Well-being, and the date of the most recent lab test and eye exam. The nurse notes did not have any header for pain; consequently, information regarding pain was only found when/if listed in the free text section giving a bullet point synopsis from each clinician seen that visit (PR, physical therapist, occupational therapist, pharmacist). The pediatric rheumatologist notes had standardized headers for interval history (where pain would be documented), physical examination (that contained the musculoskeletal examination) and investigations (where laboratory test and imagining results

were located). The free text fields introduced inconsistency and variability in documentation. To improve documentation while maintaining free-text fields (should free-text fields be desired), standardized headers would ensure consistent assessments and could improve the likelihood of more consistent documenting electronically for monitoring purposes. Drop-down boxes and numeric entry boxes would be the most desirable for a high-level summary of the clinical visit that could ensure optimal reporting.

Stakeholders for this research are decision-makers, clinicians, and JIA patients and their families. As experts providing the care for JIA patients, clinicians are the key group for this research. Clinician inputs for both medically optimal results and feasible clinical practices are required to develop standardized process KPIs.

The process for nationwide quality improvement implementation is complex and requires further stages of measuring the levels of reporting in different pediatric rheumatology centres and ongoing communication and monitoring with participating clinicians to identify challenges to select centres and the overall system. Decision-makers may eventually mandate a new set of KPIs due to medical advancements, input from clinicians would be necessary to select the KPIs and ensure their successful implementation. Further engagement on promoting KPIs could ultimately lead to involvement with the Canadian Rheumatology Association and the American College of Rheumatology and alignment with their priorities and mandating these KPIs. Benefits of this involve facilitating peer comparisons, informing patients of their standings on the quality of care they receive, guiding local and national treatment benchmarks, and focusing future research initiatives to enhance quality of care for JIA patients. A unified endorsement of KPIs will help ensure clinician uptake.

The success of the KPIs lies in their ability to be implemented into clinical practice. Understanding the challenges in the implementation process can guide the development of feasible KPIs as well as their ability to guide what information should be recorded in new record systems. The study's goal to establish the actual levels of reporting was necessary to evaluate the feasibility of the set of KPIs by documenting which KPIs were commonly recorded, and which were not. The measurement of patient outcomes KPIs have the greatest opportunity for improvement when paired with a sufficient software. The safety KPI for laboratory monitoring on DMARDs could improve through a notification system connected to the EMR software system. These concepts can be used when implementing the new province-wide electronic health record system (Epic).(43,65)

To test the implementation of their proposed process quality indicators for new breast cancer patients in France, Ferrua *et al*. had 60 volunteer hospitals report on their methodological properties to evaluate the dispersion and inter-observer reliability.(76) They found that three of their eight indicators were ready for nationwide implementation.(76) The main challenge Ferrua *et al*. noted was with the health care system that was designed to have the patient's information in different databases and institutions which cannot be easily merged.(76) This can relate to Canada's health systems where each province and territory has its own healthcare system, each system can have different electronic record keeping systems that can limit the generalizability of the results as well as the generalizability of comparing between provinces and territories and keeping track of a patient in the different administrative databases. It has been shown that performances in practices are the highest when the electronic health record system has rheumatology-specific templates in the software as it enables the collection and monitoring of key measures.(77) An important next step in the implementation of these KPIs is aligning the

measures across Canada and having them be endorsed by the Canadian Rheumatology Association. Implementing the nationally aligned and endorsed measures with a system like RISE or Rheum4U in Epic would provide the highest likelihood of physician uptake and potential for quality improvement.

Horrocks *et al*. found an important aspect that can be challenging with the implementation of quality indicators where "some teams and staff reported they had to prioritize care delivery over quality indicator audit work".(31) These time constraints relate to the current study and the anticipated process of transferring information from the paper charts to the new system, Epic. If clinicians have to spend more time transferring information and it takes away from patient care, then this needs to be a consideration of the KPIs. Electronic health records should be used to guide which process-related quality indicators are easily assessed in clinical care.(78) A priority should be on streamlining the implementation process.

Stelfox and Straus (42) recommended two key strategies of knowledge translation to facilitate the implementation of quality care measures. The first was "integrated knowledge translation" where the developers and end users of these measures play a joint role in the development process.(42) These relationships are important given the "need for indicator evaluation, refinement, and maintenance".(42) The second approach was to present indicators in a way that makes it easy for end users to access these indicators.(42) The article suggests that additional innovative methods to disseminate the information to a broader audience, including making the information available on web sites, should be used.(42) Should these KPIs be mandated and monitored, publishing the levels online could be provided to inform consumers and decision-makers.

As health systems transition to electronic health records like Epic, there should be efforts made to guide consistent data collection. It is important to understand the documentation patterns in relevant and routinely collected data to assess the feasibility of measuring the predetermined KPIs. If KPIs are not measurable, they will be challenging to implement, limiting the potential for quality improvement and practice change. Individuals and systems need the tools to enact change and having an active system of monitoring KPIs that are feasible to measure is a key step in the process towards change. Ensuring the success of a "sustainable quality improvement strategy" requires IT platforms, health system infrastructure and a shift in practice by busy providers that will likely only happen with additional resources.(74) A key theme emerging from the literature is the need for "front-end planning to influence the data architecture" of electronic medical records to support these measures.(48) Effective monitoring of quality of care by streamlining and integrating the collection of data required to measure KPIs can help increase the likelihood of clinician uptake.

The United States is advancing its Merit-based Incentive Payment System (MIPS) where physicians can receive payment for performance in quality, advancing care information, improvement activities, and cost.(79) RISE is a qualified clinical data registry (QCDR) (72) which meets the three of the four MIPS categories (79), cost is calculated separately. Although Canada does not have a system like this, the performance improvements shown through RISE and its connection to MIPS shows an incentivized direction that may need to be employed to drive sustainable quality improvement interventions.

Future steps should involve replicating this assessment in other JIA centres across Canada and reviewing the documentation frequency results with similar experts to those involved in the development of the KPIs (Modified Delphi Panel) to determine if another step to update and

confirm the KPIs is necessary before the KPIs are finalized.(59) Then, dissemination of the KPIs to clinicians involved in JIA patient care should occur to bring awareness to what data needs explicit documentation to allow for measurability and monitoring through engagement with Canadian rheumatologists. The final step to monitor these KPIs is generating an algorithm, to monitor, measure, and publicly publish the KPI levels at various JIA care centres to make them easily accessible for decision makers. This could be done similar to the RISE registry that has a dashboard display of the analyzed results from various EMRs such as Epic. In the NQF report, one organization described their purpose for using the measures by "we're trying to give consumers meaningful, actionable information so they can advocate for better care on their own behalf".(48)

4.4 Strengths and Limitations

4.4.1 Strengths

The strengths of this retrospective cohort study included the corresponding data for the previously identified patient cohort being readily available for research purposes. This contributes to the feasibility of monitoring these KPIs. The Hawthorne Effect (80) was minimized as no clinicians were able to change their behaviour in response to the study. The Alberta Children's Hospital Pediatric Rheumatology Clinic is a tertiary academic pediatric centre, where clinicians are involved in research and are likely aware of quality measures and the value of documenting their JIA management with respect to clinical guidelines. Although this represents a strength in the data being more completely documented, it limits the generalizability of the results to other centres.

As a standard data collection form was created in REDCap, no data were anticipated to be omitted by the data extractor. The study methodology required the data be entered into all

standard fields for each patient's visit. If data for a KPI was not recorded in the data source, the field in the REDCap data collection form was recorded as "not reported." To minimize the risk of error, double data extraction was conducted where both data extractors reviewed any discrepancies and then discussed the results. The data collection form and guidelines were reviewed with both researchers and pediatric rheumatologists to ensure accuracy in the data being collected.

4.4.2 Limitations

As data were only being collected from one pediatric rheumatology centre, there is a limitation on the generalizability of the results. Further research is required to assess the feasibility and performance of these KPIs in other practice settings since there may be differences in how documentation of patient data are captured and stored.

There was a potential for misclassification bias by the data extractor. An example of this can be from the misclassification of the assessment of pain KPI resulting from differences in patient and physician interpretations compared to what is recorded in the SCM visit. This could result in an underestimation of the documentation frequency of the respective KPI if, for example, the patient told the clinician they were not experiencing pain, and it was recorded that the patient had no symptoms. This could be interpreted very subjectively with a difference between the wording that is reported and what was said during the visit. This can then be misclassified by the data extractor, for example, when the rheumatologist indicates the patient experiences aches, or no symptoms when discussing pain with the patient during the visit, but the extractor can interpret this differently. To minimize this bias, pain was only recorded if the clinic notes explicitly used the word "pain" or "arthralgia."

There is a limitation made clear in the literature towards identifying TB patients in administrative data using ICD codes. The identification in the Practitioner Claims and NACRS should be taken with caution as the ICD-9 and ICD-10 codes identified few patients in each database. In NACRS, the CCI intervention code 2ZZ08MF was used to expand the potential patients identified and is for a *test, total body microorganisms [e.g., tuberculin] intracutaneous [intradermal] injection, immediate type reaction.* The challenge is that this could be for tuberculosis but can also include other microorganisms. For the identification in Practitioner Claims, to expand the potential patients identified from the ICD-9 codes used, Health Service Code 98.8 was then used which refers to *invasive diagnostic procedures on skin and subcutaneous tissue*. This was used as the specific code for a skin test (98.8A) was not found in the patient list. The code 98.8 could have been more readily documented as it was more generalized and could represent a documentation pattern. However, code 98.8 runs the risk of including procedures not related to TB screening.

Another limitation using SCM data is that this study was unable to determine if the TB test happened prior to the biologic start date because it was unknown what the date of the TB test was (besides those found in the administrative databases) and the exact biologic start date was unknown as it would require patient interaction to determine the start date.

Gathering of KPI data was limited to electronic patient summary charts and administrative data and did not include other sources such as the in-clinic paper charts. As the Practitioner Claims administrative database does not distinguish between the types of pediatricians, this study was not able to use the database to track visits with the pediatric rheumatologist. As such, only visits logged in SCM were used.

There was also a limitation of missing data/data completeness in two ways. Firstly, where the data were discussed and reported in the paper chart but did not get transferred to the electronic SCM chart and secondly, if the data were recorded in the electronic SCM chart but was missed by the data extractor. The first missing data limitation represents a data source limitation. The second limitation due to the data extractor's error was minimized through the quality assurance procedure described above and has been shown to be minimal.

There was a risk that the study's time window could miss relevant information; however, this was minimized by 1) choosing a three-year diagnosis window; specifically, patients diagnosed from 2016 to 2018; 2) by collecting data from the first clinic visit in 2016 until March 2020; and 3) using the most recent years of data reporting patterns.

The COVID-19 pandemic did not impact the results of this study as the data collection ended before the beginning of the pandemic. There was a limitation to the generalizability of the results during an era of a pandemic such as COVID-19 where telehealth (zoom portal appointments) was the primary method of clinical visits, and this study did not collect data for telehealth. Despite the convenience telehealth clinical visits provide, direct contact with patients is missed and thus make physical examinations impossible. Some surrogate measures can be used such as jumping in front of the camera; however, a joint count would be challenging to collect without a physical examination. At the ACH clinic, there are currently no electronic patient-reported outcomes so measurements such as the CHAQ would be more challenging as the questions would have to be sent in advance or completed during the virtual visit. Future research should be conducted around data collected during telehealth visits to ensure that the data for each KPI is captured and reported or if surrogate measures can be used while maintaining the standard of care.

The interpretations from this research are based on the extent to which the required data are documented accurately in SCM. The study does not address, infer, or imply any evaluation of physician performance.

4.5 Conclusions

All of the KPIs were feasible to measure; however, efforts should be focused on streamlining measurement of patient outcomes KPIs and increasing the accuracy of monitoring TB screening. This study will move us toward our ultimate goal of improving quality of care in JIA patients. The ease of measuring the KPIs can be based on whether the measures have been captured in routinely collected JIA clinical patient data through electronic medical records and administrative data. Gaining initial insight into the record keeping of clinicians is essential to understanding which measures are practical to capture in the clinical environment. Evaluation of the documentation frequencies for each KPI in the set will provide the tangible criteria to enable the development of benchmarks of care for future study that will inform and guide the implementation of system and patient level improvements. These current levels of reporting will be used to inform clinicians and decision-makers on gaps in current patient practices to focus future efforts on quality improvement for children with JIA. Although there are standard treatment pathways for JIA, there is no single treatment. The right treatment is needed for the right patient at the right time.

CHAPTER FIVE: EVALUATING KEY PERFORMANCE INDICATORS OF THE PROCESS OF CARE IN JUVENILE IDIOPATHIC ARTHRITIS

This is a manuscript-based thesis. This chapter (Chapter 5) is a manuscript that has been prepared for submission to ACR Open Rheumatology (word limit 4200 and 250 abstract word limit). The current word count for the manuscript is 4177. The current abstract word count is 247.

Cooper SM, Currie GR, Kromm S, Twilt M, Marshall DA. Evaluating key performance indicators of the process of care in juvenile idiopathic arthritis. *ACR Open Rheumatology.* Submitted 15 July 2022.

5.1 ABSTRACT

Objective

To determine whether and how often the information to measure a set of key performance indicators (KPIs) in juvenile idiopathic arthritis (JIA) is found in data collected routinely in a Pediatric Rheumatology Clinic.

Methods

A retrospective electronic chart review and administrative data analysis was conducted for a cohort of 140 patients with JIA at a tertiary Pediatric Rheumatology Clinic between 2016-2020. Documentation was assessed as a binary variable indicating whether the required information was ever found. Documentation frequency for each KPI was assessed with counts and percentages of the number of times the required information was documented for each clinic visit. Compliance with the safety KPI definitions was assessed using administrative databases.

Results

Data for each KPI were found at least once in the cohort and documentation varied in frequency and consistency. Access to care and safety KPIs were documented more frequently than patient outcome KPIs. A joint assessment was documented at every visit for 95% of patients, 46% for an assessment of pain, and none for a physician's global assessment of disease activity, an assessment of functional ability, or a composite disease activity measurement.

Conclusion

Although feasible to measure, there is an opportunity for improving the consistency of documentation. Having an active system of monitoring KPIs and tools to simplify measurement is a key step in the process toward improved patient care outcomes. Streamlining the collection of KPI data can increase the likelihood of compliance. Next steps should involve replicating this study in various centres.

5.2 INTRODUCTION

Juvenile idiopathic arthritis (JIA) is one of the most common chronic childhood rheumatic diseases.(9) Approximately 0.1% of children in Canada have JIA.(81) Without early diagnoses and timely treatment, persistent joint pain, swelling, and stiffness caused by JIA can lead to permanent disfigurement and disability.(1–3)

The Understanding Childhood Arthritis Network (UCAN) CURE team, a multicentre, international precision health program examining biology-based treatment strategies for JIA, developed a set of 10 key performance indicators (KPIs) consistent with current Canadian and international clinical guidelines and can be used to assess the quality of care for JIA.(1) KPIs are developed to provide measurable parameters to assess processes, structures, and outcomes (5) that reflect the quality of care that a patient receives. KPIs can be used to identify opportunities for quality improvements in patient care and outcomes by providing data to initiate interventions

to reduce “unwarranted variability” in practice and care.(2) The UCAN CURE process KPIs are grouped into three categories: measurement of patient outcomes, access to care, and safety (**Table 22**). The access to care KPIs (visits during the first year of diagnosis, annual follow up visits, and waiting times for rheumatological consultation) were previously examined and gaps in waiting times for older JIA patients were identified (3,82), but there have been no studies assessing the feasibility of measuring the full set of 10 JIA KPIs using routinely collected and readily available clinical data.

Evaluating the feasibility of measuring and reporting these KPIs will identify if these KPIs can be easily monitored using standard documentation in routine clinical visits. Having KPIs that are easily measured using readily collected data and then reported is a critical step toward transparency and accountability in delivering high quality patient care and improving patient outcomes. Measuring improvements for change in the quality of patient care can provide relevant information to induce quality improvements.(14) The objective of this study was to determine whether the required information to measure the set of JIA KPIs is found in data routinely collected in a Pediatric Rheumatology Clinic and report on the frequency of documentation for each KPI.

5.3 PATIENTS AND METHODS

5.3.1 Cohort Selection

Patients were identified from the Alberta Children’s Hospital (ACH) Pediatric Rheumatology Clinic, a tertiary practice and academic centre including seven pediatric rheumatologists providing care for pediatric patients up to (and including) the age of 17.(60,61) The clinic provides multidisciplinary care; patients can access care from pharmacists, physiotherapists, registered nurses, rheumatologists, and social workers.(60)

This project leveraged a dataset collected in a previous research study (62,63), which identified a JIA cohort from the ACH using an administrative data algorithm (64) for JIA and confirmed diagnosis by cross-referencing JIA diagnosis in Calgary's acute care electronic storage system – Sunrise Clinical Manager (SCM). When the diagnosis was unclear, the research team consulted a pediatric rheumatologist and patients were excluded if their diagnosis was secondary to another disease. The previous study chose the highest sensitivity case ascertainment algorithm to validate JIA diagnosis between 2011 and 2019. This two-step process was applied to increase the probability of all relevant patients being included in the cohort. As one visit would not adequately reflect a pattern of care for routinely collected data, each patient required a minimum of two clinic visits for inclusion into the cohort. Data collected within SCM consists of a summary of the clinic visit: consultation notes, nursing notes and pharmacy notes. The complete paper chart for the clinic visit is not documented within SCM.

Of the 392 JIA patients at the ACH Pediatric Rheumatology Clinic, a subset of 140 patients met the inclusion criteria of having a JIA diagnosis and first visit with a pediatric rheumatologist at the clinic between January 1st, 2016, and December 31st, 2018. This period of diagnosis was chosen to provide the most recent KPI performance levels as well as sufficient time for follow-up to capture reporting patterns. Patients were followed from January 1st, 2016, to March 13th, 2020. Additional data were collected to complete the information required for each KPI listed in **Table 22**.

Table 22: UCAN CURE JIA KPI Definitions and Operational Definitions.(1)

KPI	Definition	Operational Definition
Measurement of Patient Outcomes KPIs		
1. Rheumatological joint count	Percentage of patients where a joint count was conducted on the first visit	**Numerator**: the number of patients where a joint count was conducted on the first visit and each subsequent visit

		and each subsequent visit using a validated tool	using any reliable tool in the measurement period **Denominator**: the total number of patients seen in the measurement period
2.	Physician's Global Assessment (PGA) of disease activity	Percentage of patients assessed for a PGA using any validated tool at the first visit and at each subsequent visit	**Numerator**: the number of patients assessed for a PGA at the first visit and at each subsequent visit in the measurement period **Denominator**: the total number of patients seen in the measurement period
3.	Assessment of functional ability	Percentage of patients assessed for functional ability using any validated tool at the first visit and at every routine clinic visit	**Numerator**: the number of patients assessed for functional ability at the first visit and at each subsequent visit in the measurement period **Denominator**: the total number of patients seen in the measurement period
4.	Composite disease activity measurement	Percentage of patients with an assessment of disease activity using the cJADAS* at the first visit and at every routine clinic visit	**Numerator**: the number of patients with an assessment of disease activity using the cJADAS* in the measurement period **Denominator**: the total number of patients seen in the measurement period
5.	Assessment of arthritis-related pain	Percentage of patients assessed for pain at the first visit and each subsequent visit that occur at least 7-days apart using any validated age-appropriate tool to measure average pain	**Numerator**: the number of patients assessed for pain at the first visit and each subsequent visit using any validated, reliable, age-appropriate tool to measure average pain in the measurement period **Denominator**: the total number of patients seen in the measurement period
		Access to Care KPIs	

6.	Waiting times for rheumatologist consultation for patients with new onset JIA	The 50th and 90th percentile waiting time for rheumatologic consultation	**50th percentile**: the number of days that half the patients in the sample with new onset JIA saw a pediatric rheumatologist and half are still waiting **90th percentile**: the number of days that 90% of the patients in the sample with new onset JIA saw a pediatric rheumatologist and 10% are still waiting
7.	Patients newly diagnosed with JIA with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis	Percentage of patients with new onset JIA (incident JIA) with at least 1 visit to a pediatric rheumatologist in the first year of diagnosis	**Numerator**: the number of patients with new onset JIA with at least one visit to a pediatric rheumatologist in the first year of diagnosis during the measurement period **Denominator**: the total number of patients with new onset JIA seen during the measurement period
8.	Patients seen in yearly follow-up by a pediatric rheumatologist	Percentage of patients with JIA seen by their pediatric rheumatologist at least once every year over	**Numerator**: the number of patients with a diagnosis of JIA under the case of a pediatric rheumatologist seen in follow up by a pediatric rheumatologist at least once every year during the measurement period **Denominator**: the total number patients with a diagnosis of JIA patients under the care of a pediatric rheumatologist in the measurement period excluding patients who meet exclusions
	Safety KPIs		
9.	Tuberculosis (TB) screening	Percentage of patients screened for TB within 12 months prior to receiving a first course of therapy using a biologic DMARD†	**Numerator**: the number of patients screened for TB within 12 months prior to start of any biologic therapy using a standard TB skin test/ blood test in the measurement period **Denominator**: the total number of patients on a biologic therapy in the measurement period

10. Laboratory monitoring for disease-modifying anti-rheumatic drugs (DMARDs)	Percentage of patients who received methotrexate and leflunomide and monitored for toxicity by clinical laboratory methods	**Numerator**: the number of patients who received methotrexate and leflunomide and monitored for toxicity 1 month after the start of therapy, and every 3-4 months after by clinical laboratory methods in the measurement period **Denominator**: the total number of patients who received methotrexate and leflunomide in the measurement period

*Clinical Juvenile Arthritis Disease Activity Score (cJADAS)
†Disease modifying anti-rheumatic drug (DMARD)

5.3.2 Data Sources

Sunrise Clinical Manager

Data for each KPI were extracted from AllScripts Sunrise Clinical Manager (SCM), a Calgary-wide electronic storage system used for medical records. This system was chosen as the data source as it is currently used in Calgary and is a centrally accessible digitized summary of the in-clinic visits. SCM provides summary documents for each visit, it does not include all the information routinely collected in the clinic's paper charts. Since it is not feasible for decision-makers to go to the clinic for routine monitoring purposes, in-clinic paper charts were not used in this study.

Administrative Databases

The safety KPIs (#9 and #10) required information around tuberculosis (TB) screening and laboratory monitoring in addition to that found in SCM. This data was obtained from administrative databases: the Consolidated Laboratory Repository, Practitioner Claims, and the National Ambulatory Care Reporting System (NACRS). These three databases were used to determine whether patients had documentation in the datasets and the dates they were screened

for TB (KPI #9). Practitioner Claims uses codes from the International Classification of Disease (ICD)-9; relevant codes were 795.7 and V74 and Health Service Code 98.8. NACRS uses ICD-10 codes; this study used code Z11.1 and Canadian Classification of Health Interventions (CCI) code 2ZZ08M. The Consolidated Laboratory Repository database was used to identify if patients on a biologic had a TB blood test and if patients on methotrexate and leflunomide had the relevant laboratory tests.

5.3.3 Analysis

Data were first assessed and recorded as a binary (yes/no) variable based on the presence of data for each KPI being documented at least once in the cohort and then by the number of patients who had data for each KPI documented. The documentation frequencies were reported based on the operational definitions described in **Table 22**. For KPI definitions requiring a validated tool, data on the named tool was collected and then verified as a "validated tool" or not. The last visit at the clinic was defined as the earliest date when the patient either left the province, transitioned to adult care, or the March 13th, 2020, study cut-off date.

Ethics approval was obtained from The Conjoint Health Research Ethics Board, University of Calgary (REB19-0471).

5.4 RESULTS

5.4.1 Cohort Description

As shown in **Table 23**, 57% of the JIA cohort were female and oligo-arthritis was the most frequent JIA subtype (41%). The median age at diagnosis was 11 years old. The median time between first visit with the pediatric rheumatologist and diagnosis date was 36 days. The shortest time between first pediatric rheumatologist visit and diagnosis date was 10 days prior to the first visit (two patients were diagnosed through hospital admissions before their first visit with the

pediatric rheumatologist). The median time between symptom onset and first visit with the rheumatologist was four months and the average follow-up period (time between the first visit and the last visit at the clinic) was three years.

Table 23: Cohort demographics.

	Total Cohort (n=140)
Patient Characteristics	
Female, *n* (%)	80 (57%)
JIA Subtype Groups	
Systemic, *n* (%)	5 (4%)
Oligo-arthritis (persistent, extended, not specified), *n* (%)	57 (41%)
Polyarticular arthritis, *n* (%)	45 (32%)
Enthesitis-related arthritis, *n* (%)	24 (17%)
Other (psoriatic, undifferentiated, unknown), *n* (%)	9 (6%)
Clinical Characteristics	
Age at diagnosis (years)*	11 (6, 14), [1, 18]
Time between first PR† visit and diagnosis date (days)*	36 (0, 103), [-10, 596]
Symptom onset‡ (months)*	4 (2, 13), [0, 137]
Follow-up period§ (years)*	3 (2, 3), [0, 4]

No missing data points. All values rounded to the nearest whole number.
*Median (Q1, Q3), [min, max]
†Pediatric rheumatologist (PR)
‡Symptom onset: time between initial symptoms and first visit with pediatric rheumatologist
§Follow-up period: time between first visit at clinic and censored end of follow-up

5.4.2 Documentation

All KPIs were documented at least once in the cohort. The safety KPIs were the most documented, followed by the access to care and then measurement of patient outcomes KPIs (**Table 24**). For the measurement of patient outcomes KPIs, 56 patients had a Childhood Health Assessment Questionnaire (CHAQ) score documented in at least one visit. No other assessment of functional ability was found in the SCM records. The explicit clinical juvenile arthritis disease activity score (cJADAS) was also not found in SCM; however, 58 patients had the components required to calculate the cJADAS (joint count, physician's global assessment (PGA), and

parent/patient assessment of well-being) documented in at least one visit. The most documented of the five measurement of patient outcomes KPIs were rheumatological joint assessment and assessment of arthritis-related pain. No validated tool was specified for the joint or pain assessments. The PGA was documented in at least one visit for 47% of the patients. For the three access to care KPIs, visit dates for first year diagnosis and follow-up visits were the most frequently documented. Of the two safety KPIs, laboratory monitoring for patients on the DMARDs methotrexate and leflunomide was documented in all patients; however, TB screening was documented in 96% of the patients.

Table 24: Documentation of UCAN CURE KPIs in SCM and the administrative databases.

KPI	Documented* in at least one visit for each patient, n (%)
Measurement of Patient Outcomes KPIs	
1. Rheumatological Joint Assessment in SCM	140 (100%)
2. Physician's Global Assessment of Disease Activity in SCM	66 (47%)
3. Assessment of Functional Ability	56 (40%)
Assessment of Functional Ability using CHAQ in SCM	56 (40%)
Other Assessment of Functional Ability in SCM†	0
4. Composite disease activity measurement	58 (41%)
All Components of cJADAS present in SCM	58 (41%)
cJADAS in SCM‡	0
5. Assessment of arthritis-related pain in SCM	140 (100%)
Access to Care KPIs	
6. Waiting time between referral date and first visit in SCM	24 (17%)
7. Presence of visit dates for first year of diagnosis in SCM [n=137]§	137 (100%)

8. Presence of visit dates for follow-up visits in SCM [n=137]§	137 (100%)
Safety KPIs	
9. Tuberculosis Screening [n=56]¶	54 (96%)
Tuberculosis Screening in SCM [n=56]¶	53 (95%)
Tuberculosis Screening in Consolidated Laboratory Repository [n=56]¶	5 (9%)
Tuberculosis Screening in Practitioner Claims [n=56]¶	18 (32%)
Tuberculosis Screening in NACRS [n=56]¶	4 (7%)
10. Laboratory Monitoring for DMARDs# [n=102]**	102 (100%)
Labs Ordered in SCM [n=99]††	91 (92%)
Lab Results in SCM [n=99]††	91 (92%)
Laboratory Tests in Consolidated Laboratory Repository [n=102]**	102 (100%)

* 'Documented' – means data required for each KPI is found in at least one visit in the entire JIA cohort. If the data were found to be documented, this is shown in the table as 'Yes'. If data were not found, this is shown in the table as 'No'. If the KPI is not relevant to be reported separately for the respective visit type, it is shown in the table as N/A.
†The CHAQ was the only assessment of functional ability found.
‡The cJADA score was never explicitly found, only the components required to calculate the cJADAS (joint count, physician's global assessment, parent/patient assessment of well-being).
§n=137 because 3 patients did not have a follow-up visit after diagnosis date.
¶n=56 because this is only applicable to those prescribed biologics. Documentation of tuberculosis screening in any of the data sources used. One patient's screening was not documented in SCM but was documented in the Consolidated Laboratory Repository.
#Disease modifying anti-rheumatic drugs (DMARDs)
**n=102 because this is only applicable to those prescribed the DMARDs methotrexate and leflunomide.
††n=99 because this is only applicable to patients who had a visit after being prescribed the DMARDs methotrexate and leflunomide.

5.4.3 Documentation Frequencies

Measurement of Patient Outcomes KPIs

Rheumatological joint assessment was the most documented KPI, occurring at almost every visit for every patient (95%) and was only missed in one patient chart at the first visit (**Table 25**). This documentation frequency is considerably higher than the PGA of disease activity (only 15%

of visits). The CHAQ was the only method of assessment for functional ability found in SCM and was documented in at least one visit for less than half the cohort. The assessment of arthritis-related pain had one of the highest documentation frequencies for the number of total and first visits with documentation (**Table 25**). Documentation of this KPI dropped over time as the percentage of patients with documentation at every visit was less than half that for the first visit. The data were not able to determine if a validated tool to assess pain and a joint assessment were used as no named tools were specified.

Table 25: Documentation frequency of measurement of patient outcomes KPIs found in SCM.

KPI	Number of visits with documentation, n (%) [n=1360]	Number of first visit with documentation, n (%) [n=140]	Number of patients with documentation at every visit [n=140]
Measurement of Patient Outcomes KPIs			
Rheumatological Joint Assessment in SCM	1351 (99%)	139 (99%)	133 (95%)
Physician's Global Assessment of Disease Activity in SCM	205 (15%)	1 (1%)	0
Assessment of Functional Ability	150 (11%)	1 (1%)	0
Assessment of Functional Ability using CHAQ in SCM	150 (11%)	1 (1%)	0
Other Functional Ability Assessment in SCM*	0	0	0
Composite disease activity measurement	169 (12%)	1 (1%)	0
All Components of cJADAS present in SCM	169 (12%)	1 (1%)	0
cJADAS in SCM†	0	0	0
Assessment of arthritis-related pain in SCM	1186 (87%)	124 (89%)	65 (46%)

*The CHAQ was the only assessment of functional ability found in SCM.
†The cJADAS was never explicitly found, only the components required to calculate the score (joint count, physician's global assessment, parent/patient assessment of well-being).

Access to Care KPIs

For 24 patients, the time from referral date to first visit at the clinic was mentioned in the documentation found in SCM either numerically or with a qualitative description where a date was not able to be determined or calculated (**Table 26**). Of these patients, 18 had a quantitative timeframe mentioned and only one patient had an explicit referral date reported. For the remaining 17 patients, when the referral date was not explicit, references within the documentation were used to determine the date of referral; when only the month and not the day was reported, the 15th day of the month was used for the referral date. The cohort size for systemic JIA patients was too small to report independently. There were 14 systemic and non-systemic JIA patients that met the respective benchmarks of seven-days for systemic JIA and four-weeks for the other JIA non-systemic subtypes. Waiting time for rheumatologic consultation, defined as the 50th and 90th percentile, was 24 days and 46 days respectively.

The KPI for visits during the first year of diagnosis, defined as 12 months after diagnosis, had a sample size of 137 because three patients did not have a visit date after their date of diagnosis (two patients transitioned to adult care and one patient was lost to follow-up after diagnosis). Of these patients who had at least one visit after diagnosis, 100% saw the pediatric rheumatologist in the first 12 months after diagnosis.

Patient-centric years, defined by the anniversary of the JIA diagnosis date, were used to calculate annual follow-up visits with the pediatric rheumatologist after the first 12-month period. Over each patient's follow-up period, 77% (105 of the 137) had a visit during each

eligible interval. To be included in the denominator, patients must have visited a pediatric rheumatologist after their date of diagnosis. In the 12- to 24-month and 24- to 36-month intervals after diagnosis, 96% and 83% of patients had at least one follow-up visit. In the 36- to 48-month interval after diagnosis, 67% of patients had at least one visit with a rheumatologist. The lower performance of the 36- to 48-month interval after diagnosis is likely due to the 12-month window for some patients extending past the study's ultimate cut-off date of March 13th, 2020.

Table 26: Documentation frequency of access to care KPIs.

KPI	N (%)
Access to Care KPIs	
Waiting times for rheumatologist consultation for patients with new onset JIA	
Number of patients with a qualitative or quantitative documentation for waiting times [n=140]	24 (17%)
Number of patients with an eligible date of referral reported [n=24]*	18 (75%)
Number of patients that met benchmark of time from referral to first visit in days, [n=18]†	14 (78%)
50th percentile in days, [n=18]	24
90th percentile in days, [n=18]	46
Patients newly diagnosed with JIA with at least one visit to a pediatric rheumatologist in the first year of diagnosis	
Number of patients with new onset JIA (incident JIA) with at least one visit to a pediatric rheumatologist in the first year of diagnosis [n=137]	137 (100%)
Patients seen in yearly follow-up by a pediatric rheumatologist	
Number of patients with JIA seen by their pediatric rheumatologist at least once every year over their follow-up period [n=137]	105 (77%)
12 to 24 months after diagnosis [n=128]	123 (96%)
24 to 36 months after diagnosis [n=89]	74 (83%)
36 to 48 months after diagnosis [n=36]	24 (67%)

*Includes approximate date used for eligible date of referral reported and complete date of referral reported. When no specific date was reported and only month/year, 15th of the month was used.
†Benchmark is 7 days for systemic JIA and 4 weeks for other types of JIA and denominator is n=140

Safety KPIs

In the cohort, 56 patients were on a biologic with 71 biologic starts documented in SCM. This is because some of the 56 patients on a biologic had taken multiple biologics over the course of their follow-up period, thus increasing the number of 'starts'. Documentation for TB testing in either SCM, the consolidated laboratory repository, NACRS, or Practitioner Claims was found for 96% of the patients. Of the 56 patients, 53 patients had a documented TB test for a biologic start in SCM (**Table 27**). Screening for TB can take many different forms such as a blood test, skin test, or chest x-ray. In total, five patients met the TB screening KPI (screening within 12 months prior to first biologic), two patients were found with documentation in NACRS, and three patients were found with documentation in Practitioner Claims.

In the cohort, 102 patients were on the DMARDs methotrexate or leflunomide with a documented laboratory monitoring test (**Table 27**). Documentation in SCM required the patient to have a visit during the follow-up period after being prescribed a DMARD, thus the sample size for documentation in SCM was 99 patients. During the first month the patient received methotrexate or leflunomide, 59% of eligible patients were monitored for toxicity by clinical laboratory methods in the Consolidated Laboratory Repository. Focusing on the first two-years of eligible intervals, the percentages of patients who received methotrexate and leflunomide and were monitored for toxicity are high, ranging from 76% to 90% after the first month. The high level of testing is in accordance with the mean duration a patient was on the drug (22 months).

Table 27: Documentation frequency of safety KPIs in SCM and the administrative databases.

KPI	N (%)
Safety KPIs	
Tuberculosis Screening	

Number of patients with documentation of a TB test for a biologic start in SCM, Practitioner Claims, NACRS, or Consolidated Laboratory Repository [n=56], n (%)	54 (96%)
SCM [n=56]	53 (95%)
Practitioner Claims [n=56]	18 (32%)
NACRS [n=56]	4 (7%)
Consolidated Laboratory Repository [n=56]	5 (9%)
Number of patients screened for TB within 12 months prior to receiving a first course of therapy using a biologic DMARD [n=56]	5 (9%)
Practitioner Claims [n=18]	3 (17%)
NACRS [n=4]	2 (50%)
Consolidated Laboratory Repository [n=5]	0
Laboratory monitoring for DMARDs	
Number of patients on methotrexate and leflunomide with documentation of toxicity monitoring in the Consolidated Laboratory Repository [n=102]	102 (100%)
0-1 month [n=102]	60 (59%)
1-4 months [n=101]	85 (84%)
4-8 months [n=94]	85 (90%)
8-12 months [n=88]	77 (88%)
12-16 months [n=79]	70 (89%)
16-20 months [n=68]	53 (78%)
20-24 months [n=55]	42 (76%)
Number of patients who received methotrexate and leflunomide and monitored for toxicity by clinical laboratory methods in the Consolidated Laboratory Repository during every eligible interval [n=102]	29 (28%)
Number of patients on methotrexate or leflunomide with mention of laboratory tests ordered† in SCM at every eligible visit [n=99]*	22 (22%)
Number of patients on methotrexate or leflunomide with mention of laboratory test results‡ in SCM at every eligible visit [n=99]*	33 (33%)

*Does not include patients who began methotrexate or leflunomide at last visit and denominator is entire cohort. †Mention of laboratory tests ordered includes documentation reporting specific tests, non-specific tests, and ordering no tests.
‡Mention of laboratory test results includes documentation reporting specific tests, missing/pending/not yet available tests, non-specific tests, and documentation that no recent tests were completed.

5.5 DISCUSSION

This study assessed the documentation and frequency of the required data to measure each of the 10 JIA KPIs. The access to care and safety KPIs were documented more frequently than the measurement of patient outcomes KPIs. In terms of overall documentation for the measurement of patient outcomes KPIs, the joint and pain assessment KPIs (#1 and #5) were well documented in SCM for all visits in the cohort and can be easily used in future analyses. This study found that although the data required to measure all the KPIs were documented, the measurement of patient outcomes KPIs were not consistently documented. Although the current documentation frequencies for each of the 10 JIA KPIs are sufficient to develop benchmarks of care, there is a significant opportunity for better clinical documentation and more consistent data collection for KPIs during clinical visits, which aligns with current clinical guidelines for JIA management.(1)

A joint assessment was the most frequently documented KPI in this study. The standardized layout of the SCM form, with the physical examination having its own section, including a description of a joint assessment, could have facilitated its documentation. It is unknown whether the frequent documentation of this KPI will continue with the transition to Epic (a comprehensive electronic health record (EHR) being implemented across Alberta)(65,66). Epic is one of the EHRs commonly used with the Rheumatology Informatics System for Effectiveness (RISE) registry in the United States.

The data for the measurement of patient outcomes KPIs for physician's global assessment (PGA), assessment of functional ability, and measurement of clinical disease activity were minimally documented in SCM. One patient had documentation of a PGA, CHAQ, and

components for the cJADAS documented at their first clinic visit in SCM. This patient was seen at the early arthritis clinic (EAC) at their first visit whereas patients are typically seen at the EAC after their first visit with the pediatric rheumatologist. This explains the difference in documentation for this patient. Notably CHAQ and patient PGA are currently documented in the clinic's paper charts. Moving to Epic's electronic system should increase the frequency of documented CHAQ and patient PGA values.

In a previous study on rheumatoid arthritis (RA), a disease activity performance measure was defined as the "percent of RA patients with ≥ 50% of total number of outpatient encounters per year with assessment of disease activity using a standardized measure", and 100% of the patients met this measure.(74) This contrasts dramatically to this study with only 12% of all JIA clinic visits documenting the cJADAS in SCM. It is possible that the higher levels of reporting disease activity by any acceptable composite measure (such as Disease Activity Score 28 or the Clinical Disease Activity Index) in the previous RA study was due to the use of the data platform Rheum4U, developed for inflammatory disease patients and implemented in both clinics in the study, with a patient platform to collect the patient reported outcomes. These higher levels could mean that the data are not routinely documented unless part of a specific RA registry where patient outcome data are explicitly recorded. The ease of monitoring when the required data for each KPI are entered into a platform like Rheum4U or RISE that retrieves data for arthritis patients from selected electronic health records (EHR) systems such as Epic should be a key priority for the implementation of performance measures. A study using the RISE registry for RA found a performance rate for disease activity of 55.2% (72) and a separate RISE study found a performance of 53.6% in a random sample of RA patients (73) with the same KPI definition of documentation in ≥ 50% of outpatient encounters per year. Minimal data for these disease

activity KPIs was found in SCM, but the data may be documented in the in-clinic paper charts. The documentation of these KPIs could be improved with a streamlined transition of data from the paper chart to the electronic note. This could be facilitated through standardized headers for each clinician note, requiring data to be entered before the form can be completed, and having the software automatically calculate scores for various assessment such as the cJADAS.

The assessment of arthritis-related pain had a high documentation frequency for the total number of visits in the cohort but dropped in frequency for every visit for every patient. This could be due to the absence of a standard section for pain similar to the physical examination section for a joint assessment. The assessment of pain is typically written at the start of the note where anything that has occurred since the last clinic visit is described and it is possible that the pain information does not get transferred to SCM if the patient's pain was not significant in that visit. This could explain part of the 49% difference between the performance of these two KPIs. A specific section for pain in the SCM notes would be a step toward improved documentation patterns.

Documentation of the access to care KPIs was highly compliant except for the waiting times KPI. In SCM, the waiting time from referral was only mentioned in 17% of the cohort; however, this could be due to the use of Clinibase in Calgary, a database that contains the referral letters for each patient and is separate from SCM. Visits during the first year of diagnosis and annual visits demonstrate strong compliance as all applicable patients had a visit during the first year after diagnosis and 77% of patients had annual follow-up visits; however, this hedges on the assumption that all visits were entered into SCM. It is possible that performance is higher if some visits were not entered into SCM.

Of the two safety KPIs, TB screening was documented in SCM more consistently than the KPI for laboratory monitoring for DMARDs. The TB screening KPI was documented in SCM for 95% of eligible patients. A noted limitation with the SCM data is that the dates of TB tests were not recorded; consequently, it could not be determined if TB testing occurred prior to the patient's biologic therapy unless documented in the administrative databases. The Consolidated Laboratory Repository contains the tests for patients who received a TB screening blood test. This is typically only done for patients who recently had vaccinations or had prior TB exposure. This would explain the small number of patients who have this test reported in the Consolidated Laboratory Repository. The TB skin test is the gold standard for TB screening. NACRS or Practitioner Claims were used to identify TB screening; however, it has been consistently found that using ICD codes to identify TB screening and diagnoses has a relatively lower positive predictive value compared to other communicable diseases.(75) A TB skin test can also be performed in the Infectious Disease Clinic at the hospital which would not be found in the administrative data since claims from the hospital are not sent in. A more accurate method of identifying TB screening should be a focus moving forward.

Although the laboratory monitoring KPI for patients on methotrexate and leflunomide was well documented in SCM, the Consolidated Laboratory Repository contained more accurate data. Even so, this study was unable to determine the exact biologic start date without patient interaction documented. Accuracy for start and stop dates could be improved by using the Pharmaceutical Information Network (PIN) database to track the date the prescription was dispensed, patient feedback on their start and stop dates, or having more explicit description headers in the clinic visit note. The lower compliance levels for laboratory testing demonstrates that there is an opportunity for improvement in compliance and documentation of this KPI.

Quality measurement is dependent upon the availability of relevant data. This was cited as both the greatest factor that facilitated or impeded the use of quality measures by the National Quality Forum (NQF) report.(48) Data infrastructures need to be able to "talk to each other" and EHRs need to be "sufficiently robust" to generate the required information for "measure construction".(48) It has been shown that performances in practices are the highest when the EHR system has rheumatology-specific templates in the software as it enables the collection and monitoring of key measures.(77) EHRs should be used to guide which process-related quality indicators are easily assessed in clinical care.(78) An important next step in the implementation of these KPIs is to align the measures across Canada and have them endorsed by the Canadian Rheumatology Association. Implementing nationally aligned and endorsed measures with a system similar to RISE or Rheum4U in Epic would provide the highest likelihood of physician uptake and potential for quality improvement.

There are four data sources for performance measurement in health care: administrative data, chart review (paper and electronic documents), surveys of patients/families/staff, and data generated and extracted from EHRs.(29) Measurement using administrative data necessitates the assumption that the diagnosis and procedure coding is accurate and medication that was prescribed matches the medication taken.(29) Chart reviews are labour intensive and used to validate measures from administrative data and EHRs .(29) The use of electronic health records provides an "opportunity to access patient-centric clinical data and the ability to efficiently measure quality performance outcomes measures".(29) Technological advances have enabled data extraction from both discrete and free-text fields in EHRs.(29) Calgary's new system, Epic, has the potential to capture the required data from a variety of data locations and consolidate to a

single electronic database system, increasing the ease of monitoring KPIs by physicians and decision makers.

This study used a retrospective cohort which minimized the risk of the Hawthorne effect as no clinicians were able to change their behaviour in response to the study. A standardized data collection form was used, and double data extraction occurred in 10% of the patients to minimize any discrepancies. The Alberta Children's Hospital Pediatric Rheumatology Clinic is a tertiary centre, where clinicians are involved in research and are likely aware of quality measures and the value of documenting their JIA management with respect to clinical guidelines. Although this represents a strength in the data being more completely documented, it limits the generalizability of the results to other centres. Generalizability was also limited by the COVID-19 pandemic where telehealth was the primary method of clinical visits. This study did not collect data for telehealth visits. Further research is required to assess the feasibility and performance of these KPIs in other practice settings since there may be differences in how documentation of patient data are captured and stored. The interpretations from this research are based on the extent to which the required data are documented accurately in SCM. The study does not address, infer, or imply any evaluation of physician performance.

As health systems transition to electronic health records like Epic, efforts should be made to guide consistent data collection. It is important to understand the documentation patterns in relevant and routinely collected data to assess the feasibility of measuring predetermined KPIs. If KPIs are not measurable, they will be challenging to implement, limiting the potential for quality improvement and practice change. Individuals and systems need the tools to enact change and having an active system of monitoring KPIs that are feasible to measure is a key step in the process toward improved patient care outcomes. Effective monitoring of quality of care by

streamlining and integrating the collection of data required to measure KPIs can help increase the likelihood of clinician uptake.

Future steps should involve replicating this assessment in other centres across Canada and reviewing the documentation frequency results with similar experts to those involved in the development of the KPIs (Modified Delphi Panel) to determine if another step to update and confirm the KPIs is necessary before finalizing them.(59) Then, dissemination of the KPIs to clinicians involved in JIA patient care should occur to bring awareness to what data needs explicit documentation to allow for measurability and monitoring through engagement with Canadian rheumatologists. The final step to monitor these KPIs is to generate an algorithm to monitor, measure, and publicly publish the KPI levels at various JIA care centres to make them easily accessible for decision-makers.

References

1. Barber CEH, Twilt M, Pham T, Currie GR, Benseler S, Yeung RSM, et al. A Canadian evaluation framework for quality improvement in childhood arthritis: key performance indicators of the process of care. Arthritis Res Ther. 2020;22(1):53.

2. Childhood Arthritis - Symptoms, Causes, Diagnosis & Treatments [Internet]. [cited 2021 Jul 5]. Available from: https://arthritis.ca/about-arthritis/arthritis-types-(a-z)/types/childhood-arthritis

3. Barber CEH, Lix LM, Lacaille D, Marshall DA, Kroeker K, Benseler S, et al. Testing population-based performance measures identifies gaps in juvenile idiopathic arthritis (JIA) care. BMC Health Serv Res. 2019 Aug;19(1):572.

4. Juvenile Rheumatoid Arthritis [Internet]. [cited 2021 Jul 5]. Available from: https://www.hopkinsmedicine.org/health/conditions-and-diseases/arthritis/juvenile-idiopathic-arthritis

5. Donabedian A. Evaluating the Quality of Medical Care. Milbank Q. 2005 Dec;83(4):691–729.

6. Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century [Internet]. Washington (DC): National Academies Press (US); 2001 [cited 2022 Aug 10]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK222274/

7. Barber CEH, Barnabe C, Benseler S, Chin R, Johnson N, Luca N, et al. Patient factors associated with waiting time to pediatric rheumatologist consultation for patients with juvenile idiopathic arthritis. Pediatr Rheumatol Online J. 2020 Mar;18(1):22.

8. Barber CEH, Schieir O, Lacaille D, Marshall DA, Barnabe C, Hazlewood G, et al. High Adherence to System-Level Performance Measures for Rheumatoid Arthritis in a National Early Arthritis Cohort Over Eight Years. Arthritis Care Res. 2018 Jun;70(6):842–50.

9. Wu EY, Rabinovich CE. Chapter 180 - Juvenile Idiopathic Arthritis. In: Nelson Textbook of Pediatrics. 2020. p. 1258–68.

10. Ted Mikuls, Cannella A, Moore G, O'Dell J, Erikson A, Thiele G. Juvenile Idiopathic Arthritis. In: Rheumatology. 1st ed. CRC Press; 2013.

11. deming. Deming The Man [Internet]. The W. Edwards Deming Institute. [cited 2021 Oct 12]. Available from: https://deming.org/deming-the-man/

12. Deming WE. Improvement of Quality and Productivity through Action by Management: Management can increase productivity by improving quality. Dr. Deming's

fourteen points show the way. Why productivity increases with improvement of quality. Natl Product Rev Pre-1986. 1981 Dec 1;1(1):12.

13. Deming WE. The need for change. J Qual Particip. 1994 Dec;17(7):30.

14. Berwick DM, James B, Coye MJ. Connections between quality measurement and improvement. Med Care. 2003 Jan;41(1 Suppl):I30-38.

15. Lawrence M, Olesen F. Indicators of Quality in Health Care. Eur J Gen Pract. 1997 Jan 1;3(3):103–8.

16. AHRQ Quality Indicators [Internet]. [cited 2022 Aug 3]. Available from: https://qualityindicators.ahrq.gov/

17. Quality Measures | CMS [Internet]. [cited 2022 Aug 3]. Available from: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityMeasures

18. Majeed A, Lester H, Bindman AB. Improving the quality of care with performance indicators. BMJ. 2007 Nov 3;335(7626):916–8.

19. Bergeron BP. Key Performance Indicators. In: Performance Management in Healthcare. 2nd ed. Productivity Press; 2017.

20. Barber CE, Patel JN, Woodhouse L, Smith C, Weiss S, Homik J, et al. Development of key performance indicators to evaluate centralized intake for patients with osteoarthritis and rheumatoid arthritis. Arthritis Res Ther. 2015 Dec;17(1):322.

21. Kastrup M, von Dossow V, Seeling M, Ahlborn R, Tamarkin A, Conroy P, et al. Key Performance Indicators in Intensive Care Medicine. A Retrospective Matched Cohort Study. J Int Med Res. 2009 Oct 1;37(5):1267–84.

22. McCance T, Telford L, Wilson J, MacLeod O, Dowd A. Identifying key performance indicators for nursing and midwifery care using a consensus approach. J Clin Nurs. 2012;21(7–8):1145–54.

23. Urimubenshi G, Langhorne P, Cadilhac DA, Kagwiza JN, Wu O. Association between patient outcomes and key performance indicators of stroke care quality: A systematic review and meta-analysis. Eur Stroke J. 2017 Dec 1;2(4):287–307.

24. Bhatnagar NM, Soni S, Gajjar M, Shah M, Shah S, Patel V. Performance indicators: A tool for continuous quality improvement. Asian J Transfus Sci. 2016;10(1):42–7.

25. OECD. Performance Measurement. 2011 Sep 25 [cited 2021 Sep 20]; Available from: https://www-oecd-ilibrary-org.ezproxy.lib.ucalgary.ca/governance/performance-measurement_5js4vmnq2gbt-en

26. Ettorchi-Tardy A, Levif M, Michel P. Benchmarking: A Method for Continuous Quality Improvement in Health. Healthc Policy. 2012 May;7(4):e101–19.

27. The Mapping Medicare Disparities Tool, Technical Documentation. :66.

28. Fu R, Feng S, Wu Y, He F, Lin Z, Jiang Y, et al. Association between compliance with quality indicators and hospitalisation expenses in patients with heart failure: a retrospective study using quantile regression model in China. BMJ Open. 2020 Jul 1;10(7):e033926.

29. Alessandrini EA, Knapp J. Measuring Quality in Pediatric Emergency Care. Clin Pediatr Emerg Med. 2011 Jun;12(2):102–12.

30. Donabedian A. The quality of care. How can it be assessed? JAMA. 1988 Sep 23;260(12):1743–8.

31. Horrocks S, Cook J, Ashton N, Wye L. Made to measure? Assessing feasibility of quality indicators for district nursing. Br J Community Nurs. 2012 Jan;17(1):28–34.

32. Adair CE, Simpson E, Casebeer AL, Birdsell JM, HAYDEN KA, Lewis S. Performance Measurement in Healthcare: Part II – State of the Science Findings by Stage of the Performance Measurement Process. Healthc Policy. 2006 Jul;2(1):56–78.

33. Adair CE, Simpson E, Casebeer AL, Birdsell JM, Hayden KA, Lewis S. Performance Measurement in Healthcare: Part I – Concepts and Trends from a State of the Science Review. Healthc Policy. 2006 May;1(4):85–104.

34. Frankel A, Haraden C, Federico F, Lenoci-Edwards J. Institute for Healthcare Improvement and Safe & Reliable Healthcare White Paper on A Framework for Safe, Reliable, and Effective Care. 2017.

35. Cooper M, Rouhi A, Barber CEH. A Systematic Review of Quality Measures for Inflammatory Arthritis. J Rheumatol. 2018 Feb 1;45(2):274–83.

36. Gunn AJ, Duncan JR. Chapter 24 - Interventional Radiology. In: Radiology Noninterpretive Skills: The Requisites. 2018. p. 213–21.

37. Mant J. Process versus outcome indicators in the assessment of quality of health care. Int J Qual Health Care. 2001 Dec 1;13(6):475–80.

38. Liu LH, Choden S, Yazdany J. Quality Improvement Initiatives in Rheumatology: An Integrative Review of the Last Five Years. Curr Opin Rheumatol. 2019 Mar;31(2):98–108.

39. McDonald KM. Approach to Improving Quality: the Role of Quality Measurement and a Case Study of the Agency for Healthcare Research and Quality Pediatric Quality Indicators. Pediatr Clin North Am. 2009 Aug;56(4):815–29.

40. Time to close the gap: report card on WTs in Canada (2014) [Internet]. Wait Time Alliance (WTA); 2014 [cited 2022 Aug 2]. Available from: https://www.waittimealliance.ca/wta-reports/2014-wta-report-card/

41. Lovell DJ, Passo MH, Beukelman T, Bowyer SL, Gottlieb BS, Henrickson M, et al. Measuring Process of Arthritis Care. A Proposed Set of Quality Measures for the Process of Care in Juvenile Idiopathic Arthritis. Arthritis Care Res. 2011 Jan;63(1):10–6.

42. Stelfox HT, Straus SE. Measuring quality of care: considering conceptual approaches to quality indicator development and evaluation. J Clin Epidemiol. 2013 Dec 1;66(12):1328–37.

43. Barber CE, Patel JN, Woodhouse L, Smith C, Weiss S, Homik J, et al. Development of key performance indicators to evaluate centralized intake for patients with osteoarthritis and rheumatoid arthritis. Arthritis Res Ther. 2015;17:322.

44. Ewald DA, Huss G, Kraska RA, Geraedts M. Feasibility testing of the Core set of quality Indicators for Paediatric Primary Care in Europe, COSI-PPC-EU. Eur J Pediatr. 2019 May;178(5):707–19.

45. Saliba D, Solomon D, Rubenstein L, Young R, Schnelle J, Roth C, et al. Feasibility of Quality Indicators for the Management of Geriatric Syndromes in Nursing Home Residents. J Am Med Dir Assoc. 2004 Sep 1;5(5):310–9.

46. Maqutu D, Zewotir T, North D, Naidoo K, Grobler A. Determinants of optimal adherence over time to antiretroviral therapy amongst HIV positive adults in South Africa: A longitudinal study. AIDS Behav. 2011 Oct;15(7):1465–74.

47. Anderson CJ. Ordinal Variables in 2–way Tables. :39.

48. Damberg CL, Sorbero ME, Lovejoy SL, Lauderdale K, Wertheimer S, Smith A, et al. An Evaluation of the Use of Performance Measures in Health Care [Internet]. RAND Corporation; 2011 Dec [cited 2022 Apr 4]. Available from: https://www.rand.org/pubs/technical_reports/TR1148.html

49. RISE Registry [Internet]. American College of Rheumatology. [cited 2022 Apr 4]. Available from: https://www.rheumatology.org/Practice-Quality/RISE-Registry

50. RISE for Practices [Internet]. American College of Rheumatology. [cited 2022 Apr 4]. Available from: https://www.rheumatology.org/Practice-Quality/RISE-Registry/RISE-for-Practices

51. About | Rheum4U | Cumming School of Medicine | University of Calgary [Internet]. [cited 2022 Apr 5]. Available from: https://cumming.ucalgary.ca/departments/medicine/division/rheumatology/rheum4u/about

52. Data and Insights | Rheum4U [Internet]. Cumming School of Medicine. [cited 2022 Apr 5]. Available from: https://cumming.ucalgary.ca/departments/medicine/division/rheumatology/rheum4u/data-and-insights

53. For Researchers | Rheum4U [Internet]. Cumming School of Medicine. [cited 2022 Apr 5]. Available from: https://cumming.ucalgary.ca/departments/medicine/division/rheumatology/rheum4u/researchers

54. Our Network [Internet]. PR-COIN. [cited 2022 Apr 18]. Available from: https://www.pr-coin.org/about-network

55. Sellami M, Fazaa A, Cheikh M, Miladi S, Ouenniche K, Ennaifer R, et al. Screening for latent tuberculosis infection prior to biologic therapy in patients with chronic immune-mediated inflammatory diseases (IMID): Interferon-gamma release assay (IGRA) versus tuberculin skin test (TST). Egypt Rheumatol. 2019 Jul 1;41(3):225–30.

56. Rigby WFC, Lampl K, Low JM, Furst DE. Review of Routine Laboratory Monitoring for Patients with Rheumatoid Arthritis Receiving Biologic or Nonbiologic DMARDs. Int J Rheumatol. 2017;2017:9614241.

57. Park YS, Konge L, Artino ARJ. The Positivism Paradigm of Research. Acad Med. 2020 May;95(5):690–4.

58. Hudson LA, Ozanne JL. Alternative Ways of Seeking Knowledge in Consumer Research. J Consum Res. 1988 Mar;14(4):508–21.

59. Ferrua M, Couralet M, Nitenberg G, Morin S, Serin D, Minvielle E. Development and feasibility of a set of quality indicators relative to the timeliness and organisation of care for new breast cancer patients undergoing surgery. BMC Health Serv Res. 2012 Dec;12(1):167.

60. Pediatric Rheumatology Clinic [Internet]. Cumming School of Medicine. [cited 2021 Sep 21]. Available from: https://cumming.ucalgary.ca/departments/medicine/division/rheumatology/patient-care/specialty-clinics/pediatric-rheumatology-clinic

61. Rheumatology [Internet]. Cumming School of Medicine. [cited 2021 Sep 21]. Available from: https://cumming.ucalgary.ca/departments/pediatrics/sections/rheumatology

62. Grazziotin LR, Currie G, Twilt M, Ijzerman MJ, Kip MMA, Koffijberg H, et al. Evaluation of Real-World Healthcare Resource Utilization and Associated Costs in Children with Juvenile Idiopathic Arthritis: A Canadian Retrospective Cohort Study. Rheumatol Ther. 2021 Sep 1;8(3):1303–22.

63. Grazziotin LR, Currie G, Twilt M, Ijzerman MJ, Kip MMA, Koffijberg H, et al. Real-world data reveals the complexity of disease modifying anti-rheumatic drug treatment patterns in juvenile idiopathic arthritis: an observational study. Pediatr Rheumatol. 2022 Apr 11;20(1):25.

64. Shiff NJ, Oen K, Rabbani R, Lix LM. Validation of administrative case ascertainment algorithms for chronic childhood arthritis in Manitoba, Canada. Rheumatol Int. 2017 Sep;37(9):1575–84.

65. Epic | ...with the patient at the heart [Internet]. [cited 2022 Jun 5]. Available from: https://www.epic.com/

66. Services AH. Patients & Families [Internet]. Alberta Health Services. [cited 2022 Jun 2]. Available from: https://www.albertahealthservices.ca/cis/Page15448.aspx

67. Vassar M, Holzmann M. The retrospective chart review: important methodological considerations. J Educ Eval Health Prof. 2013 Nov 30;10:12.

68. Hallgren KA. Computing Inter-Rater Reliability for Observational Data: An Overview and Tutorial. Tutor Quant Methods Psychol. 2012;8(1):23–34.

69. Dempster H, Porepa M, Young N, Feldman BM. The clinical meaning of functional outcome scores in children with juvenile arthritis. Arthritis Rheum. 2001;44(8):1768–74.

70. Health research data access [Internet]. [cited 2022 Mar 15]. Available from: https://www.alberta.ca/health-research.aspx

71. Singh G, Athreya BH, Fries JF, Goldsmith DP. Measurement of health status in children with juvenile rheumatoid arthritis. Arthritis Rheum. 1994 Dec;37(12):1761–9.

72. Yazdany J, Bansback N, Clowse M, Collier D, Law K, Liao KP, et al. Rheumatology Informatics System for Effectiveness: A National Informatics-Enabled Registry for Quality Improvement: Using RISE Registry to Improve Quality of Care. Arthritis Care Res. 2016 Dec;68(12):1866–73.

73. Yazdany J, Robbins M, Schmajuk G, Desai S, Lacaille D, Neogi T, et al. Development of the American College of Rheumatology's Rheumatoid Arthritis Electronic Clinical Quality Measures. Arthritis Care Res. 2016;68(11):1579–90.

74. Barber CEH, Mosher D, Dowling S, Bohm V, Solbak NM, MacMullan P, et al. Implementation and Evaluation of Audit and Feedback for Monitoring Treat-to-Target (T2T) Strategies in Rheumatoid Arthritis Using Performance Measures. Rheumatol Ther. 2020 Dec 1;7(4):909–25.

75. Sickbert-Bennett EE, Weber DJ, Poole C, MacDonald PDM, Maillard JM. Utility of International Classification of Diseases, Ninth Revision, Clinical Modification Codes for Communicable Disease Surveillance. Am J Epidemiol. 2010 Dec 1;172(11):1299–305.

76. Ferrua M, Couralet M, Nitenberg G, Morin S, Serin D, Minvielle E. Development and feasibility of a set of quality indicators relative to the timeliness and organisation of care for new breast cancer patients undergoing surgery. BMC Health Serv Res. 2012 Jun 21;12(1):167.

77. Hammam N, Izadi Z, Li J, Evans M, Kay J, Shiboski S, et al. The Relationship Between Electronic Health Record System and Performance on Quality Measures in the American College of Rheumatology's Rheumatology Informatics System for Effectiveness (RISE) Registry: Observational Study. JMIR Med Inform. 2021 Nov 12;9(11):e31186.

78. Pallua J, Schirmer M. Identification of Five Quality Needs for Rheumatology (Text Analysis and Literature Review). Front Med [Internet]. 2021 [cited 2022 Jul 3];8. Available from: https://www.frontiersin.org/article/10.3389/fmed.2021.757102

79. Chen MM, Rosenkrantz AB, Nicola GN, Silva E, McGinty G, Manchikanti L, et al. The Qualified Clinical Data Registry: A Pathway to Success within MACRA. AJNR Am J Neuroradiol. 2017 Jul;38(7):1292–6.

80. Sedgwick P, Greenwood N. Understanding the Hawthorne effect. BMJ. 2015 Sep 4;351:h4672.

81. Public Health Agency of Canada. Juvenile idiopathic arthritis in Canada. [Internet]. 2020 [cited 2022 Jan 4]. Available from: http://publications.gc.ca/collections/collection_2020/aspc-phac/HP35-130-2020-eng.pdf

82. Barber CEH, Barnabe C, Benseler S, Chin R, Johnson N, Luca N, et al. Patient factors associated with waiting time to pediatric rheumatologist consultation for patients with juvenile idiopathic arthritis. Pediatr Rheumatol. 2020 Dec;18(1):22.

APPENDIX A: INTER-RATER RELIABILITY CALCULATION

For the inter-rater reliability calculation, Cohen's kappa will be calculated by:

$$\boldsymbol{Cohen's\ Kappa} = \frac{\boldsymbol{P(a) - P(e)}}{\boldsymbol{1 - P(e)}}$$

Where p(a) is the observed percentage of agreement and p(e) is the probability of expected agreement due to chance [10].