DEFINING FRAILTY WITHIN THE CONTEXT OF ELECTRONIC MEDICAL RECORDS: eCGA DATA MAPPING TO SNOMED CT

by

Sharde Marie Brown

BSN, Kwantlen Polytechnic University, 2009

A SCHOLARY PRACTICE ADVANCEMENT RESEARCH PAPER SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

(Nursing)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

March, 2019

Abstract

Background. Frailty is commonly considered an emerging geriatric syndrome that involves a decrease in the physiological ability to respond to stressors, which can lead to increased hospitalization, worsening health, and morbidity. The goals of this work are to: (1) identify frailty within primary health care as early as possible in order to prevent worsening health issues, and (2) explore information collected within electronic medical records that can be better utilized for assessing frailty. Specifically, this work: 1) conducted a literature review to identify what defining characteristics of frailty are captured in the CGA tool; and 2) matched concepts within the Comprehensive Geriatric Assessment (CGA) tool to SNOMED CT, an international standardized terminology. **Methods.** This research was conducted using a nonexperimental descriptive study design. Manual mapping and expert consensus mapping were used to match concepts from a validated frailty assessment tool the electronic CGA (eCGA) to SNOMED CT; standardized terminologies allow for the sharing and coding of clinical information across different platforms. A literature search was completed to define the relevant characteristics of frailty, and explore the most commonly used assessment tools. These findings were compared with the eCGA to assess content coverage. A visual map supported mapping activities. **Results and Conclusion.** The literature review showed that the eCGA contained all defining characteristics of frailty. One hundred and thirty-three unique assessment questions were manually mapped to SNOMED CT. Of these, 72% (96/133) were direct matches, 17% (22/133) were one-to-many matches to clinical terms within SNOMED CT, and the remaining 11% (15/133) were non-matches. Two rounds of expert clinician consensus mapping occurred. Inter-rater reliability between the two clinicians was 0.75 (Kappa). The outcome of this study is a list

of mapped eCGA elements to SNOMED CT. This list informs a new data table added to a pan-national database for chronic disease monitoring.

Table of Contents

Abstract .... **ii**

Table of Contents .... **iv**

List of Tables .... **viii**

List of Figures .... **ix**

List of Abbreviations .... **x**

Acknowledgements .... **xi**

Dedication .... **xii**

Chapter 1: Introduction **13**

1.1 Background 14

1.1.1 Primary Health Care 14

1.2 Research Questions 16

1.3 Frailty and Aging 17

1.3.1 Defining Frailty 17

1.3.2 Assessing Frailty 19

1.3.2.1 Assessment of Frailty in Primary Health Care 20

1.3.3 Use of EMR for Frailty Research Advancement 20

1.3.3.1 Canadian Primary Care Sentinel Surveillance Network (CPCSSN) 21

1.4 Conclusion 22

Chapter 2: Literature Review **23**

2.1 Introduction 23

2.2 Literature Identification 23

2.3 Validated Frailty Assessment Measures 24
2.3.1 Frailty Index 26
2.3.2 Frailty Phenotype 27
2.3.3 Clinical Frailty Scale 27
2.4 Frailty Assessment in Primary Care 28
2.4.1 CARES Model eCGA 29
2.5 Electronic Medical Record Use in Canadian Primary Health Care 30
2.6 Standardized Terminologies 32
2.6.1 Standardized Clinical Terminologies 34
2.6.1.1 Systematized Nomenclature of Medicine Clinical Term 35
2.6.1.2 Other Standardized Terminologies 35
2.6.2 Clinical Terminology Mapping 36
2.6.3 Clinical Impact of Standardized Terminology Usage 37
2.7 Summary 38
Chapter 3: Methods 39
3.1 Introduction 39
3.2 Research Questions 39
3.3 Study Design 39
3.4 Sampling Plan 40
3.5 Procedure and Data Collection 41
3.6 Phase 1: The Defining Characteristics of Frailty 41
3.7 Phase 2: eCGA Data Sources and Concepts Map 42
3.8 Phase 3: Manual Mapping to SNOMED CT 43

3.9 Phase 4: Clinician Consensus Mapping 46

3.10 Data Analysis 47

Chapter 4: Results 48

4.1 Phase 1: The Defining Characteristics of Frailty 48

4.2 Phase 2: eCGA Map of Data Sources and Concepts 51

4.3 Phase 3: Manual Mapping to SNOMED CT 55

4.4 Phase 4: Phase 4: Clinician Consensus Mapping 55

4.5 Summary 56

Chapter 5: Discussion 57

5.1 Introduction 57

5.2 Defining Frailty 57

5.3 Implications of Defining Frailty Through the eCGA 58

5.4 Manual Standardized Terminology Mapping 59

5.4.1 Lessons Learned from Manual Mapping 60

5.5 Expert Consensus Mapping 62

5.6 Implications 63

5.6.1 Clinical Workforce Education 64

5.6.2 Data Collection Quality 65

5.6.3 Mapping Research 66

5.7 Limitations 67

5.8 Recommendations 68

5.8.1 CPCSSN Database and Recommendations 69

5.8.2 Canadian Primary Care Sentinel Surveillance Network Data 70

5.9 The Role of Nursing in PHC and Frailty Research 71
5.10 Summary 73
References 74
Appendices 88
Appendix A CARES CGA Questionnaire 88
Appendix B Manual Mapping 89
Appendix C Clinician Consensus #1 94
Appendix D Clinician Consensus #2 96

List of Tables

Table 3.1 Clinical term mapping matching criteria 45

Table 3.2 Clinician mapping term matching criteria 47

Table 4.1 Defining Characteristics of Frailty 48

Table 4.2 Characteristics of Frailty in Assessment Tools..49

Table 4.3 Legend-Overall Map of Data Sources and Concepts...51

Table 4.4 Manual Mapping of eCGA to SNOMED CT 55

Table 4.5 Clinician Consensus Mapping of eCGA to SNOMED CT- Iteration #1......................56

Table 4.6 Clinician Consensus Mapping of eCGA to SNOMED CT- Iteration #2......................56

List of Figures

Figure 3.1 Overview of Study Method 40

Figure 4.1 Overall Map of Data Sources and Concepts.. 52

Figure 4.2 Data Sources.. 53

Figure 4.3 Exam Data 54

List of Abbreviations

CFS .... Clinical Frailty Scale

CGA .... Comprehensive Geriatric Assessment

CIHI .... Canadian Institute for Health Information

CMA .... Canadian Medical Association

CPCSSN .... Canadian Primary Care Sentinel Surveillance Network

eCGA .... Electronic Comprehensive Geriatric Assessment

EMR .... Electronic Medical Record

FI .... Frailty Index

ICD .... International Classification of Diseases

LOINC .... Logical Observation Identifiers Names and Codes

PCP .... Primary Care Practitioner

PHC .... Primary Health Care

SNOMED CT .... Systematized Nomenclature of Medicine Clinical Terms

Acknowledgements

I would like to acknowledge my supervisor Dr. Sabrina Wong and committee member Dr. Leanne Currie for their ongoing support, guidance, and encouragement. I would like to thank Manpreet Gill Thandi who assisted me with the clinician validation portion of this paper, and answered numerous questions regarding the application of the eCGA form. I would also like to offer a special thank you to the data managers of the CPCSSN database, who also assisted me in this endeavor.

Without the undying support from my family, completing this research project would not have been possible. I would like to thank my husband and my mother for allowing me the space to achieve my goals.

Dedication

I would like to dedicate this paper to my two daughters. I hope that I can inspire you to pursue your educational goals, no matter what stage of life you are in. I hope that I have showed you that you can do anything you set your mind to. I love you both more than you will know.

Chapter 1: Introduction

In the last decade frailty has become an increasingly discussed topic within the health care research community (Brown & Covinsky, 2018). The research to date has focused on attempting to provide a concise operational definition of frailty that can be applied in a number of clinical settings. This includes a definition of frailty, the biological components and markers that contribute to this condition, and the consequences that arise when frailty has been ascertained in an individual (Harmand et al., 2017).

Frailty is defined as a “state of increased vulnerability, with reduced physiological reserve and loss of function across multiple body systems” (Canadian Frailty Network, 2017a). As multiple physiological systems decline, the extent to which frailty manifests depends on the body’s cellular mechanisms to repair and maintain homeostasis (Dent, Kowal, & Hoogendijk, 2016). People living with frailty have a reduced ability to cope with nominal stressors which can lead to rapid changes within the health of that individual (Canadian Frailty Network, 2017a) .

While frailty does not exclusively affect people of older age, people older than 65 years currently account for the biggest proportion of the population affected (Fried et al., 2001). There are many adverse outcomes for people living with frailty that range from increased hospital stay, mortality rates and falls, to decreased mobility and overall worsening health status (Fried et al., 2001; Kenneth Rockwood & Mitnitski, 2011). The resulting factors of increased frailty can place a burden on individuals, families and caretakers, and the health care system at large. People who are frail are at greater risk for chronic illnesses, and disabilities which impact daily living activities (Van Velsen et al., 2015; Fugate Woods et al., 2005). The Canadian health care system spends upwards of $90 billion dollars on treatment of chronic illnesses (Canadian Institute for Health Information, 2016) and early identification and intervention for frailty may help reduce these costs. Multifactorial and physical therapy related intervention results provide some evidence that they can reduce the severity of frailty in individuals (Romera-Liebana et al., 2018; Theou et al., 2017). The goal for early intervention and treatment of frailty should be to improve overall quality of life, compress the timeframe of morbidity, and improve the end stages of life.

1.1 Background

In Canada, people over the age of 65 will account for approximately 25% of the population by the year 2030 (Bohnert, Chagnon, & Dion, 2015). At present, there are approximately 1.2 million Canadians living with frailty, with that number expected to increase to more than 2 million by 2035 (Canadian Frailty Network, 2017). With the expected increase in aged people, it is important to understand the impact this may have on both the healthcare system and family members who help care for their aging relatives, and identify prevention strategies if possible. As healthcare providers, it is important to understand how we can better identify and assist this growing population. If there are better tools to help identify frailty in a variety of settings, earlier interventions to mitigate some of the adverse outcomes associated with frailty may be implemented. This is especially true in the primary health care setting, because this setting is often the first and main point of contact for patients and families trying to navigate the Canadian healthcare system.

1.1.1 Primary Health Care

Primary health care (PHC) is defined as “Care which provides integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community" (Vanselow, 1995). Based on 2014 survey, it is estimated that over 80% of those aged 65 years and older in Canada have access to PHC (Canadian Institute for Health Information, 2016). In Canada, PHC services are typically delivered through a "most responsible person" which is usually a nurse practitioner or family physician. These services include, but are not limited to, routine health care as well as health promotion and disease prevention (Canadian Institute for Health Information, 2017). Because many people aged 65 years and older currently use PHC as the first point of access to healthcare, it is imperative that clinicians are provided with the tools and knowledge needed to help promote best practices to the growing population.

The Canadian Medical Association identified the need for the development of a national seniors' strategy that would address some of the current constraints while planning for the future of health care services for seniors (Canadian Medical Association, 2016). One of these strategies would be providing "improved training, resource allocation and incentives to help primary care practitioners (PCP) develop robust, around-the-clock services for frail and elderly Canadians living in the community" (Canadian Medical Association, 2016). This is especially important as currently there are only 294 Geriatricians, and 192 Geriatric Psychiatrists serving all of Canada (Canadian Medical Association, 2017). By providing PCPs with more training in frailty assessment and treatment, the limited number of Geriatricians could focus their practice on more complex patient populations, such as people suffering from multi-morbidities and degenerative diseases.

Given the need to reliably assess for frailty in PHC, and subsequently develop effective interventions, we need to better understand how to effectively utilize the existing tools available in the current practice environment. In part, this involves understanding key defining characteristics of frailty and how the PHC clinician can use this information for further assessment and care planning.

1.2 Research Questions

This project addresses two research questions:

Research Question 1: What are the defining characteristics of frailty? Are these characteristics captured in the electronic Comprehensive Geriatric Assessment (eCGA) form?

Research Question 2: What data elements from the eCGA can be mapped to existing SNOMED CT standardized terminology and what is the rate of equivalence?

The goals of this work are to: (1) identify frailty within PHC since it an ideal setting to identify and prevent worsening health issues, and (2) explore information collected within electronic medical records (EMRs) that can be better utilized for assessing frailty. Recent initiatives to increase the use of EMRs within PHC, standardize data entry, and provide networks in which to extract those data can be a source of clinical data for researchers and inform the referral process from PHC to specialized geriatricians.

This project identifies defining characteristics of frailty using a literature review and mapping process. It also identifies specific data elements through standard terminology mapping within EMRs. The ability of PCPs to accurately identify frailty within their patient populations could be used to promote better patient outcomes through health promotion, prevention, and early intervention. The identification, counselling, and preventative measures that can be taken on an individual basis will hopefully prevent future adverse outcomes associated with frailty. Finally, the accurate identification of frailty in PHC can improve the referral process to specialty care.

1.3 Frailty and Aging

While frailty primarily affects individuals of older chronological age, there are differentiations between a state of frailty and the normal aging process (Fedarko, 2011). Aging is a process that inevitably occurs, including a progressive decline and deterioration of the physiological properties at the cellular, tissue, and organ level resulting in death. Frailty is defined as the increased vulnerability and decreased physiological reserves to be able to respond to stressors, which result in a loss of function across multiple body systems (Canadian Frailty Network, 2017). Both the normal aging process and frailty have similarities and include a loss of homeostasis. While aging generally happens systemically and progressively, frailty involves the faster failure of homeostatic stability in energy metabolism and neuromuscular abilities which lead to a variety of health-related deficits (Fedarko, 2011). For example, a person who is 80 years old, is physically and socially active, with no cognitive declines may not be frail, whereas a 70 year old person with mobility issues, frequent episodic and chronic health problems might be classified as frail. To understand frailty, it is important to decouple the idea that age and frailty directly correlate with one another.

1.3.1 Defining Frailty

In the current available literature, there are multiple ways of defining frailty. One of the main objectives of current research regarding frailty involves attempts to provide one working operational definition of frailty that would satisfy health care clinicians as well as researchers. However, this has proven to be unsuccessful as the concept of frailty remains somewhat elusive. Frailty is not a diagnosable “disease state”, does not have specific biomedical markers and remains conceptually complex. Thus, the tools currently being used to assess frailty vary depending on the context in which frailty is being discussed (Harmand et al., 2017); Some of the research suggests that frailty is a syndrome (Xue, 2011), while other researchers define it as being a chronic condition (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004). Also, there are some competing thoughts as to whether or not frailty (as a condition) should include things like comorbidities and disabilities as predictors and inclusion factors in the assessment of an individual (Cesari, Calvani, & Marzetti, 2017). There have been studies showing that disability and comorbid conditions are not necessarily an inclusion factor in patients presenting as frail (Fried, et al., 2004). However there have been more recent studies that suggest comorbidity and disability overlap with frailty, especially as the severity of frailty increases (Theou, Rockwood, Mitnitski, & Rockwood, 2012). Much of the discourse related to defining frailty relates to the inclusion of specific diagnostic criteria within the definition that would make it universally accepted. Rodríguez-Mañas et al., (2013) used a Delphi method to gain consensus among a panel of experts. While their findings suggest there is agreement on the concept of frailty, a lack of consensus remains about which biophysical markers should be included within this definition and if other stressors such as psychosocial and socio-economic factors should also be assessed. There is also discourse regarding a method to assess frailty that would include the severity of these markers. Experts also disagreed about a clear chronological timeline for assessing for frailty within the patient population.

This lack of consensus leaves room for ambiguity and fails to provide a gold standard definition with which to further research in this area. If there is not one agreed upon definition, it makes it difficult to compare or replicate research or to implement quality improvement studies. This is especially true for the PHC clinician who relies on current best evidence to guide their practice. The definition of frailty that is used in this project is based on the definition from the

Canadian Frailty Network, which is comprised of health care and research networks across Canada, and is funded by the Government of Canada's Networks of Centres of Excellence program (Canadian Frailty Network, 2017). The goal of the CFN is to develop programs and products, through research and partnership that would improve the quality of economic outcomes for the Canadian health care system, as well as improve the quality of life for Canadians and families living with frailty (Canadian Frailty Network, 2017).

1.3.2 Assessing Frailty

While there is a lack of a single operational definition of frailty, there are also numerous ways in which frailty can be assessed for any given population. This has presented a problem in being able to gain consensus among health care providers, and advance research into the effectiveness of frailty prevention and treatment. Many assessment tools have been developed within the last 15 years. Currently, there are over 40 tools designed to assess frailty, with more being developed as research continues to expand in this area. Many of the frailty assessment tools have not been studied beyond their initial research papers (Theou, Walston, & Rockwood, 2015). Each of these types of assessment and screening tools claims to be able to identify frail subjects both individually and as a cohort as well as retrospectively through data aggregation. The tools differ in their inclusion of variables and outcomes (Cesari, Calvani, & Marzetti, 2017a). The assessment tools also range from identifying frailty as being present or absent, to being able to provide a range of severity from pre-frail to severely frail (Cesari, Gambassi, Van Kan, & Vellas, 2014). Having this variety in frailty assessment tools, inclusion criteria, and diagnosis outcomes, makes it difficult to pinpoint a single tool to recommend for widespread implementation.

1.3.2.1 Assessment of Frailty in Primary Health Care

Because of the lack of evidence, routine frailty assessment for all elderly patients in PHC is not currently recommended by the BC Ministry of Health (Ministry of Health, 2017). Instead, the Ministry recommends using a diligent case finding approach to identify patients with frailty, particularly among older adults who regularly or increasingly require health and social services (Ministry of Health, 2017). Currently, there is not one specific tool validated for use within the PHC practice environment. With the amount of frailty related research available, it has been difficult to synthesize and translate the findings from the various studies, specifically into the PHC practice setting (Lee et al., 2017). Many of the variables within assessment tools are not well adapted to a busy PHC environment (Hoogendijk et al., 2012). PCPs require the ability to identify frailty, but also manage the identified problems associated with that diagnosis (van Kempen, Melis, Perry, Schers, & Rikkert, 2015). Furthermore, the pace at which PCPs are having to see patients (usually in 5-15 minute slots) would also limit the usefulness of some of the lengthy assessments required to be able to screen for frailty, as some of the assessments have more than 40 variables within the tool (Lee et al., 2017). Lee et al. (2017) conclude that further research is needed to be able to identify specific frailty identifiers and recommend that assessments for use in PHC practice permit quick and efficient identification frailty (Lee et al., 2017).

1.3.3 Use of EMR for Frailty Research Advancement

One promising method to identify frailty within PHC could be through using existing EMRs. EMRs are systems that enable health care professionals to record information gathered during a visit with a patient (Canada Health Infoway, 2018b). According to a recent survey, 81%

of Canadian PCPs are utilizing EMRs (Canadian Institute for Health Information, 2016). This is in part due to government funding, and recognition of the importance of electronic health initiatives by professional organizations like the Canadian Medical Association (CMA) (Chang & Gupta, 2015). The push for EMR adoption by health care providers is to be able to provide safe and efficient patient care, provide patient access to health information, and create meaningful use of the data that is inputted (Canadian Medical Association, 2014). Meaningful use of EMR data can be described as electronic capture of medical information in a coded way, which allows for tracking of key clinical conditions, and supports disease and medication management across the continuum of care (DesRoches & Miralles, 2011). Canada Health Infoway has many initiatives to help improve PHC EMR data and information across Canada (Canada Health Infoway, 2018a). This improvement through the use of content standardization, provides a framework for data to be utilized by researchers. This content standardization, also allows for gathering of larger data sets across provinces. With the increase in the use of EMRs by providers in Canada, and the subsequent increase in available patient data, we can start to develop ways we can use this information to monitor, treat, and improve patient outcomes (Zelmer & Hagens, 2014).

1.3.3.1 Canadian Primary Care Sentinel Surveillance Network (CPCSSN)

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) is the first pan-national database repository for chronic disease surveillance using de-identified EMR data from primary care practices (Birtwhistle et al., 2009; Williamson & Green, 2014). Because of the vast amount of data that can be pulled from EMRs, the administrators of CPCSSN have decided to focus on extracting and maintaining data for eight chronic illnesses (chronic obstructive pulmonary disease [COPD], dementia, depression, diabetes, hypertension, osteoarthritis, parkinsonism, and epilepsy) that effect the Canadian PHC patient population (Williamson & Green, 2014). Because the CPCSSN extracts and monitors these eight chronic conditions and more recently, a few more, this can limit some of the usefulness of this data to apply to other conditions like frailty. In order for these data to be used nationally, the parameters for identifying frail patients would need to be added to the database architecture within CPCSSN. By mapping the defining characteristics of frailty, it allows other researchers internationally to map frailty parameters to their EMR data should they also be using SNOMED-CT. Thus, mapping between data elements that identify frailty are important for expanded research possibilities nationally and internationally.

1.4 Conclusion

Frailty is a condition affecting many Canadians; Frailty will continue to increase as the population ages. Being in a state of frailty increases the risks for hospitalization, mortality rates, and decreased state of health (Fried et al., 2001; Kenneth Rockwood & Mitnitski, 2011). While frailty research is increasing, there remains no widely agreed upon definition but an increasing number of different assessment tools. Few of these tools can easily be integrated into the PHC setting. Developing the capability to extract relevant data elements (e.g., laboratory results, prescribed medications, blood pressure, weight) out of EMRs in PHC for more meaningful use provides an opportunity to improve both assessment and research on frailty. Assessment, early identification and care planning in PHC for those who are frail may also improve the quality of patient care.

Chapter 2: Literature Review

2.1 Introduction

This chapter describes existing frailty assessment tools which make up the defining characteristics of frailty. It discusses how frailty assessments could be integrated within EMRs and the important role of standardized health informatics language. This chapter introduces the availability of Canadian practice based research networks from which to draw large sets of data.

2.2 Literature Identification

Relevant literature was identified through searches of the Medline and Cumulative Index of Nursing and Allied Health Literature (CINAHL) databases between January 2001-January 2018. Keyword search terms included: frail or frail elderly or frailty AND assessment OR diagnosis OR phenotype OR index OR definition. The following MeSH search terms were also used: Electronic Medical Record OR Electronic Health Record AND Primary Care or Family Practice AND Canada. Standardized terminology articles were identified using the keyword search terms: Standardized terminology AND SNOMED-CT or SNOMED OR Mapping. Further filters were applied to only show entries written in English. Relevant journal articles were then chosen based on their title and abstract for further exploration. After reading selected journal articles in full, the bibliographies were examined for additional research which may be relevant to the research questions. Additionally, authors who were identified as making major contributions to the subject of frailty were searched in the databases using the “author” search function for any other relevant research. Medical, Nursing, and Health Information

Technology texts were sought out as additional resources to provide information on the role of informatics.

2.3 Validated Frailty Assessment Measures

A number of tools are available to assess frailty. The tools used for frailty identification should be valid and reliable, predict adverse clinical outcomes and according to some, predict patient responses outcomes to therapies and be supported by a biological causative theory (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; Dent et al., 2016).

The tools used to assess for frailty use a variety of physical identifiers and classifiers to give a risk assessment score. Vergara et al., (2016) described how these tools fit into three different categories. The first category is identifying frailty based on the presence or absence of physical and cognitive abilities. The second category of tools use the clinical judgement of the practitioner to determine frailty. This includes having knowledge of the entire clinical picture of the patient and using that knowledge to ascertain the presence or absence of frailty. The third type of frailty tool includes identifying specified biomarkers that predispose or increase the risk of someone having frailty. These biomarkers are detected by using patient blood and DNA samples, although the validity of using this method for identifying frailty has yet to be fully determined. Finally, there are frailty tools being used in emerging research that include the use of standard lab data such as routine blood and urine tests to help identify frailty (Ritt, Jäger, Ritt, Sieber, & Gaßmann, 2017).

The most commonly used tools include the Comprehensive Geriatric Assessment (CGA), Frailty Index (FI), Frailty Phenotype and the Clinical Frailty Scale (CFS) (Fried et al., 2001; Jones, Song, & Rockwood, 2004; K. Rockwood, 2005; Kenneth Rockwood & Mitnitski, 2011).

These tools are discussed more in the following sections. Most of the assessments tools represent a continuum of frailty, from non-frail to severely frail (Dent et al., 2016). This allows the clinician to classify the degree to which a person is frail as well as allow for timely interventions to slow or reverse this condition.

2.3.1 Comprehensive Geriatric Assessment

Widely considered to be the gold standard in assessing frailty, the comprehensive geriatric assessment (CGA) is cited as being one of the most relevant and accurate instruments available to determine the medical, functional, environmental and psychosocial deficits of older persons (Jones et al., 2004; van Kempen et al., 2015). The CGA produces an inventory of personalized health problems which can lead to the creation of a targeted care plan (Pilotto et al., 2017). The CGA varies in content depending on the context in which it is administered. It has been studied in a variety of clinical settings, showing good predictive validity for adverse clinical outcomes in both hospital and community dwelling patients (Pilotto et al., 2017). One of the main drawbacks to the CGA is the time required to administer this type of assessment. It is estimated that it takes upwards of 30 minutes to complete a CGA (Hamaker, Wildes, & Rostoft, 2017). Also, traditionally the CGA has been carried out by a physician or geriatrician. However, there is research currently under way to assess the accuracy, feasibility, and outcome factors associated with having general practitioners and registered nurses perform these assessments (Ferrat et al., 2018).

2.3.1 Frailty Index

The FI is based on a theory that individuals become increasingly frail as they accumulate "deficits" (Mitnitski & Rockwood, 2014; Kenneth Rockwood & Mitnitski, 2011). A deficit is defined as a symptom, sign, disability, disease, and/or laboratory measurement which helps signify something that is "wrong" with a person (Rockwood & Mitnitski, 2007). The FI counts how many deficits a person has, rather than focusing on the specific nature of those deficits. The clinical nature of this assessment focuses on different criteria which account for the deficits in an individual. The FI assessment requires coding 40 variables, which include observing activities, assessing activities of daily living (ADL), impairments in cognition and physical performance, comorbid conditions, patient perception of health, and mood (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008). These variables are calculated into a numerical ratio (deficit score divided by number of variables), where a larger ratio indicates a greater severity of frailty (Rockwood & Mitnitski, 2011).

The FI has been well validated, and is highly cited in the literature (Buta et al., 2016; Dent et al., 2016). This FI has been applied to multiple data sets internationally, showing better predictability for adverse clinical outcomes in both community and hospital patients than other frailty assessment measures (Dent et al., 2016). The FI approach has been modified to a clinical model in mice, which is producing promising frailty intervention studies (Rockwood et al., 2017). While this method of frailty identification is robust, it remains time consuming and results are presented as a ratio, which may make it hard for clinicians who are unfamiliar with the tool to interpret the results. However, the FI can be derived from existing CGA data (Dent et al., 2016) and may provide for better long-term management and identification of worsening frailty within an individual (Cesari et al., 2014), especially if it is used in the context of an EMR which could perform the mathematical calculation automatically.

2.3.2 Frailty Phenotype

The frailty phenotype defines frailty as a syndrome that is identified when a patient presents with at least three out of five specific criteria: shrinking, weakness, poor endurance/energy, slowness and low physical activity level (Fried et al., 2001). It has been applied in multiple epidemiological studies, where it has shown good predictability of adverse clinical outcomes and mortality rates (Buta et al., 2016; Dent et al., 2016). The frailty phenotype does not necessarily require a robust examination of the patient, which may be useful in identifying individuals at risk within a practice. This tool lacks the ability to quantify the degree of frailty and specific care plan outcomes needed to monitor and treat frailty (Cesari et al., 2014). Furthermore, this tool lacks the psychosocial components associated with frailty and includes some assessments, like grip strength, which are not routinely done in PHC (Dent et al., 2016). The parameters included in the frailty phenotype assessment have often been modified by the researcher depending on the setting in which it is being administered. For example, the grip strength and gait assessments have been replaced with self-reporting measures. This modification impacts the predictive ability of this assessment (Theou, et al., 2015).

2.3.3 Clinical Frailty Scale

The CFS is another widely used tool in the assessment of frailty in PHC as it is a brief way to categorize the severity of frailty (Rockwood, 2005). Originally developed by Rockwood (2005), this scale shows similar success rates in identifying frail populations compared to FI

(Theou et al., 2017). The CFS has been studied in a variety of clinical settings including hospital, geriatric, and primary care and is predictive of risk for hospitalization and death (Theou et al., 2017). This tool uses nine different criteria to rank individuals from being very fit to terminally ill. This tool is seen as a way to summarize a more comprehensive CGA and has been widely used and validated in different areas of medicine including the acute and community settings (Theou, Walston, et al., 2015). A benefit of this tool is that it is quick and simple to use, however it can be subjective, because the practitioner is required to make a clinical judgement without having to pick specific measurable parameters to produce the score.

2.4 Frailty Assessment in Primary Care

The CGA has been mainly used in acute care settings and geriatrician practices. The FI, frailty phenotype and CFS have also been used, but mainly in acute care settings. Assessment of frailty in PHC is relatively nascent. In part, this is due to the amount of time needed to administer most of the tools. For example, there is information included in the CGA which may not be relevant to a diagnosis of frailty in PHC. Collecting historical employment and family composition information could be considered problematic for busy PHC settings, where time spent with patients is constrained.

Currently none of these tools are widely used to assess for frailty in PHC. While each of the discussed tools have their merits, it is important to select an assessment tool that is easily used, effective and not too time consuming. This will ensure that PCPs can integrate this type of assessment into their practice since most cases of frailty can be or are diagnosed in PHC settings where there is no geriatrician available.

2.4.1 CARES Model eCGA

Some researchers have been conducting a frailty assessment based on CGA data (Jones, Song, & Mitnitski, 2005; Jones et al., 2004). This frailty assessment is an adaptation the standard CGA, in combination with two validated frailty assessment tools to create a comprehensive frailty specific tool to use electronically in PHC (Garm, Park, & Song, 2018). The Community Action and Resources Empowering Seniors (CARES) model, as proposed by Garm et al. (2018) combine components of the FI and the CGA to produce what they call a Comprehensive Geriatric Assessment-Frailty Index (CGA-FI), which both have statistical merit in the diagnosis of frailty (Theou, Walston, et al., 2015).

The combination of these two tools are integrated into the Intrahealth EMR being used by PCPs in the Fraser Health Authority region of British Columbia (Garm et al., 2018). This electronic CGA (eCGA) is comprised of over 70 variables and was used as part of a comprehensive plan to measure and mitigate the effects of frailty in PHC (Theou et al., 2017). The pilot project provided education and support to PHC physicians and nurse practitioners to implement the eCGA in combination with other validated geriatric assessments to produce an FI score. The identified individuals were then provided with a wellness summary, FI score, and instructions on how to contact a free of charge telephone-based health coach to address some of the needs identified in the wellness plan. The individuals were then re-assessed six months later, where the eCGA was repeated to look for any improvement in FI scores (Theou et al., 2017). This initial pilot project showed a statistically significant decrease in the FI scores from time of assessment to the time of reassessment at 6 months (Garm et al., 2018; Theou et al., 2017) which represented an improvement in frailty levels.

Currently, work is being continued to implement this eCGA in additional municipalities within the Fraser Health Authority. It is hopeful that the addition of this frailty assessment tool embedded within the existing EMRs will allow for greater use across PHC and increase the ability for data collection.

2.5 Electronic Medical Record Use in Canadian Primary Health Care

One of the objectives of this paper is to explore how the existing frailty measurement tools can be used in combination with the data collected through the EMR in PHC. Therefore, it is important to understand the context in which EMRs are currently being used in Canadian PHC, as well as the role health informatics has in the ability to use these data. The literature available relating to EMR use in PHC in Canada is still relatively limited, and mainly focuses on research studies utilizing data from EMRs (Terry et al., 2012). Because EMR use within Canada continues to expand, it is important to understand how we can best utilize what is currently available to us to provide best practice for our patients.

EMR use within Canadian medical practices has grown exponentially over the past decade. A recent survey shows that nearly 81% of PCPs are utilizing EMRs in their practice (Canadian Institute for Health Information, 2016). According to the survey, the majority of physicians are using their EMRs for a number of patient related activities including ordering of lab/diagnostics, accessing medications lists including drug interactions, and accessing hospital discharge records. Also, nearly 42% of respondents reported accessing both provincial patient information systems, as well as utilizing decision support tools (Canadian Medical Association, 2017). This means that a growing number of physicians are inputting large amounts of clinical data into information systems across the country. As Terry et al., (2012) found, in Canada there is only a small amount of available literature using EMRs for research purposes. This provides opportunities of growth within the research. To date, to the author's knowledge, data being input by PCPs have not been mapped to the defining characteristics of frailty as expressed through the validated frailty assessment.

Because of the increase in uptake of EMR use within PHCs there have been a number of initiatives introduced at both the provincial and national level to support the meaningful use and adoption of this technology to support clinical practice and research. Funded by the Canadian government, Canada Health Infoway has invested large amounts of capital to increase the adoption and interoperability of EMR use across the country (Canada Health Infoway, 2018a). At the provincial level, Doctors of BC has introduced the Doctors Technology Office to provide ongoing clinical and technical support to all PCPs using EMR's in BC (Doctors of BC, 2017). There are also a number of research initiatives throughout the country to promote the increase in EMR-related research projects, with the aim to improve patient outcomes.

One of the main challenges is the ability to meaningfully use the clinical data from EMRs. There is also a large selection of vendors which supply EMRs both nationally and globally, though there are little data currently available to quantify which vendors are being used. There are upwards of over 20 commonly used EMRs in use, as found by doing basic vendor search queries. The choice of EMR vendor is up to each individual PHC practice and their selection of these products reflects their financial investment, product features, and ease of product use (Skolnik, Timko, & Myers, 2011). Each of these software programs have different built in features, code and store data in different ways from one another. This makes it challenging for clinicians, researchers and other stakeholders to retrieve and use these data.

Currently, PCPs enter a variety of patient and administrative data into their EMR. The types of EMR data are historical, transactional, and transmitted; Historical data consist of demographic data (e.g., age, sex, ethnicity, height, weight) and family medical/surgical histories. Usually these types of data are entered once or occasionally updated. Transactional data are usually input at each visit, containing information such as: reason for visit, diagnosis, lab/diagnostic orders and results, and prescribed treatments (Venot & Cuggia, 2014). Lastly, EMRs can accept transmitted data from outside sources. These types of data would typically include hospital discharge reports, lab/diagnostic results, and specialist consultation reports (Venot & Cuggia, 2014).

One of the other challenges of EMRs in PHC is related to the ability to transfer, and use data from one EMR system to another. This process of sharing the information between two or more systems, and use the data that has been exchanged, is referred to as interoperability (Nijeweme-d'Hollosy, van Velsen, Huygens, & Hermens, 2015). The EMR systems that are being used in PHC come from a variety of different vendors, which were not all designed to be interoperable with other systems. There are many different strategies in which to share information between these disparate systems. One of these strategies is to robustly develop standardized languages and terminologies that are understood by these different EMRs. Having standardized terminologies provides a pathway in which to reach interoperability (Dixon, Vreeman, & Grannis, 2014; Liyanage, Krause, & de Lusignan, 2015).

2.6 Standardized Terminologies

To understand the requirements for extracting relevant data to use for decision support and/or research in relation to frailty, it is important to understand the role health informatics and standardized terminology plays. A challenge in using EMR data is in part due to the various ways data can be entered into the EMR. EMR data are either unstructured (free text) or structured with discrete data. While free text entries provide the lowest barrier to adoption by the end user, structured data increases the ability for the data to be extracted and used in a more meaningful way (Cuggia, Avillach, & Daniel, 2014).

Natural language through clinical descriptions entered by the provider, are the most common way of expressing information in an EMR, and are commonly found in free text notes such as clinical visit notes or discharge notes (Cuggia et al., 2014). While historically these types of data entry have been problematic in being able to extract data, there have been continued advancements in both Natural Language Processing and standardized languages which provide researchers the increased capability in meaningful data extraction (Cuggia et al., 2014). There has also been an increased amount of awareness for standardized languages which code clinical data in a uniform way, enabling for the extraction and automatic processing for the purposes of research.

In order for the information in an EMR to be used for research purposes, there need to be standardized ways in which to receive/communicate the information. There are a number of standardized language organizations within health informatics which produce standardized languages for the purpose of coding, sharing, and use of health information internationally (Cuggia et al., 2014). Standardized languages are used to help delineate different medical conditions and terminology used within health care. There are also standardized ways in which these systems communicate the information with one another across differing platforms. Because of this standardization, it makes it easier for researchers to use the inputted data across different countries and health care settings.

2.6.1 Standardized Clinical Terminologies

There are many different standardized clinical terminologies currently in use within the healthcare domain. These clinical terminologies represent a need to be able to express clinical information in a systematic way, to enable communication of this information across heterogenous contexts, and be able to retrieve and store this information (Richesson & Krischer, 2007). Because human language is vast, and there are multiple ways of expressing complex clinical concepts and meanings, standardized language implementation remains complicated (Andrews, Patrick, Richesson, Brown, & Krischer, 2008). Because human language expresses these concepts in different ways, these multiple concept expressions can be organized into a single representative term through a network of hierarchies. Each terminology domain has specific concept relationship and guiding principles which create the standardized terminologies (or nomenclature) which are specific to that domain (Hammond, Jaffe, Cimino, & Huff, 2014; Kim & Matney, 2014).

There are two different types of terminologies which are present in EMR data entry. Interface terminologies are a systematic collection of specific health care terms, which aid the user in inputting and reading clinical information (Rosenbloom, Miller, Johnson, Elkin, & Brown, 2006). These terms are specific to the context and group in which they are being used, usually contain acronyms, and may change over time (Schulz, Rodrigues, Rector, & Chute, 2017). Reference terminologies are stable and well defined representational terms that coordinate with computer processable codes with aid in data aggregation and retrieval (Schulz et al., 2017)

2.6.1.1 Systematized Nomenclature of Medicine Clinical Term

Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) is an internationally used, multilingual, and most comprehensive clinical reference terminological system for medical nomenclature (SNOMED International, 2017). SNOMED CT is also an EMR interface terminology which can be used for clinical data entry, and represents clinical information and knowledge, and can help generate clinical decision support algorithms and retrievable clinical data (Bhattacharyya, 2016). This translates to a common language for describing patient problem lists, family histories and can be reproducible between providers. This standardized terminology is widely used, and the most common standard language currently in use in EMRs. The growth of SNOMED CT adoption has translated this as one of the preeminent standardized languages used for clinical and informatics research (Bhattacharyya, 2016)

Using SNOMED CT has both its benefits and challenges. Because it is a large repository, there are over 300,000 distinct clinical terms within it (SNOMED International, 2017). While this allows for great clinical concept coverage, it also leaves room for selection error and semantic ambiguity (Monsen et al., 2014). Having an expert clinician aid in the mapping process, as well as employing different mapping activities are some of the ways in which to ensure rigour and validity when using SNOMED CT (Block, 2016; Monsen et al., 2014).

2.6.1.2 Other Standardized Terminologies

The International Classification of Diseases (ICD) is a classification system that is used internationally, maintained by the World Health Organization, and allows for the coding of all medical diagnoses and symptoms including those which are not otherwise specified (Cuggia et al., 2014). This alpha numeric coding ensures that a medical diagnosis is understood across different languages and countries. Currently, PCPs use ICD codes to assign diagnoses for the purpose of data entry and administrative billing data.

The Logical Observations Identifiers Names and Codes (LOINC) is a classification system used internationally for the standardized coding of laboratory and clinical observations using HL7 to send these messages between platforms (Regenstrief Institute, 2017). LOINC terminology is mainly used to represent measurement data, medical tests and results, whereas SNOMED CT focuses more on clinical terms, diagnoses, procedural codes, and some process codes. Standards organizations are in the process of linking LOINC terms with SNOMED CT to ensure broader coverage of standardized terminologies. Having both of these standardized terminologies integrated into an EMR system may ensure that there are fewer gaps in clinical content coverage.

2.6.2 Clinical Terminology Mapping

Clinical terminology mapping is the process of linking a concept or code from one code set or system, with that of another code set or system with similar concept meaning (SNOMED International, 2017). The process of mapping concepts is important to be able to exchange information between various clinical systems for the purpose of data retrieval and use. This provides a means for otherwise non-interoperable systems to communicate. It also aids in the retrieval of data for analytical use by providing a defined record of computer readable coded clinical entities, which can be used in database architecture. The process of terminology mapping can happen through a variety of methods and requires clinical knowledge and scientific rigor to ensure effectiveness and reproducibility. There are special considerations and decisions that need to be pre-determined in standardized terminology mapping for matching complex and specific clinical concepts. Clinical concepts can be mapped using “pre-coordination” and/or “post-coordination” methods. Pre-coordination clinical term matching, refers to having an exact match between the desired root clinical concept and the standardized terminology in which it is being mapped to. Post-coordination involves the combination of clinical concepts to satisfy the meaning of the root clinical concept. The researcher also needs to decide on which methods will be used to map the clinical concepts, and how they can achieve scientific rigor in those results (Coiera, 2015; Rosenbloom et al., 2006). The methods in which the author undertook the terminology mapping will be discussed in the next chapter.

2.6.3 Clinical Impact of Standardized Terminology Usage

There are many advantages to having standardized terminologies within an EMR and/or research database. Benefits of having standardized terminologies in clinical practice include the facilitation of evidence-based practice through increased reliability and validity of collected data, and data mining opportunities to improve research and clinical decision making (Hardiker, Bakken, & Kim, 2011). Having coded concepts which relate to a specific disease, such as frailty, can allow for large data aggregation. This could provide researchers with the ability to identify and monitor specific parameters related to that disease within a large population. The coded list of frailty parameters could also provide researchers outside national databases information about frailty assessment and enable them to map frailty assessment to their specific EMR data.

Another possibility for using standardized terminologies within clinical practice is that it can provide a framework in which to create specific decision support tools (Bodenreider, 2008). These standardized terminologies would be linked to algorithms that allow for the detection and identification of a problem when the applicable information is entered into the EMR, which would then alert the clinician to take action, or provide them with a link to evidence-based practice. In terms of frailty, the assessment information could be entered into the EMR questionnaire, it would then alert the clinician of the patient's frailty score and provide them with real time support on how best to intervene for maximum outcome potential.

2.7 Summary

In summary, frailty assessment through validated tools incorporated into an EMR used in PHC can be a valuable tool to assess for frailty. There are available tools currently being used in an electronic format in which to assess frailty. There are also databases which collect relevant EMR patient information available for utilization by researchers. However, to the author's knowledge, frailty concepts have not been mapped to a structured EMR database. As a contribution to the existing and ongoing research in frailty within the PHC context, this paper seeks to map the components of this eCGA to standardized SNOMED CT codes. This will enable researchers to be able to add these data components to the CPCSSN database. This addition will allow researcher across the country to be able to extract defining characteristics of frailty to use for further research.

Chapter 3: Methods

3.1 Introduction

This chapter outlines the methods used to map the data elements from the eCGA form to the SNOMED CT standardized terminology. This chapter provides an overview for the study design, sampling plan, procedure and analysis of the data. This research design and execution has been in collaboration with the research supervisor and advisor to ensure rigor and validity.

3.2 Research Questions

This paper addresses two research questions:

Research Question 1: What are the defining characteristics of frailty? Are these characteristics captured in the eCGA form?

Research Question 2: What data elements from an eCGA can be mapped to existing SNOMED CT standardized terminology and what is the rate of equivalence?

3.3 Study Design

This study was conducted using a nonexperimental descriptive study design. This was completed by comparing the defining characteristics of frailty to the eCGA, then examining the rate of equivalence between the 133 predefined eCGA assessment data elements, with the corresponding SNOMED CT terms. The descriptive analysis was conducted in four phases; a) assessing whether the eCGA captures the defining characteristics of frailty as identified in the literature review; defining and comparing the characteristics of frailty with the eCGA form, b) creating a clinically relevant map of the eCGA form to help guide decision making in the mapping process, c) manual mapping of eCGA data elements to SNOMED CT; d) clinician review of mapping results (Figure 3.1). Descriptive statistics were used to assess the rate of equivalence in which frailty can be identified using standardized terminology.

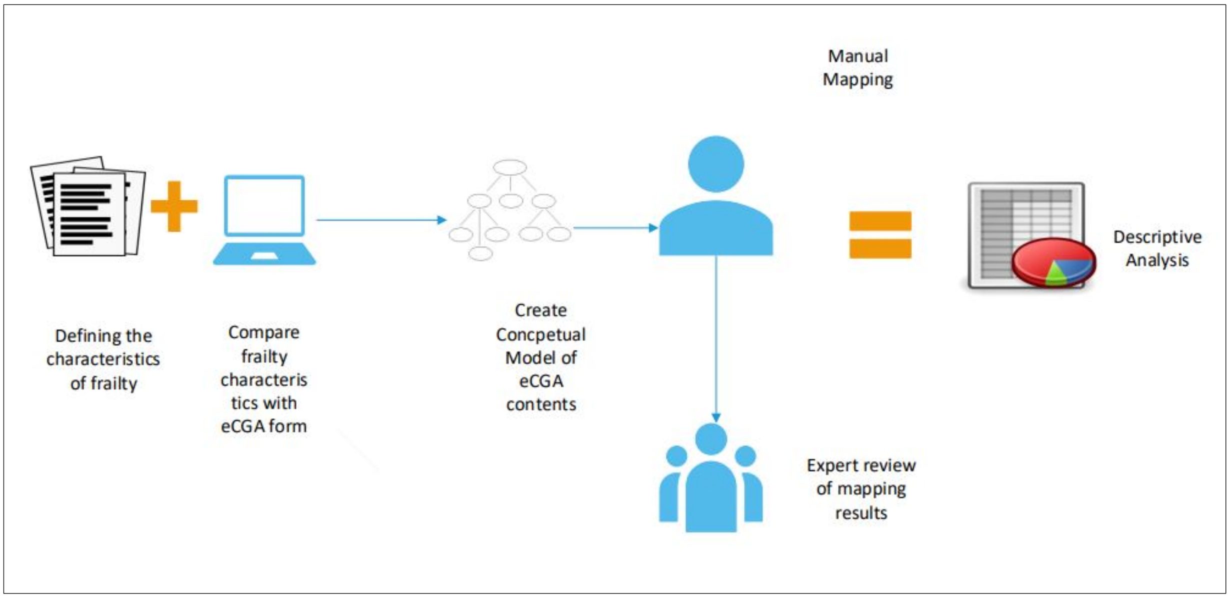


Figure 3.1 Overview of study method

3.4 Sampling Plan

To complete the manual mapping activity, the 133 frailty defining data elements of the eCGA were used (Appendix A). The eCGA form was retrieved from the Intrahealth EMR platform which is currently being used throughout Fraser Health Authority, British Columbia. The original eCGA form used within the CARES model project comprised of 172 individual data elements. For the purpose of this paper, this number was reduced to 133, as these components are the only ones used to derive a frailty index score. The use of the data elements from this form were obtained with permission from the original CARES model researchers and were provided to the author in spreadsheet format.

3.5 Procedure and Data Collection

In the first phase of this study, I created a table of the defining characteristics of frailty, based on the review of the literature, and comparing that to the data elements within the eCGA form (Appendix A). The purpose of this was to ensure that the eCGA form captured the defining characteristics of frailty. The second phase of the study was to create a visual map to represent the eCGA form. The purpose of this map was to aid the author, by grouping the eCGA form data elements into clinically meaningful groupings. This aided in the manual mapping of the elements to SNOMED CT. The third phase of this study employed a manual mapping approach of the predefined eCGA form elements to SNOMED CT terminology. This manual mapping produced a list of corresponding SNOMED CT terms with a match criterion of; direct match, indirect match, or no match. In the fourth and final phase of this study, the author's manual mapping was clinician reviewed to ensure accuracy and relevancy was appropriate.

3.6 Phase 1: The Defining Characteristics of Frailty

Because the intention was to eventually integrate the data elements from the frailty eCGA form into a database, and there have been multiple ways to both define and assess for frailty, it was important to ensure that the eCGA form is capturing the defining characteristics of frailty as expressed in the current literature. The author first examined the recent relevant literature on frailty, as well as largely cited seminal works regarding frailty definitions, to make a list of the most common defining characteristics of frailty. This was done by creating a spreadsheet of the terms used to describe the characteristics of someone having frailty.

The author then created a visual table of the clinical assessment variables for frailty, which were retrieved from assessment tools described in Chapter 2 (see Table 4.1). This table includes the eCGA form which was mapped to SNOMED CT. The author then compared columns within the table to ensure that there were no missing variables from the eCGA form.

3.7 Phase 2: eCGA Data Sources and Concepts Map

The user interface for the eCGA form is dense and cluttered, and not grouped into clinically relevant sections. To ensure that all form data elements were captured in a clinically meaningful way during the mapping procedures, and because SNOMED CT terminology is very granular, it was necessary to create a diagram model to visually display the concepts represented in the eCGA form. The creation of visual data models has been used, and shown to be helpful, in previous terminology mapping research (Block, 2016; Chow et al., 2015; Harris et al., 2015). Using a diagram map allows the researcher to visually relate the information from the form in a more clinically meaningful way, and it provides guidance to the researcher by giving context in decision making when matching clinical concepts from the root source to the standardized terminology.

The eCGA diagram model created for this paper visually depicts the different components of the eCGA form, and helps group data elements into clinically relevant categories to aid in decision making during the mapping process (Wade & Rosenbloom, 2008). The form is represented by the solid green box, with the solid dark blue boxes representing the components that derive the final frailty score. The exam data which accounts for the majority of the frailty score parameters, are then grouped into clinically meaningful groups (i.e., psychosocial, daily living) to aid the author in the mapping activity. This map was used to help guide the concept and hierarchy category selection during the manual mapping process, as well as during the clinician validation process. The exam data variables, are most closely associated with the SNOMED CT hierarchy type of “findings”. The individual components of the eCGA form which calculate the frailty score are denoted with asterisks.

3.8 Phase 3: Manual Mapping to SNOMED CT

Prior to the manual mapping activity, the author made some decisions related to SNOMED CT hierarchy type and placement of the clinical concepts in relation to SNOMED CT structure. Each SNOMED CT concept is organized into a hierarchy with preferred name and a unique numerical code. At the top of the SNOMED CT hierarchy is the root concept, to which the eCGA data elements are mapped. These concepts also contain descriptions which can contain many synonyms for the same concept. SNOMED CT relationships link like concepts to one another when their meanings are related to one another (is-a relationship) or part of a causal relationship (has-a relationship) (SNOMED International, 2017). Sub types of the root concept are referred to as ‘Top Level Concepts’ and form the major branches of the SNOMED CT hierarchy design. These top level concepts have dependent concepts, which branch out into more sub-type concepts. This type of organization leads to specific, granular, clinical concepts (SNOMED International, 2017).

It was decided that all matched terms would be labelled as “pre-coordinated”. That is, a specified term will be an exact match between the desired root clinical concept and the standardized terminology to which it is being mapped. It was also decided that most of the chosen terms should fall within two top level concept SNOMED CT hierarchy types: findings and observable entity. In SNOMED CT the findings hierarchy represents the results from a clinical observation, assessment or judgement. It also accounts for normal abnormal clinical states, and includes concepts used to represent diagnosis (SNOMED International, 2017). The observable entity hierarchy represents a question or assessment which can be performed and can produce a discrete answer. An example of this is blood pressure or gender (SNOMED International, 2017).

The eCGA form data elements (n=133) were manually and independently mapped by the author (SB) using the latest edition of the international SNOMED CT opensource browser (SNOMED International, 2018). The SNOMED CT web browser is open source and free for use with a signed online user license agreement, which is automatically generated when you open the browser. Each eCGA specific data element was entered into the browser to obtain all possible results for that concept. The selected concept was then examined further for accuracy by examining the concept summary, diagram, and details within the SNOMED hierarchy. All data were entered into an excel spreadsheet with the eCGA root concept name, form responses, form codes, full SNOMED CT concept name, SNOMED CT hierarchy type, and unique identifying number. All possible matching results were entered into the spreadsheet and given colour coding (Hardiker et al., 2011) (Table 3.1 and Table 3.2).

Clinical concepts were entered into the browser with exact wording and filtered by hierarchy type (finding). A selected SNOMED CT code could fall within the observable entity class, if the clinician physically observes the client doing the action while in the office (e.g., timed get up and go test). Another rule that was followed during the mapping process was having the selected SNOMED CT code fall within the same Parent/Child category whenever possible. For eCGA questions which are assessing patient ‘impairment’, the selected SNOMED CT code should not delve into the severity of the impairment but fit into a yes/no answer (e.g., Impaired hearing should not = moderate/severe/total hearing loss”). Finally, the selected SNOMED CT code should be descriptive of the question being asked and be reflective of what we are trying to assess in a frail patient. (e.g., Speech=talking, not Speech=communication)

The author had to broaden the search using semantically similar descriptions for a clinical concept due to the complex nature of the SNOMED CT database. For example, when searching for terms such as ‘banking’, the term ‘money’ is also searched for relevant results. To further decision making in concept selection, the SNOMED CT concept had to satisfy a question/answer relationship to be selected, as this reflects the nature of the eCGA assessment. The clinical term was considered a match in the findings hierarchy if it matched the criteria of a “question” and an “answer”.

After completing the first version of the mapping, the author then re-entered the initial results into the SNOMED CT to refine the list of any multiple possible matches, based on feedback from the scholarly advisors and local database managers, to produce a final mapping spreadsheet.

Table 3.1 Clinical term mapping matching criteria

Criteria	Definition
Direct Match	The eCGA data element matches the clinical concept available in SNOMED CT. These matches are known as pre-coordinated.
Partial Match	One-to-many: The data element could be accurately described using more than one standardized clinical concept within SNOMED CT. (ie., data element “urinary incontinent” and SNOMED CT concepts “urinary incontinent” and “continent: dependent”) OR Partial Match: The data element didn’t directly match with a SNOMED CT code, but semantically is similar enough for the clinician to feel it could be appropriate (ie. Data element “cleaning independent” and SNOMED CT concept “able to tidy house”
No Match	The eCGA data element does not have an equivalent clinical concept match in SNOMED CT

3.9 Phase 4: Clinician Consensus Mapping

To complete the clinician consensus mapping and examine inter-rater reliability, it was decided that a subset of the 133 data elements be chosen for review and consensus. For this phase, two rounds of expert consensus mapping occurred to achieve the final results. In this final step, two sets of 10 randomized eCGA questions were given to a clinician to map independently. Both sets of eCGA questions were presented in an Excel spreadsheet for the clinician to fill out. The root data points to be mapped to SNOMED CT ranged from one to three responses. The columns in the spreadsheet related to SNOMED CT concepts were left blank for the clinician to fill out independently. The clinician was also provided with the SNOMED CT *Starter Guide* for reference.

The clinician doing the mapping activity, had experience in using the eCGA form for research purposes, but had no prior informatics, standardized terminology mapping or SNOMED CT knowledge. The clinician was not part of the original manual mapping, thus giving an independent review of the results. A brief overview was given by the author to help the clinician navigate the mapping activity.

After the initial set of eCGA questions was mapped by the clinician, the author, clinician and academic advisors met to examine the results. Inter-rater reliability scores were calculated for the first round of coding. A second round of clinician consensus mapping occurred to examine if inter-rated reliability between the clinician and the author’s selected clinical terms improved. For this process, a different set of randomly selected eCGA data elements were presented to the clinician in a new excel spreadsheet. The advisors provided supervision and guidance as the author and clinician discussed the results.

After the clinician mapping process, a spreadsheet was compiled to show the comparison between the authors and the clinician's mapped results. In total, two different consensus mapping activities (n=20) were completed by the clinician subject matter expert. The criteria for matching between the author and the clinician are listed in Table 3.2.

Table 3.2 Clinician mapping term matching criteria

Criteria	Definition
Direct Match	The same SNOMED CT code was chosen for the eCGA data element.
Partial Match	A semantically similar code, or code from the same SNOMED CT hierarchy was chosen, but no direct match.
No Match	There was no match between the author and clinician SNOMED CT code selection.

3.10 Data Analysis

Data were analyzed using descriptive statistics to provide rates of equivalence between the eCGA data elements and SNOMED CT clinical terms. Rates of equivalence were calculated manually by the author. Consensus between the author and expert clinician was achieved by discussing the rationale and decision making during the selection of the SNOMED CT code, and coming to a mutually agreeable SNOMED CT code. Consensus on the data elements was also achieved through guidance from the supervising committee. A Kappa coefficient was calculated after both rounds of clinician consensus to assess how well the two observers classified the variables. The purpose of calculating after both rounds was to assess if there was any improvement after the first round.

Chapter 4: Results

There were four phases in this study. The first phase involved a literature review which identified the clinical characteristics of frailty. The second phase of the study involved creating a data sources and concept map to aid the author in subsequent phases. The third phase was a manual mapping of a frailty assessment to SNOMED-CT, and the fourth phase involved a clinician consensus mapping activity.

4.1 Phase 1: The Defining Characteristics of Frailty

Keywords used to identify frailty were placed into a spreadsheet (Table 4.1). The defining characteristics of frailty fit into a number of physical, cognitive, and psychosocial deficit components. The key deficits associated with the concept of frailty were derived by making a list of deficits described in the frailty tools discussed in the literature review. The deficits associated with having frailty include weight loss, muscle weakness, physical exhaustion, physical slowness, low activity levels, cognitive impairment, low mood/attitude, incontinence, and co-morbid conditions and need for multiple medications.

Table 4.1 Defining Characteristics of Frailty

Characteristic	Searle et al., 2008	Rockwood, 2005	Fried et al., 2001	Garm et al., 2017
Physical				
Weight Loss	x	x	x	x
Weakness	x	x	x	x
Exhaustion	x	x	x	x
Slowness	x	x	x	x
Low Activity	x	x	x	x
Incontinence	x	x	x	x
Cognition				
Cognitive Impairment	x	x		x
Psychosocial				
Low Mood/Attitude	x	x		x
Co-morbidities	x	x		x
Polypharmacy				x

Frailty has been described as being on a continuum (Cameron et al., 2015; Fried et al., 2001). It occurs on a gradient, with the first stage being classified as "pre-frail" or slightly frail. This is where a person is more susceptible to developing frailty, usually after a medical or physical "event" (Bandeen-roche et al., 2006). A person who is considered as pre-frail would have only a small number of the aforementioned deficits. At the end of the frailty continuum, a person would present with a large number of health deficits resulting in a failure to thrive, and ultimately death (Cameron et al., 2015).

The classification of frailty depends on the assessment tool being used and the way that tool quantifies frailty. Of the tools reviewed, only the eCGA FI captured all deficit components. Table 4.2 provides a visual comparison of assessment components in the frailty tools.

Table 4.2 Characteristics of Frailty in Assessment Tools

Variable and **Sub Category**	**Frailty Index**	**Clinical Frailty Scale**	**Frailty Phenotype**	**CGA-FI (CARES)**
Cognitive Status		x		x
Montreal Cognitive Assessment				x
Functional assessment staging of Alzheimer's disease				x
Dementia		x		x
Psychosocial	x			x
Low Mood	x			x
Depression	x			x
Anxiety	x			x
Depression	x			x
Energy/Outlook	x	x	x	x
Fatigue		x	x	x
Motivation				x
Health Attitude	x	x		x
Daytime Drowsiness		x		x
Control of Life Events				x
Other	x			
Sleep				x

Table 4.2 (con't) Characteristics of Frailty in Assessment Tools

Variable and Sub Category	Frailty Index	Clinical Frailty Scale	Frailty Phenotype	CGA-FI (CARES)
Physical Ability	x	x	x	x
Vision				x
Hearing				x
Pain				x
Functional reach				x
Usual Activities			x	x
Exercise		x	x	x
Strength	x		x	x
Weakness Upper Proximal	x			x
Weakness Upper Distal	x			x
Weakness Lower Proximal				x
Weakness Lower Distal				x
Mobility	x	x	x	x
Balance				x
Falls		x		x
Walk Outside	x	x		x
Walking	x	x	x	x
Aid	x	x		x
Stairs	x			
Timed get up and go	x (pace)		x (timed 15 ft)	x
Weight	x		x	x
Under			x	x
Over				x
Obese				x
Continence	x	x		x
Bowel		x		x
Bladder		x		x
ADL's	x	x		x
Cooking	x	x		x
Cleaning	x	x		x
Shopping	x	x		x
Medications	x	x		x
Bed		x		x
Driving		x		x
Banking	x	x		x
Dressing	x			x
Eating	x			x
Toilet	x			x
Bathing	x	x		x
CoMorbidities	x	x		x
# of Medications				x
# of Problems	x			x

4.2 Phase 2: eCGA Map of Data Sources and Concepts

The eCGA Map of Data Sources and Concepts (see Figure 4.1) was created to help visualize the eCGA form and to group the components of the form into clinically meaningful categories to aid in the process of manual terminology mapping. All parts of the eCGA form are expressed on this map. However, only the 133 components (see "*" in Figure 4.1, 4.2, and 4.3) which are used to derive a final frailty index score, were used to complete the terminology mapping activities. The diagram has been portioned into additional subsections for ease of readability (Figures 4.2 and 4.3), and a legend is provided below (Table 4.4).

Table 4.3 Legend-Overall Map of Data Sources and Concepts

Colour	Description
(dark blue)	Components of eCGA which derive Frailty score
(light blue)	Assessment Categories
(green)	Assessment variables

Figure 4.1 Overall Map of Data Sources and Concepts

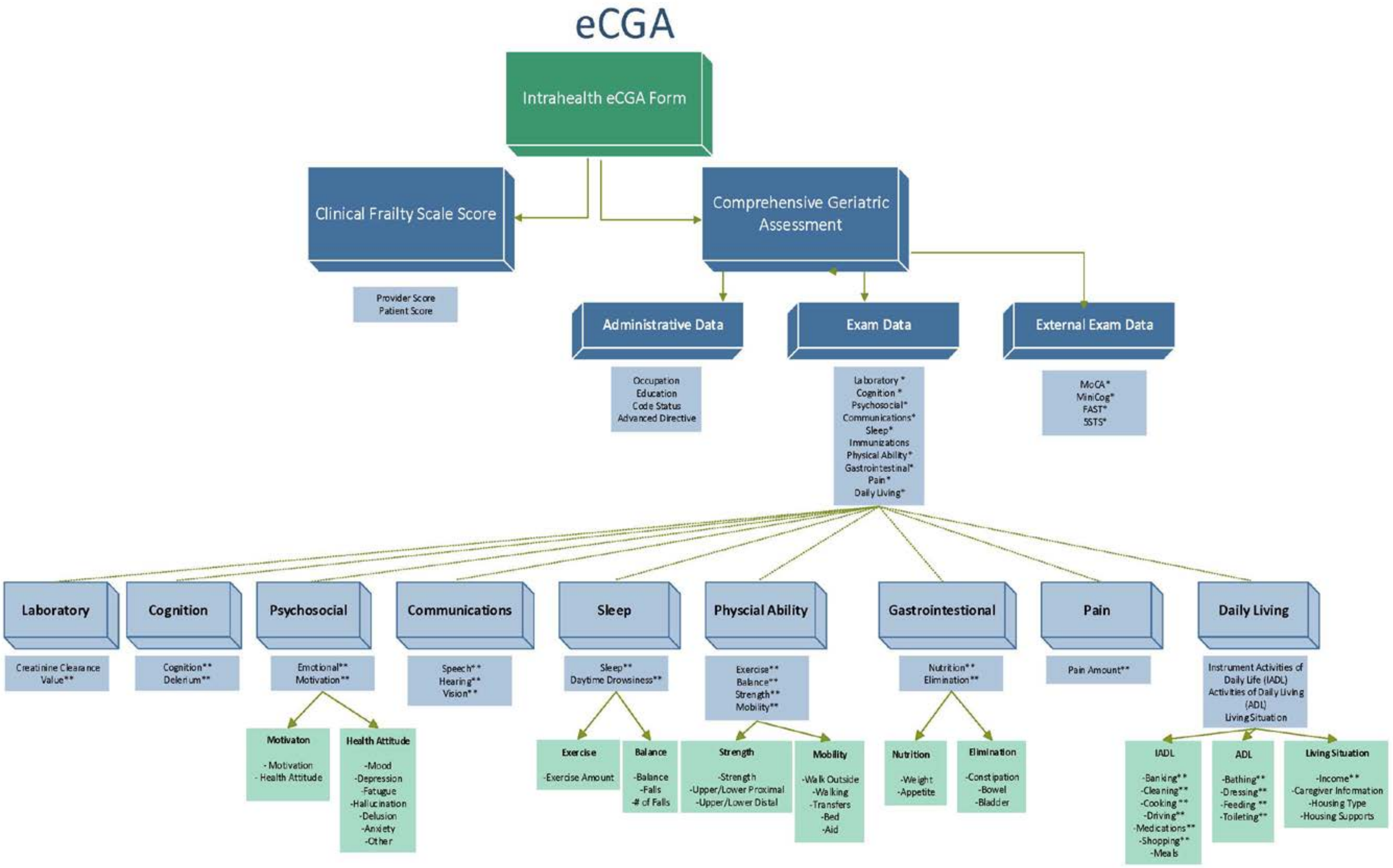


Figure 4.2 Data Sources

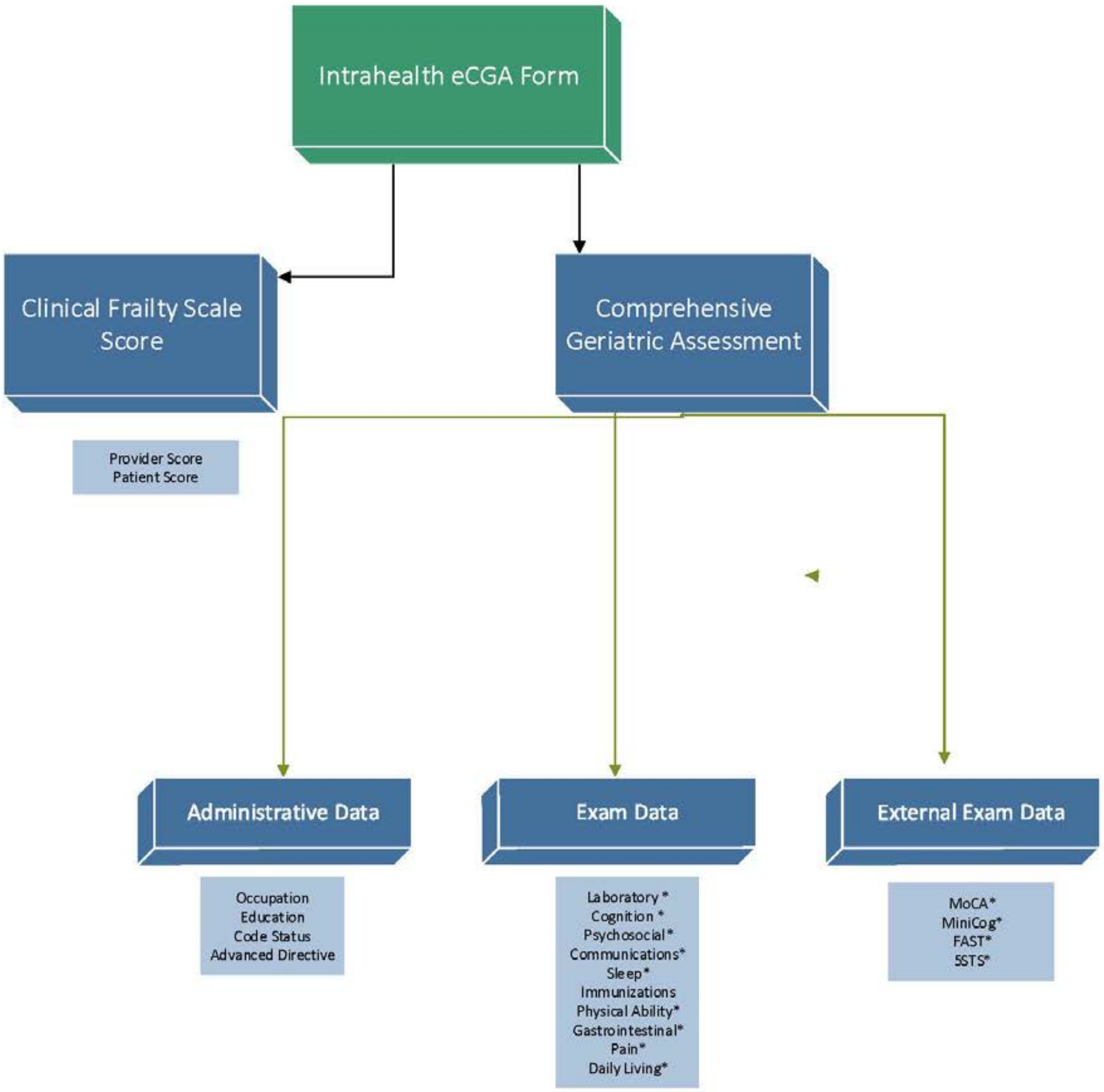
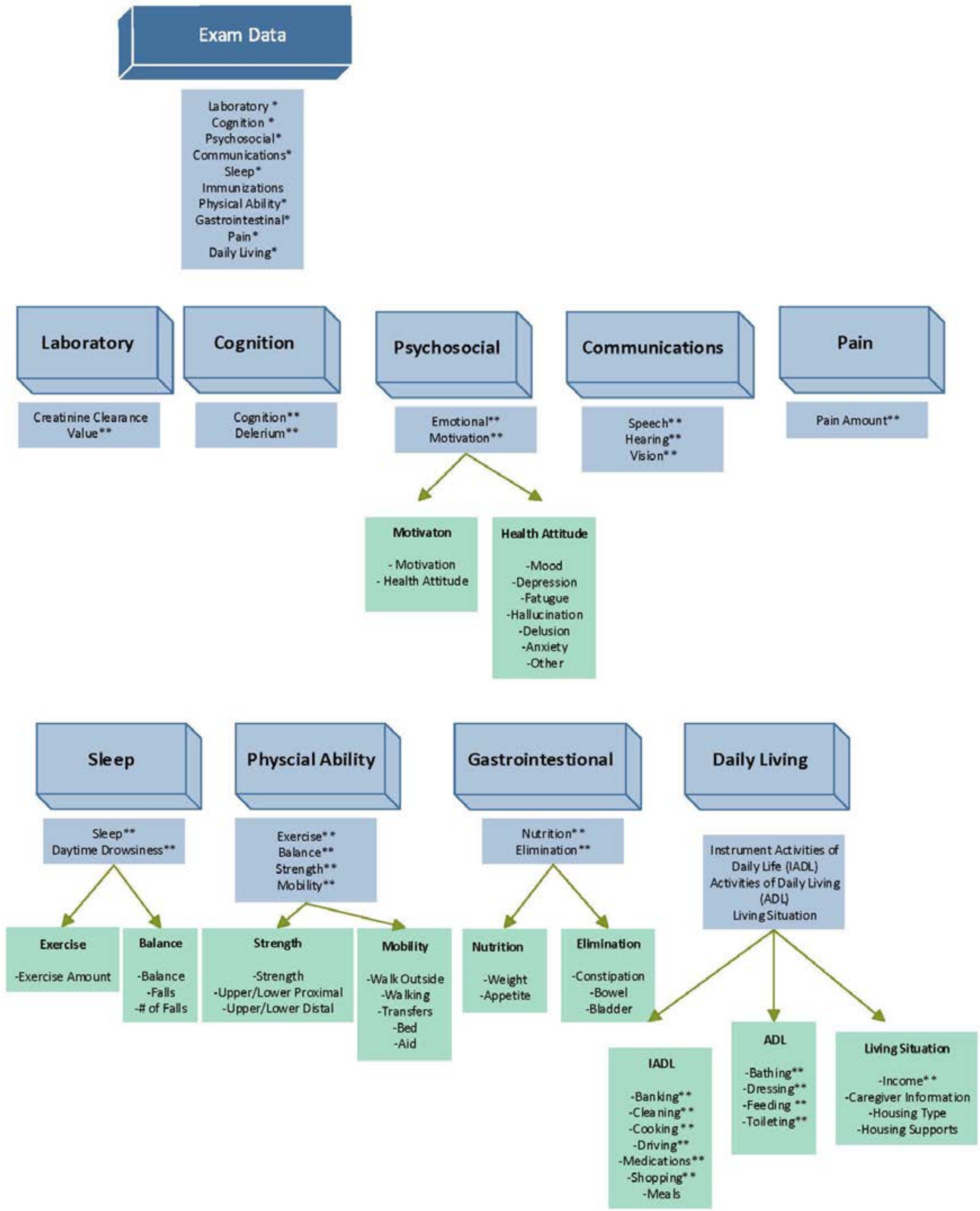


Figure 4.3 Exam Data



4.3 Phase 3: Manual Mapping to SNOMED CT

All of the frailty assessment data elements were manually mapped using words from the eCGA form, using the mapping rules created by the author, as well as referring to the clinical map for guidance, and decision making related to clinical content and meaning.

With the criteria as described for manual mapping of the eCGA data elements, a total of 96/133 (72%) had a direct match, 22/133 (17%) had a partial match, and 15/133 (11%) had no match (see Appendix B for details).

Table 4.4 Manual Mapping of eCGA to SNOMED CT

eCGA Data Elements (n=133)	Direct Match	One-to Many	No Match
Total	96/133	22/133	15/133
Percentage	72%	17%	11%

4.4 Phase 4: Phase 4: Clinician Consensus Mapping

For this phase, two rounds of expert consensus mapping occurred to achieve the final results. The initial set of eCGA questions was mapped by the clinician and the author. The initial consensus between the clinician and author was 60% direct match with one another, 10% partial match, and 30% no match (Table 4.4).

A second round of clinician consensus mapping occurred to ensure there was enough inter-rated reliability between the clinician and the author’s selected clinical terms. This iteration had an 86% direct match with one another. In each iteration, there was 100% consensus on the mapped data elements after discussion and rationale were presented (see Table 4.5 and Appendices C and D).

Table 4.5 Clinician Consensus Mapping of eCGA to SNOMED CT- Iteration #1

eCGA Data Elements (n=20)	Direct Match	Partial Match	No Match
Total	12/20	2/20	6/20
Percentage	60%	10%	30%

Table 4.6 Clinician Consensus Mapping of eCGA to SNOMED CT- Iteration #2

eCGA Data Elements (n=22)	Direct Match	Partial Match	No Match
Total	19/22	None	3/22
Percentage	86%		14%

The Kappa values were initially weak (k= 0.33 for iteration #1) but were strong (k=0.75) for iteration #2. As some of the clinician consensus mapping informed the final list of SNOMED CT eCGA mapping codes, the final list as seen in Appendix B was comprised following this stage of the research.

4.5 Summary

In this chapter, the defining characteristics of frailty, the eCGA clinical map, and results of manual and clinician consensus mapping were presented. Manual mapping results showed that 72% of the e-CGA mapped directly to SNOMED-CT, 17% were a partial match, and 11% of data elements had no match. The clinician consensus obtained a final result of an 86% direct match between the author and the clinician mapping and 14% no match. The author and clinician came to a 100% consensus on the selected terms, which produced the final list of mapped codes.

Chapter 5: Discussion

5.1 Introduction

The work mapped the defining characteristics of frailty from an electronic assessment to standardized clinical terminology. We examined the rate of equivalence between the assessment and standardized terminology. The methods included comparing the defining characteristics of frailty to the data components in an eCGA, creating a visual map, and then manually mapping these components to SNOMED CT. After two rounds of clinician consensus mapping, the rate of equivalence and interrelated reliability were calculated. The final result was a list of the 133 eCGA components mapped to SNOMED CT codes.

This discussion includes the limitations and lessons learned and explores how this type of research could inform future standardized terminology activities to help advance frailty research. It also discusses the role of nursing within community-based care contexts and the nursing contribution to informatics and research.

5.2 Defining Frailty

The defining characteristics of frailty fall into multiple deficit categories: physical, cognitive, and psychosocial. Clearly frailty, while considered a medical syndrome, is not easily identifiable with one type of diagnostic lab test or measurement (e.g., blood pressure). Key deficits associated with having frailty include weight loss, muscle weakness, physical exhaustion, physical slowness, low activity levels, cognitive impairment, low mood/attitude, incontinence, co-morbid conditions and the need for multiple medications (Fried et al., 2001; Jones, Song, & Rockwood, 2004; Rockwood, 2005; Rockwood & Mitnitski, 2011). These characteristics are consistent with retrospective frailty EMR database research in primary care patients (Anzaldi, Davison, Boyd, Leff, & Kharrazi, 2017). The Anzaldi et al. (2017) study found that patients identified as frail within the EMR also had the presence of a number of geriatric syndromes, such as incontinence, falls, and dementia, classified within the system.

The complexity of assessing frailty has led to an abundance of tools and measures used to assess frailty (Dent et al., 2016). Of the five tools or measures reviewed in this work, the eCGA most comprehensively assessed the various deficit categories and therefore it was chosen to complete the mapping activity.

The defining characteristics of frailty and the visual representation of the frailty assessment variables were used to ensure the eCGA being used for the manual terminology mapping were encompassing of the aspects which would be needed for a PCP to assess and identify frailty in a patient. It was concluded that the eCGA, which is currently being used in frailty research projects, was the most complete of the tools assessed to identify frailty and frailty severity (Theou et al., 2017). The significance of having this eCGA as a comprehensive of frailty assessment is that this particular tool could be replicated within an EHR as a way for a PCP to be able to assess for frailty.

5.3 Implications of Defining Frailty Through the eCGA

Tools such as the eCGA can be implemented within existing primary care EMRs in order to provide better frailty definition guidelines and assessment parameters. The eCGA-FI form does not appear to have any significant gaps that would prevent a clinician from accurately assessing for frailty. This could provide an accessible way for clinicians to identify patients who are frail. The goal of better frailty assessment is so that modifiable behaviours and early stage frailty interventions can be implemented in order to help prevent, slow, and/or reverse declines in health status that are not directly related to gradual losses seen in normal aging. This model of implementing multi-component modifiable behaviours and interventions has been successful within primary care and community dwelling frail patients (Serra-Prat et al., 2017; Theou et al., 2017). These interventions include physical therapy, nutritional, and psychosocial components. At the end of the studies, patients had reduced their level of frailty, and had improved. By slowing the progression of frailty, clinicians are able to improve patients' physical strength and thus their quality of life and hopefully prevent adverse outcomes such as falls, declining health, and hospitalizations (Gobbens, Luijikx, & Van Assen, 2013; Theou et al., 2017).

5.4 Manual Standardized Terminology Mapping

This paper used a manual mapping technique to match the eCGA assessment elements to SNOMED CT terminology. The final manual mapping process produced a total of 133 uniquely matched SNOMED CT terms. This type of mapping method has previously been used in other nursing led standardized terminology mapping studies (Block, 2016; Hardiker et al., 2011). A number of other studies also incorporated an automated or semi-automated approach to terminology mapping. This increases rigour and ensures the greatest amount of clinical concept coverage within SNOMED CT (Block, 2016; Harris et al., 2015; Kim et al., 2014; Monsen et al., 2014). However, due to the scope of this scholarly paper, it was decided not to incorporate an automated approach.

Previous studies have shown the importance that a clinically trained person's perspective adds to the terminology mapping process (Kim, Kim, Shin, & Kim, 2012; Richesson, Andrews, & Krischer, 2006). In the Kim et al. (2012) study, it was discovered that there was a much higher accuracy of mapped terminology when the work is done by a clinician as opposed to a nontrained clinician. In fact, the accuracy is even higher when the clinician is trained in the specific domain for which they are mapping (Kim et al., 2012). This shows the importance of having manual mapping being done by expert clinicians with knowledge of that specific domain. To satisfy this requirement, the terminology mapping was completed by the author who has terminology mapping and geriatric nursing experience. Furthermore, the expert clinician mapping was completed by a registered nurse who has experience in both assessing patients using the eCGA, but also teaching PCPs on how to use the eCGA tool.

One important aspect of the manual mapping process was the creation of a basic set of rules which the author and the clinician followed throughout the process. This rules-based system for terminology mapping has been used successfully in the past, and has been included in the recommendations of previous research (Kim et al., 2014; Wade & Rosenbloom, 2008). The creation of a set of rules is important, as it allows the terminology mapper to follow a set of guidelines to make decisions. This also increases rigour by allowing other people to use these same set of rules to complete similar mapping activities. These rules also allow for a more defined interpretation of the abundant concepts within SNOMED CT. As such, a rules-based approach can help the clinician select the most appropriate and semantically similar SNOMED CT code which they are trying to match.

5.4.1 Lessons Learned from Manual Mapping

The first round of mapping and expert consensus was done without the creation of a rule set to follow to assist with decision making. This was, in part, due to the inexperience of the author in using SNOMED CT. After the rules were established, with the advisor's guidance, a second round of mapping took place to refine the results.

The one to many matches, 17% (22/133) could be due to a lack of concept granularity or concept ambiguity both within the eCGA form and/or SNOMED CT clinical terms. An example of this is ambiguity are the eCGA questions regarding incontinence (e.g., Constipation-Yes or No). The author found two possible matches within SNOMED CT which would fit the criteria based on the rules established. The applicable answers in this case were “Infrequent Bowel Action (finding)” and “Decreased Frequency of Defecation (finding)”. While the majority of the mapped terms fell within the direct match category, it is possible that there could be more data elements which had one-to many and/or partial matches. This could be in part to the author having selection bias based on the rules established, and inexperience with mapping activities and using the SNOMED CT search engine.

The results obtained in this study show appropriate clinical concept coverage within SNOMED CT. Past work has shown manual mapping of concepts relevant to nursing and coverage in SNOMED CT to range from 58% to 83% (Harris et al., 2015, Ivory, 2016). The results obtained in this study suggest there is consistency between what was accomplished for frailty and previous work.

Some of the possible reasons for not having matches within SNOMED CT may be due to missing content within the terminology, but could also be due to the eCGA assessment form itself, and/or a lack of generalization to internationally recognized clinical terms. For example, the eCGA uses a timed sit-to-stand test, which, to the best of the author’s knowledge, is not part of the SNOMED CT database. It is possible that the timed sit-to-stand test is included in LOINC. Due to the scope of this paper, mapping to LOINC was not included. It is also possible that this content is missing, as it may not be used regularly enough for it to have been added to SNOMED CT. A third possibility for why a “no match” was found could be in part to the rules established by the author. It is possible that there could have been a possible match which fell outside of these established rules. An example of this would be a matching term, but having it fall within a “disorder” or “procedure” hierarchy. Other studies in terminology mapping have similar explanations for the varying degrees of “no match”, or missing clinical content coverage in SNOMED CT. The degree to which content is missing, varies depending on the subject matter being mapped, the methods used to map, and the rules selected to complete the mapping activities (Harris et al., 2015; Ivory, 2016; Kim et al., 2014).

5.5 Expert Consensus Mapping

Two separate rounds of expert consensus mapping occurred in this study. Expert consensus mapping was chosen to increase the possible matches, as well as to determine inter rater reliability for the manual mapping completed by the author. The clinician taking part in this exercise had clinical expertise in the assessment of frailty, which are consistent with other studies which show the importance of specialized clinical knowledge to be able to map clinical concepts (Richesson et al., 2006; Wade & Rosenbloom, 2008).

The terms selected for the expert consensus mapping were randomly selected to increase reliability and rigour in the results. The first discussion and consensus between the two experts was facilitated with the help of the academic supervisor and advisor, to ensure proper procedure was followed. The first iteration of the expert consensus mapping shows a ‘fair’ amount of agreement between the two raters (McHugh, 2012a). This low level of agreement may be in part due to inexperience in terminology mapping by the second clinician. During the consensus conversation, with facilitation by the advisors, the two experts were able to discuss reasoning for concept selection. This discussion allowed for the discovery of the need for rules in the manual mapping process. Because of the lack of agreement between the two raters, it was decided that the author should create a set of rules, in which to apply to the original list of manually mapped codes. Once these rules were applied, a second set of expert consensus mapping took place to ensure accuracy of results, once more rigour was applied to methods.

The second iteration of expert consensus mapping produced a ‘strong’ level of agreement suggesting that having a set of rules in which to base decisions on is important when completing manual mapping activities (McHugh, 2012b). It is also possible that if the second clinician had more prior experience in standardized terminology mapping, the inter related reliability would have been higher during the first iteration of consensus mapping.

In future it would be beneficial to have both clinicians be experts in the field related to the terminology mapping, and have prior mapping experience. It would therefore be beneficial, before undertaking terminology mapping, to provide basic training and education to clinicians related to standard terminologies and the process for mapping. This would ensure that the researchers have the same understanding of the terminology prior to mapping. A next step in this research would be to have a physician familiar with frailty assessment validate the list of mapped clinical terms in a similar fashion to the expert clinician consensus activity. A further possible direction of inquiry would be to have a separate mapping activity completed by a non-expert clinician, but expert terminology mapper to assess the differences between the two.

5.6 Implications

The majority of the components found in a validated frailty assessment tool are present in SNOMED CT clinical concept terms. While only one method of terminology mapping was used, this research can help guide nursing-led informatics and standardized terminology mapping activities by providing standard guidelines to follow in future endeavors. The most important implications coming from this research are related to education and data collection.

5.6.1 Clinical Workforce Education

The data available from EMRs should be reliable and accurate to the type of clinical concepts they are trying to capture. Therefore, it is important to ensure that the clinical workforce of today be aware of standard terminologies and their application, as well as its importance to quality data collection. This is important for all PCPs including registered nurses, nurse practitioners and family practice physicians. To achieve this, it is important to have informatics education provided to nurses starting at the undergraduate level, with more specialized knowledge offerings at the graduate level (Darvish, Bahramnezhad, Keyhanian, & Navidhamidi, 2014). It is also important to have a standardized set of nursing informatics competencies, which would allow for consistency in education and advancement in this growing field of nursing. This knowledge would help prepare RNs entering the workforce in an increasingly electronic clinical environment. This would also help RNs understand the importance of clinical terminologies, and their usefulness in capturing nursing ‘work’, and contribute to quality data collection. The knowledge gained from learning standardized terminologies would provide a basis for RNs to share the same basic understanding, and could provide more consistent and higher quality data collection.

From a physician perspective, it would be beneficial if informatics education was part of medical training. However, this part of the curriculum has not been well established as part of standard medical education and training, with schools being reluctant to offer this education in an already saturated program. The benefit of including such education could potentially be a better understanding of the flow of patient data, privacy and confidentiality issues, and how this data can be used in meaningful research (Shortliffe, 2010). Recent efforts have been made to study the incorporation of this type of education in medical training. Although there are many challenges to implementing this type of education, the institutions and students recognized the benefits this education provides (Sánchez-Mendiola, et al., 2012).

5.6.2 Data Collection Quality

In an EMR it is important to ensure that data collection happens in a meaningful and standardized way to ensure complex concepts, like frailty, are accurately and consistently captured. Because concepts like frailty are dynamic and multidimensional, data elements stored in the EMR must be combined in a way to capture the complexities that conditions like frailty present. Using mapped standardized terminology to capture data elements can aid in this process. We want to ensure that these concepts are captured correctly, and oversight in EMR data organization for conditions like frailty is important, as accurate identification of frailty can lead to earlier intervention, and better care planning, which can increase the patient's quality of life (Gobbens et al., 2013).

To ensure that these data are organized in a meaningful way, methods for concept mapping need to continue to evolve to ensure that quality and patient safety are achieved. If the data elements are not represented or mapped in an accurate way, an opportunity to collect meaningful data could be missed. Also, patient safety could be put at risk if these data are relied upon to inform care planning or decision support, as it may not accurately identify patients in the target population and prevent them from receiving proper treatment.

One way to mitigate these risks is by having nurses participate in more of these terminology mapping research activities. Nurses are ideal clinicians to further this research due to our educational and clinical assessment expertise. Nursing practice prepares nurses to have exceptional assessment skills in a multitude of areas. This allows nurses to better understand the context of clinical assessments and conditions for which they are trying to map to standardized terminology. Furthermore, an increasing number of nursing schools are including formal informatics training, including standard terminology, into their curriculum (Cummings, Borycki, & Madsen, 2015). This combined with basic understanding of research principles, makes RN's ideal candidates to participate in standardized mapping activities

5.6.3 Mapping Research

Currently there is only a small amount of research available to draw from for this type of mapping. Part of the reason for this is because mapping can be seen as an operational procedure, rather than a research study. However, this type of mapping research can help show the importance of having clinicians be involved in this process of mapping and validation. This research varies in type of mapping, standardized terminologies, and clinical situations. This gap in research could be in part due to a lack of defined standards to guide other researchers. Also, this type of clinical concept mapping takes a considerable amount of time which may not be feasible from a cost or time perspective to organizations and institutions. The research that does exist mostly uses automated approaches to terminology mapping. While this is an important step that should be considered in any mapping activity, we should not discount the perspective a clinically trained person brings to the semantic meaning of the clinical concepts.

5.7 Limitations

There are several limitations to this study. Due to the scope of this work, only one mapping method was used. To increase reliability and rigour, it would be advantageous to use additional mapping methods. One such method is an automated machine-based mapping process. This would enable exploration of a larger number of terms, and which might lead to different findings. It is possible that some of the results may be influenced by the author's knowledge of both the manual mapping and expert consensus mapping activities. The author and the expert clinician were both RNs though neither specializes in geriatrics. This could have possibly affected the rate of equivalence and the final clinical term selection. This study could have been strengthened if more than two researchers completed mapping activities. Having a geriatrician or PCP familiar with CGAs would have helped to increase the strength.

With all terminology mapping there can be limited pragmatic use of the findings. One reason is that it is difficult to replicate the exact mapping methods, which can affect the validity of the findings (Saitwal et al., 2012). With manual mapping, the author selecting the terms may have some inherent selection bias which may differ from person to person. Also, because SNOMED CT has constant updates, upgrades, and different versions, it may make it difficult to replicate the results of this study at a later date. This limitation also highlights the challenge of adding this information into an EMR research database. Adding the final list of the SNOMED CT codes into a national data repository would require ongoing maintenance and sustainment to ensure that the codes selected are the most relevant and up to date. This could be problematic due to the time and cost related to this maintenance. The above limitations are not necessarily unique to this study, and should be noted for any future researcher wishing to undertake similar terminology mapping activities.

5.8 Recommendations

As standardized terminologies continue to be integrated into EMRs, it is important to establish rules and parameters for researchers and clinicians to follow to ensure the meaningful use of these clinical terminologies. To strengthen the reliability of the mapped frailty assessment tool, this research should be peer reviewed and/or replicated by other researchers to validate the results. Ideally this should be done by a PCP who is familiar with performing CGAs for the purpose of identifying frailty. This would ensure that the clinical concepts selected are relevant to frailty assessment, and comprehensive of the identifying factors of frailty. It would also be beneficial if the validator had experience working with standardized terminologies such as SNOMED CT. However, if this is not feasible it would also be beneficial if the results from this research are reviewed by an informatics expert who is well versed in standardized terminology mapping. Having both an informatics and clinical expert review these findings would help ensure a high rate of reliability in the findings.

Currently, researchers and organizations are working to improve the use of standardized terminologies in EMRs to work towards greater interoperability between disparate systems, in part, by publishing inter-terminology mapping activities. To ensure that all clinical concepts are mapped, and to allow for greater interoperability between systems, it would be beneficial to also map the eCGA data elements to LOINC. Other studies have shown greater success in concept coverage, when data elements were mapped to both SNOMED CT and LOINC (Lougheed, Thomas, Wasilewski, Morra, & Minard, 2018). Because LOINC is more concerned with clinical measurement and laboratory data, it may be better at capturing some of the missing content from the eCGA. For example, there was “no match” available in SNOMED CT for the Montreal

Cognitive Assessment, or the 5 times sit-to-stand assessment. Both of these eCGA data elements are available within LOINC. The Regenstrief Institute (LOINC) and SNOMED International have an agreement to better integrate and harmonize the two terminologies to ensure less duplication through inter terminology mapping. This goal has just started to be realized, with the first edition of this cross mapping released to the public in January 2018 (SNOMED International, 2018).

Consistent with other terminology mapping studies, this research did not find complete concept coverage of the eCGA within SNOMED CT. This was in part due to missing content within SNOMED CT, specifically when assessing for the absence of a clinical problem. While the eCGA identifies frailty based on an accumulation of deficits, it is still an important step to record the absence of problems to be able to account for any changes to the baseline which could signify the onset or worsening of frailty. For example, there are questions regarding the presence or absence of a deficit (i.e., Delirium, Pain), or whether something is within normal limits (i.e., Speech). SNOMED CT is lacking the ability, in certain clinical concepts, to capture health normal baseline state, like absence of pain or delirium, but to capture that these concepts have been assessed.

5.8.1 CPCSSN Database and Recommendations

This study has been part of larger ongoing frailty research study being conducted by the academic supervisor. Part of this ongoing research involves adding a frailty case definition into a CPCSSN data repository (Birtwhistle et al., 2009; Williamson & Green, 2014). The CPCSSN collects data based on well-defined case definitions for each chronic illness. These case definitions were created using published evidence and expert physician guidance, using a combination of ICD, numerical and textual data (Williamson & Green, 2014). The case definitions were validated using a robust methodology, and showed excellent to good sensitivity and validity for the 8 described illnesses (Williamson & Green, 2014). However, these case definitions are discrete in nature. Meaning they function on a yes/no basis. Frailty for the purposes of identification and monitoring is more nuanced and on a continuum. Therefore, for the purpose of the CPCSSN database, it is important to clearly identify the characteristics of frailty.

Because the CPCSSN currently has validated case definitions for eight chronic conditions, work is currently underway to use the EMR data for a case definition of frailty. By categorizing the defining characteristics of frailty, it allows us to identify the EMR data that could capture frailty. The recommendation after creating the case definition for frailty, would be to add the mapped standardized language to this database. Having the eCGA data elements mapped to SNOMED CT allows this work to be useful across Canada and internationally.

5.8.2 Canadian Primary Care Sentinel Surveillance Network Data

The CPCSSN extracts almost all structured data (e.g. ICD-9, lab values, reason for visit, prescriptions) from community based primary care electronic medical records. These data form a large data repository which is updated with new data every six months. All data are stored on a secure network in a secure facility. No identifying information is extracted, except for postal code (Birtwhistle et al., 2009).

Data are extracted from 17 different EMRs, and sit within a relational database in different tables including: encounters, demographics, prescribed medications, risk factor data such as height, weight, smoking status, coded health diagnosis, laboratory information and physical examination data (Birtwhistle et al., 2009). CPCSSN data go through a three-step process that involves input into the CPCSSN database, data mapping to standard terms, and 'cleaning' of some data fields to make the information more usable for the end user (Birtwhistle et al., 2009). The data are loaded into a central repository where it is processed and added to the data warehouse (Birtwhistle et al., 2009).

Currently, the CPCSSN database managers have proposed and accepted a recommendation to add an additional 'measurement' table into the data schema that would allow for the collection of eCGA data for frailty surveillance. However, the eCGA data are only coming from the Intrahealth EMR, there will need to be additional efforts to ensure that additional disparate EMR data can be integrated into this table. This would likely require some data preparation and cleaning from the other EMRs to ensure that it fits the data currently being collected. An outcome of this paper is a list of codified frailty characteristics, which can also be added as a column within the aforementioned data table. This provides a framework for the CPCSSN database managers, to map future EMR frailty data elements to. Having national data collection on frailty assessment parameters would give researchers the ability to track frailty trends nationally, and help to develop clinical decision support tools. The overall outcome goal of this being improving frailty assessment and treatment in primary care.

5.9 The Role of Nursing in PHC and Frailty Research

Registered nurses have been vastly underutilized in Canadian primary care practices (Attwell, Rogers-Warnock, & Nemis-White, 2012; Kennedy, 2014; Oelke, Besner, & Carter, 2014). In part, this is due to the RN role not be well defined, leading to role ambiguity (Kennedy, 2014; Norful, Martsolf, Jacq, & Poghosyan, 2017). Registered nurses and nurse practitioners are well equipped to be integral members of the interdisciplinary PHC team. In addition to the clinical services they offer to PHC patients, they also provide a holistic care approach which has been seen as beneficial by both patients and PCPs (Ehrlich, Kendall, & Muenchberger, 2012; Kennedy, 2014; Norful et al., 2017). The training and patient/provider experience that the RN brings to PHC, allows them to be able to build trusting relationships with their patients. This helps nurses to better understand the unique sub-populations of patients in PHC (Attwell et al., 2012). Because their practice also has a grass roots approach, RNs are often able to better understand and utilize community services which may improve overall health determinants through assessment, action, and patient education (Kennedy, 2014).

Registered nurses have an opportunity to deliver invaluable services within PHC, including frailty screening and assessment. They are an optimal choice to initiate and manage chronic disease management in PHC (Lukewich, Edge, VanDenKerkhof, & Tranmer, 2014). Through their interactions with patients, RNs can more readily complete the full geriatric assessment, including any functional assessments such as the "sit to stand test". Moreover, RNs' relationship building and awareness in completing care planning, allows for a more integrated and holistic approach to frailty identification and management. Their relationships may help improve early frailty detection, and lead to improved intervention leading to better health outcomes.

Along with RN involvement in PHC, it is important that RNs continue to be involved in informatics and standardized terminology research. Organizations like the Canadian Nurses Association, Canadian Nursing Informatics Association, CIHI, and Canada Health Infoway have created an action plan to collect and use nursing data standards in Canada going forward (White, Nagle, & Hannah, 2016). It is imperative that informatics education be part of nursing education at both the undergraduate and graduate levels, to ensure RNs are prepared to assist and understand these emerging terminologies and technologies.

5.10 Summary

This paper mapped the 133 eCGA data elements to SNOMED CT, after defining the characteristics of frailty through the available relevant literature and validated assessment tools. The main outcome of this paper is a list of codified frailty assessment data elements, that have been analyzed as having an exact, partial or no match to SNOMED CT terminology. These data elements have influenced the formation of a new table of data elements within the CPCSSN. While there was a good amount of concept coverage within SNOMED CT, this study highlights gaps in current standardized terminology databases. By sharing this research with agencies such as Canada Health Infoway and SNOMED International, it will address some of this missing content and concept ambiguity. It is with hope, that this research is shared and used by researchers wishing to surveil frailty through the CPCSSN database.

References

Andrews, J. E., Patrick, T. B., Richesson, R. L., Brown, H., & Krischer, J. P. (2008). Comparing heterogeneous SNOMED CT coding of clinical research concepts by examining normalized expressions. *Journal of Biomedical Informatics*, *41*(6), 1062–1069. https://doi.org/10.1016/j.jbi.2008.01.010

Anzaldi, L. J., Davison, A., Boyd, C. M., Leff, B., & Kharrazi, H. (2017). Comparing clinician descriptions of frailty and geriatric syndromes using electronic health records: a retrospective cohort study. *BMC Geriatrics*, *17*(1), 248. https://doi.org/10.1186/s12877-017-0645-7

Attwell, D., Rogers-Warnock, L., & Nemis-White, J. (2012). Implementing Practice Management Strategies to Improve Patient Care: The EPIC Project. *Healthcare Quarterly*, *15*(2), 46–51. Retrieved from https://www.longwoods.com/product/22913

Bandeen-roche, K., Xue, Q., Ferrucci, L., Walston, J., Guralnik, J. M., Chaves, P., … Fried, L. P. (2006). Phenotype of Frailty : Characterization in the Women ' s Health and Aging Studies, *61*(3), 262–266.

Bhattacharyya, S. (2016). *Introduction to SNOMED CT*. Singapore: Springer.

Birtwhistle, R., Keshavjee, K., Lambert-Lanning, A., Godwin, M., Greiver, M., Manca, D., & Lagace, C. (2009). Building a Pan-Canadian Primary Care Sentinel Surveillance Network: Initial Development and Moving Forward. *The Journal of the American Board of Family Medicine*, *22*(4), 412–422. https://doi.org/10.3122/jabfm.2009.04.090081

Block, L. J. (2016). *Mapping Wound Care Elements to SNOMED CT*. University of British Columbia.

Bodenreider, O. (2008). Biomedical Ontologies in Action : Role in Knowledge Management , Data Integration and Decision Support, 67–79.

Bohnert, N., Chagnon, J., & Dion, P. (2015). *Population projections for Canada (2013 to 2063), provinces and territories (2013 to 2038): Technical report on methodology and assumptions*. *Statistics Canada*.

Brown, R. T., & Covinsky, K. E. (2018). Frailty as an outcome in geriatrics research: Not ready for prime time? *Annals of Internal Medicine*, *168*(5), 361–362. https://doi.org/10.7326/M17-3048

Buta, B. J., Walston, J. D., Godino, J. G., Park, M., Kalyani, R. R., Xue, Q., … Varadhan, R. (2016). Frailty assessment instruments : Systematic characterization of the uses and contexts of highly-cited instruments. *Ageing Research Reviews*, *26*, 53–61. https://doi.org/10.1016/j.arr.2015.12.003

Cameron, I. D., Fairhall, N., Gill, L., Lockwood, K., Langron, C., Aggar, C., … Kurrle, S. (2015). Developing Interventions for Frailty, *2015*.

Canada Health Infoway. (2018a). Connected Health Information in Canada: A Benefits Evaluation Study, (April).

Canada Health Infoway. (2018b). Electronic Medical Records. Retrieved from https://www.infoway-inforoute.ca/en/solutions/digital-health-foundation/electronic-medical-records

Canadian Frailty Network. (2017a). Retrieved from http://old.cfn-nce.ca/media/575584/cfn-2016-17-annual-report.pdf

Canadian Frailty Network. (2017b). *Frailty Matters*.

Canadian Institute for Health Information. (2016). *How Canada Compares: Results From The Commonwealth Fund 2015 International Health Policy Survey of Primary Care Physicians*.

Retrieved from https://www.cihi.ca/sites/default/files/document/commonwealth_fund_2015_pdf_en.pdf

Canadian Institute for Health Information. (2017). *Primary Health Care*.

Canadian Medical Association. (2014). *How can Canada achieve enhanced use of electronic medical records?* Retrieved from https://legacy.cma.ca//Assets/assets-library/document/en/advocacy/Enhanced-Use-of-EMRs-Discussion-Paper-Final-May-2014.pdf

Canadian Medical Association. (2016). *The State of Seniors Healthcare in Canada*. Retrieved from www.cma.ca/En/Lists/Medias/the-state-of-seniors-health-care-in-canada-september-2016.pdf

Canadian Medical Association. (2017). *Number and percent distribution of physicians by specialty and sex, Canada*.

Cesari, M., Calvani, R., & Marzetti, E. (2017a). Frailty in Older Persons. *Clinics in Geriatric Medicine*, *33*(3), 293–303. https://doi.org/10.1016/j.cger.2017.02.002

Cesari, M., Calvani, R., & Marzetti, E. (2017b). Frailty in Older Persons. *Clinics in Geriatric Medicine*, *33*(3), 293–303. https://doi.org/10.1016/j.cger.2017.02.002

Cesari, M., Gambassi, G., Van Kan, G. A., & Vellas, B. (2014). The frailty phenotype and the frailty index: Different instruments for different purposes. *Age and Ageing*, *43*(1), 10–12. https://doi.org/10.1093/ageing/aft160

Chang, F., & Gupta, N. (2015). Progress in electronic medical record adoption in Canada Recherche Les progrès dans l ’ adoption du dossier médical électronique au Canada, *61*, 1076–1084.

Chow, M., Beene, M., O’Brien, A., Greim, P., Cromwell, T., DuLong, D., & Bedecarré, D.

(2015). A nursing information model process for interoperability. *Journal of the American Medical Informatics Association*, *22*(3), 608–614. https://doi.org/10.1093/jamia/ocu026

Clegg, A., Young, J., Iliffe, S., Rikkert, M. O., & Rockwood, K. (2013). Frailty in elderly people. *The Lancet*, *381*(9868), 752–762. https://doi.org/10.1016/S0140-6736(12)62167-9

Coiera, E. (2015). *Guide to Health Informatics* (3rd ed.). London: CRC Press.

Cuggia, M., Avillach, P., & Daniel, C. (2014). Medical Informatics, e-Health. https://doi.org/10.1007/978-2-8178-0478-1

Cummings, E., Borycki, E. M., & Madsen, I. (2015). Teaching Nursing Informatics in Australia, Canada and Denmark. In CSHI. In *Context Sensitive Health Informatics: Many Places, Many Users, Many Contexts, Many Uses* (pp. 39–44).

Darvish, A., Bahramnezhad, F., Keyhanian, S., & Navidhamidi, M. (2014). The Role of Nursing Informatics on Promoting Quality of Health Care and the Need for Appropriate Education, *6*(6), 11–18. https://doi.org/10.5539/gjhs.v6n6p11

Dent, E., Kowal, P., & Hoogendijk, E. O. (2016). Frailty measurement in research and clinical practice: A review. *European Journal of Internal Medicine*, *31*, 3–10. https://doi.org/10.1016/j.ejim.2016.03.007

DesRoches, C., & Miralles, P. (2011). Meaningful Use of Health Information Technology: What Does it Mean for Practicing Physicians? In *Electronic Medical Records* (pp. 1–14). New Jersey: Humana Press.

Dixon, B. E., Vreeman, D. J., & Grannis, S. J. (2014). The long road to semantic interoperability in support of public health: experiences from two states. *Journal of Biomedical Informatics, 49*, 3–8. https://doi.org/10.1016/j.jbi.2014.03.011

Doctors of BC. (2017). Doctors Technology Office. Retrieved from https://www.doctorsofbc.ca/doctors-technology-office

Ehrlich, C., Kendall, E., & Muenchberger, H. (2012). Spanning boundaries and creating strong patient relationships to coordinate care are strategies used by experienced chronic condition care coordinators. *Contemporary Nurse*, *42*(1), 67–75. https://doi.org/10.5172/conu.2012.42.1.67

Fedarko, N. S. (2011). The Biology of Ageing and Frailty. *Clinical Geriatric Medicine*, *27*(1), 27–37. https://doi.org/10.1016/j.cger.2020.08.006

Ferrat, E., Bastuji-Garin, S., Paillaud, E., Caillet, P., Clerc, P., Moscova, L., & Audureau, E. (2018). Efficacy of nurse-led and general practitioner-led comprehensive geriatric assessment in primary care: protocol of a pragmatic three-arm cluster randomised controlled trial (CEpiA study). *BMJ Open*, *8*(4).

Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D., & Anderson, G. (2004). Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *59*(3), 255–263.

Fried, L , Ferrucci, L, Darer, J, Williamson, J , & Anderson, G. (2004). Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *59*(3), M255–M263.

Fried, L. P., Tangen, C. M., Walston, J., Newman, A. B., Hirsch, C., Gottdiener, J., … McBurnie, M. A. (2001). Frailty in Older Adults: Evidence for a Phenotype. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *56*(3), M146–M157. https://doi.org/10.1093/gerona/56.3.M146

Garm, A., H Park, G., & Song, X. (2018). Using an Electronic Comprehensive Geriatric Assessment and Health Coaching to Prevent Frailty in Primary Care: The CARES Model. *Medical & Clinical Reviews*, 1–5. https://doi.org/10.1088/0370-1298/69/1/308

Gobbens, R., Luijikx, K., & Van Assen, M. (2013). Explaining quality of life of older people in the Netherlands using a multidimensional assessment of frailty. *Quality of Life Research*, *22*(8), 2051–2061. https://doi.org/10.1007/s11136-012-0341-1

Hamaker, M. E., Wildes, T. M., & Rostoft, S. (2017). Time to stop saying geriatric assessment is too time consuming. *Journal of Clinical Oncology*, *35*(25), 2871–2874. https://doi.org/doi:10.1200/JCO.2017.72.8170

Hammond, W. E., Jaffe, C., Cimino, J. J., & Huff, S. M. (2014). Standards in biomedical informatics. In *Biomedical informatics* (pp. 211–253). Springer, London.

Hardiker, N. R., Bakken, S., & Kim, T. Y. (2011). Advanced terminological approaches in nursing. In K. A. M. K. Saba (Ed.), *Essentials of nursing informatics* (5th ed.). New York: McGraw-Hill Medical.

Harmand, M., Meillon, C., Bergua, V., Tabue Teguo, M., Dartigues, J. F., Avila-Funes, J. A., & Amieva, H. (2017). Comparing the predictive value of three definitions of frailty: Results from the Three-City study. *Archives of Gerontology and Geriatrics*, *72*(April 2016), 153–163. https://doi.org/10.1016/j.archger.2017.06.005

Harris, M. R., Langford, L. H., Miller, H., Hook, M., Dykes, P. C., & Matney, S. A. (2015). Harmonizing and extending standards from a domain-specific and bottom-up approach: an example from development through use in clinical applications. *Journal of the American Medical Informatics Association*. https://doi.org/10.1093/jamia/ocu020

Hoogendijk, E. O., Van Der Horst, H. E., Deeg, D. J., Frijters, D. H., Prins, B. A., Jansen, A. P.,

..., & Van Hout, H. P. (2012). The identification of frail older adults in primary care : comparing the accuracy of five simple instruments, (October 2012), 262–265. https://doi.org/10.1093/ageing/afs163

Ivory, C. H. (2016). Mapping perinatal nursing process measurement concepts to standard terminologies. , 34(7), 312. *Computers, Informatics, Nursing: CIN*, *34*(7), 312–320.

Jones D, Song X, Mitnitski A, R. K. (2005). Evaluation of a frailty index based on a comprehensive geriatric assessment in a population based study of elderly Canadians. *Aging Clinical and Experimental Research*, *17*, 465–471.

Jones, D. M., Song, X., & Rockwood, K. (2004). Operationalizing a Frailty Index from a Standardized Comprehensive Geriatric Assessment. *Journal of the American Geriatrics Society*, *52*(11), 1929–1933. https://doi.org/10.1111/j.1532-5415.2004.52521.x

Kennedy, V. (2014). The Value of Registered Nurses in Collaborative Family Practice : Enhancing Primary Healthcare in Canada. *Nursing Leadership*, *27*(1), 32–44.

Kim, T. Y., Matney, S. A. (2014). Standards. In R. Nelson & N. Staggers (Ed.), *Health informatics: An interprofessional approach* (pp. 351–369). St. Louis: Elsevier Mosby.

Kim, S. Y., Kim, H. H., Shin, K. H., & Kim, H. S. (2012). Comparison of Knowledge Levels Required for SNOMED CT Coding of Diagnosis and Operation Names in Clinical Records, *18*(3), 186–190.

Kim, T. Y., Hardiker, N., & Coenen, A. (2014). Inter-terminology mapping of nursing problems. *Journal of Biomedical Informatics*, *49*, 213–220. https://doi.org/10.1016/j.jbi.2014.03.001

Lee, L., Patel, T., Hillier, L. M., Maulkhan, N., Slonim, K., & Costa, A. (2017). Identifying frailty in primary care: A systematic review. *Geriatrics and Gerontology International*, *17*(10), 1358–1377. https://doi.org/10.1111/ggi.12955

Liyanage, H., Krause, P., & de Lusignan, S. (2015). Using ontologies to improve semantic interoperability in health data. *Journal of Innovation in Health Informatics*, *22*(2), 309–315. https://doi.org/10.14236/jhi.v22i2.159

Lougheed, M. D., Thomas, N. J., Wasilewski, N. V., Morra, A. H., & Minard, J. P. (2018). Use of SNOMED CT® and LOINC® to standardize terminology for primary care asthma electronic health records. *Journal of Asthma*, *55*(6), 629–639. https://doi.org/10.1080/02770903.2017.1362424

Lukewich, J., Edge, D. S., VanDenKerkhof, E., & Tranmer, J. (2014). Nursing Contributions to Chronic Disease Management in Primary Care, *44*(2), 103–110. https://doi.org/10.1097/NNA.0000000000000033

McHugh, M. L. (2012a). Interrater reliability: the kappa statistic. *Biochemia Medica: Biochemia Medica*, *22*(3), 276–282.

McHugh, M. L. (2012b). Interrater reliability: the kappa statistic. *Biochemia Medica*, *22*(3), 276–282.

Ministry of Health. (2017). *Frailty in Adults- Early Identification and Managment*. Retrieved from https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/frailty-full_guideline.pdf

Mitnitski, A., & Rockwood, K. (2014). Aging as a Process of Deficit Accumulation: Its Utility and Origin (Vol. 2015, pp. 85–98). https://doi.org/10.1159/000364933

Monsen, K. A., Finn, R. S., Fleming, T. E., Garner, E. J., LaValla, A. J., & Riemer, J. G. (2014). Rigor in electronic health record knowledge representation: lessons learned from a SNOMED CT clinical content encoding exercise. *Informatics for Health and Social Care,* 1–15. https://doi.org/10.3109/17538157.2014.965302

Nijeweme-d'Hollosy, W., van Velsen, L., Huygens, M., & Hermens, H. (2015). Requirements for and Barriers towards Interoperable eHealth Technology in Primary Care. *IEEE Internet Computing*, *19*(4), 10–19. https://doi.org/10.1109/MIC.2015.53

Norful, A., Martsolf, G., Jacq, K. De, & Poghosyan, L. (2017). Utilization of registered nurses in primary care teams : A systematic review. *International Journal of Nursing Studies*, *74*(November 2016), 15–23. https://doi.org/10.1016/j.ijnurstu.2017.05.013

Oelke, N. D., Besner, J., & Carter, R. (2014). The evolving role of nurses in primary care medical settings. *International Journal of Nursing Practice*, *20*(6), 629–635. https://doi.org/10.1111/ijn.12219

Pilotto, A., Cella, A., Pilotto, A., Daragjati, J., Veronese, N., Musacchio, C., … Prete, C. (2017). Three Decades of Comprehensive Geriatric Assessment : Evidence Coming From Different Healthcare Settings and Speci fi c Clinical Conditions. *Journal of the American Medical Directors Association*, *18*(2), 192.e1-192.e11. https://doi.org/10.1016/j.jamda.2016.11.004

Regenstrief Institute. (2017). What LOINC Is. Retrieved from https://loinc.org/get-started/what-loinc-is/

Richesson, R. L., Andrews, J. E., & Krischer, J. P. (2006). Use of SNOMED CT to Represent Clinical Research Data: A Semantic Characterization of Data Items on Case Report Forms in Vasculitis Research. *Journal of the American Medical Informatics Association*, *13*(5), 536–546. https://doi.org/https://doi.org/10.1197/jamia.M2093

Richesson, R. L., & Krischer, J. (2007). Data Standards in Clinical Research: Gaps, Overlaps, Challenges and Future Directions. *Journal of the American Medical Informatics Association*, *14*(6), 687–696. https://doi.org/10.1197/jamia.M2470

Ritt, M., Jäger, J., Ritt, J. I., Sieber, C. C., & Gaßmann, K. G. (2017). Operationalizing a frailty index using routine blood and urine tests. *Clinical Interventions in Aging*, *12,* 1029–1040. https://doi.org/10.2147/CIA.S131987

Rockwood, K. (2005). A global clinical measure of fitness and frailty in elderly people. *Canadian Medical Association Journal*, *173*(5), 489–495. https://doi.org/10.1503/cmaj.050051

Rockwood, K., Blodgett, J. M., Theou, O., Sun, M. H., Feridooni, H. A., Mitnitski, A., … Howlett, S. E. (2017). A Frailty Index Based On Deficit Accumulation Quantifies Mortality Risk in Humans and in Mice. *Scientific Reports*, *7*(1), 43068. https://doi.org/10.1038/srep43068

Rockwood, K., & Mitnitski, A. (2007). Frailty in Relation to the Accumulation of Deficits. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *62*(7), 722–727. https://doi.org/10.1093/gerona/62.7.722

Rockwood, K., & Mitnitski, A. (2011). Frailty Defined by Deficit Accumulation and Geriatric Medicine Defined by Frailty. *Clinics in Geriatric Medicine*, *27*(1), 17–26. https://doi.org/10.1016/j.cger.2010.08.008

Rodríguez-Mañas, L., Féart, C., Mann, G., Viña, J., Chatterji, S., Chodzko-Zajko, W., … Vega, E. (2013). Searching for an operational definition of frailty: A delphi method based consensus statement. the frailty operative definition-consensus conference project. *Journals of Gerontology - Series A Biological Sciences and Medical Sciences*, *68*(1), 62–67. https://doi.org/10.1093/gerona/gls119

Romera-Liebana, L., Orfila, F., Segura, J. M., Real, J., Fabra, M. L., Möller, M., … Foz, G. (2018). Effects of a Primary Care-Based Multifactorial Intervention on Physical and Cognitive Function in Frail, Elderly Individuals: A Randomized Controlled Trial. *The*

Journals of Gerontology: Series A, 00(00), 1–7. https://doi.org/10.1093/gerona/glx259

Rosenbloom, S. T., Miller, R. A., Johnson, K. B., Elkin, P. L., & Brown, S. H. (2006). Interface Terminologies: Facilitating Direct Entry of Clinical Data into Electronic Health Record Systems. *Journal of the American Medical Informatics Association*, *13*(3), 277–288. https://doi.org/10.1197/jamia.M1957

Saitwal, H., Qing, D., Jones, S., Bernstam, E. V., Chute, C. G., & Johnson, T. R. (2012). Cross-terminology mapping challenges: a demonstration using medication terminological systems. *Journal of Biomedical Informatics*, *45*(4), 613–625.

Sánchez-Mendiola, M. Martínez-Franco, A. I. Rosales-Vega, A., Villamar-Chulin, J., Gatica-Lara, F., García-Durán, R., & Martínez-González, A. (2012). Development and implementation of a biomedical informatics course for medical students: challenges of a large-scale blended-learning program. *Journal of the American Medical Informatics Association*, *20*(2), 381–387. https://doi.org/10.1136/amiajnl-2011-000796

Schulz, S., Rodrigues, J. M., Rector, A., & Chute, C. G. (2017). Interface Terminologies, Reference Terminologies and Aggregation Terminologies: A Strategy for Better Integration. *Studies in Health Technology and Informatics*, *245*, 940–944. https://doi.org/10.3233/978-1-61499-830-3-940

Searle, S. D., Mitnitski, A., Gahbauer, E. A., Gill, T. M., & Rockwood, K. (2008). A standard procedure for creating a frailty index. *BMC Geriatrics*, *8*(1), 24. https://doi.org/10.1186/1471-2318-8-24

Serra-Prat, M., Sist, X., Domenich, R., Jurado, L., Saiz, A., Roces, A., … Papiol, M. (2017). Effectiveness of an intervention to prevent frailty in pre-frail community-dwelling older people consulting in primary care : a randomised controlled trial, (January), 401–407.

https://doi.org/10.1093/ageing/afw242

Shortliffe, E. (2010). Biomedical informatics in the education of physicians. *JAMA: The Journal of the American Medical Association*, *304*(11), 1227–1228.

Skolnik, N. S., Timko, M., & Myers, C. (2011). A view from the trenches: primary care physicians on electronic health records. In *Electronic Medical Records* (pp. 15–36). Totowa, NJ.: Humana Press. https://doi.org/10.1007/978-1-60761-606-1

SNOMED International. (2017). 5-Step Briefing. Retrieved August 20, 2001, from https://www.snomed.org/snomed-ct/five-step-briefing

SNOMED International. (2018). SNOMED CT Browser. Retrieved August 20, 2008, from https://browser.ihtsdotools.org/?

Terry, A. L., Stewart, M., Fortin, M., Wong, S. T., Kennedy, M., Burge, F., … Thind, A. (2012). How does Canada stack up? A bibliometric analysis of the primary healthcare electronic medical record literature. *Informatics in Primary Care*, *20*(4), 233–240. https://doi.org/10.14236/jhi.v20i4.2

Theou, O., Cann, L., Blodgett, J., Wallace, L. M. K., Brothers, T. D., & Rockwood, K. (2015). Modifications to the frailty phenotype criteria: Systematic review of the current literature and investigation of 262 frailty phenotypes in the Survey of Health, Ageing, and Retirement in Europe. *Ageing Research Reviews*, *21*, 78–94. https://doi.org/10.1016/j.arr.2015.04.001

Theou, O., Park, G. H., Garm, A., Song, X., Clarke, B., & Rockwood, K. (2017). Reversing Frailty Levels in Primary Care Using the CARES Model. *Canadian Geriatrics Journal*, *20*(3), 105–111. https://doi.org/10.5770/cgj.20.274

Theou, O., Rockwood, M. R. H., Mitnitski, A., & Rockwood, K. (2012). Disability and co-morbidity in relation to frailty : How much do they overlap ? *Archives of Gerontology and*

Geriatrics, *55*(2), e1–e8. https://doi.org/10.1016/j.archger.2012.03.001

Theou, O., Walston, J., & Rockwood, K. (2015). Operationalizing Frailty Using the Frailty Phenotype and Deficit Accumulation Approaches. *Interdisciplinary Topics in Gerontology and Geriatrics*, *41*, 66–73. https://doi.org/10.1159/000381164

van Kempen, J. A. L., Melis, R. J. F., Perry, M., Schers, H. J., & Rikkert, M. G. M. O. (2015). Diagnosis of Frailty after a Comprehensive Geriatric Assessment: Differences between Family Physicians and Geriatricians. *The Journal of the American Board of Family Medicine*, *28*(2), 240–248. https://doi.org/10.3122/jabfm.2015.02.130081

Vanselow, N. A. (1995). A New Definition of Primary Care. *JAMA: The Journal of the American Medical Association*, *273*(3), 192. https://doi.org/10.1001/jama.1995.03520270026023

Venot, A., & Cuggia, M. (2014). Medical Informatics, e-Health, 349–363. https://doi.org/10.1007/978-2-8178-0478-1

Vergara, I., Rivas-Ruiz, F., Vrotsou, K., Contreras-Fernández, E., Téllez-Santana, T., MacHón, M., … Abellan, G. (2016). Validation and comparison of instruments to identify frail patientes in primary care settings: Study protocol. *BMC Health Services Research*, *16*(1), 1–7. https://doi.org/10.1186/s12913-016-1540-1

Wade, G., & Rosenbloom, S. T. (2008). Experiences mapping a legacy interface terminology to SNOMED CT. *BMC Medical Informatics and Decision Making*, *8*(Suppl 1), S3. https://doi.org/10.1186/1472-6947-8-S1-S3

White, P., Nagle, L., & Hannah, K. (2016). Strategizing for national nursing data standards. Retrieved November 28, 2018, from https://www.canadian-nurse.com/en/articles/issues/2016/november-2016/strategizing-for-national-nursing-data-standards

Williamson, T., & Green, M. E. (2014). Validating the 8 CPCSSN Case Definitions for Chronic Disease Surveillance in a Primary Care Database of Elec- tronic Health Records, 367–373. https://doi.org/10.1370/afm.1644.Department

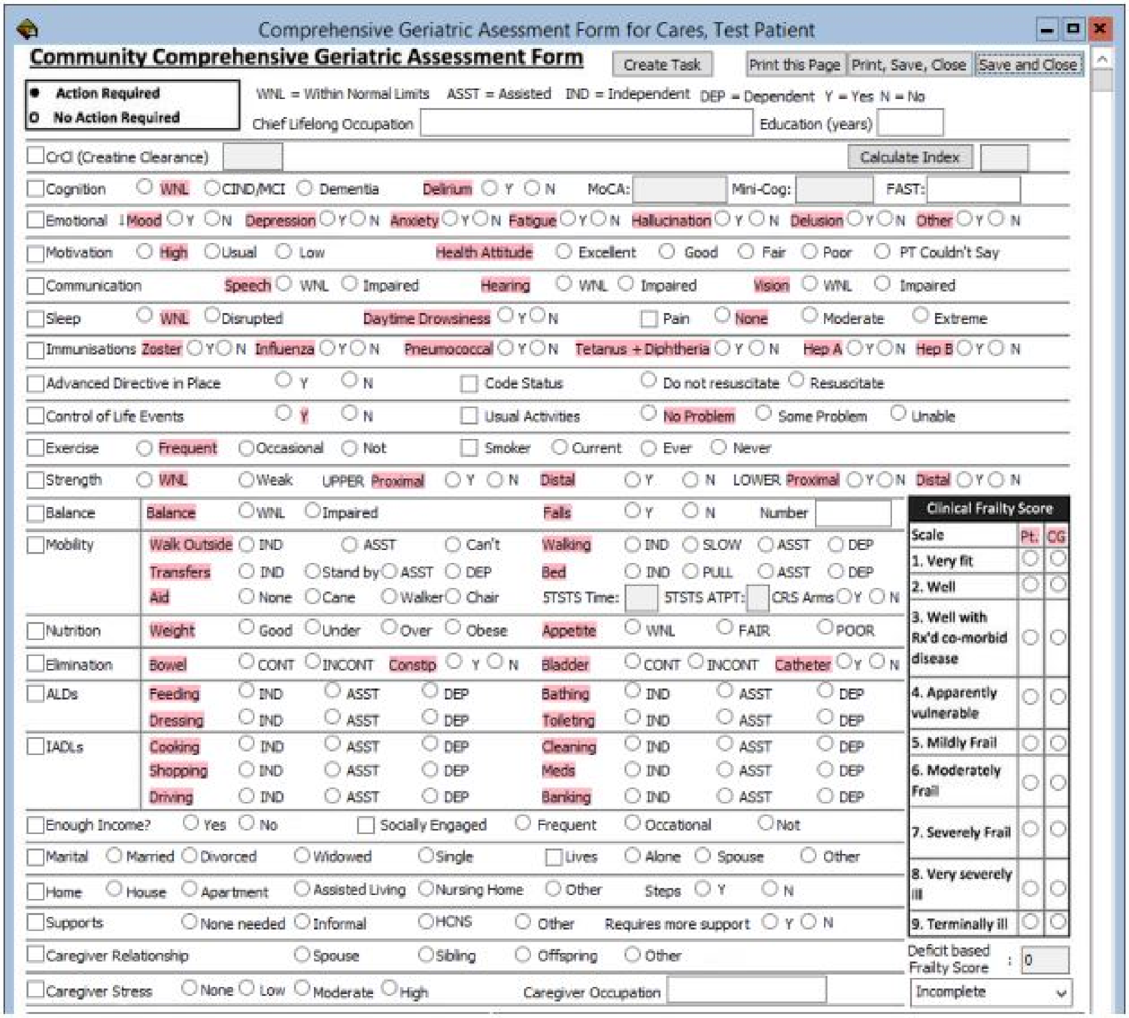
Woods, N. F., Lacroix, Ã. A. Z., Gray, S. L., Pharm, D., Aragaki, A., Cochrane, B. B., … Ãã, M. P. H. (2005). Frailty : Emergence and Consequences in Women Aged 65 and Older in the Women ' s Health Initiative Observational Study, 1321–1330. https://doi.org/10.1111/j.1532-5415.2005.53405.x

Xue, Q. L. (2011). The frailty syndrome: definition and natural history. *Clinics in Geriatric Medicine*, *27*(1), 1–15.

Zelmer, J., & Hagens, S. (2014). Advancing Primary Care Use of Electronic Medical Records in Canada. *Health Reform Observer - Observatoire Des Réformes de Santé*, *2*(3). https://doi.org/10.13162/hro-ors.v2i3.1214

Appendices

Appendix A CARES CGA Questionnaire


Comprehensive Geriatric Asessment Form for Cares, Test Patient

Community Comprehensive Geriatric Assessment Form | Create Task | Print this Page | Print, Save, Close | Save and Close

● Action Required
○ No Action Required

WNL = Within Normal Limits ASST = Assisted IND = Independent DEP = Dependent Y = Yes N = No

Chief Lifelong Occupation | Education (years)

CrCl (Creatine Clearance) | Calculate Index

Cognition ○ WNL ○ CIND/MCI ○ Dementia Delirium ○ Y ○ N MoCA: Mini-Cog: FAST:

Emotional ↓Mood ○ Y ○ N Depression ○ Y ○ N Anxiety ○ Y ○ N Fatigue ○ Y ○ N Hallucination ○ Y ○ N Delusion ○ Y ○ N Other ○ Y ○ N

Motivation ○ High ○ Usual ○ Low Health Attitude ○ Excellent ○ Good ○ Fair ○ Poor ○ PT Couldn't Say

Communication Speech ○ WNL ○ Impaired Hearing ○ WNL ○ Impaired Vision ○ WNL ○ Impaired

Sleep ○ WNL ○ Disrupted Daytime Drowsiness ○ Y ○ N Pain ○ None ○ Moderate ○ Extreme

Immunisations Zoster ○ Y ○ N Influenza ○ Y ○ N Pneumococcal ○ Y ○ N Tetanus + Diphtheria ○ Y ○ N Hep A ○ Y ○ N Hep B ○ Y ○ N

Advanced Directive in Place ○ Y ○ N Code Status ○ Do not resuscitate ○ Resuscitate

Control of Life Events ○ Y ○ N Usual Activities ○ No Problem ○ Some Problem ○ Unable

Exercise ○ Frequent ○ Occasional ○ Not Smoker ○ Current ○ Ever ○ Never

Strength ○ WNL ○ Weak UPPER Proximal ○ Y ○ N Distal ○ Y ○ N LOWER Proximal ○ Y ○ N Distal ○ Y ○ N

Balance Balance ○ WNL ○ Impaired Falls ○ Y ○ N Number

Mobility Walk Outside ○ IND ○ ASST ○ Can't Walking ○ IND ○ SLOW ○ ASST ○ DEP
Transfers ○ IND ○ Stand by ○ ASST ○ DEP Bed ○ IND ○ PULL ○ ASST ○ DEP
Aid ○ None ○ Cane ○ Walker ○ Chair STSTS Time: STSTS ATPT: CRS Arms ○ Y ○ N

Nutrition Weight ○ Good ○ Under ○ Over ○ Obese Appetite ○ WNL ○ FAIR ○ POOR

Elimination Bowel ○ CONT ○ INCONT Constip ○ Y ○ N Bladder ○ CONT ○ INCONT Catheter ○ Y ○ N

ALDs Feeding ○ IND ○ ASST ○ DEP Bathing ○ IND ○ ASST ○ DEP
Dressing ○ IND ○ ASST ○ DEP Toileting ○ IND ○ ASST ○ DEP

IADLs Cooking ○ IND ○ ASST ○ DEP Cleaning ○ IND ○ ASST ○ DEP
Shopping ○ IND ○ ASST ○ DEP Meds ○ IND ○ ASST ○ DEP
Driving ○ IND ○ ASST ○ DEP Banking ○ IND ○ ASST ○ DEP

Enough Income? ○ Yes ○ No Socially Engaged ○ Frequent ○ Occasional ○ Not

Marital ○ Married ○ Divorced ○ Widowed ○ Single Lives ○ Alone ○ Spouse ○ Other

Home ○ House ○ Apartment ○ Assisted Living ○ Nursing Home ○ Other Steps ○ Y ○ N

Supports ○ None needed ○ Informal ○ HCNS ○ Other Requires more support ○ Y ○ N

Caregiver Relationship ○ Spouse ○ Sibling ○ Offspring ○ Other

Caregiver Stress ○ None ○ Low ○ Moderate ○ High Caregiver Occupation

Clinical Frailty Score		
Scale	Pt.	CG
1. Very fit	○	○
2. Well	○	○
3. Well with Rx'd co-morbid disease	○	○
4. Apparently vulnerable	○	○
5. Mildly Frail	○	○
6. Moderately Frail	○	○
7. Severely Frail	○	○
8. Very severely ill	○	○
9. Terminally ill	○	○

Deficit based Frailty Score : 0

Incomplete

Appendix B Manual Mapping

The tables below shows phase 3 mapping of eCGA data elements to SNOMED CT terms.

Criteria	Definition
Direct Match	The eCGA data element matches the clinical concept available in SNOMED CT. These matches are known as pre-coordinated.
Partial Match	One-to-many: The data element could be accurately described using more than one standardized clinical concept within SNOMED CT. (ie., data element "urinary incontinent" and SNOMED CT concepts "urinary incontinent" and "continent: dependent") OR Partial Match: The data element didn't directly match with a SNOMED CT code, but semantically is similar enough for the clinician to feel it could be appropriate (ie. Data element "cleaning independent" and SNOMED CT concept "able to tidy house"
No Match	The eCGA data element does not have an equivalent clinical concept match in SNOMED CT

	Form Element Description	Form Code Response	SNOMED Name	SNOMED Heirarchy Type	SNOMED Code
1	CGA Anxiety	No	Normal emotional state	Finding	409068001
		Yes	Anxiety	Finding	48694002
2	CGA Balance	Within Normal Limits	Balance normal	Finding	298312007
		Impaired	Impairment of balance	Finding	387603000
3	CGA Cognition	Within Normal Limits	Normal cognition	Finding	449888003
		CIND/MCI	Minimal cognitive impairment	Finding	110352000
		Dementia	Severe cognitive impairment Dementia	Finding Disorder	702956004 52448006
4	CGA Control of Life Events	Yes	Maintains self-control	Finding	284475009
		No	Low self-control	Finding	705000008
5	CGA Delirium	Yes	Delirious	Finding	419567006
		No	No Match		
6	CGA Delusion	Yes	Delusions	Finding	2073000
		No	No Match		
7	CGA Depression	Yes	Symptoms of depression Depressive disorder	Finding Disorder	

		No	No Match		
8	CGA Daytime Drowsiness	Yes	Daytime somnolence	Finding	141000119100
		No			
9	CGA Elimination Bladder	Continent	Continence independent Bladder: fully continent	Finding	129023004 165234001
		Incontinent	Urinary incontinence Continence dependent	Finding	165232002 129077000
10	CGA Elimination Bowel	Continent	Bowels: fully continent	Finding	24029004
		Incontinent	Incontinence of feces	Finding	72042002
11	CGA Elimination Catheter	Yes	Urinary catheter in situ	Finding	439053001
		No	No Match		
12	CGA Elimination Constipation	Yes	Infrequent Bowel Action Decreased frequency of defecation	Finding	249516000 44316003
		No	Not constipated	Finding	162081000
13	CGA Emotional Other		No Match		
14	CGA Enough Income	Yes	Income sufficient to meet needs	Finding	224190007
		No	Income insufficient to meet needs	Finding	224191006
15	CGA Exercise	Frequent	Exercises regularly	Finding	228448000
		Occasional	Gets little exercise	Finding	228446001
		Not	Gets no exercise	Finding	228445002
16	CGA Fall	Yes	Falls	Finding	161898004
		No	Does not fall	Finding	298345007
17	CGA Fall Number	Free Text	Number of falls	Observable Entity	298348009
18	CGA FAST Score		Functional status index	Assessment Scale	273472005
19	CGA Fatigue	Yes	Able to sustain energy level	Finding	716453008
		No	Fatigue	Finding	84229001
20	CGA Hallucination	Yes	Hallucinations	Finding	7011001
		No	Normal perception	Finding	247700009
21	CGA Health Attitude	Excellent	General health excellent	Finding	135816001
		Good	General health good	Finding	135815002
		Fair	General health fair	Finding	135817005
		Poor	General health poo	Finding	135818000
		Pt Couldn't Say	Not sure of general health	Finding	135820002
22	CGA Hearing	Within Normal Limits	Hearing normal	Finding	162339002
		Impaired	Hearing problem	Finding	300228004

23	CGA IALDs Banking	Independent	Money managing independent	Finding	129054000
		Assisted	Money managing assisted	Finding	129028008
		Dependent	Money managing dependent	Finding	129066006
24	CGA IALDs Cleaning	Independent	Able to tidy house	Finding	286185000
		Assisted	Needs help with housework	Finding	400985006
		Dependent	Unable to tidy house	Finding	286186004
25	CGA IALDs Cooking	Independent	Independent in cooking	Finding	710763006
		Assisted	Needs help with cooking	Finding	40986007
		Dependent	Unable to cook food	Finding	286515001
26	CGA IALDs Driving	Independent	Able to drive a car	Finding	300634001
		Assisted	Difficulty driving a car	Finding	300638003
		Dependent	Unable to drive a car	Finding	300635000
27	CGA IALDs Meds	Independent	Able to manage medication	Finding	285034004
		Assisted	Difficulty managing medication	Finding	285038001
		Dependent	Unable to manage medication	Finding	285035003
28	CGA IALDs Shopping	Independent	Shopping independent	Finding	129026007
		Assisted	Shopping assisted	Finding	129073001
		Dependent	Shopping dependent	Finding	129032002
29	CGA ALDs Bathing	Independent	Independent bathing	Finding	129041007
		Assisted	Bathing assisted	Finding	129040008
		Dependent	Dependent for bathing	Finding	129043005
30	CGA ALDs Dressing	Independent	Independent with dressing	Finding	29035000
		Assisted	Needs help with dressing	Finding	129039006
		Dependent	Dependent for dressing	Finding	129065005
31	CGA ALDs Feeding	Independent	Independent feeding	Finding	65224005
		Assisted	Feeding assisted	Finding	165222009
		Dependent	Dependent for feeding	Finding	129033007
32	CGA ALDs Toileting	Independent	Independent in toilet	Finding	129062008
		Assisted	Needs help in toilet	Finding	129045003
		Dependent	Dependent in toilet	Finding	129078005
33	CGA Mobility 5 Times Sit to Stand Attempts Score	Freetext	No Match		
34	CGA Mobility 5 Times Sit to Stand Time Score	Freetext	No Match		
35	CGA Mobility Aid	None	No Match		
		Cane	Cane, device	Physical Object	87405001

		Walker	Walker	Physical Object	705406009
		Chair	Motorized wheelchair device	Physical Object	23366006
36	CGA Mobility Bed	Independent	Able to move in bed	Finding	301681008
		Pull	No Match		
		Assisted	Assistance with mobility in bed Difficulty moving in bed	Procedure Finding	713138001 301685004
		Dependent	Unable to move in bed	Finding	301682001
37	CGA Mini-Cog Score	Freetext	Mini-Cog brief cognitive screening test score	Observable Entity	713408000
38	CGA MoCA 7.3 Score	Freetext	No Match		
39	CGA Mood Down	Yes	Depressed mood	Finding	366979004
		No	Normal Mood Symptoms	Finding	134416003
40	CGA Motivation	High	Increased motivation	Finding	86808004
		Usual	Normal motivation	Finding	64423005
		Low	Low motivation	Finding	26413003
41	CGA Mobility Transfers	Independent	Independent ability to transfer location	Finding	714915006
		Stand By	No Match		
		Assisted	Able to transfer location with assistance	Finding	719024002
		Dependent	Dependent ability to transfer location	Finding	714916007
42	CGA Mobility Walking	Independent	Independent walking	Finding	165245003
		Slow	Slow on legs	Finding	249898006
		Assisted	Dependent for walking	Finding	427512004
		Dependent	Dependent for walking	Finding	427512004
43	CGA Mobility Walk Outside	Independent	Able to mobilize outside	Finding	301563003
		Assisted	Difficulty mobilizing outside	Finding	301568007
		Can't	Unable to mobilize outside	Finding	301564009
44	CGA Nutrition Appetite	Within Normal Limits	Appetite normal	Finding	161825005
		Fair	No Match		
		Poor	Decrease in appetite	Finding	64379006
45	CGA Nutrition Weight	Good	Normal weight	Finding	43664005
		Under	Underweight	Finding	248342006
		Over	Overweight	Finding	238131007
		Obese	Obese	Finding	414915002
46	CGA Pain	None	No Match		
		Moderate	Moderate pain	Finding	50415004
		Extreme	Severe pain	Finding	76948002
47	CGA Sleep	Within Normal Limits	Good sleep pattern	Finding	314939008

		Disrupted	Poor sleep pattern	Finding	314938000
48	CGA Speech	Within Normal Limits	No Match		
		Impaired	Speech Problem	Finding	267095009
49	CGA Strength Lower Distal	Yes	Distal muscle weakness	Finding	249942005
		No	Normal muscle function	Finding	20658008
50	CGA Strength Lower Proximal	Yes	Proximal muscle weakness	Finding	249939004
		No	Normal muscle function	Finding	20658008
51	CGA Strength	Within Normal Limits	Normal muscle function	Finding	20658008
		Weak	Muscle weakness	Finding	26544005
52	CGA Strength Upper Distal	Yes	Distal muscle weakness	Finding	249942005
		No	Normal muscle function	Finding	20658008
53	CGA Strength Upper Proximal	Yes	Proximal muscle weakness	Finding	249939004
		No	Normal muscle function	Finding	20658008
54	CGA Usual Activities	No Problem	Able to participate in leisure activities	Finding	300738008
		Some Problem	Difficulty participating in leisure activities	Finding	300742006
		Unable	Unable to participate in leisure activities	Finding	300739000
55	CGA Vision	Within Normal Limits	Normal vision	Finding	45089002
		Impaired	Abnormal vision	Finding	7973008

Appendix C Clinician Consensus #1

The tables below show phase 4 mapping of eCGA data elements to SNOMED CT terms.

Criteria	Definition
Direct Match	The same SNOMED CT code was chosen for the eCGA data element.
Partial Match	A semantically similar code, or code from the same SNOMED CT hierarchy was chosen, but no direct match.
No Match	There was no match between the author and clinician SNOMED CT code selection.

	Form Element Description	Form Code Response	SNOMED Name (Shardae)	SNOMED Heirarchy	SNOMED Code	SNOMED Name (Manpreet)	SNOMED Heirarchy	SNOMED Code	Original Answer	Agreed Terms
2	**CGA Balance**	Within Normal Limits	Balance normal	Finding	298312007	Balance normal	Finding	298312007	Direct Match	
		Impaired	Impairment of balance	Finding	387603000	Poor balance	Finding	249985001	Partial Match	Agreed to authors code
14	**CGA Enough Income**	Yes	Income sufficient to meet needs	Finding	224190007	Income sufficient to meet needs	Finding	224190007	Direct Match	
		No	Income insufficient to meet needs	Finding	224191006	Income insufficient to meet needs	Finding	224191006	Direct Match	
1	**CGA Anxiety**	No	Normal emotional state	Finding	409068001	No Match			No Match	Agreed to No Match
		Yes	Anxiety	Finding	48694002	Anxiety	Finding	48694002	Direct Match	
28	**CGA IALDs Shopping**	Independent	Shopping independent	Finding	129026007	Shopping independent	Finding	129026007	Direct Match	
		Assisted	Shopping assisted	Finding	129073001	Shopping assisted	Finding	129073001	Direct Match	
		Dependent	Shopping dependent	Finding	129032002	Shopping dependent	Finding	129032002	Direct Match	

26	**CGA IALDs Driving**	Independent	Able to drive a car	Finding	300634001	Finding related to ability to drive a car	Finding	365349005	Partial Match	Agree to authors code
		Assisted	Difficulty driving a car	Finding	300638003	No Match			No Match	
		Dependent	Unable to drive a car	Finding	300635000	Unable to drive a car	Finding	300635000	Direct Match	
38	**CGA MoCA 7.3 Score**	Freetext	No Match			No Match			Direct Match	
55	**CGA Vision**	Within Normal Limits	Normal vision	Finding	45089002	Normal vision	Finding	45089002	Direct Match	
		Impaired	Abnormal vision	Finding	7973008	Visual impairment	Disorder	397540003	No Match	Agreed to authors code
48	**CGA Speech**	Within Normal Limits	Able to use verbal communication	Finding	288599003	No speech problem	Situation	162293002	No Match	
		Impaired	Difficulty using verbal communication	Finding	32000005	Speech problem	Finding	267095009	No Match	Agreed to Clinican Code
22	**CGA Hearing**	Within Normal Limits	Hearing normal	Finding	162339002	Hearing normal	Finding	162339002	Direct Match	
		Impaired	Hearing problem	Finding	300228004	Hearing impaired	Disorder	15188001	No Match	Agreed to authors code
34	**CGA Mobility 5 Times Sit to Stand Time Score**	Freetext	No Match			No Match			Direct Match	

Appendix D Clinician Consensus #2

The tables below show phase 4 mapping of eCGA data elements to SNOMED CT terms.

Criteria	Definition
Direct Match	The same SNOMED CT code was chosen for the eCGA data element.
Partial Match	A semantically similar code, or code from the same SNOMED CT hierarchy was chosen, but no direct match.
No Match	There was no match between the author and clinician SNOMED CT code selection.

Form Element Description	Form Code Response	SNOMED Name (Mapper #1)	SNOMED Hierarchy	SNOMED Code	SNOMED Name	SNOMED Hierarchy Type	SNOMED Code	Original Answer	Agreed Term
CGA IALDs Shopping	Independent	Shopping independent	Finding	129026007	Shopping Independent	Finding	129026007		
	Assisted	Shopping assisted	Finding	129073001	Shopping Assisted	Finding	129073001		
	Dependent	Shopping dependent	Finding	129032002	Shopping Dependent	Finding	129032002		
CGA Delirium	Yes	Delirious	Finding	419567006	Altered mental status	Finding	419284004		Agreed to Authors Code
	No	No Match			State of mind normal	Finding	162716005		Agreed to Authors Code
CGA Emotional Other		No Match			No match	N/A	N/A		
CGA Hallucination	Yes	Hallucinations	Finding	7011001	Hallucinations	Finding	7011001		
	No	Normal perception	Finding	247700009	No match	N/A	N/A		Agreed to

									Authors Code
CGA ALDs Toileting	Independent	Independent in toilet	Finding	129062008	Independent in toilet	Finding	129062008		
	Assisted	Needs help in toilet	Finding	129045003	Needs help in toilet	Finding	129045003		
	Dependent	Dependent in toilet	Finding	129078005	Dependent in toilet	Finding	129078005		
CGA ALDs Dressing	Independent	Independent with dressing	Finding	29035000	Independent with dressing	Finding	129035000		
	Assisted	Needs help with dressing	Finding	129039006	Needs help with dressing	Finding	129039006		
	Dependent	Dependent for dressing	Finding	129065005	Dependent for dressing	Finding	129065005		
CGA Sleep	Within Normal Limits	Good sleep pattern	Finding	314939008	Good sleep pattern	Finding	314939008		
	Disrupted	Poor sleep pattern	Finding	314938000	Poor sleep pattern	Finding	314938000		
CGA Delusion	Yes	Delusions	Finding	2073000	Delusions	Finding	2073000		
	No	No Match			No match	N/A	N/A		
CGA MoCA 7.3 Score	Free text	No Match			No match	N/A	N/A		
CGA Exercise	Frequent	Exercises regularly	Finding	228448000	Exercises regularly	Finding	228448000		
	Occasional	Gets little exercise	Finding	228446001	Gets little exercise	Finding	228446001		
	Not	Gets no exercise	Finding	228445002	Gets no exercise	Finding	228445002		