Using Artificial Intelligence-Based Argument Theory To Generate Automated Patient Education Dialogues: An Interactive Educational Dialogue System For Families Of Children With Juvenile Idiopathic Arthritis

by

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ABSTRACT

Juvenile Idiopathic Arthritis (JIA) is a chronic rheumatic disease affecting between 1 and 4 out of 1000 children in Canada, with outcomes including pain, prolonged dependence on medications, and disability. To allow families to effectively self-manage chronic conditions, such as JIA, patient education is necessary. Families of children with JIA need access to the Patient Education Materials (PEM) provided by their Rheumatology clinic outside of clinic visits in a way that allows them control over what content they receive and when they receive it. This work aims to address this educational gap by using a knowledge management approach to explore how an artificial intelligence method based on the Toulmin model of argument could be used to construct an interactive dialogue that allows users to engage with PEM. Content from the PEM was computerized using a knowledge model based on the Toulmin model of argument which was also leveraged to manage the structure of the dialogue. We have evaluated the dialogue of the resulting system through cognitive walkthroughs and semi-structured interviews with JIA domain experts. The results of this study show that these methods show great promise for providing quality information to families of children with JIA when they need it.

LIST OF ABBREVIATIONS USED

AE – Argument Element

AHP – Allied Healthcare Provider

CW – Cognitive Walkthrough

DMARD – Disease-Modifying Anti-Rheumatic Drug

EMA – Extended Model of Argument

FJIA – Families of children with Juvenile Idiopathic Arthritis

HCP – Health Care Provider

HCU – Health Care User

JADE – Juvenile idiopathic Arthritis Dialogue-based Education

JIA – Juvenile Idiopathic Arthritis

JITL – Just-In-Time Learning

KT – Knowledge Translation

NSAID – Non-Steroidal Anti-Inflammatory Drug

OWL – Web Ontology Language

PEM – Patient Education Materials

PR – Pediatric Rheumatologist

SSI – Semi-Structured Interview

TMA – Toulmin's Model of Argument

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CHAPTER 1.0 INTRODUCTION

This thesis explores the use the Toulmin Model of Argument (TMA) to deliver an interactive, patient education dialogue. The TMA was created to represent the flexibility of everyday language [1] that is used in the process of justifying a statement [2]. This model has been used in previous studies to give structure to patient education content with positive results [3]–[5]. Given the variety of topics covered in Juvenile Idiopathic Arthritis (JIA) Patient Education Materials (PEM), and the formats in which the content is disseminated, a flexible model that can fit the logic of everyday discourse, such as the TMA, is needed to organize such information.

JIA is the most common rheumatic disease of childhood affecting between 1 and 4 out of 1000 children in Canada [6], [7]. JIA is a chronic condition with outcomes including pain, prolonged dependence on medications, and disability [8]. The unpredictable course of the disease can place large emotional burdens on the members of a Family of children with JIA (FJIA) [9]. FJIA need to understand the condition to be able to successfully self-manage it. Self-management in health care includes monitoring symptoms and health data, medication management, improving healthcare decision-making skills, and changing health-related behavior [10].

This understanding can be achieved through patient education, which has been shown to reduce the burden of chronic conditions, improve the patient's quality of life [11], and have a positive effect on health outcomes [12]. FJIA are currently feeling overwhelmed by the volume of information currently available to them [13]. This could be because that none of the currently used methods of patient education allow them to control what content they can view. Indeed, patient education is most effective when Health Care

Users (HCU) are given control over the content they wish to learn about [14] and multiple methods of dissemination are used in conjunction [15]. FJIA have expressed a desire for information about JIA to be provided to them from the rheumatology clinic and clinicians because they trust them [13]. To have content provided from a rheumatology clinic approved source, while also giving FJIA content control over their education, requires a computer-based solution since the verbal and paper-based methods currently used do not allow for such customization [16], [17].

Dialogue systems are automated efforts to mimic a person-to-person communication style with the aim to make user interaction easier and more intuitive [18]. When used for patient education purposes dialogue systems resulted in high user engagement and significant knowledge improvement [19], improved self-management [20], and improved health outcomes relative to control interventions [21]. These systems use a dialogue manager to formulate responses to user inputs by drawing relevant information from a structured repository of domain specific content [22].

1.1 Problem Statement

FJIA need access to the Patient Education Materials (PEM) provided by their Rheumatology clinic outside of clinic visits in a way that allows them control over what content they receive and when they receive it. We have endeavored to address this educational gap by using a knowledge management approach to view the problem from both technical infrastructure and functional information structure perspectives [23]. The technical aspect could be addressed by providing FJIA with access to a dialogue system which could draw on the PEM content already used by their clinic. The functional aspect

requires using the TMA as a knowledge model to integrate the PEM content into a structured repository.

1.2 Research Objectives

To address that problem, this thesis investigates dialogue systems for patient education through the following objectives:

1) Computerize existing patient education content by applying the Toulmin model of argument
2) Leverage the resulting knowledge model to create a dialogue system for families of children with JIA
3) Evaluate the content from the resulting dialogue system provide content for relevance, understandability, and completeness

1.3 Research Approach

To examine these questions, we have pursued a knowledge management approach to 1) integrate the JIA PEM resources available to FJIA and store them in a structured computer-readable format, 2) investigate the application of artificial intelligence based theories to conduct a structured dialogue, 3) systematically create a knowledge model to represent the two types of dialogue relevant to patient education, namely information-seeking and inquiry dialogues, and 4) operationalize the resulting model and structured information repository for patient education with regards to the clinical situation of FJIA [23]. This approach was chosen as it accounts for a variety of healthcare knowledge resources, a range of healthcare knowledge users with differing interests, situations, and abilities that change over time, and the dissemination of knowledge across all stakeholders in the system [24]. The situation for FJIA needing patient education tools

includes: a wide variety of PEM and relevant healthcare knowledge users ranging from clinicians to parents and children to teachers, all of whom have different interests and abilities, and these will change as the disease course, and their age in the case of the children and adolescents, progresses. This methodology, however, is not specific to JIA and so could be applied to patient education of other conditions. As a result of applying the knowledge management approach, this thesis will proceed along the following steps:

1) Design the architecture of the JADE system to meet the problem specifications.
2) Identify a selection of PEM, chosen from the Division of Pediatric Rheumatology at the IWK Health Centre, as a representative sample of the information given to FJIA.
3) Use an iterative process to code the content contained in the PEM identified in step 2 so that it can be integrated from those documents into a single knowledge model.
4) Formalize the resulting knowledge model into an ontology so that it can be used in a dialogue system.
5) Design and implement a dialogue manager and interactive interface to take user queries and deliver relevant responses from the PEM content in the knowledge model.
6) Finally, evaluate the content of the responses provided by the system to determine whether it is complete, accurate, and relevant.

1.4 Contributions

This thesis describes the use of TMA to deliver an interactive patient education dialogue. To achieve this, a novel methodology for creating a dialogue system for patient education

was developed. A model based on the TMA was used to integrate and computerize content from existing PEM as well as to form part of the dialogue manager for an HCU facing dialogue system for families of children with JIA. The model also allowed for the chaining of arguments together extending the dialogue that users can have with the system beyond the content of a single argument.

While other computer-based patient education systems have used the TMA to organize information for HCU consumption, they do so to answer a single question only [3]–[5]. To our knowledge, this is the first time that it has been used to organize previously existing PEM which could be used to answer a wide variety of patient education related questions. One other dialogue system has used the TMA structure in its dialogue manager [5], however it is clinician facing and does not allow connections beyond a single argument, whereas our dialogue system is HCU facing and permits the dialogue to range between linked arguments.

The methodology used in this work is generalizable to patient education for other health related conditions, and thus presents a novel method for providing an additional patient education tool for HCUs with a variety of conditions.

1.5 Thesis Outline

Chapter 2 of this thesis outlines the background and major concepts relating to this work. Chapter 3 elucidates the process by which the research solution was developed from its conceptual design to its evaluation. Chapter 4 describes the results of the evaluation study, while Chapter 5 discusses the implications of these findings. Chapter 6 examines the potential for future work on this topic. Finally, Chapter 7 summarizes the work and its contributions and concludes the thesis.

CHAPTER 2.0 BACKGROUND

Juvenile Idiopathic Arthritis is arthritis that lasts for more than 6 weeks and is first diagnosed in someone under the age of 16 years [7]. JIA affects between 1 and 4 out of 1000 children and adolescents in Canada, which makes it the most common chronic rheumatic disease of childhood [6], [7]. Children and adolescents with JIA may experience chronic pain, prolonged dependence on medications, and disability [8]. JIA has an unpredictable disease course which, in addition to the significant physical burdens, causes parents of children with JIA to report experiencing an "emotional rollercoaster" [9]. This emotional burden is exacerbated by feeling overwhelmed by the volume of information about JIA that families are exposed to, especially at diagnosis, medication change and disease flare ups [13].

Chronic medical conditions, such as JIA, require day-to-day management and monitoring that only a HCU, in this case a child or adolescent and/or their family, can be responsible for [12]. In order to benefit from various medical interventions (e.g. medications, exercise program), the interventions must be aligned with the HCU's values and preferences [25]. This requires cooperation and joint responsibility between Health Care Providers (HCPs) and HCUs [11], [26]. Patient education, therefore, is more than the transfer of knowledge but seeks to also modify behaviour towards decisions and activities that are beneficial to the HCU's health [26]. When theory-based patient education methods are used, there is a positive effect on health outcomes [12], it can reduce the burden of the chronic condition and improve the patient's quality of life [11], and reduce the financial burden on both the individual and the healthcare system [27]. Patients who are given more information about their condition and treatment, especially the purpose

and possible outcomes of the treatment, have fewer medical problems and are more likely to continue with the treatment plan [26]. As different people have different learning styles, it is important to provide patient education through a variety of methods and media [27].

The JIA patient education information provided to FJIA at the IWK Pediatric Rheumatology Clinic, it is both varied and voluminous. This breadth of content is due, in part, to the complexity of JIA itself. JIA is divided into 7 subtypes, each of which have different prognosis for remission and treatment options [28]. There is a wide range of medicinal treatments for JIA including: corticosteroids, Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) such as ibuprofen, or naproxen, Disease-Modifying Anti-Rheumatic Drugs (DMARDs) such as methotrexate, and Biologic Agents which are complex molecules made via a biological system [28]. Some of these medications have side effects such as nausea, increased risk of serious infections, and may be linked to increased risk of cancers [29]. There are also a wide range of non-medicinal treatments to help manage symptoms including physiotherapy exercises, supporting joints through splinting, and cognitive behavioral therapy for pain management.

FJIA require information about the condition to cope with a challenging and unpredictable disease. Since high quality information about the condition exists, the literature review in the following section aims to determine the best way to deliver it to FJIA.

2.1 Patient Education

Information about JIA is currently available to FJIA at the IWK pediatric rheumatology clinic through three main modalities: 1) verbally by HCPs during clinical encounters, 2)

in paper-based PEM provided by clinics and the Arthritis Society, and 3) online through various sources [13]. The best practices of the patient education field, as well as the modes of information delivery, will be reviewed here.

2.1.1 Patient Education Best Practices

Patient education is most effective when it is tailored to the HCU's needs and situation, provided when they need it, and is offered through multiple modalities. Providing personalized information tailored to an individual's situation leads to better user satisfaction than generic information [30]. Giving HCUs control over what content they want to view was found to be the best design feature of computer-based educational interventions [31]. This concept of content control can be viewed as self-personalization, as it filters what content is viewed and allows control over when information is accessed. Information provided "just-in-time", i.e. made available when the user wants or needs it, leads to more effective education [14]. Just-In-Time Learning (JITL) dovetails well with the goal of Knowledge Translation (KT) to provide "the right information in the right format to the right people at the right time" [32]. Knowledge management also aims to provide the right knowledge at the right time in the right place in the right format, but also includes keeping that knowledge correct and up to date [33].

JITL is difficult to achieve with paper-based or face-to-face communication due to the inflexibility of the content of the former and the time constraints of the latter. Providing the right knowledge at the right time is limited by the relevant information being difficult to locate within the multiple documents, or even within a single large document. The right format is dependent on the preferences and learning styles of the user [27], but paper-based documents provide no flexibility from that perspective. Finally, the ability

to keep the knowledge up to date is constrained since once a paper-based document is disseminated to a patient or family it cannot be updated remotely. Computer-based patient education systems have the flexibility required and, given access to them, do not have time constraints [34]. Giving HCUs a variety of education materials and learning methods allows them to choose the ones that work best for them [26], [27].

2.1.2 Modes Of Current JIA Patient Education

On average, at least a half of the information provided verbally by HCPs is forgotten by HCUs within five minutes, and what is remembered is not necessarily understood or implementable [35], [36]. The greater the amounts of information communicated to a HCU correlates with lower levels of ability to recall the information [37]. Having a child present while the information is being communicated was found to further reduce the abilities of a caregiver to recall information given verbally [38]. Many individual factors, such as stress, health literacy, and motivation, impact the ability to understand and recall verbally communicated information as do external factors such as interruptions, time constraints, and the relationship between HCPs and HCUs [35], [36], [38]. Despite these downsides, receiving information from HCPs remains the most trusted and desired mode of communication for HCUs [13], [37]. Methods to improve verbal communication require training and time and should exist within a multi-modal educational environment [37]. Memory aids such as note taking, printed materials, audio/visual recordings, or computer based materials to improve patient and caregiver recall of important medical information are highly recommended to be used in conjunction with verbally communicated information [35], [36], [38].

The Division of Pediatric Rheumatology at the IWK Health Centre provides clinical care for children with rheumatological illnesses. It is the only clinic of its kind in the Maritimes, and so serves children with JIA in Nova Scotia, New Brunswick, and Prince Edward Island both from the IWK Health Centre and from periodic travelling clinics [39]. The clinic has approximately 2000 visits a year [40] and administrative records for the past 6 months show that JIA accounts for roughly 40% of all visits.

At every visit, each child and their family are seen by the pediatric rheumatologist and clinic nurse and if needed, by allied health practitioners including physiotherapy, occupational therapy and social work. Patient education related to all aspects of living with JIA could be discussed by each of these providers during a single appointment. There are a few time points during the trajectory of care in which patient education is a major focus. The first is at the time of diagnosis of JIA. This is typically an appointment that will last several hours and include teaching by the pediatric rheumatologist and the clinic nurse, as well as other members of the team, depending on the needs and preferences of the child and family. The second time at which a significant amount of information is provided to the family is at times of disease flares, when previously well controlled arthritis becomes active leading to pain and disability, which are common in JIA [41]. At these time points, the family and physician will need to discuss a treatment plan which may include adjusting medication and/or adding a new class of medications to the treatment regimen. It may also include therapies suggested by the allied health providers.

Paper-based materials, such as pamphlets, can be used to give HCUs access to PEM outside of a medical encounter. At the Division of Pediatric Rheumatology at the IWK

Health Centre there are 98 documents available to provide to FJIA, 39 of which are unique PEM. These documents, although sometimes provided separately, are largely bundled into packages which are given out to FJIA at the two time points described in the previous paragraph.

In addition, links to online resources are provided to FJIA such as The Arthritis Society and if appropriate for the age of the patient, Teens Taking Charge. The Arthritis Society's website focusses mainly on adult rheumatic disease although there are some resources for those with JIA as well [42]. Teens Taking Charge is a patient education hub created by Sick Kids Hospital and is aimed at adolescents with JIA [43]. It has comprehensive and developmentally appropriate content, including videos, but has no method to provide content control to users beyond navigating its webpages.

The readability of patient education materials has an impact on their effectiveness; formatting the content into topical sections with whitespace in between improves patient knowledge [44]. A synthesis of systematic reviews and meta-analyses of different modes of patient education materials found that printed materials improved patient knowledge over verbal communication, although the effect was even better if the two modes were combined [30].

The same study found equally good results from computer-based educational interventions, even in pediatric populations, with users especially satisfied if the information was personalized to their situation [30]. Other studies have found improved knowledge from computer-based patient education relative to verbal communication, which could save time in clinic and improve the knowledge imbalance between HCPs and HCUs [16], [17]. However, accurate online information about JIA has been shown

to be scarce [45], and is not trusted by FJIA unless it is from a 'reputable' source, such as a hospital or the Arthritis Society [13].

All these modes currently available to FJIA have their strengths and weaknesses. Verbal patient education from clinicians is the most preferred by FJIA but is constrained by the limits of a clinic visit. Paper-based patient education can contain a lot of information and is accessible outside of the clinical encounter but is not updatable or searchable. Computer-based patient education interventions are accessible as long as the user has the necessary equipment and skills, and it is easily updatable and searchable. However, those currently available to FJIA do not allow for personalization or content control. A recent systematic review of dissemination strategies of recommendations for patients found that using multiple methods of dissemination are more effective than any single method [15]. Therefore, it is likely that if these modes were combined to include the information from printed PEMs in an accessible computer-based format that is amenable to content control, it would be a more effective strategy. A mode of patient education that could complement present education practices in the pediatric rheumatology in keeping with JITL style is a dialogue system.

2.2 Dialogue Systems In Patient Education

Dialogue systems are automated efforts to mimic a person-to-person communication style with the aim to make interaction for the user easier and more intuitive [18]. The dialogue can take the form of video, audio, or text and can be accessed over a variety of media such as text messaging, phone calls, and the internet [18], [19], [46]. Dialogue systems have been successful in the health care fields of mental health counselling [46], disease self-management [18], and the collection or monitoring of health data [47]. Interventions

using dialogue systems have reported high levels of user engagement [21], [48], equal health outcomes to treatment as usual while requiring fewer resources or time from clinicians [46], and effectively changing users' health behaviour [47].

Theoretically, there are six types of dialogue [49].

1) Persuasion dialogue is when there is a conflict between different points of view, with the goal of the dialogue being to resolve the issue. In this type of dialogue, one participant seeks to prove a point while the other argues against it. For example, two people discussing their difference in opinion regard the safety of a certain medication.
2) Negotiation dialogue is a conflict of interest where a reasonable settlement needs to be found. Here, the participants are trying to find common ground between their interests. For example, a company and its union meet to decide on a new collective bargaining agreement.
3) Eristic dialogue represents an interpersonal conflict where the root of the conflict needs to be revealed. A verbal fight or argument would be a good example of this type of dialogue.
4) Deliberation dialogue is where a choice needs to be made. An example of this type of dialogue would be shared-decision making where physicians and patients meet to decide which treatment would be the best option through the alignment of goals and solutions.
5) Information-seeking dialogue occurs when information is acquired in answer to a participant's questions. Asking a librarian for sources to complete a literature review would be an example of this type of dialogue.

6) Inquiry dialogue occurs when proof is needed, and the participants seek to find and verify evidence. An example of this type of dialogue would be two people discussing whether a proposed research study complies with an organization's ethics policy.

The two types of dialogue relevant to patient education systems are information seeking and inquiry, since these answer a user's questions and then allow them to verify the answers and see how applicable to their situation they are. Information seeking dialogue is exemplified in the following exchange with SimCoach, a dialogue system for helping military vets overcome post-traumatic stress disorder [50]:

User: I'm feeling depressed.

SimCoach: Okay, you said you haven't been feeling so happy lately. There could be a lot of reasons for that. But first off, have you done any exercise recently?

User: No, I haven't.

SimCoach: Well, it might be worth a try. Gettin' some exercise has been medically proven to lift people's spirits.

The user's implied question is: 'What can I do to improve my depressive state?' and the dialogue system responds with an answer that they should try exercising. Thus, providing information that the user is seeking.

An example of inquiry dialogue is shown below from a dialogue system for clinicians which recommends treatment options for patients with hypertension [5]:

User: What is the recommended treatment plan for this patient?

WOZ: Add thiazide diuretic.

User: What was the relevant patient information used to make this decision?

WOZ: It was recommended to this patient because the patient has isolated systolic hypertension, diabetes and myocardial infarction.

User: Why is that the recommendation made?

WOZ: The drug thiazide diuretic is compellingly indicated by isolated systolic hypertension and is relatively indicated by diabetes and myocardial infarction.

The first exchange between the user and the system is information seeking dialogue, while the following two exchanges are inquiry dialogue. The user is questioning the reasons that the initial recommendation was made, and the system is responding with the information the user needs to verify the veracity of the recommendation and whether it would fit their patient's situation.

The core of a dialogue system is the dialogue manager, which takes input from the user and returns a response that is relevant to the dialogue. Early dialogue systems used a dialogue grammar, or step by step process of how the dialogue should take place, however this severely limited the flexibility of the dialogue and therefore more modern systems use more complex algorithms and artificial intelligence instead [22]. In essence, the dialogue manager is the set of rules that governs the conversation [33]. The dialogue manager uses those rules to locate relevant content from a structured repository of information, such as a database, and formulate that into a response to a user's input [19]. This structured repository may include domain specific information, a history of the previous conversation, or examples of dialogue as well as the rules for how to use and

access these repositories [51]. While the variety of architectures within dialogue systems means that one system's structure cannot be generalized to all, an example of how a dialogue system could work is explained here [51]: If a user asks: *What is on TV at 10pm?* the system searches for examples of similar questions in its example dialogue database finding the question *What is on TV at 9pm?*. It takes the response structure from this example query of a TV program where the date is today, and the time is 10pm. It then searches its domain specific database on TV programs to find responses that fit those criteria. The results of this search are then formatted according to a grammatical structure and displayed to the user who could then respond if they desired.

2.2.1 Review of Patient Education Dialogue Systems in Health Care

Eleven studies were identified which used a dialogue system to educate patients on healthcare related matters. For six of these systems, however, education was not their primary goal. Three were mainly counselling systems [21], [48], [52], two were primarily health data monitoring systems [18], [53], and one functioned mostly as a test of stress management [20], though they all incorporated some educational functionality into their system. All the dialogue systems targeted the patient other than one which was designed for counsellors to use in real time while counselling patients [54]. The systems were designed for a variety of medical fields including cancer [19], [54], [55], mental health [20], [21], [48], [50], [52], hypertension [18], and diabetes [53]. All of them were designed for use in adult populations.

Of the eleven studies identified, all of them provided information-seeking dialogue, allowing users to choose what questions and topics they needed to learn about. Four of these studies may have provided an inquiry dialogue, although it is difficult to be

conclusive given the examples given in the manuscripts. For instance, the two studies by Harless et al. allowed users to ask for more information on a topic which could involve a verification process [19], [55]. The Meeker et al. report used a very flexible free text user input system and could recommend resources outside of itself, meaning that users seeking proof might be able to find it [50]. Finally, the study by Trinkhaus and Gaisser did not restrict users to specific lines of questioning which could allow, given that the system worked in concert with a human counsellor, that inquiry dialogue could be pursued [54]. It is possible that other systems could provide inquiry dialogue as well, however, this could not be determined given the information provided.

Only one of the dialogue systems was designed for a situation where a decision needed to be made. This was in the study by Bickmore et al. where the system was tested on patients with low health literacy who needed to decide to consent or not to participation in research [56]. However, the dialogue system, while it allowed users to control the content they saw, did not account for users' preferences or opinions, therefore deliberation dialogue could not occur. This type of dialogue better describes shared decision making than patient education, with its inputs of medical knowledge and healthcare user preferences and values [25], which should be done in person with the healthcare provider and not by the user alone [34].

It's possible that for the patient education domain, the three types of dialogue dealing with conflict, persuasion, negotiation, and eristic, are not applicable. While such conflict might affect, or be affected by, the process of education, patient education dialogue systems have not yet been designed to help achieve their goals. Thus, information-seeking and inquiry dialogue, are relevant to our study since FJIA want to search for

information relevant to them and be able to find and verify the evidence for that information.

In patient education, dialogue systems have been implemented to give users access to learning materials outside of limited clinic visits. They make use of a variety of platforms and media. Three dialogue systems used text to communicate with the user, two of these were mental health issues, which were provided over mobile phone, and one was for cancer, which was available via computer [21], [48], [54]. The two studies designed for the telephone used audio only [18], [53]. Three systems created for use on computers used video [19], [52], [55]. Two of these systems were for patients with cancer, while the other was to help relieve chronic stress. Three systems used both text and video for use on a computer [20], [50], [56]. Two of these systems were designed for mental health education and the third aimed to ameliorate low health literacy. This range of platforms and media demonstrates the flexibility of dialogue systems to match what users might want to access them on.

Users interacted with the 11 patient education dialogue systems primarily by choosing from multiple questions, either by physically selecting an option [20], [52], [53], [56] or by saying one of the options aloud [19], [55]. This required a set of questions or options to be built into the system and did not allow a user to make choices beyond what the system had been encoded with. Two systems suggested that users write down the questions it did not recognize to ask their doctor at the next face-to-face meeting [19], [55]. One of the systems used natural language processing to allow user engagement with the dialogue system through free text input [50]. Another used speech recognition software to pull keywords out of the conversation [54]. The remaining three used a

combination of multiple choice and keyword recognition [18], [21] or natural language processing [48] to facilitate user interaction. However, these three used their keyword recognition or natural language processing capabilities as part of their counselling or home monitoring functionalities, not their educational ones. So, while there were various forms of input, all but one of the educational dialogues occurred via multiple choice interaction from the user.

The dialogue managers of the 11 systems are important since these determine how content will be selected to fit the user's question or situation as well as how to determine the options available for those relying on a multiple-choice style of interaction. In all the identified systems, the content, while based on evidence and expert opinion, was created for the system and stored in a structured repository as part of the system. Five of the systems used a decision tree to structure the dialogue [20], [21], [48], [52], [53]. This means that the flow of the dialogue had a starting point and traveled a hard-coded path with users being given options to choose the direction of flow where the path branched. This assumes a linear flow of dialogue and does not allow the user to deviate from it, although one of the systems used natural language processing to jump to a different node of the decision tree if an user's question fit its keywords [48]. Another system also used keyword matching to find a starting place for the dialogue, but then used a model of counselling procedure to move the conversation forward, it is unclear whether this model is linear like a decision tree or more interconnected [54]. Three systems stored their content in a networked knowledge base where the information was tagged according to its subject matter which would then be selected according to the choices of the user [19], [55], [56]. A network is similar to a decision tree, in that it gives the user the choice of

paths when they come up, but it has no pre-determined linear flow and can start from anywhere in the network. One of the systems also had its content tagged by its subject matter and would use this to match educational subjects to the user's patient data [18]. Finally, one dialogue system had a dialogue manager module, but its inner workings were not discussed [50]. Thus, most of the dialogue systems used either a decision tree or network structure to facilitate responses within the dialogue, with the network structure allowing for more content control by the user.

The outcomes reported from these studies were largely positive, although three were works in progress and had no clinically relevant outcomes to report [18], [50], [54]. The positive outcomes included high user engagement and significant knowledge improvement [19], [55], high user satisfaction [48], [52], [56], improved self-management [20], and improved health outcomes relative to control [21], [48], [52]. One study reported that engagement levels with the dialogue system fell off over the course of the study [53], although, unlike the other studies where users chose when to use the dialogue system, this system called the users once every two weeks for a year.

Thus, dialogue systems show significant potential for improving patient education outcomes. Content can be displayed in a variety of methods and multiple approaches of interaction are supported providing the opportunity to start simple and scale to more complex methods if initially successful. The knowledge models used were either matching questions with answers based on their content or by creating a decision tree. The content for all these systems was created, based on evidence and expert opinion, for the systems. So, to be able to reuse the PEM content already available, a method is needed to integrate it into a format that a dialogue system could make use of.

2.3 Toulmin's Model Of Argument

Integrating the PEM poses a challenge, because while they contain validated content from evidence or expert consensus and have been vetted and recommended to FJIA by HCPs who are trusted and are families' preferred source of information on JIA [13], the information contained in PEM has no shared structure across documents, some are lists, others are FAQs, others free form prose. There is also a wide variety of content in them, from medicinal and non-medicinal treatments and descriptions of the etiology of the condition, to advice for dealing with the financial burdens of the condition and how best to contact clinicians. So, integrating PEM from a variety of sources, all of which are paper-based, requires a model to represent the information they contain.

Formal logic represents logical as mathematics, i.e. with symbols, or as syllogisms, i.e. premises leading to conclusions. It could not be used to model PEM content for two main reasons: 1) it requires all information to be explicit [1], and 2) it is deductive rather than inductive [57]. Premises or conclusions in patient education, and indeed in many real-world applications of logic, can often be implicit. For example, there may be no need to state in a PEM why lowered white blood cell counts can lead to a heightened risk of infection if they have the health literacy to understand this. The deductive nature of formal logic, building an argument from accepted premises to conclusions, does not fit well with patient education as it requires information to be provided just-in-case instead of giving the healthcare user control over the content [14], [31]. In this domain, a healthcare user wants a recommendation to treat their condition they may not want to know the entire chain of argument needed to get from their situation to the

recommendation, they want to know the recommendation and then question the logic from there. In other words, it is inductive.

Therefore, the model we are looking for needs to be based on informal logic. This includes 'non-formal' methods of assessing the natural-language arguments [58]. While the word argument in everyday use means an altercation, in the field of argumentation it is the process of justifying a claim [2]. We investigated three branches of argument theory, which has been used in the medical field to assess interactions between healthcare providers and healthcare users [59], for use as the model for PEM content. These three are argumentation frameworks as proposed by Dung [60], argument schemes [61], and the TMA [62].

Argumentation frameworks represent arguments as they relate to other arguments, however, they do not consider the internal construction of the argument itself [60]. While this is useful to determine which arguments support or rebut each other it could not model the content of PEM in a way that showed how the arguments themselves were made.

Argument schemes represent common structures of reasoning patterns that natural-language arguments take [61]. There are many such structures, generated inductively from source material. Twenty-five were defined in the domain of law and at least 6 have been defined for the medical field [63]. This method does represent the internal logic of each argument but does not provide a single model for all content. Therefore, new schemes might need to be created as new PEM content was made.

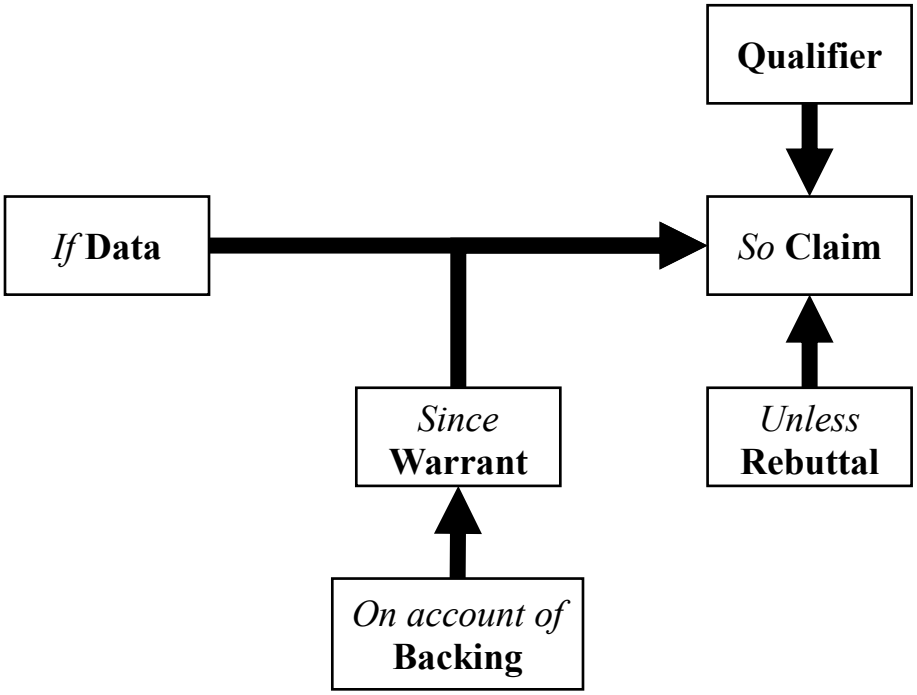
The final option we considered was the TMA. Stephen Toulmin created his model of argument in 1958 in response to the inflexibility of formal logic, which he felt could not represent the flexibility of everyday language [1]. The TMA, which is shown in its entirety in Figure 2.1., divides an argument into six elements [65]. A common example of such an argument is the following statement: *Presumably*, *Harry is a British subject, since he was born in Bermuda and a person born in Bermuda is generally a British subject as per the following legal statutes*, *unless both of his parents were not British subjects, or he has become a naturalized citizen of another country* [64]. This argument would be modeled by the TMA as follows:

1) The Claim is the statement being argued to be true, in the example the claim would be: *Harry is a British subject*.
2) The Qualifier limits the strength of the claim, in this case it is: *Presumably*.
3) The claim is supported by the Data. This is a situation for which the claim is considered true. The data in our example is that: *Harry was born in Bermuda.*
4) The Warrant is the reason why the data supports the claim. In the example the warrant is that: *a person born in Bermuda is generally a British subject*.
5) The Backing is the source(s) of support for the warrant in the form of statistics or publications, in this case it is the legal statutes mentioned.
6) The Rebuttal represents counter claims or exceptions. It is a situation where the claim is not true. In the example, the rebuttal is: *unless both of his parents were not British subjects, or he has become a naturalized citizen of another country*.

Another example of the model, based on the syllogism of Socrates' mortality, is the following: *Socrates is mortal* (Claim) *because Socrates is a man* (Data) *and all men are*

mortal (Warrant) [66]. This argument does not have all the elements described in the TMA, as arguments are not required to do so by the model. However, it does leave the Claim open to questioning based on the Backing or Rebuttals which are not present in the argument. In an example of the TMA applied to content from a JIA PEM [67] the following argument is divided into its elements: *It is extremely rare* (Qualifier) *for your child to pass on arthritis to his/her children* (Claim) *since they have JIA (Data), given that most types of JIA are not passed from generation to generation* (Warrant), *unless they have the Enthesitis-Related subtype of JIA* (Rebuttal). The Backing for this argument would be the Arthritis Society pamphlet it is found in.

Figure 2.1: The original Toulmin Model of Argument [62]



From the beginning, Toulmin meant his model to be field dependent, that is that the model could be modified to fit the domain in which it is being applied [62]. This feature, and the generalizable nature of the model, provides a theory-based framework that is flexible enough to manage the diverse content found in PEM. The TMA was chosen to

model the PEM content it fits the narrative style and everyday natural-language sued in the PEM as well as its structure designed to create a convincing argument, which will hopefully improve the acceptance of the content by the reader.

Since its creation, TMA has been expanded and updated by researchers in a variety of fields. A new argument element called Elaborations was created to conceptualize statements that clarify information contained in other elements [68]. An Elaboration might be used to define a word used in another argument element, for example: *NSAID stands for non-steroidal anti-inflammatory drug, they do not contain cortisone (steroids) and include naproxen, indomethacin and ibuprofen*. Data can be linked to the Claim through more than one Warrant [69] and the Warrant(s) can be either explicitly stated or implicitly assumed [66]. The Claim of one argument can be used as the Warrant for other arguments [70]. This allows the model to expand past the single argument by linking several together. It also means that Warrants can have Qualifiers [66]. These extensions have made the model even more flexible and applicable to the patient education domain.

In the field of patient education, TMA is usually used as an assessment framework. It has been deployed to assess the quality of patient-physician communication [59], [71], [72]. It was also used by Wolfe et al. to judge the quality of users' comprehension of a breast cancer patient education computer system [73]. In this study users were shown some information and then asked to write the gist of what they learned in their own words. The study used TMA as a framework to test the quality of these responses. A response that contained only a claim was not considered an argument, and the more argument elements a response has the higher quality it was judged to have.

When used to structure content in computer-based patient education systems, TMA often models the reasoning of everyday language [59]. Green and Stadler used TMA to model coping strategies used in genetic counselling letters to parents so that they could be automatically generated by a computer system [4]. They identified arguments used by genetic counsellors in their letters to parents to help them cope, and then broke them down into TMA subcomponents, for example: *Patient inherited genetic condition C from you both (i.e. by autosomal recessive inheritance)* (Data). *It is estimated that everyone has a number of gene changes that can cause problems in our children if our partner is also a carrier* (Warrant). *You are not to blame for patient's condition* (Claim). The Warrant of the argument was then added to letters tailored to the user's profile and the genetic diagnosis. Similarly, Project OPERA gave context to the output of a breast cancer risk assessment tool by using TMA [3]. The user's relevant medical information was the Data, the Warrant was evidence from medical literature with Backing from clinical guidelines, the Claim was the risk assessment and recommendations which had a Qualifier depending on the strength of that recommendation, and finally the Rebuttal was for patient data that is missing and could be entered for a more accurate assessment. Shankar, Tu and Musen used a very similar interpretation of TMA to the OPERA system to generate drug recommendations to clinicians for specific patients and help them construct arguments to convince their patients to follow through on that recommendation [5]. As with OPERA, the patient's relevant medical information is the Data, the Backing was clinical guidelines, the Qualifier was the strength of the recommendation, and the Rebuttal was relevant patient data that was missing. The Claim was the drug recommendation, and the Warrant was the indication to use that drug given the Data.

This information was available to the clinician as a dialogue, providing the relevant argument elements that affect the Claim for a certain drug recommendation in response to clinician input. Yet, TMA has not, to our knowledge, been used to organize content for an interactive patient education dialogue system aimed at the HCU.

2.4 Summary And Problem Definition

FJIA want accurate information about the condition to be made available to them outside of clinic, in addition to their encounter with HCPs. They want it to be delivered at a volume that is not overwhelming and in a way that they know they can trust it. Quality information for FJIA is available in the PEM, but the current delivery methods, where information is provided en masse, just in case a part of it might be useful, cause JIA caregivers to be overwhelmed. FJIA need a way to interact with PEM in a JITL style so that learning occurs at their own pace, where they can control the content they wish to see, and materials are in an understandable format.

Computer-based patient education systems offer the opportunity to make PEM available outside of clinical visits as well as content control features unavailable in paper-based documents. Although, they by no means should be used as a replacement for face-to-face health discussions between HCUs and HCPs. Dialogue systems have demonstrated promise as an effective and engaging method of improving patient knowledge across a variety of health fields and content. This content could be created for the dialogue system as was the case in all the studies discussed above, however, given the presence of quality PEM for JIA it would be wasteful not to use it. However, since the PEM contains such disparate content and forms that it is necessary to integrate it into a common structure. The TMA has been used in patient education computer-based systems to

organize content due to its flexible but logical structure. These findings from previous literature offer the foundation needed to propose a solution for FJIA patient education.

CHAPTER 3.0 METHODOLOGY AND METHODS

Since FJIA report feeling overwhelmed by the volume of patient education information there is a need for a new mode of patient education for FJIA which allows the user to control what and how much content they view at a time. As well, this new mode should meet the needs of FJIA by being available outside of clinic and draw its information from trusted sources such as rheumatology clinicians. As discussed in the previous chapter, a dialogue system can potentially provide FJIA with control over accurate patient education information outside of the clinic and if it used existing PEM content it would be trusted. To address that problem, this thesis investigates dialogue systems for patient education through the following objectives:

1) Computerize existing patient education content by applying the Toulmin model of argument
2) Leverage the resulting knowledge model to create a dialogue system for families of children with JIA
3) Evaluate the content from the resulting dialogue system provide content for relevance, understandability, and completeness

3.1 METHODOLOGY

To address these objectives, we used a knowledge management approach in our research. This approach was chosen for its ability to integrate various knowledge sources, knowledge modeling, and operationalize the knowledge model for use in a clinical scenario [23]. Applying a knowledge management approach led to the creation of six-steps for creating a patient education dialogue system. The resulting dialogue system has been named the Juvenile idiopathic Arthritis Dialogue-based Education (JADE) system. The aim of this system is to provide an accessible patient education dialogue to FJIA

using content from trusted sources that gives the user control over what content they are viewing and when. The process of designing, implementing, and evaluating the JADE system took the following steps:

1) Design and Specifications: The problem specifications detailed in the previous chapter guided the design of the architecture of the JADE system. This step involved outlining how knowledge from trusted, existing content such as the PEM could be integrated and computerized as a knowledge repository in a dialogue system and how a user's input would be used by the system to generate a patient education dialogue.
2) Knowledge Identification: A selection of PEM was chosen from the Division of Pediatric Rheumatology at the IWK Health Centre as a representative sample of the information given to FJIA. This sample was chosen because of the trusted nature of the content and to ensure the knowledge model discussed in the next step would encompass the wide variety of content subjects and formats.
3) Knowledge Modelling: An iterative process was performed to model the content contained in the PEM identified in step 2 to integrate the information from those documents into a single structure based on the TMA. This process fluctuated between extracting data from the PEM selection of step 2 into a knowledge model based on the TMA that encompassed the data from the PEM. The extracted PEM information was then coded thematically using an inductive method to group the extracted knowledge into content determined themes to enable the system to respond to user's questions in an information-seeking dialogue.

4) Knowledge Formalization: The resulting knowledge model was then formally implemented as an OWL ontology and the content extracted from the PEM during step 3 were input as instances. Since ontologies are extendible and reusable, this format of knowledge representation allows for updating the content used by the system as new PEM content is created [74]. The computerization of the content, knowledge model, and thematic coding gives the dialogue system the structured knowledge repository required to create a dialogue with the user.
5) Knowledge Translation: A dialogue manager and interactive interface was designed and implemented to take user chosen queries and reason over the ontology to deliver relevant responses, leveraging the thematic coding to create information-seeking dialogue. The implementation also allows users to verify the information by further exploring the PEM content according to the knowledge model structure.
6) Evaluation Study: Finally, an evaluation study was performed to evaluate the content of the responses provided by the system to see whether it has adequately solved the three problems.

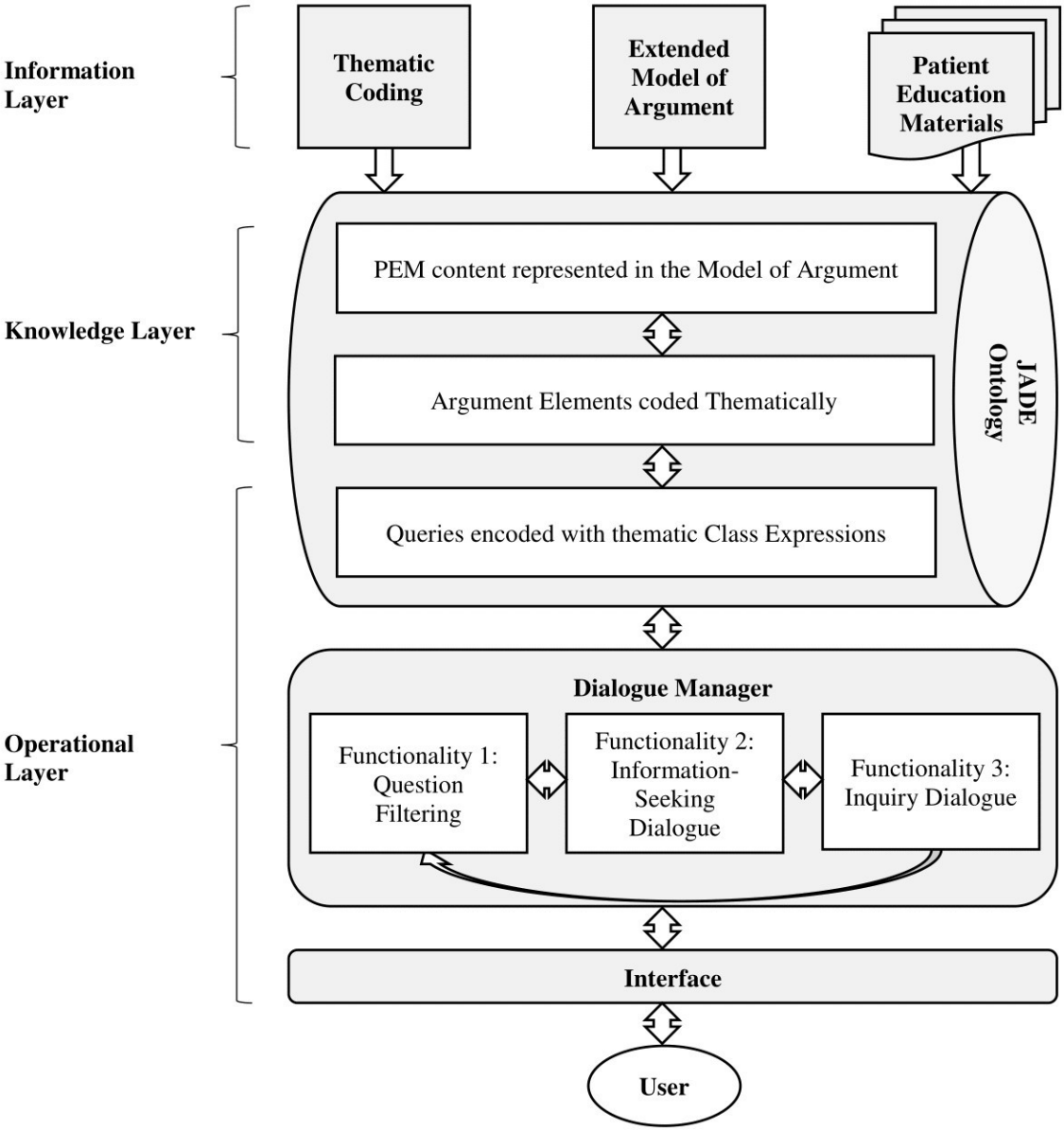
None of these methods are domain specific, and thus could be applied to create a patient education dialogue system for any medical condition. By using a chronic condition such as JIA to test this methodology which requires a large volume and diversity of PEM content to respond to user's questions, instead of a specific procedure or use case, this generalizability is showcased. This chapter expands on these steps and the methods and materials used to accomplish them.

3.2 Design and Specifications

The JADE system, to provide FJIA with what they need, has both technical and functional requirements. Technically, dialogue systems require an architecture with the following modules: 1) an interface to allow input from the user into the system and to display the systems responses, as output, to the user, 2) a dialogue manager or execution engine containing the rules of how the dialogue will be processed, and 3) a structured repository of domain specific information for the dialogue manager to draw on to provide its responses. Functionally, to meet the educational needs of FJIA, the JADE system must be able to provide 1) provide valid and trustworthy information, preferably from the HCPs they know and trust, and 2) two types of dialogue: information-seeking and inquiry. This step used the functional requirements of the system to design the technical architecture of the JADE system, which can be seen in Figure 3.1.

The need for valid, trustworthy information is best met by using the content that has already been created in the JIA PEM. These documents were created or vetted by the HCPs most knowledgeable about the condition and trusted by FJIA. However, for this information to be useful to a dialogue system, the content contained in PEM must be integrated and stored in a computer-readable format that can represent the variety of structures and topics of the knowledge contained there. To integrate the diverse content and structures of the PEM a flexible framework is needed. The TMA, with its focus on informal logic, generic elements, and field dependency, is a good candidate to start from.

Figure 3.1: Architecture of the JADE system



Inquiry dialogue needs to allow the user to explore and examine the information being provided. Here the TMA would come in useful as well, since its structure of claims, data, rebuttals, warrants and backing would give users a way to determine if the systems' responses are trustworthy and relevant to their situation.

Information-seeking dialogue requires information related to a user's question to be identified and provided to the user. While the TMA would allow for the structuring the responses to the user, it would not provide a method for identifying the relevant content. Several of the dialogue systems discussed in chapter 2 used a keyword matching system to do this, however given the large number of synonyms in the medical field and that FJIA members may not know the terms used in the PEM a keyword matching system will not be sufficient. Instead we propose a thematic matching system. The PEM content will need to be tagged based on its subject matter so that it can be searched and matched to the user's interests. These interests are represented in the system by queries drawn from the PEM content.

With the PEM content, and generated queries, organized using the TMA and the thematic coding it needs to be represented in a computer-readable way. Simple representations like dialogue grammars and decision trees, such as those used in most of the patient education dialogue systems discussed in chapter 2, will not adequately represent the many interests of FJIA or the many potential starting points for examining the PEM content. Thus, a less linear format such as a network would be better suited for the storage of the information. Ontologies have been used to good effect representing complex information in healthcare related systems [23], [75]. A Web Ontology Language (OWL) ontology is extendible and reusable [74], and since PEM are constantly being updated and replaced, as new evidence is discovered, this is necessary for the sustainability of any JIA patient education tool. As well an ontology could combine the argument model and the thematic coding together into one interconnected model. Creating a JADE ontology would allow for the PEM content and queries to be

represented both in the model of argument and by thematic codes in a network without needing to specify a hardcoded starting point for the dialogue.

Finally, a dialogue manager, and interface must be designed to operationalize the knowledge represented in the JADE ontology into a dialogue with the user. The rules would need to leverage the structure of the TMA and thematic codes to create the information-seeking and inquiry dialogues.

Thus, the proposed architecture of the JADE system contains the PEM content and queries generated from it as well as the model of argument based on the TMA. These form the Information Layer of the system and the basis on which the rest can be built. To abstract this information into knowledge the PEM must be organized into the model of argument and the PEM content and queries must be coded thematically. This must then be represented and stored in the JADE ontology as the domain specific knowledge repository of the dialogue system. The JADE ontology is the Knowledge Layer of the system. Finally, the dialogue manager and interface will serve as the Operational Layer of the JADE system.

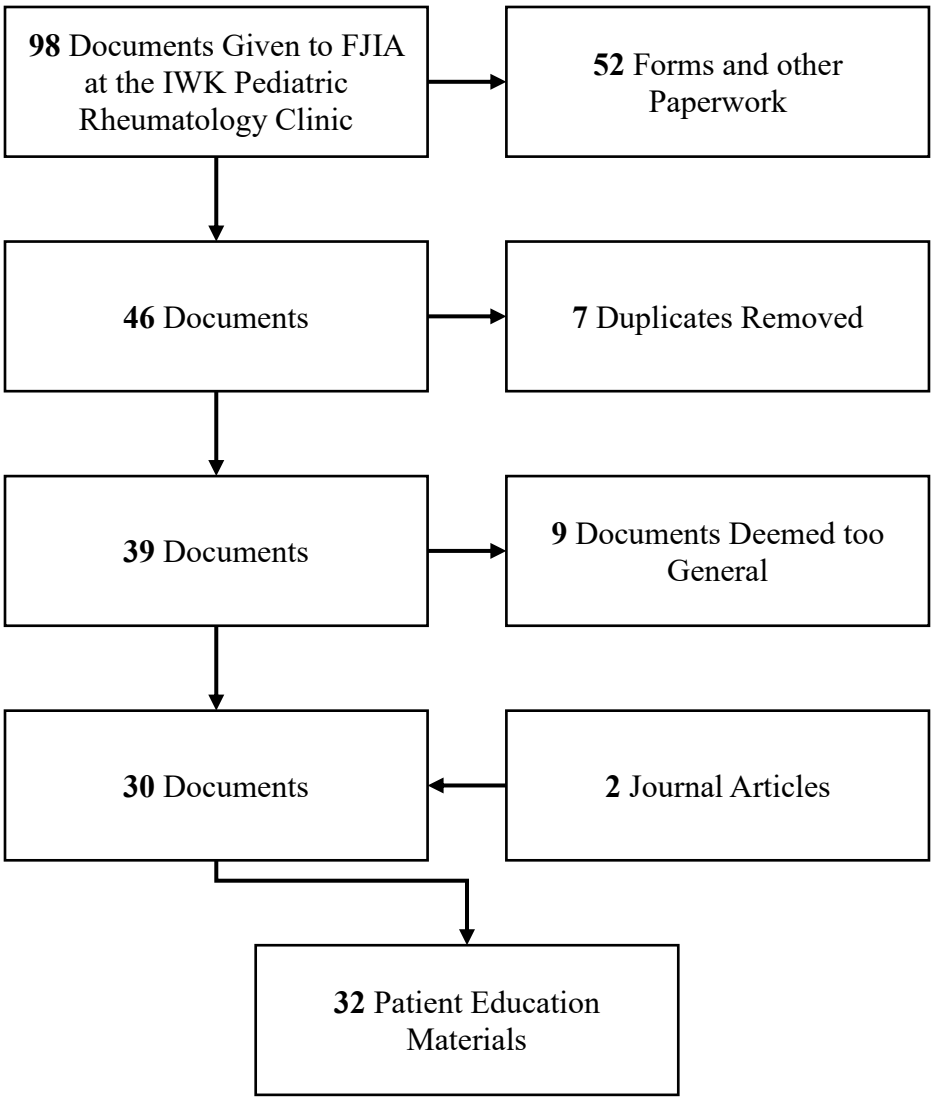
3.3 Knowledge Identification

The Division of Pediatric Rheumatology at the IWK Health Centre was chosen as a partner for this project as the author had experience with both the team and the subject matter due to his position as a research assistant there. All paper-based documents, distributed by the IWK Pediatric Rheumatology Clinic, which are given to families in packages on topics such as general JIA information, self-management, and specific medications were considered for inclusion in the study. Documents were excluded if they were not focused on patient education, were duplicates, or were deemed too general.

In total, 98 documents were identified at the Pediatric Rheumatology clinic that are given to patients and families as part of educational packages. Of these documents, 52 were excluded as they were forms and other documents not related to patient education. A further 7 were removed for being duplicates, and 9 were deemed too general, such as Canada's Food Guide. This left 30 PEM to be included in the study.

Since it has been shown that having a lay summary of research improves the KT of information from research [15] we have included two recent academic papers on the outcomes of JIA to test whether our methods would work on academic research papers as well as traditional PEM. A primary aim of these two papers is to provide knowledge for use in counselling FJIA, making them prime candidates for inclusion in this study [28], [41]. Thus, a total of 32 documents were included in the study. These range from 40-page brochures to a bookmark and cover a variety of topics in a variety of structures. A diagram of the inclusion process is shown in Figure 3.2, and a full list of the documents and their descriptions is available in Appendix A.

Figure 3.2: Diagram of the PEM inclusion/exclusion process



3.4 Knowledge Modelling

To computerize the PEM content so that it can be used to conduct an interactive dialogue for patient education, we worked with the TMA as the theoretical basis to model the PEM content. In step 3.4: Knowledge Formalization, we subsequently developed an ontological model, called the JADE Ontology, to represent TMA constructs and to computerize the PEM content. Here, we describe the knowledge modeling research that

encompasses the abstraction and classification of the PEM content in terms of TMA constructs with respect to the TMA knowledge model.

To ensure that all the content from the JIA PEM was abstracted into the model of argument, an iterative approach was used to extract the information from the PEM. This means that if PEM content could be coded into the elements of the TMA they were, however, if the content was not accurately represented by the TMA then the model was extended to fit the information. As the model was extended, information that had previously been coded was reviewed to ensure that the coding complied with the newest extension of knowledge model.

The TMA coding procedure of Fletcher and Huff consists of six steps: 1) read PEM for understanding; e.g. a reference guide for a specific treatment, 2) divide the PEM into sections relating to a single topic, i.e. how to administer the treatment, side effects, when to call your doctor 3) further divide into individual arguments, 4) identify argument elements in the following order: claim, data, qualifier, exception, backing, warrant, elaboration, 5) re-read the arguments checking for accuracy, and 6) thematically code the arguments [68]. To demonstrate how this procedure was applied we will use the patient education handout 'Using Ice and Heat at Home' as an example [76].

Step 1: The handout was read in its entirety to understand its content. The handout is nicely laid out with headings for different topics such as, 'Using ice', 'Examples of good ice sources', and 'How to safely use ice'.

Step 2: These headings made the second step of dividing the document into topical sections easier, however, sections like 'how to safely use ice' could be further subdivided

into topics such as ‘when to stop using ice’. This section would include content such as: *Ice should be removed if shivering is experienced. Some pinking of the skin is expected, however ice should never be left on long enough that the skin becomes pale and/or pain is felt as this is a sign that skin damage due to cold is beginning. Periodic skin checks while ice is applied is recommended to monitor for any ill effects.*

Step 3: Topical sections such as ‘when to stop using ice’ could be further divided into individual arguments like: *Ice should be removed if shivering is experienced* and *ice should never be left on long enough that the skin becomes pale and/or pain is felt as this is a sign that skin damage due to cold is beginning.*

Step 4: The content from each argument was coded to an argument element using Excel (Microsoft, 2017), the content was occasionally reworded so that each element could exist grammatically without the others. An argument was divided into argument elements based on their definitions as described in Table 3.1. For example, the argument: *ice should never be left on long enough that the skin becomes pale and/or pain is felt as this is a sign that skin damage due to cold is beginning* has the main statement of: *stop using ice*, this then would be the Claim. This is true in the situation: *if the skin becomes pale and/or pain is felt*, this is therefore the Data. There is an Explicit Warrant: *pale skin and/or pain is a sign that skin damage due to cold is beginning*, as this explains why the situation described in the Data element leads to the claim. The Claim has no word or phrase, such as possibly or sometimes, which limits its force, and so has no Qualifier. It does have an Exception: *some pinking of the skin is expected*, as this is a situation in which the claim doesn’t hold true. The Backing is the source of the argument which in this case is: ‘Using Ice and Heat at Home’. Finally, there is an Elaboration: *Periodic skin*

checks are recommended, which adds information to the claim in this argument. The elaboration of this argument is a claim from another argument in its own right: *Periodic skin checks are recommended* (Claim) *while ice is applied* (Data) *since skin checks monitor for any ill effects* (Explicit Warrant).

Table 3.1: Model of argument elements and definitions used to code PEM content

Argument Element	Definition
Claim	The statement the argument is trying to support [62]
Qualifier	A word or phrase that limits the force of the strength of the claim statement [77]
Data	A description of the situation in which the claim holds true
Explicit Warrant	A stated mediator between Data and Claim [62]
Implicit Warrant	A assumed connection between data and claim in the form: If Data then Claim [64]
Exception	A description of a situation in which the claim does not hold true
Elaboration	An expansion on the information contained in another argument element [68]
Backing	The PEM document from which the argument comes from

Step 5: The arguments were re-read to make sure that the PEM content was completely and accurately expressed in the model.

Step 6: The content of each argument element was thematically coded. The purpose of thematic coding was performed so it could be leveraged during information-seeking dialogue to locate relevant argument element(s) to a user's question. The thematic codes were generated inductively from the PEM content using grounded theory [78], this was

done to ensure that all the content had a thematic code linked to it. The full list of themes and their definitions is shown in Appendix B.

Content from all argument elements, except for qualifiers and backing, was included in this process, as any of them could be used as the starting point of a relevant response. For the sake of granularity, the thematic codes were attached to individual argument elements rather than the argument as a whole, and each element could contain multiple themes.

The process began with open coding. For example, the argument: *Periodic skin checks are recommended* (Claim) *while ice is applied* (Data) *since skin checks monitor for any ill effects* (Warrant) was coded as follows. The claim contains *skin checks are recommended* so it was coded as Skin checks. The claim also contains *periodic* which refers to the need for the skin checks to be timely, so it was also coded with the theme Periodic. The data was coded with the theme Ice and the warrant was coded with the themes Skin checks and Ill effects.

After the arguments were coded, similar codes were grouped together during selective coding. Thus, Skin checks were grouped with others under the theme Monitor, Ill effects were grouped with others as Adverse reactions, and Periodic was combined with Frequency and others under Duration as the discussion of specific timelines in the PEM was largely general, likely due to large variations for each child.

Finally, the consolidated themes were grouped together into categories in axial coding. So, Monitor was brought under the larger heading of Recommendation, Duration under Events, and Adverse reactions under Side effects. Events and Side effects were

themselves grouped into the category Fact, which contained all themes that described the context of the user's situation.

3.3.1 Extending Toulmin's Model Of Argument

Toulmin's original model had six argument elements to model the dialectical logic of every day arguments in 1958 [62], but researchers in a variety of fields have extended the model to used their needs. Likewise, in this work, some extensions to the TMA model were done to represent all the content in the JIA PEM in the TMA. The reasons why these extensions were needed and the extended model itself are outlined below.

During the iterative coding process, the original TMA was extended in five ways to capture content that would have otherwise been left out. All these extensions had been previously documented in argumentation literature as described in section 3.1. The four extensions were: 1) allowing an argument to have multiple warrants, 2) including the elaboration as an extra argument element, 3) allowing the claim of one argument to be another argument element in a different argument, 4) warrants were split into two types: explicit and implicit, 5) rebuttals we allowed to rebut argument elements other than the claim and were renamed exceptions. Examples of PEM content that required the extension of the model are described and explored below.

Extension 1: Previous scholars have shown that an argument can have multiple warrants that lead from the data to the claim [69]. Since, arguments in the PEM with more than one warrant, such as: *if a child is taking prednisone* (Data) *they should have their eyes checked regularly* (Claim) *because prednisone's side effects include glaucoma* (Warrant 1) *and cataracts* (Warrant 2), required that multiple warrants be allowed, we have extended the model to allow this.

Extension 2: Elaborations are an argument element which has been added to the TMA in prior research [68]. These classify the content of an argument which adds details to clarify the other elements. Images and text which added information to an argument element, such as definitions or figures, necessitated the inclusion of the elaboration argument element. An example of this is the following: *patients taking Ustekinumab* (Data) *very rarely* (Qualifier) *develop a rare brain problem called RPLS* (Claim) *whose symptoms may include: headache, seizures, confusion, and vision trouble* (Elaboration).

Extension 3: Information which acted, for example, as data in one argument could itself be the claim of another argument, conditional on their own data, qualifiers, and rebuttals. Expanding on the innovation that Claims could be Warrants of another argument [70], we allowed Claims to be any argument element of another argument other than the qualifier and backing. This is particularly useful when step-by-step directions are being given. In this example the claim of the first argument becomes the data of the second: 1) *If you are giving Subcutaneous Methotrexate* (Data) *then you will need: a disposable 1ml or 3ml syringe* (Claim), 2) *If you have disposable 1ml or 3ml syringe* (Data) *you should* (Qualifier) *next wash your hands* (Claim). This allows arguments to be chained together through their common elements, modelling the relationships between arguments as well as within them.

Extension 4: Warrants have been shown to be either explicit, i.e. directly stated, or implicit, i.e. inferred [77]. In our extended model, warrants were split into explicit and implicit warrants, as some PEM information would state the warrant while other would leave it unsaid.

Extension 5: Rebuttals have been shown to act against argument elements other than the claim [64]. In the PEM, arguments such as: *If using heat and your child's skin turns red* (Data), *although some pinking of the skin is normal* (Rebuttal), *then remove the heat source* (Claim) show that the rebuttal is referencing an element other than the claim, in this case the data. For this reason, we extended the model to allow rebuttals to act against all argument elements except for the backing and the qualifier.

In our model, we have renamed rebuttals as exceptions and use the terms 'supports' and 'excepts' to describe the relationship between data or exception respectively and the claim, to make clear that in the field of patient education these elements act as preconditions for the validity of the claim rather than its defenders and attackers. This is justified since the TMA is field-dependent, meaning that there are no standard rules for evaluating an argument [62], so the character of the elements of an argument are not fixed but change as per the needs of the domain [68]. This concept of field-dependency is relevant to this work as the content of PEM is different from that of other fields. PEM aim to communicate information which has been agreed upon by expert and/or evidence-based consensus in an understandable manner to healthcare users. Thus, while some domains need to use argument theory to evaluate the relative strengths between the data and rebuttals that try to defend or attack the claim, in patient education data elements describe scenarios where the claim has been shown or is agreed to be valid while rebuttals describe other situations where the claim is invalid. The final extended model of argument is shown in Figure 3.3.

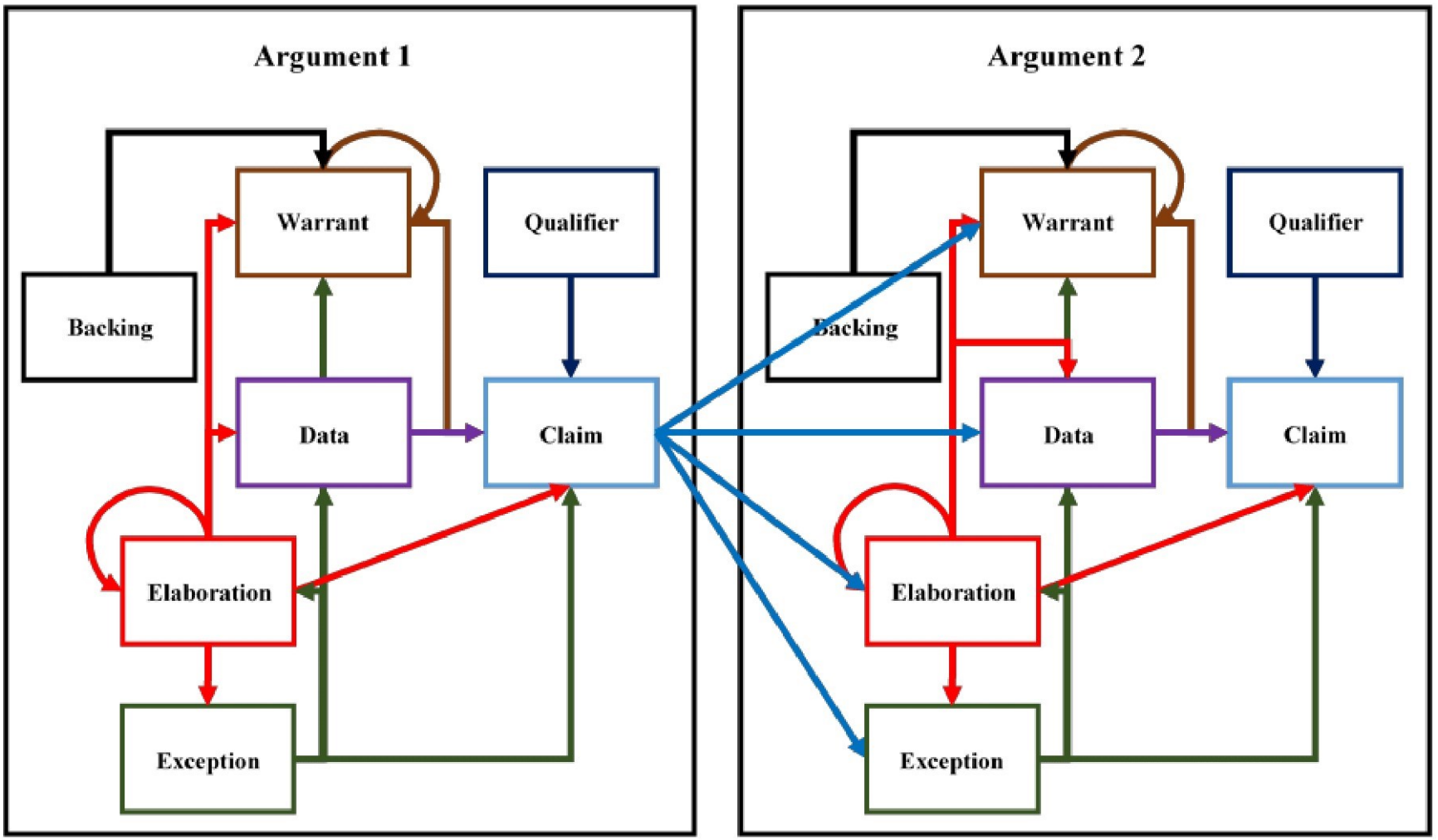


Figure 3.3: The extended model of argument used in the JADE system

The outcome of this step was that the PEM content was extracted and integrated into the Extended Model of Argument (EMA) with both thematic codes and argument elements represented. All the text and image content from the PEM was successfully represented in the EMA. Information from the two academic manuscripts was included only if deemed relevant. For example, information from the introduction and methods sections were excluded as FJIA were unlikely to be interested in this. Selections of text and images from the results, discussion, and conclusion were included if they were information deemed to be relevant to patient education and could be easily understood. In total, the 32 documents were represented in the TMA with 931 arguments. All arguments had a claim and a backing. 918 arguments had a data element, those without were largely definitions which did not need to describe a situation in which the claim held true. 400 had a qualifier, 214 had an explicit warrant, 106 had exceptions, and 235 had elaborations. Once the knowledge model was finalized and the information extracted from the included PEM, completing the Information Layer of the JADE system, it needed to be computerized as the Knowledge Layer.

3.5 Knowledge Formalization

The extended argument model and thematic coding from the knowledge modelling phase were represented in a high-level argument ontology using Protégé 5.0.0 (Stanford University, 2016) named the JADE ontology. The thematically coded arguments extracted from the PEM were then included in that ontology as instances of the argument model represented in the ontology.

Ontologies represent the concepts of a domain as classes, which exist in a hierarchy of super and subclasses. Individuals are instances of these concepts. Object properties are

the relationships between classes [79]. As an illustration, in the JADE ontology Claim is a subclass of the Argument Element class. An individual of the class Claim, for instance: *use heat for 10-15 minutes*, has the object property HasElaboration which links it to the relevant individual in the Elaboration class: *examples of heat sources: reheatable packs, hot water bottle, electric heating pad, wax bath, shower/bath*. The domain of an object property is the class(es) which is the starting point of the property, the range is the class(es) to which the domain is linked to by the object property [74]. In the last example, the domain of HasElaboration is the Claim while the range is the Elaboration. Data properties link classes to specific values [75], such as the property HasAuthor which links the Backing class to an author's name.

The Argument Model Ontology created by Vitali and Peroni had represented the TMA as an ontology and was used in this work as a guide [80]. The Argument Model Ontology has classes: argument, argumentation entity, backing, claim, evidence, qualifier, rebuttal, and warrant. The argument class represents the argument and is connected through objected properties to the argument elements it contains. The class argumentation entity is a superclass containing the argument elements. The remaining classes represent the argument elements of the TMA, although they use the term evidence instead of data. These classes are linked to each other through object properties as well. The object properties of the Argument Model Ontology along with their domains and ranges in Table 3.2, the inverse property, i.e. an object property which has the opposite domain and range of another, is shown in brackets.

Table 3.2: The domain and range of the Argument Model Ontology object properties

Domain	**Object Property**	**Range**
backing	backs (has backing)	warrant

Domain	Object Property	Range
qualifier	forces	claim
claim	is valid unless	rebuttal
warrant	leads to	claim
evidence	proves	claim
evidence	supports	warrant
argument	has claim (is claim in)	claim
argument	has evidence (is evidence in)	evidence
argument	has qualifier (is qualifier in)	qualifier
argument	has rebuttal (is rebuttal in)	rebuttal
argument	has warrant (is warrant in)	warrant
argument	has backing (is backing in)	backing

This ontology could only be used as a guide because as we had extended the model in step 3 and added thematic codes, hence, it was necessary to build on and change this ontology. The argument elements were encoded much as in the Argument Model Ontology with a few changes. Due to the extensions made to the TMA the class Elaboration was added and some of the classes and object properties, such as Rebuttal and 'has evidence', were renamed.

In the process of representing the argument model as an ontology, five challenges presented themselves: 1) what to choose as a unique identifier for each argument, 2) how to best represent the logical relationship between Data components, 3) how to represent the relationships between Argument Elements of different arguments, 4) whether the

HasBacking property should link the Backing to the Explicit Warrant, Implicit Warrant, or both, and 5) how to represent the queries users' can ask.

Challenge 1: Neither Claims nor Data are unique to an argument, as a specific instance of Data could lead to multiple Claims and a Claim could be another Argument Element in another argument. However, the Implicit Warrant, usually expressed as 'If Data then Claim' [77], would be unique for every argument. So, the Implicit Warrant became the class ArgumentAsRepresentedByImplicitWarrant and has the object property HasElement which links it to all the argument elements in an argument instance.

Challenge 2: Originally, it was thought that the entry point of an argument would be through the Data element. So, some thought was spent on how to model the 'and' and 'or' relationships between Data instances in an argument. For example, in the argument: *If using ice and child's skin goes numb or their skin becomes pale or child feels pain or is shivering* (Data) *then stop the treatment* (Claim) the Data has several components linked together by logic that is particular to this instance. Other arguments have different numbers of components and the logic between them is likely different. As this is different between instances of the same class, Data, the logical relationships could not be modelled using object properties. It could be modelled using rules, but the large volume of content needing individual rules made this solution infeasible. Thus, it was decided not to model the logical relationships between Data components and rely on the content themes to link user questions to relevant arguments.

Challenge 3: Sometimes an Argument Element in one argument is an element in another argument. For example, the exception in: *There is no cure for JIA* (Claim) *although there are medications that can reduce the inflammation and relieve the pain and swelling*

(Exception), is the Claim of another argument. While TMA models the many relationships between elements of the same argument is has no link between arguments of different elements. In the JADE ontology, the sameAs object property has been reused to link the two elements of different arguments that contain the same content.

Challenge 4: According to the TMA the Backing element is linked to the Warrant. As only some arguments in the ontology have explicit warrants but all have implicit warrants, represented as the class ArgumentAsRepresentedByImplicitWarrant, the Backing was linked to the implicit warrant through the object property HasBacking.

Challenge 5: Queries, to serve as the basis for the information-seeking dialogue, were instantiated into the ontology using class expressions. The queries were generated inductively from the information contained in the PEM and phrased in a manner that a member of an FJIA might deem interesting. The class expressions attempt to translate the English question into a syntax the ontology reasoner can understand [81]. For example, the question: *What are the side effects of methotrexate?* is expressed as the class expression:

(HasTheme some 'Side effects') and
(IsElementOf some (HasElement some (HasTheme value Methotrexate))).

This tells the reasoner to: find an instance that has a theme which is a type of side effect and is part of an argument in which an argument element has the theme Methotrexate. The ontology reasoner can use this statement to find responses such as: *methotrexate may cause inflammation or damage to the liver*. The class expressions were all written in the format of looking for one theme, or class of themes, in an instance that describes the topic of the query and one or more themes, or classes of themes, present in the argument the

instance belongs to that describe its context. In the previous example the topic theme is side effects and the context is Methotrexate.

Initially the structure of the question was linked to a specific argument element. For example, that 'why' questions, such as *'Why is blood work needed when taking methotrexate?'*, could be answered by the Warrant of a thematically relevant argument. However, that same question could be written as *'What are the reasons for needing bloodwork when taking methotrexate?'*. So, given the complexities of English grammar there was no way to reliably link the structure of the question to an argument element, and thematic content must be solely relied on.

The resulting ontology has a class hierarchy which is shown in Figure 3.4. The four super classes in the JADE ontology are:

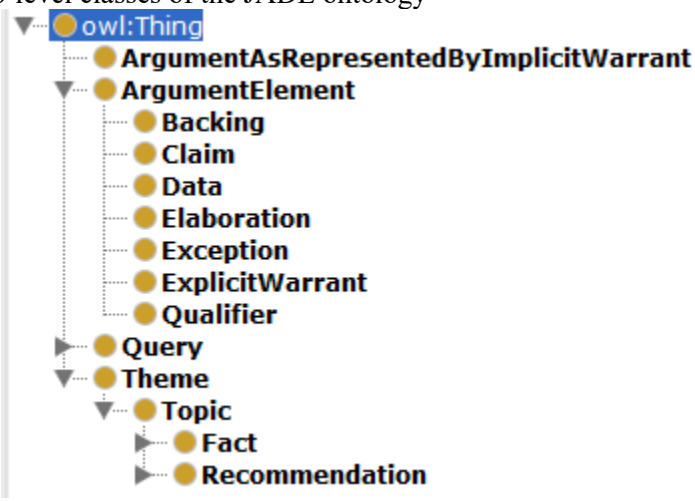
1) ArgumentAsRepresentedByImplicitWarrant: This class represents the arguments which were abstracted from the JIA PEM. Each argument has its own instance of this class. While the implicit warrant is an argument element, this class was not represented as such in the JADE ontology since it represents the argument as a whole and so cannot logically be a subclass of argument element and because the implicit warrant does not add any information to the argument which the data and claim do not already provide. This class was linked to the Backing class through the object property HasBacking as discussed in Challenge 4. It was linked to the other 6 argument elements of the EMA through the object property HasElement. While the Argument Model Ontology had individual object properties linking each argument element to the argument class, i.e. "has claim" and "has exception", we have simplified these to the HasElement property in the JADE

ontology as the specific relationships can be determined through reasoning based on the class and intra-argument object properties such as Warrants and Excepts. The object properties as well as their domain and range can be seen in Table 3.3.

2) ArgumentElement: This class represents the 7 elements of the EMA, which were represented individually as subclasses of it. Intra-argument relationships were encoded using object properties as shown in Table 3.3. Inter-argument links, i.e. where a claim acts as another argument element in a different argument, are represented using the sameAs property as described in Challenge 3. PEM content which had been coded into argument element classifications, was encoded as instances of the relevant element. For example, the argument: *If using heat and your child's skin turns red* (Data), *although some pinking of the skin is normal* (Exception), *then remove the heat source* (Claim) from the pamphlet "Using Ice and Heat at Home" (Backing) was represented in the JADE ontology as five instances: an instance of the Claim class, Data class, Exception class, Backing class, and one instance of the ArgumentAsRepresentedByImplicitWarrant class.
3) Theme: This class represents the thematic codes created during the Knowledge Modelling step. The codes are represented using a hierarchy of subclasses with the leaf codes as instances. For instance, the theme "Liver damage" is an instance of the class "Side effects" which is a subclass of the class "Fact". The instances are linked to the argument elements they had been coded to via the object property DefinesThematically.
4) Query: This class represents the questions a user might have, as discussed above in Challenge 5. Individual questions were represented as subclasses of the Query

class and each were defined with a class expression. The class expression uses the thematic codes represented in the JADE ontology and the reasoner to locate argument elements relevant to the question.

Figure 3.4: The top-level classes of the JADE ontology



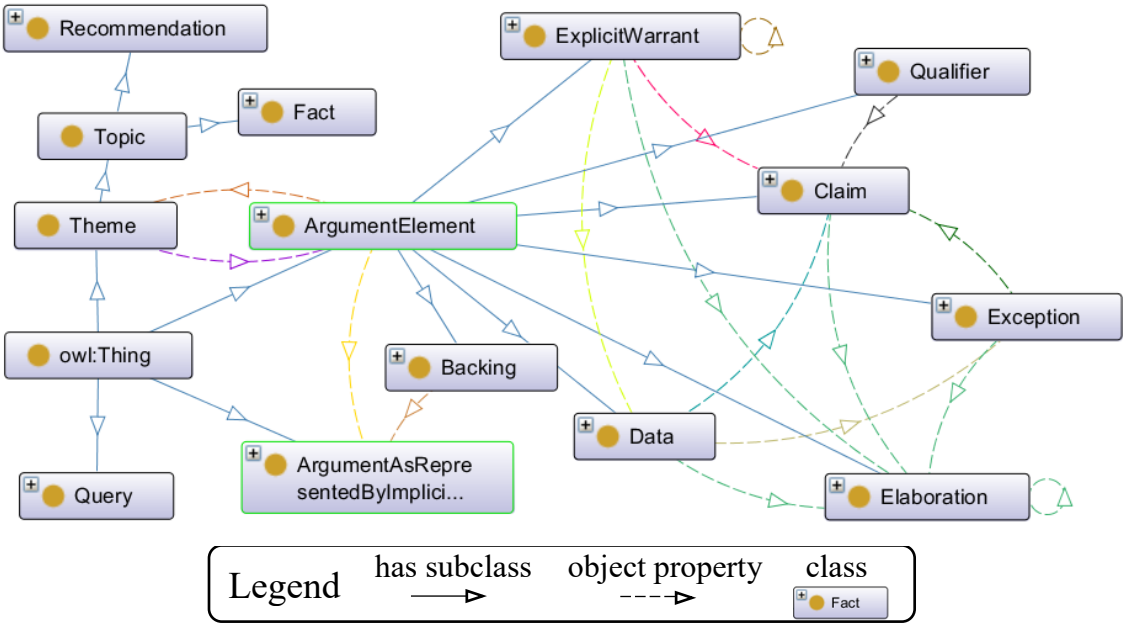
A full list of the object properties of the JADE ontology along with their domains and ranges is shown in Table 3.3. As well, a visualization of the top-level classes and their object property links is shown in Figure 3.5.

Table 3.3: The domain and range of the JADE ontology object properties

Domain	Object Property	Range
Theme	DefinesThematically (HasTheme)	ArgumentElement
ArgumentElement	IsElementOf (HasElement)	ArgumentAsRespresentedByImplicitWarrant
Backing	Backs (HasBacking)	ArgumentAsRespresentedByImplicitWarrant
Elaboration	Elaborates (HasElaboration)	ExplicitWarrant, Data, Claim, Exception, Elaboration
Exception	Excepts (HasException)	Claim, Data, ExplicitWarrant, Elaboration
Qualifier	Qualifies (HasQualification)	Claim

Domain	Object Property	Range
ExplicitWarrant	Requires (HasRequirement)	Data
Data	Supports (HasSupport)	Claim
ExplicitWarrant	Warrants (HasWarrant)	Claim
ExplicitWarrant	HasAdditionalWarrant	ExplicitWarrant
Claim	sameAs	ArgumentElement

Figure 3.5: Visualization of the JADE ontology



The PEM content that had been coded into Excel as individual argument elements was encoded in the JADE ontology as instances of the relevant argument element class and linked to the other elements in their argument through the relevant object properties. There are five Data properties used in the JADE ontology, which are used in two circumstances. The first is to link details about the Backing document such as the author's name, the date it was published, the name of the document, and source that published the document through the properties HasAuthor, HasDate, HasName, and

HasSource respectively. The second is to link image files, such as photos, graphs and charts, or original documents, to an ArgumentElement through the property HasImage.

To date, 351 of the 931 arguments of PEM content have been successfully represented as argument element instances in the JADE ontology. These 351 arguments were selected as they were directly relevant or adjacent to topics covered in the scenarios used in the evaluation step, which will be described in more detail below. They represent 8 of the 32 documents, including the two academic papers, they include text, links, lists, tables and images, and contain multiple examples of all the argument elements. Thirteen of the 16 subjects contained in the PEM are covered by this selection, as are 5/6 of the structures, namely handouts, academic articles, a business card, a pamphlet, and a brochure. The remaining arguments will be instantiated, but due to time constraints these were prioritized. Given that the extended TMA model and the thematic codes have been represented in the ontology and a representative sample of the arguments have already been instantiated into it without issues, there is no reason to believe there will be any issues in instantiating the remaining arguments.

3.6 Knowledge Translation – The JADE Patient Education System

Having completed the Information and Knowledge Layers, the Operational Layer was implemented as a web-based dialogue system for FJIA to engage with PEM at their convenience. The plan was to allow users to enter the network of argument instances contained in the JADE ontology by choosing from the queries encoded there. The queries would allow a semantic reasoner to locate argument elements equivalent to the Query class expression using the thematic coding. The user could then explore the connected information by following the structure of the extended TMA.

The JADE system dialogue manager was designed with three functionalities: 1) a question filtering functionality to allow users to find which of the 162 queries currently encoded in the JADE ontology is most relevant to them, 2) an information-seeking dialogue functionality to provide users with answers to their questions, and 3) an inquiry dialogue functionality to allow users to question and examine the PEM content. The latter two functionalities create the two types of dialogue relevant to patient education and were a key requirement based on the needs of FJIA. The first functionality facilitates access to the PEM content in the JADE ontology through helping find the Query most relevant to the family. An overview of the three functionalities can be seen in the transition diagram displayed in Figure 3.6.

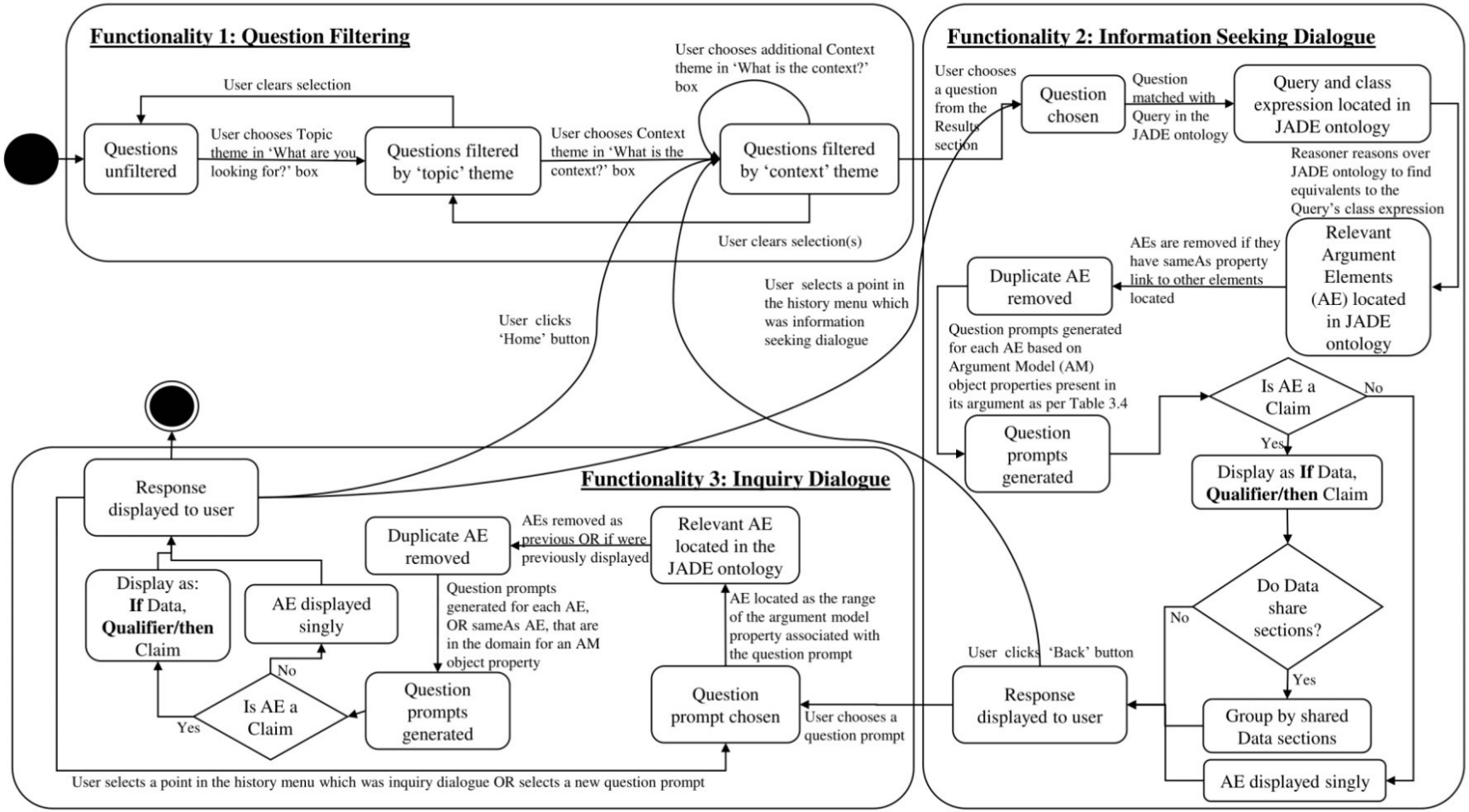


Figure 3.6: Transition diagram of the JADE system dialogue manager's 3 functionalities

Functionality 1: The question filtering functionality was designed to allow users to find the queries, which were encoded in the JADE ontology during the Knowledge Formalization step, that are relevant to them. The JADE system search page has four sections: 1) a welcome and instructional message, 2) a list of themes under the question: *What are you looking for?*, 3) a second list of themes under the question: *What is the context?*, and 4) a results section where available queries are available in a dropdown menu as seen in Figure 3.7. The user is prompted by the instructional message to first choose from the list of themes to answer the prompt: *What are you looking for?*. By clicking on a theme, the queries are filtered to show in the results section only those that have that selection as their topic theme, as defined in section 3.4. As well, the themes in the *What is the context?* section are filtered to show only the context themes, also defined in section 3.4, that are part of query class expressions with the chosen topic theme. By choosing as many of these as needed the user can further filter the queries in the results section. The number of potential questions is displayed in the Results section along with a description of what the user is searching for, for example: ***Looking for:*** *Side effects* ***about*** *Corticosteroids*. This allows users to see how effective their filtering parameters are as well as allowing them to see if the parameters are what they expected them to be. By clicking on the 'clear selection' button the user can start choosing new themes from scratch. Finally, choosing a query from the dropdown menu in the results section begins the information-seeking dialogue.

To explain how this is technically accomplished we will use the following example:

User: [Chooses Recommendation in What are you looking for? box]

JADE: [Reduces dropdown menu questions and displays a list of possible themes in the 'What is the context?' box, the number 56 next to the Results header, and the word *Recommendation* in the 'Looking for:' section]

Each question in the Results dropdown menu is linked to a Query subclass in the JADE ontology. The JADE interface filters them by which contain the topic theme chosen by the user, in this case Recommendation, yielding 56 questions. The context themes of these 56 Queries are listed in the JADE ontology hierarchy in the 'What is the context?' box. The number of questions remaining, in this case 56, is displayed next to the Results header to let the user know how effective their filtering activities have been. The Looking for: section is updated to: ***Looking for:*** *Recommendation*, so users can keep track of what themes they are filtering the questions by.

User: [Chooses Methotrexate and 'Drinking alcohol' in the 'What is the context?' box]

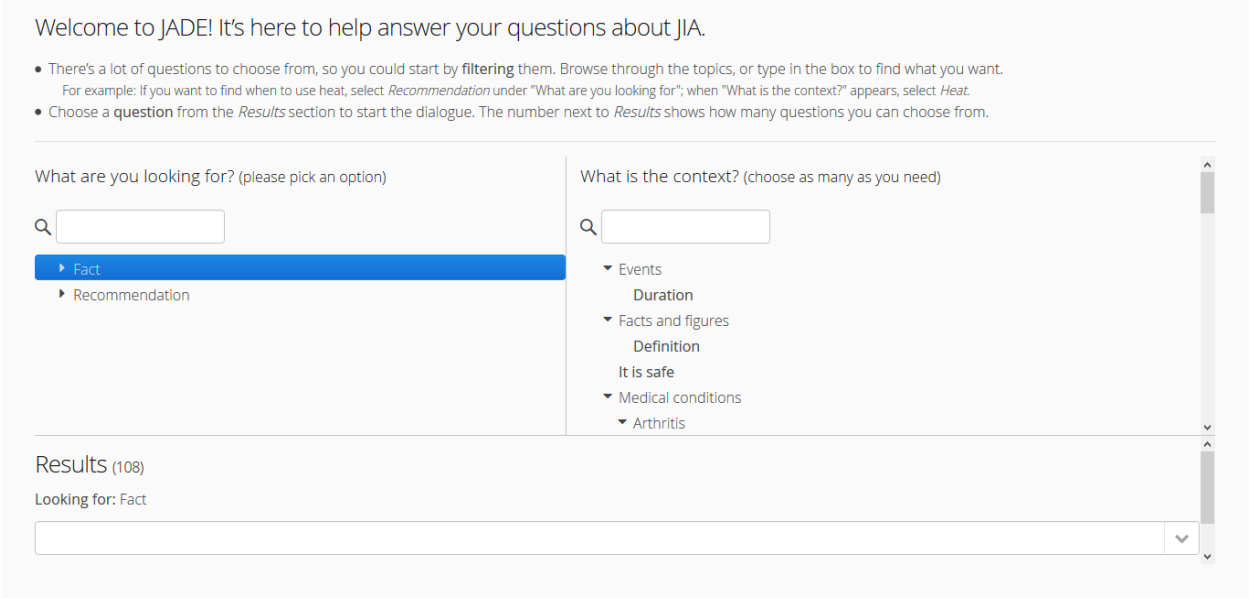
JADE: [Reduces dropdown menu queries to those including the topic and context theme(s), displays the number of potential questions next to 'Results', and displays *Recommendation about Methotrexate and Drinking alcohol* in the 'Looking for:' section]

The JADE interface further filters the previous 56 questions by which context theme(s) are chosen by the user, in this case Methotrexate and Drinking alcohol. The filtering yields 1 question: *Can I drink alcohol while taking methotrexate?*. This number is displayed next to the Results header and the Looking for: section is updated to ***Looking***

for: *Recommendation* ***about*** *Methotrexate* ***and*** *Drinking alcohol*. The user can now choose that question to move into the second functionality.

Functionality 2: The information-seeking dialogue functionality allows users to access the interconnected web of argument elements contained in the JADE ontology by finding argument element(s) which are relevant to the topic they are interested in. The JADE system matches the thematic content of a user's chosen query to argument element(s) with the same thematic content using the class expressions of the queries, which were created during the Knowledge Formalization step.

Figure 3.7: Screenshot of the search page of the JADE system - Welcome message and instructions at the top, Topic theme selection middle left, Context theme selection middle right, and Results section at the bottom.



The argument elements located by the chosen query are then displayed. Several design decisions were required about how to display these. First, a Claim is displayed with its Qualifier and Data to give enough context so that the Claim can be properly interpreted. For example, the Claim: *can cause a serious lung problem* means very little without its Data: *taking methotrexate* and is easily misinterpreted without the Qualifier: *it rarely*.

Thus, it was decided to display a Claim as: If Data, Qualifier (or the word 'then' if there was no Qualifier) Claim, which using the previous example reads: ***If*** *taking methotrexate,* ***it rarely*** *can cause a serious lung problem*. Second, if multiple arguments are to be displayed they are grouped by those that share the same Data to make reading easier and less repetitive. Finally, the qualifiers and logical modifiers, such as if and the Qualifier in the example above, were bolded to give each argument a similar structure, which aims to make them easier to read. Similarly, the words 'and' and 'or' present in the Data element have been highlighted with blue coloured text to draw the reader's attention to the logical flow of the argument and hopefully improve comprehension. An example of an information-seeking dialogue response from the JADE system can be seen in Figure 3.8.

Our example continues, demonstrating the way functionality 2 is accomplished:

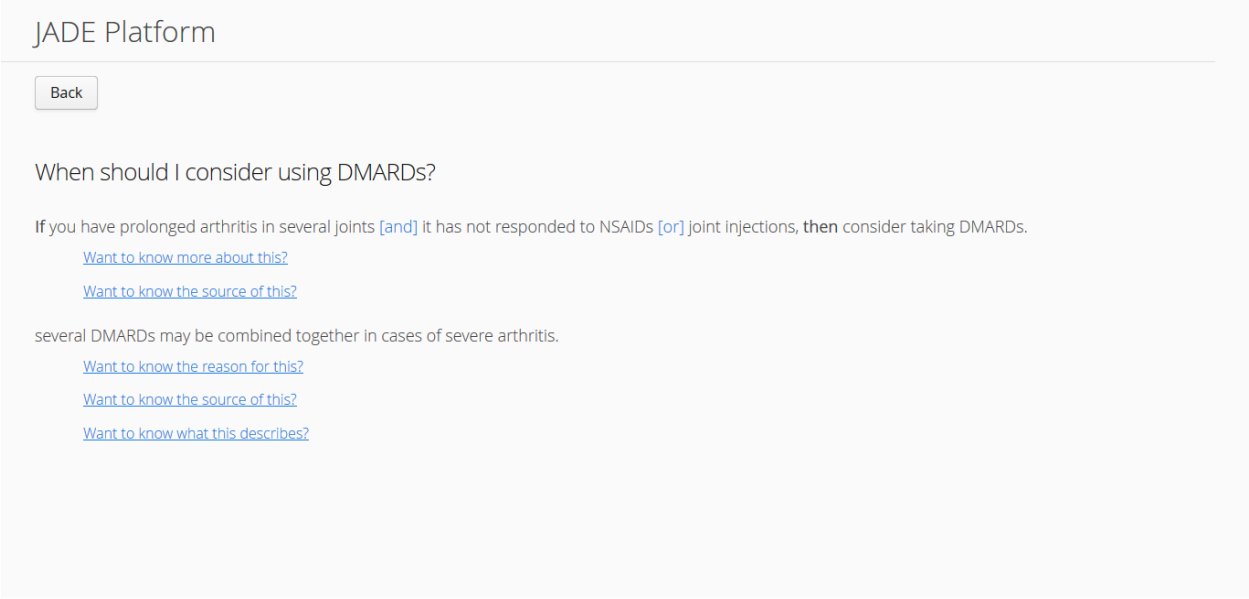
> User: Can I drink alcohol while taking methotrexate?
>
> JADE: **If** taking methotrexate, **then** it is best to avoid alcohol.
>
> Want to know the reason for this?
>
> Want to know the source of this?

The question chosen by the user is represented in the JADE ontology as the Query subclass: CanIDrinkAlcoholWhileTakingMethotrexate?, which is equivalent to the class expression:

> (HasTheme some Recommendation) and
> (IsElementOf some (HasElement some (HasTheme value 'Drinking alcohol'))) and (IsElementOf some (HasElement some (HasTheme value Methotrexate)))

The reasoner searches the ontology for instances which have a theme that is a type of recommendation and is part of an argument where argument elements have the themes Drinking alcohol and Methotrexate. It finds one relevant argument element which is the Claim: *it is best to avoid alcohol*. The argument, that the Claim is an element of, also has an ExplicitWarrant and a Backing, so the question prompts 'Want to know the reason for this?' and 'Want to know the source of this?' are generated. Since the argument element identified is a Claim, it will be displayed in the format: **If** Data, **Qualifier/then** Claim. Since this Claim has no Qualifier but does have the Data: *taking methotrexate*, it is displayed, as above, along with its question prompts.

Figure 3.8: Screenshot of the JADE system's response during an information-seeking dialogue - 'Back' button at the top, the user's selected question followed by JADE's response and suggested question prompts.



Functionality 3: The inquiry dialogue functionality leverages the object properties of the JADE ontology relating to the relationships between argument elements to create question prompts the user could use to find and verify information from the PEM. Each relationship has its own question prompt, as depicted in Table 3.4, and clicking on the

prompt would bring the user from the domain of the object property to the range. These prompts were generated for properties present within the same argument and for those in other arguments that the element currently being viewed shared the sameAs property with. Additionally, to help users keep track of where they were in the discussion a history of the question prompts they had followed was kept and the last three were displayed in a history bar on the UI. Thus, users could move forward through the chain of argument elements, or back to choose a different path. The JADE system's response from an inquiry dialogue are shown in Figure 3.9.

Figure 3.9: Screenshot of the JADE system's response during an information-seeking dialogue - 'Back' button at the top, the user's selected question followed by JADE's response and suggested question prompts.

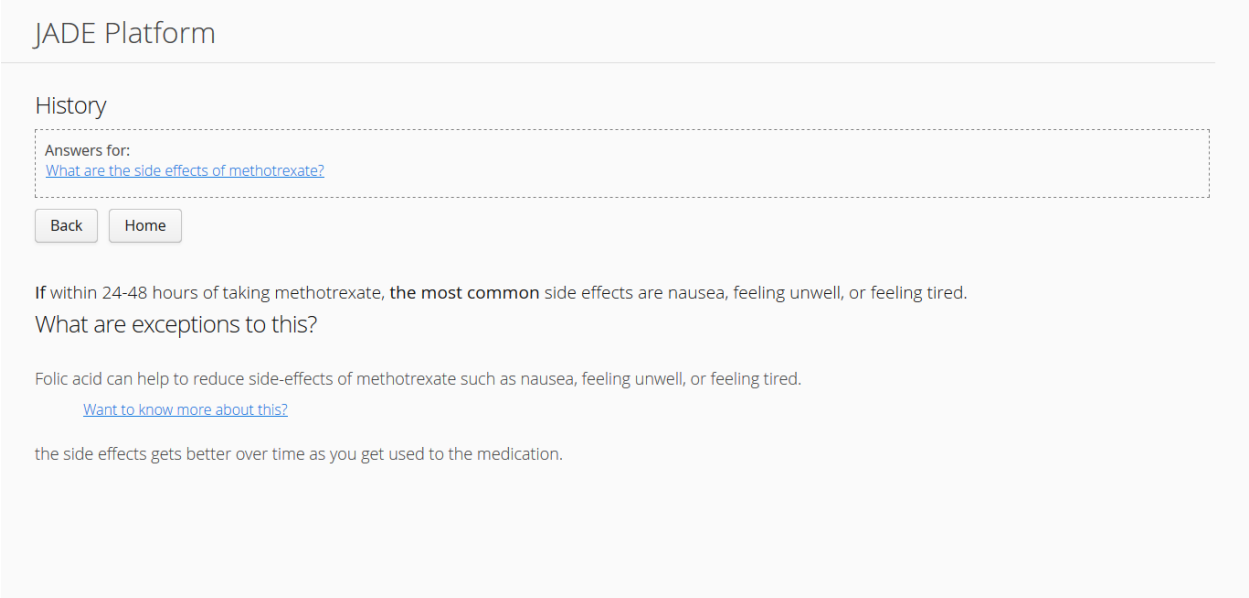


Table 3.4: Relationship of question prompts to EMA object properties

Object Property	Question Prompt
HasWarrant	Want to know the reason for this?
HasException	Want to know an exception to this?
HasElaboration	Want to know more information about this?
HasBacking	Want to know the source of this?
Warrants	Want to know what information this explains?

Object Property	Question Prompt
Excepts	Want to know what information this is an exception to?
Elaborates	Want to know what information this describes?

Continuing with the example, we show the process behind functionality 3:

> User: I want to know the reason for this?
>
> JADE: taking methotrexate and drinking alcohol could harm your liver.
>
> Want to know the reason for this?

The question prompt chosen is linked to the object property HasWarrant. The range of the object property HasWarrant, which has the previous Claim as its domain, is the ExplicitWarrant: *taking methotrexate and drinking alcohol could harm your liver*. As this argument element is not a Claim it is displayed by itself. This ExplicitWarrant is the domain of two object properties: HasSupport and Warrants, the range of which are, respectively, the Data and Claim displayed during the information-seeking dialogue above. Since they have already been viewed, they are removed to avoid looping. However, this ExplicitWarrant is sameAs a Claim from another argument which has the object property HasWarrant. Thus, one question prompt is generated for this property and not for the two from the same argument that were removed.

The main limitation of the JADE system from a design perspective is that there is no natural language processing or keyword identification component to the system which means that it does not allow free text or speech as inputs as some of the other dialogue systems did. This has the biggest impact during the question filtering process. The two

dialogue types both have question prompts to facilitate engagement with the system, but the question filtering requires the user to search out the keywords themselves and position them in a grammar of topic and context which is not intuitive. However, as this functionality is not the primary focus of the work it will serve as a placeholder for the moment. As well, the PEM has not been fully instantiated yet, which means that the knowledge base is not complete, but it is enough to test whether the system provides adequate responses. The process of instantiation is time consuming and requires a detailed knowledge of the extended model of argument and the thematic coding scheme as well as how to use Protégé. This limits the generalizability of these methods since updates and additions to the knowledge base would need to be made by someone with these skills and knowledge.

3.7 Evaluation Study

This final step assessed whether the JADE system could deliver appropriate information based on the user's queries. Using the framework for evaluating interactive applications developed by O'Grady et al. the major parameters of content measurement are: 1) Quality: the accuracy of the content, 2) Credibility: how trustworthy the presentation of the content is, 3) Utility which is composed of three sub-parameters a) Completeness: whether any content is missing, b) Relevance: the applicability of the content to the user or query, and c) Understandability: readability, explanation of medical terms etc. [82].

3.7.1 Research Objective

To assess the content Quality, Credibility, and Utility of JADE's responses to user's questions.

3.7.2 Study Design

This study used a Cognitive Walkthrough (CW) and Semi-Structured Interview (SSI) to address the research objective. CW is an evaluation technique commonly used to assess the usability of a product. The CW method involves users verbalizing their thoughts as they interact with the product in question, usually guided by a set of tasks or scenarios. Participants' interactions with the system are then recorded [83]. It is especially effective during the design phase of a product, with prototypes, and when there are no formal users, as in the situation with the JADE system [83]. The SSI will act to debrief the CW; encapsulating the entire experience of using the JADE system. Use of a semi-structured format is ideal as it allows for participant's responses to be conceptually similar enough for comparison purposes, while leaving enough flexibility to allow for the expression of concepts specific to the individual scenario or participant [84].

3.7.3 Participants

We planned to recruit 2-3 Pediatric Rheumatologists (PRs) and 3-5 Allied Health Professionals (AHPs), such as nurses, physiotherapists, occupational therapists and social workers, from the Division of Pediatric Rheumatology at the IWK Health Centre. This population was targeted for their expert domain knowledge of JIA and familiarity with the PEM used in creating the JADE system, both of which are required by the target population's profession.

The sample size should be determined by the point of saturation in a qualitative study, i.e. that adding a new participant does not add any new information. Since saturation cannot be pre-determined, we used a concept called Information Power (IP), a guideline of four concepts used to estimate the sample size needed to reach saturation [84]. These four concepts are 1) Study Aim, a broader aim requires a larger sample size, 2) Sample

Specificity, the specificity of knowledge of the sample population to the study aim, 3) Quality of Dialogue, the quality of interaction expected between researcher and participants, and 4) Analysis Strategy, the diversity of experience the study aims to describe [84]. Our study had a narrow aim, looking only at the content generated by the JADE system, not its full usability and other functionalities. Our sample was highly specific to this aim, we purposefully chose a sample which has a high degree of knowledge and experience in the content we wished to assess. The Quality of Dialogue was expected to be high, as the author had 2 years of experience working in the Rheumatology Clinic as a research assistant at the time. This was expected to lead to an already established rapport with the participants and some domain knowledge so that participants didn't have explain basic concepts to the interviewer. Finally, we created the use cases studied in the analysis which limited the diversity of experience we studied. All these factors pointed us towards a smaller sample size while still being able to ensure sufficiently high IP. Faulkner sets the sample size range in studies such as this between 5 and 50 [85]. Therefore, as per Information Power we should be in the lower end of that range, we have chosen a sample size of 5-8 participants. This study was approved by the IWK Research Ethics Board (file number: 1023261).

3.7.4 Materials

Scenarios for the CW (Appendix C) as well as an SSI guide were developed focused on the content acceptability of the JADE system. The scenarios were developed to represent the variability across four variables: 1) use cases for the JADE system, 2) thematic content of the PEM, 3) JADE system functionalities, and 4) participant expertise and experience.

The three scenarios were developed to represent the three most important use cases for the JADE system. According to Wright et al. the caregivers of children with JIA seek information about JIA at two key time points in disease course: at diagnosis and at medication change. Adolescents on the other hand seek information about symptom control [13]. An effort was made to include different thematic content from the PEM in each scenario. The first scenario focused on diagnostic tests, etiology, and the associated conditions of JIA, the second on medications, side effects, and drug-drug interactions, and the third on symptoms, non-medicinal treatments, and treatment delivery methods. Since the JADE system offers both information-seeking and inquiry dialogues each scenario contains at least one question testing each of these.

The scenarios were assigned to participant groups to reflect the skills, abilities and experiences of the groups. Pediatric rheumatologists were assigned the scenario at the time of medication change, as they would do most of the family counselling at this time point. Nurses were given the scenario at the time of diagnosis, as they have teaching sessions with the families at that time point. Finally, the other AHPs (Physiotherapists, Occupational Therapists and Social Workers) were assigned the symptom management and impact scenario as this often falls within their professional scope.

3.7.5 Procedure

Potential participants were approached in person by the author at the IWK Pediatric Rheumatology Clinic. The informed consent process was performed by the author using a written informed consent form. This was done before the research took place. Potential participants were given the opportunity to read the form, while the author

pointed out important information. They then had a chance to ask questions of the author and choose whether to take part or not.

Demographic data on the participants was gathered using a survey (see Appendix D). This data was needed to give context to the study and allow readers to determine whether the results would be transferable to their own setting. This data was only reported in aggregate so that no individual could be identified by it. During the CW, participants had an interaction with JADE, asking the system questions based on a clinical scenario that was given to participants (see Appendix C). Participants will be encouraged to "think out loud" while asking each question and reading JADE's response. After completing the scenario, participants took part in a brief SSI to give an overview on the details elicited in the CW. The interview guide consists of the five questions outlined below:

1) Was the information provided relevant to your question?

2) Was the information provided complete?

3) Was the information provided accurate?

4) How credible did you find the information provided?

5) How understandable did you find the information provided?

Each question intended to address both the initial response to the question, i.e. the information-seeking dialogue, and the further exploration of the PEM content, i.e. the inquiry dialogue. The interviewer prompted the participants if their answer did not encompass both. This process was conducted at the time and place of the participant's

choosing. Screen capture video and audio of participants' responses to the CW and the SSI was recorded.

3.7.6 Analysis

The screen capture video and audio files of the CW and SSI were analyzed using a combined inductive and deductive thematic analysis. Deductively, Directed Content Analysis was applied using the parameters from the O'Grady framework as predetermined codes [86]. Sub-themes within those categories and data not encapsulated by them were coded using inductively generated themes driven by the data using grounded theory [78]. This combination of inductive and deductive methods aims to keep the analysis focused on the research objective without losing any information participants provide about the wider context which may indirectly impact that objective. Coding of the CW and SSI results was performed by the author using Observer XT software (Noldus, 2017).

CHAPTER 4.0 RESULTS

Five clinicians participated in the evaluation study. Four were nurses and AHPs, while one was a PR. Two had less than 5 years of experience working in the Pediatric Rheumatology division, two had between 11 and 20 years of experience, and one had more than 20 years of experience. Four spent more than 0.75 FTE working in the clinic and one spent 0.5 FTE. Three claimed to be very comfortable with computers while two were moderately uncomfortable. Two reported that approximately 80% of their clinical encounters involved using PEM, one reported 75%, one reported between 25-40%, and one reported approximately 10%. The CW and SSI were conducted for an average of 24 minutes (range: 16-28 minutes).

Eight major themes were identified during content analysis. Themes were determined to be major if 40% or more of participants had responses which were categorized under that code. Saturation was achieved, as evidenced by the fact that no new codes were added after the third CW and SSI. The major themes were: 1) Positive responses to the JADE system, 2) Content was largely accurate; however, PEM may contain some inaccuracies, 3) Content was credible but could be improved through better presentation, 4) Most of the information provided was relevant, however, there were a few irrelevant responses, 5) Content was mostly complete, although there were exceptions, 6) Individual responses were understandable, but organization of the content was lacking, 7) Awkward wording and spelling mistakes occasionally made things unclear, and 8) Accessibility issues of the JADE system. An examination of these themes and their sub-themes are detailed below. Quotations are attributed to a participant number and information has been added by the author to the quotes in square brackets to give the reader context to what was being

shown by the JADE system when the participants made their comments. The parameter(s) from the O'Grady framework relevant to each theme are listed after them in brackets.

Theme 1: Positive responses to the JADE system (relevant O'Grady parameters: N/A)

All the participants were very supportive of the JADE system and giving FJIA a more flexible education tool to learn about the condition. They were impressed by the functionalities provided by the JADE system and thought they would stimulate learning.

> Participant 3: *I like the idea; the idea is great!*
>
> Participant 5: *I'm super interested in clicking on stuff. It's cool. It's funny how you just want to know more, want to know more, and all this info comes out.*

Theme 2: Content was largely accurate; however, PEM may contain some inaccuracies (relevant O'Grady parameters: Content Quality)

Overall, the participants agreed that the information provided by the JADE system was accurate, largely because it was derived from the PEM already approved and used by the clinic.

> Participant 4: *[There was] nothing that was incorrect.*
>
> Participant 3: *As far as the content goes, it's all from our pamphlets so it's going to be pretty accurate.*

However, a few pointed out that some of the information contained in the PEM was dated or lacked nuance. This level of nuance may not be necessary for families to self-manage JIA as suggested in the second quote or could lead to misunderstandings as described in the third and fourth quotes.

> Participant 3: *RheumInfo 2011, yikes, that'll be from before some of these kids were born.*

> Participant 3: *The reason that [methotrexate] causes immunosuppression is at the level of how the [white blood] cells actually work not necessarily by their [decrease in] numbers…which might be a subtlety that isn't that important.*
>
> Participant 5: *It's true that if there's pain and swelling from an inflamed joint that you would use cold, but it's different from an arthritis point of view though…If I were Jamie I'd be like "don't use heat I have an inflamed joint" when really from an arthritis point of view, we probably could be...there is evidence out there that says that heat would work better.*
>
> Participant 5: *[Exercise] should be done as prescribed to be effective, which to be fair is often daily, but not always.*

Theme 3: Content was credible but could be improved through better presentation

(relevant O'Grady parameters: Content Credibility)

Most participants thought that having question prompts about the sources of the material made the information provided by the JADE system more trustworthy.

> Participant 4: *Having the parameters where you can click into the sources is helpful.*
>
> Participant 1: *[Having links to the sources] is going to be really helpful. I know that book.*
>
> Participant 5: *I like that you had sources for each of them, so it wasn't like you just pulled this out of thin air. I know a lot of people would be very interested in making sure there is something [backing the information up] whether they click it or not.*

However, one participant pointed out that not all the argument elements displayed had the question prompts during the inquiry dialogue.

> Participant 5: *If I clicked a "tell me more about this' or 'what are the exceptions' they didn't always have sources for that part of it. If I read something I was really questioning, then I'd probably want to know where that came from.*

Additionally, two participants suggested that the sources would make the information more credible if they were displayed alongside the argument element they related to.

> Participant 3: *[Why did you have] the information and click on this to see the source rather than essentially referencing in smaller text your source all the time, which would kind of skip that step and also say this wasn't just made up by some guy, this came from the Arthritis Society.*
>
> Participant 4: *Saying what the source is would be helpful…* Moderator: *For showing where the sources come from do you mean in a more immediate way rather than having to click through to it?* Participant 4: *Yes, right…maybe on the first page.*

Finally, a couple of the participants suggested that improving the visual display of the JADE system would lend it more credibility.

> Participant 4: *Any organizations or any support organizations that collaborated with you I think also increases credibility. For instance, if you have an IWK logo…for whatever reason that tends to increase folk's credibility.*
>
> Participant 3: *The truth is when it's in a little professional document it almost feels as though it's probably more credible, despite the fact that any idiot with a computer could write whatever they wanted. But because it's in a PDF format that looks like it was belonging to this organization or that organization it does feel different than just the straight up text.*

Theme 4: Most of the information provided was relevant, although there were a few irrelevant responses (relevant O'Grady parameters: Content Utility)

Most of the information provided to the participants was deemed relevant by them.

> Participant 4: *I think it's really relevant to what the patients and families are experiencing.*
>
> Participant 2: *What I saw was relevant, it's to the point, it answers the questions very succinctly.*
>
> Participant 5: *I didn't get anything from out in left field.*

Sometimes, the information provided had some connection to the question being asked but that relevance would not be apparent to a non-expert. Further examination, by clicking the question prompts, would reveal the connection but initially the answer looked irrelevant.

> Participant 2: *I'd want to know what's the significance of being ANA positive or negative. How being positive effects the frequency of my eye exam.*
>
> Participant 5: *For the rheumatoid nodules and anemia they kind of fit in because they are side effects but that's not clear…Some of it is a bit tangential… I feel like I kind of get into a rabbit hole.*

However, three of the JADE system's answers were irrelevant and further inquiry, by clicking on the question prompts, did not reveal their connection to the question.

> Participant 3: *[Recommending methotrexate be taken on a Friday or Saturday] is not even a side effect, it's a mitigation of the fact that it might make you nauseated…This is a useful piece of information but not part of the side effects.*
>
> Participant 5: *I feel like [the definition of anemia] wouldn't have answered my question [Want to know more about rheumatoid nodules?].*
>
> Participant 5: *Interesting, because I clicked on [a question about] 'ice' and then it starts talking about 'heat' [when I click on a question prompt].*

Theme 5: Content was mostly complete, although there were exceptions (relevant O'Grady parameters: Content Utility)

Mostly, the information provided by the JADE system was deemed complete by the participants.

> Moderator: *Was there information that you thought should be there that wasn't?* Participant 1: *No, I don't think so.*
>
> Participant 3: *I think they are fine within the constraints of our patient materials.*
>
> Moderator: *Does that answer what you were looking for?* Participant 4: *Yes, it absolutely does.*
>
> Moderator: *Was the information provided complete?* Participant 5: *Eventually, with clicking…As you continued to 'want to know more about it' I think you did get all the information.*

On the occasion that there was missing content, it was sometimes attributed to gaps in the PEM.

> Participant 3: *There's going to be places where there are gaps because our patient materials have gaps. And if you've perfectly represented every piece of*

information that's there, there's going to be a bunch of questions people would ask that are either poorly answered, or not answered at all.

Participant 4: *That identifies gaps in the patient education materials. There isn't a lot on the psychological or psychosocial impacts.*

At other times the information provided was deemed to be thin, with context missing from the responses that the participants would expect to be there.

Participant 2: *When we're reviewing that with parents and they get that new diagnosis we talk a little about the difference between oligo[articular JIA] persistent and extended and what that means.* Moderator: *So, there are questions in there about persistent and extended but they aren't linked to the basic question about oligo. Would it be a good idea to link them in?* Participant 2: *Yeah.*

Participant 3: *It's probably a little bit minimal. You probably want to frame [Enthesitis-related JIA] in terms of the rest of JIA. It's probably reasonable to say that Enthesitis-related JIA is one of the subtypes of Juvenile Idiopathic Arthritis and then a distinguishing feature is inflammation of the, basically what this says. This kind of leaps straight to that…this is probably a little bit thin.*

Participant 4: *I think it would be helpful to have a [question] prompt on the first page [of answers] so that if people have had a history of physical activity impacting negatively … they're able to click in on that.*

Participant 5: *I would want to know: Why do [rheumatoid nodules] occur? What can I do about it?*

Finally, there were four instances of participants unable to find information they thought was necessary.

Participant 2: *Maybe it's in there somewhere, the frequency of eye exams would be something that is helpful to parents… cause I looked for that, I thought that would be a question [prompt].*

Participant 3: *Is there something about not getting live virus vaccines [while taking methotrexate]? Which judging from some of the other stuff you have in here you might want to also have… One of your issues is going to be how are all the links set up, because they aren't a single linear link, its lots of things that end up being a big complicated Gordian knot.*

Participant 3: *Folic acid, absolutely, but we might also use anti-nausea medications [to manage the side effects of methotrexate] … this only references nausea, feeling unwell, it doesn't address how we mitigate the impact on the liver.*

Participant 3: *This answer is only half the answer to the question [What are the chances of taking DMARDs?] because if I don't have oligo[articular] JIA this answer does not talk to me.*

Theme 6: Individual responses were understandable, but the organization of content was lacking (relevant O'Grady parameters: Content Utility)

Most of the participants thought that, generally the way the JADE system provided information in a way that was easy to understand.

Participant 4: *It's easy to understand.*

Participant 5: *I thought it was great. I didn't have any problems comprehending anything that came up.*

Specifically, that the individual responses were displayed in manner that was clear and simple.

Participant 2: *I think that's simple, to the point, uncomplicated.*

Participant 3: *The sentences are short and simple and from the point of view of someone without a university education being able to read this I think that is fine.*

As well as that medical jargon was explained in a way that made it understandable.

Participant 1: *Band keratopathy, it tells me what it is, that's really good!*

Participant 3: *You don't have lots of jargon and where there's a term like enthesitis you provided the definition up front.*

However, a couple of participants found that the lack of content organization was detrimental to learning from the information provided.

Participant 3: *You can't read this and understand how likely [each side effect] is…You have things that follow each other that are literally totally unrelated…When we're talking to families we often group things into: here are the serious medical things…but then there's the stuff you could notice yourself, which is mostly you might feel pretty barfy on it…with a big long list, people read the first two or three things and then they get bored and miss stuff.*

Participant 5: *My question was how to manage swollen joints and a thing could pop up saying it depends on the context and then 'do you want to know more'…*

> *This is more "tell me more about it" kind of stuff, which I think is probably going to come up [as I click on question prompts]. Have you ever been on webpages and there's your answer and then it has what other people search for – that's what I feel like that stuff is. So, it's not useless information, its good information, but if I was looking for the quick and dirty answer [it's hard to find with the other information included].*

As well, one participant pointed out that the medical jargon explanations may not always be made available to users when they needed it.

> Participant 1: *I think a word like uveitis, the thing is it does say [the definition] there, but it may not be the first question that you click. So, you have to use that word, we use it in clinic, but it needs to say: "or eye inflammation" ... cause it's there [when you click on the "Want to know more?" question prompt] but it may not be in the first question they pick. So, simplify that word per screen in case they click that first.*

Theme 7: Awkward wording and spelling mistakes occasionally made things unclear (relevant O'Grady parameters: Content Utility)

A couple of the participants spoke about cases where the wording or spelling displayed by the JADE system was confusing.

> Participant 3: *When could be what time of day should I use it and when could be when in my disease course should I use it…neither one of these really answers the question I think I'm asking [which was: When and how should I administer DMARDs?].*
>
> Participant 5: *Exercise is safe and important for those with JIA – what does that describe? ... It's a bit awkward.*
>
> Participant 5: *feezable bags [should be spelt freezable but could be read as feasible].*
>
> Participant 5: *There's no spaces [in the question "Is exercise good for those with JIA?"]*

Theme 8: Accessibility issues of the JADE system (relevant O'Grady parameters: N/A)

Two of the participants brought up concerns regarding barriers to various groups accessing the JADE system. This included those who have low computer or reading

literacy, those who were blind or had another physical disability, and those whose cultural approach to illness differs from the norms addressed by the PEM.

> Participant 2: *The technology piece of things…I think most people of a younger generation would be faster at figuring this out as I'm not the most computer savvy.*
>
> Participant 4: *For folks that are having difficult comprehending the information or need a bit more support navigating is there criteria that would allow them to receive support?*
>
> Participant 4: *This is very much geared towards users that have the ability to be able to navigate it physically. Are there any parameters for folks who have limitations in terms of audio or visual?*
>
> Participant 4: *The population that would access services here at the IWK just in terms of ethnic differences and whether or not there were specific modalities or treatments or alternate forms of therapy that they would engage in [that may not be represented in the patient education materials]*.

The computer literacy was underscored by some of the difficulties participants had using the JADE system for the first time, particularly the question filtering portion.

> Participant 1: *Sometimes I didn't know if I should use this box [What are you looking for?] or this box [What is the context?]*.

CHAPTER 5.0 DISCUSSION

The Juvenile idiopathic Arthritis Dialogue-based Education (JADE) system was designed and implemented to allow users from families of children with JIA to interact with PEM in a Just-In-Time-Learning (JITL) style where they control the content they wish so that learning occurs at their own pace. The goal being to add a patient education tool to those already used to improve FJIA members' understanding of the condition and empower them to better self-manage their JIA.

The JADE system is an implementation of a novel dialogue-based patient education approach. JADE uses an artificial intelligence based argument model to establish an interactive dialogue with the user, where, in an interactive manner, the user can ask questions, seek clarifications about responses/findings, learn about the evidence supporting the response and seek alternative findings. By reasoning over the argument model, JADE can select and deliver information to the user as per the discourse of their education dialogue. This just-in-time learning approach gives FJIA control over the content they wish to see, which should improve their understanding and thus ability to self-manage the condition.

5.1 Successes of the JADE System

The results from encoding the PEM and building the ontology demonstrate the success of using the EMA to represent PEM content. The fact that all the content from the 32 PEM was successfully coded to the EMA shows that the model could fully represent the structure of the PEM content as argument elements. The positive responses to the system by the evaluation participants show the promise of using the EMA and thematic coding to create a dialogue system for JIA patient education. While, there were some issues with the system's responses, which will be discussed in detail below, the methods used were

largely successful. Given the potential of the JADE system to augment the current JIA patient education environment the issues that were highlighted during the evaluation step is examined in depth in this chapter.

5.2 Accuracy of JADE System Responses

While most of the information provided by the JADE system during the evaluation study was deemed to be accurate by the participants, there were a few instances of inaccurate content found. These inaccuracies were explored and while the information was correctly modelled from the PEM content, the PEM themselves had occasional inaccuracies. The median date of publication for those PEM that reported the date published was 2013 (range: 1987-2016). So, while most information is up to date there is some inaccurate information in them. The inaccuracies and gaps in the paper-based PEM reported during the evaluation study show the importance of having a patient education system that can be updated as new information comes out.

5.3 Completeness of the JADE System Responses

Of the four cases of missing information found in Theme 5, two were found to be gaps in the PEM, one was present in the PEM but was not included in the model because it was in graphical form only, and one was instantiated in the ontology, but no link was available between it and where the participant thought it should be. There was no mention in the PEM about how to manage the harmful effects of methotrexate on the liver or how often an eye exam should be, only that it would be dependent on the risk for each child which was reported in the JADE system's answer. The information about the chances of taking DMARDs for the various JIA subtypes was available in one of the PEM [28], however it was only shown in a Kaplan-Meier chart which was deemed too complex for the average FJIA and so was missed during the coding step. This

information could be translated from the chart and described in text form, or included with instructions for how to interpret the chart [87]. Finally, there was information available in the JADE system regarding not getting live vaccines while taking methotrexate. These argument elements were available through questions such as: "What vaccines can I take while taking methotrexate?" and "What shouldn't I do while taking methotrexate?". However, they were not displayed as results to the question "What are the side effects of methotrexate?" and there is currently no path between them and the side effect of immunosuppression as the participant thought there should be. This piece of missing information leads to three questions: 1) "How much information should be displayed at one time?", i.e. should not taking live vaccines because of immunosuppression mean that they are included under the side effect information or merely linked to it, 2) "Are there any links missing between arguments that should be there?", and 3) "How well connected are the arguments in the ontology?".

The first question was seen to be a matter of personal preference, as some participants liked shorter responses while other found it thin. Solutions to this may involve engaging families of children with JIA to determine whether there is consensus on which is better for users, or alternatively, to allow personalization in the system according to each user's preference on the volume of information presented at a time. The second question is discussed in more detail in the following subsection of the discussion and the third will be addressed in more detail in the future work section.

5.4 Relevance of JADE System Responses

Another issue exposed by the evaluation study was how some argument elements were displayed as results to a question that they were not relevant to. The three cases of

irrelevant information being provided, as reported in Theme 4, highlight three structural issues within the JADE ontology. The first case was that, when asking to know what a recommendation to do periodic skin checks when using ice described, a response concerning the need to do periodic skin checks when using heat due to potential ill effects was displayed. This occurred because the recommendation to do periodic skin checks had the object property sameAs linking it to two elaborations. These elaborations were from two different arguments, one where the claim had to do with when to stop using heat and the other about when to stop using ice. Thus, the JADE system following the sameAs property suggested the question prompt "Want to know what this describes?" which would display both claims about stopping heat and ice treatments.

This case, along with case of missing information described above, lead to the issue of connectivity between arguments. Since there is no single, linear path through the content, but rather a complex network between arguments which could be approached by a user from several starting points, this is indeed a "Gordian knot" as described by one of the evaluation study participants. A connection between two arguments is represented in the JADE ontology as an argument element of one argument having the object property sameAs linking it to the argument element of another argument. This property is symmetrical, meaning it has the same connection if approached in the opposite direction. These connections are what drive the inquiry dialogue in the JADE system. However, occasionally they can, as seen in this case, lead to information being displayed that is not relevant. This case could be solved by creating two instances of the argument with the claim recommending doing periodic skin checks, one to be the sameAs the ice-related elaboration and the other for the heat-related one. Yet, the issue of the sameAs property

has a wider implication that requires a trade-off between the information-seeking dialogue and the inquiry dialogue.

The sameAs property is good for creating connections that allow users to have an inquiry dialogue that can move between arguments, however, it limits the ability of the information-seeking dialogue to return information that is strictly relevant to the question. For example, take the question: "What should I do if I will be travelling while taking methotrexate?", it has the class expression:

> (HasTheme some Recommendation) and
> (IsElementOf some (HasElement some
> ((HasTheme value Methotrexate) and (HasTheme value WillBeTravelling)))).

The answer to this question includes, among other more relevant ones, the response: *If using inactivated vaccines then it is safe for patients whose immune system is suppressed*. This is not directly relevant to the question and while the claim shown here HasTheme Recommendation, and thus fits the topic theme of the class expression, it, nor any other element in its argument HasTheme Methotrexate or 'Will be travelling'. However, the claim has the sameAs property linking it to the explicit warrant of another argument. That argument has elements with both of those two themes. Using the sameAs property here is good as it allows users to find out why certain travel related vaccines are safe to use while taking methotrexate through an inquiry dialogue, but it means that the result of the information-seeking dialogue will yield an irrelevant response. Thus, it would be worthwhile to replace the sameAs property with another that would not necessitate this trade-off between the dialogue types.

The second case of an irrelevant response was that the JADE system responded to the question: "What are the side effects of methotrexate?" with a response that included: *if taking methotrexate* (Data) *it may be easiest to take on a Friday or Saturday evening* (Claim) *in order to allow time for you to rest in case of any side effects, such as fatigue or nausea* (Explicit Warrant). This argument is displayed because it's explicit warrant HasTheme 'Side effects' and the Data HasTheme Methotrexate. So, despite matching the requirements of the class expression:

(HasTheme 'Side effects') and
(IsElementOf some (HasElement some (HasTheme value Methotrexate))),

within its own argument the information is not relevant to the question. Yet, neither the thematic coding nor the class expression can be said to be incorrect. Instead the issue is that the themes exist in the ontology with no reference to each other. Due to the lack of connections between themes the question, which wants to know side effects caused by methotrexate, is yielding responses that merely involve methotrexate and side effects. There is no way, currently, to model the causation in the class expression. This would involve a much more detailed ontological model with the themes likely represented as classes with object properties linking them together. This would the entail a change in the current class expression grammar used to query the JADE ontology.

The third and final case of irrelevant material found during the evaluation study was that a question prompt of "Want to know more about this?" for the response: *rheumatoid nodules are bumps under the skin, especially in the hands or along tendons* led to the argument element: *anemia is a low red blood cell count or a fall in haemoglobin level*. The initial response to an information-seeking dialogue question displays question

prompts based on any argument model related properties held by all elements in that argument. Since these two responses are both Elaborations of the same claim the JADE system suggested the question prompt relating to the claim of the argument, leading to a confusing and irrelevant answer. The inquiry dialogue does not consider the properties of the argument as a whole, but only the argument element in question. To avoid this type of irrelevant content being displayed the inquiry dialogue rules should be adopted across the entire system.

5.5 Understandability of JADE System Responses

Despite the few instances of the JADE system providing irrelevant information, most of the information provided by the JADE system in response to the evaluators' questions was deemed by them to be clear and understandable. Especially the structure of the arguments based on the EMA and the question prompts moving forwards from the claim to its related argument elements. This aligns with other work that has found TMA to be a structure which makes health education information understandable for HCUs [3]. While, the wording of the backwards question prompts, such as "Want to know what this describes?" could be re-worded for clarity, the structure of the EMA seems to have been successful at organizing the PEM content in an understandable manner.

At the level of granularity above that of the argument the JADE system was found lacking in the way it organized the content. This is not surprising as there was no model used by the system to organize structure at that level. This issue does not affect the inquiry dialogue, which only returns at most three argument elements, but the information-seeking dialogue has responses of up to 15 argument elements. With that many responses, the evaluation participants pointed out that organizing the information

by topic would be useful and that ranking the information by importance to the user would be beneficial. This may require changing how the information and question prompts are displayed, considering what information is most important and how related the content of the responses are to each other. To determine the relatedness of the topics of various responses a method of comparing their thematic content could be used. However, for determining the order of importance for various responses a new knowledge layer is needed. While the EMA and thematic coding represent a large portion of the knowledge contained in the PEM this intra-argument level of structure is beyond their theoretical limits. Thus, a model is needed to represent the importance levels of responses within the information seeking dialogue.

The layout of information has a large effect on the comprehensibility of a patient education tool [88]. Due to working memory limits it is suggested to chunk information into manageable pieces and exclude distracting information and superfluities [89]. This modular approach to information is important to improving understandability [90]. Thus, having headings, lists, bullets, and logical sequencing improves understandability [87],[91]. However, other work has shown that having information in a sequence that is useful to readers, rather than logical to the designer, is better for understanding [92]. Determining what is most useful to readers is difficult as topic preferences may be related to the role of the user, i.e. patient, family etc. [93]. These differences were mentioned by one of the participants in the evaluation study. They said that healthcare users were usually more interested in the everyday side effects of methotrexate such as nausea and fatigue while clinicians were focused on medical issues such as the potential for liver damage. Individual interests and differences may also impact what each user deems most

useful, which is why giving the users content control is so important [31]. Thus, determining the organization of topics might require feedback from potential users, or it could start general and work down to specific [91]. This would require a ranking system within JADE to determine either usefulness or level of generalness, as well as by thematic content.

The participants in the evaluation study also questioned the granularity of the responses. Some called a few of the answers "thin" on information, wanting more context during the information-seeking dialogue to link the information back to the bigger picture, while others wanted just the "quick and dirty" answer displayed with the rest available through inquiry dialogue. As discussed above, it is better to chunk information in patient education tools, but the quantity of information to be contained in each chunk is not well described. Too little and the information is unorganized, too much and it is difficult for users to retain. This balance between chunking and splitting information in the context of the JADE system is about the balance between the information-seeking dialogue and the inquiry dialogue. The bigger the chunks of information displayed in the information-seeking dialogue the less information there is to be explored during the inquiry dialogue. This may come down to a personal preference on the part of the user as to where the balance between the dialogues will fall. However, since the evaluation study participants found several responses irrelevant due to a lack of context there are places where there needs to be more chunking of information.

For the responses that consisted of large numbers of argument elements there were also comments during the evaluation study that the question prompts took up a lot of space and made understanding the content displayed difficult to understand. Including other

kinds of question prompts beyond those based on the TMA were also suggested, such as questions from the ontology about similar themes or suggestions based on what other users that have found this information have searched for.

Displaying the definitions of medical terms more clearly and making sure they are available independent of how a user has encountered the term would improve the understandability of the content. This could be done by leveraging the definitions already encoded thematically in the JADE ontology or one of several medical vocabularies that link medical terms with lay equivalents [94]. The definitions could be displayed by adding a "Want to know the definition of …?" question prompt below the relevant term, displaying the entire definition in smaller lettering below the term in question, or displaying it to users who hover their mouse over it. Although, the latter option has been found to be difficult for those with lower visual acuity or computer literacy [95].

5.6 Credibility of JADE System Responses

The visual design of the JADE system should also be upgraded, again with input from relevant stakeholders. The current system gets some things right according to research on the best practices of displaying patient education material such as using short sentences, high contrast between colours, and large type size [87], as well as lots of white space to improve comprehensibility [90], [92]. However, there are opportunities to improve the perceived credibility of the tool through better design. Visual design is often included as a criterion when evaluating eHealth tools [96] and, according to one study, it accounted for 46.1%, and information structure 28.5%, of why users found eHealth tools credible [97]. The visual design of an eHealth tool is a better predictor of perceived credibility than brand recognition [97]. Although, parents of children with JIA reported trusting

information from a known reputable source such as the hospital or the arthritis society [13] suggesting that both design and reputable sources have a role to play. Enlight, an evaluation tool for eHealth interventions, suggests displaying the hosting source and partnered institutions to add credibility [98]. Thus, by both improving the visual design and displaying the logos of partner organizations the perceived credibility of the JADE system content could be improved.

5.7 Awkward Wording in JADE System Responses

Other visual display issues identified during the evaluation study were spelling mistakes and awkward wording. The spelling mistakes and awkward wording are easily fixed. The questions and question prompts should be re-worded, preferably with the help of various JIA stakeholders.

5.8 Accessibility Issues in the JADE System

A final theme discussed by the evaluation study participants was the issue of accessibility. Low levels of computer literacy or a lack of access to a computer can limit the access to computer-based patient education systems and exacerbate existing healthcare inequality issues [34]. Other factors mentioned in Theme 8 such as auditory or visual impairments and cultural differences could also impact the accessibility of the JADE system [99]. Universal design principles, such as including individuals from groups with limited access in the design process, can help mitigate these issues [100]. Using these design principles could improve the system for everyone as even highly educated HCUs have low health literacy when under stress [88].

5.9 Limitations

A limitation of the JADE system is that it only uses PEM from a single site. PEM content from other pediatric rheumatology clinics may have contained content topics or

structures that could have challenged or extended the argument model used to integrate it. The evaluation study also only involved clinicians from the same single site, and while their familiarity with the PEM used in the system was beneficial to the study it potentially limits the breadth of viewpoints a broader inclusion strategy could have offered.

Similarly, the content integration from the PEM and the qualitative coding during the evaluation study were both conducted by a single coder. Due to the financial and temporal constraints of the project it was not feasible to have a second coder involved in the process. However, this means that the potential for bias is higher than it would have been if the results had been confirmed by a second coder.

Finally, while the methods used in this work are generalizable to patient education for other conditions the substantial amount of time and knowledge required to code PEM content to the argument model as well as thematically and then instantiate it into the ontology limit the generalizability of the methods. The person coding the PEM content must have a good working knowledge of the EMA as well as grounded theory for the thematic coding. They must also understand the condition described by the PEM and be able to represent the resulting codes in an OWL ontology. The time needed for this person, or persons, to do this is not trivial which also creates barriers to these methods being used.

CHAPTER 6.0 FUTURE WORK

First, the JADE system should be revised based on the findings of the evaluation study. Attention will be focused on solving the issues that led to irrelevant or missing content in the system's responses as detailed in the previous chapter. The arguments that have not been instantiated yet should be coded into the JADE ontology.

The thematic coding system should be revised, preferably with a second coder or reviewer, to better represent the concepts described in the PEM. This may involve changing the codes as well as the structure that represents them in the JADE ontology as discussed in the previous chapter. Involving JIA stakeholders such as those with JIA, their families, and the clinicians who treat them would make the codes more applicable to end users [101].

Also, as previously discussed, the sameAs property should be replaced in a manner that will maintain the link between argument elements while not making them part of the same argument. The links between arguments should then be examined to establish how connected the PEM content is in the JADE ontology, and whether there are any links which are missing. This should be performed with the guidance of domain experts. It would also be useful to ascertain how deep a dialogue can go from a starting question.

Determining the best methods to organize and display the content, engaging FJIA members using a participatory research approach, would enhance the validity, design, and applicability of the JADE system [102]. This would involve making the query filtering functionality more intuitive, organizing the system's responses for better understandability, and visual design options for improve credibility and understanding among others. Additional functionalities or ways to improve current ones, such as how to

re-word question prompts, may be suggested by these future participants which could be added to the system as well.

The current question filtering functionality is not very intuitive. Future work to improve this by moving towards a free text question asking functionality would be advisable. Perhaps using natural language processing to match user questions to thematic codes would yield positive results with better usability than the current functionality.

The differences in what information different roles described in the evaluation study deem most important, i.e. clinicians and caregivers, and in the work of Wright et al., i.e. caregivers and adolescents, shows the potential for personalizing the JADE system's responses for different users. Creating a user model including the user's role as described above as well as preferences for longer or shorter information presentation, or health literacy levels, could provide users with responses tailored to these variables.

The financial and temporal constraints of this study limited the focus to content. The usability of the system and perceived strengths and weakness of the dialogue functionalities could not be assessed here. These aspects of the updated JADE system should be evaluated involving HCUs from FJIA.

Finally, a method to make updating and adding to the knowledge base easier and require less expert knowledge. This should be created to facilitate the future generalizability of the JADE system.

CHAPTER 7.0 CONCLUSION

This thesis describes the design, implementation, and preliminary evaluation of the JADE system for families of children with JIA. The results from this work show that the JADE system demonstrated great potential to address some of the current gaps in patient education experienced by these families. The methodology used to develop the JADE system is novel in several ways. While other computer-based patient education systems have used the TMA to organize information for display to HCUs [3]–[5], to our knowledge this is the first time that it has been used to organize previously existing PEM. The structure of the EMA was also leveraged to provide inquiry dialogue as part of the JADE system's dialogue manager. One other dialogue system has used the TMA structure in its dialogue manager [5], however it is clinician facing and does not allow dialogue beyond a single argument. The JADE system is novel in that it is HCU facing and does allow for this through the chaining of arguments allowed by the EMA. We believe that the methods used in this work are generalizable to PEM for other health related conditions, and thus presents a novel method for providing additional patient education tools for HCUs with those conditions.

The potential positive impacts of an updated JADE system on FJIA include significant knowledge improvement [19], [55], high user satisfaction [48], [52], [56], improved self-management [20], and improved health outcomes relative to control [21], [48], [52]. Additionally, the JADE system showed that it could represent knowledge extracted from research articles. This could lead to improved speed of knowledge translation of research findings to families who need it [15].

In addition to these potential clinical benefits, the findings of this thesis are relevant from a health informatics perspective as well. For instance, the extension of the TMA as a knowledge model for PEM integration was highly successful, integrating content from 32 very different sources. As well the EMA worked well as a dialogue grammar for inquiry dialogue apart from some awkward wording of question prompts that still requires some work. However, as a dialogue grammar for information-seeking dialogue, the EMA was not successful and thematic coding was needed to facilitate this.

The EMA as a method for organizing PEM content was successful on an intra-argument basis, as had been shown before in other studies [3]–[5]. However, it was not useful for organizing on an inter-argument basis, and the thematic coding scheme as currently structured was not detailed enough to do this either. More work is needed to improve this level of structure for JADE system responses.

As demonstrated by the enthusiasm of our evaluation participants, a system like JADE would be a valuable addition to the patient education tools currently available to FJIA. Therefore, it is recommended that the JADE system be updated in collaboration with relevant stakeholders and pilot tested for usability by a wide range of family members of children with JIA and those with JIA themselves.

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APPENDIX A: PEM CLASSIFICATION

Title	Author	Publisher	Date	Format	Structures	Subject
Hand Back Childhood	N/A	The Arthritis Society	N/A	Bookmark	Text, Links	Self-management
Living Well: When Your Child Has Arthritis	N/A	IWK Pediatric Rheumatology Division/Social Work	2015	Brochure	Text, List, Links	Quality of life, Self-management
You, Your Child and Arthritis	Dr. Shirley Tse	The Arthritis Society	2011	Brochure	Text, List, Links, Images	Etiology, Quality of Life, Treatments, Medication, Side effects, Dosage, Job and Roles, Self-management, JIA Subtypes, Outcomes
Subcutaneous Injections: A Guide for Patients and Families	N/A	IWK Pediatric Rheumatology Division	2013	Brochure	Text, List, Images	Treatment, Self-management
How to help your child with Pill Swallowing	N/A	IWK Pediatric Health Psychology	N/A	Brochure	Text, List, Images	Treatment, Self-management
Nutrition for the Child Taking Steroids	N/A	IWK Clinical Nutrition	2014	Brochure	Text, List, Table, Links	Self-management, Outcomes
Safe food handling for Immunocompromised Individuals	N/A	Health Canada	2015	Brochure	Text, Lists, Tables, Links	Self-management, Diet
Rheumatology Clinic Nurses	N/A	IWK Pediatric Rheumatology Division	N/A	Business Card	List, Links	Contact details
Using Ice and Heat at Home	Allison Reid	IWK Pediatric Rheumatology Division	2016	Handout	Text, List	Treatments, Self-management
Joint Diagrams	N/A	Arthritis Foundation	1987	Handout	Images	Etiology, Anatomy
Methotrexate	N/A	RheumInfo	2011	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Immunizations for Children and Teens with Suppressed Immune Systems	The Hospital for Sick Children	aboutkidshealth.ca	N/A	Handout	Text, List	Outcomes, Medications

Title	Author	Publisher	Date	Format	Structures	Subject
Sulfasalazine	N/A	RheumInfo	2011	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Etanercept	N/A	RheumInfo	2016	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Tocilizumab IV	N/A	RheumInfo	2014	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Anakinra	N/A	RheumInfo	2011	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Abatacept	N/A	RheumInfo	2011	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Infliximab	N/A	RheumInfo	2011	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
The Flu Shot	N/A	RheumInfo	2015	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
What you need to know about starting a biologic	N/A	DMI	2016	Handout	Text, List	Financial implication, Medical tests
Golimumab	N/A	RheumInfo	2011	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management

Title	Author	Publisher	Date	Format	Structures	Subject
Ustekinumab	N/A	RheumInfo	2013	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Side effects of Corticosteroids	N/A	N/A	N/A	Handout	Table	Medication, Side effects
Prednisone	N/A	RheumInfo	2011	Handout	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Calcium and Vitamin D	N/A	IWK Clinical Nutrition	2015	Handout	Text, Lists, Tables, Links	Self-management, Diet
Healthy Tips and Tricks	N/A	IWK Clinical Nutrition	2011	Handout	Text, Lists, Tables, Links	Self-management, Diet
The risk and nature of flares in juvenile idiopathic arthritis: results from the ReACCh-Out cohort	Guzman et al.	Annals of Rheumatic Diseases	2016	Journal Article	Text, Charts, Statistics, Tables	Outcomes, Risk, Treatments
The outcomes of juvenile idiopathic arthritis in children managed with contemporary treatments: results from the ReACCh-Out cohort	Guzman et al.	Annals of Rheumatic Diseases	2015	Journal Article	Text, Charts, Statistics, Tables	Treatments, Outcomes, JIA Subtypes
Who is the Rheumatology Team?	N/A	IWK Pediatric Rheumatology Division	2016	Pamphlet	Text, Links	Jobs and Roles, Contact details
Naproxen: A Patient/Family Guide	N/A	IWK Pediatric Rheumatology Division	2016	Pamphlet	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Methotrexate: Patient Information	N/A	IWK Pediatric Rheumatology Division	2012	Pamphlet	Text, List	Treatments, Medication, Side effects, Dosage, Self-management
Joint Injections: Instructions for Patients and Families	N/A	IWK Pediatric Health Psychology	2012	Pamphlet	Text, List	Treatment, Self-management, Medication

APPENDIX B: THEMES AND THEIR DEFINITIONS

Theme Hierarchy	Definition
Fact	represents factors that describe the context of the argument
'External source'	represents a form of patient education external to the JADE system
'Provide instruction'	represents the act of a clinician giving medically relevant instructions
'Provide prognosis'	represents the act of a clinician giving medically relevant prognoses
'Age of child with JIA'	represents the medically relevant age of people described in the argument
'16 or younger'	represents children or adolescents 16 years old or younger
'2-4 years old'	represents children between the ages of 2 and 4 years old
'4 or younger'	represents children 4 years old or younger
'6-12 years old'	represents children between the ages of 6 and 12 years old
'Any age'	represents children or adolescents with JIA up to the age of 19
'Pre-teen years'	represents children or adolescents between the ages of 10 and 13 years old
'Teenage years'	represents children or adolescents between the ages of 13 and 19 years old
Adult	represents people over the age of 19
Young	represents children under the age of 6
'Behavioural and environmental factors'	represents the medically relevant actions or surroundings of people describe in the argument
'Breast feeding'	represents the practice of breast feeding
'Contact with a sick person'	represents the exposure to a person with a communicable illness
'Drinking alcohol'	represents the practice of drinking alcohol
'Family history'	represents a condition as being part of a family history
'Sexually active'	represents the practice of being sexually active
'Staying still'	represents the behaviour of not moving around
'Sterile conditions'	represents the environmental conditions surrounding a treatment being sterile
Climate	represents the weather of a geographical location - either in an instance or on average
Diet	represents the diet of the individual(s) described in the argument
'Body parts'	represents descriptions of particular body parts in the argument
'Finger nail'	represents the finger nail(s) of the individual(s) described in the argument
'Internal organs'	represents the internal organ(s) of the individual(s) described in the argument
Bone	represents the bone(s) of the individual(s) described in the argument
Bowel	represents the intestines of the individual(s) described in the argument
Cartilage	represents the cartilage of the individual(s) described in the argument

Theme Hierarchy	Definition
Cytokine	represents a category of small proteins important in cell signalling of the individual(s) described in the argument
Entheses	represents the place where the tendon meets the bone of the individual(s) described in the argument
Eyes	represents the eye(s) of the individual(s) described in the argument
Interleukin-1	represents the group of inter-leukin 1 proteins of the individual(s) described in the argument
Neck	represents the neck of the individual(s) described in the argument
Pupil	represents the pupil(s) of the individual(s) described in the argument
Spine	represents the spine of the individual(s) described in the argument
Synovium	represents the lining of the inner surface of certain joints of the individual(s) described in the argument
Tendons	represents the tendon(s) of the individual(s) described in the argument
TNF	represents the tumor necrosis factor of the individual(s) described in the argument
Joints	represents the joint(s) described in the argument
'Joints - All'	represents the joint class as an instance in arguments that do not specify a certain joint or group of joints
'Sacroiliac joint'	represents the sacroiliac joint of the individual(s) described in the argument
Elbow	represents the elbow(s) of the individual(s) described in the argument
Jaw	represents the jaw of the individual(s) described in the argument
'Large joints'	represents the large joint(s) described in the argument
'Large joints - All'	represents the large joint class as an instance in arguments that do not specify a certain large joint
Ankle	represents the ankle(s) of the individual(s) described in the argument
Hips	represents the hip(s) of the individual(s) described in the argument
Knee	represents the knee(s) of the individual(s) described in the argument
'Small joints'	represents the small joint(s) described in the argument
'Small joints - All'	represents the small joint class as an instance in arguments that do not specify a certain small joint
Feet	represents the foot/feet of the individual(s) described in the argument
Fingers	represents the finger(s) of the individual(s) described in the argument
Hands	represents the hand(s) of the individual(s) described in the argument
Toes	represents the toe(s) of the individual(s) described in the argument
Wrist	represents the wrist(s) of the individual(s) described in the argument

Theme Hierarchy	Definition
Events	represents an occurrence with a fixed time point
'After being injured'	represents the timepoint after being injured
'After playing sports'	represents the timepoint after playing sports
'Exposure to contagion'	represents the timepoint when a child or adolescent with JIA is exposed to a contagion
'First diagnosis'	represents the timepoint when a child or adolescent is diagnosed with JIA for the first time
'First flare'	represents the timepoint when a child or adolescent with JIA has a flare for the first time
'Missed dose'	represents the timepoint when a dose is missed
'Receiving ongoing treatment'	represents the timepoint when treatment is being received
'Routine schedule'	represents the timepoint when the schedule is normal
'School or work day'	represents a timepoint between Monday-Friday
'Start of symptom'	represents the timepoint when a symptom begins
'Started treatment'	represents the timepoint when treatment is started
'Treatment reduced'	represents the timepoint when treatment is reduced
'Treatment stopped'	represents the timepoint when treatment is stopped
'When sleeping'	represents the timepoint of sleep
'When waking up'	represents the timepoint after waking up
'Will be travelling'	represents the timepoint prior to travel
Duration	represents the span between two timepoints
'Facts and figures'	represents statistics, or definitions which is described in an argument
'Contact details'	indicates the method by which communication may be attained with a given party
'Table or graphic'	represents that an image or a table is attached here
Definition	represents that the argument defines a term
Likelihood	represents that the argument describes the quantitative and qualitative odds of something occurring
Chance	represents the mathematical odds that something will happen - often expressed as a fraction or percentage in the argument
Risk	expresses the fact that certain factors cause a risk for a certain condition or outcome is described in the argument
'Medical conditions'	represents the medical condition(s) described in the argument
'Autoimmune diseases - All'	represents the medical condition of unspecified autoimmune disease(s) described in the argument
'Band keratopathy'	represents the medical condition of band keratopathy described in the argument
'Diabetes Type 1'	represents the medical condition of diabetes Type 1 described in the argument
'Heart failure'	represents the medical condition of heart failure described in the argument
'Hepatitis A'	represents the medical condition of hepatitis A described in the argument

Theme Hierarchy	Definition
'Illness - All'	represents the medical condition(s) described in arguments that do not specify a certain one
'Imbalanced immune system'	represents the medical condition of an imbalanced immune system described in the argument
'Neurological diseases - All'	represents the medical condition of unspecified neurological disease(s) described in the argument
'Skin conditions - All'	represents the medical condition of unspecified skin condition(s) described in the argument
'Thyroid disease'	represents the medical condition of thyroid disease described in the argument
Cancer	represents the medical condition of cancer described in the argument
Cataract	represents the medical condition of cataract(s) described in the argument
Chickenpox	represents the medical condition of chicken pox described in the argument
Dactylitis	represents the medical condition of dactylitis described in the argument
Fever	represents the medical condition of fever described in the argument
Glaucoma	represents the medical condition of glaucoma described in the argument
IBD	represents the medical condition of IBD described in the argument
Immunosuppression	represents the medical condition of Immunosuppression described in the argument
Infection	represents the medical condition of infection described in the argument
Lupus	represents the medical condition of Lupus described in the argument
Malnutrition	represents the medical condition of Malnutrition described in the argument
Measles	represents the medical condition of measles described in the argument
Pregnancy	represents the medical condition of pregnancy described in the argument
Psoriasis	represents the medical condition of psoriasis described in the argument
Uveitis	represents the medical condition of uveitis described in the argument
Arthritis	represents the medical condition of arthritis described in the argument
'Arthritis - All'	represents the medical condition(s) described in arguments that do not specify a certain subtype
JIA	represents the description of Juvenile Idiopathic Arthritis in the argument
'Juvenile idiopathic arthritis'	represents the JIA class as an instance in arguments that do not specify a certain subtype
JIA Subtype	represents the subtypes of JIA
'Enthesitis-related JIA'	represents the description of Enthesitis-related Juvenile Idiopathic Arthritis in the argument

Theme Hierarchy	Definition
'Oligoarticular JIA'	represents the description of Oligoarticular Juvenile Idiopathic Arthritis in the argument
'Polyarticular JIA'	represents the description of Polyarticular Juvenile Idiopathic Arthritis in the argument
'Psoriatic JIA'	represents the description of Psoriatic Juvenile Idiopathic Arthritis in the argument
'Systemic JIA'	represents the description of Systemic Juvenile Idiopathic Arthritis in the argument
'Medical tests'	represents a medical examination that aims to determine, measure or diagnose a condition that is described in the argument
'Active joint count'	represents the medical examination of counting joints actively affected by arthritis
'Eye exam'	represents the medical examination of split lamp eye examination
'Liver enzyme (AST or ALT) test'	represents the medical examination of liver enzymes AST or ALT
'Physician global assessment'	represents the global medical examination by a physician
'Tuberculosis test'	represents the medical examination for tuberculosis
'Urine test'	represents the medical examination of urine
X-ray	represents the medical examination by x-ray
'Blood tests'	represents the medical examination of blood
'ANA blood test'	represents the medical examination of blood for ANA
'Blood work - All'	represents the blood test class as an instance in arguments that do not specify a certain test
'WBC count'	represents the medical examination of blood for white blood cells
Outcomes	represents an occurrence that happened due to one, or several, factors
'Abnormal test results'	represents the outcome of abnormal test results
'Allergic reaction'	represents the outcome of an allergic reaction
'Anesthesia difficulty'	represents the outcome of a difficulty during anesthesia
'Dental difficulty'	represents the outcome of a difficulty during a dental procedure
'Develop condition'	represents that a certain condition will come to pass as an outcome
'Develop state'	represents that a certain state will come to pass as an outcome
'Develop symptoms'	represents that a certain symptom will come to pass as an outcome
'Discontinuing treatment'	represents the outcome of a treatment being stopped
'Does not cause'	represents the lack of a causal relationship between two themes
'Drug reaction'	represents the outcome of an adverse drug reaction
'Good outlook'	represents the outcome of a good outlook
'High test result'	represents the outcome of a high test result
'Improve symptoms'	represents the outcome of improving symptoms
'Less active'	represents the outcome of becoming less physically active

Theme Hierarchy	Definition
'Limit ability'	represents the outcome of limiting a person's ability
'Low test result'	represents the outcome of a low test result
'Normal health'	represents the outcome of normal health
'Normal participation'	represents the outcome of normal participation in daily activities
'Normal test results'	represents the outcome of a normal test results
'Not extend'	represents not having inflammation spread from one part of the body to another
'Provide physical support'	represents the provision of physical supports as an outcome
'Scar tissue'	represents the outcome of scar tissue
'Small chin'	represents the outcome of a small chin
'Vision loss'	represents the outcome of vision loss
'Worsen symptoms'	represents the outcome of worsening symptoms
Blindness	represents the outcome of blindness
Cause	indicates a causal relationship between two themes
Complications	represents the outcome of medical complications
Damage	represents the outcome of bodily damage
Deformity	represents the outcome of bodily deformity
Diagnose	represents the action of diagnosing as opposed to the event
Extend	represents the spread of inflammation from one part of the body to another
Flare	represents the outcome of a flare
Effectiveness	represents the effect of a treatment
'Negative or poor effect'	represents that the effect is harmful or less than desired
'Positive effect'	represents that the effect is as desired or healthful
'Growth related outcomes'	represents outcomes relating to growth
'Abnormal growth'	represents an outcome where growth rates are not normal
'Fast growth'	represents an outcome where growth rates are faster normal
'Normal growth'	represents an outcome where growth rates are normal
'Slow growth'	represents an outcome where growth rates are slower normal
'Roles and jobs'	represents the actor(s) described in an argument
'Family doctor'	represents a GP role
'Family member'	represents a family member role
'Healthcare team'	represents the healthcare providers as a group
'Occupational therapist'	represents an occupational therapist
'Pediatric rheumatology clinic'	represents the pediatric rheumatology clinic as a group
Anesthetist	represents an anesthetist
Dentist	represents a dentist
Ophthalmologist	represents an ophthalmologist

Theme Hierarchy	Definition
Optometrist	represents an optometrist
Orthodontist	represents an orthodontist
Parent	represents a physiotherapist
Physiotherapist	represents a physiotherapist
Rheumatologist	represents a rheumatologist
'Sex of child with JIA'	represents the medically relevant sex of the people described in an argument
Male	represents male biological sex
Female	represents female biological sex
'Side effects'	represents the unintended consequence(s) of a treatment that is described in the argument
'Adverse reaction'	represents an unspecified negative side effect of a treatment
'Dry cough'	represents the side effect of a dry cough
'Feeling tired'	represents the side effect of tiredness
'Feeling uncomfortable'	represents the side effect of uncomfortableness
'Harm unborn child'	represents the side effect of harming a foetus
'Increased risk'	represents the side effect of increasing the risk of a medical condition
'Liver damage'	represents the side effect of liver damage
'Mouth sores'	represents the side effect of mouth sores
'Not addictive'	represents the absence of the side effect of becoming addicted
'Serious lung problem'	represents the side effect of a serious unspecified lung problem
'Shortness of breath'	represents the side effect of shortness of breath
'Side effects - All'	represents the side effect class as an instance in arguments that do not specify a certain side effect
'Skin becomes bright red'	represents the side effect of skin colour becoming red
'Skin becomes pale'	represents the side effect of skin becoming pale
'Skin returns to normal colour'	represents the side effect of skin regaining normal colour
'Slow growth'	represents the side effect of slow growth as a side effect
Fatigue	represents the side effect of fatigue
Nausea	represents the side effect of nausea
Numbness	represents the side effect of numbness
Rash	represents the side effect of a rash
Shivering	represents the side effect of shivering
Sting	represents the side effect of feeling a sting
'Status of medical condition'	represents the status of a condition over a period of time
'Early stage'	represents the early stages of a medical condition
'Inactive disease'	represents the inactive stages of a medical condition
'Less severe'	represents the less stages of a medical condition

Theme Hierarchy	Definition
'Not under control'	represents the not under control stage of a medical condition
'Under control'	represents the under-control stages of a medical condition
Active	represents the active stage of a medical condition
Change	represents a change in the stage of a medical condition
Healthy	represents the healthy stage of a medical condition
Mild	represents the mild stage of a medical condition
Predictable	represents the predictable stage of a medical condition
Remission	represents the remission stage of a medical condition
Severe	represents the severe stage of a medical condition
Undetected	represents the undetected stage of a medical condition
Unpredictable	represents the unpredictable stage of a medical condition
Untreated	represents the untreated stage of a medical condition
'Heredity related status'	represents the status of a condition as it related to heredity
'Not hereditary'	represents the status of a condition as not hereditary
Hereditary	represents the status of a condition as hereditary
'Infectious related status'	represents the status of a condition as it related to infectiousness
'Not infectious'	represents the status of a condition as not infectious
Infectious	represents the status of a condition as infectious
'Symptoms and signs'	represents signs (clinician or test determined) or symptoms (patient or family felt or observed) of a condition described in the argument
'Active joint count is 0'	represents the sign of having no actively arthritic joints
'Active joint count is 4 or less'	represents the sign of having 4 or less actively arthritic joints
'Active joint count is 5 or more'	represents the sign of having 5 or more actively arthritic joints
'Active joint'	represents the sign of having an actively arthritic joint
'ANA positive'	represents the sign of being ANA positive
'Become weak'	represents the symptom of becoming weak
'Difficulty chewing'	represents the symptom of having difficulty chewing
'Feeling unwell'	represents the symptom of feeling unwell
'HLAB-27 positive'	represents the sign of being HLAB-27 positive
'Lose weight'	represents the symptom of losing weight
'Muscle spasm'	represents the symptom of having a muscle spasm
'Pink skin'	represents the symptom of having pink skin
'Pitting or ridging'	represents the symptom of having pitting or ridging of the skin
'Poor appetite'	represents the symptom of having a poor appetite
'Range of motion'	represents the sign of having good range of motion
'RF negative'	represents the sign of being RF negative
'RF Positive'	represents the sign of being RF positive

Theme Hierarchy	Definition
'Rheumatoid nodules'	represents the symptom of having rheumatoid nodules
'Spiking fever'	represents the symptom of having a spiking fever
'Symmetrical active joints'	represents the sign of having symmetrical (left - right) active joints
Anemia	represents the symptom of having anemia
Inflammation	represents the symptom of having inflammation
Pain	represents the symptom of having pain
Painless	represents the symptom of having no pain
Stiffness	represents the symptom of having stiffness
Symptomless	represents the symptom of having no symptoms
Treatments	represents the treatment options described in the argument
'Birth control - All'	represents birth control methods when no specific one has been specified
'Folic Acid'	represents the treatment of folic acid
'Treatments - All'	represents the treatment class as an instance in arguments that do not specify a certain treatment
'Medical procedures'	represents a course of action meant as a treatment to a medical condition that are described in the argument
Surgery	represents a surgical procedure
Medications	represents treatments using medicines described in the argument
'Birth control pill'	represents a birth control pill
'Eye drops'	represents medically relevant eye drops
'Local anesthetic'	represents local anesthetic
'Medications - All'	represents the medications class as an instance in arguments that do not specify a certain medication
'New medication'	represents a new medication not previously used
'Sulfa antibiotics'	represents sulfa antibiotics as a treatment
'Treatment to prevent infection'	represents a general medication to prevent infection when no specific one has been specified
'Biologic agents'	represents pharmaceutical drugs created from biological sources described in the argument
'Anti-TNF agent'	represents anti-TNF agents
'Biologic agents - All'	represents the biologic agents' class as an instance in arguments that do not specify a certain biologic
Corticosteroids	represents corticosteroid medications described in the argument
'Corticosteroids - All'	represents the corticosteroids class as an instance in arguments that do not specify a certain steroid
'Eye injection'	represents the injection of steroids into the eye
'Joint injection'	represents the injection of steroids into the joint
'Oral corticosteroid'	represents steroids taken orally
'Steroid eye drops'	represents steroids taken via eye drops
Cortisone	represents the steroid cortisone
DMARDs	represents drugs which modify rheumatic disease to slow down disease progression described in an argument

Theme Hierarchy	Definition
'DMARDs - All'	represents the DMARDs class as an instance in arguments that do not specify a certain DMARD
Methotrexate	represents the medication methotrexate
Immunizations	represents compounds used to bolster the body's immune response that are described in the argument
'Vaccines - All'	represents the immunizations class as an instance in arguments that do not specify a certain vaccine
'Active immunizations'	represents those immunizations that contain live bacteria or viruses that are described in the argument
'BCG vaccine'	represents the BCG vaccine
'Chickenpox vaccine'	represents the Chickenpox vaccine
'Live vaccines - All'	represents the active immunizations class as an instance in arguments that do not specify a certain vaccine
'MMR vaccine'	represents the MMR vaccine
'Rotavirus vaccine'	represents the Rotavirus vaccine
'Typhoid vaccine - oral'	represents the Typhoid vaccine when taken orally
'Yellow fever vaccine'	represents the yellow fever vaccine
FluMist	represents the FluMist vaccine which is taken nasally
'Inactivated immunizations'	represents those immunizations that do not contain live bacteria or viruses that are described in the argument
'Diphtheria vaccine'	represents the diphtheria vaccine
'Flu vaccine'	represents the flu vaccine
'Hepatitis A vaccine'	represents the Hep A vaccine
'Hepatitis B vaccine'	represents the Hep B vaccine
'HiB vaccine'	represents the HiB vaccine
'HPV vaccine'	represents the HPV vaccine
'Inactive vaccine - All'	represents the inactive immunizations class as an instance in arguments that do not specify a certain vaccine
'IPV vaccine'	represents the IPV vaccine
'Japanese encephalitis vaccine'	represents the Japanese encephalitis vaccine
'Meningococcus vaccine'	represents the Meningococcus vaccine
'Pneumococcus Vaccine'	represents the pneumococcus vaccine
'Rabies vaccine'	represents the rabies vaccine
'TDAP vaccine'	represents the TDAP vaccine
'Tetanus vaccine'	represents the tetanus vaccine
'Typhoid vaccine - injection'	represents the typhoid vaccine taken via injection
NSAIDs	represents non-steroidal anti-inflammatory drugs described in the argument

Theme Hierarchy	Definition
'NSAIDs - All'	represents the NSAIDs class as an instance in arguments that do not specify a certain NSAID
Aspirin	represents the medication aspirin
Ibuprofen	represents the medication ibuprofen
Indomethacin	represents the medication indomethacin
Naproxen	represents the medication naproxen
'Non-medicinal treatments'	represents treatments which do not use pharmaceutical drugs described in the argument
'Alternative therapies'	represents treatments provided outside of the scope of traditional (western) medical
Heat	represents heat as a treatment
Ice	represents cold as a treatment
Orthotics	represents orthotics as a treatment
Splints	represents splints as a treatment
Physical therapy and exercise	represents physical therapy and exercise as a treatment
'Bed rest'	represents bed rest as a treatment
'High impact activities'	represents high impact activities as a treatment
'Low impact activities'	represents low impact activities as a treatment
'Physical activity'	represents physical activity as a treatment
'Therapy exercises'	represents physical therapy exercises as a treatment
Stretching	represents stretching as a treatment
'Values and preferences'	represents the thoughts and desires of the patient, caregiver, or family member
'Feeling concerned'	represents the feeling of concern
'Feeling unsure'	represents the feeling of being unsure
'Interested in'	represents the feeling of being interested in something
'No plans to stop treatment'	represents having no plans to stop a treatment
'Thinking about becoming sexually active'	represents the intention to be sexually active
'thinking about getting pregnant'	represents the intention to become pregnant
'Want to stop treatment'	represents the desire to stop a treatment
Preference	represents a preference for something
Recommendation	represents a course of action suggested by the argument
'Aggressive treatment plan'	represents the recommendation to follow a treatment plan which is deemed aggressive
'Avoid behaviour'	represents the recommendation to avoid a behaviour
'Call the rheumatology clinic'	represents the recommendation to call the rheumatology clinic

Theme Hierarchy	Definition
'Call your family doctor'	represents the recommendation to call your family doctor
'Change routine schedule'	represents the recommendation to change your routine schedule
'Consult infectious disease specialist'	represents the recommendation to consult an infectious disease specialist
'Do not take test'	represents the recommendation to not take a test
'Do not use treatment'	represents the recommendation to not use a treatment
'It is safe'	represents the recommendation that a course of action is safe
'Keep a regular schedule'	represents the recommendation to keep a routine schedule
'Keep up to date'	represents the recommendation to keep vaccinations up to date
'Not too hot'	represents the recommendation to make sure heat used a treatment is not too hot
'Reduce treatment'	represents the recommendation to reduce treatment dosage
'Rest or low activity'	represents the recommendation to rest or participate in low levels of activity
'Resume treatment'	represents the recommendation to resume treatment
'See your doctor'	represents the recommendation to see your doctor
'Stop the treatment'	represents the recommendation to stop the treatment
'Storage tips'	represents the recommendation on how to store medications
'Take test'	represents the recommendation to take a test
'Talk to your doctor'	represents the recommendation to talk to your doctor
'Use treatment'	represents the recommendation to use a treatment
'Wash hands'	represents the recommendation to wash your hands
Monitor	represents the recommendation to monitor the condition or treatment
Wait	represents the recommendation to wait before further action
Treatment Delivery Methods	represents the recommended ways in which a treatment can or should be administered
'Application - other'	represents the recommended manner in which treatment is carried out other than those described in this thematic category
'Liquid form'	represents the recommendation that the treatment comes in liquid form
'Pill or tablet'	represents the recommendation that the treatment comes in pill form
Dosage	represents the recommendation that the amount, frequency and/or timings when treatment should be taken
Injection	represents the recommendation that the treatment comes as an injection

APPENDIX C: EVALUATION STUDY SCENARIOS

Scenario 1	Taylor is the parent of a 4-year-old who was diagnosed with oligoarticular JIA at the last clinic visit a month ago. The rheumatologist indicated that it was very important for the child to have an eye examination by an ophthalmologist. Taylor can't remember the details of what was said during the clinic visit and so logs on to the JADE system.
CW 1 Tasks	*As you go through these tasks please "think out loud" focusing on the relevance, completeness, accuracy and credibility of the content the system is providing.* 1. Find out what oligoarticular JIA means. 2. For this and the other questions follow some of the question prompts that you think Taylor would be interested in. 3. Find out why an eye exam would be needed. 4. Find out what the possible outcomes of uveitis are? 5. Find out what the chances of remission are for children with oligoarticular JIA. 6. Find out what the source is for this remission information.
Scenario 2	Alex is the parent of 11-year-old who was diagnosed with enthesitis-related arthritis subtype of JIA 2 years ago. The child has been taking indomethacin since diagnosis but over the past 6 months has experienced increased morning stiffness and has had to cut back on basketball due to increased knee and foot pain. At the last clinic visit the rheumatologist found active arthritis and enthesitis and suggested adding methotrexate, a type of DMARD, to the child's treatment. Alex was overwhelmed and upset at the clinic visit. It was scary to hear about how methotrexate suppresses the immune system, and so logs on to the JADE system a week later to do some research.
CW 2 Tasks	*As you go through these tasks please "think out loud" focusing on the relevance, completeness, accuracy and credibility of the content the system is providing.* 1. Find out what Enthesitis-related JIA means. 2. For this and the other questions follow some of the question prompts that you think Alex would be interested in. 3. Find out when DMARDs are recommended for use. 4. Find out what the side effects of methotrexate are. 5. Find out if there is anything you can do to reduce the main side effects. 6. Find out what the source is for this information.

Scenario 3	Jamie is a 14-year-old who was diagnosed with Polyarticular RF positive JIA two years ago. Jamie's knees have been sore and swollen recently and s/he wants to know how best to manage these symptoms (some people say heat, some say ice) and so logs on to the JADE system.
CW 3 Tasks	*As you go through these tasks please "think out loud" focusing on the relevance, completeness, accuracy and credibility of the content the system is providing.* 1. Find out what Polyarticular RF positive JIA means. 2. For this and the other questions follow some of the question prompts that you think Jamie would be interested in. 3. Find out how to manage swollen joints. 4. Find out how one of these treatments should be applied. 5. Find out whether exercise is good for those with JIA. 6. Find out what the source is for this information.

APPENDIX D: DEMOGRAPHIC SURVEY

Please fill the following information

1. What is your role in the Division of Rheumatology? (circle one)
   - Allied Health Professional (Nurse, Occupational Therapist, Physiotherapist, Social Worker)
   - Pediatric Rheumatologist
2. How much experience do you have in this role? (circle one)
   - < 5 years
   - 5-10 years
   - 11-20 years
   - 20 years
3. What Full-Time-Equivalent do you spend working in the Division of Rheumatology? (circle one)
   - < 25%
   - 25-50%
   - 51-75%
   - 75%
4. How comfortable do you feel using computers in general? (circle one)
   - Very comfortable
   - Moderately comfortable
   - Neither comfortable nor uncomfortable
   - Moderately uncomfortable
   - Very uncomfortable
5. What percentage of family visits do you use Patient Education Materials with?

___%

Thank you!