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Providing relevant, reliable and engaging content automatically for the benefit and well-being of vasculitis patients

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of the requirements for the degree of
Master in Computer Science

Declaration

I hereby declare that this project is entirely my own work and that it has not been submitted as an exercise for a degree at this or any other university.

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Summary

Living with an illness can make everyday tasks seem impossible. An apparent lack of easily accessible information for individuals suffering from debilitating illnesses can be daunting from the outset of recovery. A high proportion of patients are resistant to researching their disease online due to the negative results that appear. A restriction on individuals living with an illness researching such illness removes the beneficial use of the internet with all the valuable information available. One solution to this is to provide content on a website or platform that can be trusted and a reliable source. Vasculitis Ireland Awareness (VIA) is a reliable source that can provide the content on two platforms, website, and mobile application.

This research investigates the use of a custom search engine and filters is developed to return only what is perceived as reliable, relevant and engaging content. The purpose is to develop a system which can fetch relevant, reliable and engaging content automatically for the benefit and well-being of vasculitis patients.

This is completed through the use of a focus group and survey as methods of data collection. The system was developed from the findings of both the focus group and survey. The focus group provided a number of beneficial insights such as more in-depth knowledge on vasculitis as a disease, gaining an idea of what type of content the participants would like to view and finally what makes a piece of content engaging and relevant. The survey assisted in the understanding of the aspects that make content engaging and relevant for vasculitis patients.

The evaluation of this system shows a number of search results being removed when the CSE and filters are applied on the query and that it is effective in providing relevant, engaging and reliable content. Whilst providing reliability, relevance and engaging content cannot be guaranteed, the system does apply filters and ranking to remove content that is perceived as not reliable, relevant and engaging which suggests that a high proportion of the remaining results are engaging, reliable and relevant. However, there are a number of further implementations before it can become a service that can be used for the benefit and well-being of vasculitis patients such as implementing the system within the VIA website, creating a user-friendly administration web tool for validation and finally a web page that displays the content.

Abstract

Living with an illness can make everyday tasks seem impossible. An apparent lack of easily accessible information for individuals suffering from debilitating illnesses can be daunting from the outset of recovery. A high proportion of patients are resistant to researching their disease online due to the negative results that appear. A restriction on individuals living with an illness researching such illness removes the beneficial use of the internet with all the valuable information available. One solution to this is to provide content on a website or platform that can be trusted and a reliable source. Vasculitis Ireland Awareness (VIA) is a reliable source that can provide the content on two platforms, website, and mobile application.

This research investigates the use of a custom search engine and filters is developed to return only what is perceived as reliable, relevant and engaging content. This is completed through the use of a focus group and survey as methods of data collection. The system was developed from the findings of both the focus group and survey. The purpose is to develop a system which can fetch relevant, reliable and engaging content automatically for the benefit and well-being of vasculitis patients.

The evaluation of this system shows a number of search results being removed when the CSE and filters are applied on the query and that it is effective in providing relevant, engaging and reliable content. Whilst providing reliability, relevance and engaging content cannot be guaranteed, the system does apply filters and ranking to remove content that is perceived as not reliable, relevant and engaging which suggests that a high proportion of the remaining results are engaging, reliable and relevant.

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1 Introduction

This dissertation outlines an investigation into whether a system can be developed such that it delivers engaging, relevant and reliable content to a group of people who have an illness called vasculitis. Vasculitis means inflammation of the blood vessel wall. Any type of blood vessel in any organ could be affected [1]. Vasculitis Ireland Awareness (VIA) are currently lacking users engaging with their website and a mobile application. A proposed plan was to create a newsletter that could present relevant, engaging content to promote more engagement with the website and mobile application.

Before discussing an approach to providing content directly to the website and mobile application, a system which fetches content that can provide relevant, engaging and reliable content to be used must be sought out. The initial plan was to have the system to be 100% automatic and have no human interaction. However, due to the high-risk factor of delivering content especially to patients, it was decided that human validation was essential.

The proposed research entailed using continuous feedback to improve the implementation of the system by receiving ongoing feedback in which the system could automatically learn and improve in providing relevant, engaging and reliable content. Due to limitations that will be discussed throughout the dissertation, user evaluations were unable to be carried out.

This dissertation will conduct an examination of content and the techniques in attempting to ensure relevance, reliability and engaging experience for vasculitis patients. A novel design for a working system that will automatically fetch engaging, relevant and reliable content and reduce the amount of human interaction needed to provide valuable content for the benefit and well-being for vasculitis patients.

In this chapter, the motivation behind the research is explained, the research question is stated, and the research objectives for the dissertation are outlined. Finally, an overview of the research and the dissertation are outlined.

1.1   Motivation

Life with an illness can make everyday tasks seem impossible. An apparent lack of easily accessible information for individuals suffering from debilitating illnesses can be daunting from the outset of recovery. Due to vasculitis being a rare disease, it can become a difficult task in gaining reliable, relevant information for the specific disease. Many fear the use of the internet due to the negative results that appear, preventing limited if any research being carried out by the patients. This study will aim to aid in the process of delivering new, relevant, reliable, and engaging content to vasculitis patients about numerous different strands including health and well-being, medical improvements, and everyday tasks.

Credible, interesting, and accurate content has become aspects that are expected when browsing online but is not always guaranteed, due to the high volume of content and that a piece of content may be considered interesting from one user but not the other. A system which fetches this content automatically can initiate the end goal, in providing vasculitis patients with appropriate content which may benefit their health and inform them on reliable content on a trustworthy platform.

1.2   Research Question

With the above research motivation and background in mind, the research question for the dissertation is:

> *How can relevant, reliable and engaging content be provided automatically for the benefit and well-being of vasculitis patients?*

1.3   Research Objectives

The main research objective is to provide a solution to vasculitis patients that will automatically fetch reliable, engaging and relevant information related and beneficial to vasculitis patient.

In order to achieve the above objective, a series of minor objectives must be completed. The first objective is to conduct a comprehensive review of the literature to confirm the rationale for proceeding with the study. Research on the methods by which content can be filtered and retrieved will be reviewed. Research into user engagement, reliability and

relevance is to be completed in order to have an understanding of what is to be achieved.

The next objective is to collect data from target users to understand their needs. An analysis from the methods will aid in the design and development of the system.

The final objective is to develop a system which automatically fetches relevant, engaging and reliable content. A system which fetches online content will be the first implementation. Once that is completed a number of tests will have to be created in order to achieve providing engaging, reliable and relevant content. The three objectives are vital requirements in order to answer the research question and the main objective.

1.4   Overview of Research

This research sets out to answer the question

> *How can relevant, reliable and engaging content be provided automatically for the benefit and well-being of vasculitis patients?*

Table 1.1 shows the 9 different stages addressed to gain an understanding of the type of content that is relevant and engaging for vasculitis patients and to use this to create a system which automatically delivers such content.

Stages	Description
Stage 1	Research question definition
Stage 2	Conduct a literature review
Stage 3	Apply for Ethical Approval Trinity College Dublin
Stage 4	Conduct Focus Group
Stage 5	Conduct Survey
Stage 6	Literature Review Repeated
Stage 7	Analyse results from focus group and survey
Stage 8	Design and implement system using results
Stage 9	Evaluate system

Table 1.1: Stages of the Research Process

1.5   Overview of the Dissertation

Chapter 1 presented the dissertation topic, the motivation behind the research, research questions and introduced the research undertaken.

Chapter 2 details the findings of the literature review. The review presents research on user engagement, content relevance, reliable content and the use of content curation and information retrieval to provide engaging and relevant content.

Chapter 3 describes the study design and research methodologies. This chapter explains the research question, aims and objectives and research approach utilised to answer the question. The discussion includes a description of the study duration and setting, data collection and ethical considerations.

Chapter 4 presents the results of the study. The insights that came from the focus group and the survey that were identified are presented. Additionally, key findings of the survey were summarised.

Chapter 5 uses the results in Chapter 4 which were obtained from the research methods described in Chapter 3 to design and implement a system which automatically retrieve engaging, relevant and reliable content.

Chapter 6 evaluates and analyse the performance of the system. The results of the study are discussed to answer the research questions and to reflect on the literature review.

In Chapter 7, the study results are reflected upon, strengths and limitations of the study are discussed, and areas for future research are identified.

2 Literature Review

This chapter presents a review of current, published evidence on the impact of content curation and information retrieval when providing engaging, reliable and relevant content to a specific audience.

2.1 Aim of the Literature Review

Studies were identified, which show the impact of receiving engaging, relevant and reliable information on patient's health and well-being. These studies showcased the techniques used for content curation and information retrieval, which enabled this.

2.2 Methods

2.2.1 Search Strategy

A systematic search was conducted using several websites. Key terms were identified for the search at first, as there was a lack of experience with this subject area. The keywords "vasculitis", "Engaging Content", "Relevance", "Reliability", "Automatic Content Retrieval", "Content Sourcing", "Content Curation" and "Information Retrieval" were the terms used to identify relevant literature published in the English language.

A list was gathered of potentially useful databases from the Trinity College University library's website of suggested databases for Computer Science research. These were then searched:

- ACM Digital Library
- Engineering Village 2
- IEEE Xplore Digital Library
- SpringerLink
- Web of Science

2.2.2   Selection Criteria

The following criteria were used to extract the relevant literature.

Study Type

Empirical studies describing quantitative, qualitative and mixed-method studies were included for research purposes. Other papers such as editorial conference proceedings, reviews, case studies, and opinions were also included in the final review. Peer-reviewed articles, written in English also considered.

Scope

Studies describing the use of content curation, or information retrieval, to benefit the reliability, relevance, and engagement of content were included. Further studies describing both user engagement and curating content were included in the review as well. Studies which observed user engagement on content that was not online was also taken into consideration and reviewed. The majority of research studies originated either from the USA or Asia. This is not surprising and may be explained due to the fact that they are the top two technology areas in the world

At first, the information was taken from literature published between 2010-2019, with a view to retrieving up-to-date information. The literature referenced content published before 2010 proved to be an important asset for this study and therefore considered, as it was seen as necessary to view it for the purpose of this research.

2.3   Definitions of Reliable, Engaging and Relevant

Authenticity, transparency, engaging, reliability, enjoyable, accurate, value and relevance are all different aspects of online content that give a user a positive experience and a strong level of quality content. Many of these aspects are very similar in definition. Therefore, three of the aspects above have been chosen to carry out research on which are considered to achieve the same high-quality content. The three aspects chosen are reliability, engaging and relevant.

2.3.1 Reliability

Reliable content can be defined as a source that provides a thorough, well-reasoned theory, argument discussion [2]. Reliability is essential when providing content to users. A guarantee of reliability is needed in order to gain trust from the readers. When attempting to provide reliable content to a certain group, it is wise to always use credible sources.

Content analysis is a social scientific methodology that requires researchers to validate and prove the reliability of their data. Stability, reproducibility, and accuracy are three distinct types of design for reliability tests in content analysis. Stability is the degree to which a process is unchanging over time. Reproducibility is the degree to which a process can be replicated by different analysts. working under varying conditions, at different locations, or using different but functionally equivalent measuring instruments. Accuracy is the degree to which a process conforms to its specifications and provides what it is designed to yield [3].

Krippendorf says that stability is

> "the weakest form of reliability and should not be trusted as the sole indicator of the acceptability of content analysis data for inference and analysis" [3].

The problem with stability is that it is solely based on one opinion. Accuracy is the strongest procedure in declaring content reliable, as it clearly established when "the handling of data is merely clerical or computational" [3]. People experienced in the field of content are usually in a position to exercise a superior perspective on the content.

2.3.2 Engaging

Until recent years, the term engaging was loosely referred to as a cognitive, effective and behavioural method of communication with a computer application that makes the user want to attend. [4]. Interactions that were viewed as engaging were thought to involve attention, interest [5, 6], interactivity [7], control [6], choice, functionality, and motivation [8]. Multiple studies from a vast range of disciplines, including presentation software, online reading, video games, and education, derived these attributes.

The model of user engagement is both a product of interaction and process. The level may alter and change during an interaction depending on the user's goals, intentions, thoughts, and the format [5]. A list of user-specific attributes are used when evaluating the term 'engaging': *aesthetic, attention, control, feedback, interest, motivation, perceived time*. These factors play a major part in successfully delivering content that is

engaging to users. Table 2.1 provides definitions for these attributes.

Attribute	Definition
Aesthetics	Visual beauty or the study of natural and pleasing computer-based environments [9]
Attention	The concentration of mental activity; concentrating on one stimulus only and ignoring all others [10]
Control	How in charge users feel over their experience with the technology
Feedback	Information that is sent back to the user about what action has been done or what result has been accomplished [11]
Interest	The feeling that accompanies or causes special attention to an object of interest or class of objects
Motivation	Elements that bring about focus or a desire to proceed with an activity [9]
Perceived Time	Users' perception of estimated time spent on task.

Table 2.1: Definitions of the attributes of engagement [5]

Making content engaging varies for each person. Therefore, making something engaging can be a difficult task to achieve as everyone is different. The smaller the cluster of people you are trying to connect with, the easier this will be. Targeting a group that all have a certain aspect in common can aid in trying to achieve the goal of producing engaging content.

A number of techniques have emerged in measuring engagement. The most common techniques have been self-report measures, for example, the 'seven item questionnaire', which contains questions on attention, challenge, and interest [6]. Another technique is to study the relationship between engagement and performance metrics, such as the amount of time completing the task and the amount of knowledge on the content [5].

Self-report measures are not as effective as performance and physiological measures, but they offer an efficient and accessible method of gaining the user's perception of an experience. As stated above a number of researchers have developed survey techniques to evaluate engagement [6], but they do not allow for domains beyond their fields. It seems that an essential way of evaluating engagement is by developing an instrument that sums up more than usability. From research, it seems that a survey instrument is the most appropriate technique for collecting a user's perception of their level of engagement.

2.3.3 Relevance

Relevance is key when providing engaging content, as without relevance there is no interest in the content. Relevance and decision-ready information are becoming a vital necessity in its own right and companies are beginning to realise the importance of understanding the needs of their consumers. Relevance is a perception the reader has of the content and, as such, is influenced by the content. If relevance is based on the perception of the reader, which can vary from person to person, it can be very difficult to make a piece of content relevant to all.

Perceiving the user's view of something that is relevant can be a difficult task. One method to achieve this is Keller's ARCs model of motivation. Keller defines relevance as a perception of personal needs being met by instructional activities or as a highly desired goal being perceived as related to instructional activities [12]. ARCs stands for attention, relevance, confidence, and motivation. This model is used in classrooms in an aim to make the content for students relevant. The idea is to first gain the student's attention. If they don't pay attention they will not be involved nor put in an effort to learn. Satisfying the student's needs and then building positive expectancies are the next steps. The final task, which is necessary for students' motivation, is satisfaction [13]. Making content relevant should be combined with strategies that gain students' attention and help them feel motivated and satisfied with the class. Keller's model is only used in schools at present, but potentially with a few alterations could be used in making content relevant for online users or a specific group of users with similar interests.

2.4 Content Curation

Online information is constant and universal, with the consequence that it can leave the user feeling overwhelmed with unfiltered, context-free content. This is fuelling a large demand for new methods to find meaningful and relevant content. It has become a difficult task to provide relevant, decision-ready information in a timely and effective manner.

A solution to these needs lies in the competencies and skills of content curation. Curation comes in many forms, from collaborative filtering to authored stories that provide new perspectives on older material. In recent years the definition of curation has expanded, as more information moves to a digital format. A museum curator, for example, does not create content but keeps abreast of trends and listens to what guests are discussing to find resources that suit well in certain areas. It is logical that it has become embraced by the internet to allow new ways of storing, categorizing and sharing data and

information.

Curation is pushing the internet away from electronic pathfinders to more flexible, dynamic and collaborative platforms for curating and sharing resources [14]. Content curation can be divided into three sections, find, curate and share. Figure 2.1 explains the process of content curation.
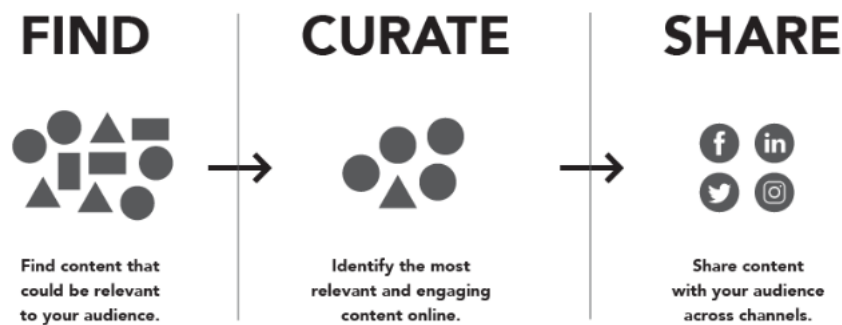

Figure 2.1: Workflow of Content Curation [15]

Social media has blossomed as a powerful content curation tool. In this era of social media and information, curation tools are a key component in fulfilling the requirements and requests of a specific user group. Content curation is still a new tool in our world, even when the practices are old. There are new technologies allowing us to utilise these practices and as we adapt to the possibilities these new technologies bring, it is easy to see the vast opportunities for storing and sharing resources.

Over the last few years, many technology tools are being used to curate and share content, with new and different features coming from these tools. It has become apparent that most technology tools depend on the algorithms as opposed to the value that human-aided curation can have. A clear example of this is online media such as tabloids, articles, and reports: they know what to answer and deliver as the public have gave their opinion in what they want to know. According to Jeff Jarvis, an American journalist, "algorithm-aided human writing will meet human-aided algorithmic curation; quality will rise" [16].

A business example can be seen in a company in Spain, who are using deep convolutional neural networks for curating content and filtering user-generated content for digital marketing tasks. The idea is to capture images from a user's Instagram and automatically enrich their data with tags that describe the content they are interested in. The tags can then be used to offer similar images with the same tasks to provide content that the user is more likely to be interested in [17].

Dell offers a platform called IdeaStorm which allows users' to submit suggestions on how

to improve existing Dell products, as well as ideas for new ones. Dell received nearly 15,000 suggestions and applied 500 of them in the form of various refinements. In allowing users' provide feedback on the products they were able to improve their products and services.

Content curation has many layers, which are all applicable to workplace learning and performance. Section 2.6 will build upon this section and discuss the three layers that are beneficial when ensuring relevant content are.

2.5   Information Retrieval

This section will discuss the 'FIND' stage in content curation which can be seen in Figure 2.1. The field of Information retrieval was born in the 1950s, Over the last forty years, the field has matured considerably. Gerard Salton, a leading computer scientist in information retrieval, proposed the following definition:

> Information retrieval is a field concerned with the structure, organization, analysis, storage, searching, and retrieval of information [18].

This definition still remains accurate and valid, despite the huge advances in the understanding of search. The term 'information' can be defined as a stimulus originating in one system. This affects the interpretation by another system of either the second system's relationship to the first. Or of the relationship, the two systems share with a given environment [19].

The term information retrieval is very general, and information retrieval includes a vast amount of work on types of information and a wide range of applications related to search. Applications of information retrieval involve multimedia documents with significant text content, pictures, video, and audio.

The main product of research in information retrieval is search engines. A search engine is an application of retrieval techniques of a larger scale of collections. The term 'search engine' can be defined as a software system, that compares queries with documents and produces a ranked list of documents. A search engine's configurations depend on the application it is designed for. Web search engines, such as Google, are expected to be able to crawl large amounts of data, and then provide results to the millions of queries submitted every day around the world. Figure 2.2 summarizes all the major problems in the design of search engines.

Custom search engines are search engines created to cohere to the creator's requests. Search engines can be created to search for information on particular topics chosen by the creator.
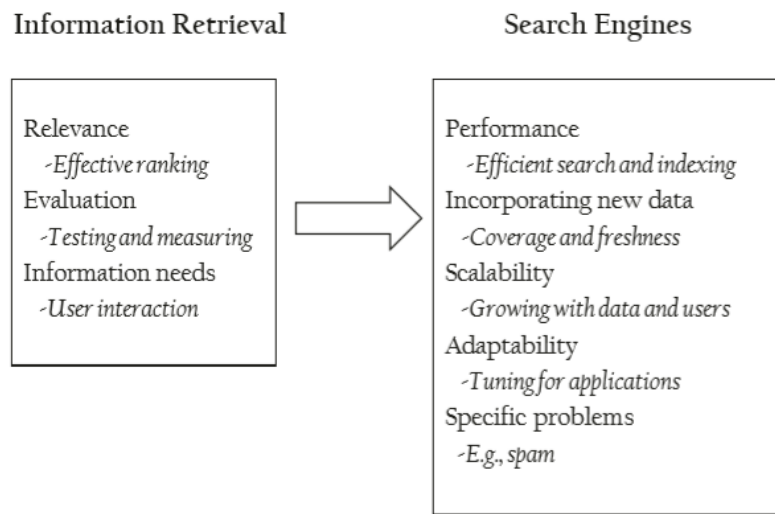
Figure 2.2: Search engine design [20]

2.6 Benefits of Content Curation when ensuring relevant content

Content curation has many layers, which are all applicable to workplace learning and performance. The five layers of content curation are Aggregation, Distillation, Elevation, Mashup and Chronology [21]. The three layers that are beneficial when ensuring relevant content are:

- **Aggregation:** Google can only attempt at giving you the most relevant content you desire, as there are millions of pages that could be returned for a search result. Aggregation is the process of curating the most viable information about a certain topic into one location. Volume is generally not an issue for aggregation, as you may have a lot of source material but it is all in a single location and not distributed across the internet.

- **Distillation:** The most valuable activity that someone could undertake, is adding a layer of simplicity. Distillation is the act of curating information into a format that is in its simplest form where only the vital, relevant ideas are shared. This can lead to some content be misplaced and removed, however, the benefit lies in the fact that anyone digesting the content will not have to go through a high volume of content and it can produce a more focused view of information.

- **Chronology:** Time is a major factor when attempting to make content relevant. The evolution of information provides an interesting insight into how concepts and our understanding of topics have changed over time. Creating a chronology is a form of curation that fuses historical data and information based on time to show the evolution of a particular topic.

The two other factors remaining are elevation and mashup which for this study are not deemed necessary to ensure relevant content. Elevation refers to curation with the purpose of identifying a trend or insight that would be considered large from a smaller daily post online. Mashups aids in creating a new point of view by merging existing content.

2.7 Benefits of Information Retrieval when ensuring relevant, reliable content

A key issue that remains in the era of web search engines is relevance. Relevance is a fundamental concept in information retrieval. A relevant document ideally contains the information that a certain person was looking for when a query was submitted. This may sound like a simple request, but there are many factors that go into a person's decision as to whether the content is relevant. These factors must be taken into consideration when designing algorithms and ranking the documents.

When evaluating relevance, it is important to distinguish between topical and user relevance. A piece of content is topically relevant to a query if it is on the same topic, whereas user relevance is solely based on the user's perception of the content. From research, it has become clear to put more focus on user relevance when targeting a specific group with similar interests.

Another core issue is evaluation. The quality of a document's ranking solely depends on how the person views the ranking which makes it necessary to develop evaluation measures early on for obtaining the data and to use it against ranking algorithms. Two of the main measures used are precision and recall. Precision is the proportion of retrieved documents that are relevant to the query, while recall refers to the proportion of the relevant documents that are successfully retrieved [20]. These two metrics are quite contradictory: techniques that hurt precision tend to improve recall and vice-versa. Many researchers have used various ranges of recall and precision to evaluate ranked retrieval. It generally depends on the system on which is more important to the users.

2.8 Conclusion

This chapter defines the background for this project. A literature search was completed on topics such as user engagement, information retrieval, and content curation. The benefits of the topics were then discussed with regards to relevance and reliability. The assumption is made that using these topics in a system to improve reliability and relevance and the level of engagement with the content may, therefore, be advantageous.

3 Methodology

This chapter describes the steps taken to address the research question in Section 1.2. Details on the methods used to collect the data from vasculitis patients collect data from vasculitis patients. These details are used to understand the needs and preferences of vasculitis patients to inform the design and implementation of the system are discussed. The research aims and objectives will be outlined. The participant selection, ethical considerations, and process involved for the study will be discussed. The final components of the chapter will discuss in detail the development, concept, pilot, and distribution of the questionnaire. Data collection, management, and analysis will conclude the chapter. Chapter 5 will describe the design and implementation of the system which was created from the findings discussed in Chapter 4 of the methodology explained below.

3.1 Aims and objectives of the study

The aim of the study is to prospectively provide a solution to vasculitis patients support organisations that will automatically fetch accurate relevant, reliable and engaging information related to vasculitis patients.

The specific objectives are:

1. Conduct a comprehensive review of the literature to confirm the rationale for proceeding with the study.

2. Carry out methods used to understand the needs and preferences of target user, i.e. vasculitis patients.

3. Analyse the results from the methods to aid in the design and implementation process.

4. Provide a system which provides content that passes certain tests to ensure a standard of relevance, engaging and reliability.

Conducting a comprehensive review of literature can be seen in Chapter 2 (Objective 1). A focus group and survey was carried out to understand the needs of vasculitis patients which are explained below (Objective 2). An analysis of the methods is discussed in Chapter 4 (Objective 3). The design and implementation of the system which provides content that passes certain tests to ensure a standard of relevance, engaging and reliability is shown in Chapter 5 (Objective 4).

A proposed work-flow was developed prior to proceeding with the research. The work-flow diagram ensured the research plan coincided with the Aims and Objectives of the study. The work-flow diagram is shown in Figure 3.1.
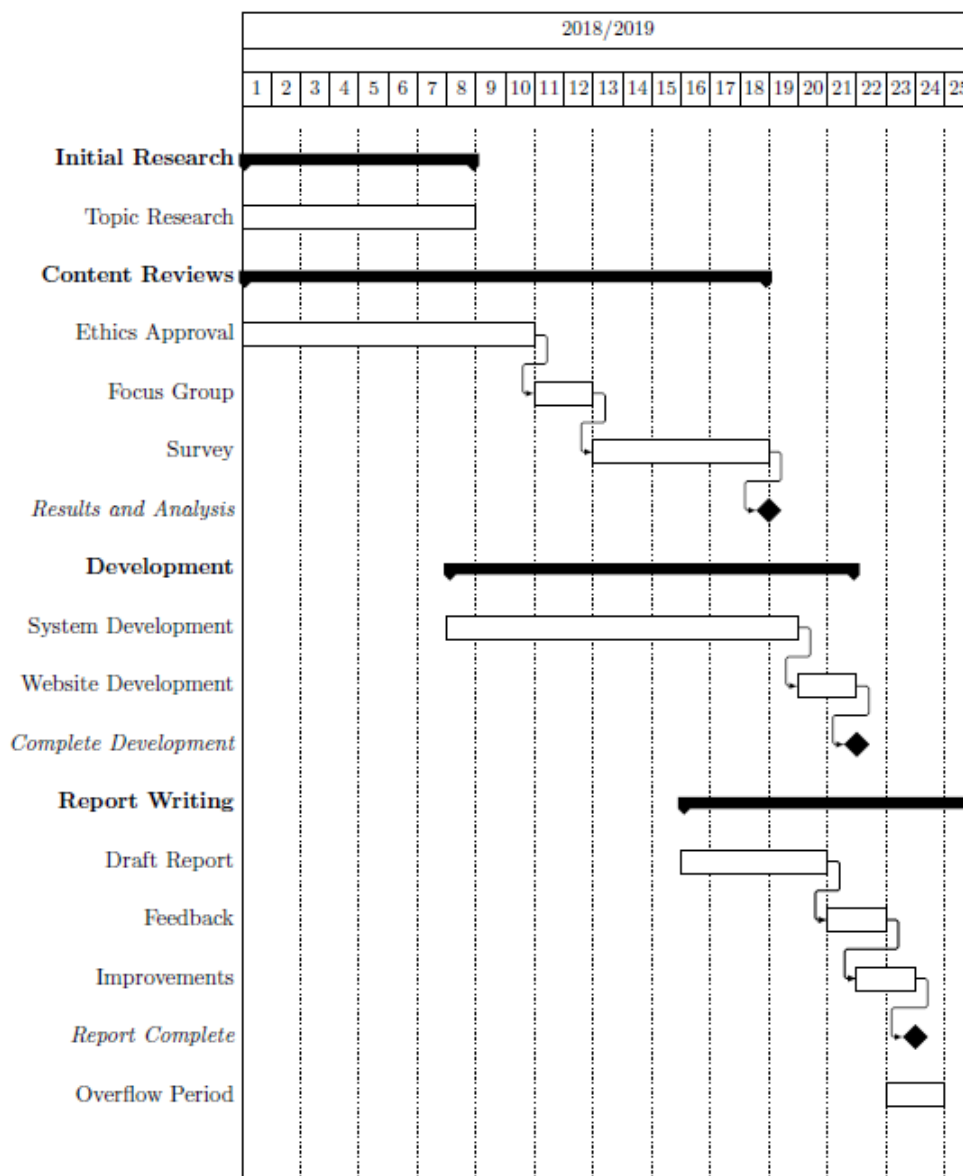

Figure 3.1: Work-flow diagram of proposed research plan

3.2 Research Methods

There are many possible approaches when undertaking a research study. The three main research paradigms are Quantitative research, Qualitative research, and Mixed methods research. Quantitative research methods are useful for studying a sample of the population and obtaining numeric data reflective of attitudes or opinions [22]. Quantitative research is often defined as an objective process where large amounts of data can be captured, culminating in the production of numerical and statistical information (Barnham2015).

In contrast to quantitative research, qualitative research seeks to elicit a more in-depth understanding from participants of a study and often involves a smaller study population [23]. Qualitative data collection includes interviews, focus groups, observation, and action research. Qualitative research necessitates a reflective approach from the researcher. Perspectives and biases are often unavoidable in qualitative research but should be avoided if possible.

Mixed methods research can be defined as a synthesis in which researchers combine qualitative, quantitative, and apply a mixed methods approach in order to integrate those studies, for the broad purposes of breadth and depth of understanding [24]. Mixed methods researchers believe this combination of methodologies decreases the risk of bias associated with using only one particular method.

Prior to selecting a methodology, a consideration in approaching the research question utilising quantitative, qualitative and mixed methods approach was carried out. It is crucial that the most appropriate data collection method was applied to the chosen research setting to guarantee accurate results are chosen [22]. The method opted to use was a mixed methods research study.

Qualitative data collection, such as face to face interviews or focus groups require interaction between moderator and participants in order to gain a more in-depth comprehension of human behaviour [23]. A beneficial insight into the research would be gained from a focus group. There is a number of quantitative data collection techniques used to gather data such as observation, experiments, and surveys. The literature review in Section 2.3.2 explains how a survey instrument is the most appropriate technique for collecting users perception of their level of engagement. It was decided that a self-administered survey and the organisation of a focus group would be utilised.

3.3   Research Design

The three elements that are used to gain an understanding from vasculitis patients in relation to content are relevance, reliability, and engagement. The elements relevance, reliability and engaging were chosen as the main factors to aim to achieve. From the review of the literature, it can be clearly seen that they are important features to provide interesting, enjoyable, and trustworthy content. One task from the focus group and survey design was to grasp an idea in what those elements mean to vasculitis patients. The review of the literature and the findings from the focus group and survey intend to aid in the process in developing the system. This system aims to fetch content that is considered engaging, relevant and reliable.

3.3.1   Focus Group Design

> "A focus group is, at its simplest, an informal discussion among selected individuals about specific topics" [25].

Focus groups have been used by sociologists and psychologists for over a century, but it is only in the last 30 years that they have become a popular method of social research. Discussions between group participants, directed by a group 'moderator', are usually transcribed. The data is then subjected to the type of qualitative analysis.

This method is distinct for its data collection procedures and for the nature of the data collected. Focus groups involve the interaction of the moderator with the group participants but also the participants with each other. The collection of this kind of interactive data is what distinguishes a focus group from a one-to-one interview.

The purpose of the focus group is to get open feedback and allow the participants express clear ideas and share feelings that may not come across from in the online survey described below. A benefit of using a focus group is allowing an open conversation among group members where topics and discussions are freer flowing and members can use comments from others to stimulate recall. This ideally will stimulate more interesting insights that could benefit the implementation of the system.

The initial plan is to recruit as many participants from Vasculitis Ireland Awareness (VIA) and start an open conversation about vasculitis and the issues around information on vasculitis. Once an initial conversation has begun, specific questions will be asked based around relevance, reliable and what features help make content engaging. Once an initial idea was planned and researched, it was time to propose an ethics application. Further discussion on the focus group can be found in Section 3.6

3.3.2 Survey Design

> "A survey is a method of collecting relevant descriptive data from a number
> of individuals, groups or representatives of groups in order to answer a
> research problem or question" [26].

The survey intends to retrieve user feedback on certain content. Feedback refers to a measure of how positively or negatively a user has reacted to an item. More specifically explicit feedback is a process that involves users assigning either scores or ratings to evaluate items recommended by the system [27]. A common feedback mechanism where a user is prompted to provide feedback about a certain item are surveys.

The intention for the survey is to provide an understanding of what content vasculitis patients consider to be engaging and relevant. Due to the rarity of vasculitis as a disease, there are limited available participants for the study. An online survey allows the range of available participants to increase providing the research with more recorded results. The following are some of the most popular forms of surveys:

- **Like:** This binary feedback mechanism gives the user a method of expressing their interest in an item. This feedback mechanism is widely used as it is very simple, but it comes with the cost of granularity and the ability to show dislike for an item.

- **Like/Dislike:** This feedback mechanism is very similar to the like mechanism but it also allows the user to dislike an item. An advantage to this feedback mechanism is allowing users to express like or dislike for items and having no granularity to the ratings so there is no worry with the users remaining consistent with their ratings. A disadvantage is there is no ability for the user to differentiate between items they like and items they strongly like.

- **Rating:** A user is prompted to give a rating for an item. This numeric rating can be done in the form of a star rating between 1 and 5, where 1 denotes a poor rating and a 5-star rating denotes a great rating. Consistency can be an issue for this feedback mechanism but the user can express a range of like and dislike for an item.

The like/dislike form of a survey was chosen for the purpose of this research as it allows the user to express their full opinion on the question in the survey. An online survey allows respondents to answer with more candid and valid answers. To get the most accurate data, you need respondents to be as open and honest as possible with their answers. An online survey also assures the participants of confidentiality within the survey. Further discussion on the survey development can be found in Section 3.7.

3.4 Ethical Approval Process

Before conducting the research, it is indispensable to consider a number of factors such as the participant's details, confidentiality and participant/organisation privacy.

3.4.1 Ethical Consideration

Data collection is the only ethical consideration for this research. All participants are volunteers and therefore have the right to withhold information or refuse to participate in certain aspects of the study. I will follow the General Data Protection Regulation (GDPR); for example, all information gathered will be disclosed to them and they will be allowed to have it deleted. All information will be used for my final year project then destroyed. All participants will remain anonymous.

3.4.2 Ethical Approval

An ethical proposal (see Appendix A1) was submitted to Trinity College Dublin's School of Computer Science and Statistics Research Ethics Committee in November 2018. Minor changes were made as suggested by the committee, before re-submission. The ethics application was approved in January 2019.

3.5 Recruitment of participants

Recruiting participants for research involving human subject is an exigent task and necessitates a number of activities such as identifying eligible participants, explaining the study to potential participants, and recruiting an adequate desired sample based on study goals and design, obtaining informed consent, maintaining ethical standards and retaining participants until completion of the study [28]. Participants for the survey and focus group were obtained from Vasculitis Ireland Awareness (VIA). The participants ideally would have vasculitis themselves but may also sign up if they have some knowledge on vasculitis. An email was sent out (see Appendix A2) which informed the participants of the research project with an information sheet and displayed the link to the survey. A separate email was sent(see Appendix A3) which invited participation to the focus group.

3.6   Focus Group

To explore what vasculitis patients would be interested in, regarding content specifically under the relevance, reliability and engaging categories, a qualitative study was formed using a focus group. Section 3.5 explains the recruitment process for the focus group. The participants received the information sheet before arrival to view. Nine participants signed up to participate in the focus group.

A technique in keeping the participants engaged and motivated is to keep the conversation natural and allow it to flow, by occasionally letting it go off topic for a few minutes. At the same time, the moderator must make sure the discussion stays broadly on-topic. This can be by asking open-ended questions and by guiding participants to consider different points of view. Another way of achieving this is to try to make each question sound natural and for the moderator avoid reading questions aloud.

3.6.1   Material

A set of questions was asked to the participants of the focus group. The questions intend to spark a conversation and facilitate thoughts on the questions but also to open a wider conversation.

The questions are closely linked to the objectives in Section 3.1. The questions aim to aid in providing a solution to the objectives and obtain as much insight from the participants on the specific topics. The material was designed to cohere with Kellers ARC model which was discussed in the literature review in Section 2.3.3. The model discusses the importance of gaining the users' attention, satisfying their needs and motivation. The plan and questions for the focus group were designed around this model.

The questions were:

1. What type of content is relevant to you?

2. What makes content engaging for you and what stands out for you?

3. What is an important feature (image, colour, short text) in an article or online content?

4. Is ensuring content is reliable a major factor for you?

3.6.2 Procedure

At the start of the focus group, the study was explained, its purpose, the role of the moderator (the researcher), and how their responses will be confidential and anonymous. Information sheets and consent forms which were all signed before commencing the focus group were handed out. Data collection included note-taking during the session.

Once the introduction and forms were completed, an initial conversation starter began that was an open question for anyone to talk about vasculitis and the difficulties of vasculitis. A more in-depth insight into vasculitis was understood.

A list of questions was read out, one by one. As the participants suggested answers, they were put on post-it notes and stuck in view for the participants to see and discuss the results. The questions helped guide the discussion and keep it on topic. The results from the participants began to open more conversations and reveal more interesting insights into the topics. Each discussion was allowed to continue until all topics had been exhausted.

At the conclusion of the focus group, the researcher gave a summary of the major points of the discussion and gave the participants the time to confirm or clarify any points or suggest any new information from the questions. This summary technique allowed the participants and moderator confirm their thoughts which were interpreted by the moderator. The moderator thanked the participants for their time and feedback, discussed contact information, requested that they also complete the online survey which is discussed in Section 3.7.2, to further contribute in the research study, and discussed the intention to share the final research with them. The post-it notes were collected and the field notes were documented.

3.6.3 Data Analysis

On completion of the focus group, the researcher reviewed the field notes. The field notes were documented with pseudonyms for confidentiality. Content analysis can be defined as "a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use" [29]. Krippendorf identifies a number of stages to undergo during content analysis for a focus group [29]. The stages are:

- Data making

- Data reduction

- Analysis

These stages were completed when analysing the field notes. They were refined and compiled to review the notes of importance. An analysis of the results can be seen in Chapter 4.

3.7 Survey

3.7.1 Survey development

An online survey was developed to include questions that would provide the relevant content in conjunction with the research question. The review of the literature revealed in Section 2.3.2 that a survey instrument is the most appropriate technique for collecting a user's perception of their level of engagement. It was considered as to whether to create a paper-based questionnaire or an online version. Exclusively providing a paper-based survey would exclude a large potential of valuable participants. It was decided to solely create an online survey to expand the number of potential participants across the sea.

The online survey was developed in Qualtrics, which is a web-based survey tool for developing, distributing and analysing surveys. The survey was tested utilising Qualtrics test and preview tools to ensure functionality and usability. The information sheet and consent form were presented initially on accessing the online link for the questionnaire which had to be approved and accepted before completing the survey (see Appendix A4 for information sheet and consent form).

3.7.2 Survey content

The survey contained 24 questions in total (see Appendix A4 for survey). The initial questions displayed the information sheet and consent form. These questions were closed questions yielding a yes or no response and would only progress with the survey if yes was selected. The next question checked if the participant has vasculitis.

The remainder of the survey consists of a number of snippets which were articles, blog or reports on certain topics around vasculitis. The two questions for each image were whether the participant found this content engaging and/or relevant. The yes or no response was chosen by the participant for whether the content was engaging and whether it was relevant. An example of a question from the survey is displayed in Figure 3.2.

Figure 3.2: Example of a question from the survey

The snippets were selectively chosen to provide certain features. The results from the focus group aided in the process of picking the snippets of content. Each picture was specifically picked from a Google Search on the basis of containing an element which may or may not enhance the decision on whether the content is engaging and/or relevant. The different characteristics, such as images, length of text and title were chosen to learn what characteristics yield a promising response. Table 3.1 defines the characteristics that are present in each image of the survey. The image for each photo corresponds with the question the image is on in the survey.

Photo No.	Contains Image	Short Title	Long text length
4	Yes	Yes	Yes
5	No	No	Yes
6	No	No	Yes
7	Yes	Yes	No
8	No	Yes	No
9	Yes	Yes	Yes
10	No	Yes	No
11	Yes	Yes	No
12	Yes	No	No
13	No	Yes	No

Table 3.1: The characteristics that are present in each snippet of the survey

An open free text question was utilised for the final question to allow for comments from the participant. This feature was added to allow for a more open-ended approach to capture more in-depth information whilst seeking to reduce bias often associated with quantitative research [22].

3.7.3 Survey pilot

The survey was reviewed and revised following feedback from the research supervisor and colleagues. The online questionnaire was tested by a member in VIA. Following the pilot of the questionnaire, further amendments were made and it was made live for participants to partake in January 2019.

3.7.4 Data Collection and Management

Data collection was achieved automatically in Qualtrics as participants submitted their completed survey. The survey was only considered completed if they accepted the information sheet and the consent form, answered every question and clicked "submit my results". The survey was considered void if this was not achieved.

The data was stored in Qualtrics. The data was exported to Microsoft Excel for analysis and to illustrate the findings. The data was stored on an encrypted personal computer. The researcher was the only person with access to the computer. No personal information was collected from participants, and therefore all participant data was anonymous. Consent forms are stored on the computer and will be deleted following the completion of the study. Creswell maintains that research data should be stored for a minimum of five years after the publication of the research [22].

3.7.5 Data Analysis

The data was captured in Qualtrics. Qualtrics provides data and analytics functionality which proved to be useful when generating the necessary analysis and reports. The Qualtrics report was exported with the data numerically coded for analysis in Qualtrics and Excel. Charts, tables, and descriptive statistics were produced to demonstrate the findings which are presented in Chapter 4.

3.8   Limitations

As explained above in Chapter 1, the initial intention was to use the focus group as the start of the research to aid in the basis of the implementation of the system and use a bi-weekly survey as continuous feedback to improve and modify the implementation. The plan was to potentially use the results from the multiple surveys to apply automatic learning to the results. Unfortunately, due to an 11 week wait for ethics approval, and a low number of available participants (due to a low population with vasculitis) for the focus group which delayed the focus group by an additional 5 weeks this was not possible. The ethics application was submitted on November 13th and wasn't approved until January 28th. Once the ethics was approved, the plan for carrying out the focus group and survey were altered. The focus group did act as an initial insight into the minds of vasculitis patients but much later in the project process than intended. The focus group was unable to be carried out until the 8th of March. The continuous feedback from the survey, unfortunately, was not able to be carried out due to time constraints and as a consequence there was no opportunity to run full user evaluations. A single online survey was released on the 2nd of February and the results were analysed which are presented in Chapter 4.

3.9   Conclusion

This chapter discussed the chosen methodology and the motivation for selecting the mixed methods research method. The aims and objectives were outlined to clarify the intended approach and rationale. The data collection techniques were outlined and discussed in great detail. The limitations due to a delayed ethics approval were outlined which altered the results which will be discussed in great detail in the next chapter.

4 Findings from Focus Group and Survey

This chapter presents the results from the research conducted using the focus group and survey described in Section 3.6 and Section 3.7 to aid in understanding the needs and preferences of target users (i.e., vasculitis patients) and in answering the research question which can be found in Section 1.2. The results will benefit in the design and implementation of the system described in Chapter 5.

4.1 Insights from focus group

The focus group as a whole provided valuable information to benefit the research study in full. The main aspects that the researcher found useful from the focus group was receiving a more in-depth knowledge on vasculitis as a disease, gaining an idea of what type of content the participants would like to view and finally what makes a piece of content engaging and relevant. All the findings from the focus group aim to aid in the design and implementation process of the system.

The focus group gave the researcher a glimpse into the everyday lives of vasculitis patients and the difficulties they go through with. Some are left with permanent physical damage, disability or psychological damage. It became clear that an important task when diagnosed with vasculitis is to educate themselves about their particular vasculitis disease, including medication, side effects, and potential problems.

A discussion about what the future newsletter will entail was outlined briefly. The system will be the method in fetching reliable, relevant and engaging content. Concepts arose, such as forums to allow users to post their stories in the hope that it may benefit other readers and the inclusion of different sections for the different types of vasculitis.

The topics which the participants thought were necessary provided relevant valuable information for the development of the system. The topics below are the few that the

researcher and the participants agreed on as the most important and relevant to use as a basis of the system. The topics that were suggested were as follows:

- Basic definition for vasculitis
- Different types of vasculitis
- Information for families
- Side effects of drugs
- Diet and lifestyle of a person with vasculitis
- Support groups and workshops
- List of Symptoms
- Clinical trials and improvements on medicine

The focus group identified multiple insights into content curating and retrieving relevant, reliable and engaging information online. A large proportion of the focus group consisted of the elements within a website which the participants find engaging. The three main insights from this question that will have an impact on the design and implementation of the custom search engine are (1) Lack of concentration, (2) Visual and hearing impairments and (3) Positivity which will all be discussed in detail below.

4.1.1 Lack of concentration

Many of the participants complained about finding it hard to concentrate on a specific task for a long period of time due to fatigue and from the side effects of the medication the participants are taking. This was emphasised throughout the whole focus group and made the main priority to be discussed once the conversation was initiated. The participants provided the researcher with some elements of online content that would aid in the prevention of the user losing concentration. Reducing and condensing the amount of text was the main aspect the participants suggested in order to combat the loss of concentration they experienced.

Discussing this issue with the participants, it was found that the use of bullet points, short paragraphs separated by images or tables were beneficial in keeping concentration when reading content online. Further analysis of this is carried out in Section 4.2.2. Ensuring that the content is a certain length will be the main priority to achieve when implementing the filters which are described in Chapter 5.

4.1.2 Visual and hearing impairments

One topic brought up was to accommodate for visually and hearing impaired patients as this is a common issue with people living with vasculitis. It was agreed that hearing

impairments would not be a major factor in the implementation process as the website intends to be a visual information system.

Visual impairments, on the other hand, should be addressed. The participants explained that their sight is not generally completely gone but it can be difficult to read small text or certain fonts. Participants explained the importance of images as they find enhancing the visual aspect of a website and content can greatly improve the readability of the content on a website.

Communicating visually is what we have done for the vast majority of human history and as Brown points out, "We are neurologically wired with an overwhelmingly visual sensory ability" [30]. Taking advantage of what communication professionals have identified as the benefits of the visual medium will aid in communicating text more effectively.

Processing an image is not only more effortless than words but also easier to remember. Pictures enter long-term memory in two codes: one visual and the other verbal, each stored in different parts of the brain, whereas when words enter they do so with a single code [31]. This increases the odds of remembering as it allows for two independent methods of accessing visual memories. A method to ensure remembering something is to use both words and pictures so we store visual and verbal memories separately.

Adding illustrations to text aids comprehension and learning. A research study discovered that the effects of text and illustrations together increased the understanding by 98 percent [32]. Pictures provide examples, extra-lingual information, and redundancy which aids recall. The participants repeatedly spoke about the importance of images to visually explain the text or information. This will not only aid with visually impaired patients but also will benefit patients with no impairment visually. This will be a major priority in the design and implementation of the system.

do you have a reference for this or are you just talking about how anytime I get a headache google tells me I have cancer, am pregnant and have an std

4.1.3 Positivity

Throughout the duration of the focus group, a word that was brought up constantly for every discussion was positivity. Many of the participants are afraid of searching online about their illness due to the fear of what they might discover. Negative results are also prone to appear from a search relating to an illness. This is a big factor for the participants and explained the importance of presenting positive results to boost morale. A 2015 Harvard study analysed 23 online symptom checkers and found that they produced an accurate diagnosis as the first result just 34 percent of the time [33].

Research studies suggest that positive thinking can boost the immune system and counter depression. Studies have shown an indisputable link between having a positive outlook and health benefits like lower blood pressure, less heart disease, better weight control, and healthier blood sugar levels [34].

A research study done at North western University Feinberg School of Medicine in Chicago, developed some skills to help foster positive emotions. One of the skills is to recognize a positive event each day. It is important to steer clear from negative content and focus solely on positive content [35] .

4.2   Evaluating results from survey

The main objective of the survey was to get an understanding of what aspects of the content the vasculitis patients find engaging and relevant. There were 40 responses in total for the survey. However, 10 of the responses were incomplete and 6 participants declined to record their responses. Therefore, data analysis was derived from the remaining 24 respondents. Out of the remaining 24 responses, two of the recorded surveys were from participants without vasculitis. The two responses were included as considered valuable results for the study.
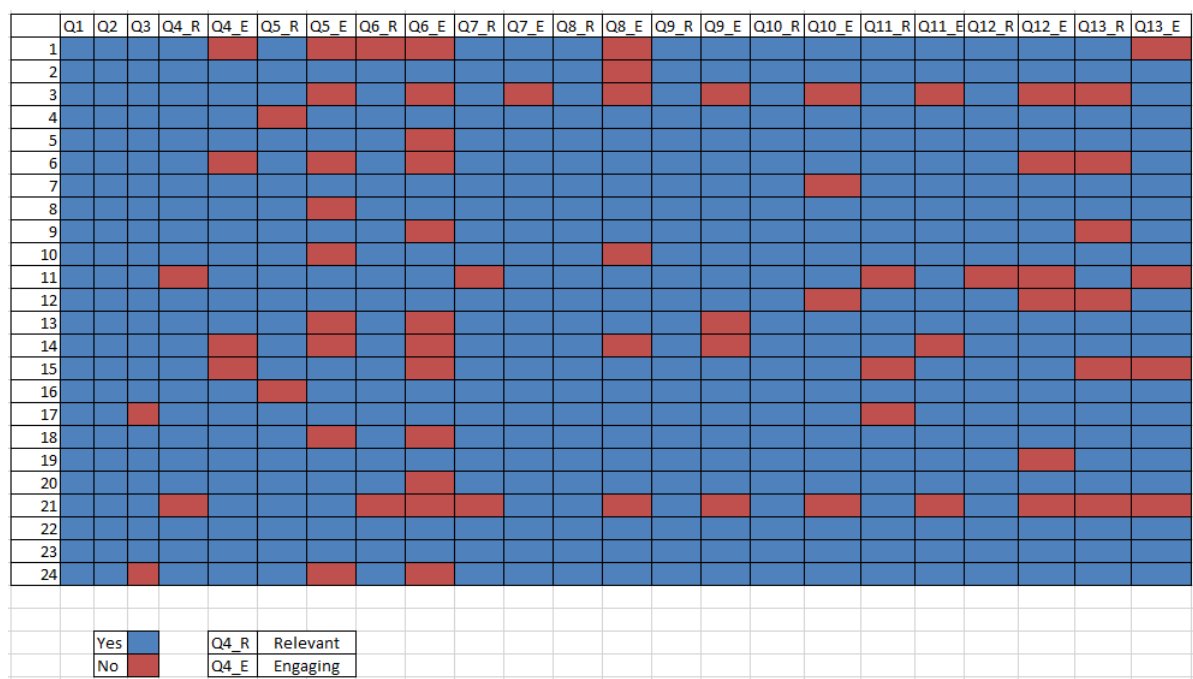

Figure 4.1: Overall results from survey

The overall results are shown in Figure 4.1. This shows the results from each of the 24 respondents. Their responses are represented in blue if voted yes and red if voted no.

Each snippet consisted of two questions, whether it was considered engaging and whether it was relevant hence the two questions for each question number. (see Appendix A4 for survey)

Photo No.	Contains Image	Academic Paper	Long text length
4	Yes	Yes	Yes
5	No	Yes	Yes
6	No	No	No
7	Yes	No	No
8	No	No	Yes
9	Yes	No	No
10	No	No	No
11	Yes	No	No
12	Yes	No	No
13	No	No	Yes

Table 4.1: The key features in each snippet of the survey

Table 4.1 displays the key features present in each snippet of the survey. An analysis of whether an image, the length of text and if it's an academic paper will be carried out on a sample of the snippets to enhance the findings from the focus group in Section 4.1 and to provide more results for the design and implementation of the system. Due to the limitations explained above in Section 3.8 and a small number of completed surveys, the results don't provide any definite answers but with them and the focus group, they aid in the design and implementation.

4.2.1   Content Analysis on the use of images

As explained above in Section 3.7.2 the images were strategically chosen from the insights of the focus group. The insights provided the preferred features to be included by patients with vasculitis. Out of the 13 snippets in the survey, only 5 contains images. Table 4.2 compares relevance and engaging coefficient on whether an image is present in the content.

	Engaging	Relevant
With Image	73%	86%
Without Image	55%	85%

Table 4.2: Relevant and Engaging coefficients on whether an image is present

The results from table 4.2 reveal a surprising finding that with or without an image the levels of relevance present doesn't change. However, in line with results of the engaging coefficient, it can be concluded that an image present in content can greatly increase the levels of how engaging it is.

To further evaluate the importance of an image to provided user engagement with the content, two of the snippets from the survey were chosen, one with an image present and one without. These two snippets were chosen as they both are not academic papers and also considered a short length of text. Comparisons of the percentages of yes in whether the content is engaging and/or relevant will be carried out.

Figure 4.2: Snippet from survey with an image present [Q7 from survey]

Figure 4.3: Snippet from survey with no image present [Q6 from survey]

Figure 4.2 displays a snippet with an image present, for which the responses from the survey are compared with that for the no-image snippet in Figure 4.3. The results from Figure 4.4 show 91% of participants believe this content to be relevant and 96% of participants find it engaging. This is a remarkable outcome and it has one of the lowest percentages from all the snippets in the survey of 'No' in both categories, relevance and engaging. This is a surprising result as the image does not even aid in the explanation of the context but it does add visual appeal to the snippet.

	Yes	No
■ Relevant	22	2
■ Engaging	23	1
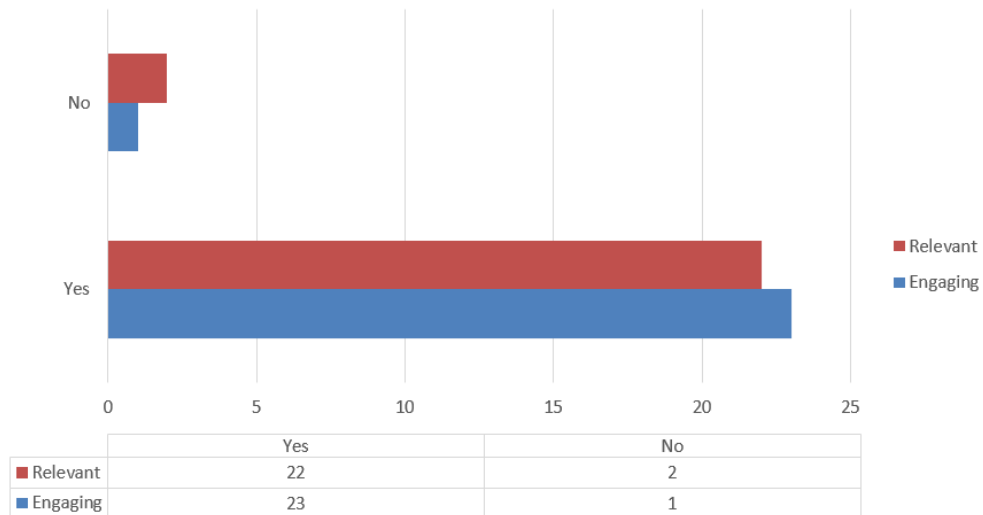
Figure 4.4: Results of how relevant and engaging Q7 is from the survey

In order to confirm the correlation between images being present in the snippets and a high level of engaging content, an analysis of a snippet without an image will be done. Figure 4.3 displays a snippet which does not contain an image from the survey in which the participants decided whether it was engaging and/or relevant.

	Yes	No
■ Relevant	22	2
■ Engaging	12	12

Figure 4.5: Results of how relevant and engaging Q6 is from the survey

The results from Figure 4.5 show 91% of participants believe this content to be relevant and 50% of participants find it engaging. That is a large decrease in comparing against the engaging percentage when an image is present. 46% decrease, which is a substantial decrease, which leads to the assumption that images and the visual appeal aid in the intention to provide content which is engaging [32].
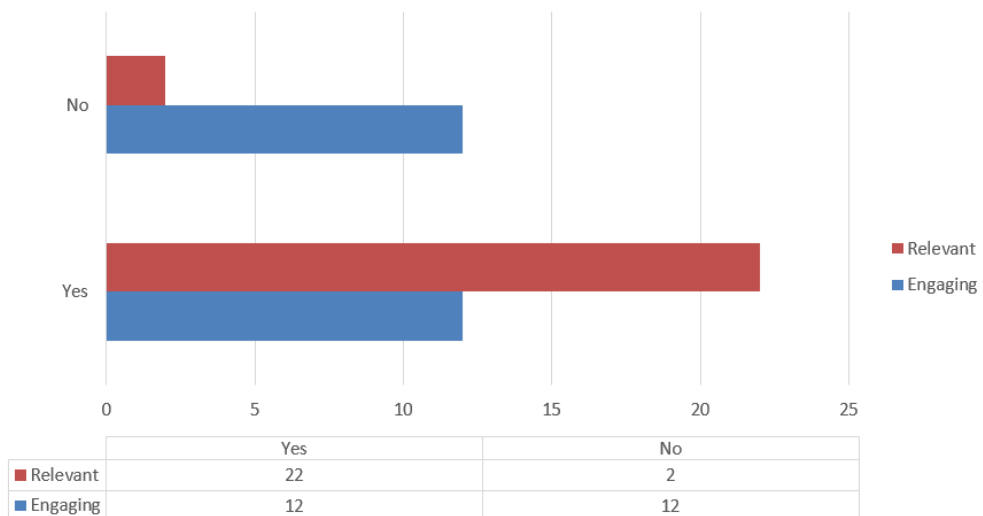
From the research above and the results from the focus group in Section 4.1, there is a clear correlation between an image being present in content and the level of how engaging the content is. This discovery will be considered in the design and implementation of the system which can be found in Chapter 5.

4.2.2   Analysing the impact on the amount of text

In order to compare and contrast the snippet with regards to the length of text in the article. A value for the threshold length of text in which the user will most likely lose concentration needs to be declared. The average reader reaches around 200 words per minute with a typical comprehension [36]. The average person has an average attention span of 14 minutes when reading online content [37]. This equates to a max of 2400 words of text before reaching the maximum levels of concentration. For the purpose of this study, the threshold was set to the average amount of words present in the snippets as to provide an accurate representation against the snippets alone. The threshold length of text is 220. Table 4.3 compares relevance and engaging coefficient on whether the content is considered a short length of text. This is further analysis from the lack of concentration insight from the focus group explained in Section 4.1.1.

	Engaging	Relevant
< threshold text length	60%	83%
> threshold text length	37.5%	86%

Table 4.3: Relevant and Engaging coefficients on whether the content is considered a short length of text

From the results above, it is clear that when the content is less than the threshold length of text it increases how engaging it is by 22.5%. However, in line with the results of the relevant coefficient, it can be concluded that the text length does not have a large impact on the relevance of the content.

To further evaluate the importance of the length of text to enhance user engagement, two of the snippets from the survey were chosen to be compared against each other. One that is less than the threshold length of text and one that is over the threshold length of text. The two snippets were chosen as they both do not have images present, but one is an academic paper which also may be the cause of a lower engaging result. Comparisons of the percentages of participants who chose yes in whether they view the content as engaging and/or relevant will be carried out. Figure 4.6 displays a snippet that is below the agreed max text length from the survey. The word length for Figure 4.6 is 152 words.

Vasculitis

👍 Like

What is Vasculitis?

Vasculitis is an autoimmune disease in which the body mistakenly sees blood vessels as a foreign invader and attacks them, causing inflammation and leading to a narrowing of the vessels. Vasculitis can occur by itself or can be a feature of a rheumatic disease, such as rheumatoid arthritis, systemic lupus erythematosus (SLE; lupus) or systemic sclerosis. In severe cases, patients can develop organ damage or death. About 100,000 Americans per year are admitted to the hospital because of vasculitis. Vasculitis can affect people of all ages, races and gender.

There are many types of vasculitis. They are classified according to the size of the blood vessels affected.

- **Large vessel.** Polymyalgia rheumatic, Takayasu's arteritis, temporal arteritis (and giant cell arteritis)

- **Medium vessel.** Buerger's disease, cutaneous vasculitis, Kawasaki disease, polyarteritis nodosa

- **Small vessel.** Behçet's syndrome, Churg–Strauss syndrome, cutaneous vasculitis, Henoch–Schönlein purpura, microscopic polyangiitis, Granulomatosis with polyangiitis (GPA), Golfer's vasculitis, cryoglobulinemia

Figure 4.6: Snippet from survey that is below the threshold length of text [Q10 from survey]

The results from Figure 4.7 show that a remarkable 100% of participants believe this content to be relevant and 96% of participants find it engaging. Relevance of 100% is an astonishing result but when comparing against the other relevance results, there is an average percentage of 86.5%. This seems to suggest that factors such as the length of text does not have an effect on relevance.

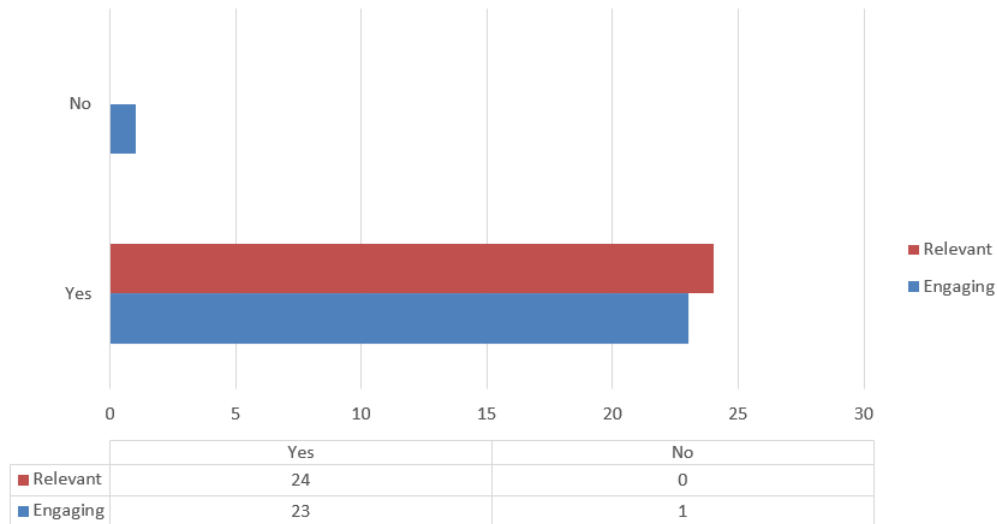|	Yes	No
Relevant	24	0
Engaging	23	1

Figure 4.7: Results of how relevant and engaging Q10 is from the survey

In order to confirm the correlation between length of text in the snippets and the content being engaging, an analysis of a snippet with the length of text exceeding the threshold length will be carried out. Figure 4.9 displays a snippet where the text length exceeds the threshold length of text from the survey. The word length for Figure 4.9 is 276 words which is above the threshold of 220 words.

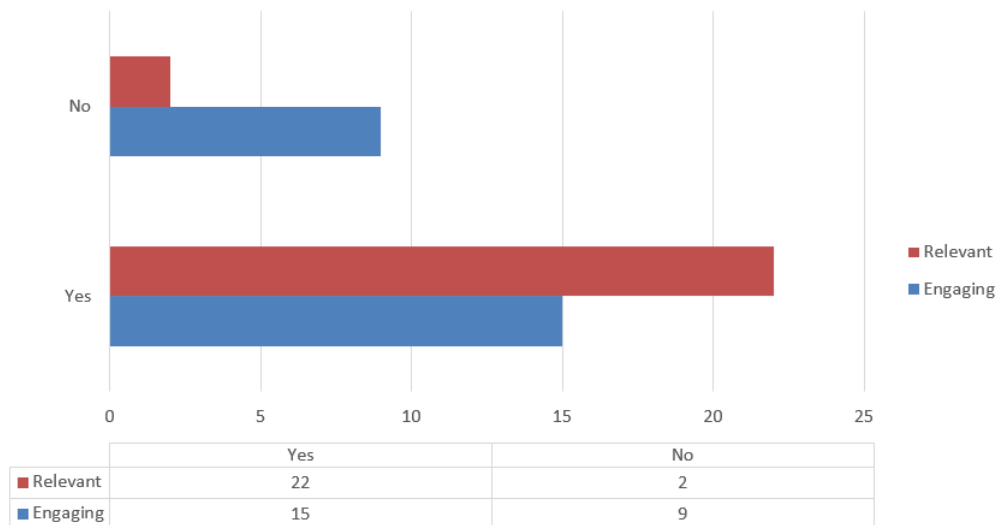|	Yes	No
Relevant	22	2
Engaging	15	9

Figure 4.8: Results of how relevant and engaging Q5 is from the survey

The results from Figure 4.8 show 91% of participants believe this content to be relevant and 62.5% of participants find it engaging. By comparing the results from 4.7, there is a considerable decrease of 20.5% between the two results. This leads to the assumption that the length of text has an impact on whether the content is viewed as engaging or not. The fact that Figure 4.9 is an academic paper could also influence this result.

Impact of vasculitis on employment and income

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Associated Data

▾ Supplementary Materials

data.
NIHMS969951-supplement-data.pdf (113K)
GUID: A57FB614-0382-4EB6-9CA4-C29B7CA21868

Abstract   Go to: ☑

Objective

Work disability associated with rheumatic diseases accounts for a substantial financial burden. However, few studies have investigated disability among patients with vasculitis. The purpose of this study was to examine the impact of vasculitis on patient employment and income.

Methods

Patients enrolled in the Vasculitis Clinical Research Consortium (VCRC) Patient Contact Registry, living in the USA or Canada, and followed for >1 year post-diagnosis, participated in an online survey-based study.

Results

421 patients with different systemic vasculitides completed the survey between June and December 2015. The majority of patients were female (70%) and Caucasian (90%); granulomatosis with polyangiitis (GPA) was the most common type of vasculitis (49%), and the mean age at the time of diagnosis was 53 years. At the time of their diagnosis of vasculitis 76% of patients were working a paid job, 6% were retired, and 2% were on disability. Over the course of their disease, and with a mean follow-up of 8±6.4 years post-diagnosis, 26% of participants became permanently work disabled or had to retire early due to vasculitis. Variables that were independently associated with permanent work disability included work physicality, less supportive work environment, and symptoms such as respiratory disease, pain, and cognitive impairment. Overall, patients reported a mean productivity loss of 6.9% and income was reduced by a median of 45%.

Conclusion

Patients with vasculitis frequently suffer substantial limitations in work and productivity, and personal income loss, due to their vasculitis.

Keywords: vasculitis, disability, employment, productivity, work

Figure 4.9: Snippet from survey that exceeds the threshold amount of text [Q5 from survey]

The two discoveries from this research will be considered in the design and implementation of the system which can be found in Chapter 5. The two discoveries being that the length of text and whether it is an academic paper has an impact into how engaging content is.

4.2.3 Open-ended question

The final question was an open-ended question which asked the participants if they had any other comments on the research. This was a valuable question as it provided some helpful responses which reinforce the assumptions above.

> "Pictures, colourful sketches make difficult concepts easier to understand. Font needs to be clear. Bullet points work in getting the message across".

> "As a "lay person" I find that illustrated diagrams/drawings help me understand the writing".

4.3 Conclusion

The results from both the focus group and online survey were discussed in this chapter. The focus group was designed to get an initial insight into what type of content the participants find relevant and interesting to view. The focus group also aided in what features of content the participants find engaging. The focus group helped in providing an initial concept of the design and implementation of the system in providing reliable, relevant and engaging content. The survey's intention was to understand what is found to be engaging and relevant with relation to online content. From the results of the survey, it seems to have provided a number of insights into engaging content. The following chapter will discuss the design and implementation of the system which utilises the results from both the focus group and survey.

5 Design and Implementation

This chapter will outline the design of the proposed system and the technologies and processes used to implement the information system, using the findings outlined in Chapter 4. The different filters applied to provide engaging, relevant and reliable content for the search engine are also described below.

5.1 Designing the Custom Search Engine

A Custom Search Engine is a search engine created to cohere to the creator's requests. A custom search engine gives the availability to enhance and customise the search engine to the developer's desire. It gives the ability to prioritize or restrict search results based on specific Web sites and pages. The two customisable search engines in discussion for the purpose of the project are:

- Google Custom Search API(CSE)

- Swiftype

Both Swiftype and Google have strong web crawlers for indexing the website's data. Additionally, both products enable the ability to provide structured data to the crawler and exclude/include portions of the website so that the search engine only searches across relevant content. CSE has the ability to customize search results by pinning content to the results for certain queries to customise the relevance search. From research Google's CSE provides a better search engine for relevance and the possibility of customisation, which makes googles custom search API the chosen search engine to aid in answering the research question in Section 1.2.

5.2 Custom Search Engine Implementation

The proposed back end solution was created as a Google CSE and written in Python. A custom search engine was created with Google and then implemented into a Python

script for utilisation and the ability to create additional features. The basic CSE returns the top 50 results from Google when a query is searched. Figure 5.1 shows the comparison in how a custom search engine differs to using regular search engine.
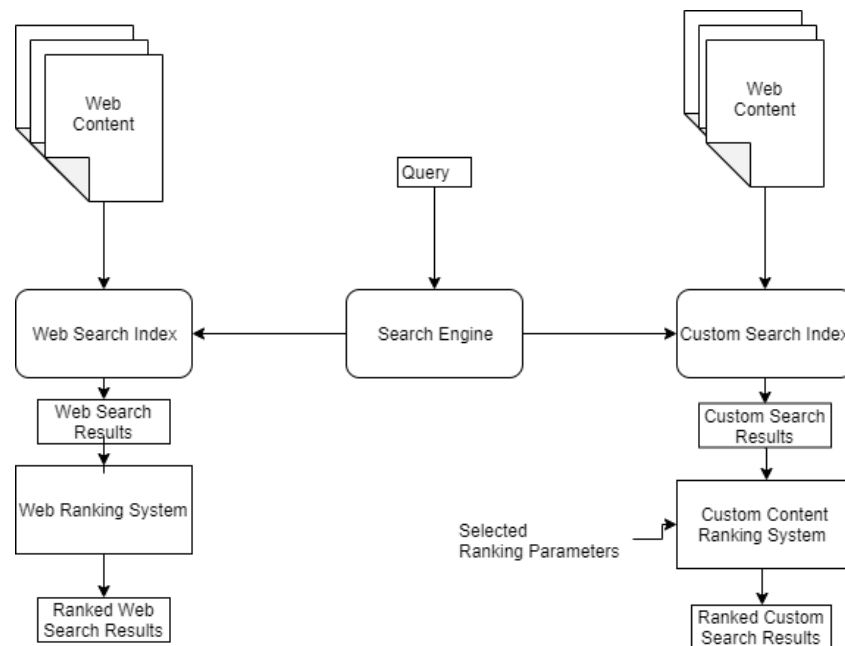

Figure 5.1: Comparison of a Search Engine and Custom Search Engine

A number of keywords were selected which tune the search engine results. The keywords describe the search engine's content and subject matter. The keywords are used to tune the search results to ensure they are as relevant as possible and to promote the most relevant pages for the search engine. At first, multiple keywords were added but using too many keywords can restrict the results in ways that may not be optimal. The final chosen keywords which were considered the most relevant in tuning the results are:

- Vasculitis

- Health

- Well-being

- Illness

A number of trusted websites were whitelisted, the search engine uses these websites as its main area of retrieving the content. The trusted websites are all associated with the vasculitis foundation or a medical website. If no results are returned a general web search excluding these websites is carried out. The whitelisting provides reliable and relevant results as they are trustworthy sources, with up to date content.

The results from the focus group and online survey in Section 3.6 and Section 3.7 revealed that academic papers are not viewed as engaging content and sometimes not relevant for the patients. Both the participants from the focus group and from the results of the survey revealed this. It was decided to blacklist the medical journals for academic papers.

Websites such as the National Center for Biotechnology Information were blacklisted. Whilst websites such as this one are reliable, they are not found to be engaging or relevant for vasculitis patients as a strong level of medical knowledge is required. A sample of the whitelisted and blacklisted websites are shown in Table 5.1.

URL	Status
https://www.vasculitisfoundation.org/	White-listed
https://vasculitis-ia.org/	White-listed
http://www.vasculitis.org.uk	White-listed
https://www.arthritisresearchuk.org/	White-listed
https://www.nhlbi.nih.gov/	White-listed
https://www.ninds.nih.gov/	White-listed
https://www.mayoclinic.org/	White-listed
https://www.medicalnewstoday.com/	White-listed
https://healthunlocked.com/	White-listed
https://www.nhs.uk/	White-listed
https://www.ncbi.nlm.nih.gov/	Black-listed
https://academic.oup.com/	Black-listed
https://www.amjmed.com/	Black-listed

Table 5.1: List of white-listed and black-listed websites

The queries used for the search engine, to deliver relevant results were obtained from the focus group discussion found in Section 3.6. The queries below are the few that were agreed on as the most important and relevant to use. These topics provide a structure and a list of results to apply filters against to enhance engaging, relevant, and reliable content. Figure 5.2 explains the process that occurs when a query is searched. The queries used are as follows:

- What is vasculitis?
- Returning to work with vasculitis
- Daily struggles with vasculitis
- How to help patients with vasculitis
- Medical breakthroughs with vasculitis
- Dieting with vasculitis
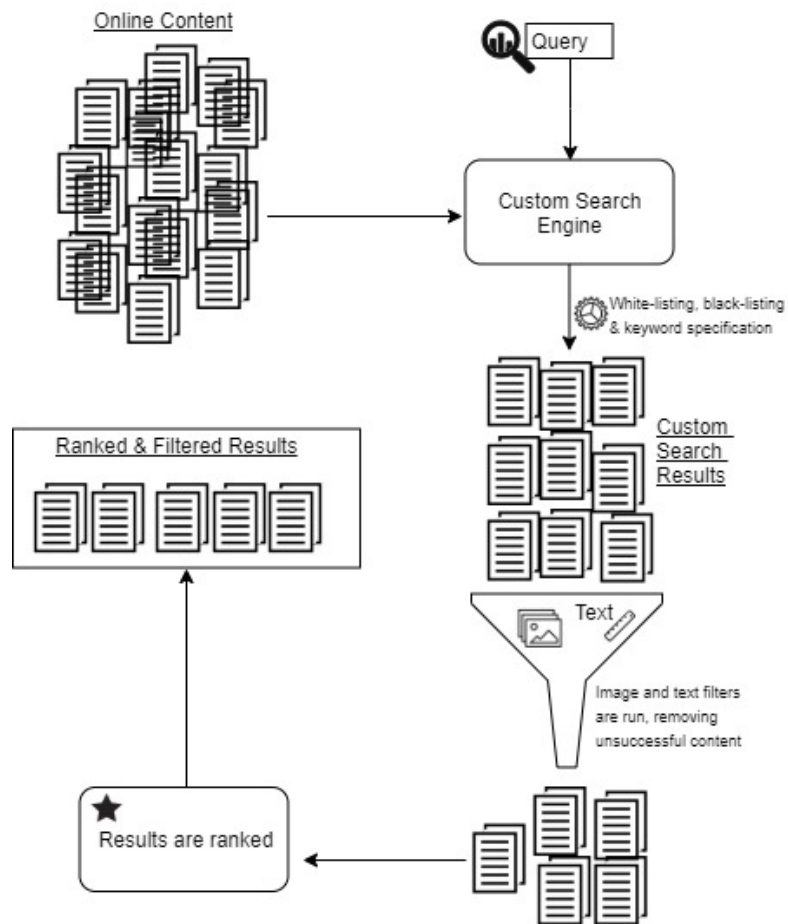- Vasculitis clinical trials

Figure 5.2: Flowchart of the system design

5.3 Error Handling

Before any filters can be applied to the results from each query, removal of duplicates and error handling must be carried out. If the result is already present, and another query returns the same result, it is removed. Multiple queries could return the same result, this removes the possibility of two of the same results in different queries.

In order to check if the web pages are accessible a test which avails of urllib.request from the library urllib is used. The urllib.request module defines functions and classes which help in opening URLs in a complex world. The library is used to read the data and cause an exception if any errors such as 404 are found. If an exception is caused the result is removed from the results.

5.4   Filters

The filters are the main process in removing content which is assumed not engaging and relevant based on the results from the focus group and survey. As previously mentioned in Chapter 2, online information is constant and universal, with the consequence that it can leave the user feeling overwhelmed with unfiltered content. A solution to these needs lies in the competencies and skills of content curation. The filters explained below were implemented to curate the content in delivering reliable, relevant and engaging content.

5.4.1   Image filter

As discussed above in Section 4.1.2 and Section 4.2.1, images can have a beneficial impact on the understanding and how engaging it is to the user. As it was not the only factor which provided an engaging experience for the participants completing the survey and focus group, the content with images were put to the top of the list of results for each query. Further filters were then applied which will be discussed below.
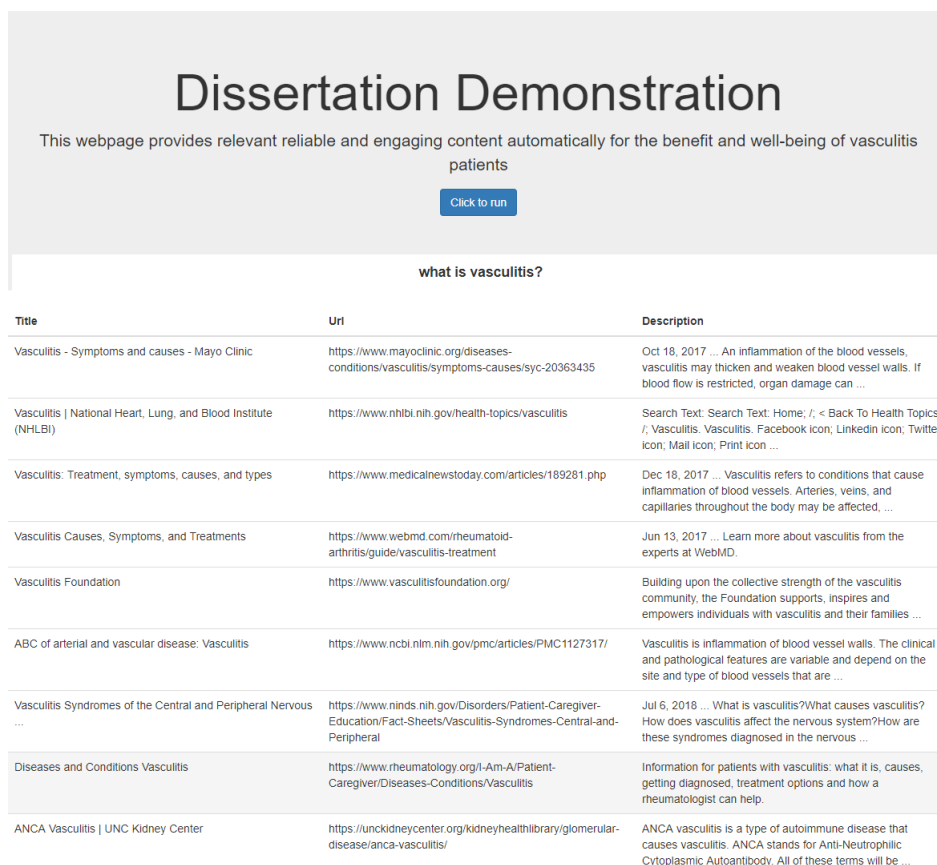
5.4.2   Text length filter

The length of text is a major factor when providing relevant, engaging content. Particularly, the participants expressed their desire for short content as they find it difficult to hold concentration for a long period of time. Due to this a maximum length of text was set which removes any results exceeding this limit. The max length of text decided is 3000 words for the body of text only.

5.4.3   New relevant results filter

In order to provide current relevant content, a filter which ranks the results in order of release date was added. This is to provide the most recent relevant, reliable, engaging data as the top suggestion. This also allows new content if it successfully passes through the filters, to be ranked at the top, and provides an updated table as new content is uploaded online.

5.5 Visual Web Tool

In order to visually view the results that is from the command line, a Django web framework was used, to see all the results in a table with each query above them. Django is a high-level Python Web framework that enables developing and running Python scripts on a server. Figure 5.3 is a snippet of the Django template running the system Python script and displaying all the results.

Figure 5.3: Visual tool to show all ranked results

5.6 Conclusion

The design and implementation of the custom search engine was discussed in this chapter. The multiple filters which aim to provide only results which are considered to be engaging, relevant and reliable are explained. The results showing the progression of each filter being applied will be reviewed in the following chapter.

6   Results

The following chapter will discuss the results from the implementation of the system described in Chapter 5 using the findings described in Chapter 4 to answer the research question in Section 1.2. The system results will be discussed with respect to the research objectives while focusing on the key elements of the research question.

Ideally, the initial plan was to use the system to generate content over a period of time and have the target users provide feedback on the suitability of the content items. As mentioned above in Section 3.8, this was not possible given the difficulties and delays in getting the focus group and survey organised. The limitations prevented the use of user evaluations and hence a manual assessment of the effectiveness of the full system was carried out. The results from each query were analysed and viewed on whether the system delivers engaging, reliable and relevant content for the benefit and well-being of vasculitis patients. A reminder of the queries used in the system are as follows:

1. What is vasculitis?

2. Returning to work with vasculitis

3. Daily struggles with vasculitis

4. How to help patients with vasculitis

5. Medical breakthroughs with vasculitis

6. Dieting with vasculitis

7. Vasculitis clinical trials

Query	Google Search	CSE	Top 50 Results	Error Handling	Image Filter	Text Filter
1	6,370,000	3,990,000	50	46	39	32
2	755,000	507,000	50	47	42	37
3	3,250,000	1,580,000	50	48	39	31
4	5,270,000	2,910,000	50	47	45	40
5	220,000	129,000	50	48	37	30
6	352,000	229,000	50	46	43	35
7	2,060,000	1,200,000	50	43	35	29

Table 6.1: Number of content items returned for each query by each stage of the system

Table 6.1 shows the number of results returned as each filter is applied for the 7 queries. The first column displays the query number which corresponds to the list of queries above. The Google Search column shows how many results appear when running that query through a Google search. The custom search engine (CSE) column displays the number of results returned when just applying the inner specifications such as keywords to tune the results, white-listing and black-listing all discussed in Section 5.2. These specifications have cut the results by an average of 40% which will provide great assistance in ensuring only engaging, relevant and reliable content. The top 50 results are taken from the CSE results and used for the rest of the implementation. The rest of the table displays the filtering process of each query and narrows the results down to engaging, relevant and reliable content.
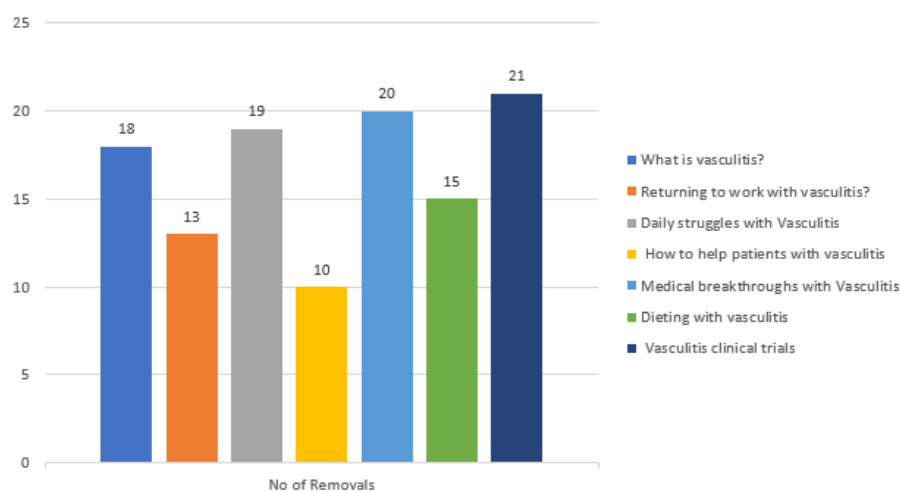
Figure 6.1: A display of the number of removals for each query

Figure 6.1 displays the number of results removed in total for each query. An average of 33% of items are removed when the error handling and filters are run on the content retrieved from the results which were already curated using the internal CSE features.

6.1   Applying filters test case

This section will dive deeper into one query to explain and show the effect of the CSE and the filters applied. The query selected to show a step by step of the process is "What is vasculitis?".

As shown in Table 6.1, when running a Google search on the query, it returns over 6 million results. Using the CSE alone removes over 35% of the results. This is due to the keywords, white and blacklisting which are discussed in Section 5.2. The system returns

the top 50 results from the CSE results but for this test case, the top 15 results will be fetched and the error handling and filters will be applied on those top 15 results. Table 6.2 displays the top 15 results from the query "What is vasculitis?".

No.	Title	URL
1	Vasculitis - Symptoms and causes	https://www.mayoclinic.org/diseases-conditions/vasculitis/symptoms-causes/syc-20363435
2	Vasculitis National Heart, Lung, and Blood Institute	https://www.nhlbi.nih.gov/health-topics/vasculitis
3	Vasculitis: Treatment, symptoms, causes, and types	https://www.medicalnewstoday.com/articles-/189281.php
4	Vasculitis Foundation	https://www.vasculitisfoundation.org/
5	Vasculitis Causes, Symptoms, and Treatments	https://www.webmd.com/rheumatoid-arthritis/guide/vasculitis-treatment
6	Symptoms of Vasculitis	https://www.hopkinsvasculitis.org/vasculitis/-symptoms-vasculitis/
7	Vasculitis Syndromes of the Central and Peripheral Nervous	https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Vasculitis-Syndromes-Central-and-Peripheral
8	Diseases and Conditions Vasculitis	https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Vasculitis
9	What is Vasculitis? Symptoms (Rash), Causes, Treatment	https://www.medicinenet.com/vasculitis-/article.htm
10	ANCA Vasculitis | UNC Kidney Center	https://unckidneycenter.org/-kidneyhealthlibrary/glomerular-disease/anca-vasculitis/
11	Vasculitis - NHS	https://www.nhs.uk/conditions/vasculitis/
12	Vasculitis Symptoms, Treatment & Causes	https://my.clevelandclinic.org-/health/diseases/12101-vasculitis
13	Vasculitis | Arthritis Foundation	https://www.arthritis.org/about-arthritis/types/vasculitis/
14	What is vasculitis?	https://www.khanacademy.org/science/health-and-medicine/circulatory-system-diseases/vasculitis/v/what-is-vasculitis
15	Vasculitis	https://en.wikipedia.org/wiki/Vasculitis

Table 6.2: Initial results from single query from the system

When applying the error handling functions, 14 results are returned, which means a single result was removed. From table 6.2, result 6 was removed. This URL was removed as an established connection failed because connected host has failed to respond. When attempting to search the URL on Google an error comes up saying that this site cannot be reached.

The first filter applied is whether the content contains an image or not which is explained in Section 5.4.1. The content is not removed if it does not contain an image but the results are ranked. If the content has no image it is put to the bottom of the results. The results are removed in future filters if they are not passed. Out of the remaining 14, only 2 of the results don't contain images. The two results are 10 and 11 in Table 6.2. Figure 6.2 is a display of the website which contains no images.

Vasculitis

Vasculitis means "inflammation of the blood vessels".

Inflammation is your immune system's natural response to injury or infection. It causes swelling, and can help the body deal with invading germs.

But in vasculitis, for some reason the immune system attacks healthy blood vessels, causing them to become swollen and narrow. This may be triggered by an infection or medication, although often the cause is unknown.

Vasculitis can range from a minor problem that just affects the skin, to a more serious illness that causes problems with organs such as the heart or kidneys.
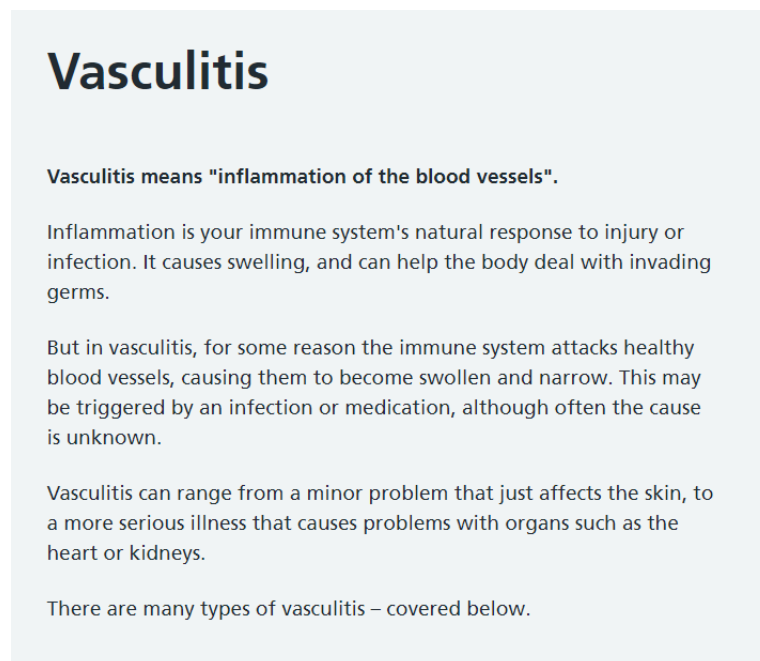
There are many types of vasculitis – covered below.

Figure 6.2: Result 11 - Content without image

Result 10 in Table 6.2 is the website where the snippet for the online survey was taken. Figure 4.3 was question 6 in the Survey (see Appendix A4 for the online survey). In Section 4.2.1 it was seen that only 50% of the survey respondents found this snippet engaging. This result was not removed yet but if it does not cohere to the desired length of text, it will be removed.

When the second filter was carried out on the remaining results, 4 of the 14 results were removed. The filter removes the result if it is not within the maximum amount of text to enhance the engaging factor of the content. A discussion on this filter is shown in Section 5.4.2.

The 4 results removed are:

- 3: Vasculitis: Treatment, symptoms causes, and types

- 5: Vasculitis Causes, Symptoms, and Treatments

- 9: What is Vasculitis? Symptoms (Rash), Causes, Treatment

- 10: ANCA Vasculitis | UNC Kidney Center

Result 10 exceeds the maximum text length and hence was removed. When analysing Figure 4.3 from the survey, it was marked as a valid length, but that was just analysing the amount of text in the snippet as that was all the participant of the survey could view. The website in full is almost over double the maximum length of text allowed to enhance the engaging level and relevance. Figure 6.3 is a snippet of the full article which was removed because of the length of the content.

Figure 6.3: Result 10 - Content removed because of length of text in full article

The final filter is to rank the results based on the most relevant and up to date results. The results that have an image are ranked first and if there are results without an image, they are also ranked but remain below the results with an image. Once run, the top result is the most up to date content, is within the desired text length and contains an image. Table 6.3 shows the final results which are as follows:

No.	Title	URL
1	Vasculitis - Symptoms and causes	https://www.mayoclinic.org/diseases-conditions/vasculitis/symptoms-causes/syc-20363435
2	Vasculitis National Heart, Lung, and Blood Institute	https://www.nhlbi.nih.gov/health-topics/vasculitis
4	Vasculitis Foundation	https://www.vasculitisfoundation.org/
7	Vasculitis Syndromes of the Central and Peripheral Nervous	https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Vasculitis-Syndromes-Central-and-Peripheral
8	Diseases and Conditions Vasculitis	https://www.rheumatology.org/I-Am-A/Patient-Caregiver/Diseases-Conditions/Vasculitis
12	Vasculitis Symptoms, Treatment & Causes	https://my.clevelandclinic.org/health/-diseases/12101-vasculitis
13	Vasculitis | Arthritis Foundation	https://www.arthritis.org/about-arthritis/types/vasculitis/
15	Vasculitis	https://en.wikipedia.org/wiki/Vasculitis
14	What is vasculitis?	https://www.khanacademy.org/science/health-and-medicine/circulatory-system-diseases/vasculitis/v/what-is-vasculitis
11	Vasculitis - NHS	https://www.nhs.uk/conditions/vasculitis/

Table 6.3: Final results for query 1 after all filtering has been applied

The final results show a final count of 10 results from the original 15. This is a 33% removal from the results which appear to be not engaging, relevant and reliable. This was the average removal rate displayed in Figure 6.1 above.

From the 10 websites in which the snippets for the survey were taken from, only 6 of the websites are returned when the updated system and filters are applied. The findings from the survey explained in Section 3.7 helped to remove the websites that are considered not engaging, relevant and/or reliable.

6.2 Conclusion

The results of the system and filters were discussed in this chapter with an in-depth analysis of one of the queries being presented. The step by step process in which the system fetches the content and applies filters to determine whether it is engaging, reliable and relevant is explained. The concluding chapter will evaluate the research objectives, discuss the future research and evaluate whether this system has achieved in producing engaging, relevant and reliable content.

7 Conclusion

This chapter will reflect on the work carried out in the dissertation. A discussion of the outcome of each individual research objective is outlined in Section 1.3. Additionally, this chapter will evaluate how the project delivers engaging, relevant and reliable content. An outline of future work that may be completed will also be discussed.

7.1 Research Objectives

This section will discuss the results of each objective, outline whether the objective has been successful, and outline any limitations related to each objective.

7.1.1 Comprehensive Review of Literature

As discussed in Chapter 2, a review of current, published literature was completed. The review consisted of research on the impact of content curation and information retrieval when providing relevant, engaging and reliable content. At first, a systematic search was conducted using key terms from the research study. A list of databases was utilised in retrieving the literature which was reviewed. An understanding of what makes content reliable, relevant and engaging enabled the ability to grasp what was to be achieved for the system. The literature review also helped in the planning process of the next objective which was understanding the needs of vasculitis patients.

To an extent, the research objective for the review of the literature has been completed. However, it is not, without its limitations. Whilst there was a large amount of research on content curation and information retrieval, there lacked any prior research on curating content for the needs of users dealing with an illness. This made it difficult to gain an understanding of what the vasculitis patients wanted in regards to online content. Due to this limitation, the survey and focus group gave a large understanding of how to deliver content to a user with an illness and the concepts to take into consideration.

Understanding the needs of vasculitis patients will be discussed in more detail as it was the next objective of the research study.

7.1.2 Understand the needs of Vasculitis Patients

To understand the needs of vasculitis patients, a number of methods were carried out. The focus group and survey acted as the methods in understanding the needs of vasculitis patients in general, but also in attempting to provide engaging, reliable and relevant content. Chapter 3 explains the reasoning for the focus group and survey, describes the design and planning process for both methods and discusses the focus group event and the development of the survey.

Despite the limitations of the survey, this research objective is still considered to be achieved. The intention of the survey was to act as a method of continuous feedback to learn from as the implementation improved. Unfortunately, due to time constraint, this was not the case. The survey was a once off survey taken by vasculitis patients to understand what they perceive as engaging and/or relevant. Whilst the continuous feedback from the multiple surveys may have been the initial plan in the progression of implementing the system, the single survey did provide valuable insights.

7.1.3 Analyse the Focus Group and Survey

The analysis of the focus group and the results from the survey gave a beneficial insight into what should be delivered within the system. The focus group explained the difficulties of vasculitis which was a very important factor in the development process as they are the main target audience. Difficulties such as having a low concentration level due to medication, visual or hearing impairments and to provide positive content were all considered in the design and implementation of the system. The survey also aided in gaining an understanding of what content is viewed as engaging and relevant.

The focus group and survey provided a number of considerations in the implementation of the system, but due to the number of time constraints such as the delayed ethics approval, it was a difficult task in achieving them all. The main limitation was to put more focus on providing positive content. Unfortunately, this was not able to be considered in the implementation of the system. As it was a major focus point from the focus group, it will be one of the main aspects of future work which will be discussed in Section 7.2. Despite the positivity limitation, this objective is considered completed.

7.1.4 Develop a system which fetches relevant, engaging and reliable content

The final research objective was to develop a system that returns engaging, reliable and relevant online content. The steps taken to implement the system are outlined in Chapter 5, and the results from the system are shown in Chapter 6. The results show an average of 33% of results being removed when the top 50 results are taken from the custom search engine (CSE) results. An explanation for the three elements to be achieved will be discussed below.

Reliability

A guarantee of reliability is needed to gain the trust of the readers. Credible sources were used as the main area in retrieving content. Other sources were also used once the content from the credible sources was retrieved to not eliminate any other content. The credible sources were obtained from members of Vasculitis Ireland Awareness (VIA) which provides a trustworthy website that provides reliable content. Whilst ensuring reliable content, accuracy is the strongest element and the credible sources provide a very accurate record for reliability as they were obtained from VIA. Accuracy is the degree to which a process conforms to its specifications and yields what it is designed to yield [3]. To conclude, it cannot guarantee 100% reliability, but a high level of accuracy has been achieved.

Engaging

Out of the three elements, ensuring engaging content is the most complex to achieve as engaging content varies for each person. A list of user-specific attributes are used when evaluating the term 'engaging': aesthetic, attention, control, feedback, interest, motivation, perceived time [5]. Motivation, interest and feedback, attention were all elements shown by the participants of the focus group. Aesthetics, control and perceived time are all factors which are essential for the newsletter. Due to the system being directed to a small cluster of people who have a similar interest, it reduces the difficulty slightly. The implementation of the filters and ranking system also aid in providing engaging content for vasculitis patients.

To conclude, it is not a guarantee that the system provides engaging content all of the time. It can be guaranteed that it applies filters and ranking to remove content that is perceived as not engaging, such as academic papers which suggests that a high proportion of the remaining results are engaging. The system provides engaging content

based on the factors that were given by the future target audience which leaves the assumption that providing engaging content was achieved.

Relevant

Relevance was a key feature to achieve as without relevance there is no interest in the content. Relevance is a perception the reader has of the content and, as such, is influenced by the content. A strong level of relevance was guaranteed with the use of Google's custom search API. The input of keywords within the CSE also aided in ensuring the content was relevant. As mentioned above in Chapter 2, Keller defines relevance as a perception of personal needs being met by instructional activities or as a highly desired goal being perceived as related to instructional activities [12]. The main factor in promising relevant content was that the queries used were given by the participants of the focus group. These participants have vasculitis which can ensure that the results from each query will be content that the patients are influenced by and interested in. To an extent, the queries used are relevant which should provide a strong level of relevant content which leads to the idea that providing relevant content has been achieved.

7.2   Future work

This section will discuss the work that can be carried out that could solve some of the limitations discussed throughout the dissertation, or improve the overall system.

- As mentioned in Chapter 1, this is only a piece of the final product. This dissertation provides all of the research and implementation on retrieving engaging, relevant and reliable content. The next step is to implement a web-tool within the VIA website which allows a member of VIA to choose a result and display the content in a newsletter format to allow the vasculitis patients to view the content. This research study also presents some insights from the focus group on what they want implemented which is discussed in Section 4.1.

- Positivity was a major discussion within the focus group. A sentiment analysis process could help in identifying whether the content is expressed as positive or negative which could enhance the system in only providing positive content to the patients.

- Continuous feedback which was a part of the initial project plan could help in providing more information and insights for the development of the system. The use of a recommender system could learn from the feedback and provide content

related to the user's evaluation of the system. This could decrease the amount of human validation needed significantly

7.3   Concluding remarks

This dissertation set out to answer the research question in proving how can relevant, reliable and engaging content be provided automatically for the benefit and well-being of vasculitis patients. In this dissertation, a system was designed and implemented that utilised a custom search engine, in providing relevant, reliable and engaging content.

Throughout the process of achieving the research objectives, a number of limitations were highlighted and encountered during the time of the research. Further implementation would need to be carried out before the engaging, relevant and reliable content is available to the vasculitis patients on the VIA website and app. Further research would need to be conducted to solve certain limitations, such as the implementation of a recommender system to remove human validation. However, as previously mentioned in Chapter 1, there needs to be some human validation as a computer is not 100% in fetching reliable, relevant and engaging content.

The concluding remark is that while the system is very effective, there are a number of further implementations it must achieve before it can become a service that can be used for the benefit and well-being of vasculitis patients.

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A1   Ethical Approval from Trinity College Dublin

A1.1   Information Sheet

<div align="center">

TRINITY COLLEGE DUBLIN

INFORMATION SHEET FOR PROSPECTIVE PARTICIPANTS

</div>

Title of research project: Providing automatically sourced content for the benefit of the wellbeing and health for vasculitis patients.

Name of Lead Researcher: Kevin Morris

Email: morrisk3@tcd.ie

Phone: 0857140321

Name of Supervisor: Lucy Hederman

Background context: This project aims to carry out a measurement study on the automation of sourcing content for a specific topic. Participants will be members of Vasculitis Awareness Ireland or Vasculitis UK. Participants will be recruited through the newsletters of Vasculitis Awareness Ireland and Vasculitis UK. Patients with vasculitis will be invited to volunteer by emailing an intermediary. It will involve individual patients providing information of the type of content they wish to view. The content will come from reliable trusted websites that focus on vasculitis. This will consist of a focus group to gain a large view on what types of content is in interest. The patients will lead me to what content is of relevance, to aid me into delivering a solution.

Procedures relevant to the participant You are being asked to provide feedback on online content sourced by the research. No names will be recorded on at the focus group. The survey lasting from 45 minutes, is to get an understanding of what kind of content they, as vasculitis patients, would be interested in.

Declarations of conflicts of interest The participants will not know me. There is no conflict of interest that will create any issues, as you will be informed on the importance of this research and you will know that I am seeking criticism.

Voluntary nature Participation is voluntary. You have the right to withdraw and to omit or withdraw individual responses without penalty.

Expected duration The focus group will require up to 45 minutes.

Anticipated risks/benefits to the participant There are no anticipated risks. The anticipated benefits are that you will help this project which will eventually provide useful information to you or people like you.

Anonymity

This study will guarantee the preservation of participant and third-party anonymity in analysis, publication and presentation of resulting data and findings. Once participants have reviewed the information they have given, and approved it for use, I will anonymize all of the data.

Cautions about inadvertent discovery of illicit activities In the extremely unlikely event that illicit activity is reported to us during the study we will be obliged to report it to appropriate authorities.

Direct quotes It is possible that you will be quoted directly in the report of the project, but all quotes will be anonymous. All direct quotes being used will be verified for context before us.

A1.2 Consent Form

TRINITY COLLEGE DUBLIN

INFORMED CONSENT FORM

LEAD RESEARCHER: Kevin Morris

BACKGROUND OF RESEARCH: The project aims to provide automatically sourced content for Vasculitis Awareness Ireland patients. The project requires (1) an understanding of what kind of content vasculitis patients might be interested in and (2) feedback from patients on the relevance of sourced content.

PROCEDURES OF THIS STUDY: This study will involve participants attending a focus group lasting up to 45 minutes, to get an understanding of what kind of content they, as vasculitis patients, would be interested in.

PUBLICATION: Information gathered as part of the research will be used as part of my Dissertation.

Individual results will be aggregated anonymously, and research reported on aggregate results.

DECLARATION:

- I am 18 years or older and am competent to provide consent.

- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.

- I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity.

- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.

- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.

- I understand that my participation is fully anonymous and that no personal details about me will be recorded. I have received a copy of this agreement.

A2   Survey recruitment email

Dear _,

Researchers at Trinity College are looking for vasculitis patients to help in their efforts to automatically source online content for vasculitis patients, which might appear on the VIA website or in the patientMPower Vasculitis app.

If you agree to participate you will be asked to answer a survey in which you will be presented with images of content that might be of interest to vasculitis patients. For each you will be asked to consider whether the item is relevant and whether it is engaging. These terms will be explained in the survey. Each image will have two questions below it and you will tick the boxes you feel are accurate for the certain piece of content. We expect it will take no more than 5 minutes.

The participant information sheet is attached to this email, and is also at the start of the survey.

Please click the link below to start the survey,

https://scsstcd.qualtrics.com/jfe/form/SV_7VXPPlkAmOmM6Dr

If you have questions please contact Kevin Morris (morrisk3@tcd.ie) or reply to this email.

Thanks, Kevin Morris Student of Computer Science at Trinity College Dublin

A3 Focus Group recruitment email

Dear _,

Researchers at Trinity College are looking for vasculitis patients to help in their efforts to automatically source online content for vasculitis patients, which might appear on the VIA website or in the patientMPower Vasculitis app.

If you agree to participate you will be asked to participate in a focus group in which you be asked a number of questions related to vascultis, online content and user engagement. You will be asked to provide feedback on online content sourced by the research. No names will be recorded on at the focus group. The focus group lasting from 45 minutes and will be to get an understanding of what kind of content vasculitis patients, would be interested in.

The participant information sheet is attached to this email.

If you have questions please contact Kevin Morris (morrisk3@tcd.ie) or reply to this email.

Thanks, Kevin Morris Student of Computer Science at Trinity College Dublin

A4   Survey

Are you a vasculitis Patient?

○ Yes   ○ No

You will now be presented with images of content that might be of interest to vasculitis patients.
For each you are asked to consider whether the item is relevant and whether it is engaging.
Each image will have two questions below it and you will tick the boxes you feel are accurate for the certain piece of content.

RELEVANT: The content is relevant if it provides information in the text that is beneficial for you as a patient with vasculitis.
ENGAGING: The content could be considered as engaging content if it is attractively communicated, enticing and appealing to you.

What is vasculitis?

Vasculitis is the inflammation of the body's blood vessels. Vasculitis can affect very small blood vessels (capillaries), medium-size blood vessels, or large blood vessels such as the aorta (the main blood vessel that leaves the heart).
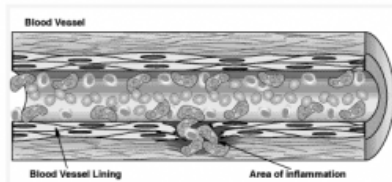
When inflamed, the blood vessels may become weakened and stretch in size, which can lead to aneurysms. The vessels also may become so thin that they rupture resulting in bleeding into the tissue. Vasculitis can also cause blood vessel narrowing to the point of closing off entirely (called an occlusion). If blood flow in a vessel with vasculitis is reduced or stopped, the tissues that receive blood from that vessel become injured and begin to die.

What causes vasculitis?

In most cases, the exact cause is unknown; however, it is clear that the immune system (the system that keeps the body healthy) plays a big role. While the immune system usually works to protect the body, it can sometimes become "overactive" and end up attacking parts of the body. In most cases of vasculitis, something causes an immune or "allergic" reaction in the blood vessel walls. Substances that cause allergic reactions are called antigens. Sometimes certain medicines or illnesses can act as antigens and start this process.

What are the symptoms of vasculitis?
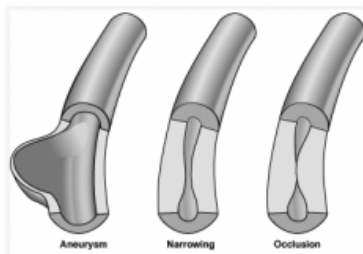
Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

Impact of vasculitis on employment and income

Lillian Barra, MD, MPH,[1] Renée Borchin,[2] Cristina Burroughs,[2] George Casey, MBA,[3] Carol A. McAlear, MA,[4] Antoine Sreih, MD,[4] Kalen Young, MA,[3] Peter A. Merkel, MD, MPH,[4,5] Christian Pagnoux, MD, MSc, MPH,[6] and for the Vasculitis Clinical Research Consortium and the Vasculitis Patient-Powered Research Network

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Associated Data

▾ Supplementary Materials

data.

NIHMS969951-supplement-data.pdf (113K)
GUID: A57FB614-0382-4EB6-9CA4-C29B7CA21868

Abstract

Go to: ☑

Objective

Work disability associated with rheumatic diseases accounts for a substantial financial burden. However, few studies have investigated disability among patients with vasculitis. The purpose of this study was to examine the impact of vasculitis on patient employment and income.

Methods

Patients enrolled in the Vasculitis Clinical Research Consortium (VCRC) Patient Contact Registry, living in the USA or Canada, and followed for >1 year post-diagnosis, participated in an online survey-based study.

Results

421 patients with different systemic vasculitides completed the survey between June and December 2015. The majority of patients were female (70%) and Caucasian (90%); granulomatosis with polyangiitis (GPA) was the most common type of vasculitis (49%), and the mean age at the time of diagnosis was 53 years. At the time of their diagnosis of vasculitis 76% of patients were working a paid job, 6% were retired, and 2% were on disability. Over the course of their disease, and with a mean follow-up of 8±6.4 years post-diagnosis, 26% of participants became permanently work disabled or had to retire early due to vasculitis. Variables that were independently associated with permanent work disability included work physicality, less supportive work environment, and symptoms such as respiratory disease, pain, and cognitive impairment. Overall, patients reported a mean productivity loss of 6.9% and income was reduced by a median of 45%.

Conclusion

Patients with vasculitis frequently suffer substantial limitations in work and productivity, and personal income loss, due to their vasculitis.

Keywords: vasculitis, disability, employment, productivity, work

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

Frequently Asked Questions About Vasculitis

- What causes vasculitis?
- What is going to happen to me?
- Is vasculitis curable?
- Is vasculitis hereditary?
- Does diet affect vasculitis?
- Will my vasculitis return?
- How should I guard against the occurrence of a disease flare?
- Why do I have to have bloodwork checked frequently?

What causes vasculitis?

The causes of most forms of vasculitis remain unknown. Infections are strongly suspected of playing a role in in forms such as the association of hepatitis B (a virus) and polyarteritis nodosa, and hepatitis C (another virus) and cryoglobulinemic vasculitis. Bacterial infections have been suspected of playing a possible role in granulomatosis with polyangiitis (GPA, formerly known as Wegener's) which is the reason that some patients with GPA that is limited to the upper respiratory tract are treated only with an antibiotic, Bactrim (trimethoprim/sulfamethoxazole). A general theory that applies to many types of vasculitis is that the disease results from the occurrence of a particular infection in a person whose genes (and other factors) make him/her susceptible to developing vasculitis.

What is going to happen to me?

The course of vasculitis is often difficult to predict. Some types of vasculitis may occur only once and do not return. Other types are prone to recurrences. For all patients with vasculitis, it is essential to be evaluated by physicians who are experienced in the treatment of these diseases. Vasculitis is treatable, and many patients achieve remissions through treatment. It is important to balance the types of medications necessary to control the disease and the risk of side effects that those medicines often bring. A primary aim of several ongoing new studies in vasculitis is to find drugs that help maintain remission.

Is vasculitis curable?

Most forms of vasculitis are **treatable** if detected early enough, before substantial organ damage has occurred. While often effective, however, the treatments remain imperfect and require improvement. Further research is needed in all forms of vasculitis. Greater knowledge of these diseases will lead to better treatments and, some day, to cures.

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

Living With Vasculitis

→ Common Experiences with Vasculitis

→ Health, Medical and Caring Information

→ Vasculitis in Children

→ NHS Patient Choices

→ Personal Stories

→ Government Benefits

→ Health Services and other Organisational Support

→ Insurance

→ Studying with Vasculitis

→ Travel

Living and Coping with Vasculitis

Here you will find a wide variety of information on how to cope with life with vasculitis on a daily basis, including general health issues, dealing with the NHS, workplace issues, DWP benefits claims and insurance for those with pre-existing medical conditions. Also sections for carers and matters relating to children and young people.

For many people, having vasculitis is a life-changing experience which affects every aspect of life. It also affects those around - family and friends as well as the ability to work. Some are left with permanent physical damage or disability or psychological damage.

In this section you should find information and advice on just about every aspect of living with vasculitis.

If you don't find your answer, look at the Frequently Asked Questions (FAQ) section. See also Inspirational Stories to see how others have coped.

Do you find this content engaging and/or relevant?

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Relevant	○	○
Engaging	○	○

ANCA Vasculitis

ANCA vasculitis is a type of autoimmune disease that causes vasculitis. ANCA stands for Anti-Neutrophilic Cytoplasmic Autoantibody. All of these terms will be explained here, including how the disease works and what we can do for it. You may hear different names or terms for this disease, including ANCA vasculitis, ANCA disease, ANCA-associated vasculitis. Other names include small vessel vasculitis or pauci-immune vasculitis.

What is vasculitis?

Vasculitis is swelling or inflammation of blood vessels ("-itis" = swelling or inflammation and "vascular" = blood vessels). Blood vessels in the body carry blood from the heart to all the different organs/tissues, and then back again. Arteries, veins, and capillaries are different kinds of blood vessels. Blood vessels are different sizes depending on where they are in the body- as they get further away from the heart they branch and get smaller. The inflammation in vasculitis is caused by white blood cells attacking blood vessels. White blood cells are cells in the body that are part of the immune system. As part of the immune system, they can help fight infection and can cause inflammation. Many different things can cause vasculitis, including infection and autoimmune diseases. Here we will talk about autoimmune causes since ANCA vasculitis is a type of *autoimmune vasculitis*.

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

Treating Vasculitis

There are two phases in the treatment of vasculitis - "Remission Induction" therapy (getting the disease under control) and "Remission Maintenance" therapy (keeping the disease under control). Both phases normally involve immunosuppressive drugs.

Remission Induction therapy - Usually requires a combination of immunosuppressive drugs to control the inflammation. The drugs given will vary according to the specific disease and the severity of the disease. These drugs are commonly high dose steroids (prednisolone) and additional treatment with drugs such as cyclophosphamide or methotrexate may be given.

In some types of vasculitis newer antibody treatments (eg rituximab or infliximab sometimes called "biologic therapies") are starting to replace the older treatments such as cyclophosphamide. Usually the amount of steroid treatment will be reduced quickly over the first few weeks and then more slowly. The common side effects of drugs used in remission induction phase are infections because of the suppression of the immune system. Often additional drugs will be given to protect against infection and other side effects of the treatment. See: Glossary of Drugs and Side Effects

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

Vasculitis

What is Vasculitis?

Vasculitis is an autoimmune disease in which the body mistakenly sees blood vessels as a foreign invader and attacks them, causing inflammation and leading to a narrowing of the vessels. Vasculitis can occur by itself or can be a feature of a rheumatic disease, such as rheumatoid arthritis, systemic lupus erythematosus (SLE; lupus) or systemic sclerosis. In severe cases, patients can develop organ damage or death. About 100,000 Americans per year are admitted to the hospital because of vasculitis. Vasculitis can affect people of all ages, races and gender.

There are many types of vasculitis. They are classified according to the size of the blood vessels affected.

- **Large vessel.** Polymyalgia rheumatic, Takayasu's arteritis, temporal arteritis (and giant cell arteritis)

- **Medium vessel.** Buerger's disease, cutaneous vasculitis, Kawasaki disease, polyarteritis nodosa

- **Small vessel.** Behçet's syndrome, Churg–Strauss syndrome, cutaneous vasculitis, Henoch–Schönlein purpura, microscopic polyangiitis, Granulomatosis with polyangiitis (GPA), Golfer's vasculitis, cryoglobulinemia

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	◯	◯
Engaging	◯	◯

Diet

A healthy diet is important for the vasculitis patient, especially for those who are struggling with food intake.

Healthy eating will, by definition, help anyone who has diabetes or who have gained weight and wants to do all they can nutritionally to stave off infection and disease long term.

Some vasculitis patients will require a special diet and this will be arranged via the hospital dietician. It is important to adhere to this regime.

For those with kidney involvement you may find the kidney care cookbook **Rediscovering Food and Flavours** from Kidney Research UK helpful. This cookbook was created by TV Chef Lawrence Keogh, Head Chef at Roast and BBC's Saturday Kitchen along with Renal Dietician, Diane Green. The book contains 16 recipes. It is now available free of charge from local Dieticians for patients who need to control their diet due to chronic kidney disease. It can be downloaded at: Kidney Research UK

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

A Normal artery
Artery wall
Normal blood flow
Artery cross-section

B Narrowed artery (with inflammation)
Inflammation
Decreased blood flow

C Totally occluded artery
Inflammation and scarring
No blood flow

D Aneurysm
Abnormal blood flow
Dilation containing very thin arterial wall
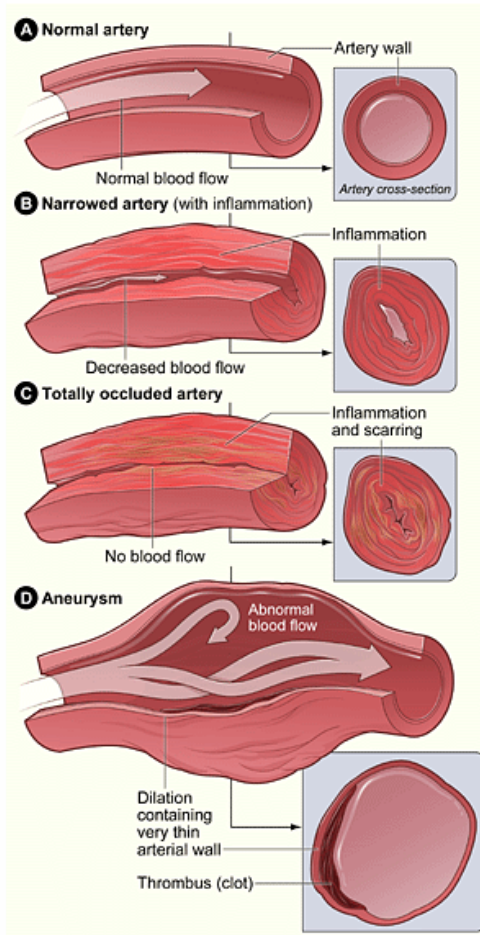Thrombus (clot)

Figure A shows a normal artery with normal blood flow. The inset image shows a cross-section of the normal artery. Figure B shows an inflamed, narrowed artery with decreased blood flow. The inset image shows a cross-section of the inflamed artery. Figure C shows an inflamed, blocked (occluded) artery and scarring on the artery wall. The inset image shows a cross-section of the blocked artery. Figure D shows an artery with an aneurysm. The inset image shows a cross-section of the artery with an aneurysm.

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

What you need to know

Here are seven things you should know about vasculitis:

1. Vasculitis is inflammation of blood vessels. The body's immune system regulates inflammation.

2. Vasculitis is a family of multiple different diseases. The types of vasculitis differ in whom they affect and the organs they involve. Some forms are mild. Others are more severe.

3. Vasculitis can affect any of the body's blood vessels. In vasculitis, the blood vessel walls can thicken, leading to vessel narrowing or blockage. If the flow in a blood vessel with vasculitis reduces or stops, the tissues that receive blood from that vessel begin to die. Vasculitis can also weaken blood vessels, leading to enlargement of the vessel (called an aneurysm) or disruption of the blood vessel wall, with bleeding into the surrounding tissue. In some forms of vasculitis, inflammation can occur in tissues other than blood vessels.

4. The cause of most forms of vasculitis is unknown.

5. Symptoms of vasculitis vary. They can include nasal congestion joint pain, mouth ulcers, hearing loss, skin lesions, headache, vision problems, numbness, weakness, cough, shortness of breath, fever, weight loss and many others symptoms.

6. Vasculitis is treatable. The type of treatment will depend on the form of vasculitis, the affected organs and disease severity. The main goal of treatment is to

Do you find this content engaging and/or relevant?

	Yes	No
Relevant	○	○
Engaging	○	○

If you have any other comments, please enter below

Please click submit if you wish to record your responses

◯ Submit   ◯ Cancel and Discard