Evaluation of Consumer Health Informatics Definitions: A Systematic Review of the Peer-Reviewed Literature, 1995-2012

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Introduction: Consumer health informatics (CHI) is an emerging field that utilizes technology to provide tailored health information for the consumer. It is multidisciplinary in nature and stands at the crossroads of a multitude of other disciplines. It is also one of the most rapidly advancing and challenging subfields in medical informatics. However, there is no single accepted definition of CHI in the literature and a consensus definition would be important for pedagogical reasons, to build capacity, and to reduce confusion about what the discipline consists of. Therefore, the objective of this thesis research was to systematically review the published definitions of consumer health informatics and evaluate them based on a set of assessment criteria to gain a better understanding of their quality.

Methods: Five databases were searched (Embase, Web of Science, MEDLINE, CINAHL, and Business Source Complete) resulting in 1109 citations. Twenty-three studies met the inclusion criteria. Definitions were appraised using 5 criteria (with each scoring out of 1): use of published citation, multidisciplinarity, journal impact, definition comprehensibility, and text readability.

Results: Most definitions scored low on citation (mean±SD: 0.22/1 ±0.42/1), multidisciplinarity (0.15±0.28), and readability (0.04±0.21) and somewhat higher on impact factor (0.35±0.45) and definition comprehensibility (idea density) (0.87±0.34) criteria. The highest scoring definition was written by Shaikh et al. (2011) and achieved a score of 3.5, with the lowest definition score attributed to Gibbons et al. (2009) which received a score of 0. Overall, the quality of the published definitions was low 1.63±0.80 (out of 5).

Conclusions: The definitions of CHI were variable in terms of the quality assessment criteria. This finding suggests the need for continued discussion amongst consumer health informaticians and other key players to develop a clear consensus definition about CHI. This unified definition could in turn inform the development of core competencies for this discipline and its utility in public health practice.

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Chapter 1
Introduction

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For nearly two decades, an ever growing number of professionals have been researching and creating innovative health applications aimed at the consumer. These professionals have popularized the term "consumer health informatics", a phrase introduced by Ferguson in 1993 (Nelson & Ball, 2004). Consumer health informatics (CHI) is an important field that can be utilized by consumers and public health practitioners to aid and bolster healthcare. However, since it is extremely broad in reach, and applications can be targeted towards a variety of health issues (i.e., from smoking cessation, to cancer information, to suicide prevention), key challenges, such as accuracy of information, end-user uptake, and ease-of-use, are difficult to resolve.

Still, there are many examples of successful applications that have proven CHI's benefits for patients and the general public. One such example is the Comprehensive Health Enhancement Support System (CHESS) which has been around for more than 20 years and is defined as a "computer-based system of integrated services designed to help individuals cope with a health crisis or medical concern" (CHESS, University of Wisconsin, 2014). For several

studies designed to evaluate at the efficacy of the CHESS software on women with breast cancers, Gustafson and colleagues have shown that CHESS significantly improved user information competence, social support, participation in health, and confidence in their doctor over patients who used only the Internet (Gustafson, 2001, 2008).

The CHESS program is just one example of a successful CHI application. Consumer health informatics has the potential to improve outcomes across a spectrum of diseases and health problems via applications (or electronic tool, system, or technology) that provides tailored information for the individual (Eyler, 2011). According to the American Medical Informatics Association (AMIA), CHI provides "information structures and processes that empower consumers to manage their own health - for example health information literacy, consumer-friendly language, personal health records, and Internet-based strategies and resources" (para.1, 2013).

Fundamentally, consumer health informatics is about providing individuals with relevant, accurate, and accessible health information. Access to information allows consumers to make informed decisions about their health, both individually, and shared with their doctor. Another goal of CHI is fostering patient empowerment and removing the uncertainty that the patient has when discussing health concerns with physicians. An informed consumer would lead to an informed patient, which would potentially lead to a more efficient doctor-patient relationship, as the physician could spend less time explaining health problems and more time discussing treatment options, etc.

There appears to be a lack of agreement in the definition of CHI (Arocha & Hoffman-Goetz, 2012; Houston et al., 2001; McDaniel et al., 2008). Given the rapid growth of CHI by

the health conscious public, and the diverse nature of the field, it is important that researchers agree on what CHI encompasses relative to other informatics subspecialties.

Without a clear definition of the field, it may be difficult to develop core competencies for the training of consumer health informatics professionals. Bernstam et al. (2010) provides an important rationale for why it is necessary to develop definitions in the informatics field, using the example of bioinformatics. Arising from formally defining bioinformatics, these researchers suggested that there were a number of practical implications including 1) educational program design, which allows for a clear vision of the field for students and guides curriculum development and evaluation within training programs; 2) administrative decisions, which allows administrators to make the case for resources to structure informatics units (academic and service-oriented) with respect to hiring faculty or staff, relationship to other organizational units and performance metrics; and 3) communication, which allows internal communication among informaticians and external communication with those outside of the field (Bersntam et al, 2010, p. 11). In other words, having a consensus definition about a field can help match current and potential collaborators, guide professional and practice societies such as the American Medical Informatics Association and the International Medical Informatics Associations (AMIA and IMIA, respectively), and help funding agencies and members of the general public understand their roles and contributions.

To date, there has been no unified definition of CHI put forward by an expert consensus organization, despite the many references to CHI in the literature. Yet, several of the fields related to CHI, such as medical informatics and public health informatics, have clearly articulated core competencies. For example, Canada's Health Informatics Association

(COACH), in coordination with health informatics academics and professionals, recently developed guidelines that outline the core competencies needed to perform as a Health Informatics Professional (COACH, 2012).

Similarly, the CDC and the U.S. Department of Health and Human Services developed a list of 14 core competencies for public health informaticians and senior public health informaticians to help establish training and the advancement of the field (CDC, 2009). In both cases, professionals from their respective fields agreed on the core competencies for health informatics and public health informatics to build the foundation for education and training in these fields. However, it would have been difficult to arrive at agreement about core competencies and specific skills needed for medical and public health informaticians, if there had been no consensus about what constitute these disciplines. Indeed, a clear definition was the starting point for the advancement and development of these respective core competencies.

The aim of this thesis research was to systematically review published definitions of consumer health informatics and assess these definitions for quality. Five questions were used to guide the systematic review in terms of assessment of the CHI definitions: (1) What is the likely impact or reach of the definition in the academic and practice communities? (2) Does the CHI definition emphasize a multidisciplinary, interdisciplinary, or unidisciplinary approach to the field? (3) Does the CHI definition contain reference to other published literature? (4) Are the underlying ideas or concepts in the CHI definition difficult to understand by educated readers? And (5) is the CHI definition text readability appropriate for the general population? The underlying motivation of this research was to stimulate scholarly discussion

amongst researchers, practitioners, and consumer end users about the CHI components necessary to enhance consumer and patient-oriented health care decision making.

Chapter 2
Background

This literature review describes the early idea of putting the patient (or consumer) first in the healthcare system, the rise of health information online, and the emergence of consumer health informatics. The background review will then describe how CHI is situated amongst other cognate fields, and provide some salient examples of CHI applications. Finally, this review of the literature will consider components of a definition, some criteria used to evaluate definitions, and why there is a need to define CHI per se.

2.1 Shift from Physician Centered Care to Consumer Centered Care

Physician centered care is organized primarily from the 'provider perspective', with professionals taking the lead in deciding about the quality of care, and with a somewhat authoritarian approach to patients (Bensing, 2000). Patients would generally take on a more passive role when meeting with their physician; often patients felt as if they were treated as carriers of disease, instead of as people with a health problem (Kremer et al., 2011).

However, recently patients have become more active 'consumers' in choosing treatment options, asking questions, and participating in health decisions as they become more informed (Houston & Ehrenberger, 2001). Thus, consumer (or patient) centered health care is a concept that arose from the idea that the consumer, not the healthcare professional (i.e. physician), should be at the center of the healthcare system (Hanna, 2010). This shift from physician to patient centered care has proven beneficial to both patients (in the quality of

treatment they receive) and to providers (in cost reduction) when executed correctly (van der Eijk et al., 2013)

Studies show that when patients, healthcare administrators, and providers work in partnership, the quality and safety of healthcare rises, cost decreases, and provider and patient satisfaction increase (Commonwealth Fund 2010, IPFCC, 2008). For example, Bertakis and Rahman (2011) showed patients who saw a family physician practicing patient centered care, as opposed to a general internist who was not practicing patient centered care, led to a significantly decreased number of visits for specialty care, less frequent hospitalizations, and fewer laboratory and diagnostic tests. In addition, the total medical charges were also significantly decreased over the one year period indicating that patient centered care is associated with lower total annual charges and a decreased utilization of health care services (Bertakis & Rahman, 2011).

Two key elements of patient centered care are effective communication between the physician and patient, and a shared decision making process (Hanna, 2010). Both of these elements imply that patients are able to present and discuss information regarding their health with their physician. A more participatory, informed consumer is largely made possible due to the increased access of health information on the Internet.

2.2 Consumer Health Information on the Internet

Health information on the Internet is abundant and readily available for those who are willing to seek it out. The public frequently accesses health websites with approximately 70% of Canadian users reporting that they use the Internet to search for health information (Statistics Canada, 2010).

However, health information on the Internet varies significantly with respect to quality; indeed, Web users have been repeatedly advised about the possibility of incomplete, misleading, or inaccurate medical information available on the Web (Hanif et al., 2009). For example, in a study done to screen the quality of breast cancer websites using a set of quality criteria (e.g., site disclosure, site currency, source attribution, and authorship/ownership), Hoffman-Goetz and Clarke (2000) found that majority of the 136 websites screened lacked accountability, attribution, and currency. Online health information is often utilized and therefore needs to be accurate, understandable, and readable. More than 70% of Internet users reported that the information they find online has influenced their decision on a treatment option (Fox & Jones, 2009; Underhill & Mckeown, 2008).

2.3 Emergence of Consumer Health Information and Technology: Web 2.0 and eHealth

2.3.1 Web 2.0

The terms Web 1.0 and 2.0 refer to how the Internet or World Wide Web (WWW) was used in the past and how consumers currently use it. Generally, Web 1.0 refers to the early WWW, which was characterized by an organizational-led system (companies, government, universities, etc.) and was organized in a linear manner, with information flow being one-directional. Web 1.0 was static, content driven, and created by a Webmaster, with little or no user input. In contrast, Web 2.0 refers to a more dynamic type of website, which supports user involvement (Cormode, 2008). With Web 2.0, people who use the Internet can create, publish, and interact with almost any aspect of the Internet and have more of a participatory role. Web 2.0 has many user driven websites and is more focused on social interaction (O'Reilly, 2005).

The healthcare community has started to use Web 2.0. For example, RSS (Rich Site Summary) feeds, blogs (an abbreviated version of Web-log), and YouTube videos can be an accurate and reliable source of medical information, especially for patient education (Giustini, 2005). Web 2.0 was the beginning of a process whereby healthcare professionals could create and share medical information with anyone who wanted access (Giustini, 2005). If used effectively, the many applications and utilities that Web 2.0 has created can enhance and deepen patients', doctors', and students' respective learning (Boulos & Maramba, 2006). Furthermore, the use of Web 2.0 and especially newer technologies (such as Microsoft's HealthVault [available in Canada as TELUS Health Space] and WebMD Symptom Checker)

could lead to fundamental transformations in the way healthcare is provided and potentially change the nature of health informatics in a lasting way (Eysenbach, 2008).

2.3.2 eHealth

The term 'eHealth' is generally used to describe anything having to do with the use of computers and medicine (Eysenbach, 2001). Health Canada defines eHealth as "an overarching term used today to describe the application of information and communications technologies in the health sector. It encompasses a whole range of purposes from purely administrative through to health care delivery" (2010, para. 1). The World Health Organization (W.H.O.) describes eHealth as "the transfer of health resources and health care by electronic means" (2012, para. 1). The W.H.O. further identifies three main areas that eHealth encompasses: the use of the Internet to deliver health information, the use of information technology and e-commerce to improve public health services through training and education, and using the practices of e-commerce and e-business to improve health systems management (W.H.O., 2013).

Similar to consumer health informatics, there are many definitions of eHealth. Oh et al. (2005) undertook a study in which they systematically reviewed the published definitions to gain a better understanding of what the field entails. These investigators came to the conclusion that the term is used quite variedly, but health, technology, and commerce were the main concepts expressed.

The Electronic Health Record (EHR) was also a crucial building block of eHealth, as it facilitates the sharing of essential health information between the various types of healthcare providers and across institutions (Health Canada, 2010). However, an electronic health record

that is made available to the individual, and not just used by healthcare providers, could be an important CHI application. An EHR is already tailored to the individual, and created by a reliable (medical) source. Therefore, use of an EHR by consumers would remove the need for searching the Internet for accurate information.

Although the field of consumer health informatics could be considered a component of eHealth, CHI is differentiated by being a process of delivering health information for the purpose of the consumers use, whereas eHealth is about the process of delivering health information via technology.

In the next section, how CHI fits in to the larger field of health informatics (HI) will be briefly reviewed. How CHI is related to other HI branches, such as public health informatics, nursing informatics, and biomedical informatics, will also be described.

2.4 Consumer Health Informatics Domain

Consumer health informatics (CHI) is part of the much larger field of health informatics (HI). Health informatics – sometimes called healthcare informatics – is also complemented by related fields that have overlapping areas of focus. For instance, biomedical informatics is the term used by American Medical Informatics Association. The AMIA positions biomedical informatics as it relates to biological science and medical practice. Other professional organizations, such as the Healthcare Information Management and Systems Society (HIMSS), use the term health informatics to specifically describe the field as it relates broadly to health care, including public health, nursing and consumer health. Another related term is bioinformatics, which refers to the application of computer technology to the biological sciences to acquire, organize, store, analyze and visualize biological data to expand their use

(Shortliffe et al., 2005). Clinical informatics is the term to describe the application of informatics to problems in clinical care, usually but not always, by physicians (AMIA, 2014)

2.4.1 Cognate and Contributing Fields

Biomedical Informatics:

Biomedical informatics is an encompassing field that includes health informatics (Kulikowski et al., 2012). Health informatics is comprised of clinical informatics, several subfields (medical, nursing, and dental informatics) and public health informatics (of which CHI is a component) (Kulikowski et al., 2012). According to the AMIA, CHI is a combination of both clinical and public health informatics.

Public Health Informatics:

An important distinction to make is one between Consumer Health Informatics and Public Health Informatics (PHI). The focus of PHI is on the public (and/or the entire population) rather than the individual consumer. Public Health Informatics applies informatics tools and technology to the practice of public health (Friede, Blum, & McDonald, 1995). These tools are useful for tasks such as biosurveillance, prevention, and electronic laboratory reporting (AMIA, 2014). Public health, and therefore PHI, is largely oriented towards prevention of illness (Yasnoff et al., 2000).

Nursing Informatics:

Similar to consumer health informatics, nursing informatics (NI) is also poorly defined. Because of the clinical focus, NI is sometimes included within the larger scope of health informatics (Staggers & Thomson, 2002) but not always (Masys et al., 2000). However, NI is considered to be a contributing discipline to consumer health informatics because of its emphasis on the patient (or consumer) instead of the physician (Eysenbach, 2000). Thus, NI would potentially have information for specific individuals (e.g., consumer health history) that could be available to nurses and patients.

2.5 Categories of CHI Applications

Consumer health informatics as a field has developed from various types of health informatics technologies. There are a number of applications that exist today which were created for the purpose of serving the consumer. The University of Victoria published a report on the taxonomy of the various consumer health informatics applications (or "apps") and services (Jahnke et al., 2011). The study was a systematic review which looked at what CHI applications had emerged over the previous decade. The applications were then organized into five categories: information aids – which provide consumers with ways to access, store, control, and distribute their personal health information; decision aids – which are computer based tools that take into account personal health information to help people make informed choices about their healthcare decisions; education aids – which are tools that generally promote health literacy for the consumer or patient; management aids – which support the

consumer in the long-term, ongoing management of their health and are best exemplified by support group services and subscription messaging services; and rating services – which allow consumers to rank and share information about the quality of health providers, treatments and interventions, consumer health informatics apps or websites, or any other aspect of healthcare that is of interest.

It should be noted that the survey was not exhaustive, but selective, as there may be many more applications outside of these categories. However, this survey does show the breadth of services that CHI can provide, and its utility in health. Given how CHI has advanced in practice, it may be necessary to gain a conceptual understanding of CHI as well. A definition of the field that is consensual may serve as a starting point to develop a coherent understanding of the field as it will likely only continue to grow.

In the following section, the concept of 'definition' is presented and criteria that are important for developing a robust clear definition are given.

2.6 Defining a Field

Defining is a process of condensing and simplifying something while maintaining the correctness of whatever it is that is being defined (Bernard, 1941). This can be a very difficult process especially for a new field, such as CHI, because of the tremendous amount of information that needs to be condensed and summarized in only a few words or sentences. CHI is also a technology-based field, which makes defining even more challenging as it advances rapidly.

A definition is an equality between two expressions or components: the definiendum - which is the expression that is being defined, and the definiens – the defining expression (Hart, 1948). Using the World Health Organization's definition of eHealth as an example, "eHealth" is the definiendum and "the transfer of health resources and health care by electronic means" is the definiens (W.H.O., 2012, para. 1). All of the definitions reviewed in this thesis research will follow this format, where consumer health informatics will always be the definiendum and the respective author will provide the definiens.

2.7 Hart's Criteria of a "Good Definition"

Literature on how to evaluate a definition, and more specifically, on what constitutes a "good definition" is scarce, and often leads to older, philosophical articles (Beck, 1956; Edwards, 1966; Pap, 1964). An extensive search for peer-reviewed published criteria aimed at evaluating definitions was undertaken as part of the background literature. None could be

found in the health sciences area. However, guidelines have been published about improving sociological definitions. Hart (1943) indicates there are seven criteria that are necessary for sociological definitions. Two of these criteria are applicable to the evaluation of health definitions: comprehensibility and simplicity. The other five criteria (accurate identification of symptoms and causes, inter-consistency, consensus, special research, and reliability) have more limited utility in definitions of health or could not be operationalized for the purpose of defining CHI. **Table 1** below outlines the two criteria proposed by Hart of what constitutes a good definition and how these criteria might apply to CHI definitions. The emphasis of both criterion is to make sure that the definition is readable and understandable.

Table 1. Hart's criteria for evaluating definitional quality.

Criteria For Defining a Topic, Area, or Item	Comprehensibility	Simplicity
Application of Hart's criteria (sociological perspective)	"That sociological writings may be more accurately and clearly comprehensible by other sociologists and by non-sociologists" (Hart, 1943, p. 337).	"Subject to the foregoing ends, that the most basic and simple characteristics be used as differentiae." (Hart, 1943, p. 337).
Application to Consumer Health Informatics	The researchers and practitioners in the various cognate academic fields must understand the definition of CHI.	The definition should be easy to understand and not wordy.

The emphasis of the "comprehensibility" and "simplicity" criteria is to try and maximize the number of people who understand the content. These criteria are relevant today, with the dissemination of health information via the Internet reaching larger audiences than when these criteria were created by Hart.

2.8 Why the Need to Define CHI

The rationale for defining consumer health informatics (CHI) as a field is threefold. The first reason is to help guide the public in making informed health and healthcare decisions. The application of the Internet for obtaining health information is well established (Fox, 2011; Statistics Canada, 2010). Health information is a necessary (but not sufficient) factor in how people make decisions that affects healthcare (Stansfield et al., 2006). For example, more than half of those who use the Internet said that it has improved their ability to obtain health information they needed; seventy percent indicated that the information obtained affected a personal healthcare decision (Fox & Raine, 2002). A clear definition of CHI will also guide the various public health practitioners, who can then utilize such a definition in the development of appropriate and useful health information content for the public.

The second reason to clearly define CHI is to build capacity for the growth and advancement of this field. A study by Houston and colleagues (2001) surveyed members of the American Medical Informatics Association (AMIA) seeking a consensus on the description of the field of consumer health informatics. Survey respondents listed the top themes that were important facilitators for the growth of the discipline of CHI. These were the following:

developing an identity for CHI, increasing funding, increasing research and evaluation, increasing consumer access/demand, increasing multidisciplinary collaboration, education and training of health/professionals, consumers and CHI professionals, and the ability to maintain privacy. However, these themes are dependent on those engaged in the area as to having a clear definition of CHI. Without an accepted (and acceptable) definition and statement of scope of the area, the usefulness of CHI for advancing client-centered health decision-making will remain problematic.

The third reason to define the field is to help develop core competencies for the training of consumer health informatics professionals. Such professionals can teach/aid the public in important aspects of accessing health information through existing channels, and also ones that will be created in the future. A recent survey of CHI courses and training programmes in Canada indicated a serious deficit: only two post-secondary courses were available that specifically focused on CHI (Arocha & Hoffman-Goetz, 2012). The reasons for the virtual absence of CHI courses (even within the broader Health Informatics domain) may be related to a lack of clarity and knowledge on what competencies would best serve a consumer health informatician, and a consumer health informatics programme (Arocha & Hoffman-Goetz, 2012). However, it is difficult to arrive at an agreement about core competencies and specific skills for consumer health informaticians, if there is no consensus by those working in the field on what the field of consumer health informatics itself entails.

In the next chapter, the research gap, the specific objectives of the thesis research, and the rationale for choosing the objectives will be highlighted.

Chapter 3
Research Gap, Objective, and Rationale

There is no single obvious reason why researchers and professionals in the CHI field have not reached a consensus definition. However, there are at least two possible factors for the lack of a consensus definition. First, consumer health informatics is a multidisciplinary field, where nursing informatics, public health, health promotion, health education, library science, and communication science (Eysenbach, 2000) all play a role in the development and implementation of applications and services. With so many contributing disciplines, arriving at a consensus definition may be a difficult task. The various researchers and practitioners view consumer health informatics with their own perceptions and disciplinary biases.

Another potential reason for the lack of a unified definition is that CHI is a technology-based field, and advances in technology are common and rapid. These rapid changes make CHI difficult to define, and doing so might exclude important contributions that could happen in the near future (Mantas, 2007). CHI has grown alongside the major advances in technology (i.e., broadband Internet, Web 2.0) potentially altering what some researchers might have once thought was a fixed component of the field. Due to this lack of definitional clarity in consumer health informatics, the following two research questions are asked in this investigation.

1. ***What are the peer-reviewed published definitions of consumer health informatics?***

The rationale behind this question is that there are dozens of published definitions of consumer health informatics in the literature today. Yet there is no dominant consensus on which one (if any) is best suited for use in the field (Houston et al., 2001; McDaniel et al.,

2008). Scoping out the existing definitions will allow a better understanding of how many original definitions have been published, and a better understanding of their content.

2. Do any of the published definitions meet the five criteria of what makes a good CHI definition?

The rationale for this question is that given the rapid growth and the multi-disciplinary nature of the field (ranging from health librarians to software engineers) (Eysenbach, 2001), there may be competing definitions and an evaluation tool will help provide a better understanding of their quality.

Figure 1 is an illustration showing the two research questions and the underlying aim of the research.

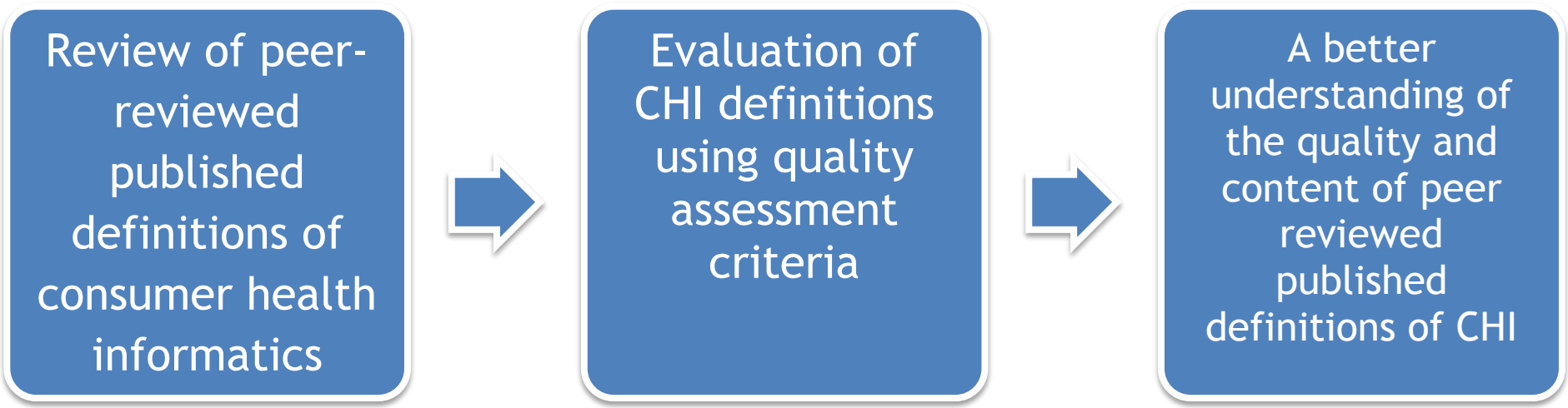

Figure 1. Illustration of the two research questions and their intended goal of a better understanding of the published CHI definitions.

Given the lack of a consensus definition, the importance of CHI in enhancing shared patient-provider communication, healthcare decision-making, and providing accurate tailored information, the focus of this research is on surveying and evaluating the existing definitions of consumer health informatics in the peer-reviewed literature

In the following chapter, the design and research methodology to meet the research questions are described.

Chapter 4
Methodology

This research study will systematically review the existing published definitions in the peer- reviewed literature and assess those definitions using criteria based on the characteristics of a 'good definition'. The overall objective is to clarify and providing insight on the quality and content of consumer health informatics definitions in the literature.

4.1 Search Strategy

The systematic review methodology utilized in this study is informed by similar studies that aim to clarify the definitions of Health 2.0 (Van De Belt et al., 2010), eHealth (Oh et al., 2005), competency based education (Frank et al., 2010), and biomedical informatics (Bernstam et al., 2010). A systematic review was undertaken in January 2013 using the guidelines of Petticrew and Roberts (2006) and the Cochrane Collaboration (Higgings & Green, 2011) to obtain peer-reviewed articles with definitions of consumer health informatics. Systematic reviews involve mapping areas of uncertainty, identifying where little or no relevant research has been done, and indicating where new studies are needed (Petticrew & Roberts, 2006). Only peer-reviewed articles were included in the search, as these are more widely accessed by health informatics researchers, and professionals are most likely to define the field of consumer health informatics in the peer-reviewed literature.

The search string and databases were chosen with the help and guidance of the University of Waterloo health librarian. Several small pilot searches were done to "test" the various databases and search terms and browse the first several pages of results for relevance. The search string and databases chosen were done so as they produced the most relevant results at

the time. The databases searched and the number of articles screened for each database included Embase (n=467); Web of Science and PubMed, via Web of Knowledge (n=447); CINAHL (n=175); and Business Source Complete, via EBSCO (n= 12). All eligible years were searched. However, the years 1995-2013 captured all relevant articles.

Search terms were generated from the topic of the systematic review (i.e., consumer health informatics), keywords from articles of relevance, MeSH terms, and consultation with the university health librarian. Medical Subject Headings, or MeSH terms, consist of a thesaurus of medical terms developed by the U.S. National Library of Medicine. It is a set of synonyms and related descriptors organized in a hierarchical structure that allows one to search at various levels for an identified concept or topic. Reference lists from the identified articles were also hand searched for relevant studies that were not captured from the databases. Since "Consumer Health Informatics" was not a MeSH term and the searches capture both the fields of consumer health and all areas of informatics, two search strings were combined. The first string used the following terms: *consumer, consumer health information, patient participation*. The second string (combined with Boolean operators "AND","OR") included the terms: *informatics, medical informatics*.

4.1.1 Inclusion/Exclusion Criteria

Eligible studies were included if they were written in English and contained text that defined consumer health informatics in explicit terms. Articles were identified from a title/abstract/keyword search and the abstracts were then read for relevance. If the article appeared to be relevant, it was retrieved and read in full for a definition of CHI within the article or text. All study types were included in the review (i.e., editorial, review, clinical

review, etc.) Furthermore, reference lists from the identified articles were hand searched for relevant citations. An article was excluded if it did not contain a definition of CHI.

Data extraction included author, title, source, date of publication, article type (e.g., review, meta-analysis, clinical report), and the exact definition used in the article. These variables were transcribed into a matrix modified from Van De Belt and colleagues (2010).

4.2 Systematic Review

In total, 1101 records were identified through database searching (Embase, CINAHL, Web of Knowledge, MEDLINE, and Business Source) and an additional 8 records were identified through reference list scans of relevant articles (**Figure 2**). After duplicates were removed, 914 articles were screened, and 808 were excluded as not relevant. The remaining 106 full text articles were read and assessed for eligibility. Of these 83 were excluded for not containing a definition of consumer health informatics. In total, twenty-three articles that had definitions of consumer health informatics were included in the review. These articles are listed in **Table 2** (Ferguson, 1995; Jimison & Sher, 1995; GAO/AIMD, 1996; Bader & Barude, 1998; Anonymous, 1998; Bouhaddou et al., 1998; Brennan, 1999; Rhodes, 2000; Eysenbach, 2000; Committee, 2000; Houston et al., 2001; Lewis & Pesut, 2001; Gustafson, 2002; Eysenbach, 2003; Perry & Weldon, 2005; Bakker et al., 2005; Khan et al., 2007; Keselman, 2008; Gibbon et al., 2009; Alamantariotou, 2010; Ho, 2010; Shaikh et al., 2011; Arocha & Hoffman-Goetz, 2012).

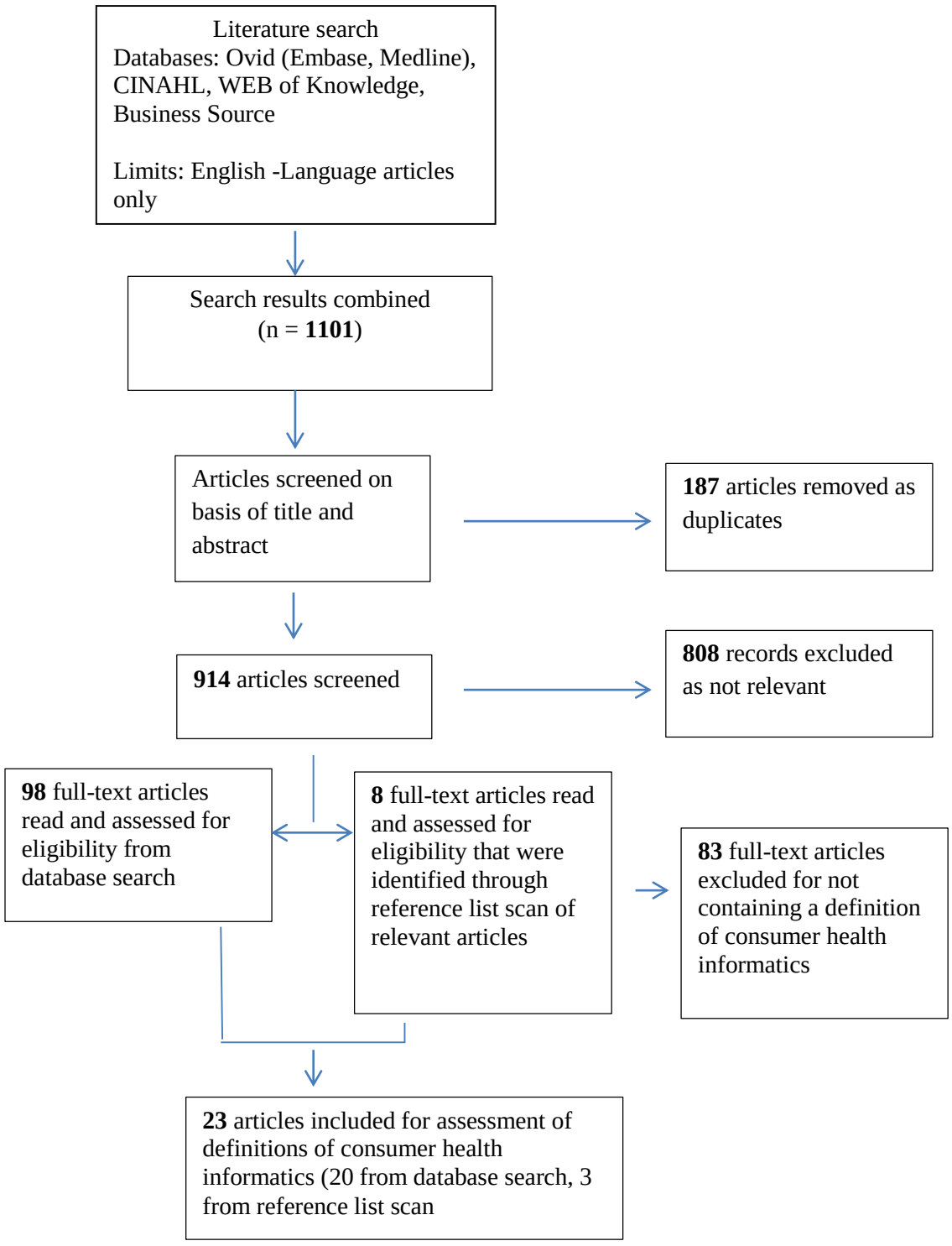

Figure 2. Flow chart of selection of items for systematic review

Table 2. Consumer health informatics definitions and citations included in the review

Ferguson 1995	Jimison & Sher (1995)	GAO/AIMD (1996)	Bader & Barude (1998)	Anonymous (1998)	Bouhaddou et al. (1998)	Brennan (1999)	Rhodes (2000)
An exciting new field of medical computing, consumer health informatics, is devoted to the study and development of a new breed of computer and telecommunication systems designed for use by laypersons.	Consumer health informatics represents a diverse field devoted to the development, implementation, and research on telecommunication and computer applications designed to be used by consumers to access information on a wide variety of health care information.	Consumer health informatics is the union of health care content with the speed and ease of technology.	Information supplied to patients using advanced information and communicatio n technologies.	CHI generally encompasses two areas: the use of Internet technology to connect to online services for health care information, such as that contained in medical journals and professional publications; and systems and software provided by clinicians to patients to help in the diagnosis and treatment of specific conditions and diseases.	CHI can be defined as any information that enables individuals to understand their health and make health-related decisions for themselves or their family (Eysenbach, 2000).	Special-purpose computer tools referred to as Consumer Health Informatics (CHI) represent the application of computer and information technologies specifically to support the health information and communication needs of patients and lay persons.	Consumer informatics is defined as the use of computer to support consumers in obtaining information, analyzing unique care needs, and helping to make decisions about healthcare and health promotion (GAO/AIMD, 1996)

Eysenbach (2000)	Comm. on enhancing the Internet for health apps. (2000)	Houston et al. (2001)	Lewis & Pesut (2001)	Gustafson et al. (2002)	Eysenbach (2003)	Perry & Weldon (2005)	Bakker et al. (2005)
Consumer health informatics is the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems. Consumer informatics stands at the crossroads of other disciplines, such as nursing informatics, public health, health promotion, health education, library science, and communication science, and is perhaps the most challenging and rapidly expanding field in medical informatics.	… the set of activities aimed at giving consumer a more pronounced role in their own health and healthcare, ranging from the development of tools for self-assessment of health risks and management of chronic disease to home-based monitoring of health status and delivery of care	Consumer health informatics is a subspecialty of medical informatics which studies from a patient/consumer perspective the use of electronic information and communication to improve medical outcomes and the healthcare decision-making process.	"Consumer Health Informatics" is an emergent property of the seamless networks of data, services, information, and connectivity available through the Internet.	Consumer Health Informatics Systems (CHIS) include patient-oriented interactive computer-based programs that provide-information, decision, behavior change and emotional support for health issues (Eng 1999, Slack 1997).	`Consumer health informatics' is the emerging science at the crossroads of health informatics and public health which deals with investigating determinants, conditions, elements, models, and processes to design, implement, and maximise the effectiveness of computerised information and telecommunication and network systems for consumers.	A branch of scholarship, referred to as consumer health informatics (CHI), has recently developed with the purpose of understanding how consumers use advanced information management and delivery technologies such as the Internet in order to gather and ultimately act on information about health– for themselves or for those they care for.	Consumer health informatics (CHI) is a rapidly evolving sub-discipline of medical informatics.

Khan et al. (2007)	Keselman et al. (2008)	Gibbons et al. (2009)	Alamantariotou (2010)	Ho (2010) [51]	Shaikh (2011)	Arocha & Hoffman-Goetz (2012)
Consumer health informatics has emerged as a strategy to inform and empower patients for self-management of their health.	Consumer health information resources provide health information to lay users, hopefully to empower patients, caregivers, families, and consumers; improve decisions; and ultimately foster better public health outcomes.	Consumer health informatics is defined as any electronic tool, technology, or electronic application that is designed to interact directly with consumers, with or without the presence of a health care professional that provides or uses individualized (personal) information and provides the consumer with individualized assistance, to help the patient better manage their health or health care.	Consumer health informatics is a part of medical informatics that has as first priority to analyse the interaction between Information Technology (IT) and health consumers. Consumer health informatics applications are designed to interact directly with the customer with or without the essential presence of healthcare.	Consumer health informatics is no different to the branches of informatics in healthcare other than it primarily represents the consumer interests and is about providing the consumer with the right tools, skills, support and knowledge to better manage their health care.	*Consumer health informatics* refers to health information technology that utilizes data enabled by cyber infrastructure, or in other words the computer, mobile, and Internet platforms necessary for coordinating care delivery by health systems and clinical and public health professionals, as well as for consumers to be empowered to manage their own health (Alamantariotou 2010; Marchibroda 2008).	An important component of health informatics, consumer health informatics, has been defined as a field that 'analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems' (Eysenbach 2000).

4.3 Critical Appraisal of Consumer Health Informatics Definitions

Each definition was evaluated against a set of criteria, two of which were adapted from published work about the components necessary for good definitions (Hart, 1943). The other three criteria were based on objective measures or metrics (described below) that have been validated elsewhere, and are directly applicable to the evaluation of definitions. All 5 assessment criteria used were weighted as a maximum of 1. A score of 0 was assigned for 'no' or 'not applicable' or 'condition not met', and a score of 1 was assigned for 'yes' or 'condition fully met'. A score of 0.5 was given where partial fulfillment of the criterion occurred. A maximum score of 5 was possible for each definition summing across all criteria. The criteria and rationale for each criterion are described below.

4.3.1 Criterion 1 (Citation)

A definition that is supported by citations from previous work suggests the author has reviewed the literature, and is making an informed decision on what CHI encompasses. Furthermore, science is built on the foundation and work of others. By citing previously published work, authors show where their understanding of a given topic comes from (Misser & Bell, 2013). This is especially relevant for consumer health informatics, as it was created by adapting pre-existing informatics technologies. Therefore, even the originator of the term (definition) should reference their work using informatics literature. In addition, citation is fundamentally about building knowledge about CHI. Each piece of cited research adds to the collective body of work about the newer, emerging field. CHI definitions that had a published or referenced source were scored as 1. Definitions that were wholly original, and/or did not provide a reference or citation to a published source were scored 0.

4.3.2 Criterion 2 (Multidisciplinary)

Consumer Health Informatics lies at the intersection of several fields: medical informatics, nursing informatics, social care, public health, health promotion, health education, marketing, and communication science (Mantas, 2007). Furthermore, in a consensus discussion amongst members of the American Medical Informatics Association, the consensus panel concluded that a working definition of CHI should stress the multidisciplinary nature of the field (Houston et al., 2001). Therefore, it is important that the definition provided in a published article either identified this significant characteristic or provided an explanation of other disciplines as contributing to CHI. A score of 1 was given if the definition mentioned the multidisciplinary nature of CHI and explicitly named other fields relevant for CHI. A score of 0.5 was given if the definition acknowledged the multidisciplinary nature of CHI, but failed to identify any disciplines or knowledge areas that contribute to the field or, alternatively, mentioned the contributing domains but failed to mention multidisciplinary nature of CHI. A score of 0 was given if the definition did not mention the multidisciplinary nature of CHI nor other contributing fields.

4.3.3 Criterion 3 (Impact)

Impact factor (IF), although imperfect (Brody, 2013), is often used as a proxy measure of the scholarly prestige of a journal (Garfield, 2006). It is a single statistic that captures the average citation performance of articles in a specific journal over a period of one, two, or three years. Generally speaking, the higher the journal IF, the more attention is given to articles in the journal. Although there has been criticism about the overall value and calculation of IF (Seglen, 1997), journals with high impact factors tend to have greater reach and influence in

the scientific and public media (Arnold, 2003). Discourse in the public media would be particularly relevant given the focus of CHI is on the consumer. The two year Impact factor (IF) for each journal in which a definition of CHI was found was retrieved from the ISI Web of Knowledge Journal Citation Report. If the definition was published in a journal with an IF of < 1, it was scored as 0; a journal IF between 1 and 2 was scored as 0.5; and an IF > 2 was assigned a score of 1. Articles (definitions) were scored as 0 if the journal was not included in the ISI database. An IF of 2 was chosen as the upper limit because informatics journals do not have as large of a readership as a more general health journal (e.g., New England Journal of Medicine) and tend to have lower impact factors. A list of impact factors for medical informatics (which includes health informatics) journals in the ISI Web of knowledge shows the 23 journals range from 3.768 (Journal of Medical Internet Research) to 0.704 (Health Information Management Journal). This is in contrast to general, broad medical journals such as the British Medical Journal (IF = 17.215) and the New England Journal of Medicine (IF= 51.658)

4.3.4 Hart's Criteria

As noted earlier (section 2.7), there is very little published literature on how to evaluate definitions, especially for quality based criteria purposes. An exhaustive search was done in the health sciences area (PubMed, Scopus, and Web of Science) before broadening the search to sociology and philosophy databases. The database JSTOR was searched as it encompasses a variety of non-health disciplines (area studies, arts, business and economics, history, humanities, law, science and mathematics, social sciences). Hart's paper, "improving sociological definitions" was the only one found while scoping JSTOR that was remotely

applicable to health (i.e., philosophical articles included epistemological approaches to definitions which were not conceptually relevant to health or CHI).

Criteria 4 and 5: Critical appraisal of what constitutes a good definition in the social sciences (into which Consumer Health Informatics falls as a discipline) was described by Hart (1943). He identified a number of criteria in sociology, two of which were modified and applied for appraisal of consumer health informatics definitions. These criteria were comprehensibility and simplicity of the definitions. Comprehensibility was determined by text complexity and simplicity by text readability. These are described below.

4.3.5 Criterion 4 (Comprehensibility)

Comprehensibility is a key factor for researchers and professionals to adopt a proposed definition. If the definition is too complex, it will likely not be easily understood, remembered, or adopted for use. Propositional analysis is a method for the investigation of discourse comprehension. Propositional density (P-D), a measure of comprehensibility based on propositional analysis, was used to score the definitions for their underlying complexity. Both reading time and recall are key measures of comprehensibility and the greater the number of propositions per unit of text the more reading time is required (Kintsch, 1974). Therefore, a higher P-D score suggests the more difficult a definition will be to read. The definition received a score of 1 if P-D was < 0.50 (brief, clear and concise), and a score of 0 if it is > 0.50 (indicating a semantically dense, and wordy definition).

4.3.6 Criterion 5 (Simplicity)

A good definition should be clear and written in a way that is easy for the reader to understand (Hart, 1943). Dictionary definitions are normally written and framed in the context

of common knowledge for accessibility purposes, whereas academic definitions are usually written in a more scientific manner for a more specific audience (Bunge, 1998). However, even academic definitions should not be encumbered by excessive use of jargon and complex language that an educated layperson cannot understand. In other words, a good definition should be understood not just by the specialized expert but also by the public. There are a number of readability formulas to assess text simplicity. Readability formulas measure structural difficulty of text (i.e., vocabulary, word length) at the sentence level, but do not consider other factors related to reading difficulty (i.e., reader characteristics, material organization, text coherence) (Woods et al., 1998). One of the most widely used is the Simplified Measure of Gobbledygook (SMOG) (McLaughlin, 1969) and has been used to assess text difficulty of printed health information (Hoffman-Goetz & Friedman, 2006). SMOG provides a reading grade level (RGL) metric and is calculated in six steps: 1) Count all of the polysyllabic words in the text, 2) count the number of sentences, 3) find the average number of polysyllabic words, by dividing the total number of polysyllabic words by the number of sentences, 4) multiply that average by the number of sentences short of 30, 5) add that number to the total number of polysyllabic words, and 6) Find the square root and add 3 (McLaughlin, 1969).

Definitions of CHI were scored as 1 if the RGL was < or = to Grade 12 (high school) of formal education (i.e., simpler and easier to read) and a score of 0 if the RGL was > Grade 13 (post-secondary education; greater text difficulty). The underlying assumption was that good definitions are written in clear, plain language that is easy to understand by the non-

technical, but educated reader (i.e., a librarian working with the public, but not necessarily a medical librarian specializing in informatics) as well as the public with a high school education.

4.4 Latent Semantic Analysis

To further compare the published definitions, and quantify their similarity, Latent Semantic Analysis (LSA) was used to provide a score of similarity among definitions. LSA is a statistical method for determining the meaning of texts in context (e.g., word-word, word-sentence, word-text passage relations) including the semantic similarity of words and passages through analysis of a body of text (Landauer et al., 1998). The theory behind LSA assumes that the meaning of the passage is contained to the words that are used in the text, and that the "aggregate of all the word contexts in which a given word does and does not appear provides a set of mutual constraints that largely determines the similarity of meaning of words and sets of words to each other" (Landauer et al., 1998, p. 259).

LSA has been proven to be a valuable analytical tool for a variety of applications, such as information retrieval (Deerwester et al., 1990), information filtering (Foltz & Dumais, 1992), and language and knowledge acquisition (Landauer & Dumais, 1997; Bellegarda, 1998).

The mathematical foundation behind LSA is complex, but it is based on the concept of 'vector space models', which uses linear algebra to automatically retrieve information from a corpus of body of text (Landauer et al., 2011). Essentially LSA works by treating the text as a linear equation and then compares it to a body of words, which it also treats as a large set of equations. The formula then provides a resulting cosine, which is interpreted as a score of similarity between any two passages. Below are some examples of sentence and phrase cosine

similarities (from Landauer et al., 2011) which parallels how LSA is used in this thesis research. In the first example, the two statements are addressing the same topic, but have no shared words and the latter is using more specific language, resulting in a moderately high (0.66) cosine.

Example 1:

"Several doctors operated on a patient"
"The surgery was done my many physicians" (cosine =0.66)

In the second example there are shared words, but as the meaning changes the resulting cosine becomes weaker. Wherein "circle's diameter" has little relation to "music of the spheres"

Example 2:
"A circle's diameter":
"Radius of spheres" (cosine=0.55)
"Music of the spheres" (cosine =0.03)

The third example shows that LSA analysis will also understand differences when analyzing words that have more than one meaning, and will grade the most commonly used definition higher.

Example 3:

"Swallow" – "The process of taking food into the body through the mouth by eating" – (cosine = 0.57)
"Swallow" – "Small long winged songbird noted for a swift graceful flight and the regularity of its migrations" (cosine = 0.30).

4.5 Analysis

All studies were coded using the criteria described above. To ensure reliability, a second researcher independently coded an approximate 26% (6/23) random sample of the definitions. The definitions were numbered from 1 – 23 and an online random number generator (random.org) was used to select 6 articles, which were then sent to the external coder. IBM SPSS Statistics 21 was used to conduct an inter rater reliability, to which there was no variation between the two coders, indicating complete agreement (kappa score =1). Descriptive statistics for the five criteria were conducted using IBM SPSS.

For assessing criteria 4 (propositional density) and 5 (text readability), the following analyses were also used. The analysis for propositional density (criterion 4 for comprehensibility) was done using the Computerized Propositional Idea Density Rater (CPIDR) V5.1 software (2012). CPIDR works by "measuring the idea density of text by using a part-of-speech tagger, then counting the appropriate parts of speech and applying corrective rules to adjust the count in certain situations" (Covington, 2009). Each definition was broken up into 'propositions' or 'idea units', these units are then divided by the number of words in the sentence to deliver a propositional density score. The software has also shown to be in agreement with the consensus of a panel of trained P-D raters better than the raters agreed with each other (Brown et al., 2008), proving its reliability. A screen capture of how the CPIDR application was used is provided in Appendix B.

For criterion 5 (simplicity/readability) the Reading Grade Level (RGL) using SMOG score was calculated by hand (using the formula described in section 4.3.6). The calculation

was based on the formula for text using fewer than 30 sentences since none of the definitions were longer than 30 sentences (McLaughlin, 1969). An example is provided in **Table 3.**

Table 3. Example of SMOG calculation

Definition	SMOG Evaluation
Consumer health informatics is a part of medical informatics that has as first priority to analyze the interaction between Information Technology (IT) and health consumers. Consumer health informatics applications are designed to interact directly with the customer with or without the essential presence of healthcare.	2 sentences, 17 polysyllabic words 30/2x17=255 √255+ 3=18.96 RGL = 19

The final analytical software that was used in this research was created by the Science and Applications of the Latent Semantic Analysis Group at University of Colorado at Boulder (1998). The definitions were entered into a 'Matrix Comparison' LSA web based tool and a corresponding score (ranging from -1.00 [unrelated definitions] to 1.00 [related definitions] for each was given depending on the similarities between them. An example is provided in **Table 4**.

Table 4. Example of LSA Matrix Comparison (from Landaeur et al., 2011)

Document	mouse	cat	dog	house
mouse	1	0.42	0.14	0.05
cat	0.42	1	0.19	0.05
dog	0.14	0.19	1	0.02
house	0.05	0.05	0.02	1

"Document" is the inputted text (where CHI definitions would be) and the corresponding numbers indicate the similarity between each word (or definition). The similarity between "cat" and "mouse" (0.42) is much greater than the similarity between "mouse" and "house" (0.05). Each definition is compared to itself (i.e. mouse x mouse) and every other definition inputted.

Chapter 5
Results

5.1 Description of Definitions

A total of 23 definitions were found. Definitions ranged in length between 12 and 72 words (M±SD: 33.9±15.9). The majority of definitions were one sentence long with the exception of the definitions of Eysenbach (2000) and Alamantariotou (2010), which were two sentences long. The year of publication spanned from 1995 to 2012 (**Figure 3**) with most (n= 13) being published within the first 7 years. Eysenbach (2000, 2003) was the only author to have published two definitions of consumer health informatics.

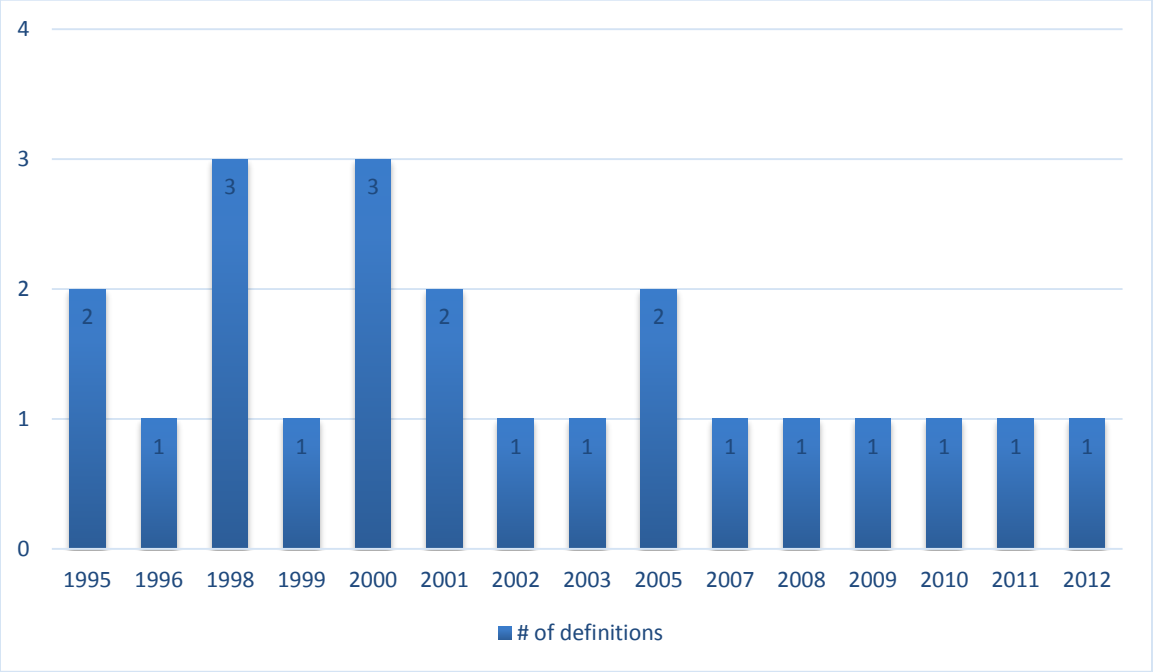

Figure 3. Number of CHI definitions published per year

Table 5 shows the most frequently occurring words (excluding words such as "of", "and", "the", etc.) that appeared in the definitions. The 5 most frequently appearing words were "health" (48 times), "consumer(s)" (37), "informatics" (28 times), "information" (26), and "medical" (10).

Table 5. Most frequently used words in CHI definitions

Health	48	Designed	4
Consumer(s)	37	Defined	4
Informatics	28	Communication	4
Information	26	Tools	3
Medical	10	Technologies	3
Care	10	Studies	3
Systems	7	Science	3
Computer	7	Models	3
Technology	5	Management	3
Patients	5	Making	3
Healthcare	5	Electronic	3
Support	4	Development	3
Public	4	Delivery	3
Patient	4	Decisions	3
Needs	4	Better	3
Internet	4		

5.2 Criteria Scores

A simplified breakdown of how each definition scored in the evaluation, along with the mean and standard deviation, is included in **Table 6** (the complete description of how each definition was scored is included in Appendix B). None of the published definitions met all criteria used in the evaluation. The mean score overall was 1.7 out of 5, and the most frequently met criterion was propositional density (criterion 4) with 20/23 definitions (87%) achieving the requirement of having a score lower than 0.50. The key results are highlighted below.

5.2.1 Criterion 1 (Citation)

Eighteen of the 23 definitions (78.3%) were scored as 0 on the first criterion and five (21.7%) (Bouhaddou, 1998; Rhodes, 2000; Gustafson et al., 2002; Shaikh et al., 2011; Arocha & Hoffman-Goetz, 2012) of the 23 definitions achieved a score of 1 meaning the definition cited published literature. None of the definitions cited the same paper. Bouhaddou's (1998) definition – "CHI can be defined as any information that enables individuals to understand their health and make health-related decisions for themselves or their family" referenced Patrick and Koss (1995). Rhodes' 2000 definition – "Consumer informatics is defined as the use of computer to support consumers in obtaining information, analyzing unique care needs, and helping to make decisions about healthcare and health promotion" referenced the GAO/AIMD (1996) report. The Gustafson and colleagues' (2002) definition of CHI – "Consumer Health Informatics Systems (CHIS) include patient-oriented interactive computer-based programs that provide- information, decision, behavior change and emotional support for health issues" cited two articles: Eng and Gustafson (1999) and Slack (1997). Shaikh and colleagues (2011) cited two articles in their definition –

"*Consumer health informatics* refers to health information technology that utilizes data enabled by cyber infrastructure, or in other words the computer, mobile, and Internet platforms necessary for coordinating care delivery by health systems and clinical and public health professionals, as well as for consumers to be empowered to manage their own health" referenced Alamantariotou and Zisi (2010) and Marchibroda (2008). Finally Arocha and Hoffman-Goetz's (2012) definition – "An important component of health informatics, consumer health informatics, has been defined as a field that 'analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems'" referenced Eysenbach (2000).

5.2.2 Criterion 2 (Multidisciplinary Focus)

Five definitions (21.7%) met the requirements for criterion 2 (multidisciplinary). Of these, four (Anonymous, 1998; Committee, 2000; Eysenbach, 2003; Shaikh et al., 2011) received a score of 0.5 and one (Eysenbach, 2000) received a full score. Of the four definitions which received a partial score of 0.5, these stated multiple components within CHI but not that the area was specifically 'multidisciplinary'. This is exemplified by Shaikh et al.'s definition "Consumer health informatics refers to health information technology that utilizes data enabled by cyber infrastructure, or in other words the computer, mobile, and Internet platforms necessary for coordinating care delivery by health systems and clinical and public health professionals, as well as for consumers to be empowered to manage their own health" (2011). These researchers state

that care is delivered by health systems, public health professionals, clinical professionals and consumers

The definition provided by Eysenbach "Consumer health informatics' is the emerging science at the crossroads of health informatics and public health which deals with investigating determinants, conditions, elements, models, and processes to design, implement, and maximise the effectiveness of computerised information and telecommunication and network systems for consumers" (2000) was the only one to receive a full score. CHI was specifically identified as multidisciplinary and provided actual examples (e.g., such as nursing informatics, public health, health promotion). The remaining 17 definitions (73.9%) received a score of 0 and failed to mention the multidisciplinary focus of CHI and/or give examples of component disciplines. This is illustrated by the definition used by Rhodes stating, "Consumer informatics is defined as the use of computer to support consumers in obtaining information, analyzing unique care needs, and helping to make decisions about healthcare and health promotion" (2000).

5.2.3 Criterion 3 (Impact Factor)

Seven definitions (30.4%) achieved a score of 1 indicating the definition was published in a journal with a high impact factor. The IF ranged from 2.005 to 17.215. As indicated in section 4.3.3, the scale was collapsed so that if the journal had an impact factor of greater than 2, it received a score of 1. Jimison and Sher (1995) published a CHI definition in the *Journal of the American Society for Information Science and Technology* which had an IF of 2.005. Bader and Barude (1998) published their definition in *Academic Medicine*, which has an IF of 3.292. Eysenbach's (2000) definition was published in the journal with the highest IF, the British Medical Journal, with an impact factor of 17.215. Lewis and Pesut (2001) published the CHI definition in *Nursing*

Outlook with an IF of 2.359. Gustafson and colleagues (2002) published their definition in the *International Journal of Medical Informatics* which has an IF of 2.061. Keselman and colleagues (2008) published their definition in *Journal of the American Medical Informatics Association* which has an IF of 3.571. Finally, Shaikh et al. (2011) published in the *American Journal of Preventive Medicine* with an impact factor of 3.945.

Two definitions scored 0.5. These were Brennan (1999) who published in *Methods of Information in Medicine*, with an impact factor of 1.6, and Arocha and Hoffman-Goetz (2012) published in *Informatics for Health and Social Care* (IF of 1.273). The remaining 14 definitions received a score of 0, all of which were published in journals that were not listed in the ISI database, and therefore had no recorded impact factor.

5.2.4 Criterion 4 (Idea Density)

Idea density was measured using the CPIDR software, which counts the number of 'ideas' divided by the number of words in the text; this results in 'density score'. This score is on a scale of 0-1, with 0 being not idea dense at all (very easy to understand) and 1 being extremely dense (difficult to understand). The overall mean of the idea density (ID) score was 0.45 out of 1 with a standard deviation of 0.05, meaning that definitions generally ranged from 0.4-0.5. It was the most frequently met criterion with twenty (87.0%) definitions meeting the requirements (at least partially) having an ID score of 0.50 or less (Ferguson, 1995; Jimison & Sher, 1995; GAO/AIMD, 1996; Bader & Barude, 1998; Anonymous, 1998; Bouhaddou, 1998; Brennan, 1999; Rhodes, 2000; Houston et al., 2001; Lewis & Pesut, 2001; Gustafson, 2002; Eysenbach, 2003; Perry & Weldon, 2005; Bakker et al., 2005; Khan et al., 2007; Keselman, 2008; Alamantariotou, 2010; Ho, 2010; Shaikh et al., 2011; Arocha & Hoffman-Goetz, 2012). The highest scoring definition was

Eysenbach (2000) with an ID score of 0.55 (24 propositions/44 words). The lowest scoring definition was GAO/AIMD's definition (1996) with an ID score of 0.35 (6 propositions/17 words).

5.2.5 Criterion 5 (Readability)

The overall mean RGL calculated for SMOG for the 23 definitions was very high at 20.6 (± 3.5). It was the least met criterion with only one (4.3%) definition (GAO/AIMD, 1996) scoring 1 (a text reading grade level of high school or less). The definition written in the GAO/AIMD paper had the lowest readability score at 12.5 (high school) whereas the highest readability score was tied between Arocha and Hoffman-Goetz (2012) and Anonymous author (1998) at a RGL of 25.6 (post-secondary).

5.2.6 Definition with the Highest/Lowest Score on Assessment Criteria

The definition with the highest score was that of Shaikh and colleagues (2011) (**Table 6**). This definition fulfilled 4 of the 5 criteria with an assessment score of 3.5/5. This definition included a score of 1 for citation, 0.5 for multidisciplinary focus (mentioning three contributing fields but not stating that CHI is multidisciplinary), 1 on impact factor (being published in a journal with an impact factor of 3.95), 1 on propositional density with a score of 0.500, and a 0 on the text readability with a SMOG reading grade level of 24.9.

One definition (Gibbon et al., 2009) received an overall score of 0 out of 5 indicating poor quality on all of the assessment criteria. This definition scored 0 on the citation criterion as it did not reference any published literature for the source of the included definition; 0 on the criterion of multidisciplinary as there was no identification of either the multidisciplinary nature of CHI or identification of contributing fields; 0 on the criterion of Impact Factor as it was published in a journal which did not have an IF listed in ISI; 0 on the criterion of idea density with a propositional

density score of 0.52 which exceeded the 0.50 threshold, and 0 on the criterion of text simplicity with a RGL of 25, far exceeding the threshold of high school (grade 12) or less.

Table 6. List of definitions and their corresponding score

Definition Source	Criterion1 (Citation)	Criterion2 (MD)	Criterion3 (IF)	Criterion4 (PD)	Criterion5 (RGL)	Score Out of 5
Ferguson (1995)	0	0	0	1	0	1
Jimison & Sher (1995)	0	0	1	1	0	2
GAO/AIMD (1996)	0	0	0	1	1	2
Bader & Barude (1998)	0	0	1	1	0	2
Anonymous (1998)	0	0.5	0	1	0	1.5
Bouhaddou et al. (1998)	1	0	0	1	0	2
Brennan (1999)	0	0	0.5	1	0	1.5
Rhodes (2000)	1	0	0	1	0	2
Eysenbach (2000)	0	1	1	0	0	2
Comm. on enhancing the Internet for health apps. (2000)	0	0.5	0	0	0	0.5
Houston et al. (2001)	0	0	0	1	0	1
Lewis & Pesut (2001)	0	0	1	1	0	2
Gustafson et al. (2002)	1	0	1	1	0	3
Eysenbach (2003)	0	0.5	0	1	0	1.5
Perry & Weldon (2005)	0	0	0	1	0	1
Bakker et al. (2005)	0	0	0	1	0	1
Khan et al. (2007)	0	0	0	1	0	1
Keselman et al. (2008)	0	0	1	1	0	2
Gibbons et al. (2009)	0	0	0	0	0	0
Alamantariotou (2010)	0	0	0	1	0	1
Ho (2010)	0	0	0	1	0	1
Shaikh (2011)	1	0.5	1	1	0	3.5
Arocha & Hoffman-Goetz (2012)	1	0	0.5	1	0	2.5
Mean, Standard Deviation, Total	M= 0.22 SD= 0.42 Total = 5/23	M = 0.13 SD = 0.27 Total = 5/23	M=0.35 SD=0.46 Total=9/23	M=0.87 SD= 0.34 Total =20/23	M=0.04 SD=0.21 Total=1/23	M=1.63 SD=0.80

5.3 Latent Semantic Analysis

Table 7 shows the full matrix of definitions with along with a corresponding key which matches the definition number to the author.

As the 'matrix comparison' matches each definition to one another, a total of 529 LSA scores (23x23) were produced. The mean LSA score was 0.79 out of a possible 1.00 with a standard deviation of 0.11. The median was 0.81 and the most frequent score of similarity was 0.86. The range of LSA scores were from a low of 0.37 (GAO/AIMD [definition 2] and Bader & Barude [def. 1]), to a high of 0.94 (Anonymous [def. 5] and Gibbons et al [def. 4].; and Eysenbach [def. 13] and Arocha & Hoffman-Goetz [def. 20]). It should be noted that Arocha & Hoffman-Goetz quote Eysenbach's definition in their own, which explains the high LSA score between these definitions. Gibbons and colleagues (2009)[def. 4] definition had the highest average LSA score at 0.86, meaning it was the most similar to all of the other definitions. Lewis and Pesut's (2001) [def. 7] had the lowest average LSA score at 0.67 meaning it was the least similar to the other definitions.

Table 7. LSA Matrix results

Document	*Def. 1*	*Def. 2*	*Def. 3*	*Def. 4*	*Def. 5*	*Def. 6*	*Def. 7*	*Def. 8*	*Def. 9*	*Def. 10*	*Def. 11*	*Def. 12*	*Def. 13*	*Def. 14*	*Def. 15*	*Def. 16*	*Def. 17*	*Def. 18*	*Def. 19*	*Def. 20*	*Def. 21*	*Def. 22*	*Def. 23*
Def. 1	1	0.37	0.68	0.77	0.72	0.70	0.39	0.77	0.55	0.66	0.61	0.72	0.72	0.74	0.61	0.75	0.70	0.73	0.68	0.69	0.68	0.66	0.71
Def. 2	0.37	1	0.67	0.65	0.68	0.72	0.68	0.45	0.84	0.48	0.67	0.61	0.69	0.64	0.82	0.46	0.61	0.50	0.68	0.69	0.57	0.74	0.59
Def. 3	0.68	0.67	1	0.91	0.86	0.92	0.73	0.81	0.81	0.68	0.77	0.86	0.88	0.86	0.79	0.74	0.85	0.86	0.87	0.90	0.83	0.87	0.80
Def. 4	0.77	0.65	0.91	1	0.94	0.92	0.70	0.89	0.85	0.77	0.82	0.90	0.92	0.91	0.83	0.85	0.86	0.91	0.91	0.93	0.86	0.88	0.88
Def. 5	0.72	0.68	0.86	0.94	1	0.88	0.69	0.87	0.84	0.82	0.83	0.86	0.91	0.88	0.82	0.83	0.86	0.84	0.86	0.88	0.85	0.86	0.86
Def. 6	0.70	0.72	0.92	0.92	0.88	1	0.73	0.84	0.84	0.70	0.78	0.91	0.91	0.87	0.80	0.78	0.86	0.91	0.89	0.91	0.82	0.87	0.83
Def. 7.	0.39	0.68	0.73	0.70	0.69	0.73	1	0.52	0.71	0.45	0.68	0.64	0.69	0.76	0.74	0.43	0.66	0.62	0.76	0.74	0.68	0.79	0.62
Def. 8	0.77	0.45	0.81	0.89	0.87	0.84	0.52	1	0.70	0.73	0.74	0.88	0.84	0.83	0.68	0.91	0.81	0.88	0.79	0.83	0.78	0.75	0.84
Def. 9	0.55	0.84	0.81	0.85	0.84	0.84	0.71	0.70	1	0.73	0.80	0.77	0.86	0.77	0.81	0.69	0.76	0.75	0.81	0.85	0.76	0.82	0.77
Def. 10	0.66	0.48	0.68	0.77	0.82	0.70	0.45	0.73	0.73	1	0.67	0.68	0.78	0.68	0.60	0.76	0.68	0.71	0.62	0.69	0.72	0.65	0.67
Def. 11	0.61	0.67	0.77	0.82	0.83	0.78	0.68	0.74	0.80	0.67	1	0.79	0.82	0.86	0.88	0.75	0.78	0.70	0.87	0.79	0.80	0.86	0.78
Def. 12	0.72	0.61	0.86	0.90	0.86	0.91	0.64	0.88	0.77	0.68	0.79	1	0.88	0.87	0.77	0.82	0.84	0.88	0.87	0.86	0.77	0.80	0.87
Def. 13	0.72	0.69	0.88	0.92	0.91	0.91	0.69	0.84	0.86	0.78	0.82	0.88	1	0.88	0.82	0.80	0.92	0.87	0.87	0.94	0.86	0.88	0.88
Def. 14	0.74	0.64	0.86	0.91	0.88	0.87	0.76	0.83	0.77	0.68	0.86	0.87	0.88	1	0.89	0.78	0.87	0.82	0.93	0.87	0.89	0.92	0.85
Def. 15	0.61	0.82	0.79	0.83	0.82	0.80	0.74	0.68	0.81	0.60	0.88	0.77	0.82	0.89	1	0.68	0.76	0.67	0.90	0.81	0.80	0.90	0.77
Def. 16	0.75	0.46	0.74	0.85	0.83	0.78	0.43	0.91	0.69	0.76	0.75	0.82	0.80	0.78	0.68	1	0.75	0.79	0.74	0.76	0.72	0.69	0.82
Def. 17	0.70	0.61	0.85	0.86	0.86	0.86	0.66	0.81	0.76	0.68	0.78	0.84	0.92	0.87	0.76	0.75	1	0.81	0.82	0.89	0.82	0.83	0.83
Def. 18	0.73	0.50	0.86	0.91	0.84	0.91	0.62	0.88	0.75	0.71	0.70	0.88	0.87	0.82	0.67	0.79	0.81	1	0.83	0.86	0.80	0.78	0.82
Def. 19	0.68	0.68	0.87	0.91	0.86	0.89	0.76	0.79	0.81	0.62	0.87	0.87	0.87	0.93	0.90	0.74	0.82	0.83	1	0.90	0.86	0.91	0.85
Def. 20	0.69	0.69	0.90	0.93	0.88	0.91	0.74	0.83	0.85	0.69	0.79	0.86	0.94	0.87	0.81	0.76	0.89	0.86	0.90	1	0.84	0.89	0.88
Def. 21	0.68	0.57	0.83	0.86	0.85	0.82	0.68	0.78	0.76	0.72	0.80	0.77	0.86	0.89	0.80	0.72	0.82	0.80	0.86	0.84	1	0.91	0.74
Def. 22	0.66	0.74	0.87	0.88	0.86	0.87	0.79	0.75	0.82	0.65	0.86	0.80	0.88	0.92	0.90	0.69	0.83	0.78	0.91	0.89	0.91	1	0.78
Def. 23	0.71	0.59	0.80	0.88	0.86	0.83	0.62	0.84	0.77	0.67	0.78	0.87	0.88	0.85	0.77	0.82	0.83	0.82	0.85	0.88	0.74	0.78	1

Key for Definitions used in LSA	
Def. 1	Bader & Barude (1998)
Def. 2	GAO/AIMD (1996)
Def. 3	Alamantariotou (2010)
Def. 4	Gibbons et al. (2009)
Def. 5	Anonymous (1998)
Def. 6	Perry & Weldon (2005)
Def. 7.	Lewis & Pesut (2001)
Def. 8	Committee … (2000)
Def. 9	Houston et al. (2001)
Def. 10	Bakker et al.(2005)
Def. 11	Gustafson (2002)
Def. 12	Bouhaddou et al.
Def. 13	Eysenbach (2000)
Def. 14	Shaikh et al. (2011)
Def. 15	Brennan (1999)
Def. 16	Khan et al. (2007)
Def. 17	Eysenbach (2003)
Def. 18	Ho (2010)
Def. 19	Rhodes (2000)
Def. 20	Arocha & Hoffman-Goetz (2012)
Def. 21	Ferguson (1995)
Def. 22	Jimison & Sher (1995)
Def. 23	Keselman et al. (2008)

Descriptive Statistics	
Mean	0.79
Median	0.81
Mode	0.86
Standard Deviation	0.11

Chapter 6
Discussion

6.1 Overall Findings

To my knowledge this is the first systematic review of peer-reviewed published definitions of consumer health informatics. There are a number of proposed definitions of CHI, which encompass many of the same ideas, but there is no globally accepted definition. A set of assessment criteria about what makes a "good definition" was used to more objectively evaluate the existing CHI definitions. However, no judgment was put forward about which definition, if any, is "best" for adoption as that would ideally be decided by the various researchers, practitioners, and professionals working in the field.

A total of 23 unique definitions of consumer health informatics from 914 articles screened (after duplicates were removed), written by 22 different authors, spanning a total of 17 years (1995-2012), were found in the peer-reviewed literature. The expectation was that the number of definitions found would be comparable to reviews of eHealth (Oh et al, 2005) and health 2.0 (Van De Belt et al., 2009) due to the similarity of the fields. However, Oh and colleagues found a total of 51 definitions of "eHealth" in the literature and Van De Belt et al. found a total of 47 definitions of "health or medicine 2.0". It should be noted the Oh et al. and Van De Belt et al. reviews included grey literature, which may have contributed to high the numbers.

Other systematic reviews of health definitions on preventable harm (Nahban et al., 2012) and health literacy (Sorensen et al., 2012) did not include grey literature and found a lower number of definitions. Sorensen and colleagues found 17 definitions of "health literacy" in their search of peer-reviewed literature, whereas Nahban and colleagues found only 7 definitions of "preventable harm"

in their search of the academic literature. However, in all four of these studies (Oh et al., 2005; Van De Belt et al., 2009; Nahban et al.; Sorensen et al., 2012) the definitions were sought out and extracted for the purpose of a topic, thematic, or framework analysis.

One study assessing the empirical definition of clinical supervision used a set of criteria to evaluate definitional quality (Milne, 2007). Although the criteria were only used to evaluate the most popular definition of clinical supervision, the author reported that it failed to meet the all of the evaluation criteria (precision, specification, operationalization, and corroboration) (Milne, 2007). However, Milne used the criteria as a foundation for the development of his own definition of clinical supervision. Thus, the number of definitions obtained in this thesis study is fewer than that reported for reviews of definitions in cognate disciplines which included the grey literature but in line with those of Sorensen on definitions of health literacy.

The results of the criteria assessment were generally poor, as none of the 23 published definitions met all five criteria used to evaluate the features of a good CHI definition. This result is not surprising, as the criteria chosen to evaluate the definitions were assembled from various fields. Moreover, it is unlikely that an author developing a definition for CHI would incorporate the five criteria which were used here for evaluation. Indeed, when development of a definition occurs by a researcher or practitioner, the focus is often on the content of the discipline, rather than the more theoretical basis.

In contrast to the low criteria scores, the LSA numbers were high. Latent Semantic Analysis is not a commonly used methodology in health research, but it was uniquely suited to quantify the similarity of the definitions and to gain a better understanding of the extent to which these definitions were congruent overall. The high LSA mean (0.79) for all definitions indicates that the subject matter

among the 23 definitions is quite similar. This finding suggests that although there may not be a formally agreed upon definition of CHI, there is an implicit consensus amongst the authors of what the field entails.

A count analysis of the most frequent words that appeared in the definitions provides further insight into what has been the most prominent aspects of CHI from 1995-2012. The frequency of certain words of phrases can also help to serve as a potential starting point for researchers developing a future consensus definition. The words “consumer”, “health”, and ”informatics” are obviously featured the most, but “medical”(10 times) “care” (10 times) “systems” (7 times) and “computer” (7 times) are also quite common emphasizing the health informatics origins. The more technology based words such as “Internet” (4 times), “communication” (4 times), “telecommunication” (3 times) are not as common, but still serve a vital purpose in a potential consensus definition as they are foundational to CHI and need to be stressed.

Figure 4 below summarizes the overall findings, the implications for CHI, and the suggested recommendation for action.

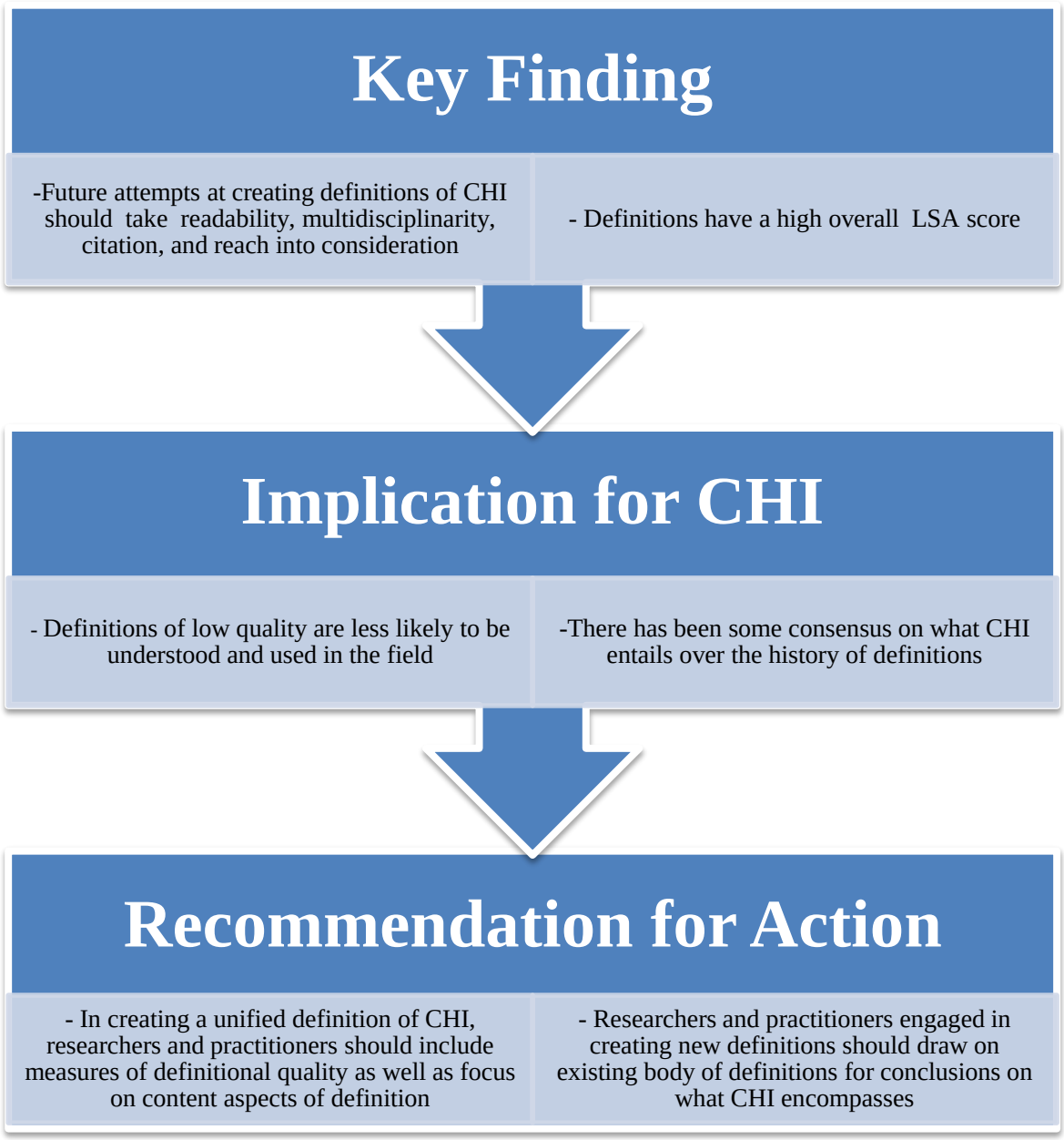

Figure 4. Overall findings, their implications for CHI, and suggested recommendation for action

6.2 Criteria Assessment

There was an interesting dichotomy between the complexity and readability of the definitions included in this review. Twenty of 23 definitions (87.0%) had a maximum score of one on the idea density criterion. A score of one meant that the idea density was low and the definition was not difficult to comprehend (i.e., few ideas per unit of text). In contrast, criterion 5 assessed the readability of the definitions and showed that the majority of them used difficult, complex words and jargon, and were written at a post-secondary reading grade level.

These two measures of textual complexity provide insight into potential usefulness of the definitions for adoption by a wide spectrum of users. Whereas propositional density assesses the underlying conceptual complexity, readability measures the linguistic complexity of a body of text. Ideally, for the definitions to be optimally understandable by diverse users ranging from experts to consumers, they would be written so that both the underlying propositional structure (PD) and the surface linguistic form (RGL) are at a low complexity level. Using propositional density analysis and reading grade level together to analyze the same piece of text is a novel aspect of this research. Although both of these measures were used for the purpose of better understanding the written definition, they are independent of one another, and work best complementary to one another (Ta-Min et al., 2007). In other words, one cannot assume that in writing a definition with a low RGL a low PD will also occur (and vice versa).

The findings show that most definitions were not particularly idea-dense, making them understandable and not difficult to remember. However, this was partially offset by the finding that most definitions (22/23 or 96%) were written in poly-syllabic language. Therefore, rewriting in plain language could help to decrease the complexity of the definition, and potentially increase the number of people who can understand it.

Another interesting finding from this systematic review was that about one-third (9/23) of the definitions appeared in articles published in journals with an impact factor (IF) greater than 1, potentially giving them a further reach in the academic field than the definitions published in journals with low or no IF. This is exemplified by Eysenbach's (2000) definition of CHI, published in the British Medical Journal (BMJ) which has an IF of 17.2. BMJ regularly produces press releases, and BMJ articles are consistently picked up by the mass media such as The Huffington Post (2013) and the Los Angeles Times (2013); BMJ also keeps track of the 'latest BMJ articles in the news' on their website (BMJ, 2013). Similarly, Bader and Barude's (1998) definition was published in Academic Medicine (IF of 3.292), and although Academic Medicine does not have as big of a media presence as BMJ, editors of Academic Medicine allow members of the press to access articles early and send out releases to those who sign up. However, neither Eysenbach's, nor Bader and Barudue's articles were reported by the mass popular media; nevertheless, the chances are undoubtedly greater of being a newsworthy item in the popular press than if the definition/article was published in a smaller, less prestigious journal (i.e., Alamantariotou's definition which was published in the International Journal of Electronic Healthcare, not listed in ISI, and also not picked up by the media).

Impact factor is important when considering the potential reach of the definitions. Journals with very high IF`s (e.g., British Medical Journal or Journal of the American Medical Association) have media relation teams, and subsequently produce press releases with their most recent and relevant articles that are sent to news journalists (Woloshin & Schwartz, 2002). This process of selecting which articles are included in press releases is the same for many high IF journals (i.e., BMJ, JAMA, Lancet). The journal editor or press office selects articles on the basis of perceived newsworthiness, and the releases are written by the in house press officers (Woloshin & Schwartz, 2002). Articles

included in these releases are likely to be presented in the news media, and therefore to reach the public (Arnold, 2003).

The newsworthiness and journal IF are important for the field of Consumer Health Informatics. Indeed, once a consensus definition has been reached, publishing the definition in a journal with a high impact factor could help to widen dissemination and reach across the component disciplines and the interested public.

Additionally, it appears that neither the popularity nor originality of a definition is any indication on whether or not it is accepted as the single definition of a field. The popularity of Eysenbach's (2000) definition, which has 604 Google citations (the second highest is Gustafson's which has 186), would make it the obvious choice for being the sole definition of CHI; yet 10 additional original definitions were written after his 2000 publication. The originality of Ferguson's (1995) early definition of CHI did not prevent other (later) authors from attempting to define the field. A possible reason for minimal adoption of Eysenbach and Ferguson's CHI definitions might be linked to the lack of a thorough search by researchers for existing definitions in the literature. Based on Criterion 1 in this study, only 5 out of 23 definitions referenced previous CHI definitions. A multitude of definitions can create confusion for the reader, especially if the reader wants to understand a new field such as CHI. A potential solution to this problem could be to first scope or systematically review the literature in search of an existing definition. If one can be found, then researchers can update or adapt the existing definition, and reference the original. This would allow authors to update the definition as necessary (which is important for a technology based field such as CHI), and also maintain consistency for the reader. The origin of a definition should be traceable, and referencing original work is one way to ensure this.

6.3 CHI Definitions – Next Steps

Overall, the criteria proposed in this research are useful as a starting point for examining the core components of consumer health informatics and developing a definition that would encompass the major areas and activities of the discipline. Consideration of the importance that health science librarians can have in the creation of a new CHI definition/core competencies, and of the inclusion of mHealth as a key component of CHI, are discussed below.

6.3.1 Librarians Role in Consumer Health Informatics

Part of the rationale behind creating a unified definition is to help develop core competencies with application in the training of a consumer health informatician. This training component would be, in part, filled by health librarians. They could play a key role in helping consumers navigate the many health applications and websites available. This could be done in several ways using online guides, tutorials, and basic health literacy instructional sessions (Hasman, 2011).

Furthermore, in a policy statement by the Medical Library Association which was developed by the Consumer and Patient Health Information Section, the authors outline six key roles that health librarians can play in the delivery of health information to the consumers (1996). The first would be in the collection and management of new CHI materials, wherein the librarian would identify new information for review, as well as organize and maintain them. The second role would be in knowledge and resource sharing about CHI, which involves networking with other health librarians, patients/consumers, and public health unites/hospitals. The third role of the CHI librarian would be in advocacy, where open access to health information for the public would be made available. The fourth role would be in the provision and dissemination of information, which would involve sending

health information to consumers who requested it, acting as a quality assessment evaluator or gatekeeper for consumers, and even creating health information centres (i.e., in respective libraries) to disseminate information. The fifth role that health librarians could play would be in education. Education would work in several ways; librarians would be responsible for educating health professionals about the health information needs of consumers, educating other librarians on the provisions of CHI, and educating the general public in evaluating health information. The sixth and final role health librarians would play in the provision of consumer health informatics would be in research. Librarians could act as participants in CHI research and apply research to consumer education activities and needs (MLA/CAPHIS, 1996).

Consumer health librarians could also contribute to assisting seniors in the search and retrieval of health information on the Internet (Hoffman-Goetz et al., 2006). Seniors already have a positive opinion towards librarians and libraries, and consider them reliable sources of information (Gollop, 1997). Workshops geared for seniors providing effective health seeking search skills on the Internet have been shown to be effective and positively received (Hoffman-Goetz et al., 2006). Such health information Internet workshops could be available for the general population as well.

Due to frequent contact with consumers, librarians' trustworthiness, and their role as an arbiter of information in general, librarians are uniquely positioned to help those who are seeking health information (especially the elderly and those who are not technologically savvy) (Hoffman-Goetz et al., 2006). 'Consumer health information' librarians could fill the gap and should be key consultants in creating a new unified definition and core competencies of CHI.

6.3.2 Consumer Health Informatics Smart Phone Apps (mHealth)

One of the most promising new advancements in consumer health informatics is the emergence of health applications or "apps". This relatively new field, referred to as mHealth (mobile health), also does not have a standardized definition. However the Global Observatory for eHealth (GOe), a component of the W.H.O., defined it as:

> …medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices. mHealth involves the use and capitalization on a mobile phone's core utility of voice and short messaging service (SMS) as well as more complex functionalities and applications including general packet radio service (GPRS), third and fourth generation mobile telecommunications (3G and 4G systems), global positioning system (GPS), and Bluetooth technology. (2011, p.5)

Essentially, mHealth allows any consumer with a smartphone (e.g., iPhone, Samsung, Blackberry) to download health related applications that serve a wide variety of purposes. For example, there are apps for monitoring diabetes, handling emergency situations, general health reference purposes, symptom checking, tracking calories, calculating body mass index, and enhancing workouts (Hasman, 2011). Cell phones, and text messaging in particular, have already proven to have benefits as a successful management aid in chronic diseases, including diabetes, asthma, and hypertension (Franklin et al., 2008; Ryan et al., 2005; Logan et al., 2007).

However, since these applications are still in their infancy stages, and largely dominated by for-profit software manufacturers, there is still a question of quality, as standards are not in place to

prevent inaccurate information from being used. One study on smoking cessation apps, recommended that many of the current health apps need to be revised and future ones should be created in accordance with peer-reviewed evidence-based research (Abroms et al., 2011). This is an important niche that could be filled in the potential training of a future consumer health informatician.

mHealth will certainly be a large component in the future of consumer health informatics due to its ability to send health information to nearly anyone, anywhere on the planet, as it utilizes the already vast infrastructure of mobile phones. To put this into context, there were 6.8 billion mobile phone subscriptions in 2012 according to the International Telecommunication Union, and nearly 85% of the world is covered by a commercial wireless signal (W.H.O., 2011). This reach, combined with the ability of smartphones to take pictures and video with fast data transmission, highlights the promise of smartphones to affect health outcomes (Hasman, 2011).

As researchers and practitioners of CHI move forward developing a consensus definition, discussions about mHealth, mobile health, or smartphone applications in the definiens might help bring positive attention to the field. Smartphone applications are a big part of consumer health informatics and could be an important facilitator for building capacity in the future. The popularity of these applications will bring new personnel (e.g., researchers, doctors, and software designers) to CHI which in turn could lead to positive growth and utility in the field.

6.4 Core Competencies

CHI as a field has progressed practically, but there are still gaps in the creation, implementation, and dissemination of CHI applications that would be best suited for a consumer health informatician to fill. Yet there is still a deficit in the education, and subsequent training, of

consumer health informaticians that could be due to the lack of core competencies (Arocha & Hoffman-Goetz, 2012).

Professional organizations, such as COACH and AMIA, have put forward core competencies of health informatics in the past, which makes these organizations logical starting points for developing ones for CHI. Additionally, a smaller group (Consumer Health Informatics Working Group) is discussed in the next section as a potential leader for the development of core competencies as the stated objectives and work indicate willingness to advance the field.

6.4.1 Organizations and Core Competencies

COACH (Canada's Health Informatics Association) has outlined core competencies for the health informatics professional (COACH, 2012). The expert panel of COACH provided a definition of health informatics, and proceeded to identify three general areas and seven advanced corresponding sub-areas that are needed: Information Sciences (information management, information technology), Health Sciences (clinical & health services, Canadian health system), and Management Sciences (organizational & behavioural management, project management, and analysis & evaluation). The discipline of Consumer Health Informatics would benefit from a similar document as that done for health informatics.

The American Medical Informatics Association (AMIA) has also recently developed a definition and set of core competencies to guide curriculum development in biomedical informatics (Kulikowski et al., 2012). The AMIA panel also proposed a core definition "that could be adopted for ongoing use by AMIA and would capture the field's scope and focus" (p.8) (2012). Houston et al. (2001) began this work identified by the AMIA by seeking out a consensus description of the

field from other AMIA members. However, consumer health informatics was a relatively new field at that time, and it was difficult to present a consensus definition/description. Continuing the work started by Houston and colleagues could lead to both a definition and core competencies, as CHI has progressed considerably.

The Consumer Health Informatics Working Group (CHIWG), a member of International Medical Informatics Association (IMIA), could potentially assist in the creation of core competencies. In the latest conference of CHIWG in the fall of 2013, members highlighted recent activities and objectives which focus on increasing the reach and communication of CHI activities, news, and findings. In the summary report, the CHIWG panel stated that the future objectives were to focus on expansion and exposure, to produce more research and publish it in informatics journals, and to share the CHI related information with other informatics working groups around the world (Wetter, 2013). There was also an emphasis on academic issues, such as releasing a new CHI textbook, and adding new MeSH terms. Consulting with CHIWG on what are important aspects of consumer health informatics would be useful in the development of core competencies.

Chapter 7

Conclusions and Implications for Further Research

7.1 General Conclusions

There are many proposed definitions of consumer health informatics, most of which encompass similar ideas. Nonetheless there is no widely accepted single definition. With the growth of the Internet, similar fields like health 2.0, eHealth, and social media platforms such as Facebook, have also emerged. These fields and multiple information portals makes it confusing for the consumer and professional alike as to what CHI entails. One of the goals of this current research was to provide insight into the existing definitions and help bring some clarity to the field.

As stated earlier, none of the 23 definitions included in this review completely fulfilled the five criteria used to assess definitional quality. The results suggest the need for dialogue amongst professionals within the field in order to develop a unified definition. CHI is multidisciplinary in nature, and therefore the key stakeholders and leaders of the multiple fields that contribute should agree on an inclusive definition.

To emphasize the rationale behind this research, a clear definition is important for the development of new CHI applications and initiatives, improving the communication among the many organizations and individuals who use the term, and also for the comparability of new developments in research (i.e., CHI vs eHealth). Therefore, agreement about a single definition would help with the progression of CHI, which could potentially result in better use of health information by consumers.

7.2 Why Consumer Health Informatics is Difficult to Define

There are several reasons why consumer health informatics (CHI) is difficult to define. First, as a field CHI has progressed quickly, due in large part to accessibility to the Internet and the ubiquity of personal computing (both mobile and stationary). This growth has been both a positive and a negative for the field. The positive aspect is the potential to provide health information to consumers, whenever and wherever they need it. This is thought to be beneficial for the individual and healthcare in general. The negative aspect of rapid growth is the dependence on technology, which also changes quickly. For researchers and practitioners of CHI who aim to develop a coherent definition of the field, there are questions of whether to include recent technological and conceptual advancements (e.g., mHealth) or to keep the definition more general by using non-specific terms (e.g., "technologies").

Second, due to its multidisciplinary focus, CHI stands at the crossroads of many fields, all of which bring knowledge and disciplinary biases to the area. A definition written by a health librarian may not be applicable to what a clinician feels is essential for the consumer to know. Consensus will require ongoing discussions among professionals in many fields – a difficult, time consuming, and potentially very expensive task.

Third, CHI has been difficult to define in a consensus-like fashion because the fields that contribute to CHI are not specifically delineated. The potential exclusion of key fields further confounds the process when trying to come to a consensus definition. This problem is exemplified in Eysenbach's (2000) definition which states that public health, health promotion, nursing informatics, heath education, library science, and communication science are all contributors to CHI. Yet, that description excludes other fields, such as software engineering, graphic design, and

communication studies, which are also potentially important contributors and components of consumer health informatics.

7.3 Future Research in Consumer Health Informatics Definitions

Further research needs to survey consumer health informatics researchers, members of health informatics organizations, and other key players (from each of the contributing disciplines) on what they specifically consider to be core competencies for CHI. In conjunction with the survey, a thematic analysis, using a constant comparison method, could be done to cross-reference the results to produce a single definition of consumer health informatics.

The methods and criteria used by Milne (2007) could assist with the creation of a CHI definition. Milne (2007) utilized logical analysis to draft a working definition of clinical supervision, and completed a systematic review to identify published definitions. The results from the systematic review were used to test and improve the working definition for clinical supervision. Two of the four criteria that were used could potentially be adapted to evaluate CHI definitions. The first relevant criterion evaluated the 'precision' of the working definition by checking if the working definition incorporated most of the definitional material from the reviewed sample studies (Milne, 2007). The second relevant criterion evaluated the specification' of the working definition, which was tested by comparing the definition with other published definitions (Milne, 2007). The other two criterion which evaluated the definitions on 'operationalization' and 'corroboration', were suited for clinical measurement purposes and cannot be used in this context.

Finally, Landauer, Foltz, and Laham (1998) outlined several other applications of latent semantic analysis which could be used in the development of a consensus definition. LSA has been used in estimating passage coherence, the learnability of text passages by individual students, and estimating the quality and quantity of knowledge contained in a document. Although some of these methods are not appropriate to single sentence analysis (as was used in this thesis research) they are suitable for comparisons between documents, and for before and after testing of written passages (for comprehension). Since the research presented in this thesis shows there is a high LSA score amongst existing definitions, a new definition could be compared to the results obtained here, to gauge its coherence with other documents and definitions.

Chapter 8
Limitations

There are several limitations to this study. First, it has been suggested that systematic reviews may have less validity when a field or discipline is new (Ravetz, 1973), such as CHI, because a few studies in the discipline will have been published. However, Petticrew and Roberts (2006) state that "even when a field is immature, it is important to cumulate prospectively rather than wait for some later date when ''enough'' evidence has accumulated, and consolidation can occur" (2006, p. 35).

A second limitation is in regards to the criteria used to evaluate the definitions of CHI. Three of the five criteria have been applied and validated elsewhere: the Simplified Measure of Gobbledygook readability index (Ley & Florio, 1996) and the Computerized Propositional Idea Density Rater calculator (Brown et al., 2008). The ISI journal impact factor rating has been validated for content validity (Saha, 2003). However, none of these three criteria have been directly applied to assessment of definitional quality. The other two criteria, citation/referencing and multidisciplinary focus, were intended to be as objective as possible. Thus, using other criteria for quality assessment could have led to entirely different results about the quality of CHI definitions.

Third, it is important to note the limitations in the use of SMOG when applying it to both short text, and medical terminology, as these factors can heavily influence the resulting reading grade level. Medical terminology is often laden with unavoidable multisyllabic words (e.g., informatics). Definitions present in the studies reviewed here were generally short in length, giving the text an unbalanced number of "difficult" words which can inflate the score. Still, SMOG is useful despite these limitations. The nature of readability gives the authors a benchmark reading grade level for before and after testing, and also a method of comparing their work to other (possibly more well-

known) definitions. It is also the only formula that is appropriate for analyzing materials with fewer than 100 words (Bastable, 2006). Additionally, using a different reading grade level formula (e.g., Flesch-Kincaid, FRY) could result in different RGL's for the definitions.

A fourth limitation is that the elements considered as necessary for a good definition are drawn from the sociological rather than the informatics literature (Hart, 1943). A definition is a thorough description of the meaning of a term (e.g., Consumer Health Informatics). Hart's criteria were originally developed to improve sociological definitions and were adapted in this study for health definitions. Because health and sociology are different fields of study (with different assumptions, conceptual foundations, history, emphasis, etc.) specific aspects of Hart's criteria might be less relevant for CHI definitions. However, the core meaning of 'comprehensibility' and 'simplicity' criteria translate well, and are captured by the propositional density and SMOG analyses.

A fifth limitation is with respect to criterion 3 (impact factor). A truncated scale was used in scoring the studies (journals), wherein any definition that was published in a journal with an IF of greater than 2, received a full score on that criterion. The rationale for this truncation was because of the relatively low IF that informatics journals typically have. However, this also means that a definition published in a journal with an IF of 2.5 is scored the same as a definition published in a journal with an IF of 15.

Similarly, for criterion 1 (citation), wholly novel definitions were collapsed with definitions that did not reference other work. The rationale for this criterion is that science is built on the foundation of what other researchers have begun, and referencing is an important way to expand the work and continue the "conversation" about a given topic. It also shows that the author has conducted

adequate background research and is not frivolously writing a definition of their own. However, it is possible that a completely original and unreferenced definition was written by a credible researcher in the consumer health informatics field. This would be scored as zero, and in so doing negatively bias the overall score for definitional quality.

A sixth limitation is that the grey literature was not included in the searches. The reason grey literature was excluded from the search was that the peer-reviewed definitions of CHI are more likely to be widely cited, and influential in the field. Furthermore, one of the criterion for evaluating the definitions was Impact Factor which applies to peer-reviewed journals only.

It was the case that the methodological quality of the study for each article (e.g., randomized trial vs case control design) was not included in the assessment. While research design and population characteristics are crucial for systematic reviews of the clinical literature, they may be less important for the research described in this thesis. The purpose of the research was to assess only the definition, not the study design in which the definition may have been applied.

Although there were many limitations with this systematic review of definitions, this study is the first to assess quality characteristics of this important definitional component of CHI. A such, it is a starting point for future discussions and the templates needed to fully clarify what consumer health informatics entails and how core competencies can be developed.

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Appendix A

Glossary of Acronyms and Terms Used in this Thesis

CHI – Consumer health informations

HI – Health informatics

NI – Nursing informatics

PHI – Public health informatics

AMIA – American Medical Informatics Association

IMIA – International Medical Informatics Association

COACH – Canada's health informatics association

CHIWG – Consumer

EHR – Electronic health record

RGL – Reading grade level

IF- Impact factor

P-D – Propositional density

I-D – Idea density

LSA – Latent semantic analysis

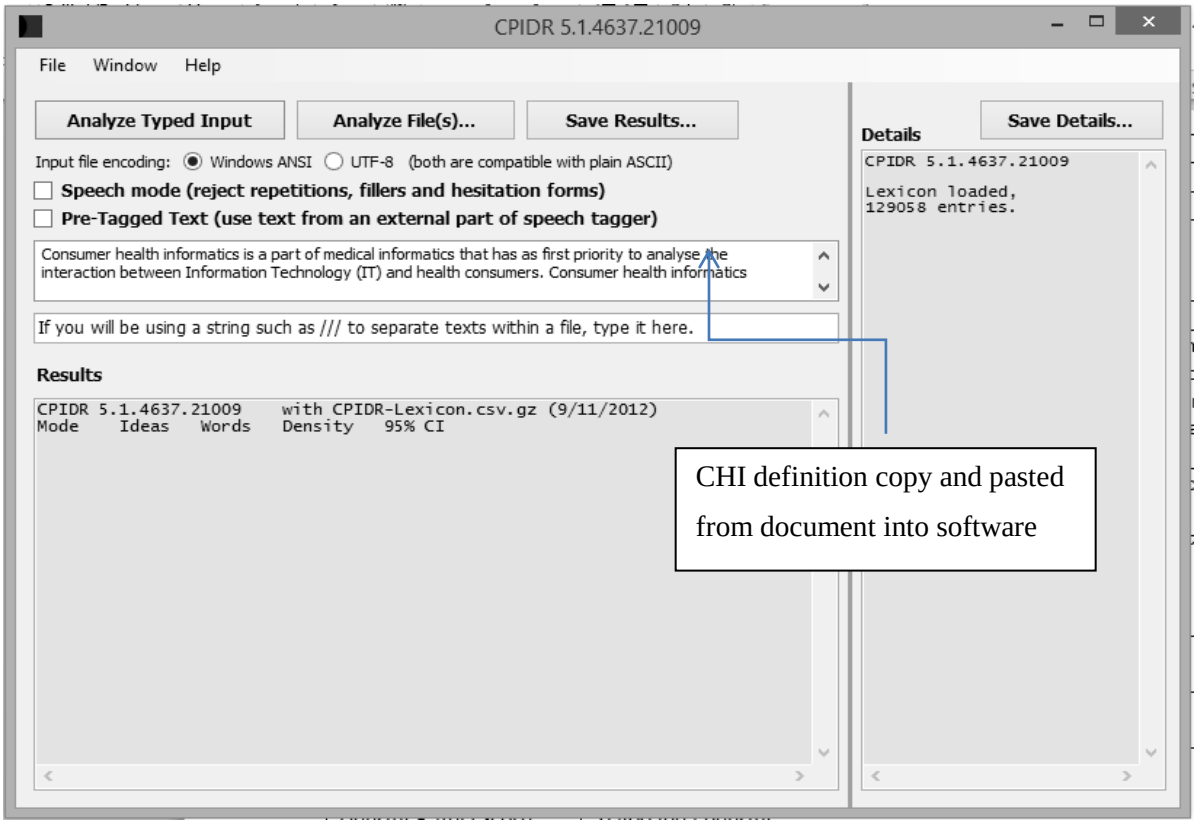
Definiendum - a word, phrase, or symbol that is the subject of a definition

Definiens – a word, phrase, or symbolic expression used to define something

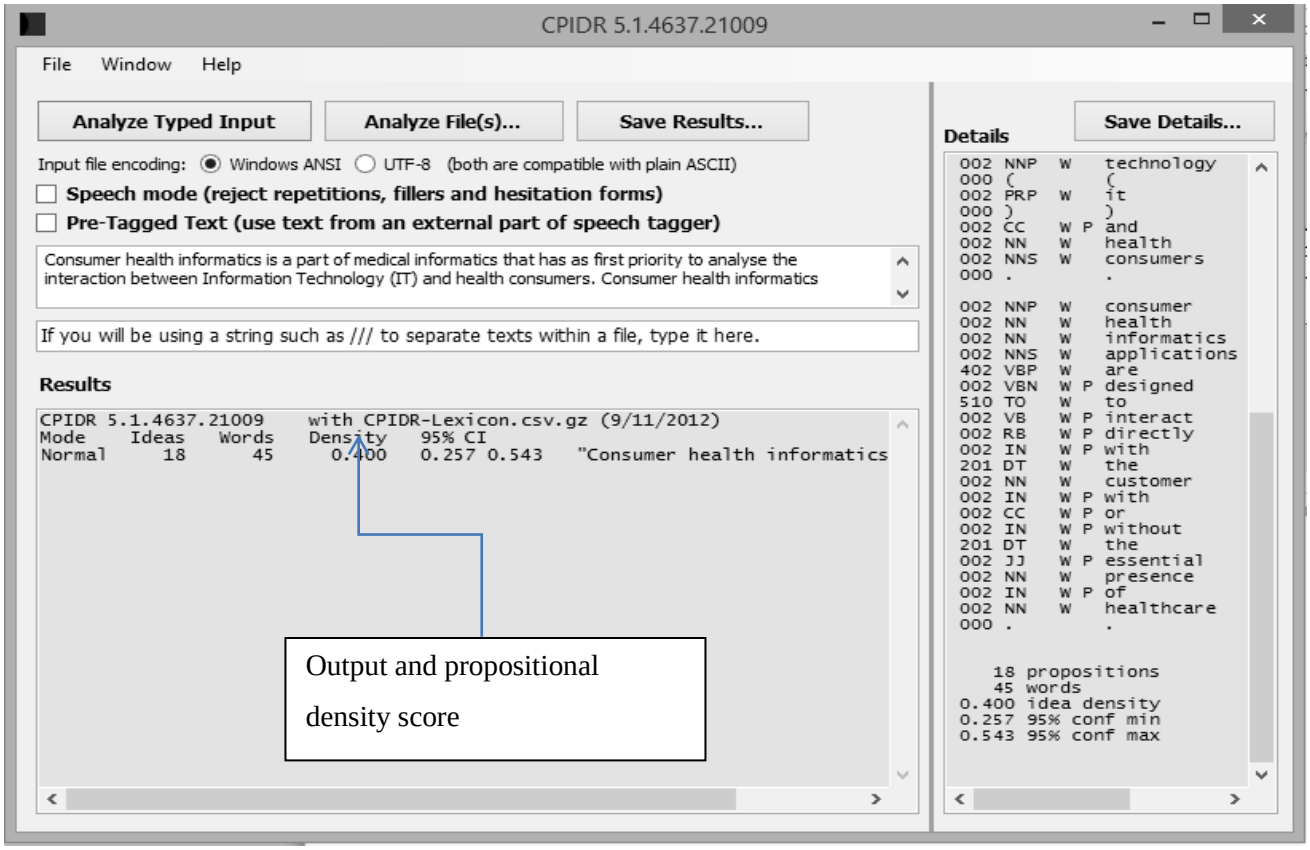
Appendix B

Example of CPIDR Software

Step 1) Definition input into window



Step 2) Click "Analyzed Typed Input"



Appendix C

Definition Analysis

1

Definition	An exciting new field of medical computing, consumer health informatics, is devoted to the study and development of a new breed of computer and telecommunication systems designed for use by laypersons.
Citation	Ferguson, T. (1995). Consumer health informatics. *The Healthcare Forum Journal, 38*(1), 28-33.
Impact Factor	0 (Not Listed)
Google scholar	Cited by 47
CPIDR (Computerized Propositional Idea Density Rater) Score	15 propositions 31 words 0.484 idea density 0.308 95% conf min 0.660 95% conf max
SMOG Score	1 sentence, 10 words 30/1x10=300 √300+3=20.3 RGL - 20.3
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1

2

Definition	Consumer health informatics represents a diverse field devoted to the development, implementation, and research on telecommunication and computer applications designed to be used by consumers to access information on a wide variety of health care information.
Citation	Jimison, H., & Sher, P. (1995). Consumer health informatics - health information technology for consumers. *Journal of the American Society for Information Science and Technology*, *46*(10), 783-790. doi: 10.1002/(SICI)1097-4571(199512)46:10<783::AID-ASI11>3.0.CO;2-L
Impact Factor	2.005
Google scholar	Cited by 18
CPIDR (Computerized Propositional Idea Density Rater) Score	14 propositions 36 words 0.389 idea density 0.230 95% conf min 0.548 95% conf max
SMOG Score	1 sentence, 13 words 30/1x13=390 √390+3=22.7 RGL – 22.7
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0.5
Criterion 3 – IF	1
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	2.5

3

Definition	Consumer health informatics is the union of health care content with the speed and ease of technology.
Citation	GAO/AIMD (1996). *White paper: Consumer health informatics: emerging issues*. http://www.gao.gov/archive/1996/ai96086.pdf
Impact Factor	0 (Not listed)
Google Scholar	No citations
CPIDR (Computerized Propositional Idea Density Rater) Score	6 propositions 17 words 0.353 idea density 0.126 95% conf min 0.580 95% conf max
SMOG Score	1 sentence, 3 words 30/1x3=90 √90 +3 = 12.5 RGL-12.5
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	1
Total Score	2

4

Definition	"Patient informatics"- information supplied to patients using advanced information and communication technologies.
Citation	Bader, S. A., & Braude, R. M. (1998). 'Patient informatics': Creating new partnerships in medical decision making. Academic Medicine, 73(4), 408-411.
Impact Factor	3.292 – 2 year
Google	Cited 89 times
CPIDR (Computerized Propositional Idea Density Rater) Score	5 propositions 12 words 0.417 idea density 0.138 95% conf min 0.696 95% conf max
SMOG Score	1 sentence, 5 words 30/1x5=150 √150 +3= 15.3 RGL-15.3
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	1
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	2

5

Definition	CHI generally encompasses two areas: the use of Internet technology to connect to online services for health care information, such as that contained in medical journals and professional publications; and systems and software provided by clinicians to patients to help in the diagnosis and treatment of specific conditions and diseases.
Citation	Anonymous. Online services facilitate self-care practice. (1998). Employee Benefit Plan Review, 52(11), 51.
Impact Factor	0 (Not Listed)
Google Scholar	No citations
CPIDR (Computerized Propositional Idea Density Rater) Score	25 propositions 50 words 0.500 idea density 0.361 95% conf min 0.639 95% conf max
SMOG Score	1 sentence, 17 words 30/1x17=510 √510+3=25.6 RGL - 25.6
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0.5 (Mentions different areas – but not multidisciplinary nature)
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1.5

6

Definition	CHI can be defined as any information that enables individuals to understand their health and make health-related decisions for themselves or their family [1].
Citation	Bouhaddou, O., Lambert, J. G., & Miller, S. (1998). Consumer health informatics: Knowledge engineering and evaluation studies of medical HouseCall. Proceedings / AMIA ...Annual Symposium.AMIA Symposium, , 612-616.
References used in definition:	Patrick, K., & Koss, S. (1995). Consumer health information: white paper [draft]. Consumer Health Informatics Subgroup, Health Information and Applications Workgroup, Committee on Applications and Technology, U.S. Information Infrastructure Task Force
Impact Factor	0 (Not Listed)
Google Scholar	Cited by 23
CPIDR (Computerized Propositional Idea Density Rater) Score	11 propositions 23 words 0.478 idea density 0.274 95% conf min 0.682 95% conf max
SMOG Score	1 sentence, 9 words 30/1x9=270 √270+3=19.4 RGL - 19.4
Criterion 1 – Citation	1
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	2

7

Definition	Special-purpose computer tools referred to as Consumer Health Informatics (CHI) represent the application of computer and information technologies specifically to support the health information and communication needs of patients and lay persons.
Citation	Brennan, P. F. (1999). Health informatics and community health: Support for patients as collaborators in care. Methods of Information in Medicine, 38(4-5) (pp 274-278), ate of Pubaton: 1999.
Impact Factor	1.6
Google scholar	Cited by 52
CPIDR (Computerized Propositional Idea Density Rater) Score	13 propositions 32 words 0.406 idea density 0.236 95% conf min 0.576 95% conf max
SMOG Score	1 sentence, 11 words 30/1x11=330 √330+3=21.2 RGL - 21.2
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0.5
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	0.5

8

Definition	Consumer informatics is defined as the use of computer to support consumers in obtaining information, analyzing unique care needs, and helping to make decisions about healthcare and health promotion (GAO/AIMD, 1996)
Citation	Rhodes, E. (2000). Consumer informatics: Helping patients to access health information via the Internet. Nursing Connections, 13(1), 33-42.
References used in definition:	GAO/AIMD. (1996). *White paper: Consumer informatics: emerging issues*. http://www.gao.gov/archive/1996/ai96086.pdf
Impact Factor	0 (Not Listed)
Google scholar	Cited by 9
CPIDR (Computerized Propositional Idea Density Rater) Score	14 propositions 29 words 0.483 idea density 0.301 95% conf min 0.665 95% conf max
SMOG Score	1 sentence, 9 words 30/1x9=270 √270+3=19.4 RGL - 19.4
Criterion 1 – Citation	1
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	2

9

Definition	Consumer health informatics is the branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems. Consumer informatics stands at the crossroads of other disciplines, such as nursing informatics, public health, health promotion, health education, library science, and communication science, and is perhaps the most challenging and rapidly expanding field in medical informatics;
Citation	Eysenbach, G. (2000). Recent advances - consumer health informatics. British Medical Journal, 320(7251), 1713-1716. doi: 10.1136/bmj.320.7251.1713
Impact Factor	17.215
Google scholar	Cited by 556
CPIDR (Computerized Propositional Idea Density Rater) Score	37 propositions 72 words 0.514 idea density 0.398 95% conf min 0.629 95% conf max
SMOG Score	2 sentences, 29 words 30/2x29=435 √435+3=23.9 RGL - 23.9
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	1
Criterion 3 – IF	1
Criterion 4 – PD	0
Criterion 5 – SMOG	0
Total Score	2

10

Definition	the set of activities aimed at giving consumer a more pronounced role in their own health and healthcare, ranging from the development of tools for self-assessment of health risks and management of chronic disease to home-based monitoring of health status and delivery of care
Citation	Committee on enhancing the Internet for health applications: technical requirements and implementation strategies CSaTB, national research council. Networking Health: Prescriptions for the Internet. Washington, DC: National Academy Press; 2000. Committee on Enhancing the Internet for Health Applications: Technical Requirements and Implementation Strategies. Retrieved from: http://www.ncbi.nlm.nih.gov/books/NBK44724/
Impact Factor	0 (Not Listed)
Google Scholar	No citations
CPIDR (Computerized Propositional Idea Density Rater) Score	24 propositions 44 words 0.545 idea density 0.398 95% conf min 0.693 95% conf max
SMOG Score	1 sentence, 7 words 30/1x7=210 √210+3=17.5 RGL - 17.5
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0.5 (mentions different areas but not multidisciplinary nature)
Criterion 3 – IF	0
Criterion 4 – PD	0
Criterion 5 – SMOG	0
Total Score	0.5

11

Definition	a subspecialty of medical informatics which studies from a patient/consumer perspective the use of electronic information and communication to improve medical outcomes and the healthcare decision-making process.
Citation	Houston TK, Chang BL, Brown S, Kukafka R. Consumer health informatics: a consensus description and commentary from American Medical Informatics Association members. Proc AMIA Symp. 2001: 269-273
Impact Factor	0 (Not Listed)
Google Scholar	Cited by 13
CPIDR (Computerized Propositional Idea Density Rater) Score	11 propositions 27 words 0.407 idea density 0.222 95% conf min 0.593 95% conf max
SMOG Score	1 sentence, 10 words 30/1x10=300 √300+3=20.3 RGL - 20.3
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1

12

Definition	"Consumer Health Informatics" is an emergent property of the seamless networks of data, services, information, and connectivity available through the Internet.
Citation	Lewis, D., & Pesut, D. (2001). Emergence of consumer health care informatics. *Nursing Outlook, 49*(1), 7-7. doi: 10.1067/mno.2001.113260
Impact Factor	2.359
Google Scholar	Cited by 2
CPIDR (Computerized Propositional Idea Density Rater) Score	8 propositions 21 words 0.381 idea density 0.173 95% conf min 0.589 95% conf max
SMOG Score	1 sentence, 9 words 30/1x9=270 √270+3=19.4 RGL - 19.4
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	1
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	2

13

Definition	Consumer Health Informatics Systems (CHIS) include patient-oriented interactive computer-based programs that provide-information, decision, behavior change and emotional support for health issues 1,2
Citation	Gustafson, D. H., Hawkins, R. P., Boberg, E. W., McTavish, F., Owens, B., Wise, M., . . . Pingree, S. (2002). CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved. *International Journal of Medical Informatics, 65*(3), 169-177. doi: http://dx.doi.org/10.1016/S1386-5056%2802%2900048-5
References used in definition:	T. Eng, D. Gustafson (Eds.), Wired for Health and Well-Being: The Emergence of Interactive Health Communication, US Department of Health and Human Services, Washington, DC, 1999. W. Slack, Cybermedicine, San Francisco Josse-Bass, 1997.
Impact Factor	2.061
Google Scholar	Cited by 171
CPIDR (Computerized Propositional Idea Density Rater) Score	8 propositions 22 words 0.364 idea density 0.163 95% conf min 0.565 95% conf max
SMOG Score	1 sentence, 9 words 30/1x9=270 √270+3=19.4 RGL - 19.4
Criterion 1 – Citation	1
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	1
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	3

14

Definition	`Consumer health informatics' is the emerging science at the crossroads of health informatics and public health which deals with investigating determinants, conditions, elements, models, and processes to design, implement, and maximise the effectiveness of computerised information and telecommunication and network systems for consumers.
Citation	Eysenbach, G. (2003). The semantic web and healthcare consumers: A new challenge and opportunity on the horizon? *International Journal of Healthcare Technology and Management, 5*(3-5) 194-212
Impact Factor	0 (Not Listed)
Google scholar	Cited by 18
CPIDR (Computerized Propositional Idea Density Rater) Score	21 propositions 42 words 0.500 idea density 0.349 95% conf min 0.651 95% conf max
SMOG Score	1 sentence, 16 words 30/1x16=480 √480+3=24.9 RGL - 24.9
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0.5
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1.5

15

Definition	A branch of scholarship, referred to as consumer health informatics (CHI), has recently developed with the purpose of understanding how consumers use advanced information management and delivery technologies such as the Internet in order to gather and ultimately act on information about health–for themselves or for those they care for.
Citation	Perry, G., & Weldon, S. (2005). Consumer health informatics research: Implications for consumers, health information professionals, and researchers. *Journal of Consumer Health on the Internet, 9*(2), 1-10.
Impact Factor	0 (Not Listed)
Google Scholar	No citations
CPIDR (Computerized Propositional Idea Density Rater) Score	24 propositions 50 words 0.480 idea density 0.342 95% conf min 0.618 95% conf max
SMOG Score	1 sentence, 15 words 30/1x15=450 √450+3 = 24.2 RGL - 24.2
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1

16

Definition	Consumer health informatics (CHI) is a rapidly evolving sub-discipline of medical informatics.
Citation	Bakker, T. A., Ryce, A. N., Logan, R. A., Tse, T., & Hutcherson, L. (2005). A consumer health informatics (CHI) toolbox: Challenges and implications. AMIA ...Annual Symposium Proceedings / AMIA Symposium.AMIA Symposium, , 21-25.
Impact Factor	0 (Not Listed)
Google Scholar	Cited by 4
CPIDR (Computerized Propositional Idea Density Rater) Score	5 propositions 12 words 0.417 idea density 0.138 95% conf min 0.696 95% conf max
SMOG Score	1 sentence, 7 words 30/1x7=210 √210+3=17.5 RGL - 17.5
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1

17

Definition	Consumer health informatics has emerged as a strategy to inform and empower patients for self-management of their health.
Citation	Khan, S. A., McFarlane, D. J., Li, J., Ancker, J. S., Hutchinson, C., Cohall, A., & Kukafka, R. (2007). Healthy Harlem: Empowering health consumers through social networking, tailoring and web 2.0 technologies. *AMIA ...Annual Symposium Proceedings / AMIA Symposium. AMIA Symposium,* , 1007.
Impact Factor	O (Not Listed)
Google scholar	Cited by 6
CPIDR (Computerized Propositional Idea Density Rater) Score	8 propositions 18 words 0.444 idea density 0.215 95% conf min 0.674 95% conf max
SMOG Score	1 sentence, 5 words 30/1x5=150 √150+3=15.2 RGL – 15.2
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1

18

Definition	Consumer health information resources provide health information to lay users, hopefully to empower patients, caregivers, families, and consumers; improve decisions; and ultimately foster better public health outcomes.
Citation	Keselman, A., Logan, R., Smith, C. A., Leroy, G., & Zeng-Treitler, Q. (2008). Developing informatics tools and strategies for consumer-centered health communication. *Journal of the American Medical Informatics Association, 15*(4), 473-483. doi: http://dx.doi.org/10.1197/jamia.M2744
Impact Factor	3.571
Google scholar	Cited by 54
CPIDR (Computerized Propositional Idea Density Rater) Score	12 propositions 27 words 0.444 idea density 0.257 95% conf min 0.632 95% conf max
SMOG Score	1 sentence, 11 words 30/1x11=330 √330+3=21.2 RGL – 21.2
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	1
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	2

19

Definition	Consumer health informatics is defined as any electronic tool, technology, or electronic application that is designed to interact directly with consumers, with or without the presence of a health care professional that provides or uses individualized (personal) information and provides the consumer with individualized assistance, to help the patient better manage their health or health care.
Citation	Gibbons, M.C., Wilson R.F., Samal L., Lehmann C.U., Dickersin K., Lehmann H.P., Aboumatar, H., Finkelstein, J., Shelton, E., Sharma, R., Bass, E.B. (2009). Impact of consumer health informatics applications. *Evidence report/technology assessment*. 188:1-546
Impact Factor	0 (Not Listed)
Google Scholar	Cited by 5
CPIDR (Computerized Propositional Idea Density Rater) Score	29 propositions 56 words 0.518 idea density 0.387 95% conf min 0.649 95% conf max
SMOG Score	1 sentence, 16 words 30/1x16=480 √480+3= 24.9 RGL- 25
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	0
Criterion 5 – SMOG	0
Total Score	0

20

Definition	Consumer health informatics is a part of medical informatics that has as first priority to analyse the interaction between Information Technology (IT) and health consumers. Consumer health informatics applications are designed to interact directly with the customer with or without the essential presence of healthcare.
Citation	Alamantariotou, Kleopatra (2010). Consumer health informatics and interactive visual learning tools for health. *International journal of electronic healthcare*, 5 (4), 414 -424.
Impact Factor	0 (Not listed in ISI)
Google Scholar	Cited by 3
CPIDR (Computerized Propositional Idea Density Rater) Score	18 propositions 45 words 0.400 idea density 0.257 95% conf min 0.543 95% conf max
SMOG Score	2 sentences, 17 words 30/2x17=255 √255+ 3=18.96 RGL = 19
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1

21

Definition	Consumer health informatics is no different to the branches of informatics in healthcare other than it primarily represents the consumer interests and is about providing the consumer with the right tools, skills, support and knowledge to better manage their health care.
Citation	Ho, J. (2010). Consumer health informatics. (Health Informatics - An Overview.) doi: http://dx.doi.org/10.3233/978-1-60750-476-4-185
Impact Factor	0 (Not Listed)
Google scholar	Cited by 1
CPIDR (Computerized Propositional Idea Density Rater) Score	20 propositions 41 words 0.488 idea density 0.335 95% conf min 0.641 95% conf max
SMOG Score	1 sentence, 10 words 30/1x10=300 √300+3=20.3 RGL- 20.3
Criterion 1 – Citation	0
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	1

22

Definition	*Consumer health informatics* refers to health information technology that utilizes data enabled by cyber infrastructure, or in other words the computer, mobile, and Internet platforms necessary for coordinating care delivery by health systems and clinical and public health professionals, as well as for consumers to be empowered to manage their own health [7,8]
Citation	Shaikh, A. R., Prabhu Das, I., Vinson, C. A., & Spring, B. (2011). Cyberinfrastructure for consumer health. American Journal of Preventive Medicine, 40(5 SUPPL. 2), S91-S96. doi: http://dx.doi.org/10.1016/j.amepre.2011.02.012
References used in Definition	Alamantariotou K, Zisi D. (2010)Consumer health informatics and interactive visual learning tools for health. International Journal Electronic Healthcare. 5(4):414 –24. Marchibroda J.M. (2008). The impact of health information technology on collaborative chronic care management. J Manag Care Pharm. 14(2S):S3–S11.
Impact Factor	3.945
Google Scholar	Cited by 3
CPIDR (Computerized Propositional Idea Density Rater) Score	26 propositions 52 words 0.500 idea density 0.364 95% conf min 0.636 95% conf max
SMOG Score	1 sentence, 16 words 30/1x16=480 √480+3=24.9 RGL - 24.9
Criterion 1 – Citation	1
Criterion 2 – Multidisciplinary	0.5
Criterion 3 – IF	1
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	3.5

23

Definition	An important component of health informatics, consumer health informatics, has been defined as a field that 'analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers' preferences into medical information systems' [18]
Citation	Arocha, J. F., & Hoffman-Goetz, L. (2012). A survey of public health and consumer health informatics programmes and courses in canadian universities and colleges. *Informatics for Health & Social Care, 37*(4), 242-252. doi: 10.3109/17538157.2011.647937
References used in definition:	Eysenbach G. Consumer health informatics. British Medical Journal 2000;320(7251):1713–1716.
Impact Factor	1.273
Google scholar	No citations
CPIDR (Computerized Propositional Idea Density Rater) Score	20 propositions 41 words 0.488 idea density 0.335 95% conf min 0.641 95% conf max
SMOG Score	1 sentence, 17 words 30/1x17= 510 √510+3=25.6 RGL - 25.6
Criterion 1 – Citation	1
Criterion 2 – Multidisciplinary	0
Criterion 3 – IF	0.5
Criterion 4 – PD	1
Criterion 5 – SMOG	0
Total Score	2.5

Appendix D

Example of Latent Semantic Analysis Software

Matrix Comparison program from the Latent Semantic Analysis at Colorado University Boulder