Coventry University

DOCTOR OF PHILOSOPHY

Design and development of COCO a model to facilitate access to high quality consumer health information

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Award date:
2015

Awarding institution:
Coventry University

Link to publication

Design and development of COCO: A model to facilitate access to high quality consumer health information

By

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September 2015

A thesis submitted in partial fulfilment of the University's requirements for the Degree of Doctor of Philosophy

Abstract

The NHS is providing patients with access to summaries of their individual health records, so that they can understand and manage their conditions more effectively. At the same time, the government is encouraging patients to be more involved in the decisions made about their direction of care, as evidence shows that outcomes improve if decision-making is shared. As the Internet grows, people are using it as a major source of health information. However, anybody can post information to the Internet, and there is no guarantee that it is reliable, accurate, based on research, or relevant. Therefore, people searching online for health information, using generic search engines, are at risk of finding information that may have a detrimental effect on their health and wellbeing.

The aim of this research is to produce a model of a multi-approach evidence-based, post-diagnosis support system for patients and carers in England.

The literature review carried out by the author identified 300 papers which looked at both the importance of patient participation in decision-making, and the issues with finding and using health information for patients and carers, but not together in the same research. While much has been written about evidence based practice for health professionals, there is a gap in the research about evidence-based patient choice and information service provision and skills for the general public. This is an issue for health professionals because patients are being actively encouraged to participate in the choices made about their treatment, but while there is evidence demonstrating the effectiveness of patient participation, there is no evidence to say that they have adequate access to information and the skills to use it. Health services need to know if there is appropriate information support for the general public, otherwise there is a risk that patients will not have the right information to help them make the best choice.

To assess the information-seeking behaviour of the general public, a mixed-study analysis was performed using quantitative and qualitative surveys, and 139 responses were collected and analysed. The population included people suffering from Alzheimer’s disease and their carers. The evidence and the survey results confirmed that people do want to make decisions with their doctor, and that they do search for information, but do not always find what they are looking for. They said that they would value librarian support and information skills training, but would also find an all-encompassing consumer health information web-site useful.

A consumer health information literacy framework was developed based on the existing SCONUL Seven Pillars of Information Literacy framework and the five steps to evidence based practice concept. This framework provided the foundation for the design and development of COCO, an innovative model to facilitate access to high quality consumer health information using existing NHS online information products combined with the information skills of public and medical librarians. The innovations of COCO are that it focuses on the whole population, supports those who are and are not computer literate, creates an opportunity for collaboration within the library sector, and builds on existing NHS online resources rather than creating new ones. COCO provides people with a central access point to reliable and relevant online consumer health information to help them make informed decisions about their care pathway. The collaborative element of the model ensures that is accessible to everyone, without incurring significant costs to public services.

The main output from this research synthesis, is an original needs-based model (COCO), designed to simplify the consumer health information-seeking process for the general public, enabling them to access the right information to fulfil their information needs and help them make evidence-based treatment decisions with their doctors. The design of COCO was reviewed, validated and improved using structured opinions of experts in consumer health information, evidence based practice, information literacy, and information technology. Real-life consumer scenarios were used to manually test COCO against free text searches in Google. The search results from COCO and Google were analysed and compared using six validation metrics. This demonstrated the efficiency of COCO in providing significantly better quality information relevant to patients and carers, compared to Google. A mock-up of the final design and search results of COCO were then prepared, along with recommendations for future research.

Dedication

This research is dedicated to:

- My husband, Padraig De Brún, who has believed in me and encouraged and challenged me throughout this process. Without him, I would never have made it this far;
- Belinda Hylton, a tremendous librarian whose courage and professionalism continues to inspire me, and whose struggle to find relevant consumer health information initiated this research;
- My wonderful family, who have given me my love of books and information and the strong foundations, which have enabled me to complete this research.

Acknowledgements

I would like to thank my current and original Supervisory Teams, Professor Ian Marshall, Professor Elena Gaura, Professor Raouf Naguib, and Dr Rajeev K Bali. Professor Marshall and Professor Gaura, in particular, have helped turn my initial concept into a valid piece of research. I have learnt so much from them, and I am very grateful for their time and patience. Thank you also to the Progress Review Panel who met with me each year to assess my progress and challenge my thinking and processes. Special thanks go to Tim Sparks, Senior Lecturer, statistics advice and support, who patiently explained statistical tests to me.

Thank you to Andrew Booth, University of Sheffield, for his advice on research methodology, and the CILIP Information Literacy Group for providing advice on information literacy. Thank you to Sir JA Muir Gray, Anne Brice, Centre for Evidence Based Medicine, and Minervation, who have all given me the chance to participate in fantastic evidence-based practice activities, many of which have informed this research.

A big thank you goes to the library staff at the Bow Idea Store, in particular, Denise Bangs, Dementia UK, Scottish Dementia Clinical Research Network, Frontotemporal Dementia Support Group, Dementia Cafés in West Midlands via the Accord Group, and Dr Amir Hannan of the Haughton and Thornley Medical Centres, all of whom distributed the survey to the general public. Further thanks are offered to the Communications Team at NHS East London and the City, Mark Duman, Chair of the Patient Information Forum, Shane Godbolt, Director at Partnerships in Health Information, and Angela Coulter, Director of Global Initiatives at Foundation for Informed Medical Decision Making.

Grateful thanks are offered to Sir Iain Chalmers, James Lind Initiative, Colin MacKenzie, The Information Standard at Capita, Bob Gann, NHS England and NHS Direct, Jon Brassey, TRIP Database, Rebecca Mogg, CILIP Information Literacy Group, and Dr Amir Hannan, Haughton Thornley Medical Centres, for validating the COCO model.

Thank you to those people who have inspired me with their clinical histories, which I used to test the model. I have kept your anonymity, but you know who you are.

Thank you to my wonderful friends and family all over the world, who have tolerated my anti-social behaviour over the past few years, and most of all thank you to God for giving me a life with all these amazing opportunities.

Publications and presentations

A number of publications and presentations have been produced as part of this research and these are included in Appendix 14, and listed below:

- Presentation: 'No decision about me without me': collaborative opportunities to support shared decision-making in the NHS – presentation at Librarians' Information Literacy Annual Conference (LILAC) 2012
- Chapter author: Chapter 13: Patient information: sources, in Searching Skills Toolkit: Finding the Evidence, 2nd ed.
- Chapter contributor: Chapter 16: E-health: Focusing on people-centred dimensions, in Critical issues for the development of sustainable e-health solutions
- Article co-author: What's the evidence for evidence? Review of abstracts of studies of clinicians' information seeking behaviour, in The International Society for Evidence-Based Health Care Newsletter 4, July 2011

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Acronyms

24/7	24 hours a day, 7 days a week
AD	Alzheimer’s disease
ALS	Amyotrophic Lateral Sclerosis
BMA	British Medical Association
CASP	Critical Appraisal Skills Programme
CFIDS	Chronic Fatigue Immune Deficiency Syndrome
CFS	Chronic Fatigue Syndrome
CILIP	Chartered Institute for Librarians and Information Professionals
DH	Department of Health
DUETs	Database of Uncertainties about the Effects of Treatments
EBM	Evidence Based Medicine
EBP	Evidence Based Practice
EBPC	Evidence Based Patient Choice
EHR	Electronic Health Record
EMIS	Egton Medical Information Systems
ESOL	English for Speakers of Other Languages
GP	General Practice
HTMC	Haughton Thornley Medical Centres
IBD	Inflammatory Bowel Disease
IL	Information Literacy
IPDASi	International Patient Decision Aid Standards instrument
KM	Knowledge Management
LBTH	London Borough of Tower Hamlets
LGA	Local Government Association
ME	Myalgic Encephalomyelitis
MeSH	Medical Subject Headings
NHS	National Health Service
NHSE	NHS England
NICE	National Institute for Health and Care Excellence
NPfIT	National Programme for Information Technology
PALS	Patient Advisory and Liaison Services
PAMO	Search method: Person, Approach, Media, Output

PHE	Public Health England
PICO	Search method: Patient/problem, Intervention, Comparison, Outcome
PIF	Patient Information Forum
QIPP	Quality Innovation Productivity Prevention
RSS	Really Simple Syndication
SCIE	Social Care Institute for Excellence
SCONUL	Society of College National and University Libraries
SIGN	Scottish Intercollegiate Guidelines Network
TRIP	Translating Research Into Practice
URAC	Utilization Review Accreditation Commission
URL	Uniform Resource Locator

Chapter 1 – Introduction

Mark Twain

1.1. Introduction

This chapter provides the background to the thesis, its focus, research questions and objectives, an introduction to the model, the development of which will be informed by future chapters, including a review of the literature highlighting gaps in current research, and the results of surveys carried out on the target audience.

1.2. Context

For 20 years or more, putting patients (and carers) first has been a major goal for the NHS (Foot et al., 2014). In 1999, as part of the National Programme for IT, it was agreed that providing patients with access to their electronic health records would reduce errors and improve health care quality (Silow-Carroll et al., 2012). In the 21st century, people are also being encouraged to participate in the decisions made about their treatments, as this has been shown to improve compliance and experience and reduce litigation (Wilson et al., 2010). However, treatment decisions need to be based on unbiased, up-to-date research, which is easy for health professionals to access, but not so for patients and carers. The level of quality of online health information varies greatly, and people do not always have the skills to recognise the good from the bad. Some people are even self-diagnosing to the detriment of their health (Yan and Sengupta, 2013). Health professionals are supported by medical libraries, and decision support tools available at the point of care. There are resources for patients and carers, but awareness of these resources is poor. At this time of patient-centred care, it is essential that people have the right information at the right time so that they can make the right decisions for their personal circumstances.

The quote “*knowledge is the enemy of disease*” (Pang et al., 2006), originated from Sir J.A. Muir Gray, in 1999, when the National Library for Health was being created, a web portal for health professionals, developed by clinicians and librarians. When this phrase was first coined, it was aimed towards clinicians, the idea being that the more the health professionals know and understand about a condition and the treatment options available, the easier it is to cure the condition or at least, alleviate the symptoms. Decisions at this time were made predominantly by the health professional. However, in more recent times, there has been a greater move towards shared decision-making between the health care delivery teams and the patients, because research has shown that if people are involved in the choices made about their treatment, they are more likely to follow the care pathway, and have better outcomes, which is good for them and for the health service (Wilson et al., 2010). The more the public knows about health and wellbeing in general, the better they are able to prevent the occurrence or recurrence of illness, resulting in better quality of life and fewer re-admissions. Furthermore, health services will be able to better allocate and manage resources, an essential requirement in today’s austere society, with the Government requiring the public sector to do more with less, and the NHS having to make £20 billion in savings (Hurst and Williams, 2012).

The problem is that if they are to make an informed decision, patients and carers need to have access to good quality information, written in plain English, for the lay-person to be able to understand and use. They need to understand the potential side effects, the prognosis, and the alternative options available to them. The author has co-written a book on searching skills for health professionals (De Brún and Pearce-Smith, 2014, De Brún and Pearce-Smith, 2009) and has identified a wealth of good quality resources for health professionals, which are easily accessible, but she has noticed that this is not the case for patients and carers. Personal online health information seeking is on the increase (Fox and Purcell, 2010, Fox, 2006, Ciber (Centre for information behaviour and the evaluation of research), 2004, Innes, 2013, Lau and Coiera, 2008), and whilst there are a number of information providers publishing good quality online consumer health information, the content is difficult to find. Health professionals have central points of access to good quality, tailor-made health information, but the general public does not. They also have no medical librarian support, and their searching skills vary (Greenhalgh et al., 2010a, Corcoran et al., 2010, Neal et al., 2012, Peterson et al., 2003).

1.3. Aim and scope of the study

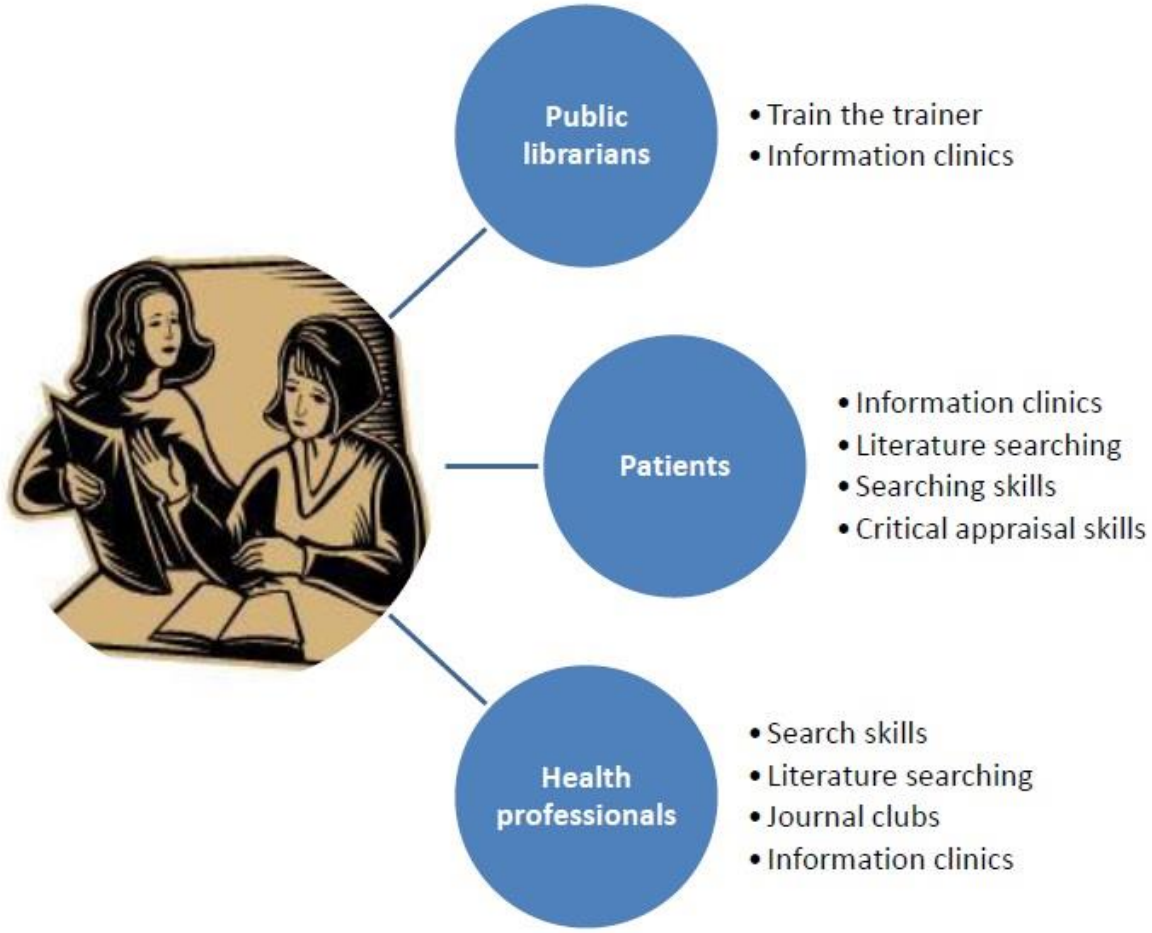
The aim of this research is to confirm a need for consumer health information literacy support for the general public in England and to define a feasible solution that will fulfil that need, one that is more effective than existing solutions. Informed by the literature review and surveys, described further in Chapters 2 and 3 respectively, this final output will build on existing resources, both human (librarians and other information professionals) and technical (quality health information web-sites, decision aids, etc.) and frameworks (SCONUL Seven Pillars of Information Literacy), and create one resource where people can find what they need easily. The results of the literature review clearly show that there is a variation of access to health information resources available to the general public. A more consistent model is required which caters for all members of the general public, and not just patients, and this is the aim of this research, to develop such a model.

This research will demonstrate via literature review and survey analysis why an intervention is required to facilitate access to good quality health information for patients and carers. The scope is predominantly focusing on online consumer health information and its accessibility and reliability. However, in England, there are more than 10 million people who have never been online, so for the solution to be inclusive, it needs to be both technical and human. Provision is made for both patients and carers, because in many cases, such as people with impaired cognitive ability, it is the carer that searches for the information because the patient is not capable of doing so.

The intention is to give patients and carers access to similar quality health information that health professionals have access to, but prepared specifically for them, in lay-man’s terms, so that it can be easily understood and used. Carers, particularly those who look after the elderly, are more likely to use the Internet to search for information, because they will have limited time available away from the person they are caring for (Kernisan et al., 2010). This is why a solution is necessary not just for patients but for all members of the public, particularly those providing informal care.

Because there are already many technical information solutions available, the author would have preferred to identify a non-technical solution, such as the one illustrated in Figure 1; the peripatetic librarian, who would travel around the county providing one-to-one information support at public libraries and GP surgeries. However, the author recognised that this would not be physically or logistically feasible as service level agreements would need to be developed between several, different public sector organisations, each with different ways of working. Therefore, the revised aim is to incorporate aspects of the peripatetic librarian into the final solution, described in Chapter 4.

Figure 1: First iteration of the model: peripatetic librarian



1.4. Research question and research objectives

For the purposes of this research, the research question is:

What information support does the general public need to learn more about their clinical conditions and how to manage them?

The final set of research objectives are to:

1. Demonstrate synergies between the literature on shared decision-making, health information literacy, and quality of health information, identifying gaps in the research with regards to access to good quality consumer health information.
2. Elicit people's preferences about the emerging shared decision-making agenda and their role in treatment choice.
3. Identify people's knowledge and use of existing, designed-for-purpose, health information resources, and understand if they do not use them, why not.
4. Explain the benefits of well-informed patients and carers to the health economy.
5. Review the parallels between existing evidence implementation frameworks, and adapt them to formulate a framework for consumer health information.
6. Apply the synthesised data, research evidence and framework to the design and evaluation of a consumer health information literacy solution providing information support to users enabling them to make informed decisions with health professionals.

1.5. Significance of the study

A recent thesis investigated the translators of patient information leaflets and looked at the role of communication (Jensen, 2013). The focus on that research was leaflets rather than all online information products, which are the focus of this research. The author for this research is looking at the quality of health information, delivered in the form of published research, lay-person summaries, leaflets, videos, web-sites, and decision aids, to name but a few. However, the research by Jensen in Denmark and Australia, and also other doctoral research on the communication of medical knowledge (Mager, 2010), electronic health information literacy in America (Hanik, 2011), knowledge management in Canada (Boateng, 2007), and database of informed lifestyle choice in South Africa (Cottrell, 2008), demonstrates that the research that the author is carrying out, is an important and complex issue, not just in England, but all over the world. Hanik's research into electronic health information literacy looks at the information skills of people training to become health educators; people who give health information to those who need it, rather than the information skills of the people themselves. He concluded that "*many students possess weak e-health literacy competencies, which limit their ability to search for, retrieve, utilize and evaluate electronic resources to obtain quality health information*" (Hanik, 2011). He uses the phrase e-health information literacy, which the author has not seen applied elsewhere, but is very relevant to this area of research. E-health literacy has been written about, but looks at searching behaviour and skills (Norman and Skinner, 2006b) of people looking for health information online, rather than the understanding of the information. The author describes the differences between health literacy and health information literacy further on in 2.2.5.8. This research supports the work of Mager because she believes that health professionals should work with patients who are informed rather than trying to educate them (Mager, 2010). The model proposed in this research provides people with the tools they need to become better informed. It would also complement the development of a database of wellness information, the results of research carried out in South Africa (Cottrell, 2008), as it provides access to health information about existing clinical conditions and how to manage them.

There has been much research about the poor quality of online health information for patients, but the solutions have been either human or technical (Harrison, 2009, Martínez-Pérez et al., 2013, Samoocha et al., 2010). The author's research combines both technical and human elements, building on existing resources, and facilitating collaboration among library staff from different sectors.

The benefits this research is intending to achieve include:

- For patients and carers:
    - Improved access to relevant online consumer health information for patients and carers, designed for their needs and expectations.
    - Stress reduction and improved outcome for patients because they will be able to manage their conditions more effectively and help them take more control of their health and health care.
- For health professionals:
    - Improved outcomes as the patient is more likely to comply with the treatment regime because they understand the consequences involved, and how to manage them.
- For managers and policy-makers:
    - Greater patient involvement will improve outcomes and care management, resulting in reduced litigation.
    - Improved patient satisfaction, leading to a stronger reputation for the hospital.
    - Cost-savings because existing resources will be used more effectively and more often, and hospital length-of-stay will be reduced, which would support the Department of Health’s QIPP (Quality, Innovation, Productivity and Prevention) agenda (Hurst and Williams, 2012).
- For librarians:
    - Increased professional development for library staff, who will enhance their skills by sharing knowledge and experience between sectors.

This will be an innovative piece of research because it:

- Focuses on the whole population, thereby including carers, and not just patients.
- Supports people who are computer literate and those who are not.
- Provides a model which supports collaborative working between public, academic, and health libraries.
- Builds on existing initiatives rather than creating new ones.

1.6. Overview of the thesis

This thesis consists of six chapters, the first providing the background to the research and identifying the research question and objectives. The second chapter presents the literature revealing the gap which the proposed model intends to fill. Chapter 3 describes the research methodology and analyses the results from the surveys carried out to confirm the gap identified in the research review. Chapter 4 presents the framework used to develop the model alongside the results of the validation process. Throughout the thesis there will be discussion, leading to the final chapter, which brings the research to a conclusion, aligning with the first chapter and the research question and objectives.

As part of this research, the author compared the five steps to evidence based practice (Akobeng, 2005) with the seven pillars for information literacy framework (SCONUL Advisory Committee on Information Literacy, 1999), and created an adaptation (Table 5) to reflect the stages of information literacy for patients and carers.

1.7. Chapter summary

Working in a medical library in an NHS hospital in London, the author noticed that patients and carers had nowhere to go for health information support. Her professional expertise and interests lie in improving health information literacy skills for health professionals and medical students. On seeing the lack of resources for the public, and on identifying gaps in service provision in the literature, her first instinct was to create an information literacy programme, where information skills would be taught to the general public by a peripatetic librarian who would travel the county delivering the service. However, after reviewing the survey results and the literature, the author realised that while people want to be able to search for quality health information, in times of illness there are other priorities and therefore, the author concluded that it would be more useful to create a user-designed portal to existing NHS and related high quality consumer health information resources and combine it with access to librarians who could carry out searches for the general public, if that were the preferred option. The author strongly believes that it is important to teach these skills to the general public, but currently, while public sector funding is being cut, it would be more appropriate to use existing resources, and adapt them to suit the need, rather than expecting each county to fund a new post. It would be more financially efficient, and also enhance the role and skills of medical and public librarians.

The expert patient is vital in improving outcomes for the patient and value for the health service. Research into improving knowledge for patients and carers should be invested in for the long-term health and financial benefits of all.

This thesis will discuss many themes related to improving access to good quality health information for patients and carers. Themes include information literacy, shared decision-making, patient empowerment, knowledge management, and electronic health records. It needs to encompass all these elements, because it is important to justify why access to good quality health information is needed. Evidence-based patient choice (Figure 3) is a complex concept and involves many facets, including the:

- preferences of the patient, and where appropriate the carers,
- experience of the health professionals,
- best available research,
- individual patient data which identifies any comorbidities and other confounding factors, such as allergies, which might affect the decision made.

The next chapter will describe the literature review which confirms the gaps in knowledge and the need for this research.

Chapter 2 –Literature review

Benjamin Disraeli

2.1. Introduction

This chapter describes the purpose of the literature review and how it was carried out. The resulting evidence will be used together with the survey analysis described in Chapter 3 to inform the development of a model to help the general public find good quality consumer health information.

The purpose of the literature review was to identify gaps in information provision for patients and carers, particularly in England, where the government is giving people access to their Summary Care Records, and encouraging them to participate in the decisions made about their treatment choice.

Evidence shows that people who are actively involved in their health, are more likely to improve, while health organisations may see cost savings as a result of patient involvement (Robert Wood Johnson Foundation, 2013a). An essential part of "*informed decision-making and participation in health*" (Hirschberg et al., 2013) is evidence-based practice, and this review will demonstrate the lack of resources available for patients and carers to help them apply the evidence to their decision-making.

Each day, 75 trials and 11 systematic reviews are published (Bastian et al., 2010). Health professionals do not have the time to stay on top of all the latest evidence and convey it to patients in a useful format, while maintaining high standards of clinical care. As the average doctor's appointment is about 10 minutes (Pollock and Grime, 2003), it makes sense for the general public to become information competent, in order to identify good quality health information themselves.

For the purposes of this research, consumer health information is defined as online resources that provide reliable, good quality, and accurate, information on the diagnosed condition and the clinical management of that or those condition(s); designed to help people and/or carers make an informed decision about which treatment regimen to follow. Therefore, the focus is on illness, rather than wellness, and condition management, rather than diagnosis.

Out of scope is information providing instructions for the use of a particular drug, individual patient data, information about self-diagnosis of conditions, and information about improving lifestyles. Also out of scope, due to study limitations, (a consequence of time and financial constraints), is the assessment of foreign language and alternative format health information. As NHS England serves a multicultural and diverse population and all are entitled to useful and reliable health information, this would be a topic worthy of further research, and beneficial to the world in general, and not just England.

This literature review is not intended to be an exhaustive overview of the literature but, rather, to identify and discuss key themes and findings that may support the implementation of shared decision-making in health care, and provide an indication of the issues facing patients and carers when looking for good quality consumer health information online. This is particularly important in this new media environment, with people searching for health information on their tablets and smart phones, in addition to their personal computers.

2.2. Literature search methodology

With access to the Internet so readily available, in libraries, schools, at home or at work, via mobile phone or lap/desktop, more people are using it to find the answers to their queries, and this includes enquiries about health. However, whereas the quality, reliability, and accuracy of the information is important with all types of Internet searches, such as travel, education, employment, housing, etc. it is vital with health information. As Mark Twain said, "*be careful about reading health books – you may die of a misprint*."

This chapter has been structured so that it follows five steps (Goldner et al., 2011):

1. Development and focus of research objectives with which the review can align
2. Identification of relevant information sources
3. Retrieval of papers meeting the scope
4. Organising identified papers by relevance
5. Correlating and analysing the literature

2.2.1. Development and focus of research questions

The research question and accompanying objectives were described in Chapter 1. Further questions were identified providing the focus of the literature review so that it would identify the gaps in existing research, setting this research into context, and providing the necessary background information required to demonstrate the importance of this work:

1. Does access to electronic patient records and the shared decision-making agenda increase searching activity, and if yes, do patients have the necessary skills to find and appraise online consumer health information?
2. What are the health information needs of the public? Do they want to search for information or would they prefer someone to provide it to them? Is there a bigger role for librarians?
3. Are there differences in access between people with high and low levels of education? Do they have the necessary education and skills to identify and understand the information that they find, and are they aware of the right information sources that can help them become more informed? There are a range of purpose-built online resources for the general public in England, but is there any evidence to show that people are aware of and are using these resources?
4. If patients are better informed and involved in their treatment choices, does this improve compliance and reduce litigation costs?
5. Can existing frameworks, such as the SCONUL seven pillars of information literacy (SCONUL Advisory Committee on Information Literacy, 1999), and the five steps to

evidence-based medicine (Akobeng, 2005), which have been have been written for different audiences, namely education and health respectively, be adapted to suit health consumers?

2.2.2. Identification of relevant information sources

With these questions in mind, a search strategy was developed. This initial search focused on consumer health information and it's availability on the Internet. This in itself was a difficult task as there are so many synonyms for the terms "Internet", "consumer health information", and "information-seeking".

When searching for the evidence in clinical care, a framework to help focus the clinical research question is used. PICO (Population, Intervention, Comparison, Outcome) (Erlich-Jones et al., 2008, Schardt et al., 2007) provides the searcher with a logical method for creating a list of synonyms, which can then be used to construct the search strategy.

The author has adapted the PICO model for this literature review, resulting in PAMO (Person, Approach, Media, Output). PAMO refers to the person who might be looking for the information, the approach they would take to find it, what media they would look for, and in what format the information would be delivered, the last being particularly important as there is such a range of formats by which information can be disseminated. Table 1 below shows the search terms chosen for the search:

Table 1: PAMO (Person, Approach, Media, and Output) framework

Person	**Approach**	**Media**	**Output**
Patient Consumer Client Carer Carer Family/ies Legal guardian Next-of-kin Relative	Search Searching behaviour Retrieve Information storage and retrieval Browse/ing Information seeking behaviour	Internet Online systems Online sources Web-sites Web-pages World Wide Web WWW Information prescription(s)	Leaflets PILS Patient education handout Advice Social media Multimedia Video Audio Braille

The literature search was run on Cochrane Library, CINAHL (Cumulative Index of Nursing and Allied Health Literature), LISTA (Library, Information Science and Technology Abstracts), Medline, and PsycInfo, and updated throughout the research process, as this is such a growing are of research.

The search was made up of a combination of MeSH (**Me**dical **S**ubject **H**eadings) and free text terms. MeSH terms are index terms and each article added to a bibliographic database is assigned a set of approximately ten index terms (De Brún and Pearce-Smith, 2014). When using MeSH (also known as thesaurus or subject headings), the database retrieves papers specifically about that or those terms. Searching MeSH will also include synonyms and variations in spelling, e.g. American versus British spellings. However, it can take a couple of months to assign index terms, or new topics, such as new drugs, may not have an Index term. Therefore, when searching comprehensively, it is important to use a combination of free text (where the term appears anywhere in the text, and therefore is not always specific), and MeSH, refining the search by adding more terms from the PAMO list. Each section of PAMO was individually searched, so all the words identified under "*Person*" (P) were combined with OR (one of the many Boolean Operators used to construct searches). The same was done for "*Approach*" (A), "*Media*" (M), and "*Outcome*" (O). Once they were combined in their individual sets, the results were added together using AND, so that only papers matching the research questions would be retrieved.

2.2.3. Retrieval of papers meeting the scope

Using this methodology, a total of 734 results were found. These were sifted through and discarded if they did not meet the inclusion criteria. Records were only included if they were about:

- online health information – educational information as opposed to clinical data about individual patients
- quality of consumer information about the condition and treatment options, to inform choice
- "illness" rather than "wellness"

- quality evaluation techniques of health-related web-sites, particularly on Alzheimer's disease
- patient/carer searching behaviour
- health information literacy and not health literacy (definitions provided further on in this chapter)
- shared decision-making and patient empowerment
- benefits of access to good quality health information
- electronic health records
- structure of the National Health Service

References were excluded if they were about self-diagnosis, as using the Internet for the purposes of self-diagnosis, can be dangerous (Usborne, 2009, Innes, 2013), as one set of symptoms can be the same for several different conditions, some more serious than others.

After the first sift, only 414 papers remained. In addition to the database searching, 214 additional papers were identified through hand-searching specialist health informatics journals and grey literature.

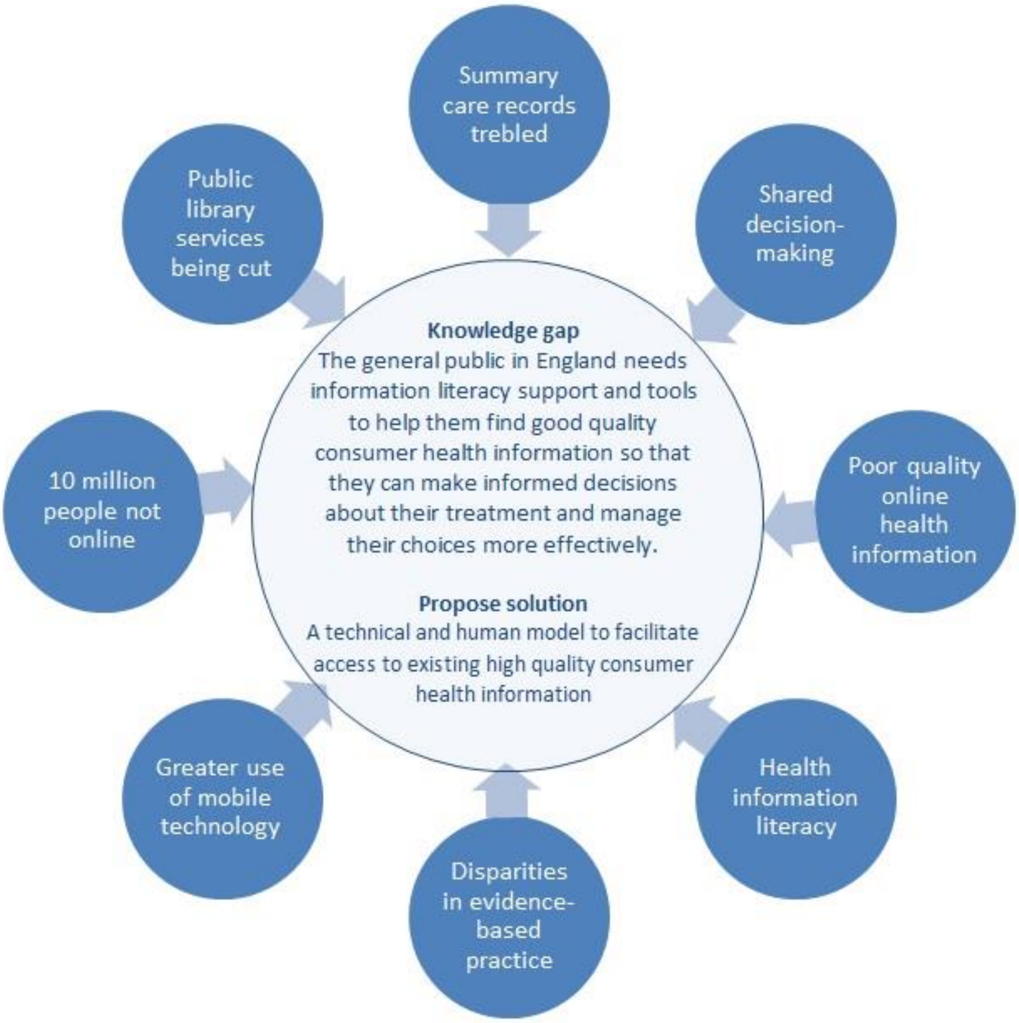
The papers found were categorised by matching them with the questions they answered. Appendix 1 is a framework for organising results and provides more details about the search results and the categories. Needless to say, this amount of evidence was unwieldy, and as this research was never intended to be a systematic review, a revised approach was taken. In addition to key papers identified from the literature search, three other techniques were used to identify additional, relevant papers: citation pearl searching (identifying additional papers using the "related items" feature on the database), snowballing (following up the references in highly relevant papers), and horizon scanning (monitoring trends by regularly scanning news items and relevant organisations).

Finally, 300 of these papers were identified as highly significant and meeting the inclusion criteria described earlier. The key papers were chosen because their content was mainly in a UK setting, but also drawing from experiences further afield. It was felt that these papers would successfully provide the rationale behind the research. A final source was identified, a very comprehensive list of papers on online information-seeking behaviour written by a PhD student at the University of Haifa in Israel (Barak, 2010).

2.2.4. Organising identified papers by relevance

Papers were collated and reviewed against the inclusion criteria listed in section 2.2.3., and the references were collated in folders, named to reflect the key themes. Once organised, syntheses were prepared on each topic and these are presented in section 2.2.5. Figure 2 identifies the gaps in knowledge related to consumer health information literacy, highlighting the key themes which are driving the need for this research:

Figure 2: Issues and solutions for consumer health information literacy



2.2.5. Correlating and analysing the literature

2.2.5.1. Context – The NHS and self-management of chronic disease

The National Health Service in England (NHSE), is the fifth largest organisation in the world, and treats 64 million people. The workforce is made up of *"147,087 doctors, 371,777 qualified nursing staff, 154,109 qualified scientific, therapeutic staff and 36,360 managers"* (Hunt, 2014), dealing with over 1 million patients every 36 hours via a range of specialist services. There are 8,230 GP practices (primary care) (Gregory, 2009), about 2,300 hospitals, 160 acute hospital Trusts (secondary care), 56 mental health trusts, 10 ambulance trusts, and 129 NHS Foundation Trusts (N.H.S. Choices, 2011, Department of Health, 2013b, De Brún, 2007, Hunt, 2014). On 1st April 2013, a new structure came into place for NHS England, as part of the Health and Social Care Act 2012. This restructure has led to a change in commissioning responsibilities with local authorities responsible for public health commissioning (British Medical Association, 2013), and now the general public has more choice and control over their care pathway (N.H.S. Employers, 2013), making the NHS more patient-centred in its service delivery. Part of this involves giving patients access to their electronic health records.

With access to their Summary Care Records (electronic health records), people are being actively encouraged to participate in the decisions made about their treatments (Department of Health, 2010a). However, to do this, they need to know and understand their treatment options, and with advances in mobile technology, the Internet is becoming the main source for consumer health information. But finding the right information can be difficult without knowing exactly where to look. The obvious choice would be to create an online resource, such as an app, or a portal or a gateway to quality health information sources. Public health initiatives are focusing on prevention and raising awareness of health risks. The Internet, in particular social media/web 2.0, is an ideal channel for facilitating this, and communicating public health messages quickly and effectively (Robillard et al., 2013), but needs to be used safely, using appropriate language (Dobransky and Hargittai, 2012). However, many web-sites like this already exist, but are not used because people are either not aware of them or find them too difficult to use (Greenhalgh et al., 2010a). Research shows that people with chronic health conditions are often the same people who do not have access to the Internet or do not use the Internet (Fox and Purcell, 2010). Therefore online access to health records and patient information would not fulfil their information needs.

Chronic diseases, or long-term conditions, are illnesses that cannot be cured, but can be managed, for example, dementia, diabetes, heart disease, epilepsy, asthma, inflammatory bowel disease, chronic obstructive pulmonary disease, multiple sclerosis, etc. The number of people suffering from chronic disease is on the increase, "*in particular those with two or more conditions*" (Ipsos MORI, 2011, N.H.S. England, 2013). In England, around 15 million people, approximately one third of the population, suffer from at least one long term condition (Morioka et al., 2013), putting a huge strain on the health economy in terms of the cost of regular drug treatments or other therapies, readmissions to hospital, out-patient care, and home visits. It also puts a tremendous strain on carers, both formal (social services) and informal (family).

This research focuses particularly on consumer health information for people with dementia or Alzheimer's disease, and their carers, as dementia is "*one of the most important health and care issues the world faces as the population ages*" (Department of Health, 2013a). Alzheimer's disease is one of the most common types of dementia. It affects the memory, moods, and causes communication problems, and the symptoms gradually worsen, identifying it as a chronic condition (N.H.S. Choices, 2012, Alzheimer's Society, 2013).

To reduce pressure on NHS services, patients suffering from chronic illness are being encouraged to self-manage their conditions, meaning that they have to make decisions about how to manage their condition. Self-management can help people significantly improve their quality of life by reducing the risk of complications. However, to self-manage, they need to have access to the best quality information to ensure that they are fully informed about their condition and treatments available to them so that they can manage their health more effectively, and this is not always easy to find.

A recent study evaluated the quality of Internet-sourced information for patients and found that "*good quality information about chronic pain is unlikely to be retrieved by our patients on the Internet*" (Corcoran et al., 2009). This is unfortunate, as another study found that "*as the number of chronic conditions rises, so does the frequency of Internet use to retrieve health information*" (Ayers and Kronenfeld, 2007), so despite there being a need for good quality health information, it is not always available. Furthermore, often people with chronic illness have low levels of education, and may be on benefits or on the minimum wage, making them more vulnerable, possibly malnourished, and therefore more susceptible to illness (Fox and Purcell, 2010).

Carers also benefit from being well-informed, as they feel more useful to the patient and understand how best to help them. Research has shown that ensuring carers are well-informed, reduces stress levels and improves their well-being (Boots et al., 2014, Age UK et al., 2013). This is essential as informal carers, such as family and friends significantly reduce the burden of care of people with Alzheimer's disease in the NHS. In 2014, in England, more than 50,000 informal (not professionally-trained) carers left their jobs to care for someone suffering from dementia (Centre for Economics and Business Research, 2014). Depending on the severity of Alzheimer's disease in patients, it is often the carers who seek information; general information about the condition, and also specific information about the patient's experience, such as treatment options and prognosis. Clearly, carers play an important role in patient welfare, and need to have access to the best quality 'patient' information so that they can make sure the best option is decided upon for the patient if they are not able to make the decision for themselves. That is why the solution for this research will be designed for both patients and carers.

2.2.5.2. Summary care records

As alluded to in 2.2.5.1., part of patient-centred services involves the absorption of patients in the decision-making process, and one step towards this is providing patients with access to their individual Summary Care Records (http://www.nhscarerecords.nhs.uk/). These records are part of the National Health Service England's equivalent to the national shared electronic health record (EHR) systems (Cruickshank et al., 2012), that are also being introduced elsewhere in the world (Protti, 2007). The electronic record-keeping system allows for the exchange of individual data between primary and secondary providers of health care, locally and nationally, of various types of patient details, such as information about the medication they are currently taking, their medical history, including allergies, results from laboratory tests, referral letters, and discharge summaries (Greenhalgh et al., 2010b). For example, if a patient has demonstrated an allergic reaction to penicillin in a previous medical situation, this will be noted on the record for other medical staff around the country to see so that if the patient requires treatment, penicillin will be avoided. The aim is to reduce the incidence of medical errors or the loss of paper medical records as they are transferred between health centres, and improve quality of care delivery, and ultimately, patient experience (Robertson et al., 2010, National Health Service, 2010).

To facilitate condition-self-management, patients can also record their own data, such as blood sugar levels for diabetics, and weight loss/gain. Once all this data is submitted, patients can print off their personal health summaries together with graphs, and they can set their target, e.g. for weight or alcohol consumption. These summaries can then be shown to their GPs or other health professionals. However, this data is patient-generated and reliant on the patient to provide an honest account of his/her health status.

In 2013, only 2% of the general public were able to access their electronic health record (N.H.S. England, 2014b). At the end of July 2014, 40 million patients had a Summary Care Record, and "*21% of patients in England have been able to access their medical records online.*" This success is leading to a roll-out in A&E, NHS111, and GP out-of-hours services (N.H.S. England, 2014a), which will greatly improve patient safety in these areas, where clinical staff may not have met the patients previously and so may not know their backgrounds. Along with this work, the Department of Health is aiming to deliver a paperless NHS by 2018 (House of Commons Committee of Public Accounts, 2013), and this means that all the documentation they produce will only be online. However, with 10 million people not yet online (Digital Inclusion, 2010), there is a risk of digital exclusion.

Electronic health records are often accessed via the GP web-site or patient portals, such as HealthSpace and HealthVault, which will be discussed in section 2.2.5.4. However, patient portals do not provide consumer health information support (Kruse et al., 2015), so while they have the data about their condition, the test results, etc. they do not have automatic access to relevant information about their condition or the treatments involved. This is important for this research, because if people are to be empowered, they must have access to all the relevant information that the NHS provides for them, in a format that is most beneficial to them. It must also be in plain English, for example, lay versions of care pathways and guidelines, to ensure they understand all the options and consequences, so they can make informed choices.

One group of practices where they have actively encouraged their patients to sign-up to access their medical records is the Haughton Thornley Medical Centres, in Cheshire. There, in January

2011, they announced that they had signed up their 1,000th patient for online access to their medical records (Barr, 2011).

At the general practices in the UK where patients have been given access to their Summary Care Records, the response has been positive, with many patients feeling empowered by this access, as it gives them "*a greater sense of control of their care*" (Woods et al., 2013) and helps *"break down barriers between them and the doctor"* (Honeyman A et al., 2005). Patients understand the benefits and the side effects of the treatment, and are more willing to adhere to the treatment regimen and accept any adverse events, should they occur, thus potentially avoiding litigation. One general practice in London found that more than three quarters of its patients felt that having access to their notes provided them with the opportunity to give additional information which might be useful in deciding on the best treatment path to take (Honeyman A et al., 2005).

However, some health consumers, particularly those with chronic conditions, are still sceptical about electronic personal health records and are wary of their usefulness and trustworthiness, particularly in the way they are delivered, via patient portals (Kruse et al., 2015). To increase uptake, developers and health service providers must demonstrate the value of an electronic records system to improve health outcomes and service delivery. As part of this, developers must ensure that there are links to good quality health information, so that whenever people go to look at their individual health data, they can access information that will help them make informed choices. This already happens within clinical information systems for health professionals, but not yet for patients.

2.2.5.3. Digitally excluded

The government wants everything to be online so that data can easily be shared between relevant departments, reducing medical errors, improving consistency in service delivery across the country, and enabling savings of between £1.7bn and £1.8bn for service users and providers (Government Digital Service, 2012, House of Commons Committee of Public Accounts, 2013).

eHealth initiatives are an important aspect in health care improvement. If used appropriately, they have the potential to empower the general public by overcoming barriers to accessing health care services (Marschang, 2014).

The establishment of programmes like Go On UK (http://www.go-on.co.uk/) and The People’s Network (http://www.peoplesnetwork.gov.uk/) initiatives demonstrate that there is no reason why people in England should not be able to access consumer health information online, should they so desire.

The aim of the government’s Digital Inclusion Strategy (Government Digital Service, 2014) is “*to get every capable person online by 2020*”. However, it has calculated that 10% of the population in England (4.7 million people) will never go online. Although this is less than 10% of the adult population, the UK does need to implement systems which take into account the “*long-term excluded*” (Middleton, 2014), and also the increasing migrant population with their language issue, which costs the NHS a significant amount, £33million per year, in translation costs (Gan, 2012, Beckford and Adams, 2015). Medicines optimisation is part of health information literacy (Picton and Wright, 2013), and the ‘right information’ must be delivered in the ‘right format’ for example, hard copy and online (Treadgold and Grant, 2013), to overcome the digital divide, facilitating an understanding of the implications of taking the appropriate treatment.

Conservative MP and former GP, Sarah Wollaston has advised caution with the use of health care technologies, (and this includes using only technology to disseminate consumer health information), or we may “*end up widening health inequalities in the process*” (UK Digital Skills Taskforce, 2014).

The Tinder Foundation has recently led a project to get more people online in the UK, because digital exclusion is a burden on the UK economy. Poor information literacy skills affect "*pay, health, educational attainment and more*" (McDonald, 2014). From a psychological point of view, people can lose confidence, and feel isolated without these skills. However, not everyone wants to have access to the Internet or they may not be ready to take on new skills, which is why the proposed model is so important because it takes into consideration the human and technical elements of information literacy.

2.2.5.4. Quality of online health information

Quality refers to the accuracy, relevance, lack of bias, consistency, and currency of health information. The Internet is a "*plethora of information*" (American Hospital Association Committee on Research, 2013), and quality has always been a concern (White, 2002). Access to good quality online information is important, not only for patients, but particularly for carers, who are often restricted to the patient's environment and may not be able to get out much for support (Hirakawa et al., 2011). But the issues of bias, misinformation, lack of quality assurance, relevance, and currency (Silberg et al., 1997) can mean that patients will identify incorrect information leading to poor, and potentially dangerous, decisions being made. Furthermore, the misinformation that can be spread by the Internet can often lead to confusion and misspent time during consultations while discussing inappropriate information (Westgate, 2012). Credible information from a trusted source has the "*potential to influence behaviour*", which can improve service delivery, and the experience of the patient (Macpherson and Chamberlain, 2013). But even information from credible sources can be confusing, if there are several sources giving similar but differing information. Searching for health information online can be overwhelming, particularly for carers who have many other responsibilities to cope with (Kim et al., 2014). There must be nothing that will affect the integrity of the information, because otherwise it may contribute to an adverse health event. For example, many web-sites are sponsored by commercial organisations who advertise drugs related to the condition, which may be misleading to a patient or carer.

Quality of consumer health information for specific clinical conditions

Despite, Alzheimer's disease being the clinical condition of focus for this research, the author has referred to papers on the quality of patient information for a variety of chronic conditions to demonstrate that there are issues with quality across the board, not just for one condition. Therefore, the conditions covered are Alzheimer's disease, inflammatory bowel disease (IBD), HIV/AIDs (Human immunodeficiency virus/Acquired immunodeficiency syndrome), carpal tunnel syndrome, and asthma. This provides a broad spectrum of long-term conditions, by looking at gastroenterology, infectious disease, neurological conditions, and respiratory disorders.

Table 2 summarises the findings of eight key papers looking at the quality of online consumer health information for a range of clinical conditions:

Table 2: Key findings of 8 papers about online consumer health information quality

Citation	**Topic**	**Methodology**	**Number of web-sites reviewed**	**Bottom line**	**Comments**
Beredjiklian, P.K. et al., 2010. **Evaluating the source and content of orthopaedic information on the Internet: The case of carpal tunnel syndrome**. *The Journal of Bone and Joint Surgery*, 82-A(11), pp.1540–1543.	Carpal tunnel syndrome	They looked at the top fifty web-sites from each of five search engines, and built up a list of 250 web-site addresses to assess, scoring each site for authorship and content.	250	Less than a quarter of sites were "*authored by a physician or an academic organization*", and almost two thirds of the sites were commercial, with half of those selling products related to the condition.	Web-sites providing health information to consumers should not be advertising anything, especially medicinal products as this may cause confusion.
Bernard, A. et al., 2007. **Systematic review of patient inflammatory bowel disease information resources on the World Wide Web.** *American Journal of Gastroenterology*, 102(4), pp.2070–77.	Irritable Bowel Disease	They searched Google for patient information on inflammatory bowel disease (IBD), but used the terms "Crohn's disease" or "ulcerative colitis", and scored using a combination of four scores looking at quality evaluation, global quality, integrity, and reading level.	34	"*Many web sites suffered from poor quality but there were five high-scoring web sites*."	The search is flawed because they did not search for inflammatory bowel disease or IBD. Consumers may not know the alternative terms that are Crohn's disease or ulcerative colitis.

Citation	Topic	Methodology	Number of web-sites reviewed	Bottom line	Comments
Dillon, W.A., Prorok, J.C. & Seitz, D.P., 2013. **Content and quality of information provided on Canadian dementia web-sites.** *Canadian geriatrics journal: CGJ*, 16(1), pp.6–15.	Alzheimer's disease	They searched Google using the terms dementia and Alzheimer and then compared the contents to 16 guideline recommendations from the Canadian Consensus Conference on Diagnosis and Treatment of Dementia.	7	*"The quality of information provided on the web-sites varied, and many web-sites had several areas where the quality of information provided was relatively low according to the DISCERN instrument."*	They specifically looked for Canadian web-sites, so the number of sites to review was very small. They reviewed seven and found only three to be adequate.
Haigh, C.A., 2011. **Wikipedia as an evidence source for nursing and healthcare students**. *Nurse education today*, 31(2), pp.135–9.	Asthma	They looked at the quality of evidence obtained from more than 2,500 references taken from 50 Wikipedia pages.	2,598 references for 50 Wikipedia pages	They found that the references were "*of sufficiently sound quality to suggest that, for health related entries, Wikipedia is appropriate for use by nursing students*".	It was not possible to replicate this search, which makes the results weak. There have also been reports that some drug companies have deleted or altered data about side effects, "*to downplay the risk of their drugs*" (Freeman 2014; Hasty et al. 2014), so there really is no guarantee of the quality of the content on Wikipedia, as with other peer-reviewed information sources.

Citation	Topic	Methodology	Number of web-sites reviewed	Bottom line	Comments
Horvath, K.J. et al., 2010. **Online resources for persons recently diagnosed with HIV/AIDS: an analysis of HIV-related webpages**. *Journal of health communication*, 15(5), pp.516–31.	HIV/AIDS	They searched only one search engine and limited to the first page of search results.	10	They found that the impact of people accessing low quality resources can result in emotional distress, and dated and irrelevant information, confirming that there are issues with the use of online consumer health information.	By limiting to the first page of search results, the authors are at risk of not replicating the searching style of consumers. 2006 report on eye-tracking (iProspect 2006), which says that "*62% of search engine users click on a search result within the first page of results*." So, 38% search engine users would pick up more web-sites by going to the next page, and therefore, there is slight bias in this paper.
Meadows-Oliver, M. & Banasiak, N.C., 2010. **Accuracy of asthma information on the world wide web**. *Journal for specialists in pediatric nursing: JSPN*, 15(3), pp.211–6.	Asthma	They applied very systematic and comprehensive methodology, searching for only one term – asthma – on fourteen search engines.	68	They studied 68 web-sites about asthma, and found that "*only six (8.8%) provided accurate information*", based on the Guidelines for the diagnosis and management of asthma, published by the National Heart, Lung and Blood Institute.	This research searched more search engines, and concluded that very few of the web-sites reviewed gave accurate information. However, while the methodology was robust, they only used one relevant, American guideline to assess the quality of the information. This guideline may be different to one, on a similar topic, published by the UK's National Institute for Health and Care Excellence, and therefore, the findings of this research may be skewed towards an American audience.

Citation	Topic	Methodology	Number of web-sites reviewed	Bottom line	Comments
Scullard, P., Peacock, C. & Davies, P., 2010. **Googling children's health: reliability of medical advice on the Internet**. *Archives of disease in childhood*, 95(8), pp.580–2.	Paediatrics	They searched Google for advice for five common paediatric questions. The authors found that only 39% out of 500 sites searched gave correct information, 11% were incorrect and 49% failed to answer the question.	500	"*The reliability and accuracy of health information on the internet ranges from very poor to excellent, depending on the topic*."	Google is one of the information sources that the general public are most likely to use, and yet, the researchers who reviewed the findings found that less than 50% gave correct information.
Starman, J.S. et al., 2010. **Quality and content of internet-based information for ten common orthopaedic sports medicine diagnoses**. *The Journal of bone and joint surgery. American volume*, 92(7), pp.1612–8.	Orthopaedics	The authors reviewed 154 sites providing information on the top ten common orthopaedic sports medicine diagnoses.	154	They found that the most common were commercial, followed by academic sites.	Where commercial organisations are concerned, there is a strong possibility of bias in the information provided.

All in all, more than 1,000 web-sites were assessed, although there may have been some overlap with the asthma papers as there were two articles on this topic. Despite this, and although the quality of the analysis varied, several of the studies had very robust methods, and all of the studies concluded that quality of the content varied and improvements could be made to the production of consumer health information.

Interestingly, none of these papers was written in collaboration with medical librarians, and none of them proposed the involvement of this professional group in the education of the general public. The only paper that involved patients in their research was the one looking at information sources for HIV/AIDS. There is opportunity for information specialists/librarians in public or medical libraries to publish research from a non-clinician point-of-view.

The paper on Wikipedia (Haigh, 2011) was aimed at nursing and health care students and was included, because Wikipedia pages often come to the top of search engine results. Haigh looked at the quality of the references, rather than the content of the Wikipedia pages. This is problematic, because while the references are high quality, unless the person writing the content for Wikipedia is a clinician or an expert in critical appraisal (librarian), he/she may not translate the research accurately for lay-people. It would have been more useful to verify the authors to see how many are qualified, evidence-based practitioners (Hasty et al., 2014, Philipson, 2014).

Although individual papers were condition-focused, the overall findings agreed that the quality of consumer health information on the Internet is low. The methodologies applied in each article were different but the findings were still very similar. It is interesting to see that despite the wide date spectrum, with the oldest paper being published in 2000, and the most recent in 2014, the same conclusions were reached about the low quality levels of online health information throughout. Even though access to, and demand for online patient information has increased, it would seem that, judging by these papers, the focus has been on quantity of output rather than quality.

From this sample of papers on the quality of consumer health information, it would seem that there is indeed evidence to show that the quality of online consumer health information is poor, and in particular for online information about chronic conditions (Corcoran et al., 2009).

It has been suggested that health professionals should guide their patients towards reliable web-sites and online forums (Ward and Leach, 2012), and even search like a patient to understand why they are not adhering to the treatment regime (Lewis Dolan, 2013) but often health professionals are not confident in using the Internet, or they may not have the time to do so or the skills to assess whether the resource is appropriate or not (Sense About Science, 2013), so this is not really a practical solution. Once again this demonstrates the value of using librarians/information professionals as intermediaries, with health professionals taking on the role of interpreter or guide (Hesse, 2012) for any literature found.

One way to identify quality sources is to find URLs (Uniform Resource Locators)/web addresses ending in a public sector site domain, as these addresses are considered to be of higher quality (Ansani et al., 2005). In the UK, limiting searches by .nhs.uk, .ac.uk or .gov.uk would more likely return less biased health information, but would block out patient information produced by the voluntary sector. Non-profit organisations might use the site domain .co.uk or .org.uk, but these sites may be sponsored by advertisers which may be inappropriate for patients. For example, a search for information on diabetes on Patient.co.uk had adverts for non-clinical products such as Sky, Bupa, and Barclaycard, and also clinically-related products, such as MediGuard, a free service which aims "*to reduce your risk of drug interactions and safety surprises*." MediGuard is offering advice about medications, and although it does have a disclaimer saying it is not a substitute for professional medical advice, it would seem inappropriate to have such an advertisement on a site that is supposed to provide independent access to quality health information. Only qualified health professionals should be advising about drug interactions, not commercial web-sites or organisations.

Online consumer health information evaluation support

Guidance is required to help people filter for high quality information (Rafe and Monfaredzadeh, 2012) and there are many tools to help people evaluate the quality of online health information.

Two researchers (Deshpande and Jadad, 2009) identified five different categories that "*could be used to classify assessment instruments to evaluate the quality of online health information:*

1. *Codes of conduct e.g. American Medical Association*
2. *Quality labels e.g. HONcode (*http://www.hon.ch/home1.html*) - the Swiss Health On the Net Foundation*
3. *Online checklists e.g. DISCERN (*http://www.discern.org.uk), IPDASi (http://www.ipdasi.org/)
4. *Subject gateways which act as a filter e.g. Intute (*http://www.intute.ac.uk/)
5. *Third-party certification e.g. Utilization Review Accreditation Commission (URAC).*"

But which one should the lay-person use? With the codes of conduct, does each international medical association have a code of conduct, and if yes, does one apply the AMA (American Medical Association) code of conduct when evaluating American health sites, and the BMA (British Medical Association) code of conduct (if one exists) for UK health sites?

The HONcode, a quality label, developed in Switzerland, is a searchable database, containing more than 5,000 accredited medical and health web-sites, assessed according to the HON Code of Conduct. It is a recognised standard which can be awarded to consumer health information web-sites, and it is also a checklist that patients can use to measure the quality of the site. While useful, it does find information from around the world, which might not be applicable to the UK population, as treatments and drug dosages vary between countries. In 2013, a news item described the severe allergic reaction, of a young boy, to a drug for the management of epilepsy (Hodgekiss, 2013). There was no warning about this potential side effect on the drug packaging in England, although there was a warning on the packaging in America. This is a tragic example of how information can differ between countries. The top result in a search of HONCode, for patient information on diabetes, was plagued with advertisements and was not produced by a non-commercial or health organisation. While these tools should be there to make things easier for the patient and carers actually they are making it even harder to find good quality information because it adds another step.

The next two in the list, are quality checklists and filters, although Intute (http://www.intute.ac.uk/) is no longer funded and has not been updated since 2011. DISCERN (http://www.discern.org.uk) is a useful checklist comprising of 16 questions which provides users with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem. However, someone in desperate need for reassuring information, may find this process too time-consuming. A briefer version is available (Khazaal et al., 2009). IPDASi (International Patient Decision Aid Standards instrument) (Elwyn et al., 2009) is another checklist, this time, helping people to evaluate the quality of patient decision aids. Decision aids have been proven to be effective in helping people make decisions about their care pathway (Stacey et al., 2012). However, there are barriers to their implementation, including health professional and patient/carer awareness of these aids. Unless people are aware of decision aids, they face the same problem that other NHS information resources have faced, and will not be used, making them redundant.

Finally, third-party certification: in America, they have an accreditation company called URAC (Utilization Review Accreditation Commission), which evaluates US consumer health information sources. In England, there is the NHS England Information Standard (http://www.theinformationstandard.org/), a quality standard, which invites UK patient information producers to undergo a rigorous, independent accreditation process, which evaluates the consumer health information production process and awards certification. At the end of the process, they are awarded a certificate and unique certification number, which they can display on their web-sites and information products. NHS Choices has achieved the Information Standard accreditation status. However, it should be noted that not all the organisations that provide patient information on NHS Choices have achieved this status, so what does this mean for patients? Can they be confident that all the health information on NHS Choices is good quality? Furthermore, achieving the Information Standard is a costly process and not all organisations, particularly charitable institutions, can afford to achieve this Standard, which means that if an organisation does not have it, should consumers be worried or should they apply a quality checklist when reviewing the content?

Once again, the Deshpande and Jadad paper shows the difficulties involved in finding good quality health information because there are so many ways to either evaluate or find evaluated content. In less than a decade, the number of instruments to measure the quality of online health information has more than quadrupled (Deshpande and Jadad, 2009) and some researchers suggest that continuing this pursuit of measuring quality is pointless. Another paper reviewed 273 tools, and found that although many are available, "*few can actually be used by health care consumers*" (Bernstam et al., 2005). This is another example of lots of resources being developed, but not to suit the needs of the general public. Another paper offers suggestions for the development of "*quality standards for decision aids in the future*" (McDonald et al., 2014), another tool for people to be aware of.

One might consider that the issue is that there are too many tools and that they are looking at all the patient information on the Internet, rather than localising it. It is true that there are patients with the same condition all around the world, but their lifestyles, diet, ethnic breakdown, health systems, treatment choices, and medication dosages may differ from country to country. What a patient can expect regarding treatment care in America will differ to what a patient in England can expect, not only because of lifestyle, but also because of the differences in health systems. It would make sense to develop a tool for individual countries.

Existing NHS consumer health information sources

The UK government has invested a great deal of time, money and expertise in developing resources to help patients access their patient data and quality health information (Table 3). Patient information products, although costly to the NHS, are very useful because they help patients, and their carers, "*to make informed choices, to take treatments appropriately,*" and perhaps to take part in clinical trials which could improve health service delivery in the future (Garner et al., 2012). However, an important observation, made by Norman and Skinner, points out that e-health products are only useful if people have the skills to use them (Norman and Skinner, 2006a, Norman and Skinner, 2006b).

Table 3: Consumer health information products used in the NHS:

Resource name	**Access details**
Behind the Headlines	Established 2007 - http://www.nhs.uk/News/Pages/NewsIndex.aspx
HealthSpace	Closed March 2013
Healthtalk and Youthtalk Online	Established 2001 - http://healthtalkonline.org/
HealthVault	Established May 2013 - https://www.healthvault.com/gb/en-GB
Information Prescriptions	Established January 2007 - http://www.nhs.uk/ipg/Pages/IPStart.aspx
The Information Standard	Established 2009 - http://www.theinformationstandard.org/

Resource name	Access details
NHS 111	Established 2014 – http://www.nhs.uk/111
NHS Choices	Established 2007 - http://www.nhs.uk/Pages/HomePage.aspx
NHS Direct	Closed March 2014
NHS Shared Decision-Making	Established 2012 - http://sdm.rightcare.nhs.uk/
Patient.co.uk	Established 1997 - http://www.patient.co.uk/
Patient Online	Established May 2014 - http://www.england.nhs.uk/ourwork/pe/patient-online/

Many of the resources listed above provide similar, but differing advice, some listing more symptoms than the other resource. An interview with the National NHS Patient Champion showed that although he was familiar with NHS Direct and NHS Choices, he was unaware of the other resources listed. It is worth noticing that there have been many changes over the years, and this is confusing for users, because even when they are aware of a resource, there is a risk it will shut down for whatever reason, e.g. NHS Direct, and then they have to identify and use a new information source.

NHS Choices has replaced the consumer health information side of NHS Direct, while NHS111 has replaced the treatment advisory service. The NHS Choices Annual Report said that "*use of NHS Choices results in fewer GP visits, bringing cost-savings to the NHS and demonstrating the opportunities offered by putting appropriate information and services online*" (N.H.S. Choices, 2011). Patient.co.uk is similar to NHS Choices, in that they both provide patient information on common conditions and procedures. However the content produced by each of these resources is sometimes different, with one listing more symptoms than the other, and this may be misleading to a patient. For example, NHS Choices has a specific leaflet for Alzheimer's disease and a separate one for dementia, while Patient.co.uk has a leaflet on Memory Loss and Dementia, which incorporates information about AD. This is very confusing for people, and one could question how they should know that one is better than the other. Furthermore, GP surgeries use clinical support systems, such as EMIS, which help GPs manage the treatment process, and these systems can provide patient information leaflets, which come from http://www.patient.co.uk. It would be more appropriate to offer consumer health information, produced by NHS Choices, which is publicly-funded, and developed by the NHS.

The Information Standard invites UK patient information producers to undergo a rigorous accreditation process to achieve a Department of Health quality standard. The process looks at who has written the content, whether it has been tested on its target audience, and how often it is reviewed, among other quality criteria.

Behind the Headlines produces a short evidence review of health-related articles that have appeared in the daily papers. It is very useful for patients, carers, and health professionals, because it looks at the original research behind the media headlines and assesses whether it is good quality research or not, and then provides a brief summary together with links to all the relevant papers, both tabloid and research.

Other good quality health information resources include the Information Prescription and Healthtalkonline. The Information Prescription is a web-site where patients can type in their condition and their postcode and the site will provide them with localised, relevant patient information about the condition itself, and appropriate, local NHS services. Healthtalkonline provides access to more than 2,000 people's experiences of health and illness, which patients and/or carers can listen to, watch or read. The information on Healthtalkonline is based on qualitative research into patient experiences, systematically collected by experts at the University of Oxford.

But the situation constantly changes. For example, when this research first began, there was a resource called HealthSpace (N.H.S. Connecting for Health, 2011), a web portal that allowed access for patients to their Summary Care Record. It was part of the National Programme for IT (Department of Health, 2002), and in 2012, the decision was made to cut some aspects of NPfIT. HealthSpace was discontinued due to lack of use, as in February 2011, it was revealed that out of almost 5 million people with a Summary Care Record, only 60 patients a month were using it (Perry, 2011). An earlier study found "*patients perceived HealthSpace as neither useful nor easy to use and its functionality aligned poorly with their expectations and self management practices*" (Greenhalgh et al., 2010a). Once again, due to insufficient funds, there had barely been any promotion for this project, and people were unaware of it, and therefore unable to use it. The Department of Health has recently launched a resource called HealthVault, which will have a similar purpose to HealthSpace. However, unless people are made aware of this resource, there is a risk that it will follow the same route as HealthSpace. It is a catch-22 situation as the NHS is commissioning these resources, but due to the cost savings that the Department of Health is required to make, in the author's professional experience, marketing budgets are not a priority. Without promotion, these products will continue to go unused, despite the research showing that there is a proven need for patient and carer information support (Treadgold and Grant, 2013). NHS re-branding is another issue for people to overcome. NHS organisations frequently re-structure, and re-brand, making it confusing for people to find the information that they need. For example, NHS Direct was created, became widely recognised and used, and a few years later, NHS Choices and NHS 111 were developed alongside NHS Direct, which was eventually dissolved in 2014.

Patient Online is another resource that has recently been launched. It is an NHS England programme designed to support GP practices to offer and promote online services to patients, including access to records, online appointment booking and online repeat prescriptions. However, it does not go that one extra step and connect people to the information that they need to make informed decisions. People want to have more control of their own health and wellbeing, and digital technology can facilitate this, but it needs to satisfy all the needs of health consumers, and not just the ones that make service accessibility easier (N.H.S. England, 2014a).

"*Patient education is a vital component of health care*" (Friedman et al., 2011). Not only are patient-centric resources beneficial to improving health and well-being, they also support the QIPP (Quality Innovation Productivity Prevention) agenda. Friedman et al found that targeting teaching towards the individual population, rather than generic teaching to the population as a whole, is more effective. This applies to the production of high quality information products. An investment of £400 per person, used to produce good quality health information can increase the self-management of long-term conditions creating "*an average net saving of £1,800 per chronically ill patient per year*" (Treadgold and Grant, 2013). However, they must be written for the target audience, involving both patients and carers (Dillon et al., 2013), in the production process, and must be produced in a range of media (online, print copy, audio, braille, large text, etc.).

Liberating the NHS: an Information Revolution (Department of Health, 2012), described the next steps in providing patients with access to health information. However, when this document refers to health information, the Department of Health means data from individual patient records rather than good quality health information to inform decisions.

Health professionals apply evidence based practice with the support of medical librarians. patients and carers do not have this support. There are other information sources available to patients and carers, but no support for navigating them or understanding which are more appropriate for their needs. There are now so many different access points to different sets of quality health information, it is difficult to know which to use. And yet, from a different perspective, researchers have found that "*nearly nine in 10 physicians feel that improved access to online medical information and resources has improved the quality of care at their practice*" (Wolters Kluwer, 2012). If patients have the same level of access to resources and support, then they too will be able to improve their health and wellbeing, which will benefit them and the health service providers.

Other resources, such as patient decision aids (N.H.S. Direct, 2011), are also being developed and hosted by the NHS Shared Decision Making Programme, to help people make decisions. "*Decision aids, action plans and goal setting, training for patients, training for professionals*," can all support shared-decision making (Da Silva, 2012). Decision aids have been designed for patients who are facing difficult decisions about medical tests or treatments, when there is no clinical evidence that one treatment is better than another and they do not know which will be best for them. They increase patients' awareness of the expected risks, benefits and likely outcomes, empowering them to make informed choices about their care. This helps ensure NHS resources are used more effectively. Since 2011, the NHS has been developing decision aids online (N.H.S. Direct, 2011) to help patients make informed health care choices in the first national web-based project of its kind in the UK. The pilot saw NHS Direct working in partnership with NHS Institute for Innovation and Improvement, East of England SHA, Department of Health, Foundation for Informed Medical Decision Making and BUPA Dialog (Laitner and Walker, 2010). Three papers (Stacey et al., 2012, Carman et al., 2010, Woodall et al., 2010) found that patients using decision aids:

- improve their knowledge and understanding of their options;
- empowers patients giving them a sense of control and increasing their self-esteem;
- are more aware of the benefits and risks;
- make choices that complement their preferences;
- become more involved in the decision about their treatment options;

- are more confident in making decisions;
- are more compliant with the treatment regimen – some treatments for example, chemotherapy, have very unpleasant side effects which might discourage people from following that route. However, if the patient completely understands the side effects and the long-term prognosis, then they are more likely to continue with the treatment until it is complete. If the treatment is working as expected then patients will feel better and have a more satisfactory experience, including a shorter hospital stay and hopefully less likelihood of readmission

However, on the web-site for these decision aids, no reference is made to other existing initiatives, such as The Information Prescription or The Information Standard, which are also there to support decision-making. These resources should clearly interact with each other so that the general public can make the best use of all NHS resources. Patient decision aids are a relatively new information source, and therefore, there is no significant evidence that shows their economic benefit yet. However, the evidence does show that following the use of decision aids, patients are more likely to "*choose more conservative approaches*" to their care pathway (Walsh et al., 2014).

The resources currently available are suitable for common primary care ailments, but the information gap lies with the rarer conditions and people with comorbidities, where published information and guidelines are harder to find. For rarer conditions, the general public does have access to PubMed, a bibliographic database of health research, containing more than 19 million citations from biomedical literature. As journals become more readily available via open access schemes, it is often quite possible to find, not only the citations, but also the full text of the paper. However, unless they know how to search effectively, it is very hard for lay people, with no medical training, to find the information that they need to help them make informed decisions. Additionally, when they do find the relevant papers, they might not have the skills to appraise the quality of the research. Not all research is produced to high standards. Again, health professionals learn critical appraisal skills, but patients and carers do not have easy access to these skills, although tools to support the appraisal of consumer health information are available, they are not particularly well-known.

Online patient information needs to be readily accessible to patients, and must be added to the Internet with relevant metadata, so that it can easily be found when searching via search engines (Morris et al., 2008). All resources designed for and funded by the NHS must be inter-linked so that patients and carers see all the resources available. They must also be consistent with each other's content, so that people do not receive two varying types of information. It would perhaps be more useful to patients if all the organisations that are involved with quality health information were to operate more synergistically so that patients and carers could have just one resource to access. By linking all the sites, only one password would be required, which would improve access to resources. At the moment, people can go to various portals, some password protected, and all with different interfaces, making it difficult to search for information to help them make informed decisions. All the sites must link to and interact with each other. The search facility must have an option to search NHS Choices and the Information Standard and there must be a clear link or a widget for Information Prescriptions, which, in turn, should link back to the Information Standard and NHS Choices.

In this chapter, the author has emphasised that there are a range of good quality information sources for patients and carers, but they do not know about them. The NHS funds the development of these resources, but because of current budget restraints (Hurst and Williams, 2012), the author has observed that marketing is not actively encouraged. Policy-makers need to be aware of this contradiction so that awareness can be raised, and the products used. Unless their existence is known, searching for consumer health information will be much harder, which will make it more difficult for people to make informed decisions. "*Information must now find people, otherwise it remains unseen*" (Enspektos LLC, 2012).

2.2.5.5. Shared decision-making

Shared decision-making is "*the process by which the optimal decision may be reached for a patient at a fateful health crossroads and involves, at minimum, a clinician and the patient, although other members of the health care team or friends and family members may be invited to participate*" (Barry and Edgman-Levitan, 2012, Brooks and Cochran, 2007). It enables health professionals, patients, and carers to look through all the available options and evidence in terms of tests, treatment, and support packages and make a joint, fully-informed decision (The Health Foundation, 2010). "*The ideal goal* [in shared decision-making] *is to improve health* *outcomes linked to patient values and satisfaction while minimizing costs and litigation*" (Woolf et al., 2005, British Broadcasting Corporation, 2009).

As mentioned in 2.2.5.1. health systems around the world are working towards person-centred care (Foot et al., 2014), which involves "*placing people at the forefront of their health and care*" (National Voices, 2014). This is becoming more of a reality because policy-makers have realised the benefits of patient participation. The key components of person-centred care include:

- Encouraging patients to self-manage their conditions and prevent adverse events, under the guidance of their health professionals – this requires patients to understand what is wrong with them and how best to look after themselves.
- Enabling patients to share in the decision-making process – to do this patients and carers need to be fully informed with the latest, best research written in plain English.
- Improving health care experience by empowering people through involvement.
- Making sure that patients and carers are not only fully-informed, but they understand the information given to them and the consequences involved.

Research shows that interventions to increase patient involvement in decision-making may be an important means of improving care for, and outcomes of, long-term conditions, such as depression (Clever et al., 2006, Parchman et al., 2010). Effective communication and collaboration between the physician, the patient, and the carer, improves adherence, satisfaction, and outcomes (Mitchell and Selmes, 2007). Patient participation has the potential to save the NHS £4.4 billion a year in "*reduced A & E attendance, planned and unplanned admissions, and outpatient admissions*" (Khan, 2013). It leads to improved patient safety and treatment compliance, while managing integrated care, and reducing medical errors and compensation claims (Osborn and Squires, 2012, Joosten et al., 2008, Kennedy et al., 2002, Edwards et al., 2004, Wilson et al., 2010). In 2009 alone, "*the NHS had to put away £787 million to cover the costs of claims*" (British Broadcasting Corporation, 2009, Coulter, 2002). If patients take an active role in the decision-making process, regarding their treatment, this is more likely to influence their reaction favourably if any adverse events were suffered in the course of their treatment, because they are more likely to understand the risks involved.

It is said that the concept of shared decision making is a relatively new one. The Department of Health (England) published "*The expert patient*" (Department of Health, 2001), which builds on observations often made by health professionals caring for people suffering from chronic conditions, such as diabetes, Alzheimer's disease, epilepsy, etc. that "*my patient understands their disease better than I do*". The report recognises that "*the patient has for too long been an untapped resource.*" But the Nuremberg Code was one of the first international documents to introduce the concept of informed patients. The Code was initiated following the cruel and life-threatening experiments carried out by Nazi soldiers. The trials of these soldiers led to the formulation of the Nuremberg Code which says that the individual "*should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision*" (International Military Tribunal, 1949).

Although in earlier times, consent was not required from the patient, there is evidence that people from all backgrounds were encouraged to share their medical experiences. Herodotus (Herodotus, 2001) tells the following story:

"*They have no physicians, but when a man is ill, they lay him in the public square, and the passers-by come up to him, and if they have ever had his disease or have known anyone who has suffered from it, they give him advice, recommending him to do whatever they found good in their own case, or in the case known to them; and no one is allowed to pass the sick man in silence without asking him what his ailment is.*"

The example of Herodotus demonstrates that exchanging personal experiences and values to inform the treatment choice is not a new idea, but has perhaps been put on the back-burner for many years, as the field of medical education has grown and patients have been less involved in their treatment decisions. Care has been provided and decisions made by doctors.

In past times, health professionals have had a more superior relationship with their patients, and it was unlikely that a patient would have questioned their doctor's decisions. However, in the latter half of the 20th century, people began to take more responsibility for their welfare, and this has reinforced the importance of involving patients in their treatment decisions and obtaining their consent, as a means of protecting and improving the patient experience.

Many organisations, including the coalition government are keen to ensure that patients take part in the decision-making process about their conditions. At the Salzburg Global Seminar

(Alambuyam et al.), participants from 18 countries agreed a statement that calls on patients and clinicians to work together to be co-producers of health. One of the key components to this statement is that "*We call on patients to seek and use high-quality health information*". "The Salzburg statement also says that "*clinicians have an ethical imperative to share important decisions with patients, and patients have a right to be equal participants in their care*".

This is such a simple demand, but the practice requires collaboration between the public, patients, health professionals, information providers, and librarians. A survey of 2,000 people (Daily Mail Reporter, 2014) carried out by AXA PPP insurers (http://www.axa.co.uk/healthcare/) found that 31% of people visiting their GP leave the appointment with their information needs unfulfilled. People are anxious about asking questions because they are embarrassed by their condition or their ignorance, or they are worried about taking up too much of their GP's time. Many changes to the culture of health care organisations will be required, to ensure that shared decision-making is successful (Stiggelbout et al., 2012).

In 2006, 'Our health, our care, our say' (Department of Health, 2006) was written, in which the Department of Health made a commitment to improving access to good quality health information.

While there is concern about the security of data held on their Summary Care Records, there is public commitment to shared decision-making and that people do want to be informed of treatment alternatives and to be involved in treatment decisions when more than one treatment option exists (Department of Health, 2010a, Alston et al., 2012, Guadagnoli and Ward, 1998). However, effective systems are not yet in place to make this a realistic option for everyone. Giving patient and carers the support they need in terms of quality information and decision-making tools, will lead to innovative care pathways. As they participate by presenting their views and preferences, health services will have to change to meet those requirements, making the health service patient-centric, as per the current national health strategy. Patients experiencing a better service, are more likely to improve because they don't have additional stress to hinder their clinical improvement (All Party Parliamentary Groups on Global Health, 2014).

2.2.5.6. Evolution of mobile technology

"*Increasingly, patients are finding health-related information on Internet sites*" to help them make life-changing decisions about their health, particularly those suffering from chronic or long-term conditions (Schwartz et al., 2006, Childs, 2007). In the UK, a survey by The Information Standard has shown that four in ten people are diagnosing via the web, rather than visiting their GP, putting their lives at great risk, because of the varying levels of quality of online information. Interestingly, some studies show that patients made alternative treatment choices after becoming better informed (Mulley et al., 2012), and this may have consequences in terms of health service costs, compliance and length of stay/frequency of admissions.

Mobile smartphone users use the Internet more frequently than those who access the Internet via personal computer (Zach et al., 2012). Cyberchondria describes the phenomenon of people using smartphones to access health information (Fox and Duggan, 2012, Innes, 2013). Future research should look into the usefulness of apps, as they are "*likely to be a new source of information*" (McCartney, 2013) for patients and carers. There are currently estimated to be between 40,000 and 60,000 health and wellness applications on the market (Silow-Carroll and Smith, 2013, McCracken, 2011), but there is a strong variation between the most prevalent conditions. For example, diabetes has many apps, while low vision has fewer available (Martínez-Pérez et al., 2013).

The Bupa Health Pulse 2010 international health care survey (McDaid and Park, 2011) asked 12,262 people in 12 countries for their views on key health issues looking into the areas of ageing, chronic disease, and health and wellbeing. This report and others (Digital Inclusion, 2010), show that almost 11 million people (17.5%), in England either do not have access to the Internet or do not have basic computing skills, such as being able to complete online forms, staying safe online, and identifying quality information sources. Having no access is slightly misleading, as while these people may not have private access to an Internet connection, they can access it via education establishments, Internet shops, and public libraries using The People's Network Initiative (http://www.peoplesnetwork.gov.uk/). The People's Network (Library and Information Commission, 1997, Spacey et al., 2015) installed computers in public libraries, giving high speed access to the web for everyone. In total the network in libraries offers over 60 million hours of computer use every year, most of it free. On average, that works out at just over 5 hours per year for each of the 11 million people. This is not much time, and makes the provision of relevant information literacy support even more crucial.

A more recent report (Tinder Foundation, 2014), says that 7 million people in the UK, including "*3.98 million disabled adults* (Office for National Statistics, 2012), have never used the Internet. As this report has been published after the deadline for RaceOnline2012 (Digital Inclusion, 2010) has been met, and while Go On UK takes over, it can be assumed that the figure has been reduced as a consequence of these government initiatives. Many of the 7 million are over 65 years of age or people with low incomes, and this is an issue because research shows that people on low incomes are more likely to have poor health and therefore need more support and information about managing their conditions effectively (Baker et al., 2007, Raynor, 2012, Berkman et al., 2011, Bostock and Steptoe, 2012, Fox and Purcell, 2010).

There are many reasons why these people choose not to use the Internet. They may not have the skills to search effectively, and, as they only have limited free access with The People's Network, effective use of time will be of the essence. Just figuring out the best information sources and sorting the good results from the bad is highly time-consuming. Regardless of that, 79% of England's library services do offer Internet access, with 91% of library services helping people get online, either on a one-to-one basis or in group training sessions (Davies and Peck, 2010).

It is possible that people choose not to access the Internet, particularly if they are suffering from a sensitive condition. While public libraries endeavour to maintain the privacy of their users, it is still difficult for someone to search for sensitive issues without another member of the public noticing. Furthermore, search engine filters may block potentially useful sites, such as sexual health information. This issue is being addressed by the MAIPLE project (Spacey et al., 2015), Non-users of the Internet may be reluctant to divulge private information on an unsecured form of communication, e.g. in a public library or on a public network. Some potential users may be housebound due to the nature of their condition and therefore cannot get access to a computer.

Mobile technologies and social media provide people with greater access to information, but individual access and use varies greatly around the world. Compared to America, Canada and Australia, surprisingly, the United Kingdom has the greatest proportion, with 89.8% of the population (Miniwatts Marketing Group, 2014) being able to access the Internet (Figure 3):

Figure 3: Internet penetration around the world

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Source: (Miniwatts Marketing Group, 2014)

With recent advances in technology, such as greater access to the Internet via mobile technologies and the development of the Summary Care Records, access to online health information is becoming a greater priority for members of the general public in England. The Bupa survey (McDaid and Park, 2011), found that in the UK, more than 70% of the population use the Internet to search for advice about health, medicines, or medical conditions. There has also been an increase in the level of research for this topic area, which correlate with the findings of a similar study (Fox and Purcell, 2010).

Research shows that the number of elderly people searching online for health information is on the increase, with 52 million (17% of online consumer health information seekers) searching for information on Alzheimer’s disease and related topics, such as memory loss and dementia (Palmour et al., 2013). However, there are not many e-resources about dementia aimed at primary care professionals (Raymond et al., 2013). This could be because even though dementia makes up more than “*50% of the combined health and social care costs of cancer, stroke and heart disease, dementia only receives 6% of the combined research funding available for these conditions*” (Crisp, 2011).

With people living longer and more people than ever being diagnosed with dementia, making sure that patients and carers are fully and accurately informed, and produced by relevant experts in a language befitting to all becomes a key objective for health and care services (Robillard et al., 2013).

At the 20th Annual Social Marketing in Public Health Conference, held in America, experts from Porter Novelli, an international marketing consultancy, shared their expert opinion on health literacy and social marketing (Porter Novelli, 2010). Their research has shown that when asked how they find the answer to a medical query, 65% of people surveyed choose to search the Internet, 43% ask their doctor, 27% gather information via television programmes, and only 14% use government health information services. A related survey of patients, not the general public as a whole, found that 80% of patients surveyed <u>did</u> seek information about how to cope with health problems. This time, three-quarters cited their doctor as the most important source of health information, but a third did search the Internet (Coulter et al., 2006).

Approximately 160 million health-related searches are carried out worldwide each day on Google, and most at the start of the working week (Ayers et al., 2014). This is something to bear in mind when publishing consumer health information; publish on Monday or Tuesday to increase the probability of reaching target audiences. A recent newspaper article said that 44 per cent of patients admit to making a self-diagnosis before visiting their doctors (Hatch, 2013), and many of these people are putting their lives at serious risk of illness or death, by wrongly diagnosing their condition (Macrae, 2013). Sir William Osler once said “*A physician who treats himself has a fool for a patient*”. And yet, with greater access to the Internet, people often use search engines for the purposes of self-diagnosis (Yan and Sengupta, 2013). However, a study showed that the main reasons for wanting health information were for reassurance, second opinion, and better understanding of existing information (Powell et al., 2011).

Table 4 summarises potential sources of consumer health information, together with a list of the advantages and disadvantages of using each of these sources.

Table 4: Sources of consumer health information

Patient information source	Advantages	Disadvantages
• Doctor	• Accurate information	• No time • Wrong literacy level
• Carer/friends/family	• Sympathetic support	• Inaccurate information • Biased, e.g. based on own experiences, which might not match • Might not want to share the problem if it is sensitive or may cause concern
• PALS	• Awareness of good sources of information	• Don't always provide access to patient information – sometimes only logistics information, e.g. how to get to the hospital
• Medical/Patient Library	• Accurate information	• Not always accessible to patients
• Public library	• Awareness of good sources of information	• Might not want to share the problem if it is sensitive • Might not be able to access a public library, depending on mobility levels
• Internet	• Easily accessible 24/7	• Hard to find good quality consumer health information sites • Advertising bias • Inaccurate content written by non-experts
• Web-sites designed for NHS consumers	• Easily accessible 24/7 • Good quality patient information	• Only most common conditions, so harder to find content on rarer conditions • Difficult to know which web-site to use, because there are so many
• Chat rooms and forums	• Easily accessible 24/7	• Peer bias • Different context for each person

Other consumer health information sources include health service providers, support groups, and local authorities. As public services are becoming more integrated, it would be useful if, when producing information for the general public, health and social care providers work together with local councils so that patients and carers receive one piece of good quality, comprehensive information rather than several pieces of varying information (Manthorpe et al., 2013).

Several studies have found that people with chronic diseases use the Internet to look for health information. One paper found that the more chronic conditions a person has, the more they search for health information on the Internet (Ayers and Kronenfeld, 2007). This is problematic because searching for information on comorbidities (multi-conditions) is harder than searching for just one condition. The Coulter paper (Coulter et al., 2006) says that younger and more educated people are more likely to go online, while the findings by the Pew Research Centre (Fox and Purcell, 2010), which said that in America, people without chronic illness (81%) were more likely to search online for health information, than those with chronic conditions (62%). The Pew report also found that adults managing more than two chronic diseases went online less frequently than those with fewer than two, which conflicts with the findings of Ayers et al. If it is the case that they go online less frequently, it may be because of poor access to technology, and/or inadequate information skills.

The Pew report discovered that chronic disease is associated with being older, less educated and living in a lower-income household, these three factors all being potential barriers to Internet use. The authors concluded that it was a lack of access to the Internet, rather than a lack of interest that meant poorer people were less likely to search online for information about their condition. According to the Office for National Statistics in England, only a third of elderly people have ever used the Internet (Office for National Statistics, 2012). This means that the people who need the information the most do not have sufficient resources or skills to access good quality online health information.

In particular, people with mental health or neurological conditions, such as Alzheimer's disease may not have the cognitive ability to search online (Larner, 2011), and then information-seeking may be a role that carers take on. Carers, particularly young carers, need to be given support as "*more than seven out of 10 online carers use the internet to search for information related to caring, and almost half of these are searching at least once a week*" (Burgdorf, 2011, Grässel et al., 2009). It is important to recognise carers as stakeholders in this area of research, because their invaluable support ensures that patients and the NHS and accompanying services will be supported better (Age UK et al., 2013).

People have their own methods of searching for information on the Internet, and they might apply their own filters. Mothers may rely on their own judgement, or use sites recommended by their social networks, for example MumsNet (http://www.mumsnet.com/). Then there are search engines, which will interpret the search terms in their own way. Finally, there are the filters on the computer, which refine the search, but might affect the results that are retrieved (Enspektos LLC, 2012).

It is essential that their information retrieval experiences are positive or people may not feel encouraged to participate in the treatment decision-making process (Tu HT, 2011). However, there are three main barriers to searching the Internet for quality health information, and the first is quality. There is so much information on the Internet, and, particularly with regards to health information, there are some excellent information sources, and some very poor sources. Issues that arise are:

- **Inaccuracy** – the information may not have been written by a reliable source, for example, a clinical expert.
- **Irrelevant** – the information is written for a different audience, and therefore the information can be inappropriate. In America, drug doses differ to those in England, and the same drugs can have different names, for example, Tylenol is the American version of Calpol.
- **Bias** – the author has not disclosed all the information, possibly leaving out details of side effects, to encourage uptake of the treatment.
- **Consistency** – some web-sites will carry similar but not the same information, which is confusing, because people will not know the best one to use.
- **Out-of-date** – the information may have been updated on another site, and so this one might be giving out incorrect information.

The second is using the right terminology and spelling. America and England use different spellings and terminology for the same condition. For example, in England, we have Myalgic Encephalomyelitis, also known as M.E., whilst in America, they call the same condition Chronic Fatigue Syndrome or Chronic Fatigue Immune Deficiency Syndrome (Fabricant et al., 2013). By just searching for one of the terms or phrases, e.g. chronic fatigue syndrome, there is a risk of missing out on vital information, which refers to the condition by one of the other names, or of getting information written for an American audience, where the treatment regimen is different. Another example is ALS (Amyotrophic lateral sclerosis, a neurodegenerative disorder, also known as Lou Gehrig's disease and sometimes Charcot disease, and in England Motor neuron disease). People may not know or understand the correct names for the condition they have been diagnosed with. Medical terms are quite complex and have variations, such as hypertension (high blood pressure) and hypotension (low blood pressure); the first can lead to stroke, while the second can lead to dizziness. A recent survey of 2,000 people carried out by AXA PPP insurers (Daily Mail Reporter, 2014) found that 8% of the people surveyed thought that “haemorrhage” was another word for “piles”, and 10% thought that the term “benign” actually means “terminal” creating unnecessary anxiety for people. This issue does not just affect the general public, but also health professionals. The authors of a study on inflammatory bowel disease online sources (Bernard et al., 2007) are clinicians working in the areas of anaesthesiology and gastroenterology. They searched Google for patient information on inflammatory bowel disease information (IBD), but used the terms “Crohn’s disease” or “ulcerative colitis” rather than inflammatory bowel disease. They did not provide an explanation as to why they did not use the phrase used in the title of their paper. This already demonstrates the difficulty with terminology, as one must question whether a patient or carer would know of these alternative terms (Fabricant et al. 2013). In an attempt at replication of the search methodology, four quick searches on Google for IBD, inflammatory bowel disease, Crohn’s disease, and ulcerative colitis, retrieved a different set of results each time, with Wikipedia being one of the top results, followed by information from American sources, and finally UK sources. Wikipedia is a very popular information source but the quality of the information can be undermined because there is no validation process in place to confirm the author's credentials, and therefore the accuracy of the content cannot be guaranteed. While one might feel that the study does not replicate the searching methods a patient/carer might apply, it does confirm the difficulties with regards to applying appropriate terminology that patients and carers face when searching for quality health information (De

Brún et al., 2012). Information providers must make sure that they avoid the use of confusing medical terminology and acronyms or explain them very clearly (World Health Organization, 2009).

The third barrier is the lack of skills among the general public to effectively trawl through all the information on the Internet, identifying quality online information, and knowing how to appraise and use the information found. The problem with the Internet is that anyone is free to publish content with no need to demonstrate levels of expertise. There is no requirement for publishers of online consumer health information to adhere to any standards for reliability, relevance, or accuracy (Beredjiklian et al., 2010), and the quality of these resources is unmonitored (Scullard et al., 2010). Therefore, it may be unclear to people how accurate and relevant the information that they are finding is to their personal situation. There are few quality measures on the Internet. Searching the Internet relies on the individual to make the judgement, and it is often very difficult to assess the quality of the information, particularly if the terminology is not familiar to the reader.

The Haughton Thornley Medical Centres, in Cheshire, who advocate their patients going on-line to access their Summary Care Records, also believe that people need access to reliable information, and have developed their web-site to facilitate this. They have ensured that their surgery web-site (http://www.htmc.co.uk) provides a long list of good quality health information sources. However, the site contains so many sources, including NHS Choices and Patient.co.uk (both of which provide similar but different information), it may be confusing for patients and carers, as to which source they should use.

There are several information products developed in the NHS for patients and carers in England, (described in section 2.2.5.4.), but not many people are aware of them, and therefore do not use them.

2.2.5.7. Disparities in evidence-based practice

Formally defined in the 1990s, by two Canadian physicians, evidence based medicine (Guyatt, 1991, Sackett, 1997) is a concept that involves the "*integration of best research evidence with clinical expertise and patient values*," (see Figure 4 for a visual depiction of this concept). This means taking knowledge gained from published research and applying it together with professional clinical expertise and patient preferences to make sure that the best treatment choice is made for the patient. By combining clinical expertise and the patient self-knowledge with the best evidence, research has shown that care, satisfaction, and outcomes, can be improved and savings made (Fox, 2013). When discussing the evidence with their doctors, "*patients are particularly receptive*" to these conversations, and are more likely to adhere to the final decision made (Alston et al., 2012). Over the years, this concept has evolved so that it not only focuses on medicine, but also decisions regarding health management, nursing, and mental health, resulting in the more all-encompassing, generic term of "evidence based practice".

Figure 4: Evidence-based practice concept

Source: (Sackett, 1997)

There are five steps to evidence based practice (Akobeng, 2005) and these are:

1. Formulate answerable clinical questions
2. Find the evidence:
    a. identify appropriate sources
    b. identify all relevant terms
    c. conduct the search
3. Appraise the evidence
4. Apply the evidence
5. Evaluate performance – for example, is it improving patient care?

Further on in this chapter (section 2.2.5.8.), evidence-based practice is compared to the SCONUL seven pillars of information literacy framework, which describes the steps towards life-long literacy.

Health professionals suffer from information overload (Smith, 2010, Bastian et al., 2010), but the general public will also suffer from information overload, as they try to make informed decisions, and therefore the intermediary services of librarians/information professionals are vital for evidence-based patient choice (Figure 5), adapted from the existing evidence-based practice concept. The difference between evidence-based patient choice and evidence-based practice is that it not only takes in to account the patient's values and preferences, but also their individual patient data, test results, allergies, etc., collected from the electronic health record. This makes the care pathway much more focused on the individual rather than the condition. It could be argued, that the health professional will naturally refer to the electronic health record, but the author feels that it should be more explicit to demonstrate all the factors required for shared decision-making.

Figure 5: Evidence-Based Patient Choice

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Source: (Sackett, 1997, De Brún et al., 2012)

Finding the evidence is extremely time-consuming, but over the years, many resources have been developed for health professionals, to facilitate their retrieval and evaluation of health information. These include:

- Cochrane Collaboration
- NICE Evidence Search (formerly National Library for Health)
- TRIP Database
- Clinical databases, such as Medline, Embase, PsycInfo, AMED, CINAHL, and HMIC
- Critical Appraisal Skills Programme (CASP)

Medical librarians have also been essential in the support of evidence based practice (McKibbon, 1998), and over the past ten years, the role of the health informatician has greatly evolved (Scherrer, 2002), so that there are now clinical and outreach librarians working alongside health professionals on the ward or in GP surgeries, at the point of care.

Unfortunately, the same human and technical resources are rarely accessible to patients and carers. A similar set of technical solutions, designed for the lay-person, is required if patients are to be involved in the decisions made about their treatments. They can rarely access medical libraries who are skilled in finding the evidence. Health consumers have access to public librarians, who are skilled in understanding the needs of the local community, but not necessarily in finding good quality health information. Public librarians have access to the audience, but not necessarily the relevant subject knowledge. Medical librarians have the relevant subject knowledge but rarely access to consumers. This identifies a discrepancy in access to consumer health information support for the general public.

2.2.5.8. Health information literacy

Low literacy levels, in terms of reading, and being able to find, understand, and apply information, are a barrier to successful patient participation. People of all ages, backgrounds, and education levels need health information, but often find it is difficult to find and understand.

For the purposes of this research, it is necessary to distinguish between "*health literacy*" and "*health information literacy*", as the author has seen the phrase "health literacy" applied in various contexts, and would like to make her interpretation and usage clear.

Health literacy

Health literacy is the ability to understand instructions about treatments. For example if the label on the prescription says "Take three tablets daily", does this mean take three tablets at the same time or take one tablet three times a day? In this case, the health professional needs to communicate effectively, but the patient also needs to understand the instructions given.

In the UK, "*around one in five adults cannot read or understand simple instructions or labels such as those found on medicine bottles*" (Treadgold and Grant, 2013, Bostock and Steptoe, 2012). Low health literacy is now seen as a whole system problem, and not just the problem of the individual. The inability to read can result in patients taking medicines at the wrong times, not following dosages correctly, or not understanding instructions properly (Glassman and Almader-Douglas, 2013). This can result in poorer health outcomes, increased incidence of chronic conditions, greater use of emergency services, and increased hospital stays (Schillinger et al., 2002, Remshardt, 2011, Berkman et al., 2011, Baker et al., 2007, Raynor, 2012). Poor literacy has also been linked to increased mortality, and becomes more problematic as incidence of long-term conditions, such as Alzheimer's disease, is on the increase (Baker et al., 2007, Nielsen-Bohlman et al., 2004, Coulter et al., 2008, Baker et al., 1998).

Identifying people at risk of low literacy can often be difficult because of the attached stigma, which means that people often hide their true levels of reading skills and understanding (AHC Media LLC, 2000). Therefore, when communicating with patients, it is important for health professionals to be able to gauge the understanding of their audience (Easton et al., 2013), so that they can translate the information effectively, in an appropriate format, "*easily readable and understandable*" (Behar-Horenstein et al., 2005) as many people do not understand their conditions and the consequences involved (James, 2013).

Health information literacy

Information literacy (IL) is the ability to identify a knowledge gap, find the information required and apply it as necessary. Health information literacy has a more in-depth scope, and refers to the competencies required to effectively identify, understand, and use good quality health information to make an informed decision (Koh et al., 2012).

The Medical Library Association in America has developed a definition of health information literacy:

"Health Information Literacy is the set of abilities needed to:

- *recognize a health information need;*
- *identify likely information sources and use them to retrieve relevant information;*
- *assess the quality of the information and its applicability to a specific situation;*
- *and analyze, understand, and use the information to make good health decisions."* (Medical Library Association, 2003)

Health information literacy is not only about access to the Internet and online health information, but also about having the skills to retrieve that information and appraise it, and this is where health *information* literacy becomes relevant to this research.

The National Statistics web-site (http://www.statistics.gov.uk/hub/index.html) found that in 2010, 19.2 million households in the UK had an Internet connection. This represents 73% of households. Those that did not have an Internet connection were asked why they did not have one. 39% said that they did not need one, and 21% said that they lacked the required skills to use the Internet, so even though there is more access to computers, for the general public, the skills in using them are lacking (Meijman and Boot, 2010). "*Studies show as many as half of all adults in all socio-economic levels struggle with health* [information] *literacy, defined as the ability to read, understand and act on spoken and written health information from medical professionals*" (Landro, 2003). This lack of skills, emphasises the digital divide between access and ability, and highlights another barrier for people to overcome when searching for reliable health information.

At the High Level Colloquium on Information Literacy and Lifelong Learning, in 2005, the participants proclaimed that "*Information literacy lies at the core of lifelong learning*" (Participants in the High Level Colloquium on Information Literacy and Lifelong Learning, 2005). It is not just a set of skills required in school, but for all activities in life, including health. With the growth in technology, there is a greater need for improved skills in IL and many countries are coming up with frameworks to support this.

In 2008, Scotland published its draft framework (Irving and Crawford, 2008) based on the SCONUL (Society of College, National and University Libraries) Seven pillars model (SCONUL Advisory Committee on Information Literacy, 1999). More recently, in 2011, Wales published its own framework, which was informed by the Scottish version. In England, the Chartered Institute of Library and Information Professionals (CILIP) is in the process of developing an English framework for IL. While the IL strategy for England will have an element of consumer health information attached, other countries, e.g. Australia (The Royal Australasian College of Physicians, 2009), are developing specific health information literacy strategies, to help people make informed decisions about their health. Both the Scottish and the Welsh frameworks focus mainly on what IL competencies are required at the different stages of education, through school to university, rather than health. They do point out that these skills are transferrable to other settings and support life-long learning, providing new opportunities for information professionals. As an example of IL applied in a health-setting, the Welsh framework highlighted the information competency standards, published by the Royal College of Nursing, which said that "*The drive for evidence-based practice within health care and the recent trend towards eHealth, is dependent on staff being able to handle information effectively, by maintaining standards in their own practice, and by supporting the informed patient*" (Royal College of Nursing, 2011). This good practice example is in-line with an editorial, published in the Journal of the Medical Library Association (Schardt, 2011), which consolidates the concepts of health information literacy and evidence-based practice, explaining that health professionals must help patients "*think more critically about the evidence used to substantiate medical claims*". As they have the skills, time, and relevant information sources available, this is an ideal opportunity for information professionals from all sectors to work together with health care organisations, patients, and carers, to take this agenda forward.

The seven stages of SCONUL seven pillars are:

1. Recognise a need for information.
2. Distinguish ways in which the information 'gap' may be addressed.
3. Construct strategies for locating information.
4. Locate and access information.
5. Compare and evaluate information obtained from different sources.
6. Organise, apply and communicate information to others in ways appropriate.
7. Synthesise and build upon existing information, contributing to the creation of new knowledge.

The aims and principles of health information literacy and evidence-based practice are the same; to illustrate the skills required to find, appraise, and apply information in practice. The author has compared the SCONUL seven pillars information literacy framework (SCONUL Advisory Committee on Information Literacy, 1999) and the five steps to evidence-based-practice concept (Akobeng, 2005, Sackett, 1997), adopted by health professionals around the world to show how the seven pillars maps to EBP (evidence-based practice). She has then adapted both frameworks to create a similar framework, shown in Table 5, third column, for the general public. This will form the foundation upon which the final model will be based. The final column shows who is responsible for each step of the consumer health information literacy translation in column 3:

Table 5: Translation of the seven pillars information literacy framework

Stages of SCONUL 7 pillars	**EBM five steps**	**Consumer health information literacy translation**	**Responsibility**
Recognise a need for information.	Formulate answerable clinical questions.	Identify a knowledge gap, e.g. desire for more information about a condition and/or treatment.	Patient and/or carer, together with an independent facilitator, such as a librarian.
Distinguish ways in which the information 'gap' may be addressed.	Find the evidence - identify appropriate sources.	Recognise a source that can fulfil that knowledge need, e.g. health or information professional, library, or reliable online source.	Patient/carer and librarian.
Construct strategies for locating information.	Find the evidence - identify all relevant terms.	Speak to health or information professional about the different terms related to that condition.	Patient/carer and librarian, with input from the health professional.
Locate and access information.	Find the evidence - conduct the search.	Retrieve the information from the health or information professional or online source.	Librarian.
Compare and evaluate information obtained from different sources.	Appraise the evidence.	Check whether it is relevant and reliable using Silberg's 4 standards: 1. Authorship - Who wrote the content and what are their credentials? Are they qualified to provide this information? 2. Attribution - is it clear how the information was generated, e.g. is it referenced? 3. Disclosure - is the web-site sponsored by anyone who might have a commercial gain? When did they write it? Who did they write it for? 4. Currency - is there a date to indicate age of the content? (Silberg et al., 1997)	Librarian and patient/carer.

Stages of SCONUL 7 pillars	**EBM five steps**	**Consumer health information literacy translation**	**Responsibility**
Organise, apply and communicate information to others in ways appropriate.	Apply the evidence.	Make a list of questions arising from the information and discuss with the health professional.	Patient/carer.
Synthesise and build upon existing information, contributing to the creation of new knowledge.	Evaluate performance - is it improving patient care.	Make an informed decision about the treatment being proposed, and keep monitoring the literature, to stay informed about new developments.	Patient and health professional.

It is not just at a particular point of their illness that they need support; people need support at all stages of their illness as their information needs will change (Chen, 2012, Treadgold and Grant, 2013). Older people in particular may need special support to help them understand and evaluate the different levels of information quality available on the Internet (Miller and Bell, 2012).

Since the average doctor’s visit in America lasts 12 minutes (Chobot, 2010), in England, 8-10 minutes (Pollock and Grime, 2003), patients need to be ready to ask smart questions. Helping patients to self-manage by improving their health literacy and health information literacy skills will benefit both the patient and the health system (The Royal Australasian College of Physicians, 2009).

Without the right skills, finding good quality, online health information can be difficult for anyone, particularly for people with disabilities. This is why librarians play an essential role in helping people to develop their information literacy skills, by signposting them to the best sources, and teaching them to search, retrieve, and appraise what they find (Neal et al., 2012). Librarians cannot be expected to teach people to read and write, but they can connect people to accessible and appropriate information sources which people can take with them when they next meet with their doctor, or which they can show to a family member or carer for discussion. People have varying levels of search and appraisal skills, (Peterson et al., 2003) and some will need more help and others less, but it is important that they have access to support, tools and resources to help them when they need to find health information.

Both health literacy and health information literacy should be acknowledged as part of the other literacy life skills, such as digital literacy, and financial literacy. Digital health literacy, also known as eHealth literacy (Watkins and Xie, 2014), is another form of information literacy, and is described as the possession of a "*set of skills and knowledge that are essential for productive interactions with technology-based health tools"* (Chan and Kaufman, 2011). Supporting these initiatives will not be cheap and will be hard work, but the long-term benefits in terms of improved health, better quality care, and cost savings, will be significant as not only will people manage their care more effectively, they will also understand when self-management is not the most appropriate solution for them (The Royal Australasian College of Physicians, 2009).

The benefits of improved health information literacy apply to the patient and the health service provider, and it is logical to invest resources in making these skills accessible to all, not just for improving health status, but also general quality of life. Years ago, Maimonides, a Spanish philosopher said *"Give a man a fish and you feed him for a day; teach a man to fish and you feed him for a lifetime."* This quote reflects the importance of information literacy, because if you find the information for the patient, his query will be satisfied, but if you teach him to search, he will never be ignorant.

2.2.5.9. Knowledge management and the future of public library services

The phrase, "knowledge management" (KM), has risen and fallen in popularity over the years, particularly in health care, where it is seen as a management responsibility, rather than the responsibility of all. Yet, KM is something that people do on a daily basis. A simple definition is building and adapting existing successes to create something new and learning from past experience (Sensky, 2002). However, because it is often linked to business settings and profit-making, the term does not sit easily in not-for-profit organisations, such as health services. But, the benefits are not just increased profit. Improving service delivery by streamlining services, making best use of resources by operating more efficiently, will improve the patient experience, reduce harm, and make savings for the health care organisation.

Royal Dutch/Shell's definition of knowledge management is "*The capabilities by which communities within an organisation capture the knowledge that is critical to them, constantly improve it and make it available in the most effective manner to those people who need it, so that they can exploit it creatively to add value as a normal part of their work*" (British Standards Institution, 2001). As part of the National Library for Health Knowledge Management Specialist Collection, the health care translation was defined as "*The way in which multi-disciplinary teams, working in health care, harvest the personal expertise that is essential to patient safety, learn from it, adapt it to local situations and individual patients, and distribute it via reliable networks to the people caring for the patients, so that they can use it to improve the quality of care delivered*" (De Brún, 2007). And this definition can work for other non-profit sectors, including the library sector.

KM is relevant to this research because one of the key components of the final outcome of this work will involve public and medical librarians working together, and sharing good practice to support consumer health information seekers. Collaborative working is an integral part of knowledge management, and public librarians understand the needs of the target audience, while medical librarians have the skills to find the relevant information needed. "*The contribution of librarians is often greatly under-valued*" particularly as they are very adept at reacting and adapting to community user needs (The Labour Party, 2012). Health information literacy and "*communication, trust, and understanding are the keys to successful knowledge management*" (De Brún, 2007).

From 2013, the European Commission is going to support activities aimed at increasing peoples' digital health literacy. This is an ideal opportunity for librarians, from all relevant sectors to work together, demonstrating their expertise in this area, in terms of knowledge of resources, critical appraisal skills, and public engagement (European Commission, 2012).

Proposed future direction for libraries

A recent article regarding the effectiveness of medical librarians, found that "*patient length of stay was reduced when clinicians requested literature searches related to a patient's case*" (Perrier et al., 2014). Medical libraries demonstrate value to the health service because they provide services which save time for health professionals and provide them with reliable and relevant research so that they can make informed decisions with the people in their care. UK public libraries have the potential to offer similar services to the general public, but they are under threat; facing cuts to stock, staff and opening hours. More than 400 have been closed, handed over to volunteers, or are facing threats of closure (The Labour Party, 2012). With the current austere economic climate as it is, it would seem smart to adopt a knowledge management model, applying lean concepts and creating operating partnerships between public and medical libraries, and perhaps even school libraries, sharing expertise and resources, and developing innovative information services for the general public. It is imperative that NHS/medical libraries work together with public libraries "*to contribute to health and wellbeing*" and that policy makers, both regional and national, recognise the value that public libraries bring to community wellbeing and life-long learning (The National Library of Wales, 2012). A useful collaboration between medical and public libraries will empower people by helping them access the good quality and reliable consumer health information that they need, to make an informed choice about their care pathway.

"*Public library activity in the areas of health and well-being*" (Hicks et al., 2010) and Knowledge for healthcare (Health Education England, 2014), outline how public libraries, in England especially, can support the health information literacy agenda. Recommendations from this report include building synergies with local and national health strategies, and working to ensure that their own library strategies respond to those of the Department of Health and the Strategic Health Authorities, now replaced by Health Education England.

There is research to show that there is a demand for consumer health information literacy services and that health information literacy programmes run independently by public, academic or medical libraries (Chiarella and Keefe, 2008, Henner, 2009, Werner and Chimato, 2005), have been set up around the world to improve access to consumer health information. A programme exists in Australia, where clinicians working with a clinical librarian, invite consumers to a health library, rather than a public library, for information skills training. The project report (Harrison, 2009) makes recommendations for future, similar projects. The only other examples of collaborative initiatives are between either university and school libraries or national library and public libraries (Haynes, 2004, Oermann et al., 2005). A study by the National Library of Medicine (Wood et al., 2000) looked at how they could work with public libraries to promote consumer access to health information. The findings suggested a few items for consideration, including offering training for public libraries and emphasising partnerships with health professionals rather than medical libraries.

In Tucson, Arizona, USA, a project has been active, where five public health nurses work with six local libraries, providing health education to the general public (Robert Wood Johnson Foundation, 2013b).

In a project carried out by researchers at the University of Salford, they found that "*further collaboration and partnerships between NHS and public libraries are a potentially viable option and should be explored further*" (Brettle and Ormandy, 2008).

Outreach services already operate from several medical libraries. The University of Oxford Health Services Library operates an outreach library service, delivering library services to primary care services in Oxfordshire, and a clinical librarian service, delivering library services to the wards, at the point of need, and there are other examples of similar activities taking place around England. One possible model would be for the outreach librarian service to extend their services to public libraries, and provide regular clinics set up within public libraries, where members of the general public can meet privately with a medical librarian to discuss their health information needs.

Other options might involve a partnership between PALS (Patient Advisory and Liaison Services) and public libraries. Medical librarians can provide literature searching services to PALS or teach them how to search more effectively so that they can better help people looking for consumer health information. This might overcome software licensing issues as PALS staff are entitled to access the NHS Core Content databases (available to all NHS staff), while public librarians are not.

An extension of this research would be the support of people whose mother tongue is not English. In England, around one in thirteen people use English as an additional language, and in the past three financial years, the NHS has spent £64.4 million on translation services, with London Trusts being "*responsible for 31% of the total spend*" (Gan, 2012). Basic, generic searching and critical appraisal skills can be applied regardless of language. If these skills were taught to the general public, then they might feel confident to search for high quality health information published in the country they originate from, in the language that they are most likely to understand. This has the potential to generate significant cost savings which could be deployed elsewhere in the NHS, just by reducing translation services, while improving access to patient information for all people, not just those speaking English as a first language.

A further solution might be the development of a patient decision support system, connecting NHS Choices and the Care Services Record, accessible to patients, permitted carers, and staff in the NHS. The foundations are already laid; the possibilities endless, particularly with librarians, patients and carers being involved in the design and development process.

Students in schools and colleges have no need for public or medical libraries as most have "in-house" learning resource centres. However, this population must not be forgotten in this programme or work, as adolescents also have very specific health information needs, such as mental health, skin health, and sexual health.

2.3. Discussion

The clinical decision support systems and health information resources for health professionals, and the lack of support for health service consumers, prompted the author to investigate a solution for patients and carers so that they can make the right, evidence-based choices regarding their health care pathway.

The literature collected for this review, (key themes summarised in Figure 2 at the start of the chapter), shows that people benefit from having access to good quality health information because it enables them to make informed decisions and follow their treatment regimens more effectively and safely (Peterson et al., 2003). Patients feel empowered, compliance to the treatment programme is improved, and length of stay and admissions are sometimes reduced. This improves the patient experience and supports the NHS cost and quality agenda – "Doing more with less" (Hurst and Williams, 2012). However, people from lower socio-economic groups, who are more likely to suffer from chronic illness, and therefore need that additional information, tend to have less access to the Internet, and poorer literacy skills.

Searching for and retrieving quality health information is a major barrier to evidence-based patient choice, a phrase first expressed in 2001 (Eysenbach and Jadad, 2001). Research has shown that collaboration between the patient and the physician, where both retain their values, leads to, not only greater wellbeing for the patient, because they feel that their preferences are being taken into account, but also less stress for the physician, because he/she does not have to persuade the patient on the best approach. Where the patient has not felt included in the decision-making process, they are less likely to comply with the treatment recommendation, leading to dissatisfaction of both the physician and the patient because of a poor outcome (Lefer et al., 1962).

With the increasing demand for patients to access their own electronic health records and participate in the choices made about their treatment pathway, it is essential that they either are automatically connected to good quality consumer health information or they are able to search and identify it for themselves. However, the information products that are available for the general public are rarely interlinked, and they do not signpost to each other, so people have to navigate several different sites to find the information they need, sometimes needing to remember several different passwords. A recent report concluded that while people prefer using the Internet as a source of consumer health information, they find the different search processes difficult to navigate (Fiksdal et al., 2014). Finding good quality, reliable, consumer health information is very difficult to do, as there is so much to think about when searching the Internet, e.g. terminology, relevance, etc. It is like searching the Internet for a mortgage and picking the first one, without critically evaluating the other options.

Libraries and librarians are a core asset for this work because they already have the resources, skills, and processes in place. Medical librarians are highly skilled in performing clinical literature searches and delivering searching and critical appraisal skills training to health professionals. Public librarians have access to the target group, the general public, and their trust because they are known to them. Research has shown that people would like assistance, from their public libraries, in finding quality health information, but with all the government cut-backs, providing this support is not possible.

Health information literacy is an area where all libraries can lead on, whether medical, public or academic. Creating health information literacy support programmes and resources is a new area for medical, public, and academic libraries to work and lead on together, which would be of benefit in terms of professional development and more efficient working practices. By sharing resources and skills, libraries can operate more effectively and demonstrate greater value to their users and stakeholders. The question arises, however, whether libraries are prepared to take this lead. Historically, medical libraries have only been for doctors, and it is only in the last half century that nurses and other health disciplines have been allowed access. Many health professionals see the library as a sanctuary, where they can discuss and research cases without fear of interruption. If patients and carers are allowed access to medical libraries this would change and may not be welcomed by health professionals. There is also the aspect of patient confidentiality which needs to be adhered to. Confidential discussion spaces would need to be created, and this will have cost and safety implications. Staff, both clinical and library, may be put at risk, if, for example the patient is suffering from a serious mental health condition. It will also be a major cost-pressure for medical libraries as patients would require specialist resources, designed for their needs.

In the UK, partnership-working in the public sector is on the increase, particularly in health care (Cairns et al., 2011), and issues are arising such as library user confidentiality, copyright, and software licensing agreements. If the public librarian asks the medical librarian to search for the information, how much personal information about the requestor can the public librarian divulge? If the public librarian can do the search, there is an issue about how he/she will access the relevant information sources. Clinical databases are very expensive. The NHS has a national subscription (National Core Content), as do most academic libraries, and under the licensing agreements, they are not permitted to share access with external users, such as public libraries.

Digital exclusion also impacts on the outcome of this research. While supporting online consumer health information searchers is essential, it is also important that those who are not computer literature are given access to support. By improving access to clear, current, accurate, and understandable consumer health information, health inequalities can be reduced and patients will feel more empowered (World Health Organization, 2009).

2.4. Chapter summary

While the government is advocating the importance of involving patients in the decision-making process, and getting people online, government documents fail to refer to patient information, libraries, librarians, information services, information literacy, or searching skills. The foreword of ‘Liberating the NHS: An Information Revolution’ (Department of Health, 2010b), states: “*High quality health and care services depend on good information. The right person having the right information at the right time can make all the difference to the experience of a patient, service user or carer*.” The aim of this consultation was to give patients, service users, carers and families greater choice and control over care and treatment (N.H.S.

Confederation, 2010). However, the document focuses on individual patient data, such as laboratory test results, rather than information. To make an informed choice, patients need to be aware of the facts about their condition, the options available to them, and the potential risks and side effects, and not just their test results.

This literature review confirms that the main knowledge gap is the lack of research and resources to support evidence-based patient choice (Figure 5) and health information service provision for the general public. While papers were found on the importance of shared decision-making, access to electronic health records, and the varying quality of online health information, there was limited research on the searching behaviours of the general public.

The following eight key messages derived from this literature review show that there is a case to support evidence-based patient choice:

1. Patients respond better to treatment if they are involved in the decision-making process.
2. Patients and carers, particularly those diagnosed with chronic illness, do search online for information about managing their conditions.
3. The quality of online consumer health information varies greatly.
4. Patients and carers need information literacy skills to help them make an informed choice.
5. Librarians from all sectors have the skills and resources to improve access to quality consumer health information.
6. Patients do want to be part of the care pathway decision-making process.
7. Good patient information reduces the need for GP visits and hospital re-admission, thereby reducing the burden on the NHS.
8. Patients and carers need a solution both technical and human to help them navigate the complex web of consumer health information.

With the increasing demand for patients to access their own electronic patient records and to take control of their health, it is vital that they are aware of existing information products, and know how to use them and retrieve the information that they need. Teaching patients and carers information literacy skills so that they can find and appraise health information on the Internet will help them make effective decisions. Informed patients has led to positive treatment outcomes, improved patient experience, and cost savings for health organisations. However, to ensure that everyone is included, the solution needs to be able to adapt to different situations, and therefore needs to be a human and a technical solution. For some people, a technical solution will be appropriate, but for the people who are not online or computer literate, access to someone, a librarian preferably, with the necessary information literacy skills, would be the most useful option.

This review found that patients have better health outcomes when they have participated in the treatment choice. They understand the risks and what is required of them in terms of treatment compliance, and they feel more confident because their own views are being listened to. However, there is a lack of accessible health information support for the general public, and people often turn to Internet search engines, such as Google (Innes, 2013, Yan and Sengupta, 2013). Health professionals have a resource called NICE Evidence Search available to them; a gateway to over 1000 trusted and accredited clinical information sources. Patients and carers can access most of the site too, but the majority of the content has been written by clinicians for clinicians. A similar resource is needed for the general public, and would make it easier for them to access the existing information products that have been designed for them, which would also be good for the NHS, because then those products will be used more regularly, and will therefore be more cost-effective. Librarian involvement would extend health information service provision to those who are not computer literate.

Whether they search for themselves or get support from information professionals, facilitated access to quality consumer health information empowers patients, provides reassurance for them and their carers, and helps them make better decisions with their health care professional.

The NHS must make sure that patients and carers are equipped with the right tools and information to help them understand all their options and their outcomes, so they can tell their doctors how they would prefer to be treated (Mulley et al., 2012). It is essential that health organisations and staff learn how to communicate effectively with patients and the public (Stevenson, 2012), so that everyone understands the risks and consequences.

The author of this research has noticed that since its inception, there has been a growing interest in online consumer health information, and this has led to an increase in research in this area, and related topics, such as mHealth, eHealth, telemedicine, and assistive technologies, and the number of health informatics journals published.

The next chapter will describe the methodology which will be applied to develop a framework and model to support evidence-based patient choice.

Chapter 3 – Research methodology, case studies, survey analyses

John F. Bookout, Jr.

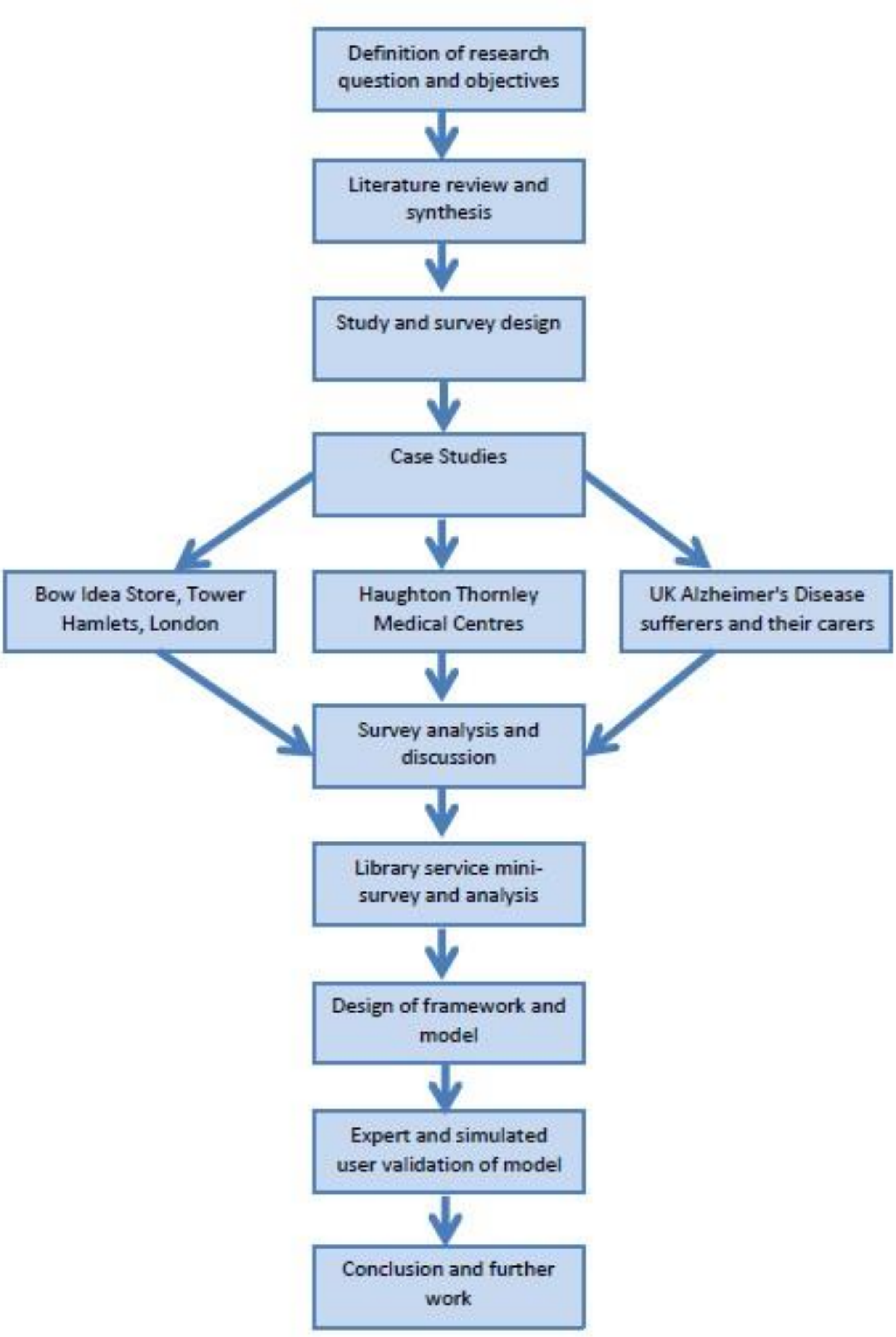
3.1. Introduction

This chapter describes the research methodology, introduces the case studies that provide the responses to the survey, describing the populations and why they were chosen, before concluding with the survey analyses. The author complied with local ethical procedures, by obtaining low risk research ethics approval according to the guidelines of Coventry University. The ethics approval certificate has been supplied in Appendix 2.

The strategy of inquiry selected is an evidence-based, mixed-methods study, comprising of a literature review substantiated with quantitative and qualitative data obtained from surveys, interviews, and case studies. The reason for this mixed method approach was that while it was necessary to find out what people need in terms of information provision, it is also important to understand the reasons why, and this does not always come across in just surveys alone (Creswell, 2008). The literature review was carried out, initially to provide evidence that the research is justified, and then to ensure that this is an innovation, suitable for PhD research.

Figure 6 is a visual depiction of the process followed.

Figure 6: Diagram depicting research process



There are two outputs to this research, and the first output (survey results and literature review) will determine how the second output (model) will be developed. The question this research will answer is “***What information support does the general public need to learn more about their clinical conditions and how to manage them?***”

The evidence in the literature review in Chapter 2 demonstrated that people do search for health information online, healthy people more so than people with chronic diseases (Fox and Purcell, 2010), but that, due to the variability in quality of online consumer health information, there is a need for support in identifying good quality content. As described in 2.2.5.4. the Department of Health, and related organisations, have developed several resources and tools to help people find and use good quality health information, but the existence of these is not always successfully communicated to their target audience. The purpose of this chapter is to confirm these findings, substantiating the case for a new intervention to improve access to good quality health information for the general public. If the survey results demonstrate that there is a significant lack of interest in searching for health information, then there will be no need for output two (the final model), and there will need to be a review of the research or it will have to be abandoned. However, as discussed in Chapter 2, the literature does show that there is an increasing interest in access to consumer health information.

3.2. Collaborating partners

The author contacted several organisations to gauge their interest in collaborating on this research, including the Chartered Institute for Library and Information Professionals (CILIP) and Race Online 2012, before establishing partnerships with three communities, two chosen for their geographical setting, and one for their condition-focused setting:

1. Bow Idea Store, London Borough of Tower Hamlets, an innovative library service, specialising in the support of health information provision to the general public.
2. Haughton Thornley Medical Centres, a GP practice leading in their support of patients accessing their electronic records.
3. UK Alzheimer’s disease (UKAD) sufferers and their carers.

The three different settings were chosen to inform the development of a flexible solution, which will work with NHS systems, such as electronic health records, and existing information products, such as decision aids, and be useful to the population as a whole, and not just people who are techno-literate.

3.3. Study design

There is a wide variety of research types, including quantitative and qualitative research (Anderson and Poole, 1994, Denzin, 1998). Quantitative research involves experimentation and is usually associated with science-based disciplines as findings are expressed in numerical form. Qualitative research presents findings expressed as words, rather than numbers, and is used to explore and understand people's experiences and needs. Therefore, although "library and information studies" is classified as a science-based discipline, and therefore should, by these definitions, apply quantitative methods, the planned outcome of this work requires this research to follow qualitative methodology. This is because it is an applied research degree and must result in a model that can be applied in practice, which will be based on the attitudes and needs of the general public.

As mentioned earlier, there are two outputs to this research. The first output involves one survey being distributed to three different populations. Its purpose is to gather quantitative and qualitative data, e.g. demographic statistics and also opinion about existing resources and information retrieval techniques. The aim of the survey is to identify how adult members of the general public access online health information. It was decided to survey the general public, rather than patients alone, firstly out of respect for those who are suffering from a condition and might not want to be bothered with a survey, and secondly to reduce the incidence of bias. By surveying everyone, people have the choice to respond or not, and the author will get the opinions of both healthy and poorly people. Furthermore, if only patients are surveyed, then this would exclude carers and family members from the survey, and their opinions are equally important to this research, particularly if they have to search on behalf of someone else who is incapacitated.

3.4. Case studies

Questionnaire surveys were carried out in the London Borough of Tower Hamlets (LBTH), via the Bow Idea Store, the Haughton Thornley Medical Centres (HTMC), and UK Alzheimer's disease (UKAD) sufferers and their carers.

3.4.1. Case study 1: Bow Idea Store, London Borough of Tower Hamlets

The population of London Borough of Tower Hamlets is 241,747 and continues to grow, with a projected population increase of 33% by 2020 (London Councils, 2012, Uddin, 2010). It is diverse, both in terms of socioeconomics and ethnic group membership. More than a third are Bengali (Bangladeshi ethnicity) and only 50% are white ethnicity, which includes Irish and Eastern European (Williams et al., 2011). Other ethnic groups include black Caribbean, black African, Indian, Pakistani, Chinese, and Vietnamese (Greater London Authority, 2009). The number of mother tongues (English as a second language) is one hundred (Uddin, 2010). The majority of the population is aged between 20 and 39 years, with only a small proportion of people over the age of 65 living in the Borough (Madelin, 2011).

Although vibrant in its culture, "*deprivation is widespread in Tower Hamlets*" (Spence, 2011) and it is often described as being one of the most deprived boroughs in the country. The Indices referred to are, deprivation, with regards to levels of income, employment, health and disability, education, skills and training, housing and services, living environment, and incidence of crime. "*Unemployment and crime rates are twice the national average and illegal drug use is high*" in this Borough (Noble et al., 2012). The deprivation experienced in this Borough means that the "*health of people in Tower Hamlets is generally worse than the England average*" (Network of Public Health Observatories, 2011). LBTH has a high prevalence of non-communicable disease (diabetes, cardiovascular disease, chronic respiratory disease and cancers) (Noble et al. 2012) and has the highest or second highest mortality in London for cardiovascular diseases, cancer, and chronic obstructive pulmonary disease (COPD) (Barham, 2011). Obesity, often resulting in the aforementioned chronic conditions, has been identified as one of the top public health priorities in Tower Hamlets (Williams et al., 2011). Electronic summary care records (SCR) were introduced throughout LBTH in 2010, and yet, the socioeconomic factors described above, would, according to the research described in Chapter

2, indicate poor health information literacy, meaning that people who are ill in this Borough may not have the skills to make an informed decision about their treatment choice.

Consumer health information service provision in LBTH

Britain's public library services are in crisis (Davies, 2008), with funding being cut, resulting in service reduction and loss of qualified staff. As with all public sector services, libraries need to take action and adapt to suit the changing needs of their users, or risk facing cutbacks. The Idea Stores are an innovation, which have been developed to overcome these threats. Prior to their existence, Tower Hamlets had 7 full-time libraries, 5 part-time libraries, a mobile library, an outreach library service, 6 adult education centres, 40 smaller outreach sites, and Tower Hamlets College on 6 main sites with dozens of smaller outreach sites. Following an extensive library consultation exercise, where people said that they wanted a quality library service where they could combine a visit to the library with a visit to the shops, and where there would be education support as well as information, the concept of the Idea Store was developed. There are now 10 Idea Stores around Tower Hamlets, all located near to shopping centres, plus a mobile unit and a home delivery service, and all attracting large numbers of users. They provide information, learning, and a safe place to meet in the community. As well as the traditional library service, the Idea Stores offer a wide range of adult education classes, along with career support, training, meeting areas, cafes, and arts and leisure pursuits. These changes have led to a significant increase in their user figures (London Borough of Tower Hamlets, 2009). In 2002, the Idea Stores, out of a general population of 197,100, had 29,867 active members, i.e. people who have a membership card and have borrowed something in the previous year. In 2010, out of a population of 219,400, they had 43,352 active members, an increase of 45%, since 2002. The number of visitors to the Idea Stores, including people who visit for training or for Internet use, has increased by 233% from 621,556 in 2001-02 to 2,071,933 in 2009-10 (Idea Stores, 2012). Visitors cover all age ranges, although younger users do outweigh older ones with the 25-34 age bracket providing the greatest membership. The population for Tower Hamlets broken down by age, shows that the number of 25-34 year olds (13%) living in Tower Hamlets in 2011 is significantly higher than for people aged 55+ (3%), (Tower Hamlets Council, 2011) so it may be that the age group of members and visitors to the Idea Store reflects the age range of the general population in Tower Hamlets.

Each Idea Store has a different focus, to reflect the interests of the population, and the one for the Bow Idea Store is health. In 2010, the Bow Idea Store had a Health Information Point, where people could check their weight and blood pressure and keep a record of these for future use. It also had two members of staff delivering consumer health information sessions to the general public, which highlighted relevant information sources, suitable for retrieving good quality consumer health information. They have also developed a Health Gateway, which they would demonstrate during these sessions, and supporting leaflets, which they distributed in the Idea Stores. The trainers taught library users how to identify good quality sites, and they would go through a checklist of questions that people should address before using a web-site. Between January and June 2011, the Bow Idea Store ran 66 health information sessions. However, as a result of budget cuts, these sessions are no longer being run, despite the obvious demand for this service.

Other potential local and national information service providers in LBTH

The Bow Idea Store was the only organisation in LBTH that provided health information support to its patrons. There are other services available in LBTH that have the skills and resources available to help the general public find good quality health information, but they use them for other purposes and/or audiences:

- Queen Mary Hospital Medical Library - they allow only one open access visit per year, and people are then only allowed to read and photocopy material.
- Social Action for Health (http://www.safh.org.uk) - on their web-site it says that they give information "*in a form that people can hear and take in*", but they do not go into greater detail about the information that they provide, and to whom.
- NHS London leaflet distribution service - provides mainly NHS leaflets to surgeries and clinics, but not directly to the general public.
- LBTH health trainers' programme – supports health improvement through focused motivational support, but do not formally search for information on behalf of their users.
- Patient Advisory and Liaison Services (PALS) - these exist throughout England, to help patients, their relatives, carers, and friends, find answers to their questions and resolve their concerns as quickly as possible. Their remit says that they can provide accurate information about their Trust's services and other health related issues, using reliable sources. However, PALS health information provision does vary from Trust to Trust. The PALS in Tower Hamlets does not provide health information. When

approached via email, they said that they refer people to relevant national support organisations, such as MIND, for mental health issues. The national PALS web-site (http://www.pals.nhs.uk) does refer people to NHS Choices, a site which contains information on common conditions, but not for rarer conditions.

Limitations to carrying out the research in London Borough of Tower Hamlets

One of the barriers to carrying out the research in LBTH, is that in the NHS, there is a lack of incentive for people from other countries to learn English. The NHS patient engagement team support the production of information in community languages (Dublin, 2008). Another project, the "Health Guides Project" in East London trains local people to act as health guides within their own community in their own language. These initiatives, while seemingly supportive to people with English as their second language, may actually have a negative impact on their health care as they will not have access to the best available, localised, information on their conditions. The report by 2020HEALTH recommends that materials are written in easy-read English, while collating a central repository of information created in other languages (Gan, 2012). This would seem like a sensible recommendation and beneficial to the whole community rather than minority groups.

Case study conclusions

People living in LBTH are deemed to be deprived, both in terms of health and education, and are therefore, as sections 2.2.5.1. and 2.2.5.8. highlight, more likely to have poor information literacy competences. Furthermore, much of the population has English as a second language, providing another barrier to good quality health information. Even with access to the Internet, which is freely provided throughout LBTH via the Idea Stores, they still require skills to access and manage the information. The successful uptake of the programme of health information training sessions delivered by Bow Idea Store demonstrates the demand, which is no longer being met. This goes towards building the case for this research, showing that people do want to look for health information, and do need support to do so. Realistically, in these times of austerity, funding cuts do need to be made, but this is why it is so important for this research to identify a solution that will meet the needs of the people, while adapting to the current economic circumstances, and doing more with less.

3.4.2. Case study 2: Haughton Thornley Medical Centres

HTMC comprises two GP surgeries, Haughton Vale Surgery (Denton) and Thornley House Medical Surgery (Hyde), both located in the Metropolitan Borough of Tameside, which is just seven miles outside Manchester. HTMC provides primary care services to 11,696 people (University of Durham, 2014), of whom 32% (3,776) have access to their electronic health records. Demographics for Denton and Hyde were not obtainable, but the demographics for Tameside, where they are both located are available. In 2011, Tameside's population was 219,300, and therefore, in comparison with LBTH, it is slightly smaller. However, unlike LBTH, the population is predominantly White British (201,468 people in 2001) and just over 11,500 people come from minority ethnic groups (Tameside Metropolitan Borough, 2004). Therefore, the language differences in Tameside are less likely to have as great an effect on health service access as they might in LBTH.

The reason for including HTMC, in particular, was because the author wanted to have a picture of the information needs of people who have access to their electronic health records, and this is something that HTMC are in a position to provide, as they are leading in this area in the Borough.

HTMC encourages all their patients to access their electronic health records and discuss them during their consultations so that they can share in the decision-making process. HTMC has worked hard to regain the trust of its patients as the practice was formerly run by Dr Harold Shipman, the British doctor found guilty of murdering 15 of his patients (Manchester Evening News, 2007). By encouraging patients to access their own health records, HTMC is giving them control over their own treatment regimens and making sure that fewer, and preferably no mistakes are made.

This is a very innovative example of patient empowerment, which is being shared across England. HTMC have created an online portal (http://www.htmc.co.uk/pages/pv.asp?p=htmc0522), providing general information on their patient services alongside a comprehensive list of quality consumer health information sources. However, it is a long list, with no guidance on which is better than the other, and how to use the information that they find.

Case study conclusions

HTMC have been very proactive in getting their patients to access their electronic health records and take control of their care management. They are also trying to support informed decision-making by providing access to good quality information sources. However, without knowing how to use these resources, or understanding which is most appropriate, the portal will only be useful to people who are familiar with the resources. Therefore, an intermediary is required to help people navigate the portal and use it to best effect. This research aims to provide that intermediary, and bridge the gap between electronic health records and access to quality health information.

3.4.3. Case study 3: UK Alzheimer's disease (UKAD) sufferers and their carers

Symptoms of dementia include loss of memory, mood instability, and communication problems (N.H.S. Choices, 2012). An estimated 750,000 people in the UK suffer from dementia (Crisp, 2011), and this figure has increased by 62% over the past seven years (Prescribing and Primary Care Team, 2014). The cost to the NHS is £26.3 billion a year (Alzheimer's Society, 2014). Alzheimer's disease is *"the most common cause of dementia"* (N.H.S. Choices, 2012), and was first presented in 1906 by a German doctor called Alois Alzheimer (Ansari et al., 2006). It is a progressive illness, which can only get worse. Unlike other chronic conditions, it is often carers, family, and friends who will need good quality health information, and not just the patients (Alzheimer's Society, 2013).

In London, The Alzheimer's Show was due to take place in July 2013, and as dementia is also a key target of the Department of Health, it was agreed that this would be the condition of focus. Initially, the plan was to attend the Alzheimer's Show and distribute questionnaires. However, on arrival at the event, it became clear that this was not an appropriate course of action. There were several presentations describing distressing scenarios of the battle that patients and carers face to get sufficient support from health and social care. It was very useful to get an insight into the issues that these people are facing, and it demonstrated that more support, including information support is vital. A revised approach was taken, with attendance at the Alzheimer's Show used to identify networks that might be willing to distribute the survey to their members.

Several organisations were identified and contacted following the show:

- Dementia UK.
- Scottish Dementia Clinical Research Network.
- Frontotemporal Dementia Support Group.
- Yecco – social network for the elderly.
- Alzheimer's Society.
- Dementia Friends.
- Dementia Cafés in West Midlands – Accord Group.

Case study conclusions

The inclusion of this population demonstrated the importance of developing a solution, not just for patients, but for their carers too, who may not be formally trained, but would need to understand the implications of treatment options, and be prepared to take part in the decision-making process. The carers, may be elderly, looking after spouses, or younger, children looking after a parent or parents and needing information support to help them get the best care. Section 2.2.5.1. describes in more detail the significant role of informal carers, and how important it is to support them.

3.5. Survey design

The survey questionnaire was designed for people with and without illness, the latter referring to informal carers such as friends, children, spouses, and parents. It aimed to find out the following:

- If people would like to be involved with decisions about their treatment;
- If they look for health information;
- For whom they search, e.g. themselves, friends, children, etc.;
- Why they search;

- Where they search;
- What they want to find out;
- Who the publisher of the information was;
- How the information was used;
- How they felt emotionally if they didn't find any information;
- Who they thought should provide health information services;
- What services they would like to receive to help them find information;
- If they have heard of electronic health records, and if they have accessed their own, and how;
- If they have heard of information products, such as HealthSpace, Information Prescriptions, the Information Standard, NHS Choices, or NHS Direct and whether they have ever used any of them;
- Whether they have a long-term condition or not – the purpose of this question was to identify whether the person was a patient or not. In hindsight, it would have been useful to include a question identifying carer status, e.g. whether any respondents were full or part-time carers.

Some demographic information, such as age, ethnic background, and employment status was collected. The different ethnic backgrounds listed in the survey are mapped to the headings used by Tower Hamlets in their data collection activities for consistency. An article (Mathur et al., 2011), about prescribing in general practice for people with coronary heart disease used the ethnic background categories outlined in Social Trends (Office for National Statistics, 2010). A comparison was made between the two sets of groupings, and it was found that there were some minor differences, but nothing that would affect the research.

The final questionnaire design can be viewed in Appendix 3. It was tested on Idea Store staff, health care professionals, librarians, and members of the general public, to make sure that it would retrieve the information required. It was then piloted via Facebook and family members.

A minor addition was made to the final version of the survey, for the Alzheimer's disease population, creating a difference between that and the first two surveys. At the start of this research, it had been hoped that a technical solution could be avoided because there are several purpose-built, online health information sources already available. However, the literature review and the survey responses from the first two surveys, described further on in this chapter, demonstrated that patients and carers would like to find health information on the Internet, but they were not aware of existing resources. The author concluded that, to be most useful, the final model would have to be a combination of a web-site and librarian support. Therefore, in the final survey to AD patients and carers, to confirm that this was the case, there was an additional choice to the question "What services should be provided to help you find good quality health information?" which was "*One web-site connecting all the best quality information sources*."

Schools, and colleges were not included at this stage of the research; people under the age of 18 years old were not specifically invited to participate in the survey, but as it was open to all should they like to participate, their views would not be excluded. The searching behaviour of young people is of great importance to this programme, and it is suggested in Chapter 6 that future research on this topic be carried out.

3.6. Survey progress

The survey was due to run for three months, but after 14 days only 6 responses had been received. There followed major efforts by the Bow Idea Store and the author to promote the survey, (examples of promotional materials available in Appendix 4). A press release was sent to the local newspapers, - The Wharf, East London Advertiser, and East End Life. Race Online 2012 was approached for assistance as there are clear synergies between the aims of their work – to get 10,000 people online – and this research. However, they were only interested in the final output. The author also wrote to each of the 39 GP practices in Tower Hamlets to request support in promoting the survey.

After 45 days, the number of survey responses had risen to 9. The author made contact with a GP in Cheshire, whom she had met at the "Internet-Informed Patient Symposium" at University of Cambridge in March 2011 (Cambridge University, 2011). Dr Amir Hannan's practice, Haughton Thornley Medical Centres, has been very proactive in encouraging his patients to access their electronic health records and seeing the benefits of this research, he agreed to distribute the survey via his networks, so that a geographical comparison could be made between Cheshire and London.

In September 2011 a risk to the future of this research emerged, as it was announced that the National Programme for IT, which was leading the Summary Care Records programme, would be dissolved. In December 2011, however, the risk was diminished as the government pledged that everybody in England would still have online access to their GP records by the end of this parliament in 2015. This is relevant because patients and carers are being given access to their Summary Care Records so that they can be more active in the decision-making process. However, as the evidence-based practice (Figure 4) and the evidence-based patient choice (Figure 5) diagrams show, patients do not just need access to their individual data, but also reliable and accurate information to make a fully-informed decision. Therefore, patients will still need information support to help them find this information if they do not have the skills to do so themselves.

The results from the surveys carried out in geographical settings remained poor, and it was felt that a new approach was required. Therefore, the survey was made available to members of the general public who either suffered from Alzheimer's disease or cared for someone who did.

3.7. Analysis of survey results

As observed in Chapter 2, the published research does demonstrate a need for support in the areas of information-seeking and appraisal by the general public, and the final survey results confirm this, as will now be demonstrated. Appendix 5 contains the statistical breakdown of all the final results, while individual survey results for each population setting are available in Appendix 6.

It is unusual for three separate surveys to be carried out, but it was deemed necessary because individually, despite the results of the literature review, they would not have provided the case to continue with this research. The author noticed that following the first two surveys, although only 43 responses were received, there were clear similarities in the responses despite geographical location, which demonstrated that regardless of where people are located, there is still a desire to participate in treatment decision-making, and that information support would be valued. However, these results were still insufficient to justify the development of a model to support the perceived information needs of patients and carers, based on the findings of the literature review. Therefore the author together with her original supervisory team decided to carry out the final survey among a chronic condition-based population, and chose Alzheimer's disease for four reasons:

1. Unlike many other conditions, where people can manage on their own, people with AD often have carers, and as the final output would be designed for patients and carers, this is a relevant audience to seek responses from.
2. Dementia and its related condition, Alzheimer's disease, is on the increase (Prescribing and Primary Care Team, 2014).
3. Dementia is high on the government agenda and therefore this research may inform future government initiatives.
4. Anyone over the age of 65 years old is at risk of dementia, (with Alzheimer's disease being the most common type of dementia diagnosed), so there is no pre-condition that can pinpoint who is at risk.

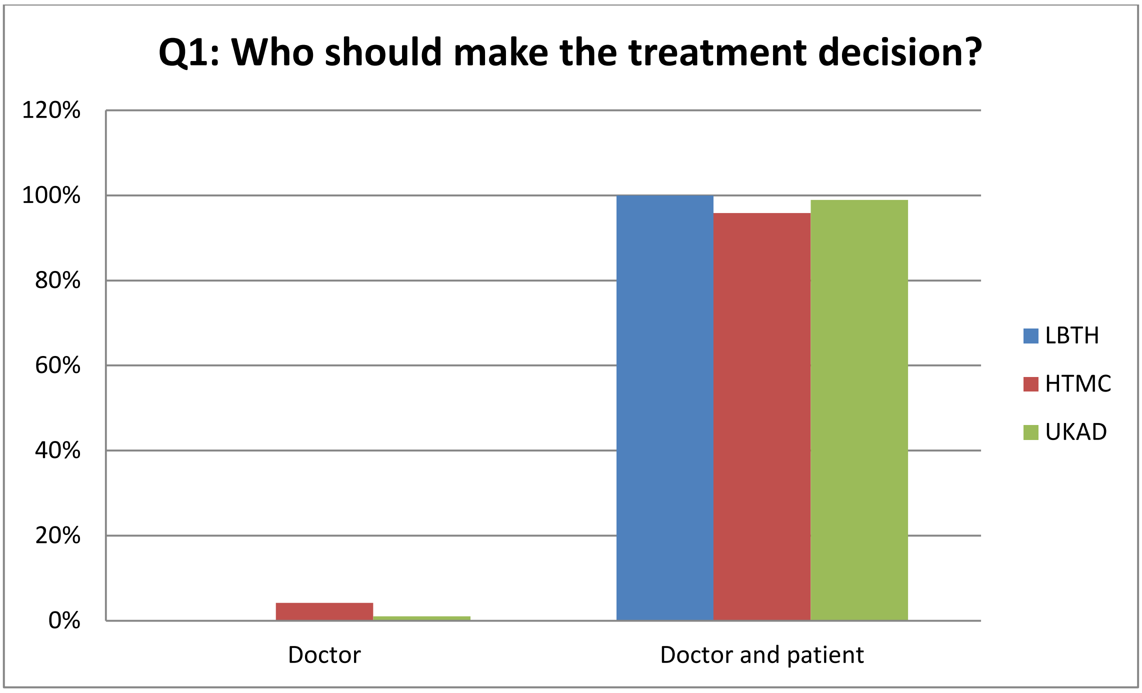
An additional 96 responses were received from this group, making a combined total of 139 people who completed the survey. This is still a very low figure, when one considers that the Alzheimer's population in England is 850,000 (Alzheimer's Society, 2015), and the population of the UK is 64.1 million (Office for National Statistics, 2014). Regardless, the similarities between the responses of the three different populations, described more explicitly in the next section, do suggest that they can be used as a basis for further investigation, possibly with a shorter questionnaire, based on the key questions identified in section 3.7.1.

Two statistical tests can be applied to assess whether the data gathered from the three surveys are similar and, if so, can be treated as a single sample. The chi-squared test and Fisher's exact test examine the relationship between two categorised variables. However, due to the low number of results, the chi-squared test is not appropriate. Therefore, significance was inferred using the Fisher's exact test (GraphPad Software, 2010), which has been applied to the results of the survey questions to justify the combining of the surveys. The full results of the Fisher's exact test are available in Appendix 7. Fisher's exact test could not be performed on four of the questions because N was greater than 90. Where the test was successfully carried out, the probability ranges were between p=<0.001 and p=1.00, which means that the results are not significant, and therefore can be combined, as there are no differences which might confound the final analysis. Further analysis to confirm that the three populations are comparable was carried out on six of the key questions, and the results of that analysis is described in the next section.

3.7.1. Key question analysis

Most of the questions in the survey were used to understand the experiences of the general public when looking for consumer health information, and these are analysed further in section 3.7.2. But there were 6 key questions, which were included to identify what people want in terms of involvement in the decision-making process, and information services and support. These questions are listed below together with graphs to show how, despite the differences in the three populations, - London Borough of Tower Hamlets (LBTH), Haughton Thornley Medical Centres (HTMC), and UK Alzheimer's disease (UKAD), - the responses correlate with each other:

Chart 1: Who should make the treatment decision?



Despite the differences in population, Chart 1 confirms that the majority of respondents believe that treatment decisions should be made together with the doctor. This is relevant because much is being invested internationally to support shared decision-making, as the benefits are significant to patients, carers, and the health economy.

Chart 2: Who do they get health information from?

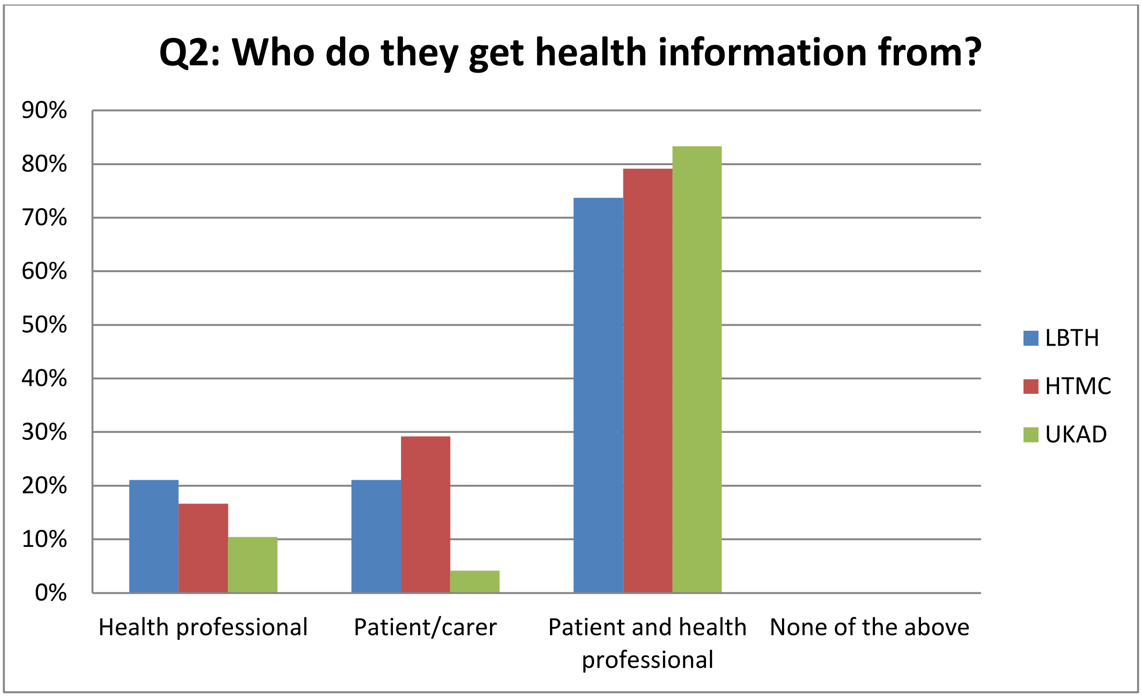
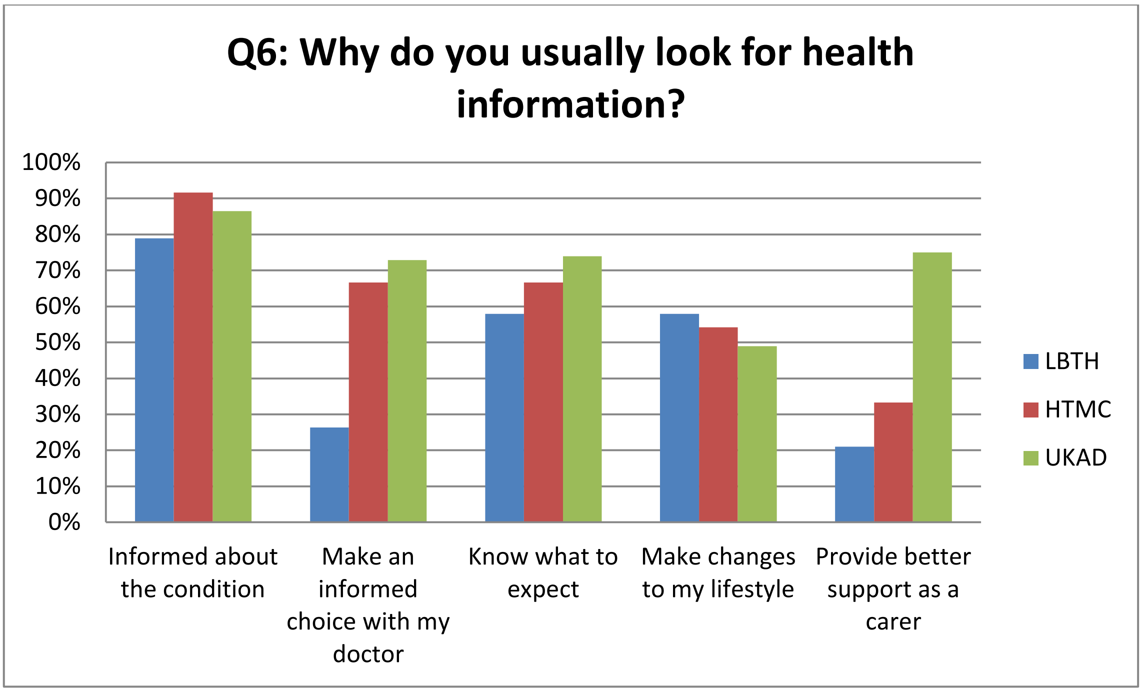


Chart 2 shows that all the populations agree that while some get the information from their health professional, they also search for it themselves, which shows that there is the potential need for an independent, user-friendly information support intervention, and this is further confirmed in Chart 5.

Chart 3: Why do you usually look for health information?



Again, in Chart 3, most of the options demonstrate a correlation between the 3 populations. Option 2 - "*make an informed choice with my doctor*" - has the most significant difference, with the respondents from LBTH being less likely to use the information to make an informed choice with the doctor. Chart 1 showed that most of the respondents do want to make decisions with their health professional, but perhaps in LBTH, they rely on the doctor to present the evidence to them. Further investigation is required to assess the information needs of the LBTH population. Again, with the last option, there is a significant difference between the populations. This is because the UKAD population had more responses from carers, because of the nature of the condition.

Chart 4: What do you want to find out about?

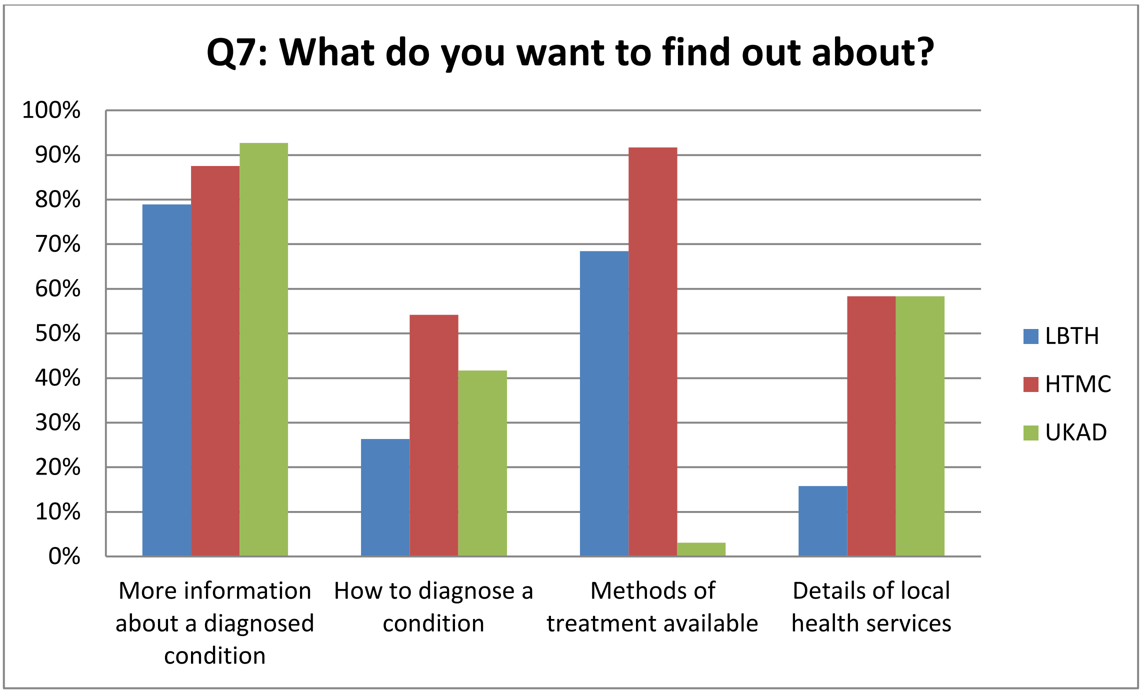


Chart 4 is important because it informs the design of the final model, as it shows the types of information that people will be looking for. It appears that people do use online health information to self-diagnose, which is an important observation, although the focus of this research is on the effective management of a condition rather than its diagnosis. It is interesting to see that the respondents from HTMC, where the patients are actively-encouraged to take control of their health care, are more likely to use information for self-diagnosis purposes. The UKAD population are less likely to look for treatment methods available, and this may be because treatment for AD is clearly defined and there are not many options available.

Chart 5: Do you usually find the information you need?

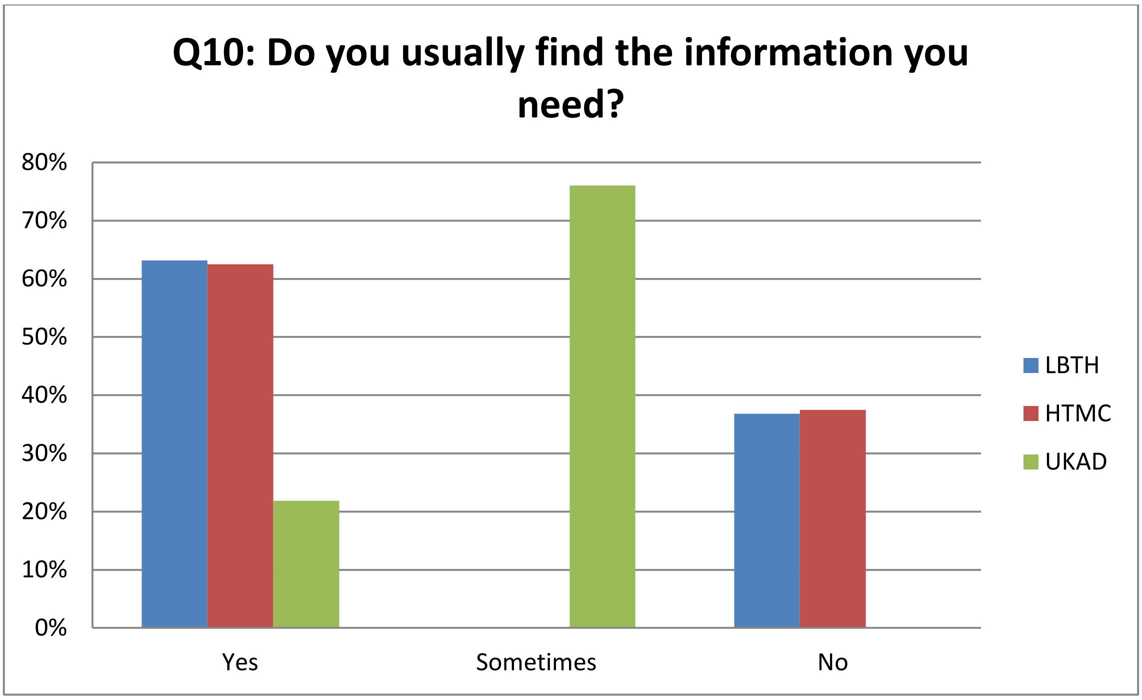


Chart 5 shows that some people find what they are looking for and some do not. This is relevant because it shows that there may be a lack of information skills and/or knowledge about information sources, which means that information support is needed by the general public.

Chart 6: What services should be provided to help you find good quality health information?

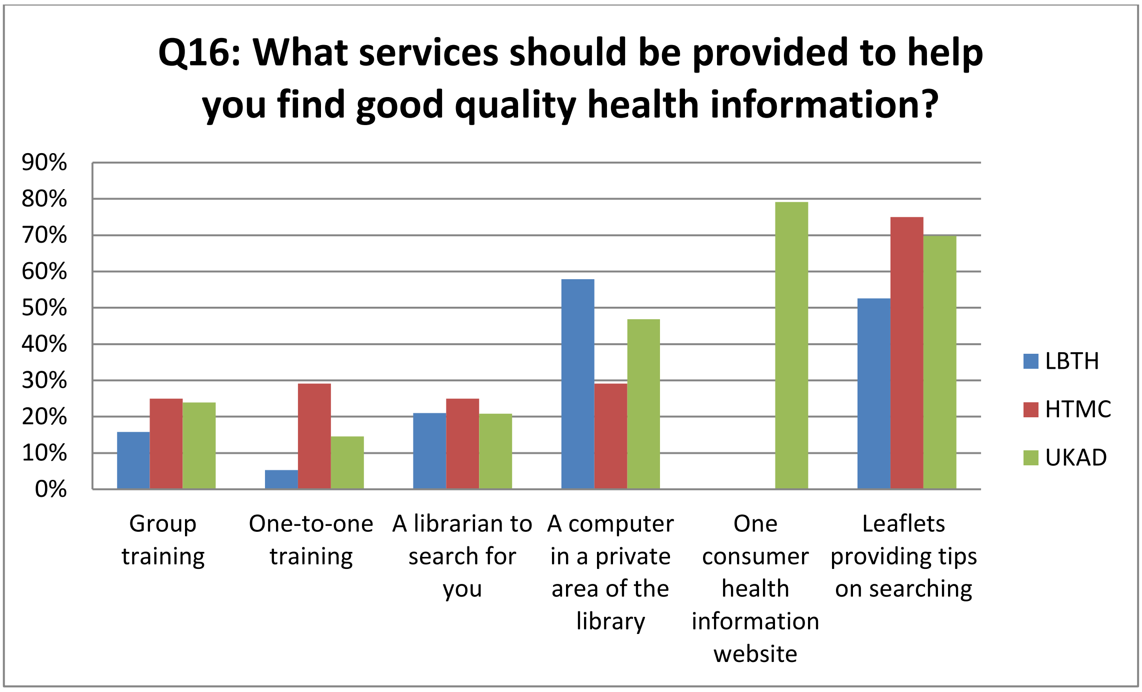


Chart 6 shows the type of support that people would like to receive. There are some differences between the populations. For example, one-to-one training was a more popular option in the HTMC population, whereas a computer in a private area of the library linking to good quality consumer health web-sites was preferred in the LBTH and UKAD populations. There is discrepancy with the option for one consumer health information web-site because at the start of this research, the author was intending to provide a human solution rather than a technical one. The original survey was designed to identify whether people wanted librarian support rather than a web-site, but because the Bow Idea Store information service was cut, the author realised that even though a physical library service would be more useful, it would probably not be sustainable. This is why the survey was amended to reflect an alternative option. It might be said that the author has influenced the respondents by adding this element. However, the UKAD community had not seen previous versions of the survey, and therefore would not see this as a new option.

This chart is very relevant to the research outcome because it demonstrates that people have different information support needs, and therefore, the solution must be flexible to suit these different needs.

Despite the population differences and the number of responses received, these charts show that people do want:

- to participate in the decision-making process;
- to make informed decisions;
- information literacy support, whether it is one-to-one or group training, instructional leaflets, or for someone to do the searching for them.

3.7.2. Full survey analysis

As pointed out earlier, almost all of the respondents (99%) want to be involved in the decision-making process, rather than letting the doctor make it for them, with one exception, who wanted the doctor to make the treatment choice. This corroborates the research in the literature (Wilson et al., 2010, Coulter et al., 2008, Edwards et al., 2004, Robert Wood Johnson Foundation, 2013a), that people do want to be involved in the decisions made about their treatments. Most people (81%) want to get information from their health professional and to find it for themselves, rather than one or the other. However, one of the respondents pointed out that as we have different educational levels, with some more educated than others, it is "*important that we have SOME input, but it must be optional and not mandatory and the doctor needs to have the final say*."

More than half the respondents looked for information when they needed to, which means they have either been diagnosed with a condition, or they are caring for someone else who has been positively diagnosed. Regardless, it is not a time when people are going to want to spend quality time searching for information. Therefore, support in finding good quality information is required, but is not available, as the additional surveys, (described further on), to public and medical libraries show. More than 70% search when either they or someone close to them is unwell.

64% of searchers are patients and 64% are informal carers (family member). This means that many people are both patients and carers, and so really do not have the time to search for quality health information. It also means that the solution proposed within this research must be designed to support patients and carers.

People, or people caring for people with AD, look for health information for a number of reasons:

- to become more informed;
- to make an informed choice;
- to know what to expect;
- to make lifestyle changes;
- to provide better support as a carer.

One person said that they look for health information "*to find out about alternative treatments.*" There were several descriptions of what they might want to find out about, including:

- to find out more about the condition diagnosed;
- how to diagnose a condition;
- treatment options, and local health services.

The results showed that 86% of people surveyed wanted to find out more about the condition and treatment options available to them, which demonstrates that people do have health information needs to fulfil. Other respondents wanted to find out more about side effects, clinical trials, details of support groups, occupational health issues, patient rights and equality of access, and what to expect in the future.

When asked from where they get the information that they need, more than 90% of people said the Internet, with the second highest source being the GP surgery, which is problematic because time is limited during consultations, so they may not be able to get all the information that they need.

90% of respondents felt that GP surgeries should provide good quality information, followed by pharmacies. Ideally, if there was a national resource which all these organisations could confidently refer patients and carers to, this would improve knowledge levels, without taking up valuable consultation times. Only 58% said they would like public libraries to provide access, which is a relatively low number, and one has to question why public libraries are not seen to be a source of health information.

68% said they wanted leaflets giving guidance on searching the Internet effectively. Medical librarians create these already and it is possible they could be adapted, in collaboration with public librarians, to suit the general public, and made available online, especially via the proposed model, but also in GP surgeries, hospitals, pharmacies, libraries, schools, churches, etc. Building on existing, successful innovation is key to this research as the purpose is not to create new resources, but to develop existing resources so that they:

- improve service delivery;
- support patients and carers in the way they need;
- reduce wastage, and
- increase consistency, sustainability, and usage.

A quarter of people always found the information that they needed, while the other three quarters only sometimes did. This implies that people who only sometimes find what they need may not know the correct sources to use, or how to use them, and therefore, additional information support may be beneficial to them.

The most popular publishers of the information that they did find were the NHS (74%), followed closely by support groups (70%). However, with regards to support groups, even if people share the same condition, they are less likely to find information by people with the same personal circumstances, so caution is required. 9% used information that they obtained from drug companies, but it is not clear if this includes patient information leaflets or whether they are using information from drug companies to make an informed choice.

Only a third used information published in a research journal, but this might be because of the lack of access to full-text research. One respondent said "*I think it would be very helpful for ordinary members of the public to be able to access articles in medical journals – impossible at present without taking out expensive subscriptions. Knowledge that has been publicly funded should be freely available*." This is a very valid point, particularly as the NHS does subscribe to a core collection of electronic journals for NHS staff, at great cost to the taxpayer. Furthermore, much of the original research has been funded by the general public, via taxes, and yet they are not permitted to access it. Fortunately, more and more researchers are starting to make their research freely accessible to all via open access journals, such as BMJ Open, (http://bmjopen.bmj.com/) and Biomed Central (http://www.biomedcentral.com/), and the proposed model should make it clear when articles are freely available.

Most people used the information that they found for reassurance purposes. Stress can expedite symptoms, so it is to everyone's advantage to facilitate the information-seeking process. Two thirds of respondents used it to discuss the options with their doctor, and some (39%) shared it with their families. In addition, people used the information to:

- *"share with other members of a support group for partners of people with dementia;*
- *share with work;*
- *be aware of the limitations of and recommendations for others;*
- *be better informed;*
- *inform friends, to accumulate knowledge and as a starting point for hypotheses;*
- *know what questions to ask and what to expect;*
- *recognise symptoms and progression of disease;*
- *inform myself and others."*

People expressed a range of feelings to explain how they felt when they could not find the information that they wanted. Most of the respondents felt frustrated, while others felt frightened, helpless or confused, with very few feeling fine. Alternative suggestions to the specified responses included disempowered, more informed, but also depressed, and angry. All of these emotions are negative and not beneficial to the wellbeing of patients and carers, or service providers, because they can affect the overall health outcome, increasing the length of time they require treatment.

When they were unable to find health information, many people went back to their doctor for more guidance. More information is needed as to whether their doctors had enough time to speak to patients and carers during consultations, which are time-limited. Some of the respondents, sought information elsewhere, including:

- *"speaking to the pharmacist or the nurse for additional information;*
- *using other sources by continuing to search;*
- *asking on chat forums, Twitter or Facebook for anyone with similar experience;*
- *discussing with professional carers;*
- *speaking to dementia helplines."*

However, 8% of respondents did nothing, meaning that they still had their knowledge gap, and would go into their treatment plan, possibly not understanding, and not fully aware of the implications. As pointed out in the literature review, involvement in the treatment decision-making process, improves compliance with the treatment regime, and in the long-term, better outcomes (Joosten et al., 2008). However, if patients do not have access to all the information, then they cannot be expected to make an informed decision, and furthermore, if they do not understand all the instructions about their health care, then it may be more difficult for them to adhere to the treatment programme.

When asked how services should be provided to help people find health information, 79% of the AD population wanted to have one web-site linking all the existing health information resources, in a logical way. Only the AD population were asked this question, because the initial solution for this research was supposed to be human, but with the literature search and the earlier survey results, it became clear that a human and a technical solution would be most appropriate. 45% of all respondents wanted a private area with a computer which only provides access to good quality health information. This would be a good idea, particularly as librarian support would be on hand, but logistically, in terms of available space and resource, it is unlikely to be possible, when a strong case would be needed for each library. Patient information kiosks have already been invented and placed in hospital settings, so perhaps this would be an appropriate solution, although there is not much research about their usage, successful or not, and access is sporadic. The popularity of this option does imply that trust and privacy are issues for patients and carers, and that they might not like to share their problems with other members of the public in a group training session, or with a librarian. In fact, the responses to the next question show that 37.5% wouldn’t want to discuss their condition in a public environment, with 50% preferring to get the information from a medically-trained person. More than half of respondents (67%) did say that they would like to have leaflets providing tips on searching. This is something that would be relatively easy to implement, as most medical libraries will have created a range of leaflets for medical students and staff alike, and these could be adapted, creating one generic leaflet on searching skills and another on critical appraisal, which could then be published and distributed nationwide.

One respondent suggested that the Information Standard should be promoted more, via beer mats, events (road-shows), and information champions, such as Dementia Friends.

Another respondent said that there should be “*more down-loadable medical titles of quality*,” and this is being addressed with the availability of more open access research from publishers, such as BIOMED Central, PubMed Central, and the Cochrane Collaboration. Some subscription journals have created areas for patients, for example, the Journal of the American Medical Association publishes topic summaries for patients, but again, this tends to be mainly for common diseases, and varies depending on the preferences of the publishing organisation.

One respondent observed that “*these days we need more detailed clear accurate information – misdiagnosis is known to happen even with the most informed practitioners.*” Organisations, such as Sense About Science (http://www.senseaboutscience.org) are working towards this, by encouraging research students to write lay summaries for each paper that they have published.

When it came down to discussing the available technology, although more than two-thirds (73%) had heard about electronic patient records, only 27% had accessed them. This is quite poor, given how much money has been invested into NPfIT. One respondent said they were grateful to the survey “*for informing me that I can access my records electronically. I had not heard of Healthspace, Discern or HonCode*.”

The figures for knowledge and use of existing NHS resources were also quite poor. Most people (86%) had heard of NHS Direct, but that has since been replaced by NHS111 (http://www.nhs.uk/111). 63% had heard of NHS Choices, but only 46% had used it, while 72% had used NHS Direct. This is surprising, because NHS Choices has been widely publicised, while NHS Direct has now been closed down and replaced by NHS 111. The NHS is trying to improve access to health information for the general public, but by withdrawing NHS Direct, one has to question whether they are listening to their consumers. Only 3% of people knew about the Information Standard, which is quite worrying as the Department of Health has invested resources into developing and promoting this accreditation system, which has been active since 2009.

24% said that they had never used any of the high quality information sources listed, which suggests that health professionals and the government need to invest more in promoting these services and resources, particularly as they have been developed with the user in mind, and often with user involvement. One of the respondents said he/she "*would be more inclined to use a trusted brand e.g. NHS. The proliferation of resources is problematic because I am unlikely to know of them*." The survey showed that many people start searching using Google, so they are clearly looking for one resource to find the answers that they need. However, Google, and other general search engines, are limited in what they can offer because of the amount of web-sites that they trawl. Furthermore, they sort by relevance rather than quality, and information providers can pay to boost their site ahead of others. Search engines are a useful resource, but it is hard to refine a search and users are often faced with information overload. A filtered search engine, designed for patients and carers, would be more useful, something like NICE Evidence Search (publicly-funded) or TRIP Database (privately-funded), both of which are designed by and for health professionals.

The respondents were a mix of carers and patients suffering from chronic conditions, the majority from England, with 5.6% from Scotland. 57% were carers of people with Alzheimer's disease, but only 4% of respondents actually suffered from Alzheimer's disease, with 59% suffering from a long-term condition. Limited cognitive abilities of AD sufferers may restrict them from completing the survey. More than two-thirds (73%) of the respondents were female. The ages represented were between 26 and 76+ years old, with more than two-thirds over the age of 51 years. This may be skewed because of the nature of the population for the third survey, which are more likely to be middle-aged or elderly. The age factor may also have affected the employment status numbers, as the majority of respondents were a mix of employed and retired,

The minority ethnic groups were very poorly represented, with almost 90% of the representatives being white British. This may be because of language limitations, but further work in this area is proposed in section 6.5.

3.8. Discussion of the case studies and survey results

The survey response rates, though small, tally with the results of the literature review. Information literacy requirements and programmes available are varied and this reflects the diverse population that is the general public. Therefore, the model that must be applied for this research must be flexible to ensure relevancy and sustainability. Together with the literature review and the results of these surveys, a model will be developed and validated to provide an outcome for this research.

The reasons for the poor survey response from the general public could be one of three things:

1. **Inadequate language skills** – while the survey was designed to be easy to complete, it was still quite long and perhaps difficult for people with English as their second language (ESOL) to complete. This would have been a barrier, particularly for people living in Tower Hamlets, where over 100 additional languages are spoken, and only 26% of inhabitants have English as their first language (Uddin, 2010). The choice was made to publish the survey in English, because it would be unrealistic to translate the questionnaire into potentially 100 languages. LBTH do not translate their materials either, so while this is a limitation, it is also the norm for the Borough.
2. **Absence of need** – the question that arises is whether people actually need to look for health information. Case study 1, earlier in this chapter, describes access to health information in Tower Hamlets as poor, so it is unlikely that this is the reason that people did not respond.
3. **Lack of interest** – it might be that people are just not interested in finding quality online health information, are content to be informed by their health professional, or for them to make the treatment decision, without their input. If this is the case, then there is a huge disparity between government thinking that people do want to participate in treatment decision-making, and reality. Alternatively, the issue may lie with health professionals. A recent article (Adams, 2014) said that a telehealth initiative launched in 2011, which enabled patients to monitor themselves for blood pressure and blood sugar readings and send the results to their GP remotely, had been quietly axed because GPs could not cope with the additional data being sent to them.

The important points to remember from the survey are that people do:

- want to take part in the decision-making process;
- look for health information on the Internet, to reassure themselves or to find out more;
- find information from the NHS and support groups online, but it may not be comprehensive enough for their needs;
- want support when searching for information, whether it is someone searching for them or providing tools and leaflets to help them;
- lack the skills to find information themselves and therefore need a third-party to help teach them these skills.

3.9. Additional survey to public and medical library services

During the second year of this research, two additional, mini-surveys were carried out to ascertain what levels of health information provision already exist for people in England. These surveys were not piloted, because the author wanted the opinion of her peers, to provide a brief overview of consumer health information services in England. The need for the surveys arose as a result of an incident that occurred involving the author, highlighting the difficulties that members of the general public have in finding the health information they need to make an informed choice. The vignette overleaf describes the incident in greater detail, and generated several questions both for public and medical librarians, about the level of library services provided to the general public:

Vignette 1

From a medical librarian's point of view:

"One of the concerns with asking public librarians to help people find health information for their customers is that it may be traumatic to support someone who has been diagnosed with a chronic or terminal condition. Additionally, there is the risk that they will expect library staff to make a diagnosis, which of course, they cannot.

In November 2011, I was given the opportunity to experience this first-hand. I am being vague about the details out of respect for the person concerned. I am a medical librarian, and one morning, one of my colleagues on the issue desk, asked me to help a patient who had rung in for advice.

The library where I work is for medical staff and students and therefore we do not usually deal with patient enquiries. The hospital does have a patient library, but it only stocks fictional books and does not deal with enquiries as the staff are all volunteers. There is a patient advisory and liaison service (PALS), but they assist with logistical enquiries, such as how patients can get to the hospital. There is not a place for patients to get health information, which is one of the justifications for my research. My colleague put the call through to me and the enquiry that followed opened up a range of emotions.

The caller told me that she has cancer and that she needs to have major surgery. However, she also has coronary heart disease and needs to have a procedure before she can have the major surgery. Her consultant has told her that she can have the procedure up to 4 weeks before her operation. But she has read other guidelines on the Internet that say that the procedure should take place no less than 6 weeks before major surgery, otherwise there is a risk of serious complications and possibly death. The patient would like to see the hospital's guideline on this procedure so that she can compare it with the other guidelines that she has read. With her condition, time is of the essence. I had not expected this enquiry to be so complex. I advised her to speak to her consultant, but she insisted that she needed to see the guideline. The guidelines are available on the Intranet, but I am unable to find them as the system is not particularly well-designed. I contact the relevant guideline department and also the PALS team, but receive no response. I do not know how to help, but I cannot ignore this request. I have the skills and the resources to find health information, and yet I cannot find this particular local guideline. I feel desperately sad for all that this woman is suffering, and she has made a simple request, but I cannot find the answer. It feels as though that just isn't good enough, but what else can I do?

Would a public librarian feel the same way, or are they able to distance themselves from this sort of enquiry? I have been asked a difficult question which runs contrary to what the consultant is advising. The patient is using the Internet wisely and I don't know what the answer is, so that raises a series of questions about my position. Is my responsibility to the patient or to the hospital or to the consultant? What if I was to give out the wrong information? Are these questions faced by public librarians and if yes, should they be put in this position to deal with them? This whole vignette shows that despite all the resources, there is a gap in the ability to help people fulfil their health information needs."

Two, short surveys were sent to relevant electronic mailing discussion lists. The first set of four questions was sent to public librarians via the JISCmail mailing list lis-pub-libs (https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=LIS-PUB-LIBS) on 22/11/11:

1. Do you ever have to answer health information enquiries from the general public?
2. Do you feel confident that you can answer health-related questions?
3. What sources do you use for health information?
4. If you have answered queries from people suffering from a health condition, would you mind if I contacted you privately to find out more about your experiences?

The second set of three questions was sent to NHS Trust medical librarians, via the JISCmail mailing list lis-medical (https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=lis-medical&X=D00C406F479B38DE40&Y) on 22/11/11:

1. Does your medical library provide health information to patients and/or carers?
2. If yes, do you also provide information skills training to patients?
3. If no, can they get health information elsewhere in your organisation, and if yes, where?

There are more than 4,000 public libraries in England (Culture Grid, 2012), but not all of them are represented on the lis-pub-libs, and there are 1,275 medical librarians in England (Hill, 2008). This means that for both surveys, the statistics are not significant, but rather present an idea of the current situation of information provision for the general public.

3.9.1. Results of the survey sent to public librarians

The first set of questions, sent to the public librarians, gathered the following responses:

Nine public libraries in England replied and out of those, 8 answer health information enquiries from the general public, with one dealing with more than 25,000 enquiries per year. Another library has a dedicated consumer health information service, and in one county, they have two Macmillan cancer information points. One library service has provided their staff with NHS Choose and Book training (an NHS service that enables people to choose and book hospital appointments online), and is reviewing further training on health information. Two public libraries work in partnership with health librarians in hospitals and/or their local university. Another library has had a dedicated consumer health information service for the past 23 years.

The responding public libraries also described the reference sources they used to answer the questions, and these included:

- Books.
- Encyclopaedias.
- Journals from charities and support groups.
- DVDs, and online sources, such as NHS Choices, Patient UK, NHS Direct.
- Local health web-sites.
- Specialist support organisations, for example Macmillan, Stroke Association, and Arthritis Care.

The information sources that they used, while evidence-based, may not be comprehensive to answer complex questions from people wanting information about rarer conditions or co-morbidities. This might be a limiting factor, particularly for older people who are more likely to suffer from more than one condition.

The full results of the survey can be found in Appendix 8.

3.9.2. Results of the survey sent to medical librarians

The second set of questions, sent to the medical librarians, generated these responses:

34 UK organisations and 1 Spanish medical library responded to the survey. NHS Direct (now replaced by NHS 111 and NHS Choices, neither of which answers individual enquiries), deal

with 500,000 health information requests per year from the general public. They do not provide training, although they would like to.

Out of the 33 remaining UK-based Trusts that responded, ten of them provide health information to patients on different scales of service provision, for example, from providing reference-only access to answering specific enquiries.

Two libraries provide training for public librarians to support their information skills, and this is exactly what this research would like to support and develop.

Another Trust provides mediated searches, where the librarian/information specialist sits at a computer with the patient, so that they can search together, and so that the patient can learn how to search for themselves.

One Trust trains hospital volunteers who work in the health information room in the hospital to point patients towards good quality Internet resources.

All of the respondents, with the exception of one, said that patients could get health information from other sources within their organisations, such as PALS (Patient Advisory Liaison Services), internally developed patient information leaflets, and even dedicated patient enquiry services. In other Trusts, while patient libraries do exist, they often do not contain health information; they provide books for patients to read during their hospital stay. Many hospitals also have PALS (Patient Advisory and Liaison Services) but these often just provide logistical information, rather than health information, and they tend to work independently of the medical library, as do the patient libraries. In the Trust where the author worked, there was no consumer health information service provision for patients or carers, despite there being a medical library, PALS, and a patient library. More research is required to ascertain whether this is the case throughout England, as it is clear that there is variation in the level of services provided for patients and carers.

The full results of the survey can be found in Appendix 9.

3.9.3. Mini-survey conclusions

These surveys were carried out over three days, to get some immediate feedback as to the current situation of service provision. From her professional experience, the author was aware of the lack of information services available to the general public in her region (London), and wanted to have more anecdotal evidence from elsewhere in the UK, with which to describe the situation further. These two mini-surveys confirm how variable the level of health information support for the general public is. The public libraries do not have adequate access to resources to help them answer complicated health-related conditions, and the biggest consumer health information service, NHS Direct, has been replaced, which means that people have to rely on finding the information themselves. This is significant because the survey results and the literature review in Chapter 2, confirm that people do want help, so the removal of a national service that was previously used heavily, and could still have helped them had it not been cut, is going to increase the need for a sustainable solution.

3.10. Chapter summary

As pointed out earlier in this chapter, it is uncommon for one survey to be presented to three different populations, but it was necessary for the purposes of this research. Following the results of the first two surveys, there were clear similarities in the responses despite geographical location, but very few responses. The author had established reasons for the poor response rate in London Borough of Tower Hamlets, e.g. lack of translation facilities. The poor response from the second survey is unexplained, although the GP who distributed the survey said that he was not surprised by the lack of response. The third survey gathered more responses, and this was perhaps because it was distributed via support groups, rather than public services.

The total sample size was 139, which is small and is not representative when compared against the total population of the UK, which is 64 million. Sample size is important, because the bigger the sample, the more likely one is of finding a statistical difference. In the case of this research, a statistical difference has not been found. Nevertheless, the majority of the responses compare favourably with the findings of the earlier literature review, and support the eight key messages, summarised in Chapter 6, and this substantiates the case for the development of a consumer health information literacy intervention. Therefore, despite the low response rate to the survey, the combined results confirm that patients and carers:

1. Want to be involved in the treatment decision-making process;
2. Do search for health information online;
3. Are unaware of all the resources available to them;
4. Experience difficulties finding good quality consumer health information;
5. Would like easier access to good quality health information;
6. Would like to either learn to search more effectively or to have someone to search for them, or resources to help them with their searching.

Of importance for the future investment in consumer health information products, there was a significant lack of awareness of many of the information products produced by the National Health Service. This is a big concern, because they have been designed for the target audience who, according to the literature and the survey results, are not aware of, or using them. This is a costly investment for the government, and the NHS needs to support interventions which will increase the use of these resources. This might come in the form of additional training for health professionals, public, and medical librarians, who are in the best position to promote these resources to users, without incurring considerable promotional costs.

The surveys to the public and medical libraries, while the results again are not statistically significant, provide a glimpse into the poor information service provision available to consumers. However, they also demonstrate a willingness and opportunity for collaboration between these two groups and this will be reflected in the final outputs of this thesis, and will go towards developing a human and technical solution, to reduce the risk of exclusion.

The next chapter presents the framework and model that is being recommended and describes the results of the validation process carried out to verify the model.

Chapter 4 – Presentation and validation of model

T.H. Davenport

4.1. Introduction

This chapter describes the design and validation of the model the author has developed following analysis of the research literature, survey data from the target audience, and the framework adapted from the seven pillars of information literacy and evidence based practice.

"*A model is an abstract representation which helps us understand something we cannot see or experience directly*" (Conole, 2008). In other words, it helps us visualise how a concept will work. It is a "*representation with a purpose"* (Beetham, 2004, Milstein and Chapel, 2013) with an intended user; a visible plan with a specific outcome.

A framework outlines the principles that provide the foundation for the practical model (Richardson, 2004). They are the steps that the model has to apply to realise the framework. The model, while built for a specific audience, in the case of this research, the patients suffering from dementia and Alzheimer's disease and their carers, should be replicable and transferrable to other audiences. It must be adaptable to suit other similar situations. So, the model enables the framework and should deliver the principles outlined in the framework (Ostrom, 2007, Richardson, 2004, Booth, 2012).

For the purpose of this research, a model is proposed, based on an existing framework, adapted to suit the intended users, patients and their carers. The model improves access to high quality, reliable health information for the general public, in particular patients and carers, by co-ordinating existing information sources. It provides a host and search platform of existing NHS information resources and other high quality consumer health information sources. In addition, the model applies a collaborative feature involving the transfer of skills and experiences between public and medical librarians, enabling a technical and human solution to support the needs of all patients and carers.

This research will not produce an information literacy (IL) strategy for England, because this is being achieved by the Chartered Institute for Library and Information Professionals, but it uses and adapts the same seven pillars framework (Table 5) as a foundation for the model that will be proposed further on in this chapter.

The model evolving from this framework provides a system and tools to support consumer health decision-making and evidence-based patient choice (EBPC) (Figure 3), the author’s patient-focused, adaptation of evidence-based practice. The desired outcome for the patient will be taken into account, prompting them to reflect on how their lifestyle will change. Sometimes side effects can be worse than the condition, so it is important that people understand the implications of what they are undertaking. Vignette 2 presents an example of how a clinician's preferred outcome may differ from the preferred outcome of the patient.

Vignette 2

Good outcomes as perceived by the patient and the clinician:

A woman with chronic knee pain is offered the option of knee replacement therapy. She asks if this will cure her knee pain and is told yes, so she agrees to the treatment, thinking that that is the best option, and not considering other options such as physiotherapy. However, her health professional has not factored in the woman's personal preferences. In reality, she has a beautiful garden, which she loves to maintain. When she has had her knee replacement therapy, she finds she is unable to bend her knees and cannot kneel, so she is unable to work in her beloved garden. Her consultant's outcome has been met, as the treatment has cured the chronic knee pain; hers has not. Her outcome has not been met. She wanted to improve her quality of life, but she has decreased it instead. Physiotherapy may have been an alternative option, perhaps not providing a cure-all, but alleviating the symptoms {Cambridge University, 2011).

In this vignette, the clinician wants to achieve a cure for the chronic knee pain, but does not consider how the side effects of the intervention will affect the patient. Another example, is that a carer may need an operation, but needs to consider the impact this will have on his/her ability to care for their dependent.

Patients, and people who care for others, must have their preferences considered when designing a system to help people find information quickly and effectively. Everyone with a pertinent view must be included in the treatment decision-making. Health information retrieval systems should be designed to suit the preferences of the individuals who are searching for quality information, so that they can find it as easily and as quickly as possible (Zhang, 2013).

4.2. The problem requiring a solution

Picture this scenario: *A patient is diagnosed with early on-set Alzheimer's disease, and he and his family want more information about treatment. Where does he get this information?* He could:

1. Ask his doctor or nurse, but health professionals often have limited time.
2. Search for the information himself or he could ask his carer to search, but there is so much information available, and not all of it is reliable, accurate or relevant. Furthermore, the terminology can be confusing, and they may not have the skills to search effectively.
3. Contact Patient Advisory Liaison Services, but often they do not have the necessary searching skills, and tend to focus on logistical support for patient, such as getting them home safely following discharge and advising on additional support from social services.
4. Contact the library, although medical librarians are not always accessible to patients and carers, and while public libraries are, they may not have the necessary skill base with regards to searching for quality health information.
5. Contact the national support group, e.g. Alzheimer's Society, who will be able to provide some information, but not necessarily in the detail required, particularly if it does not cover the treatment the patient is interested in.

This scenario shows that there are at least five ways the patient can find out more about his treatment. However, each method has its own obstacles; lack of time, skills, service provision, and access. Patients and carers should not have to face these obstacles as they have enough to be concerned about, and therefore, either they need information support, or an easier means of navigating the existing information products.

The literature review in Chapter 2 and the survey results in Chapter 3 also identify these obstacles and others, such as lack of language skills. They present a picture of what people want with regards to information support, and some people have said that they want to search for themselves and others want someone to find the information for them. Because of this input, the final outcome has changed to reflect existing practice and user preferences. At the start of this research, the author wanted a human response to the problem, involving a peripatetic librarian (Figure 1), described in greater depth in Chapter 1, because she felt that there were too many technical solutions already available. However, as this research has evolved, it is clear that a human and technical solution is more viable because, if designed properly, it will be able to adapt to different information needs. The human solution, on its own, would be impractical and too costly, while the technical solution, on its own, would exclude people without the relevant skills or who do not have access to the Internet, and therefore would find access to a librarian with the necessary information skills more useful. Furthermore, with the technical solution, there would be the risk that, like the other e-health information products that have been created, there would be inadequate promotion and so people would not know about them, to use them (Greenhalgh et al., 2010a). The surveys carried out as part of this research corroborate this lack of awareness of NHS-provided information support.

During these austere times when cost savings in the public sector are required, collaborative working between medical and public librarians is an innovative and ideal opportunity enabling library staff across both sectors to share experiences, build on good practice, and develop their own professional skills. While medical and public librarians both exist, they do not currently work together to support the general public in England, and there is no evidence of such collaboration in other countries either.

On the technical side, there are many online consumer health information sources, but not one all-encompassing site, so people need to:

a) remember different web addresses;
b) be able to evaluate the sites they use;
c) register for different usernames and password, depending on the resource.

These factors can be frustrating and a barrier to quality health information, particularly for those who are less technically-minded. The proposed solution will use existing information sources, but will automatically approach the most appropriate first, which a patient or carer may not know.

4.3. COCO model: an introduction to the model

Based on the survey data, the comprehensive literature review, and the framework in Table 5, the author has developed a model, which reflects the needs of patients and carers, while being sustainable in terms of resources. The model is a hybrid solution of the first two iterations of the model, described above, combining technical with human resources. The proposed outcome is a collaborative initiative between medical and public librarians, combined with existing online consumer health information sources. The initial entry point is a technical solution, but the option for human interaction is available throughout.

The model that the author has created provides a simple interface with a memorable web address, e.g. http://www.coco.nhs.uk; a one-stop-shop for all NHS and related quality consumer health information products. It will also be available as an app for tablets and smartphones so that it is accessible in a number of ways.

As referred to earlier, when searching for evidence to help frame their information need, health professionals use a concept called PICO (Patient/Problem/Population, Intervention, Comparison, Outcome) (Schardt et al., 2007, Erlich-Jones et al., 2008). As a result of this research, the author has devised a similar, more personalised version for patients called COCO (Condition, Option, Choice, Outcome). In this case, "Option" refers to treatment choice or intervention, “option” being more meaningful to patients, as this is often the terminology health professionals use with their patients: "*You have diabetes, and these are your options.*" The “Outcome”, while having the same meaning as the outcome in PICO, may have different interpretations. For the health professional, it may mean cure or alleviation of symptoms. However, for a patient, he/she may be more interested in a better quality of life. Being cured might mean a better quality of life, but not always.

The proposed model factors in the desired outcome for the patient, prompting them to consider how their lifestyle will change. Sometimes side effects can be worse than the condition, so it is important that people understand the full implications of what they are undertaking.

4.3.1. Types of information products

COCO will include consumer health information products in various forms with some created specifically with the general public in mind as the target audience:

- **Systematic reviews** – these are the highest level of evidence because they bring together all the research to answer a focused question, appraise it, and present a comprehensive overview.
- **Lay summaries** – more publishers, particularly open access ones, and organisations, such as the Cochrane Collaboration PLoS Medicine, and eLife, are including lay summaries of their research articles. These are synopses of their research, written in plain English, that can be understood by all, and not just scientists.
- **Guidelines** – these are similar to systematic reviews, as they pull together all the best evidence, to answer a specific question, but they provide guidance on how best to diagnose and manage the condition, including when and how to apply treatments, and side effects to watch out for.
- **Uncertainties** – sometimes, even with all the research available, the researchers cannot come to a consensus about the best option available, and therefore there is no

right or wrong answer, resulting in uncertainties. It is important for patients and carers to know the unknown as well as the known, so they can make fully-informed decisions.

- **Patient experience** – case studies/stories are a very important way of learning because they bring in a human element, a way for people to understand what is going to happen to them. There is a risk that if not collected formally, patient experience can be biased and may not be relevant. Fortunately, University of Oxford has developed a method for collecting patient stories/experiences from adults and teenagers, publishing them in a range of formats, to support all literacy levels.

- **Decision aids** – these are a relatively new tool, and are being developed to support the shared decision making agenda (Alambuyam et al.). They are checklists for patients to take with them, providing them with information and prompts, so that they know what questions they need to ask of their health professional. Decision aids mean that they can use the time with their clinician more effectively and with more confidence, so that they can make an empowered and informed decision together with the health professional.

4.3.2. Information sources

COCO will search the following information sources:

1. NICE Evidence Search – guidelines and uncertainties (DUETs – Database of Uncertainties about the Effects of Treatments).
2. HealthTalkOnline.org – patient experiences formally gathered from adults and teenagers.
3. NHS Right Care - decision aids.
4. NHS Choices – patient information products and support groups.
5. The Information Standard – patient support groups producing quality health information products.
6. Cochrane Library – systematic reviews and related lay summaries.

7. TRIP Database – primary (e.g. randomised controlled trials) and secondary (e.g. systematic reviews) research.
8. Current Controlled Trials meta Register of Controlled Trials.
9. Open access journals – PubMed Central, PMC Europe and BIOMED Central all provide access to peer-reviewed health research, freely available to all, including the general public.

4.3.3. “Ask A Librarian” option

Not everyone is Internet literate or has access to a computer, so throughout the COCO search experience, the patient/carer will have the option to send the search directly to the public librarian, via the “Ask A Librarian” button, which will connect to an online form. This is directed to a generic email address, which can be accessed by all librarians involved, although managed by one overarching triage role. The public librarians will be trained and supported by medical librarians, this being the knowledge management element of the model, which involves the sharing and transfer of knowledge and skills. Public librarians already have the customer-base and the trust, and medical librarians have the necessary information skills and access to the relevant information sources. This is an ideal collaboration where the skills and connections are brought together to provide an information service for the general public, which does not impose a great financial burden to the public sector, as it is building on existing human resource, sharing resources, and developing the skill-set.

A telephone and a unique telephone number will also be made available in each GP surgery, pharmacy, hospital, and PALS, connecting to a public librarian, who has been trained, and is supported by medical librarians. He/she can take details of what is required and send the information within 5 working days, depending on the format the requestor has specified, e.g. electronic or paper, and staffing capacity levels. A priority service can be provided for urgent cases, where time is of the essence, but this would need to be managed carefully so that people’s expectations can be met. This model would require commitment from the General Medical Council, Health Education England, local authorities, and the Chartered Institute for Libraries and Information Professionals.

The request can come from a patient or carer, or a health professional can make the request on their behalf. The telephone access point is similar to the taxi telephones that can be found in hospitals, where you pick up the phone and are automatically connected to a taxi service, so that you do not have to worry about finding a number. Obviously, unlike the taxi service, resources would not allow for a librarian to be available 24/7, but it would be quite feasible during normal working hours. There is a previous example of 24/7 librarian access for clinicians, when southern and northern hemisphere medical librarians worked together to provide immediate access to literature searching services (Rockliff et al., 2005), and perhaps if the model is successfully received, an additional, international collaboration could be the next development.

4.4. Additional components of the model

The model includes the following additional features to ensure that the patient and/or carer receive all the information support that they need to make an informed choice:

4.4.1. Electronic health records

Patients can only make informed choices about their care pathway, if they have access to the best research and clinical knowledge, and their own health data, so as an essential part of this model, there will be a link which will enable them to access their GP electronic health record. The link will take them to a page, which offers various access points including the patient's local GP surgery, or HealthVault, the portal developed by Microsoft to help patients access their individual electronic health records. Up until now, patient portals have linked to the electronic health records, but not the evidence required to help them make informed decisions. COCO brings together both elements to support evidence-based patient choice. The added value of having access to good quality consumer health information and individual patient data, may encourage people, particularly those with chronic conditions, to make more use of their electronic health record, which has proven to be beneficial both to the patient and the health service (Robertson et al., 2010, National Health Service, 2010).

4.4.2. Uncertainties about the effects of treatments

This content refers to the uncertainties about the effects of some treatments, and as part of their treatment choice, it is important for patients and carers to know and understand about uncertainties. Evidence of the side effects of a treatment may not always be available or clear, and patients and carers may not realise this. While all drug treatments undergo rigorous trials to make sure they are fit for human consumption, firstly, the full findings are not always available, and this is why appraising the literature is important, and secondly, sometimes there are uncertainties in how the treatment might react in a particular circumstance. The UK Database of Uncertainties about the Effects of Treatments (DUETs) has been developed by the James Lind Alliance (http://www.lindalliance.org/) and is now part of the NICE Evidence Search. The Database collects all known uncertainties, so that researchers, clinicians, and patients are aware of them. Anyone who identifies an uncertainty, including patients and carers, can submit an uncertainty for inclusion, with the hope that one day these uncertainties will be researched and the evidence provided, and the knowledge gap filled.

4.4.3. Clinical trials

Knowledge of current, ongoing clinical trials is also important for the patient, so that they can decide if they want to participate or not, or so that they can monitor trial results for future consideration. The question arises, about whether it should be part of the COCO search or a separate search aspect. The author originally proposed that COCO users could search for ongoing trials via a separate link through to the Current Controlled Trials meta Register of Controlled Trials (http://www.controlled-trials.com/mrct/). However, one of the validators, Sir Iain Chalmers of the James Lind Alliance advised that the ongoing trials be integrated into the model, allowing users to feedback during the user-testing sessions, to see if this would be the best way forward. He feels that it is important that patients/carers have all the information available so that they can make a decision about whether or not to participate in a trial. He has extensive expertise in this area, and for that reason, the initial version of the model was changed to reflect his observations. The original reason for keeping it separate was that otherwise, if the ongoing trial results come in together with the evidence results, it may be confusing for the patient and/or carer because there would be a mix of validated and nonvalidated research. However, the confusion can be overcome in the way the results are presented, by displaying them under a hierarchy of levels of evidence.

4.4.4. Other resources

In addition to the specially designed interface, searching a collection of quality health information sources, and the link to the professional librarian, the site will also link to complementary resources. These include:

- NHS Choices symptom checker – to enable people to make a tentative diagnosis and identify which health service they should use, e.g. GP practice or accident & emergency department;
- NHS Choices Behind the Headlines – to help people to understand health news in the media;
- Critical appraisal resources - to facilitate evaluation of content found, e.g. DISCERN;
- Decision aid template - to help people make decisions, e.g. a generic aide-memoire.

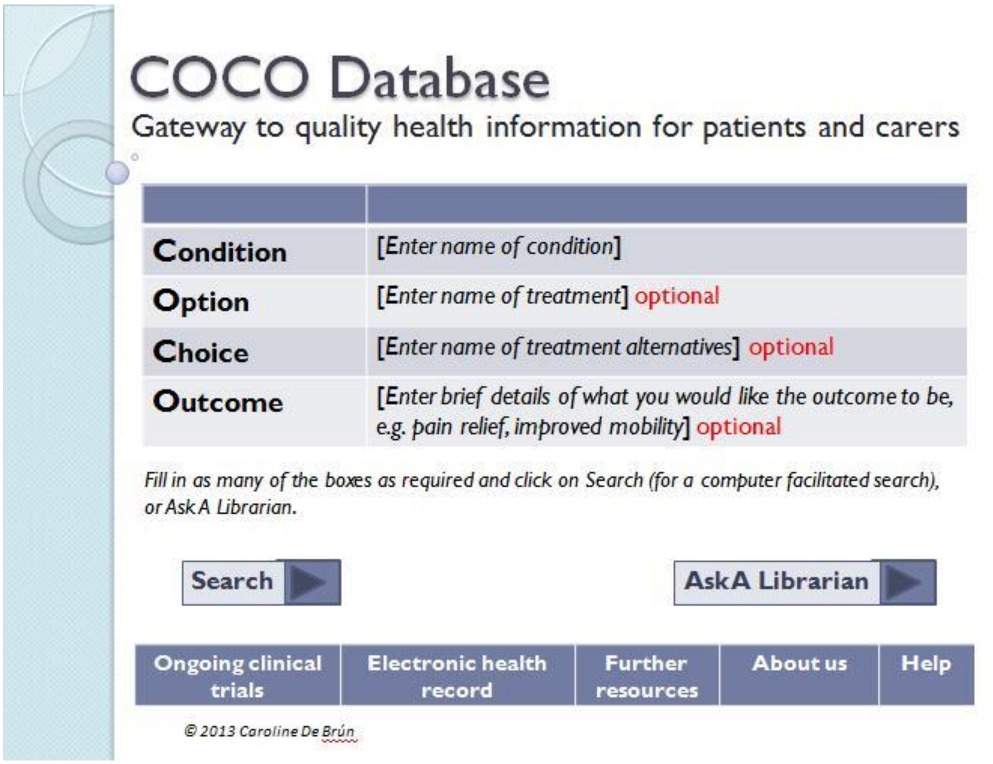
The idea of the model is to make sure that patient and carers can access all the resources available to them, without having to navigate lots of different web-sites and passwords, and if they aren't computer literate, they will be able to contact a librarian, either via the web-site or a dedicated phone number, so it caters for users who do go online and those who do not.

4.5. COCO Database: how it operates

The aim of the COCO Database is to facilitate access to good quality and relevant consumer health information, and librarian support, via one gateway, bringing together all the existing health information products, and connecting to human support where required.

Figure 7 shows what the COCO homepage will look like, and further on in this chapter, there will be a description showing how each feature will function. The user can enter as much information as they would like to. If they are looking for more information about a condition, then they fill in the first box. If they want to know about a particular treatment that has been prescribed to them, then they fill in the first two boxes. If they have heard of another treatment, and they want to compare it to the treatment they have been prescribed, then they fill in the first three boxes. The final box can be used with all the other options or just with the condition, or with boxes 1 and 2.

Figure 7: Initial mock-up of the COCO Database pre-validation



COCO Database

Gateway to quality health information for patients and carers

Condition	[*Enter name of condition*]
Option	[*Enter name of treatment*] optional
Choice	[*Enter name of treatment alternatives*] optional
Outcome	[*Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility*] optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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There are several additional features. Users can:

1. Link to their electronic health records (EHR) – this is the main purpose of COCO, to provide the evidence to support the personal data on the EHR, so that people can make evidence-based decisions.
2. Contact library staff and find out more about the service by clicking on the About Us button.
3. Learn to search more effectively by clicking on the Help Button, which will link to downloadable leaflets providing hints and tips for more effective searching.
4. Access further resources – this provides users with additional support, such as:
    a. Symptom checker – COCO is not a diagnostic tool and should not be used as such. All diagnoses should be made by a qualified health professional. Symptom checker, however, can reassure people and provide them with guidance about what they should do next. It is also useful for identifying new terms to add to searches.
    b. Behind the Headlines - this is a service providing unbiased and evidence-based analyses of health stories that appear in the news. Newspapers often print sensationalist stories about new treatment effects or lifestyle recommendations. The analysts for BTH look at the original research, and present the facts in plain English (Bazian, 2007).
    c. Critical appraisal tools, so that, particularly with scenario 4, further on in this search, if they find research papers, they can then evaluate their quality. DISCERN is one of these tools and can be used to evaluate web-sites that have not been given any quality guarantees. It is particularly useful for information on rarer conditions, which may produce good quality health information, but which have not been formally quality-evaluated.
    d. Generic patient decision aid – decision aids are being developed for many conditions, but not every condition has one yet, as they are fairly new. This generic patient decision aid can be used to prompt users to ask the right questions during their consultation times, so that they can get the information that they need.

4.5.1. Scenarios and functional description of how the model works

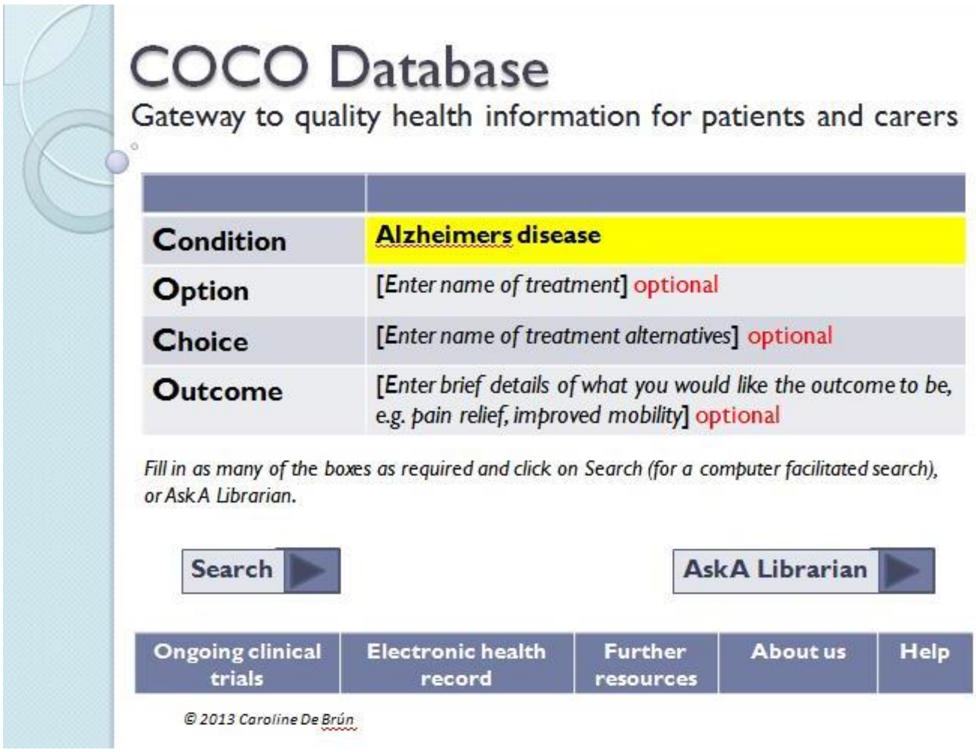
The following four scenarios, about a person who has been diagnosed with Alzheimer's disease and his family, have been gathered from examples on the Alzheimer's Society (http://www.alzheimers.org.uk/) homepage, and the author's professional experience. They are being used to illustrate how the model can be used by the patient or carer to fill their information gaps. This exercise is for the benefit of the author so that she can make sure that the model is doing what she expects it to do, and the validators, so that they understand how the system will work.

Each scenario is followed by a description and a mock-up for each scenario, demonstrating how the model might help patients and carers find good quality health information easily. At the end of this chapter, there is a visual adaptation for each of these scenarios.

4.5.1.1. Scenario 1

For the past few months, Benjamin P. has been struggling with his memory and has been finding conversations difficult because he gets his words confused. After several visits to his GP and then a specialist, he is diagnosed with early on-set Alzheimer's disease. He isn't clear what this means, and although his doctors have explained it to him, he, and his family who will care for him, want to find out more about his newly-diagnosed condition and what they can expect.

Figure 8: Mock-up of scenario 1 pre-validation



COCO Database

Gateway to quality health information for patients and carers

Condition	**Alzheimers disease**
Option	*[Enter name of treatment]* optional
Choice	*[Enter name of treatment alternatives]* optional
Outcome	*[Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility]* optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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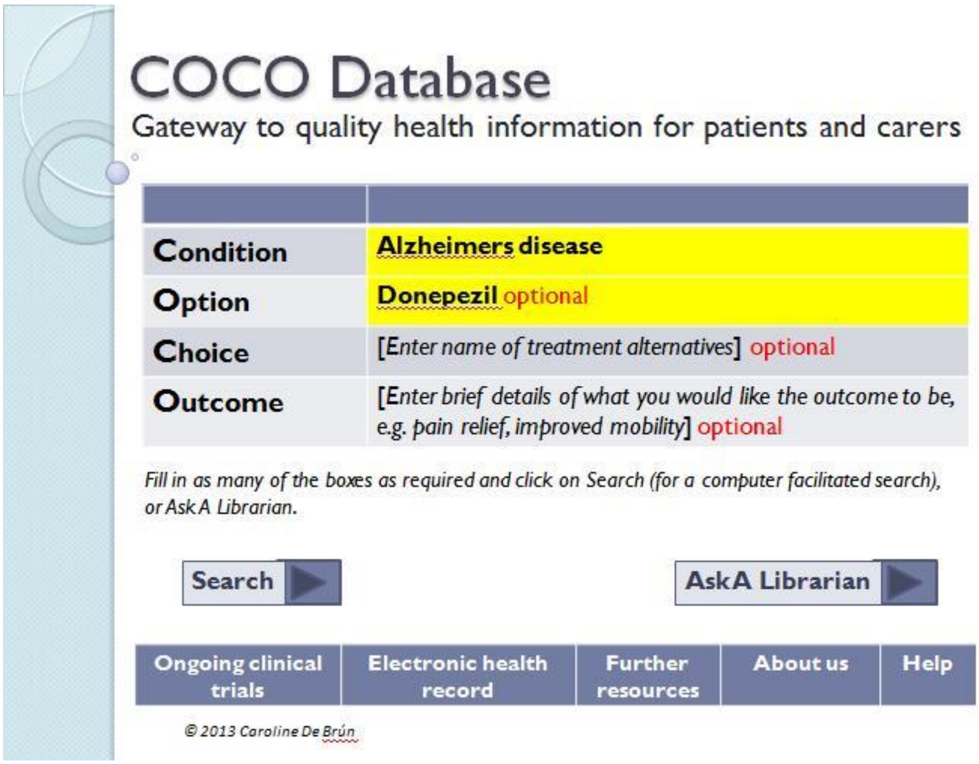
The patient or carer types in the condition name only. The software will automatically map to an index term, which will add all alternative synonyms to the search. Many conditions have different names. For example, Myalgic Encephalomyelitis is also known as Chronic Fatigue Syndrome, so it is important to include all the relevant terms in the search. However, a patient/carer might not be familiar with all the variations, which is why it is essential that the software will perform this stage automatically. Fortunately, clinical databases, such as the National Library of Medicine, in America, have created indices for this purpose, called MeSH (Medical Subject Headings), and this can be built into the software to achieve this objective. Clinical databases have a thesaurus, an index of terms which have been assigned to all the content so that when a user searches the database using the index terms, only content specifically about the index term will be retrieved. Index terms also include synonyms so that users only need to type in one term and the computer automatically maps it to the index term. The reason for the human element is for people who are not very information literate, but actually using thesaurus mapping, where the computer maps terms to one index term and automatically identifies related terms, would overcome poor information literacy, and make the search more robust.

The patient/carer clicks on search and the software will search for high quality patient information products and support groups, via NHS Choices and The Information Standard. If the patient/carer prefers, they can just click on Ask A Librarian and their request will be sent to a public librarian.

4.5.1.2. Scenario 2

Alzheimer's disease cannot be cured, but there are various medication options available. Benjamin has been prescribed donepezil, an acetylcholinesterase (AChE) inhibitors (National Institute for Health and Care Excellence, 2011) *for the early stages of Alzheimer's disease, and he and his family want to know more about how this drug will affect him and if there are any side effects they should be aware of.*

Figure 9: Mock-up of scenario 2 pre-validation



COCO Database

Gateway to quality health information for patients and carers

Condition	**Alzheimers disease**
Option	**Donepezil** optional
Choice	[*Enter name of treatment alternatives*] optional
Outcome	[*Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility*] optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or AskA Librarian.

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The patient/carer enters the condition name in the C box and the treatment option in the first O box. Again, these will be mapped to all the synonyms, which is particularly useful for drug treatment options, which often have generic and trade names, e.g. Donepezil and Aricept. The patient/carer will then click on search and the software will search four key resources:

1. NICE Evidence Search for guidelines, published by NICE (National Institute for Health and Care Excellence), SIGN (Scottish Intercollegiate Guidelines Network) and professional organisations, such as the Royal College of Psychiatrists, and topic pages

on the treatment of the condition, and treatment uncertainties and unknowns from the Database of Uncertainties about the Effects of Treatments).

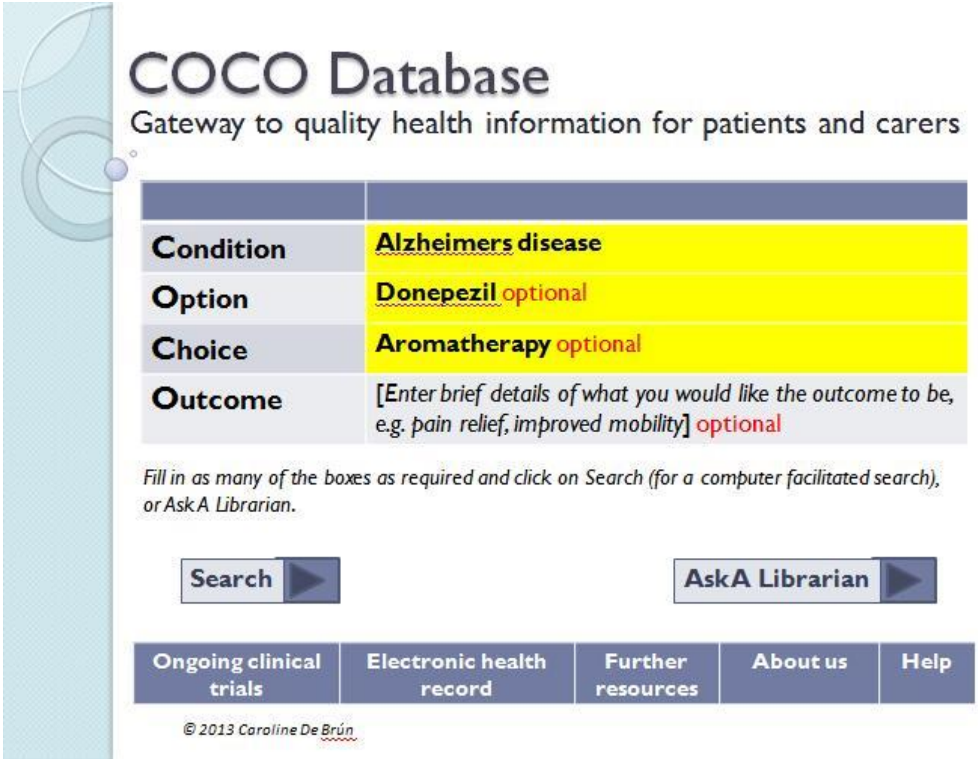
2. Decision-making tools, such as decision aids, which are tools being designed by the NHS, for patients, that present all the possible options in a clear and concise format, to help them make informed decisions with their health professionals.
3. Ongoing clinical trials via the Current Controlled Trials meta Register of Controlled Trials (http://www.controlled-trials.com/mrct/), so that patients and carers can see if there are any new treatments being tested, and perhaps even take part in the trial.
4. True stories, produced by HealthTalkOnline (http://www.healthtalkonline.org/), which are patient experiences, formally recorded in various formats, and covering a range of conditions and treatments, to help patients and carers get an idea of what they can expect.

Again, if the patient/carer prefers, they can just click on Ask A Librarian and their request will be sent to a public librarian.

4.5.1.3. Scenario 3

Benjamin has been on his treatment for 3 months, and while his symptoms are more under control, he has been feeling depressed at his situation. His daughter has heard that some aromatherapy oils can improve cognition and alleviate symptoms of depression (Alzheimer's Society, 2013)*, and they would like to find out more about this as a complementary option to his current drug treatment regime.*

Figure 10: Mock-up of scenario 3 pre-validation



COCO Database

Gateway to quality health information for patients and carers

Condition	**Alzheimers disease**
Option	**Donepezil** optional
Choice	**Aromatherapy** optional
Outcome	*[Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility]* optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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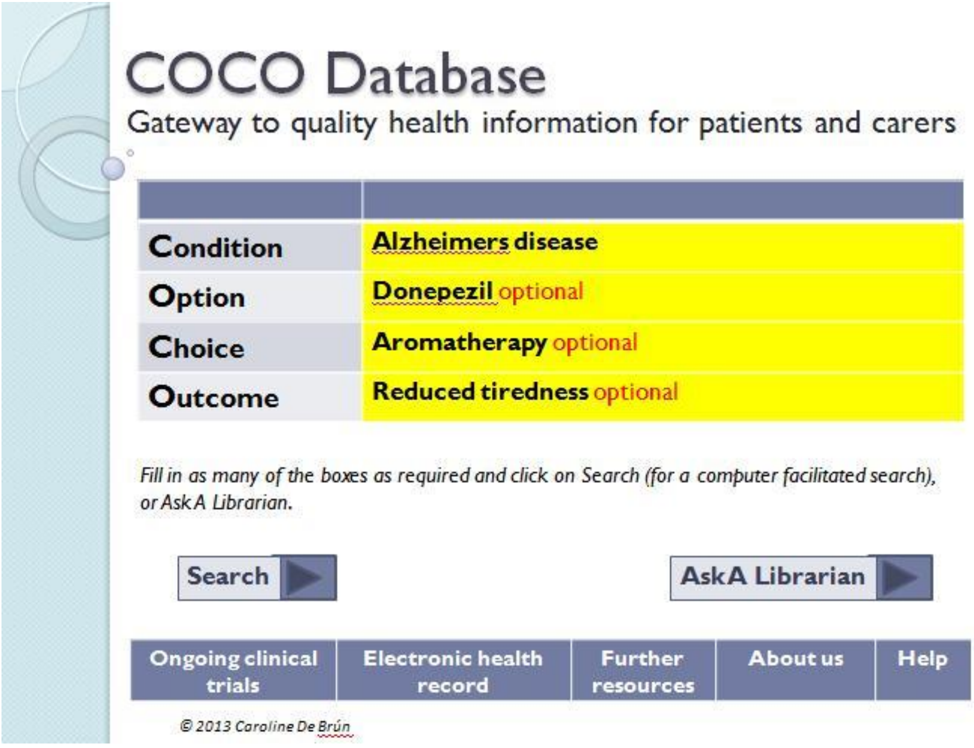
The patient/carer enters the condition name in the C box, the treatment option in the O box, and the alternative treatment in the second C box. Again, these will be mapped to Index terms. The patient/carer clicks on search and the software searches the TRIP Database for research evidence comparing two or more treatment options, decision aids, and the Ongoing clinical trials via the Current Controlled Trials meta Register of Controlled Trials, for details of ongoing trials. TRIP searches the Cochrane Library and PubMed and will find comparative studies providing the information required. The research will be divided into levels of evidence, with decision aids at the top, so that people can start reading those first. The decision aid will be easier to read than the research and more honed to the patient/carer needs, but there are not many currently available and so providing the best research evidence, together with critical appraisal tools is the next best thing, particularly if lay-person summaries are attached. As always, if the patient/carer prefers, they can just click on Ask A Librarian and their request will be sent to a public librarian, trained by a medical librarian, who will return relevant results as and when required.

4.5.1.4. Scenario 4

Before his illness, Benjamin was very active, working in volunteer shops, and a participating member of the local golf club. With the treatment he is on, he is finding that he is getting very tired, particularly as he often finds it difficult to sleep (N.H.S. Choices, 2012)*, common side effects when taking Donepezil. This is having an impact on his quality of life as he is not able to play golf as often as he would like, and therefore isn't meeting his friends as much, so his social life is also being affected. He would like more information about how he can improve his quality of life, while controlling his symptoms.*

Figure 11: Mock-up of scenario 4 pre-validation



COCO Database

Gateway to quality health information for patients and carers

Condition	**Alzheimers disease**
Option	**Donepezil** optional
Choice	**Aromatherapy** optional
Outcome	**Reduced tiredness** optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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The patient/carer enters the condition name into the C box, the primary treatment option proposed in the O box, the comparative treatment choice (if there is one) in the second C box, and finally in the second O box, the outcome or outcomes that would suit them most. Again, all the terms are mapped to Index terms. This is a more complex search, and so when the patient/carer clicks on search, the request is sent automatically to the librarian. This is because COCO is not all-encompassing. It searches a specific set of resources containing information designed for patients and carers. Therefore, the response to this question will not be found using these resources, and a systematic search must be carried out by a librarian, who will have a wider range of subscription-based resources to search, such as clinical databases. The librarian will run the systematic search and return relevant results as and when required. If the patient/carer wants to have an immediate response, then the software can search the TRIP Database and NICE Evidence Search, but the results may not be as relevant, because it is difficult to map quality of life terms to the Index because they are so personal. The librarian will be able to interview the patients and carers to identify, in greater detail, the types of terms that might arise in a search, making the results more relevant.

This final image shows what the page linking to Further Resources will look like:

Figure 12: Mock-up of the page about Supporting tools and information pre-validation

COCO Database

Supporting tools and information

- •NHS Direct
- •NHS Choices symptom checker
- •Behind the Headlines
- •DISCERN – patient information checklist
- •Generic patient decision aid - with questions to ask the doctor

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4.6. Limitations of the model

Co-morbidities/multi-morbidities are more complex and require support and guidance from the health professional. While this model can support multi-morbidities, all decisions should be made with the health professional, as the software may not be as effective when combining several different conditions with a number of treatment options. There are drug databases that compare drug interactions so that you can see if the prescribed drugs can be combined or not, and perhaps this should be a future enhancement of the software, but the current drug interaction software is designed for qualified medical professionals and therefore it would be best to talk to them about adverse drug interactions. It is important to differentiate between English and American drug databases though, because the doses are different.

4.7. Benefits of the model

The main benefits of the model are that it is very flexible and customer-oriented, serving both Internet and non-Internet users. Other benefits include:

- Improved access to health information for the general public, which will help them make informed choices and support the shared decision-making agenda (Alambuyam et al.).
- Improved use of existing NHS patient information resources, thus reducing waste and re-invention in the health service.
- Less demand from health professionals for more information.
- Efficiencies arising due to collaboration between public and medical libraries, and health organisations, in terms of cost, time, and re-use of existing resources.
- Professional development in terms of knowledge-sharing for librarians.

The model also complements forthcoming NHS England programmes, such as:

- The online health literacy programme, which aims to train people from disadvantaged communities, and,
- 'Patients in control', *"a comprehensive programme including practical training, support and tools to support local communities to deliver shared decision-making, personalised care planning, and better self-management of their health*" (Patients and Information Directorate, 2013).

4.8. Model verification and validation

In order for this model to be accepted and used in the decision-making process, it is necessary for it to be verified and validated. If it does not go through this process then it is unlikely that people will trust that it is appropriate for purpose. Models cannot be developed based on the literature alone. Input from users and experts is required to make sure that the final output is fit for purpose and meets the requirements of the users. There will be diversity in opinion, and judgements will have to made, so that compromises can be reached, but this validation process will make the final product so much more relevant and worthwhile.

Verification means that the system operates as expected and that there are no errors, while validation means that the model resolves the problem it is meant to (Macal, 2005). Full validation and verification can only be guaranteed once the model has been fully-developed in to a fully-functioning system. Therefore for this research, verification and validation will be assessed based on the successful operation of the model in theory.

4.8.1. Validation participants

The following six organisations were invited to validate COCO. The invitations were issued based on the expertise they could apply during the evaluation process. The author has either worked with them during her professional career or met them via events attended as part of this research:

- NHS (primary care) and Haughton Thornley Medical Centres - Dr Amir Hannan.
- James Lind initiative - Sir Iain Chalmers.
- TRIP Database and Public Health Wales - Jon Brassey.
- Chartered Institute for Library and Information Professionals (CILIP) Information Literacy Group - Rebecca Mogg.
- NHS England The Information Standard - Colin MacKenzie.
- NHS England and NHS Direct - Bob Gann.

Each candidate was sent an email asking them to participate in this process. The email (Appendix 10) contained a brief introduction and provided a link to the survey, which was delivered via SurveyMonkey, and a list of the questions in case the candidates wanted to respond via email. A separate document (Appendix 11) was attached to the email, which described the context of the research, the framework, and the model for the validators to comment on. One of the questions asked if they would like to be granted anonymity, but all were happy for their names, and the names of their affiliations to be public. More details about the validation process are provided in section 4.8.2., including the list of questions.

4.8.1.1. Haughton and Thornley Medical Centres - NHS general practitioner

The author met Dr Amir Hannan (DAH) at the “Internet-Informed Patient Symposium” at University of Cambridge in March 2011 (Cambridge University, 2011). He was included because of his understanding of what information people need to make an informed treatment choice, and also because of his knowledge about, and proactivity towards the implementation of the electronic health record programme.

As well as being a practising GP, DAH is also the Primary Care IT lead at NHS North-West, a member of the Health Informatics Clinical Advisory Team, and an editorial board member of the Journal of Communication in Health Care. DAH firmly believes that patients should be in control of their electronic health records because it ensures that medical errors are less likely to occur. At his practice, 2,000 patients have access to their GP and electronic health records and have an understanding of what the content means. DAH has developed a patient information portal so that his patients can look at their electronic health records and find good quality health information so that they can make informed decisions about their care pathway. He is firmly committed to involving patients in the decisions made about their treatment, and actively encourages his patients to access their own electronic health records and take control of their health. He took over the practice of Dr Harold Shipman, the notorious serial killer, and needed to build up his patients’ trust (Manchester Evening News, 2007). He has managed this by creating a very secure portal via which they can access their own records and monitor what is being prescribed to them. He has made sure that the practice’s web-site provides access to high quality patient information. DAH's work has resulted in him being invited to speak at many national conferences, to share his experiences and expertise.

4.8.1.2. James Lind Initiative

The author has observed Sir Iain Chalmers (SIC) for many years, and has had the privilege of working on related projects with his eminent colleague, Sir Muir Gray, Chief Knowledge Officer for the NHS. The author wanted SIC’s organisation to validate this model because of its experience in promoting access to quality health information for patients and carers.

For over four decades, SIC has worked to improve methods for gathering evidence on the effects of health care interventions, and to promote public understanding of these methods. He qualified as a clinician in the 1960s, and spent seven years working as a clinician with the NHS and the United Nations Relief and Works Agency in the Gaza Strip. Between 1978 and 1992, he was the Director for the National Perinatal Epidemiology Unit in Oxford, which co-ordinated research, including systematic reviews of biomedical literature and randomised controlled trials. In 1992 he co-founded the Cochrane Collaboration, and was Director of the UK Cochrane Centre until 2002. The Cochrane Collaboration *“believes that effective health care is created through equal partnerships between researcher, provider, practitioner and patient*” (The Cochrane Collaboration, 1999). In recent years, to support the shared decision-making initiative, the Collaboration has been asking researchers to produce lay summaries alongside their full systematic reviews, for patients and carers so that they can have equal access to high quality research, in a more accessible format. He is currently co-ordinating the James Lind Initiative, which promotes joint research priority setting by patients and clinicians via the James Lind Initiative, and has established the UK Database of Uncertainties about the Effects of Treatments, which highlights gaps in the knowledge. For the past 30 years, SIC's priority has been to ensure that health professionals, and patients have free access to unbiased evidence of treatment effects.

4.8.1.3. TRIP Database Ltd

The author has met with Jon Brassey (JB) at several events related to patient information, including one organised by the Department of Health Information Standard, where the author was presenting. JB specialises in understanding and meeting the information needs of clinicians, rather than patients and carers. The author wanted his organisation to be one of the validators because of its experience in developing an evidence-based search engine. His technical expertise is important for evaluating the author’s model and highlighting any flaws in the design and functionality.

JB has been involved in clinical knowledge management and evidence based practice for 15 years, and the TRIP Database is his creation. Created in 2001, it is a filtered, clinical, search engine, which only searches high quality information sources and then arranges the results by levels of evidence, such as UK, and then international guidelines, systematic reviews, etc. It is designed to help clinicians find the best evidence to answer their clinical questions. The author has asked JB if he is going to develop something similar for patients and carers, but he says that it is not something he has the capacity for at the moment. JB is also the Director of ATTRACT, Public Health Wales, the clinical question and answering service for primary care in Wales. The various teams involved with TRIP and ATTRACT have answered more than 10,000 clinical questions.

4.8.1.4. CILIP Information Literacy Group

The CILIP Information Literacy Group (ILG) was included in the validation process, so that it would ensure that the framework upon which the model is based is robust and logical, and therefore providing strong foundations for the model. If the framework is flawed, the model will not work effectively. The author was the Group's representative for health libraries between 2009 and 2014.

Rebecca Mogg (RM) is the Deputy Chair of the Chartered Institute of Library and Information Professionals (CILIP) Information Literacy Group, which provides information literacy awareness and training support to library and information professionals in all sectors, including health, education, and public. Their support comes in the form of online training, face-to-face training, advocacy, and annual Librarians' Information Literacy Annual Conference (LILAC). Her interests lie in digital and information literacy and the development of reusable materials.

4.8.1.5. NHS England Information Standard

The author included The Information Standard in the validation process because it has strict criteria on what makes good quality health information and she felt that their experience would identify any issues with the information sources chosen for the model. She has been the Technical Expert for The Information Standard since 2009.

Colin MacKenzie (CM) is the Contract Director at Capita, and was responsible for managing and delivering The NHS England Information Standard. It is a recognised qualification awarded to patient information providers who have undergone a rigorous process to demonstrate that they have the systems in place for producing quality health information for patients and carers.

4.8.1.6. NHS England and NHS Direct

The author has been aware of Bob Gann's (BG) work as they have both worked on related Department of Health projects, such as the National Library for Health and NHS Direct. COCO will support the work of NHS England, so it is essential that it is using the information sources appropriately. BG has been involved with consumer health information since 1990, and his role has evolved as technology changes. For this reason, his expertise is invaluable for making sure that the model is fit for purpose.

BG is Head of Strategy and Engagement for NHS Choices, England's biggest health web-site providing the general public with information to make informed choices and improve their wellbeing. NHS England has a programme called widening digital participation, of which BG is the Programme Director. This programme aims to combat digital exclusion, increase health literacy, and widen digital participation. He has worked on NHS Direct from its start and was the Director of Partnerships and Strategy for NHS Choices, the online gateway to NHS services and information. It was important to include NHS England in this process because together with the Department of Health:

- it has produced most of the information sources that COCO will search;
- it is responsible for the delivery of health care to the general public in England, and
- it is making electronic health records available to patients.

These organisations were chosen because of their experience of consumer health information, electronic health records, and the development of resources to improve access to good quality health information. The general public was not invited to validate the system as they had had the opportunity to voice their requirements via an earlier survey to ascertain the need for this model. If the model should be developed, testing involving the general public will be a necessary stage of the implementation process. Representatives of organisations that represent the voice of the general public were given the opportunity to respond and this was felt to be sufficient for the validation process.

4.8.2. Validation process

As described in section 4.8.1., each of the potential validators was sent an email (Appendix 10) with the questions listed below, and with a separate document describing the background to the development of the model, including an introduction to the framework (Appendix 11), which provided the foundations for the resource, and a visual representation of the model, which can be found in section 4.9.1-4. further on in this chapter. They also received a set of four scenarios describing how the model would work together with a mock-up of what it would look like. A brief survey was produced using SurveyMonkey (http://www.surveymonkey.com), and participants were invited to read the background and model description and then answer the following questions:

1. Are there any parts of the consumer health information literacy stage of the framework that are unclear?
2. Does the model satisfy all the points in the consumer health information literacy stage? If not, please specify which ones are not satisfied.
3. Does the model do what you expect it to? If not, please specify what you expect it to do.
4. Can you spot any errors in the model?
5. Can you see if anything is missing from the model?
6. Do you think this model will be useful to patients and carers?
7. Is the model too simple/too complicated/just right?
8. Which organisation are you affiliated to? This is important so that the author can ensure the validation chapter is fairly represented.
9. The author will be quoting responses in the validation chapter. Would you like these to be anonymised?
10. If you have any additional comments to make about this work, please write them here.

Questions 8 and 9 ensured that the validators would have control over the publication of their comments in this thesis. Validators were given one month to respond. Responses were received from representatives of expertise in the areas of consumer health information, information literacy, search engine development, electronic health records, NHS general practice, and uncertainties in research outcomes. All responses are summarised further on in this chapter, and can be viewed in full, upon request.

4.8.3. Validation responses

4.8.3.1. Haughton and Thornley Medical Centres

Dr Amir Hannan (DAH) made no specific comments but agreed that the model would be useful to patients and carers, and would be interested in piloting the model should it become a live product.

4.8.3.2. James Lind Initiative

Sir Iain Chalmers (SIC) provided very useful discussion about the proposed model, starting by saying that "*my principal 'wonder' while reading through the material you sent to me was 'Will this work?' I didn't spot any reference to the recognition/conceptualisation of this question, let alone any discussion of how it might be addressed.*" He did not feel he could comment on the second question as he is not familiar with the consumer health information literacy stage. When asked if the model would do what it is expected to do, SIC said that "*it seems logical*." He was not convinced by the distinction that is made between the health professionals' interpretation of 'Outcome' and that of a patient, and feels that a patient with dementia would be delighted if their dementia could be cured. This is true, but it might not be true for all conditions. For example, a knee replacement option might produce the best outcome for a doctor, but it might not be the best option for a patient who is also a carer of another person as they would be immobile for some time while they heal and then who would look after their dependent? SIC said that he hopes the model will be useful, but that it does need to be tested, which is of course very true, and has been recognised earlier in this chapter. He does, however, feel that it is "*certainly good enough for testing*." As part of the survey, SIC made this final comment: "*This is important work. Predictably I am very pleased by your references to UK*

DUETs and the need to search for ongoing trials. I hope you may reconsider your decision to deal with these challenges in a separate search." Originally, before the validation process, there had been an option to search separately for ongoing clinical trials, as it was thought it might be too confusing to incorporate these with the results from the search for evidence.

An email discussion followed this comment, about the justification for keeping the search for ongoing trials separate from the COCO search engine. The initial thought was that if the ongoing trials were integrated into the results then there would be too much information. SIC feels that while it is right to be concerned about this, "*it would be worth finding out*" during user-testing to see, if by integrating the ongoing trials, there would or would not be information overload. SIC also asked about awareness of PubMed Health as he feels this is "*going to be a very important development.*" This has not been included as an information source at this stage, but upon further investigation, it may be, if it is relevant to the UK general public.

4.8.3.3. TRIP Database and Public Health Wales

Jon Brassey (JB) has already created a highly successful clinical search engine and therefore he was able to advice on the technical validity of the model. He does not feel that there are errors in the model, but he has made some observations. However, from the model description, he has understood that the consumer needs to recognise a source of information and says that COCO should recognise the most appropriate source, and not the patients and carers. To clarify, the patients and carers do not need to recognise sources of information. They just need to input as much information as they can about their condition and treatment, and then the COCO Database will choose the most appropriate source(s), and identify the best evidence for the consumer. With regards to the third step, about speaking to a health or information professional about different terms, JB says that by adding "*a human element you add cost, uncertainty and delay.*" He thinks the human element could be removed, with the key words mapping to index terms and other synonyms, which is a fair suggestion, but would exclude people who do not have the relevant computer literacy skills.

JB also felt that encouraging patients and carers to make a list of questions to take to their health professional "*opens a can of worms*". He wonders "*if there is a role for peer support*", possibly even discussion forums. The author does not understand why making a list of questions would be an issue, because patients and carers need to be fully informed when making treatment decisions and in evidence-based practice, this means that they need the best research evidence, their own preferences, and the clinical expertise. A list of questions will result in a focused dialogue between patients and their health professionals, with the patients and carers being clear about what they need to know. Peer support is an option, although may result in confusion as people might have other elements to their conditions, such as allergies, or additional conditions, and geographical variations in treatment (Right Care Atlas Team, 2011, Graley et al., 2011), possibly confounding advice from peers by giving the patient/carer irrelevant and inappropriate information. However, JB has raised it as an issue, and therefore, it will be addressed at the development stage.

JB does feel that it will be a useful model for patients and carers, but says that "*the key is implementation*." He asks "*what's to stop them always clicking on the 'Ask a librarian' link?*" This is true; there is nothing to stop them from clicking on the Ask a Librarian, but as long as there are sufficient human resources available, then this will not be an issue. The author understands JB's earlier comment that adding a human element to the model will incur additional cost, delay, and uncertainty, but the human resource is already in place, in academic, public, and medical libraries. The idea of the model is to ensure that patients/carers can get the information they need via a channel that suits them best, whether technical or human. The human solution will require staffing and time resource, but if people do choose the human solution, then this can be used as evidence of a service provision/training gap and the government will need to provide a solution if it wants people to participate in decisions made about their care pathway. One of the strengths of the technical solution is that it is available 24 hours a day, 7 days per week, with almost immediate response, while the human solution is not. This might discourage people from using the Ask A Librarian option, unless they really need to. Regardless, during the user testing stage of the model development process, the number of times the people clicking on the "Ask A Librarian" button will need to be measured to ensure that the model is financially feasible.

4.8.3.4. CILIP Information Literacy Group and Cardiff University

With her expertise in information literacy, Rebecca Mogg (RM) commented on the framework, saying that she does not feel the SCONUL criteria quite maps to evaluating performance in the

EBM five steps as she sees "*these as being distinct activities*". However, she does think that the consumer health interpretation "*does map well to the synthesis area of the SCONUL framework (although not creation of new knowledge)*", and therefore feels that this probably is not an issue. RM does not think that the "'*check relevant and reliable' stage [in the framework] is clearly addressed by the model*." This possibly is not clear from the model mock-up, but there will be links to critical appraisal tools and checklists to help patients and carers evaluate the quality of lower levels of evidence on the web-site. Furthermore, the content will be from reputable information sources, much of which will already have been evaluated. Rebecca is from an academic, but not health background, and therefore may not be aware of the levels of evidence (Haynes, 2006) in health care and the information sources available. She also asked if there is a prompt to address stage 5 of the framework which refers to keeping up to date with the literature for new developments. This is a good and valid observation, and something that should be built-in to the model. This can easily be done with RSS feeds and/or email alerts. It was imagined that people would only need to look for information once, but realistically, patients with long-term conditions would need to refresh their knowledge as their condition progresses and their treatment options change. Another very worthy observation from RM is about how the information will be presented to the patient. This is something that will need to be designed and tested with consumers of health information. The initial thought is to organise the information by levels of evidence, but this might not be appropriate, as they may not understand the difference between the different study types. Organising by treatment pathway would probably be useful, like the NHS Information Prescriptions (http://www.nhs.uk/ipg/Pages/IPStart.aspx#), which provide information on treatment, day to day living, general information, and living with the condition. This would be a more practical way of delivering the information to end users. RM also pointed out that "*the 'Option' search box could be difficult for patients to complete*" because they don't have full details of the options. She suggests having "*a 'did you mean…' search assistant added into it if the search terms entered by the patient don't get mapped correctly automatically*". This is a very helpful observation and it is another thing that can be evaluated during the testing period. Finally, RM has asked that the statement about the 'option' being more meaningful to patients than the PICO terminology be evidenced. There is no evidence to confirm this, and so again, perhaps the terminology should be tested on the target audience before the final launch of the model. In evidence-based medicine, there are two versions of the clinical 'PICO' framework. There is also 'PECO', where "intervention" is referred to as "exposure" (Maia and Antonio, 2012). A more generic term, such as “options” would perhaps be preferred, but this would need to be observed during the development and testing programme, with input from patient groups and organisations such as the Patient Information Forum.

4.8.3.5. The Information Standard at Capita (now with NHS England)

Colin MacKenzie (CM) said that it would be helpful to describe what health literacy is and why it is important. This has been written about in early chapters, but perhaps should have been written in the document sent to the validators, rather than just assuming that they understand what health literacy and health information literacy are. CM also suggested that the term “information leaflets” should be avoided and that “information products” should be used instead “*with recognition that patient information can be delivered through many different channels – products, online, mobile, video*”. This is a fair comment to make, as the COCO database will search for videos of patient experience, and as technology evolves, more media formats will become available. He also said that the proposed framework, involving the translation of the SCONUL 7 pillars framework and the 5 steps to evidence-based medicine, into a lay-person’s framework was “*really helpful and insightful*” and thought that “*it was very powerful*”. CM confirmed that “*the models and logic did make sense to me*”. He suggested that instead of referring to The Information Standard, the model should say “*The Information Standard certified information providers*”, which is a valid suggestion and text about the model will be amended to reflect this. He made a comment about the overall look and feel of COCO, saying that “*it feels more clinician focused (quite formal) than public*”. Although he stressed that this is his personal view, with his expertise around the production of patient information, it must be taken into account. The site must be accessible to its users otherwise it will be pointless. This is just the concept stage. As the model is developed, the general public will be involved to ensure that it is relevant and applicable to the target audience. Another observation, made by CM, about the design of the COCO database is that “*a description of which of the 4 categories to enter information may be required for the general public*”, as they might not understand where to put the drug name. This is a reasonable comment, and can be managed by installing information buttons with the descriptions at the end of each box. This would make sure that the page does not become too cluttered, but also makes sure the user can get hints about what should go in the box. CM concluded by saying that the model “*looks encouraging*” and suggests considering a mobile or App option.

4.8.3.6. NHS England and NHS Direct

Bob Gann's (BG) first comment is that he found that the framework was unclear. While his expertise lies in the NHS and patient information and engagement, it is possible that he is not familiar with the SCONUL 7 pillars of information literacy, and perhaps that is why it is not clear. Two other people had expressed an opinion about the clarity of the framework and so this needs to be reviewed. It was originally created as an aide-memoire to the development of the model, to ensure that all elements of the consumer health information literacy process are accounted for. BG pointed out that the model goes up to the evaluating and synthesising stages of information literacy, "*but doesn't seem to include whether the information can be acted on.*" He asks if this is out of the scope of this research and the model. It is out of scope because it is something a computer or a librarian cannot do. Once the patient/carer has the information that he/she needs, only they and their health professional can decide how to act on the information. BG points out that this is "*a binary model where the user either Ask a Librarian or self services via accessing COCO database.*" He suggests that the model integrates a similar system to NHS Direct and other customer service environments, whereby if the user runs a search but still needs more assistance, they can click on the Ask a Librarian button. This is easily done by making the Ask a Librarian visible on the search results page. BG feels that this will be a really useful resource as it highlights information sources that consumers may not be aware of, such as the TRIP Database. However, he does find it too complicated. He said that "*I found it a bit difficult to understand at first and I know quite a bit about this area*." This is concerning, because as he points out he is expert in this area. It might be an idea to run a series of focus groups with the general public before proceeding with the development of the product. The National Institute for Health Research Collaborations for Leadership in Applied Health Research and Care (NIHR CLAHRC) works with patients and the public to involve them with research. These groups would be ideal for developing and testing the model.

4.9. Validated model

The data taken from the validators' responses have not been checked by independent observers, and therefore there is a risk of observer bias. However, the comments that were made are available on request, and should there be a question of observer bias, the author's research has been carried out in a transparent manner, and any questions can be resolved.

Six people, from key organisations working in the area of patient information, have validated the model and they all agree that it is a worthwhile project, but they have made some suggestions, and these have been considered and changes made to the model to reflect the expert recommendations. Table 6 is a summary of the suggestions made:

Table 6: Summary of proposed changes to model following validation

Summary of proposed changes	Description
Integrate clinical trials	Clinical trials will help patients and carers identify new treatments that are in development.
Consider PubMed Health as an information source	This is a collection of summaries of clinical research, written in plain English for patients and carers.
Mapping to medical thesaurus	This exists already, but was not made clear enough in the description.
RSS feeds and email alerts	This will mean people can keep up-to-date without constantly having to re-run the search.
Refer to information products rather than leaflets	With developments in technology, information is available in a range of media.
Installing information buttons	These buttons would help people understand how to fill in each section.
Ask A Librarian on the search results page	This will enable people to ask for additional help whenever they need it.

These suggestions are described in greater depth below:

- **Integrating ongoing trials into the model** – initial thoughts had been that clinical trials should involve a separate search rather than being integrated into the main COCO search tool. Access to clinical trial information may create confusion by adding a choice which might not be appropriate for the patient or may raise expectations. Clinical trials are quite specific about the population they need to recruit and a patient might see a recruiting trial but might not meet the inclusion criteria, which might lead to disappointment and frustration. However, SIC from the James Lind Initiative (Chalmers et al., 2013) pointed out that we do not know if this would be the case and that perhaps we should try integrating them into the main search function and then testing them on the target audience.

- **Reviewing whether PubMed Health should be added as an information source** – Sir SIC suggested that the database might consider including PubMed Health as an information source. While this is an excellent resource and the COCO database does retrieve results from PubMed via the TRIP Database, providing access to quality health information written for an American population might be counter-productive as patients and carers will already have access to content on similar, if not the same conditions, and therefore it would make sense to link to publications written for a UK audience rather than US. Furthermore, the information about treatments will differ between England and America, particularly with regards to drug dosages. However, if no other information is available then PubMed Health would be a reliable alternative.
- **Linking the search to a medical thesaurus** – this was raised by JB, representing the TRIP Database and Public Health Wales, and perhaps it was not made clear in the description of the original model, but the COCO Database will link to the National Library of Medicine's Medical Subject Headings Database (http://www.nlm.nih.gov/mesh/MBrowser.html), which is a medical thesaurus. This means that when the user types in a medical term, it goes straight to the Index to find a match, and this match will include all the synonyms and alternative spellings, so that the patient/carer does not have to worry about thinking of all the related terms. For example, typing in Deep Vein Thrombosis will map to Venous Thrombosis, and find results for deep vein thrombosis, DVT, venous thrombosis, and phlebothrombosis, all terms for the same condition. Therefore, no change is required following this feedback, as it is already accounted for in the design.
- **Building in RSS feeds and email alerts to stay up-to-date** – RM, CILIP Information Literacy Group, pointed out that the model does not address stage 5 of the framework which refers to keeping up to date with the literature for new developments. The new, validated version of the model has RSS feeds and the option to set up email alerts, so that when new content is added to any of the information sources, the patient/carer will be informed via RSS feeds or the email alerts.

- **Changing information leaflets to information products** – CM, of The Information Standard at Capita, suggested that the model refer to information products rather than information products, to reflect the different media available, for example, videos, etc. This makes sense as the COCO Database will be searching resources such as Healthtalkonline, which contains videos of patient experiences.
- **Installing information buttons at the end of each search box** – BG, representing NHS Direct and NHS England, said that people might not understand what the different search boxes mean, so the new design will have an information button at the end of each box, which users can hover over for more information.
- **Ask A Librarian button on the results page** – so that people can have a go themselves and then refer to a qualified librarian for additional support.

These are all functional changes and their feasibility will be assessed during the testing period. Also during the test sessions, at which target users will have the chance to explore the model in practice, specific observations will be carried out, such as:

- how many times people just click on the "Ask A Librarian" button;
- whether a "Did you mean...? search assistant" would be useful, and
- whether PICO is better than COCO.

Therefore, the validated model now looks like this (please note that changes following the validation process are in red):

Figure 13: Revised mock-up of the COCO Database post-validation

COCO Database

Gateway to quality health information for patients and carers

Condition	[Enter name of condition]
Option	[Enter name of treatment] optional
Choice	[Enter name of treatment alternatives] optional
Outcome	[Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility] optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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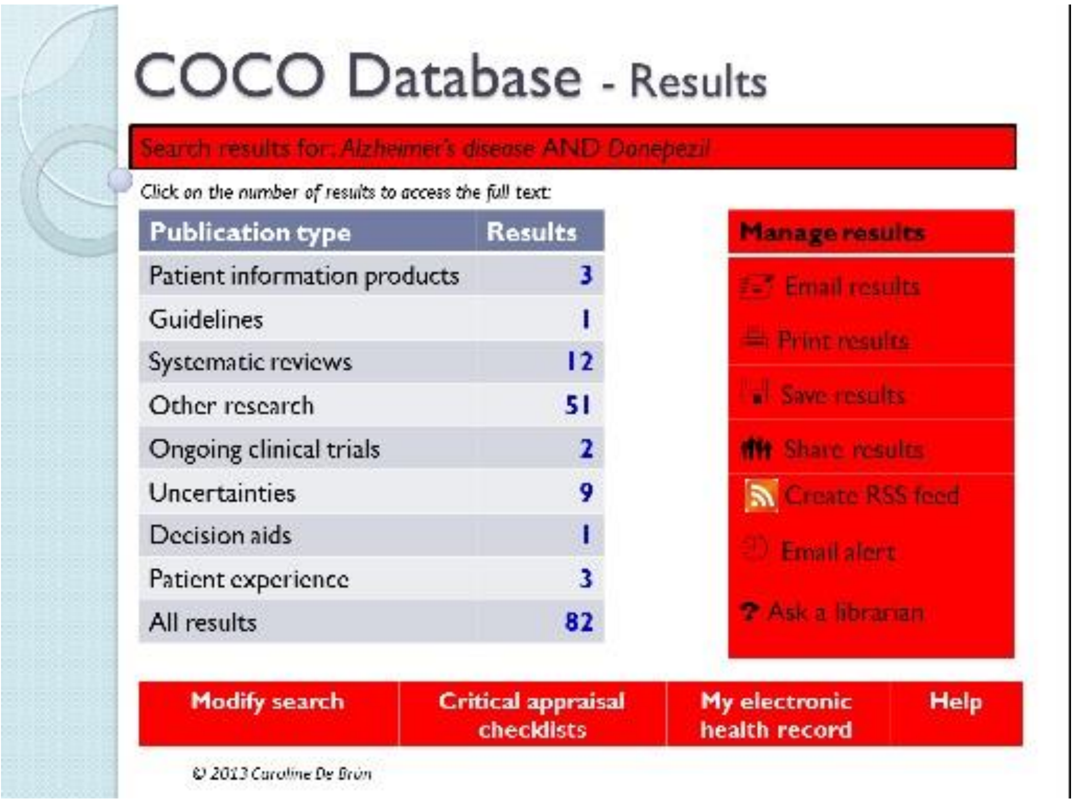
Results will be displayed as follows, with the option to modify the search if required:

Figure 14: Mock-up showing how results will be displayed on the COCO Database



COCO Database - Results

Search results for: *Alzheimer's disease AND Donepezil*

Click on the number of results to access the full text:

Publication type	Results
Patient information products	3
Guidelines	1
Systematic reviews	12
Other research	51
Ongoing clinical trials	2
Uncertainties	9
Decision aids	1
Patient experience	3
All results	82

Manage results

- Email results
- Print results
- Save results
- Share results
- Create RSS feed
- Email alert
- Ask a librarian

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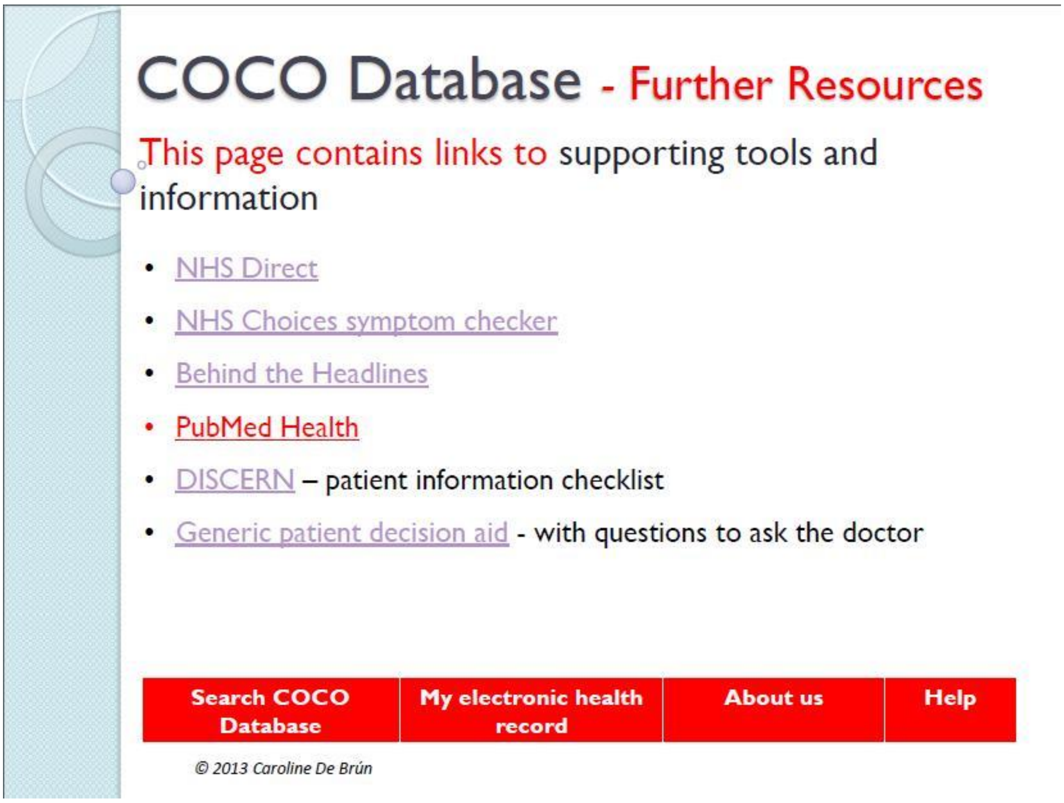
This final mock-up shows the revised “Further Resources” page, following validation

Figure 15: Mock-up of revised “Further Resources” post-validation



COCO Database - Further Resources

This page contains links to supporting tools and information

- NHS Direct
- NHS Choices symptom checker
- Behind the Headlines
- PubMed Health
- DISCERN – patient information checklist
- Generic patient decision aid - with questions to ask the doctor

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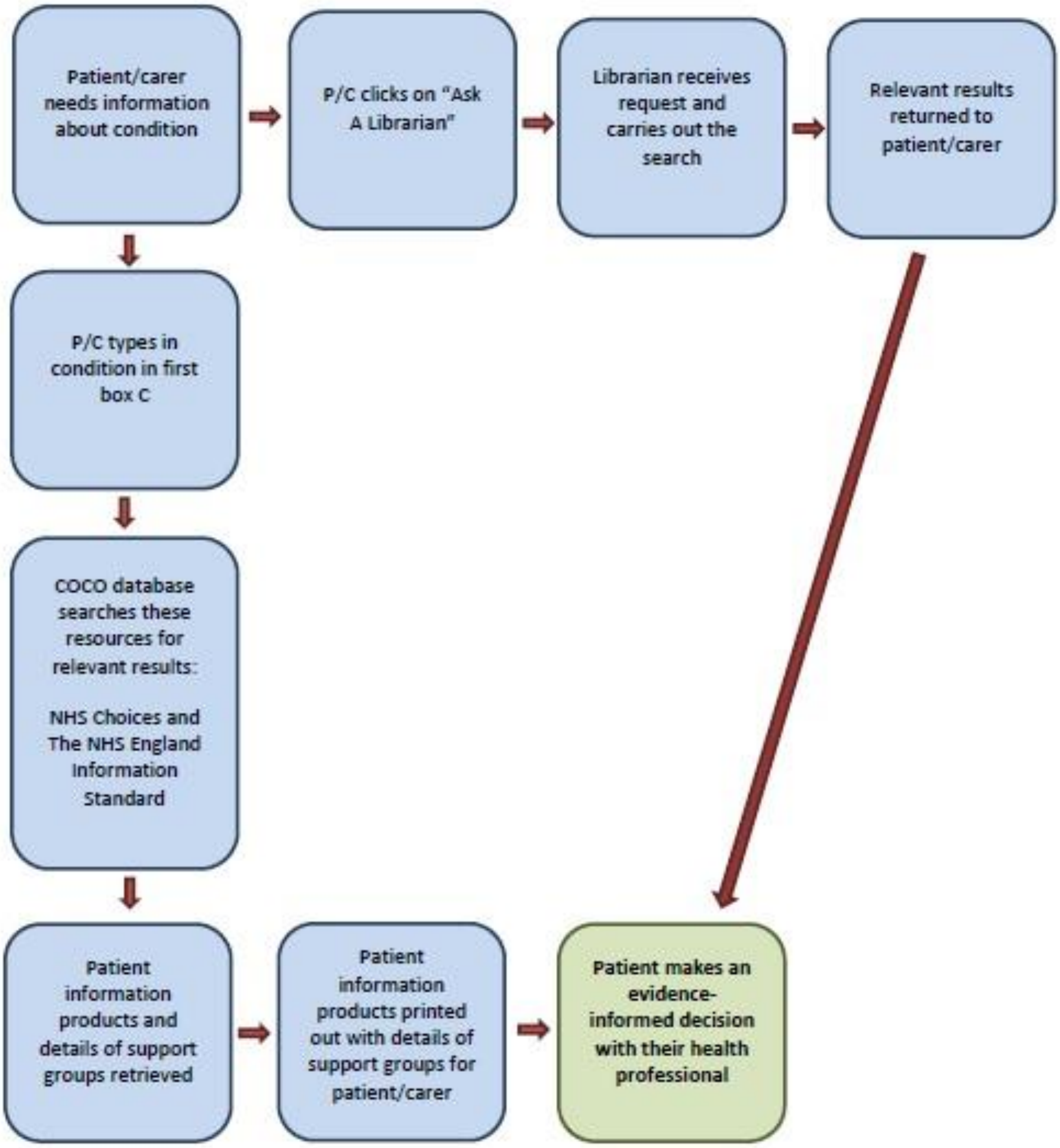
Please note: As of April 2014, NHS Direct no longer exists so this will not exist in the final product.

The following pages provide a visual explanation of how the database will work for each of the earlier scenarios:

4.9.1. Model scenario 1

For the past few months, Benjamin P. has been struggling with his memory and has been finding conversations difficult because he gets his words confused. After several visits to his GP and then a specialist, he is diagnosed with early on-set Alzheimer's disease. He isn't clear what this means, and although his doctors have explained it to him, he, and his family who will care for him, want to find out more about his newly-diagnosed condition and what they can expect.

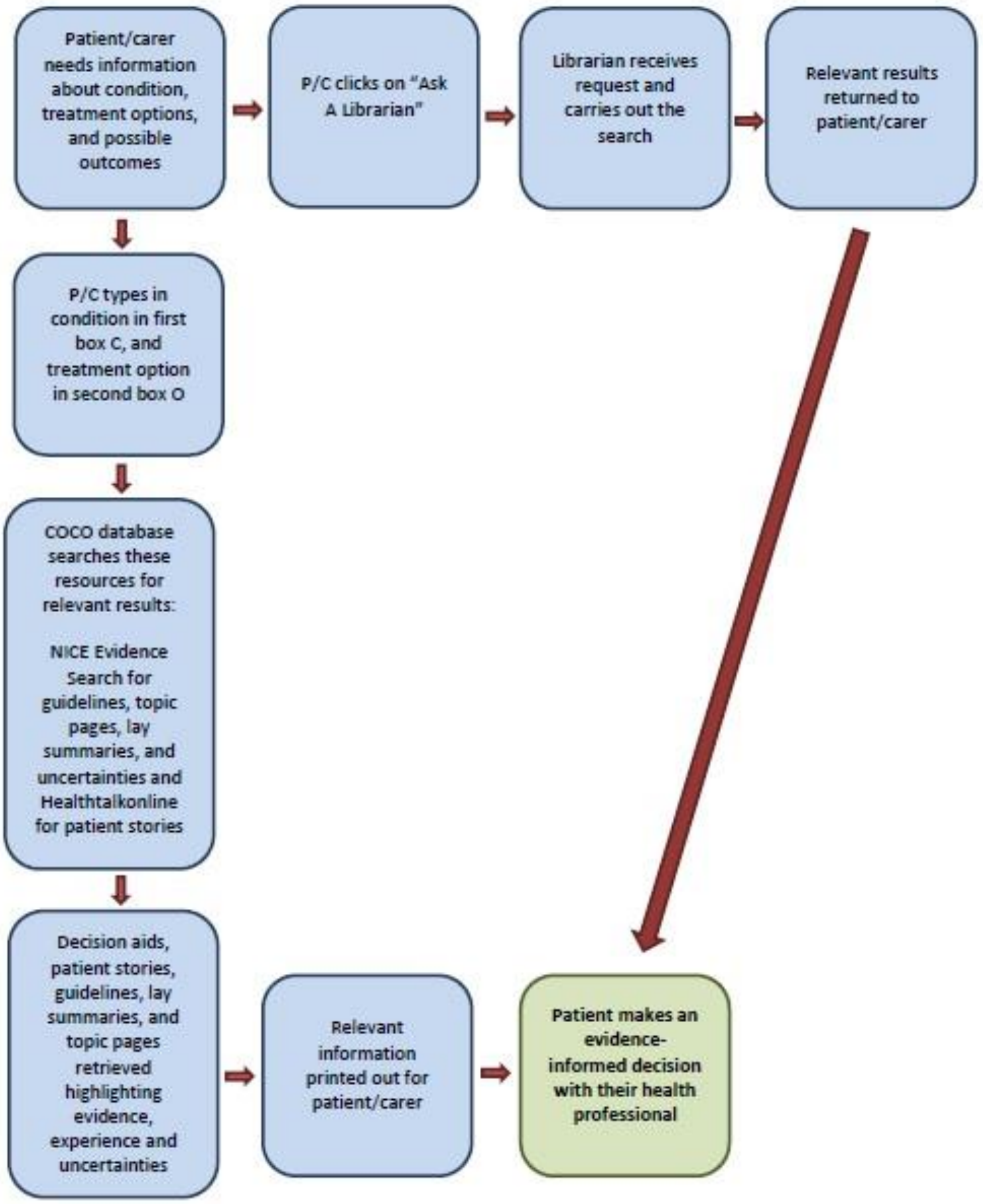
Figure 16: Visual depiction of scenario 1



4.9.2. Model scenario 2

Alzheimer's disease cannot be cured, but there are various medication options available. Benjamin has been prescribed donepezil, an acetylcholinesterase (AChE) inhibitors (National Institute for Health and Care Excellence, 2011) for the early stages of Alzheimer's disease, and he and his family want to know more about how this drug will affect him and if there are any side effects they should be aware of.

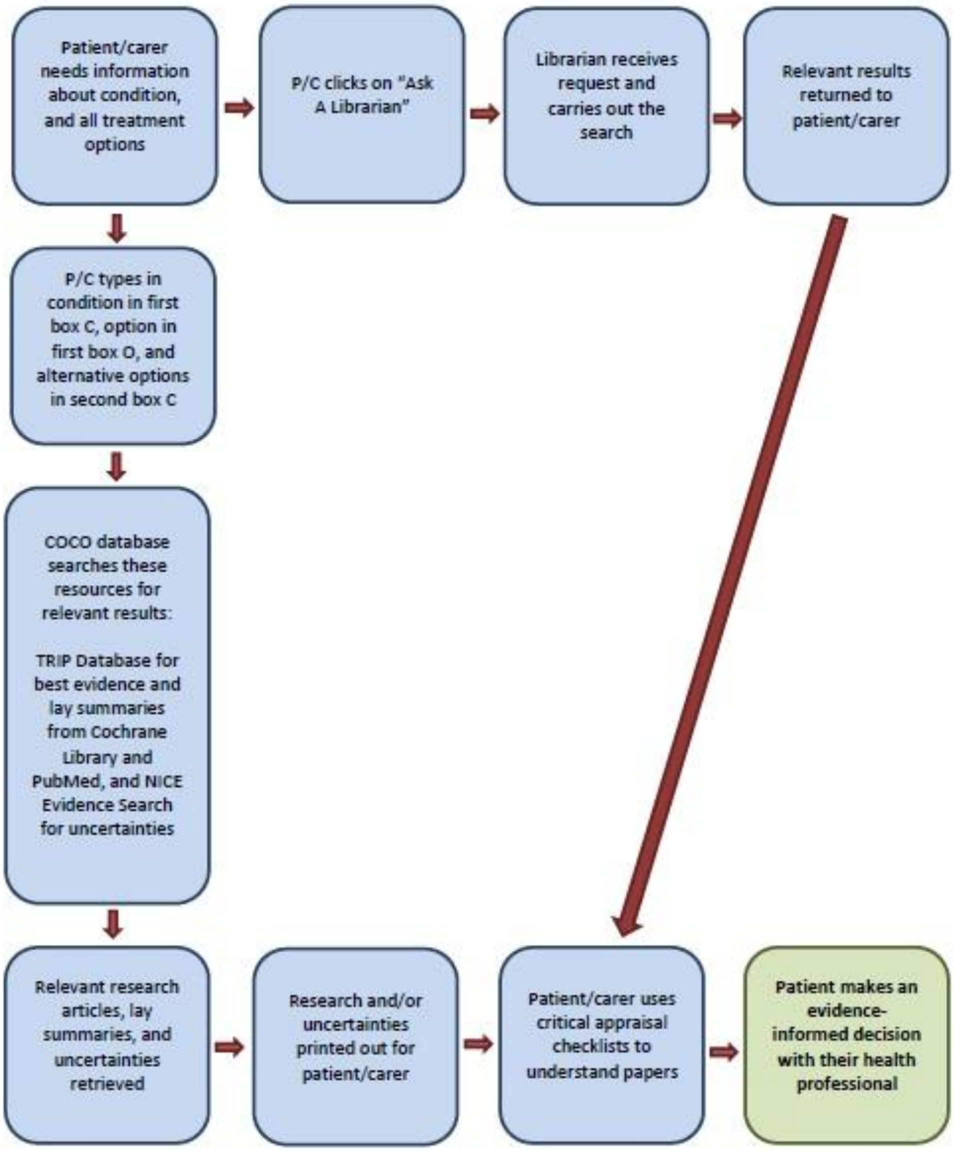
Figure 17: Visual depiction of scenario 2



4.9.3. Model scenario 3

Benjamin has been on his treatment for 3 months, and while his symptoms are more under control, he has been feeling depressed at his situation. His daughter has heard that some aromatherapy oils can improve cognition and alleviate symptoms of depression (Alzheimer's Society, 2013), and they would like to find out more about this as a complementary option to his current drug treatment regime.

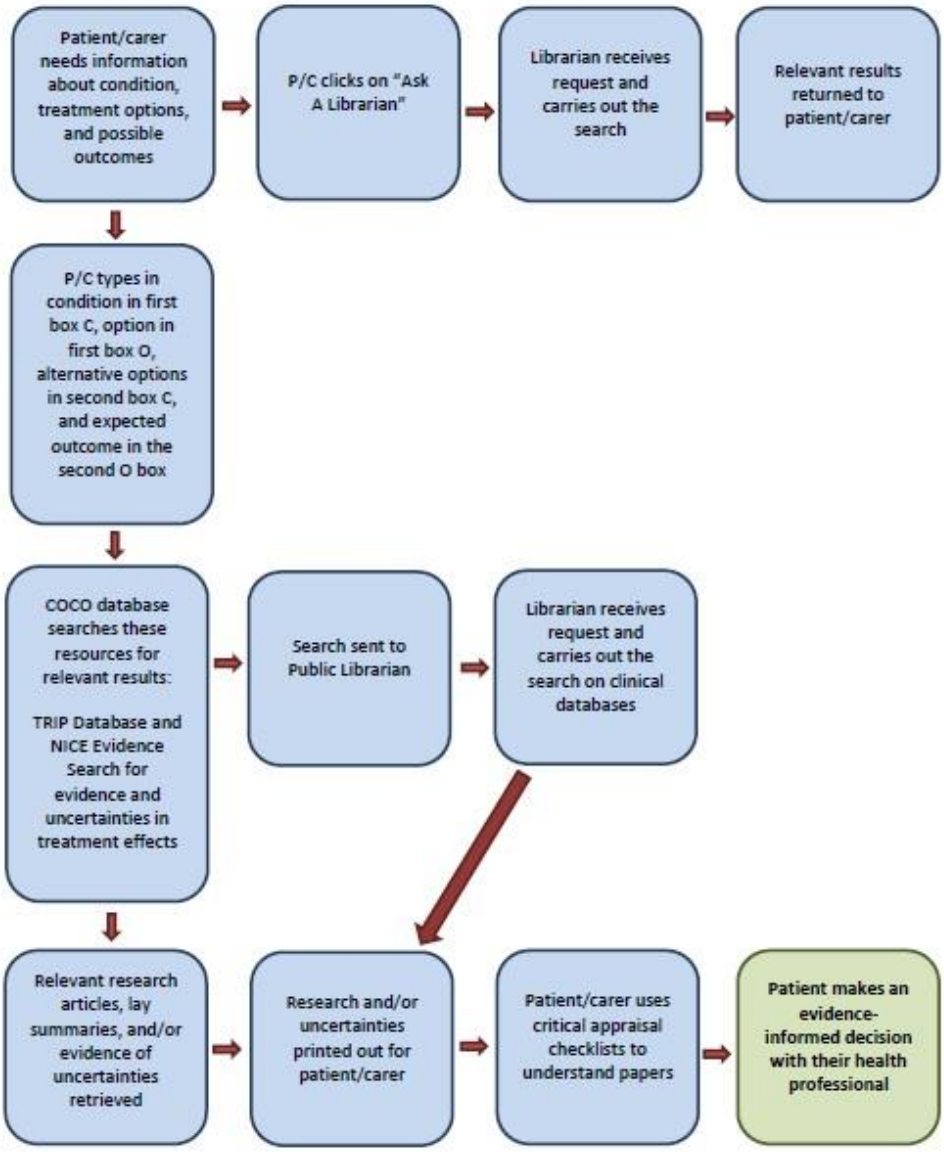
Figure 18: Visual depiction of scenario 3



4.9.4. Model scenario 4

Before his illness, Benjamin was very active, working in volunteer shops, and a participating member of the local golf club. With the treatment he is on, he is finding that he is getting very tired, particularly as he often finds it difficult to sleep (N.H.S. Choices, 2012), common side effects when taking Donepezil. This is having an impact on his quality of life as he is not able to play golf as often as he would like, and therefore isn't meeting his friends as much, so his social life is also being affected. He would like more information about how he can improve his quality of life, while controlling his symptoms.

Figure 19: Visual depiction of scenario 4



4.10. Chapter summary

Model validation is necessary because it allows researchers to "*choose among alternative models or decide whether a model is acceptable or not*" (Liu et al., 2011). The model that has been validated is the second iteration, the first being the peripatetic librarian, described in section 1.3, which was dismissed as impractical for logistical and financial reasons. This newer model has been developed with the evidence-based medicine concept in mind. The literature review presents the evidence, stakeholders, in the form of patients and carers have described their preferences via the survey carried out, and finally, the model has been validated by experts in the areas of consumer health information and information literacy. The literature provides the proof that there is a need for a solution, while the patient/carer survey responses help drive how the model should be developed, but these responses are very much focused on the individual. The role of the validators is to make sure that the model can be applied to the population as a whole. All in all, solutions cannot be created on evidence alone, human judgement gathered from individuals and relevant groups is essential to producing a robust outcome.

This is a knowledge management model, building on existing expertise and resources, and the sharing of experience and knowledge, to deliver an innovative service. It is innovative because there is not a technical solution available to patients at the moment, as there is for health professionals, and a collaboration between two library sectors is not currently being applied. An important part of this work will be demonstrating to the NHS that this work is integral to the patient involvement programme, because without access to good quality health information, it will be very difficult for people to make informed decisions about their treatment choice. The verification and validation process has demonstrated that experts in the area of consumer health information literacy and education agree that this is an appropriate model, but that some adjustments are required, in addition to testing, to make sure that it is fit for purpose.

The main benefit of COCO is that people can go to one site to access all the resources, including their electronic health record, and they would only have to register once and have one password. They will only have to navigate one interface, without having to know about all the sources that are included in COCO. Furthermore, should new resources be created within the NHS, they can be integrated as part of COCO, ensuring that people do not have to learn a new system to access the information that they need.

The next chapter will test the model using real-life consumer scenarios, comparing Google with COCO and demonstrating how COCO will make the searching experience easier for users.

Chapter 5 – User validation

Peter Drucker

5.1. Introduction

The previous chapter introduced the validated model, but the success of the model cannot be predicted without user involvement. For the purposes of this research, users are defined as members of the general public who either suffer from a diagnosed condition or care for someone with a diagnosed condition.

5.2. User validation methodology

While the author has access to potential users, as they are unwell, user involvement is be based on health questions that the author has collected from the general public while working as a medical librarian, and from family members and friends.

The validation process taken involved two stages:

1. The author searched Google for the answers to the following four scenarios, using keywords suggested by the people related to the question. There are other search engines that the author could have used, but the author chose Google because it is the most popular, with a global market share of 66.44% (Net Market Share, 2014). The first page of Google results was reviewed for quality, using Silberg's criteria (Silberg et al., 1997), summarised in Table 5, section 2.2.5.8., and for relevancy to the population described in the scenarios. Silberg's criteria was used because although there are other checklists available, such as Intute and Discern, they are much longer and more comprehensive, and the author is attempting to replicate how a user would approach quality assessment, and is confident the simpler the process, the more useful.

A traffic-light approach was taken to distinguish the good from the bad results, with red being poor quality and irrelevant, and not meeting any of Silberg's criteria, amber being potentially good quality, and possibly relevant, and green being the best quality and very relevant. The full analysis, with the author's commentary, can be found in Appendix 12. Silberg's criteria, although written in 1997, are still pertinent to information today, and are easy to apply by both health professionals and lay-persons. As a reminder, Silberg's 4 standards are:

- Authorship - Who wrote the content and what are their credentials? Are they qualified to provide this information?
- Attribution - is it clear how the information was generated, e.g. is it referenced?
- Disclosure - is the web-site sponsored by anyone who might have a commercial gain? When did they write it? Who did they write it for?
- Currency - is there a date to indicate age of the content? (Silberg et al., 1997)

2. As COCO is not a live model yet, the author has replicated the Google searches on the different information sources pertinent for each of COCO's four stages:

    - Scenario 1 – NHS Choices, NHS England Information Standard
    - Scenario 2 – NICE Evidence Search
    - Scenario 3 – TRIP Database
    - Scenario 4 – Ask a Librarian, TRIP Database, NICE Evidence Search

    Please see Chapter 4 (sections 4.9.1.-4.9.4.) for more information about the design of COCO.

The author used the following validation metrics (Liu et al., 2011) for this process, and the results will be discussed after the analysis of the results in section 5.4.:

- Evidence-based – does the content provide a list of references?
- Relevance – can the information be applied to the scenario in question?
- Meet Silberg's quality criteria – does the content meet the 4 quality criteria (as described in Table 5, section 2.2.5.8.)?
- Independent quality check process – has the organisation and/or author of the content been through a formal process of quality assessment, such as the NHS England Information Standard, or peer review?

This activity will be useful for testing the final live product, as it demonstrates what is expected of COCO, and when the live version is tested, these will be the sort of results that it should retrieve.

5.3. Scenarios used

The author has gathered four real-life scenarios from her professional experience, friends, and family. The stories are anonymous to protect their privacy.

5.3.1. Scenario 1

Person A has just been diagnosed with Myalgic Encephalomyelitis (M.E.), a growing and debilitating condition, which tends to present following glandular fever or mononucleosis. It is particularly difficult to search for, because it has several alternative names. In England, it is commonly known as M.E. but in America, it is referred to as Chronic Fatigue Syndrome or Chronic Fatigue Immune Deficiency Syndrome (CFIDS).

Table 7: Example of Scenario 1 terms entered in COCO

C	Chronic fatigue syndrome
O	Not required
C	Not required
O	Not required

Google results – scenario 1:

QUESTION: **What is myalgic encephalomyelitis (M.E.)?**

SEARCH TERMS: myalgic encephalomyelitis – retrieves 335,000 results and chronic fatigue syndrome – retrieves 10,300,300 results.

DATE SEARCHED: 29/11/14

In Google a search for ME retrieves 1,790,000,000 hits, but this will include papers about the pronoun "me". Entering "myalgic encephalomyelitis" retrieves 355,000 results and they are very relevant, including information from the ME Association, NHS Choices, and Action for ME, but it is a very difficult phrase to type in, and spelling mistakes can be made. Clinicians, researchers, and NHS organisations are using the term Chronic Fatigue Syndrome more widely now in England, and the US, and this retrieves 10,300,300 results, fewer than ME, but significantly more than myalgic encephalomyelitis. However, the results start off with three adverts, which may be misleading. In fact, one of the adverts (Chronic fatigue syndrome - www.mollysfund.org/chronic-fatigue) actually talks about Lupus, a different condition, which may cause confusion and additional concern for the person looking for information on chronic fatigue syndrome. This last search does bring up papers via Google Scholar, and the first three seem very relevant, but were written in 2001, 2002, and 1994 respectively, and research into ME has moved on significantly since then. There were an additional 9 web-sites listed followed by three in-depth articles. None of the three in-depth articles were rigorous pieces of research. In fact, although this is a simple search for more information about a condition, out of 18 results, only 3 are high quality and relevant to the target audience.

COCO results – scenario 1:

QUESTION: **What is Myalgic Encephalitis (M.E.)?**

SEARCH TERMS: Myalgic Encephalomyelitis

INFORMATION SOURCES: NHS Choices – retrieves 15 results, The Information Standard – retrieves 0 results, although Chronic fatigue syndrome found 25 results.

DATE SEARCHED: 29/11/14

The author searched NHS Choices and the NHS England Information Standard for information about Myalgic Encephalomyelitis. This term was typed in to NHS Choices (http://www.nhs.uk) and automatically mapped to Chronic fatigue syndrome, the alternative name for M.E. Fifteen results were retrieved. The search was also run on The Information Standard (http://www.england.nhs.uk/tis/). No results were retrieved for Myalgic Encephalomyelitis, but forty documents were retrieved for Chronic fatigue syndrome. The top four were completely relevant and patient/carer oriented, and come from NHS Choices, the web-site created by the Department of Health, to ensure that the general public has access to the best quality health information. This information has been accredited with the NHS England Information Standard:

Table 8: Results for Scenario 1, retrieved from COCO

Results	Details	Comments
1	**Chronic fatigue syndrome – overview, symptoms, causes, diagnosis, treatment – NHS Choices** http://www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/introduction.aspx	This information has been created with user involvement, and written in an appropriate for the target audience. It has also been through the NHS England Information Standard accreditation system
2	**Chronic fatigue syndrome – NHS Choices Health Unlocked community** http://www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/community.aspx	This is a secure, online environment designed for NHS Choices, to help sufferers share experiences.
3	**Clinical trials for Chronic fatigue syndrome** http://www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/clinical-trial.aspx	This information is provided by the World Health Organization International Clinical Trials Registry, and enables patients and carers to find information about ongoing clinical trials related to Chronic fatigue syndrome.

Results	Details	Comments
4	**Map of Medicine: chronic fatigue syndrome** http://www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/mapofmedicinepage.aspx	This is a visual depiction of the treatment pathway, a patient will follow, based on the best and latest evidence.

5.3.2. Scenario 2

Person B is a woman in her early forties, recently diagnosed with peritoneal mesothelioma, and wants to know if taking alternative medicines will extend the prognosis. The mesothelium is the clinical name for the lining that covers many of the body's internal organs. Mesothelioma is a cancer which grows from mesothelium cells. It is thought to be caused by asbestos exposure. There are various types of mesothelioma, including pleural mesothelioma (lining protecting the lungs), and the rarer peritoneal mesothelioma (stomach lining). Person B's search was entered in COCO as follows:

Table 9: Example of Scenario 2 terms entered in COCO

C	Peritoneal mesothelioma
O	Alternative therapies
C	Not required
O	Not required

Google results – scenario 2:

QUESTION: **Are there any alternative therapies which can treat a rare form of cancer called peritoneal mesothelioma?**

SEARCH TERMS: peritoneal mesothelioma alternative therapy – retrieves 530,000 results.

DATE SEARCHED: 29/11/14

This is a rare condition and it is very difficult to find good quality health information about it. From the first ten results in Google, only one may have been useful, but it is written for an American audience and the treatments may not be available in the UK. Because the condition is believed to stem from asbestos exposure, there are often litigation cases arising following diagnosis, so on the American web-sites, there are many links to legal information and lawyers, which will not be relevant in the UK. Some of the results looked as though they might be evidence-based, but either there were no references or author credentials, or if there were references, they were old and the information had not been reviewed or updated.

COCO results – scenario 2:

QUESTION: **Are there any alternative therapies which can treat a rare form of cancer called peritoneal mesothelioma?**

SEARCH TERMS: peritoneal mesothelioma alternative therapy

INFORMATION SOURCES: NICE Evidence Search, Database of Uncertainties of Effects of Treatments, and HealthTalkOnline – retrieves no results.

DATE SEARCHED: 29/11/14

The terms peritoneal mesothelioma alternative therapy were typed in to NICE Evidence Search (http://www.evidence.nhs.uk, which includes the Databases of Uncertainties of Effects of Treatments, and HealthTalkOnline (http://healthtalkonline.org/). Unfortunately, no results were found using COCO's methodology. This is because it is such a rare condition, and the information sources that COCO applies, focus on more common conditions. The user could now use the Ask A Librarian feature, requesting a more in-depth search, which include searching relevant databases, such as AMED (Allied and Complementary Medicine Database). Alternatively, she can use a broader term, and search for cancer and alternative therapy instead. This would retrieve the following results, which may usefully answer her question.

The author searched NICE Evidence Search for information about cancer and alternative therapies. The symptoms and treatment for ovarian cancer and peritoneal mesothelioma are similar. There were 10,586 results in total, which although many, is still considerably fewer than Google. The top ten were mostly relevant (with the exception that some are set in Australia and New Zealand) and the top three are completely relevant:

Table 10: Results for Scenario 2, retrieved from COCO

Results	Details	Comments
1	**Alternative therapies for ovarian cancer** http://www.cancerresearchuk.org/about-cancer/cancers-in-general/cancer-questions/alternative-therapies-for-ovarian-cancer Cancer Research UK February 2014	Cancer Research has been accredited with the NHS England Information Standard, and therefore the information provided is reliable and has been written for the target audience. While the information is about ovarian cancer, it will hopefully provide information about using alternative therapies to manage other forms of cancer, including peritoneal mesothelioma.
2	**Efficacy of complementary and alternative medicine therapies in relieving cancer pain: a systematic review** http://www.crd.york.ac.uk/crdweb/ShowRecord.asp?LinkFrom=OAI&ID=12007001592 Database of Abstracts of Reviews of Effects May 2009	This paper has been quality-assessed at the University of York. It is a research paper, so not targeted towards the general public, but information can be gleaned from it, that can be discussed with her consultant.
3	**Use of the best case series to evaluate complementary and alternative therapies for cancer: a systematic review** http://www.ncbi.nlm.nih.gov/pubmed/12516038 Seminars in Oncology December 2002	This is the abstract of a research paper that, so again, it is not targeted towards the general public, and it is not freely available to Person C in full text. Therefore, she would need her physician's assistance or that of her local paper to retrieve the full-text. However, there is also quite a lot of information to be taken from the abstract of an article. Person C can also find the contact details of the author of the article and contact them directly for more information.

5.3.3. Scenario 3

Person C is a young woman in her early thirties, who has been diagnosed with a gastrointestinal disorder known as Crohn's Disease. She experiences immense abdominal pain and bouts of sickness. She has been prescribed steroids to relieve the symptoms, but she has heard that changing her diet can make a difference to her quality of life and would like to find out more. It is difficult to find the best information without knowing which terms are the most relevant to use. This condition is also known as ulcerative colitis, and the broader term, inflammatory bowel disease. Furthermore, there is the issue with spelling. Crohn's is not easy to spell, and can be spelled as Crohns or Crohn's. Person C wants to know if a change in diet can be applied alongside conventional therapies such as steroids:

Table 11: Example of Scenario 3 terms entered in COCO

C	Crohns disease
O	Steroids
C	Diet
O	Not required

Google results – scenario 3:

QUESTION: **Can a change in diet be used as an alternative to steroids in the treatment of Crohn's Disease?**

SEARCH TERMS: crohns steroids diet – retrieves 438,000 results.

DATE SEARCHED: 04/12/14

This is a very common condition, and one would expect there to be good quality results readily available. However, on Google, from the first ten results, not one would answer the user's question. There was one site which was written for a UK audience, but it was a patient information leaflet, providing an overview of Crohn's disease, its symptoms, diagnosis and treatment, but nothing comprehensive. This may be because the wrong terminology was used, but would a patient or carer have time to try different terms? Would they understand that there are other names for the condition? All of the information, including the NICE guideline, focused on the steroid aspect of the diet, rather than diet, so it was irrelevant to the scenario. Some of the information came from commercial organisations, so there may be bias.

COCO results – scenario 3:

QUESTION: **Can a change in diet be used as an alternative to steroids in the treatment of Crohn's Disease?**

SEARCH TERMS: crohns steroids diet

INFORMATION SOURCES: TRIP Database – retrieves 256 results, Cochrane Summaries – retrieves 0 results, PubMed Central – retrieves 43 results, NICE Evidence Search - retrieves 344 results.

DATE SEARCHED: 04/12/14

The author searched the TRIP Database first and found 256 results organised by quality. There are two methods for viewing the information, by type or by levels of evidence. By evidence, there were 8 evidence-based synopses, which are summaries of the best evidence. There were 10 systematic reviews, 78 guidelines, 3 clinical Q & As, 2 pieces of key primary research, 41 controlled trials, 11 extended pieces of primary research, and 108 eTextbooks. Further results were found on PubMed Central (open access journal articles), Cochrane Summaries, and NICE Evidence Search, making a total of 643 results. The author has not reviewed all the results, because having looked through the first set of results, she has identified several sources that are up-to-date and answer Person C's question. It should however, be noted that this resource is designed for health professionals, and therefore the information should be shared with the clinician. The links provided below have been selected from all those results and were chosen because of their relevance to the original question, the language applied, e.g. written in plain language, and the quality of the content. This is a simulation, and the author has applied her information literacy skills when making the selections. When COCO is live, techniques will be applied to ensure that the most relevant content from all of these information sources will be boosted to the top of the list. The author has tried to demonstrate this effect in her choices. The following content is quality evidence, freely available, demonstrating that appropriate diet can relieve the symptoms of Crohn's disease:

Table 12: Results for Scenario 3, retrieved from COCO

Results	Details	Comments
1	**Food and IBD** http://www.crohnsandcolitis.org.uk/Resources/CrohnsAndColitisUK/Documents/Publications/Booklets/Food%20and%20IBD.pdf Crohn's and Colitis UK 2012	This is the ideal resource for Person C as it has been written by a patient support group which has been awarded the NHS England Information Standard for quality. The content is completely relevant as it looks at the type of foods that are right and wrong for sufferers of Inflammatory Bowel Disease, with which Crohn's is associated.
2	**Lifestyle-related disease in Crohn's disease: relapse prevention by a semi-vegetarian diet** http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2877178/ World Journal of Gastroenterology, 2010, 16(20):2484-2495	This is a good quality research paper which is freely available to the general public and relevant to Person C's requirements.
3	**Crohns disease** http://www.bupa.co.uk/health-information/directory/c/crohns-disease BUPA Health Information 2012	Although this is published by a commercial organisation, the information is supported by three standards: Plain English Campaign, the NHS England Information Standard, and the HONcode. There is a review date, details about their health editors and a link to the references that informed the information. Therefore, it is a reliable source for Person C to use.
4	**Nutritional therapy for active Crohn's disease** http://www.ncbi.nlm.nih.gov/pmc/articles/pmid/18666339/ World Journal of Gastroenterology, 2008, 14(27):4420-3	This is a good quality research paper which is freely available to the general public and relevant to Person C's requirements. It is more about nutritional therapy, e.g. supplements, rather than change in diet, but it will be informative.
5	**Higher predicted vitamin D status is associated with reduced risk of Crohn's disease** http://www.ncbi.nlm.nih.gov/pmc/articles/pmid/22155183/ Gastroenterology, 2012. 142(3):482-9	This is a good quality research paper which is freely available to the general public and relevant to Person C's requirements.
6	**Vitamin D-mediated calcium absorption in patients with clinically stable Crohn's disease: a pilot study** http://www.ncbi.nlm.nih.gov/pmc/articles/pmid/20306476/ Molecular Nutrition and Food Research, 2010, 54(8):1085-91	This is a good quality research paper which is freely available to the general public and relevant to Person C's requirements. The language might be quite technical, but together with the health professional, it can be used to make a shared decision.

Results	Details	Comments
7	**Omega 3 fatty acids (fish oil) for maintenance of remission in Crohn's disease** http://summaries.cochrane.org/CD006320/IBD_omega-3-fatty-acids-fish-oil-for-maintenance-of-remission-in-crohns-disease Cochrane Summaries February 2014	This is a very good quality resource as it has been produced by the Cochrane Collaboration. Cochrane is an international network bringing together health practitioners, researchers, and patient advocates, to turn the vast amount of research evidence into useful research that can be used to make informed health care decisions. Recently, the network has been asking authors to write lay summaries specifically aimed at the general public, so that they can get the overall picture, without having to plough through in-depth research analysis, which can be daunting if you are not a researcher.
8	**Zinc** http://www.nlm.nih.gov/medlineplus/druginfo/natural/982.html Medline Plus: a service of the U.S. National Library of Medicine, National Institutes of Health April 2013	This is a high-quality American web-site, which draws from international evidence. The information provided should be discussed with the health professional to see whether Zinc supplements would be an appropriate supplement to take.

5.3.4. Scenario 4

Person D is a keen cyclist, in his mid-fifties, who more recently has started to suffer from hypoglycaemia (low blood sugar/glucose) after cycling, leading to collapse, hospital admission, and memory loss. He is not diabetic. In his words, "*What's supposed to happen is that the brain realises I need glucose and releases hormones to get the liver to start producing it. For some strange reason, my brain occasionally works in reverse and so I produce insulin instead of norepinephrine and my blood sugar disappears. Brain get's very unhappy without glucose so shuts down!*" The doctors do not know what is wrong, so Person A has been searching the Internet to find out solutions. He searched Google, using the terms "hypoglycaemia in cyclists". He found that "*Google offered many of forum waffle but also the option on 'scholarly articles' and it was here I found an article that rang true, titled 'Pre-exercise ingestion of carbohydrates and transient hypoglycemia'. This article was highly informative and has proven to be the backbone of much of my follow up searches, obviously trying to familiarise myself with various terms, hormones and the endocrinology involved.*" This is a good way to search for the evidence, but it is time-consuming, and difficult, particularly if ones literacy skills are not very strong. The author replicated his search, but as she discovered through later emails, his condition could be neurological, and therefore, his original search terms may not be appropriate and rather than a search in the area of endocrinology, it should be in neurology. This demonstrates how difficult it is for the general public to search for the right information, and why a qualified librarian can help. His search can be entered on COCO as such:

Table 13: Example of Scenario 4 terms entered in COCO

C	Hypoglycaemia
O	Carbohydrates
C	Glucose
O	Cycling

Google results – scenario 4:

QUESTION: **What can endurance cyclists do to prevent hypoglycaemia during exercise?**

SEARCH TERMS: cycling hypoglycaemia (British spelling) – retrieves 8,110,000 results.
cycling hypoglycemia (US spelling) – retrieves 187,000 results.

DATE SEARCHED: 29/11/14

This is a problematic search:

a) because of the difference between American and British English spellings, e.g. hypoglycaemia and hypoglycemia. There is a significant difference in the number of results retrieved for each and the information sources provided;

b) this condition is usually associated with diabetes, and Person D does not have diabetes, so the majority of research is inapplicable to his condition.

Using COCO would overcome the spelling issues, because it would automatically search for both terms so it would not matter if there was doubt over the spelling. There were two results that might be useful, because they present alternative term which the author had been unaware of, namely “The Bonk”, and “Hitting the wall” both of which mean hypoglycaemia incidence in endurance running and cycling. This is a complex search, because the condition is so rare. COCO may not be able to find the results, but then there would be the option to contact a highly qualified librarian who would be able to search a greater range of sources that the COCO database would not have access to, including grey literature, theses, and conference papers, which might contain new, as yet unpublished research.

COCO results – scenario 4:

QUESTION: **What can endurance cyclists do to prevent hypoglycaemia during exercise?**

SEARCH TERMS: cycling hypoglycaemia and cycling hypoglycaemia

INFORMATION SOURCES: No results were found on the COCO database, because of the rarity of the condition. A complex search strategy (Appendix 13) was run on Medline, a clinical database, and 43 relevant results were retrieved.

DATE SEARCHED: 29/11/14

As a medical librarian, the author ran the search as she would in her professional practice, and searched relevant clinical databases, Medline (bibliographic database covering the international biomedical literature from 1974 to present date) and Embase (bibliographic database covering European biomedical and pharmacological literature and conference abstracts). Relevant information was found using a very comprehensive search algorithm created by the author, and available in Appendix 13. The results were sent to the user, who used them during consultation times. Person D would probably not have access to the full text, (although open access to research papers is on the increase), but the health professional would probably have been able to get the full-text. Legally, with current copyright laws as they are, the health professional would be unlikely to share the full-text with the Person D, which is another barrier to overcome, but they would be able to discuss the findings:

Table 14: Results for Scenario 4, retrieved from COCO

Results	Details	Comments
1	**Neuronal damage and cognitive impairment associated with hypoglycemia: An integrated view** http://www.ncbi.nlm.nih.gov/pubmed/23876631 Neurochemistry International, 2013, 63(4):331-343	This is relevant, because it focuses on brain issues rather than metabolism, which is highly pertinent to Person D. However, upon receiving this article from the author, he said "*It makes for scary reading but fortunately I forget many of it quite quickly these days*." This is why research papers need to be discussed with the health professionals, if a lay-summary is not available, so that any confusion can quickly be clarified to avoid additional anxiety in the patient/carer.
2	**The myths surrounding pre-exercise carbohydrate feeding** http://www.karger.com/Article/FullText/322698 Annals of Nutrition and Metabolism, 2010, 57(Suppl.2):18-25	This is very pertinent to Person D, if his problem is endocrinological rather than neurological, because it discusses diet and exercise, which can have an effect on blood sugar levels.
3	**Effects of carbohydrate-hydration strategies on glucose metabolism, sprint performance and hydration during a soccer match simulation in recreational players** http://www.ncbi.nlm.nih.gov/pubmed/23702257 Journal of Science & Medicine in Sport, 2014, 17(2):239-43	As above (record 2).
4	**The use of carbohydrates during exercise as an ergogenic aid** http://www.ncbi.nlm.nih.gov/pubmed/23846824 Sports Medicine, 2013, 43(11):1139-55	As above (record 2).
5	**Carbohydrate-protein ingestion improves subsequent running capacity towards the end of a football-specific intermittent exercise** http://www.nrcresearchpress.com/doi/abs/10.1139/h11-097#.VIDo2TGsUcQ Applied Physiology, Nutrition, & Metabolism = Physiologie Appliquee, Nutrition et Metabolisme, 2011, 36(5):748-57	As above (record 2).

5.4. Validation metric analysis

As described in section 5.2., the author has applied the following validation metrics to evaluate COCO from the user perspective:

- Evidence-based – does the content provide a list of references?
- Relevance – can the information be applied to the scenario in question?
- Meet Silberg's quality criteria – does the content meet the 4 quality criteria (as described in Table 5, section 2.2.5.8.)?
- Independent quality check process – has the organisation and/or author of the content been through a formal process of quality assessment, such as the NHS England Information Standard, or peer review?

Tables 7-10 provide a breakdown of the results of the evaluation, with analysis of the results provided afterwards. The sample sizes vary between the two resources because of the number of results displayed on the first page of the various interfaces. Google has one interface while COCO has potentially, at the backend, several. This is a limitation to the metric analysis, and more in-depth analysis is required, but it does provide an idea of how searching COCO can find fewer, but more reliable and trustworthy results than Google.

Table 15: Summary of validation metric analysis: Scenario 1

Validation metrics	**Scenario 1**	
	Google	**COCO**
Number of results	10,300,300	96
Sample size	18	4
Evidence-based	7	4
Relevance	6	4
Meet Silberg's quality criteria	4	4
Independent quality check process	5	4
TOTAL	22	16

Table 16: Summary of validation metric analysis: Scenario 2

Validation metrics	**Scenario 2**	
	Google	**COCO**
Number of results	530,000	10,586
Sample size	10	4
Evidence-based	3	1
Relevance	0	1
Meet Silberg's quality criteria	0	1
Independent quality check process	4	4
TOTAL	7	7

Table 17: Summary of validation metric analysis: Scenario 3

Validation metrics	**Scenario 3**	
	Google	**COCO**
Number of results	438,000	256
Sample size	10	8
Evidence-based	2	8
Relevance	2	8
Meet Silberg's quality criteria	4	8
Independent quality check process	6	8
TOTAL	14	32

Table 18: Summary of validation metric analysis: Scenario 4

Validation metrics	**Scenario 4**		
	Google UK	**Google US**	**COCO**
Number of results	8,110,000	187,000	43
Sample size	10	10	5
Evidence-based	1	0	5
Relevance	0	0	5
Meet Silberg's quality criteria	1	0	5
Independent quality check process	0	0	5
TOTAL	2	0	20

The most significant figures to notice are the differences between the numbers of results retrieved. In all 4 scenarios, Google retrieved thousands, and in some cases, millions more results than COCO.

Logistically, it is not possible to evaluate all the Google results, so only the first page of results was reviewed. Evidence shows that when searching Google, users are unlikely to look at the subsequent results pages, if they find what they are looking for on the first one (Hotchkiss et al., 2005), so it is acceptable to restrict the number of results in this way. When the searches were run on COCO, the author included the first few results on the first page of results which would answer the question, because they were retrieved from information sources that have undergone rigorous accreditation and/or peer review, hence the variation in sample sizes. With Google, all content that matches the search terms is included, regardless of whether it has undergone review processes, which is why there are so many results of varying degrees of quality. In the first scenario, for example, 18 Google results are compared with 4 COCO results. All four results found by COCO met all the criteria in the metric analysis, thereby demonstrating that the user can find accredited, consumer health information using COCO and they need look no further. However, with the 18 Google results, because of the ad-hoc information production process, e.g. no regulatory system, it is harder to sift through the results and retrieve good quality consumer health information. This evaluation process is tainted by observer bias, and more research is needed with user involvement.

For scenario 1, all of the results chosen from COCO met all the metrics, while with Google, less than half of the results did, so while the user gets more results about the condition, the majority are not useful or relevant to the user.

With scenario 2, the results are less satisfying with regards to COCO, and this is because it is a rare condition, and the information products that are searched on COCO have been designed to focus on more common conditions. One result was found for ovarian cancer, and peritoneal mesothelioma can sometimes present as ovarian cancer (Taskin et al., 2012), as the symptoms and the treatment options are the same. Therefore, this information might usefully inform the patient/carer, alongside the advice of the health professional. In this case, it would be more pertinent to Ask A Librarian for assistance as they would be able to do a more comprehensive search to identify the research evidence for this condition. Had it been a more common form of cancer, COCO would have found evidence which met all the validation metrics. However, the author was using real-life scenarios to demonstrate how COCO would work in a real situation. Regardless, the results were still an improvement on the Google results, which although evidence-based, the evidence found was out of date, and more current results were available. Furthermore, some of the results highlighted by Google had been through the HONcode evaluation system, which accepts web-sites which contain misleading and/or irrelevant adverts, and for this reason, the author does not accept that this information is appropriate for patients and carers. She is aware that other researchers may disagree with her on this matter.

Scenario 3 worked very well on COCO, and all the results fulfilled all the validation metrics. This shows that COCO will be useful when people are comparing different treatment options. It also shows how COCO deals satisfactorily with the different terminology, e.g. Crohn's disease and IBD, as it retrieved results for both. Google on the other hand, did not find as many results to be of use to the user.

The final scenario, demonstrated the benefits of being able to contact an information expert to find the evidence. COCO offers this feature, while Google does not. This scenario is confounded by the fact that hypoglycaemia is associated with diabetes, which is not what Person D suffers from, so the results retrieved by Google, are largely irrelevant, and those that might be relevant are not evidence-based, and are often anecdotal, which is problematic, because one person's situation is unlikely to match that of another person. The COCO results for scenario 4 came from a comprehensive literature search, the algorithm for which is in Appendix 13, carried out by the author, a qualified information specialist and co-author (De Brún and Pearce-Smith, 2014, De Brún and Pearce-Smith, 2009). She was asked to carry out this search on behalf of Person D, independently of this research.

The author recognises that this metric system is flawed, because the sample sizes are not the same, and with the COCO searches, the author is manually searching each of the information sources. However, with this process, the author wants to demonstrate that it is easier to use COCO than Google, the main reason being that there are significantly fewer results, but those that are there, are of a much higher quality, having been through rigorous accreditation processes to guarantee their quality. When COCO is live, users will not have to go to each resource individually, as COCO will do this automatically. Furthermore, there are techniques to help boost relevant content to the top of the list. The National Institute for Health and Care Excellence (NICE) has applied this validation methodology process and the techniques to boost content in NICE Evidence Search.

Using COCO reduces the processing steps needed to find relevant information, because, due to the specific information sources it searches, patients and carers do not always have to appraise the quality of the content. They also do not have to look through millions of results, because COCO focuses on a core set of quality information sources. In the case of Google searches, so few results met all the criteria that more time would need to be spent on appraising the results, which for a patient or carer would be an additional burden for them to overcome and one that should be avoided. This process further demonstrates that the development of COCO is feasible and will facilitate access to quality health information for users and carers.

5.5. Discussion

The results retrieved via COCO were considerably better quality, more reliable, and relevant than those found on Google. They met the criteria outlined by Silberg (Silberg et al., 1997), summarised in Table 5, section 2.2.5.8, were on topic, were appropriate publication types, and fulfilled the validation metrics. It can be said that Google, and other search engines, can point people to information. However, because of the bias in the algorithms they use to prioritise the information they retrieve, e.g. web-site owners can pay to promote their sites higher in the results listings, there is no guarantee of the quality of the highest results, particularly for less common conditions. Even with Google Scholar, the information found was not the most recently published on the topic, and while there are filters to restrict the search by date, patients and carers may not be aware of this feature. Furthermore, Google found significantly more results than COCO. The author did not look at all the Google results, only those on the first page. Unlike COCO, where the results were all evidence-based, there were different types of publication, including anecdotal pieces, adverts, and other content, which was not research-based or written for the target audience.

Both Google and COCO found results which were relevant to the target populations of the scenario, although Google found more results aimed towards an American audience, and one of the results for scenario 1 was about lupus rather than Myalgic Encephalomyelitis, a different condition.

Having run these searches, it is clear that not each question will fit neatly into the COCO framework, and therefore initially, it may be that users will click on the Ask A Librarian option before attempting the COCO search mechanism. However, there will be a time delay with the Ask A Librarian option, as it is not available 24 hours a day, 7 days a week, so users will find that they will have to use COCO and experiment with its features, if they need health information. When they see the results, they will notice a significant difference compared to the Google results, and it is hoped that they will see the benefits in using the technical version of COCO more readily, as a tool to help them focus their search. This will be further tested during the development stage with user involvement.

With Scenario 1, it might be said that the patient/carer could have gone straight to NHS Choices, which is true, but COCO offers so much more, including searching assistance from a professional librarian, and access to their electronic health records. This will be a one-stop-shop for a range of resources and personal data, and the COCO interface will remain the same, regardless of the resource it is searching, enabling users to become familiar and comfortable using it, even if the informing information sources change.

Scenario 2 demonstrated that COCO cannot answer all questions, particularly if it is a rare condition. However, it can search a range of resources and find the next best set of results, which might be broader, but might still be applied to a rarer condition. This requires more ‘thinking out of the box’ but might provide greater options for the user. It would be daunting if the user had to do this on their own, but with COCO, there is support available, should they need it, via the Ask A Librarian feature.

COCO was very successful in identifying relevant results for scenario 3, despite the potential issues with terminology, and this is one of the main benefits of COCO. It means that people can type in the name of the condition, without having to know about the other names associated with that condition. As pointed out in section 2.2.5.4. Crohn's disease is known by other names, such as IBD, inflammatory bowel disease, Crohn's disease, and ulcerative colitis. COCO is designed to take this and also language differences, into consideration, and will retrieve related papers, demonstrated with scenario 3, by the first reference which is about IBD.

With scenario 4, Google identified 8,110,000 results using the British English spelling of hypoglycaemia, and 187,000 results using the American English spelling of hypoglycemia. Not only are there an impossible amount of results to manage, but they would all need to be reviewed, to ensure they are accurate, reliable, and relevant.

Ideally, the author would have shown the results to the relevant person with the condition. However, this was only possible for one of the scenarios, the final one. The first scenario is taken from an online forum for people diagnosed with Myalgic Encephalomyelitis. The author is not in communication with the person who was looking for the information, as it was an anonymous request made on the discussion list. Scenario 2 relates to the person who inspired this research in the first place. The author originally searched on the person's behalf and knows the type of information that would have been useful and relevant to the person and family. The author realises that there is a high risk of observer bias in this situation, but believes that as the results have also been tested against Silberg's criteria, the risk of bias is lessened. The results of scenario 3 have not been sent to the person with the condition, because the issue has been resolved and it is no longer of interest. However, the top result has been produced by an organisation, which has been awarded the NHS England Information Standard, a process, which guarantees that the information produced has been written for and tested on the target audience.

The results for the final scenario were sent to the person concerned who used it to identify a new potential treatment option, which he is discussing with his health professionals. This is an example, which demonstrates the importance of involving the patient in the decision-making process and the librarian in the information retrieval process. The health professional does not have the time to search for information on more complex issues and the patient/carer may not have the skills or access to the resources. Involving information professionals overcomes this barrier, so that the right information is identified, using their searching skills, the patient/carer’s preferences, and the expertise of the health professional.

5.6. Chapter Summary

This has been a very basic form of user validation, because the author was unable to recruit potential users, e.g. patients, without requesting ethical approval from the NHS, which would have taken too long at this stage of the research. It has always been the intention of the author to gather survey data from the general public and not specifically patients, because she wanted to get an overarching view of people's health information needs. However, with the user validation process, it would have been more appropriate to ask specific patients for their opinion on COCO. Without NHS ethical approval this was not possible, hence the reason the author used her professional experience, and examples from friends and family. For the continued development of COCO, the author would obtain NHS ethical approval and involve patients and carers in focus groups to ensure that the final product would be useful and sustainable to users and service providers.

Based on these results, the author would not make changes to the initial design of the model. She does recognise that it is not perfect, but having tested the processes involved, she can see that in theory, the system does work, but that more validation and testing is required before the creation and launch of the final product. The author does not have sufficient expertise in computer system design, but is very experienced in the areas of clinical database use, quality of information, user needs, and information literacy in health care. The author needs to work with someone experienced in programming to take this initiative forward and ensure that it works. An opportunity might arise at NHS Hack Days (http://nhshackday.com/), regular events where people working in a health setting can submit a technical health innovation proposal to a group of software developers and if there is interest, they can work together to turn the idea into a viable concern. Alternatively, the author could contact Jon Brassey (validator and creator of the TRIP Database), who is very experienced in this area and might be willing to provide guidance and expertise.

The next chapter will conclude this research and make recommendations for the implementation of the model.

Chapter 6 – Conclusions and future work

Muir Gray

6.1. Introduction

This research began in April 2010, and has seen many changes in the structure of health services in England, and the increase in user involvement in all aspects of service delivery, including decision-making. The main drivers for the research were the gaps between the need for access to quality consumer health information for informed decision-making, increased access to individual electronic health records, and the inaccessibility and lack of awareness of existing information sources produced by the NHS. The literature review carried out by the author confirmed that the main knowledge gap was evidence-based patient choice and information service provision for the general public. With this in mind, the research question that is answered with this research is "*What information support does the general public need to learn more about their clinical conditions and how to manage them?*"

When a patient is making a decision about their health, they need to have the full picture. Search engines, such as Google will give them a range of opinions, at different levels of quality. NHS Choices will give them access to patient information leaflets on a broad but limited range of common, clinical conditions. Using clinical databases such as the Cochrane Library and PubMed will help people to find research, but perhaps not written in a style appropriate for patients, and if they don't know the right terminology, e.g. inflammatory bowel disease, ulcerative colitis, Crohn's disease, they might miss out on key research. Researchers are being encouraged to write lay summaries as part of their research, but this initiative is still in the early stages of development. Therefore, without support from information specialists, people may struggle to find the information they need to make an informed decision about their treatment, which will be frustrating for them, and for their health professionals, and possibly delay their recovery. This demonstrates why the development of the model, COCO, described in Chapters 4 and 5 is so important.

This thesis has demonstrated that people do want to be involved in the decisions made about the treatment options available to them, but they do need help in finding the information to help them make an informed decision. The expert patient is beneficial for the patient, the carer, and the health service, because well-informed patients are able to make better decisions and are more likely to comply with the treatment regime, resulting in a better experience for them, and reduced costs for health services.

The model proposed builds on existing concepts and frameworks (SCONUL 7 pillars, 5 steps to evidence based practice), and resources, both human (librarians and other information professionals) and technical (quality health information web-sites, decision aids, etc.) to create one resource where people can find what they need easily.

The model has been validated by experts in the areas of consumer health information, evidence based practice, information literacy, and information technology. It has been further validated using real-life scenarios. It is clear that at present there are flaws in the COCO concept, some dependent on the information sources that inform it, but others related to the design. The former will improve as COCO works with the other information source developers, and the latter will improve with user testing. The model is ready for the next step, development with user involvement and this will hone the design, making it more useful to the user.

One of the main problems is that most of the current, best information sources are designed for the health professional and not the health consumer. Organisations are beginning to realise this, for example, Cochrane Libraries has developed Cochrane Summaries, and Sense About Science, is encouraging authors to write summaries for the lay-person. Not everything is in place yet, but it is getting there, and COCO will be the perfect gateway to integrate all these up-coming consumer health information sources. In the meantime, it will be a useful gateway for co-ordinating existing, best quality health information, making it easier for patients/carers, to access the best quality health information currently available.

As part of this research, the author wanted to create a resource that would be accessible to everyone. She believes COCO achieves this because it empowers people to find information themselves in a focused manner, but also provides human assistance if required. It provides them with the support they need, when they need it, without incurring major costs to public sector budgets. It is a simple solution, which should make a big difference to the National Health Service, and the health and wellbeing of the population.

Further on in this chapter, the author critically reviews the research objectives, describing how they have been met, talks about the limitations, describes the next stages for this research, and identifies related future research options.

6.1.1. Key messages gathered from this research

The literature review and the subsequent surveys identified eight key messages:

1. Patients respond better to treatment if they are involved in the decision-making process.
2. People, particularly those diagnosed with chronic illness, do search online for information about managing their conditions.
3. The quality of online consumer health information varies greatly.
4. Patients and carers need information literacy skills to help them make an informed choice.
5. Librarians from all sectors are in a strong position to improve access to quality consumer health information.
6. People do want to be part of the care pathway decision-making process.
7. Good patient information reduces the need for GP visits and hospital re-admission, thereby reducing the burden on the NHS.
8. People need a solution both technical and human to help them navigate the complex web of consumer health information.

These messages demonstrate the important role that information and information services have to play in the health and wellbeing of the general public, and the state of the health economy.

6.1.2. Contributions to research

There are many resources available to patients and carers, but they are all on individual web-sites, some password protected, making it difficult for people to access them. Furthermore, NHS organisations frequently re-structure, and re-brand, making it confusing for people to understand which resource is best for them. While potentially dangerous, it is easy to understand why users go straight to Google or similar search engines to satisfy their information needs. They are much easier to use and access, but this is not acceptable, as the information may be inappropriate to the needs of the individual. Earlier research, as demonstrated in the literature review, has shown a need for information support for patients and carers, and the survey results confirm this. There are examples of possible solutions in existence around the world, but they have either been technical or human, and not a combination of both. This research, rather than creating a new information product, brings together existing products, while providing access to qualified information professionals, for people who do not search online. This is an example of knowledge management in practice, where medical and public librarians, cascade information skills where they are needed, sharing resources, and improving the value of library services to the general public. The benefits include:

- optimal use of health information resources developed for the general public, reducing wastage and increasing awareness;
- better-informed patients and carers, and
- an increased skills base for library staff, again raising awareness of library services, and enabling role rotation between organisations, so a better use of staff resource.

To overcome the issue of rebranding and new products, the model will maintain the interface, while integrating any changes or additions, behind the scenes, so that throughout their lifetime, people can access a resource which has been designed with their needs in mind. It is similar to Google in terms of ease of use, but it searches relevant, good quality information sources.

Health professionals have access to resources tailor-made for them already, and they also have levels of evidence to guide them, and medical librarians to provide them with training and support. If the general public is going to be expected to participate in decisions made about their treatment, then they will need access to similar resources, designed with users' needs in mind. As part of this research, the author wanted to create a resource that would be accessible to everyone. She believes that COCO achieves this because it empowers people to find information themselves in a focused manner, but also provides human assistance if required. It is a simple format, and following user involvement in the design process, and additional in-depth user-testing, will be user-friendly and fit-for-purpose.

6.2. Review of research objectives

At the start of this research, six research objectives were set. This section will review these objectives and demonstrate how and where they have been met.

6.2.1. Research objective 1

Demonstrate synergies between the literature on shared decision-making, health information literacy, and quality of health information, identifying gaps in the research with regards to access to good quality consumer health information.

In Chapter 2, the author describes the literature review process applied for identifying the best evidence on several themes pertaining to the original aim of the research. This was not a systematic search, but it was robust and via different searching methods, retrieved many research papers and reports about:

- why people need access to good quality health information – the increasing incidence of chronic disease, the shared decision-making agenda, and access to electronic health records, encouraging self-management of conditions;
- what information skills they already possess and/or support that they need;
- who uses the Internet for searching and who does not;
- how people search the Internet and use the information, and the barriers they face;

- the quality of online consumer health information and use of existing NHS information products;
- the role of library services in supporting health information literacy initiatives.

The literature review is very comprehensive and has been updated throughout the research process to ensure that the topics covered are still relevant. The research demonstrated that there are strong links between the themes mentioned in this objective. People with chronic disease are the candidates who are being encouraged to self-monitor and manage their conditions, and are more likely to need information. However, more often than not, they do not have the skills or the resources to find this information. Therefore, without having the relevant information, there is a risk that they do not understand what is required of them. This means that it will take longer for them to recover, increasing the length of time treatment is required, and therefore raising costs for the health service, while decreasing the quality of life for the patient and carer.

6.2.2. Research objective 2

Elicit people's preferences about the emerging shared decision-making agenda and their role in treatment choice.

The author gathered this information by using a series of surveys, two carried out in geographical settings, and one carried out in a health population setting. The results, broken down in greater detail in Chapter 3 and Appendices 5 and 6, were not significant, with 139 responses being received, most of which came from White British people.

Despite the poor response, the results did correlate with the findings of the literature review, confirming that people do:

- want to participate in the choices made about their treatment programme;
- search online for health information;
- need information skills training or additional information support.

However, these are based on the views of one ethnic group, and England is made up of many ethnic groups, so it would be preferable to have greater diversity in the survey responses to ensure that all needs are recognised and responded to. However, it is possible that people with English as their second language were not able to complete the survey, as the surveys were only available in English. Were this survey to be replicated advice would be sought from black and ethnic minority groups to identify more effective methods of obtaining responses. Translating the survey would have been an option, but the public services are being criticised for the translation costs they are accumulating. Furthermore, in the London Borough of Tower Hamlets alone, there are 100 mother tongues. Therefore, focus groups within the communities would perhaps be more effective, although still time-consuming and costly.

Another reason for the lack of response to the survey may be the apparent apathy towards good quality, the preference for quick and convenient, such as Google, to the slower but more reliable and fit-for-purpose information products produced by the NHS. It appears to be easier to get a quick response from Google, even though it is most likely to be unfit-for-purpose. This apathy is demonstrated by some doctors who, in a recent survey, admitted to occasionally using Google to diagnose patients (Ellis, 2015), when they have even greater access than patients to the best evidence.

6.2.3. Research objective 3

Identify people's knowledge of existing, designed-for-purpose, health information resources, and understand why they do not use them.

The purpose of this objective was to further justify the need for consumer health information support, and potentially inform information providers how best to reach their consumers. The majority of this information was taken from the survey results described in greater detail in Chapter 3, with a few papers confirming the lack of awareness (Perry, 2011, Greenhalgh et al., 2010a). The NHS has developed a range of products to help people make decisions about their health care, but as the surveys show, people are not aware of them. Most people have heard about NHS Direct, but that service was withdrawn in 2013, despite heavy usage. Many people have heard about NHS Choices, but there were still many people who had not. Very few people had heard of the NHS Information Standard and this is a concern because it does require heavy time and cost investment by the government, and the information providers, which are often small charities. As mentioned in section 6.2.2., the survey responses were not large enough to be significant, but the responses that were collected were in agreement, and they did demonstrate that there is a worrying lack of awareness of these resources. It is important for policy-makers to realise that without promotion, information products, which have been proven to improve patient care and experience, will not be used as people will not be aware of them.

6.2.4. Research objective 4

Explain the benefits of well-informed patients and carers to the health economy.

This research objective was met through the literature review in Chapter 2, where analysis of 300 papers identified the 8 key messages listed earlier in this chapter. Well-informed patients and carers lead to:

- better patient experience, because the treatment process is more likely to be understood and adhered to, so people recover more quickly, which improves their quality of life;
- lower medical costs, because informed patients will follow the dosage correctly and run its course, so that they will not require extra time in hospital or more treatment;
- less risk of litigation, because if the patients understand all the risks involved, they make an informed choice, and therefore, decide if they want to take the risk or not, so there is less chance of an adverse event requiring compensation.

These observations were drawn from the research literature. However, until now, no studies were identified that proved the direct benefits of informed patients on quality of life, incidence of litigation, and the health economy. One paper did find that using evidence-based communication tools did increase understanding, but that there was "*variable access to such tools in practice*" (Trevena et al., 2006). A paper published at the end of January 2015 has found that "*higher levels of knowledge were shown to be associated with significantly lower health care costs*" (Colombara et al., 2015). This was only a small study of 91 one patients, but it demonstrates to what earlier research has alluded to. More research of this nature would build a stronger case for the importance of supporting the information needs of patients and carers.

6.2.5. Research objective 5

Review the parallels between existing evidence implementation frameworks, and adapt them to formulate a framework for consumer health information.

This research supports innovation, but also knowledge management, where innovation is created as existing resources are adapted to suit newer purposes and/or audiences. To meet this objective, in Chapter 2, the author reflected on the stages of the SCONUL 7 pillars and the five steps to EBM, and identified synergies, translating them in to a framework identifying the steps patients and/or carers might take when fulfilling an information need. The author demonstrates this revision of the previously mentioned concepts in Table 5, describing who should be responsible at each stage of the process. The process of patient information-seeking and appraisal has not been documented like this before, so while building on existing work, which has been validated by relevant professional groups, a new concept has evolved, which can help information producers improve the products they create.

6.2.6. Research objective 6

Apply the synthesised data, research evidence and framework to the design and evaluation of a consumer health information literacy solution providing information support to users enabling them to make informed decisions with health professionals.

At the start of this research, the author had a human intervention in mind as the final output. However, having synthesised the survey results and evidence-base, it became clear that this would not resolve the issues identified, and therefore, the solution must have technical and human aspects. Chapters 4 and 5 describe the development and validation of COCO, a technical and human model, connecting the general public to the best available, patient-focused evidence, and librarian support, to help them make informed decisions. The validation process is theoretical, because COCO is not a “live” product, and therefore, the concept has been validated, but the final product must be developed with involvement from information technology experts and the general public. The author has based the design of the validation process on her experience of working with evidence based products, such as the National Library for Health and NICE Evidence Search, both of which were designed for and by clinicians, and the NHS England Information Standard, a patient information accreditation system, which has been designed specifically for consumer health information products. During the validation process, issues were raised in Section 4.10 and Table 6, and some were resolved in the design process. However, others can only be overcome during the next stage of the research process as additional expertise will be recruited to help with the development of the final product. The idea of COCO has also not been tested on medical or public librarians, and their input is vital, because they can assess whether it will work or not. With her background in medical, academic, and outreach librarianship, the author believes the model will work, but she has no experience of collaborative working with local authorities. The author has demonstrated the mutual benefits of public and medical librarians working together, but without managerial support, it is not a sustainable idea. The experience with the Bow Idea Store demonstrates that there is a risk of insufficient support for this idea, but if public libraries and medical libraries can work together, there will be a positive impact on public sector expenditure, job satisfaction, and user experience.

6.3. Limitations of the research

There are limitations to this research and these are described here:

6.3.1. Poor survey response

As described in Chapter 3, the results of the survey were not representative. While corroborating the results of the literature review, it would have been preferable to have a larger set of survey results. The survey was originally piloted to several different audiences, including potential users, and therefore, it is difficult to understand why people did not complete it. The survey was quite long and focused heavily on peoples’ experience with existing consumer health information products. Response may have been more effective with a shorter survey, focusing on the five key questions, highlighted in section 3.7.1. This will need further investigation for future research, and perhaps in light of this, focus groups would have been more effective in finding out what people want in terms of consumer health information support.

6.3.2. Organisational restructures and funding configuration

The original partner for this research, the Bow Idea Store was initially the perfect candidate. Their focus was health, and they were already delivering a regular programme of information support to their users. However, a few months into the study, their funding was cut and they were no longer able to offer support for this research. This hindered access to the population that were to be surveyed and also meant that focus groups could not be arranged.

Within the NHS, there have also been several restructures since the author began writing this thesis. Key organisations and work-streams, including the National Programme for Information Technology, were dissolved. In June 2012, key functions of the National Patient Safety Agency were transferred to the NHS Commissioning Board Special Health Authority, now NHS England, as of April 2013. NHS Direct, one of the more well-known and popular resources providing health information support to the general public was closed down in 2014, and replaced with a new service, NHS111. There are plans for changes to NHS Choices, but these have not occurred as yet. HealthSpace, a resource designed for patients to help them manage their electronic records, was discontinued because of lack of use, although the survey results and the literature review from this research show that people just were not aware of it. While these restructures have been taking place, the Government has been putting in steps to involve patients with the decisions made about their treatment choice. They are developing initiatives to facilitate this work, such as decision aids, but there is still a huge variation in the level of information available for all the different clinical conditions. These changes have made it difficult to visualize exactly how the final model will be managed.

6.3.3. Lack of user involvement in the validation process

The author did not involve patients in the model validation process, because she had not sought NHS ethical approval at the start of the research, and initially, the model was not going to involve a technical solution. This research would have been more robust had patients been involved in the process, and in order to continue with the implementation process, the author will identify ways of working with the target audience.

6.3.4. Restricting information technology policies

While not a limitation of the research, this is a limitation for the success of the final model, as there is a risk that the technical element of the final output, COCO, may not be eligible for an NHS URL, and therefore, may be blocked as a consequence of strict Trust and local government IT policies. These vary across geographical locations, as there is no overall information technology (IT) policy in the public sector. Many NHS Trust IT Departments block web-sites like Blogger (http://www.blogger.com) and Twitter (http://www.twitter.com). This can be detrimental to staff knowledge levels, as many leading health communicators share their knowledge via social media, and it is a useful way to find out about the latest research while moving between clinics. It also means that the health professional cannot see the same information that the patient/carer is seeing and so cannot assess the quality of the resource, unless the patient/carer brings a print-out of the material.

For these reasons, stakeholders of the COCO model must include key organisations, such as the National Institute for Health and Care Excellence (NICE), Social Care Institute for Excellence (SCIE), British Medical Association, Department of Health (DH), NHS England (NHSE), Public Health England (PHE), the Patient Information Forum (PIF), and the Local Government Association (LGA). There is evidence that some of these organisations are already keen to work in these areas, and the author has been involved in some of this work. The author can provide further information about this, but as discussions are still in early stages and have been postponed due to the recent Ebola infection outbreak, she is not in a position to provide published evidence. However, representatives from some of these key organisations were involved in the validation process of the model, which will be a useful start for achieving integration of COCO.

Finally, there are also restrictions on which Internet browsers are supported within NHS Trusts, and this must be taken into consideration when testing COCO. It must be a simple system, which does not require the downloading of large amounts of data, and it must be accessible, at least by standards compliant web-browsers.

6.4. Future research opportunities

The author has identified additional areas for future research, and these are described further in this section.

6.4.1. Development and implementation of COCO

There are many opportunities to continue this work. It is not only a key issue for England, but also for other countries, as informed, shared decision-making is key to health improvement (Alambuyam et al. 2011). In section 4.8.3.6., Bob Gann responds on behalf of NHS England and NHS Direct and says that even though he is familiar with this area of work, he does find it [the model] too complicated. Therefore, as part of the development process, the author will work with relevant patient involvement organisations, such as The National Institute for Health Research Collaborations for Leadership in Applied Health Research and Care (NIHR CLAHRC), who work with patients and the public to involve them with research. The author will see if it is possible to run a series of focus groups with these groups before proceeding with the development of the product, because this group would be ideal for developing and testing the model.

Once COCO has been created with user input throughout, it should be tested on the target audience, and then piloted in four counties before launch, to make sure it does what it is meant to do. This resource needs to be used, for it to be useful. Part of the implementation programme must include evaluation, because if COCO is not useful, then there will be yet another pointless resource available. Once it has been evaluated, it can be rolled out to the rest of the country together with relevant support materials.

The NHS, and the public sector, needs to be seen to be making savings, and as such marketing budgets have been cut. However, there is no point in investing in developing resources for patients and carers, if they are not being promoted to the target audience. Should this model come to fruition, it will need publicity for it to work, and it will require national support and commitment, both strategic and financial, from NHS decision-makers. Promotion on a budget can be achieved via the extensive public and medical library networks that exist, as library staff are familiar with promoting their services creatively on a tight budget.

If COCO has inadequate information on a particular, popular, topic, an option might be for PALS, librarians and clinicians, to collaborate together to develop guidance, which could be accredited by the NHS England Information Standard and then be made available on COCO. Topics might be identified via user searches or requests and selected on the basis of demand. This would take time to set-up, but it is a justifiable service, which would reduce duplication of information production, again reducing costs, and also ensuring equal access to the same information for everyone. An editorial board/steering group will be required, and they can help with this work. The will also be instrumental in deciding if newly-developed, evidence-based information sources should be integrated in to the COCO database.

6.4.2. Potential related areas of research

As a result of this thesis, a number of opportunities for related research have also become apparent, and these are described here:

6.4.2.1. Effect of informed patients on the health economy

Secondary outcomes of primary research have indicated that ensuring patients and carers are fully-informed of all the possible treatment outcomes, leads to a decrease in health service usage and a better patient experience. More robust research, where the primary outcome looks at these benefits needs to be carried out, to inform service improvement.

6.4.2.2. Complementary partnerships

Investigation into a partnership between Cottrell's WELLNESS database (Cottrell, 2008) and the COCO portal would be useful, so that people have access to good quality health information to inform lifestyle and treatment choice. The model would also be a useful way to increase the usage of the NHS England Information Standard, which would encourage more information providers to apply for the Standard, leading to ever-improving quality of consumer health information.

6.4.2.3. Tool to measure understanding

The development of a tool to measure whether patients/carers understand what they need to do to get the best outcome from their treatment choice, or provide the best support, would prove most beneficial to information providers as it would help them design their products more effectively.

6.4.2.4. IT security, social media, and barriers to evidence-based practice

One of the issues highlighted earlier was the blocking of web-sites at local Trusts. The level of IT security in NHS Trusts varies significantly across the country. It would be helpful to gain an insight of the IT security priorities for all NHS Trusts in England, particularly how many of them block social media sites, and which sites they block. This could advise a national IT security policy, so that IT access is consistent throughout England. With health, social care, and local authorities working more closely together, it would also be relevant to see how social media is dealt with in each of these sectors.

On a related theme, an important piece of research would be to find out how NHS staff keep up-to-date with latest research, if social media sites are blocked. Is evidence-based practice compromised in Trusts?

6.4.2.5. Overcoming language barriers and reducing translation costs

The majority of survey respondents were White British, and therefore, to understand the needs of people with English as a second language, further research is required. As described in section 2.2.5.3., the NHS spends a vast sum of money on translation services, demonstrating that information support in other languages is necessary. To overcome the language barriers, particularly as there are so many mother tongues in England, perhaps research looking into a collaboration between Health Information For All 2015 (HIFA 2015 http://www.hifa2015.org/), and the NHS England Information Standard could be arranged to enable information products to be translated in a range of languages, or information to be provided from the native countries. HIFA 2015 says that many people in developing countries die because they don't have access to the information and knowledge they need, when they need it, to make appropriate decisions and save lives. In England, there is patient information, but not the ability to translate it into all the required languages. If this patient information were to be given to the HIFA 2015 campaign, perhaps the mother nations could translate it and make it accessible to these countries and to England so that it can be used by people who have left those countries and now live in England. A collaboration of this nature might result in an international repository of quality consumer health information leaflets, available in a range of different languages. The concepts of health information literacy can be translated into other languages providing foreign language speakers with the skills to search for good quality health information in their own language. There are organisations that publish health information in other languages, and lists of these could be made widely available in NHS organisations, and public, academic, and health libraries. The author has raised the issue of different countries having different prescription information and procedures, but basic information about the condition and treatment options could be made available, reducing the significant translation costs that the NHS is faced with.

6.4.2.6. Developing the role of the peripatetic librarians

Another option stemming from the results of this research is to develop the role of peripatetic librarians, where county-based health librarians working with public librarians, GP surgeries, and hospitals, travel around the county, providing regular health information to support the general public. This would be a more costly affair and could only be considered were sustainable funding to be made available throughout England. Perhaps more importantly, it would be useful to see whether primary care and secondary care services provide guidance for patients on finding the evidence or provide services to help them access high quality patient information.

6.4.2.7. Experience-sharing via online forums

One of the papers identified via the literature review in Chapter 2, was on chat rooms and discussion groups (Witteman and O'Grady, 2008), and a recent survey (Fox, 2011) said that "*one in four Internet users living with chronic conditions had gone online to find others with similar health concerns*". This aspect, while important, has not been covered in this thesis because the quality of information available from chat rooms and discussion groups has not been formally evaluated yet. However, with the evolution of social media, it should be considered for further research, with a focus on explicit knowledge, e.g. published, and also tacit knowledge, derived from experience, and obtained via social software.

6.4.2.8. Systematic review of information literacy terminology

Another area for future research could involve a systematic investigation of all the terminology related to the areas of consumer health information literacy. In section 2.2.5.8., this thesis identified confusion between the understanding of the terms health literacy and health information literacy, and it is important that the differences of each are clearly understood.

6.4.2.9. Identification of health information needs of adolescents

As referred to in section 3.5, young people under the age of 18 years were not included in this research. It was felt that their needs would be different and may require an alternative approach, which might be developed in collaboration with school/college nurses and librarians.

6.4.2.10. Perception of public libraries as health information providers

In section 3.7., it was reported that only 58% of people surveyed said that they would like public libraries to provide access to consumer health information. Further research is needed to find out why people do not want public libraries to provide access to health information support, because there could be a very simple reason, which might be easily resolved, to provide another means of support for the general public and reduce the burden on NHS services.

6.4.2.11. Development of an international metadata dictionary

One limitation with the model, which is beyond the author/developer’s control is that because COCO amalgamates many different information sources, such as NICE Evidence Search, the TRIP Database, Cochrane Library, etc. it is reliant on the way they categorise/retrieve their information, and the metadata that is applied. There may be a solution to this, so that only the metadata is searched, but the author does not have the technical skills to know this and would need support from a computer programmer throughout the development process. Ideally, an international metadata dictionary or combined database thesaurus, which amalgamates all the different indexes into one meta-index, would be created to resolve this issue.

6.5. Chapter summary

This chapter has revisited the original research objectives, demonstrating where they have been met and any flaws and limitations in the process. There is room for improvement in the processes, but the author feels that there is still a strong case for the development of COCO, because of the following innovations:

- Focus on the whole population, thereby including carers, and not just patients.
- Support people who are computer literate and those who are not.
- Apply a knowledge management solution which supports collaborative working between public, academic, and health libraries and the professional development of staff.
- Build on existing information products rather than creating new ones.

The increase in consumer health informatics research publications, described in Chapter 2, confirms the growing interest in this area of research, and demonstrates that this research is timely.

However, the limitations to this research demonstrate that more in-depth user-analysis is required, before the final product can be developed. Furthermore, additional technical expertise will be needed to ensure that COCO is developed in a robust and sustainable manner.

Likewise, the framework, described in Table 5, is a first step and needs more work and testing, with the relevant expertise, but the author believes that in time, it is a useful tool to help people understand their consumer health information needs.

Medical library services have proven beneficial to health service delivery, in terms of time-saving and ensuring that clinical decisions are based on the best available evidence (Perrier et al., 2014). It stands to reason that if health professionals need the best evidence to make clinical decisions, then so do patients and carers, and they also need similar information support. The author illustrates this point via Figure 5 Evidence-based patient choice, an adaptation of the evidence-based medicine concept, originally designed for doctors. The research has shown that solutions are available for the general public, but unlike COCO, they are either human or technical solutions.

There are several initiatives to support shared decision-making between patients and health professionals, but the author did not find research that confirms that this is what people want. She did find research highlighting the benefits of patient participation for patients, carers and the health service, and together with the survey results she has reached the conclusion that people do want to be involved in the choices made about their treatment pathway.

This area of research is very new, and technology is constantly changing, so it is going to take time to get it right, but it is important not to keep on creating new resources because people will lose interest, and use resources they are familiar with, whether reliable or not. COCO will initially be new, but once completely developed, it will rely on existing quality information resources. It maintains the same interface which users can become familiar with. Should new, accredited products be developed, these, together with changes to existing products will be integrated with COCO, so that users will not have to do anything differently. Furthermore, for those uncomfortable with, or without access to technology, they can feel safe in the knowledge that they can still access good quality health information, using the services of qualified librarians.

COCO is a work in progress that will continue to evolve to suit the needs of its users, supporting shared decision-making, improving patient experience, and reducing health care costs.

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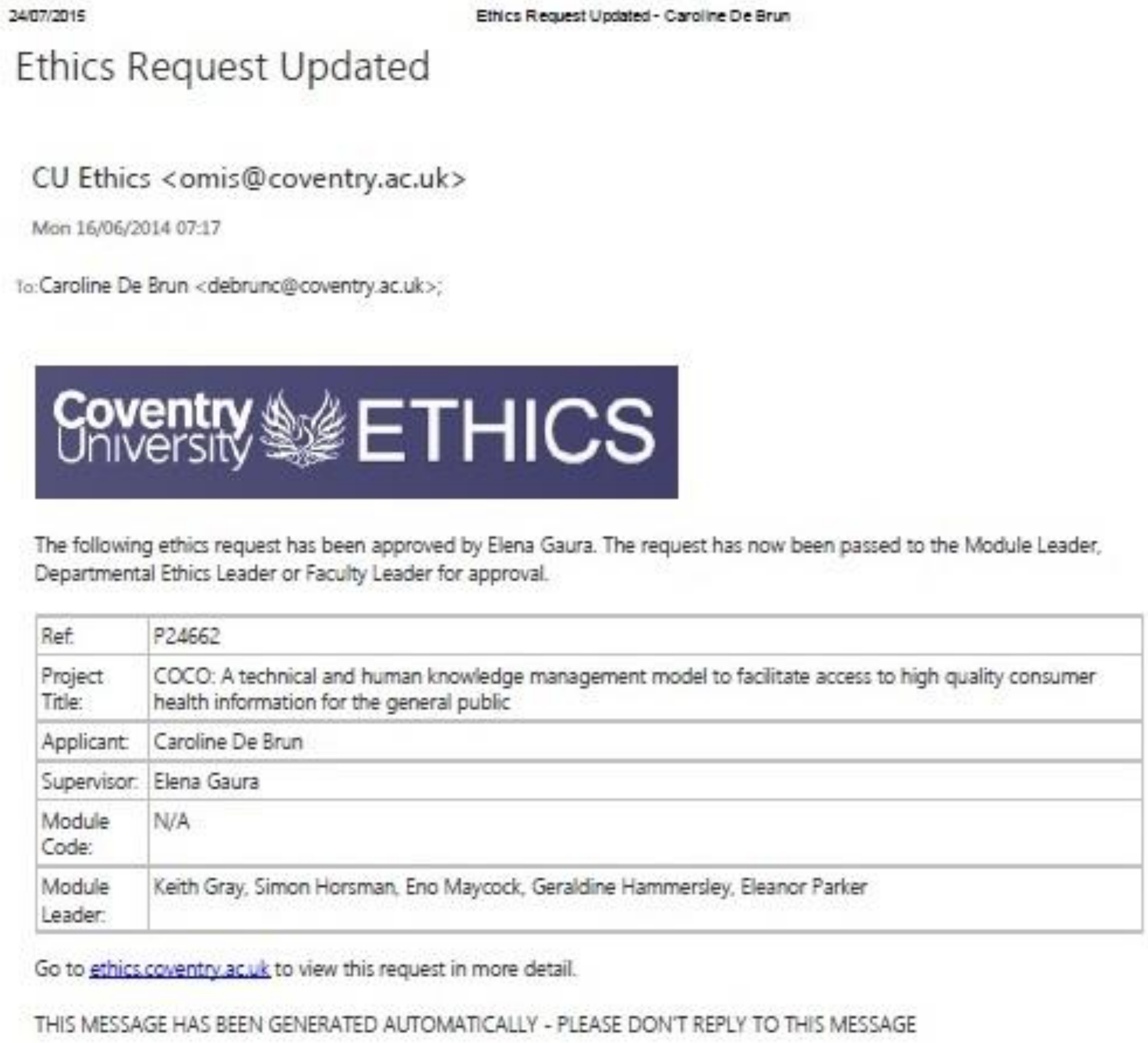
Appendices

Appendix 1 – Breakdown and categorisation of literature search results

Database searched	**Date of search**	**Search details**	**No. of hits**
Cochrane Library	4th August 2010	as per methodology	1
CINAHL	18th August 2010	as per methodology (EBSCO Host - University of Coventry)	341
LISTA	18th August 2010	as per methodology (EBSCO Host - University of Coventry)	9
Medline	18th August 2010	as per methodology (EBSCO Host - University of Coventry)	368
PsycInfo	18th August 2010	as per methodology (EBSCO Host - University of Coventry)	15
			734
		Electronic database searching	
		Total before deduplication	734
		Total no of duplicates	60
		Total no of articles (after deduplication)	674
		Total discarded - out of scope or off topic	260
		Total after first sift	414
		Hand-searching	
		Access to health information	37
		Background information	8
		Barriers to evidence based patient information	5
		Consumer guides	6
		eHealth	16
		Electronic patient records	6
		Good versus bad web-sites	19
		Health in the news	1
		Knowledge translation	1
		Litigation	1
		Miscellaneous	5
		Online EB tools	3
		Patient experience and shared decision making	33
		PICO	1
		Quality health information on the Internet	27
		Research methods	5
		Searching methods and behaviours	40
		Total from hand-searching and grey literature searches	214
		Additional publications from updated searches	86
		Total to be included in PhD	**300**

Appendix 2 – Ethics approval certificate



24/07/2015 Ethics Request Updated - Caroline De Brun

Ethics Request Updated

CU Ethics <omis@coventry.ac.uk>

Mon 16/06/2014 07:17

To: Caroline De Brun <debrunc@coventry.ac.uk>;

Coventry University ETHICS

The following ethics request has been approved by Elena Gaura. The request has now been passed to the Module Leader, Departmental Ethics Leader or Faculty Leader for approval.

Ref:	P24662
Project Title:	COCO: A technical and human knowledge management model to facilitate access to high quality consumer health information for the general public
Applicant:	Caroline De Brun
Supervisor:	Elena Gaura
Module Code:	N/A
Module Leader:	Keith Gray, Simon Horsman, Eno Maycock, Geraldine Hammersley, Eleanor Parker

Go to ethics.coventry.ac.uk to view this request in more detail.

THIS MESSAGE HAS BEEN GENERATED AUTOMATICALLY - PLEASE DON'T REPLY TO THIS MESSAGE

Appendix 3 – Survey to determine how people find health information

Survey to determine how people find health information

The purpose of this survey is to determine how members of the general public find information to answer questions related to health and to measure familiarity with resources provided by the NHS (National Health Service). The results of this survey will be used as part of my PhD thesis to inform the development of a health information literacy framework. This will help people find good quality health information. Your responses will help me identify what is needed to develop this framework and I am grateful for your time and honesty.

The survey will take about 15 minute to complete.

1. If you were ill or someone you cared for was ill and there was a choice of treatment, would you want to: (*Please tick one of the following option*s)
    a. Make the treatment choice together with the doctor? ☐
    b. Allow the doctor to make the treatment choice for me? ☐

2. If you need health information would you:
    a. Get it from the doctor or other health professional? ☐
    b. Find it for myself? ☐
    c. Both of the above? ☐
    d. None of the above? (***Please go to question 18***) ☐
    e. Other (*Please specify*) ☐

    ----

3. How often do you look for information about health?
    a. Daily ☐
    b. Weekly ☐
    c. Monthly ☐
    d. Once a year ☐
    e. More than 4 times per year ☐
    f. When I need to ☐
    g. Never (***Please go to question 15***) ☐

4. When do you look for health information? (*Please tick all that apply*)
    a. When I am ill ☐
    b. When someone I know is ill ☐
    c. When I am well ☐
    d. Other (*Please specify*) ☐

    ----

5. Who is the information usually for? (*Please tick all that apply*)
    a. Myself ☐
    b. Adult relation/partner ☐
    c. Child relation ☐
    d. Friend ☐

e. All of the above ☐
f. Other (*Please specify*) ☐

----

6. Why do you usually want to look for health information? (*Please tick all that apply*)
   a. So that I am more informed about the condition ☐
   b. So that I can make an informed choice with the doctor ☐
   c. So that I know what to expect ☐
   d. So that I can make lifestyle changes ☐
   e. So that I can provide better support as a carer ☐
   f. Other (*Please specify*) ☐

   ----

7. What might you want to find out about? (*Please tick all that apply*)
   a. More information about a condition diagnosed by a doctor ☐
   b. How to diagnose a condition ☐
   c. Methods of treatment available ☐
   d. Details of local health services ☐
   e. Other (*Please specify*) ☐

   ----

8. Where might you look for health information? (*Please tick all that apply*)
   a. Public library ☐
   b. School or college library ☐
   c. Medical Library ☐
   d. Book ☐
   e. Magazine ☐
   f. Support group ☐
   g. Other people ☐
   h. GP surgery ☐
   i. Patient Advisory Liaison Service (PALS) ☐
   j. Pharmacy ☐
   k. Internet ☐
   l. Online networks (e.g. Facebook, Bebo, MySpace, LinkedIn, Plaxo) ☐
   m. Blogs (online journal) ☐
   n. Online chat room/forum/discussion list ☐
   o. Other (*Please specify*) ☐

   ----

9. Would you use different sources of information for adults and children? (*Please tick one of the following options*)
   a. Yes ☐
   b. No ☐
   c. Not applicable ☐

10. Do you usually find the information you need? (*Please tick one of the following options*)

a. Yes ☐
b. Sometimes ☐
c. No (***Please go to question 13***) ☐

11. When you have found health information on the Internet, who were the publishers? (*Please tick all that apply*)
    a. NHS ☐
    b. Support group ☐
    c. Patient with the same condition ☐
    d. Researcher (e.g. article in a professional journal) ☐
    e. Drug company ☐
    f. Other (*Please specify*) ☐

----

12. How do you usually use the information? (*Please tick all that apply*)
    a. To reassure myself ☐
    b. Share it with my family ☐
    c. Share it with the patient ☐
    d. Discuss the options with the doctor ☐
    e. Other (*Please specify*) ☐

Please go to question 15

13. How do you feel if you do not find the information you want? (*Please tick all that apply*)
    a. Frustrated ☐
    b. Frightened ☐
    c. Fine ☐
    d. Helpless ☐
    e. Confused ☐
    f. Not applicable ☐
    g. Other (*Please specify*) ☐

----

14. What do you usually do next?
    a. Speak to my doctor ☐
    b. Speak to my nurse ☐
    c. Speak to my pharmacist ☐
    d. Nothing ☐
    e. Other (*Please specify*) ☐

----

15. Which of the following should provide services to help people find good quality health information? (*Please tick all that apply*)
    a. Public libraries? ☐
    b. School, further or higher education libraries? ☐

c. GP surgeries? ☐
d. Pharmacies? ☐
e. Town hall? ☐
f. The Internet ☐
g. None of the above (***Please go to question 17***) ☐
h. Other (*Please specify*) ☐

----

16. What services should be provided to help people find good quality health information? (*Please tick all that apply*)
    a. Group training to help me find the information myself ☐
    b. One-to-one training to help me find the information myself ☐
    c. A librarian to search for the information that I need ☐
    d. A computer in a private area of the library, accessing good quality, online health information ☐
    e. One web-site linking to all the best quality information sources ☐
    f. Leaflets providing tips on searching for good quality health-related information ☐
    g. None of the above ☐
    h. Other (*Please specify*) ☐

    ----

17. If you answered “None of the above” to question 16, could you explain why that is?
    a. I wouldn’t want to discuss my condition in a public environment ☐
    b. I would prefer to get the information from a medically-trained person ☐
    c. Other (*Please specify*) ☐

Please go to question 19

18. In question 2, which asked how you would find information if you need it, you said “None of the above”. Why did you choose this response? (*Please tick all that apply*)
    a. I have never needed to look for information ☐
    b. The doctor (or other health professional) provided me with all the information that I needed ☐
    c. It didn’t occur to me to look for information ☐
    d. Other (*Please specify*) ☐

    ----

19. Have you heard about electronic patient records (National Summary Care Record)?
    a. Yes ☐
    b. No (*Please go to question 22*) ☐

20. If yes, have you accessed yours?
    a. Yes ☐
    b. No (*Please go to question 22*) ☐

21. How did you access your electronic patient record?
    a. GP surgery web-site ☐
    b. HealthVault ☐
    c. Health Space ☐
    d. Other (*Please specify*) ☐

    ----

22. Which of the following have you heard of? (*Please tick all that apply*)

Resource	**Yes**
HealthSpace	
HealthTalk Online	
HealthVault	
Information Prescriptions	
Information Standard	
NHS Choices	
NHS Decision Aids	
NHS Direct	
Discern	
HonCode	
None of the above	

23. Which of the following have you used? (*Please tick all that apply*)

Resource	**Yes**
HealthSpace	
HealthTalk Online	
HealthVault	
Information Prescriptions	
Information Standard	
NHS Choices	
NHS Decision Aids	
NHS Direct	
Discern	
HonCode	
None of the above	

24. Please provide details of any other web-sites that you use to find health information? (please specify)

    ----

25. Do you suffer from (*please tick all that apply*):
    a. Alzheimer's disease ☐
    b. Arthritis ☐

c. Dementia ☐
d. Diabetes ☐
e. Heart disease ☐
f. Epilepsy ☐
g. Asthma ☐
h. Inflammatory bowel disease ☐
i. Chronic obstructive pulmonary disease ☐
j. Multiple sclerosis ☐
k. Other long-term chronic condition ☐
l. None of the above ☐

26. Do you care for somebody who is suffering from Alzheimer's disease?
a. Yes ☐
b. No ☐

27. Do you live in:
a. North West England ☐
b. Yorkshire and the Humber ☐
c. East Midlands ☐
d. West Midlands ☐
e. East of England ☐
f. London ☐
g. South East England ☐
h. South West England ☐
i. Wales ☐
j. Scotland ☐
k. Northern Ireland ☐
l. Elsewhere in the World ☐

28. What is your gender?
a. Male ☐
b. Female ☐

29. Are you a:
a. Patient ☐
b. Carer ☐
c. Both ☐
d. Neither ☐

30. What age group are you in?
a. 18-25 years ☐
b. 26-35 years ☐
c. 36-50 years ☐
d. 51-65 years ☐
e. 66-75 years ☐
f. 76+ years ☐

31. What is your ethnic background?
a. Arab ☐
b. Asian or Asian British: Bangladeshi ☐

c. Asian or Asian British: Indian ☐
d. Asian or Asian British: Pakistani ☐
e. Asian or Asian British: Other Asian ☐
f. Black or Black British: Black African ☐
g. Black or Black British: Black Caribbean ☐
h. Black or Black British: Other Black ☐
i. Chinese or Other Ethnic Group: Chinese ☐
j. Chinese or Other Ethnic Group: Other ☐
k. Mixed: White and Asian ☐
l. Mixed: White and Black African ☐
m. Mixed: White and Black Caribbean ☐
n. Mixed: Other Mixed ☐
o. White: British ☐
p. White: Irish ☐
q. White: Other White ☐

32. Are you (tick all that apply):
a. Employed ☐
b. Self-employed ☐
c. Unemployed ☐
d. Student ☐
e. Retired ☐
f. Full-time parent ☐

This space is for any additional comments that you might like to make:

Thank you for taking the time to answer these questions. Your responses are extremely important. If you have any questions arising from this survey or if you would like any further information about the resources described, please contact Caroline De Brún at debrunc@uni.coventry.ac.uk or via her blog http://patientsandcarers.blogspot.co.uk/

If you would like to be involved in further research about this topic, please let me have your contact details.

All information will be stored in compliance with the Data Protection Act 1998.

Appendix 4 – Promotional materials for launch of survey

Letter introducing the survey:

I am a student at Coventry University and a medical librarian at the Royal Free Hospital in London and I help health professionals to find good quality health information so that they can make informed decisions with their patients. I want to do the same thing for members of the general public and so I am doing a PhD to try to improve access to good quality health information for patients and their families and carers.

This is particularly important as patients are being encouraged to participate in the decisions made about their treatment, so they need to be fully-informed about the risks and benefits of the treatment. However, there is so much information on the Internet, it is really difficult knowing what sites to use, and how to judge whether they are good or bad. I would like to identify what would be useful for people, to help them get the information that they need, but I can only do this with the opinions of the people who need it, e.g. patients, family members, and carers.

I have created an online survey and I was wondering if you could help me with my research by circulating the survey to your members or by advertising the link on your site please. I am focusing in particular on people with Alzheimer's disease and related conditions, and their families and carers.

The survey is available here, if you would like to find out more:

http://www.patientsandcarers.blogspot.co.uk/

It should take 10-15 minutes to complete, and it is anonymous and non-intrusive.

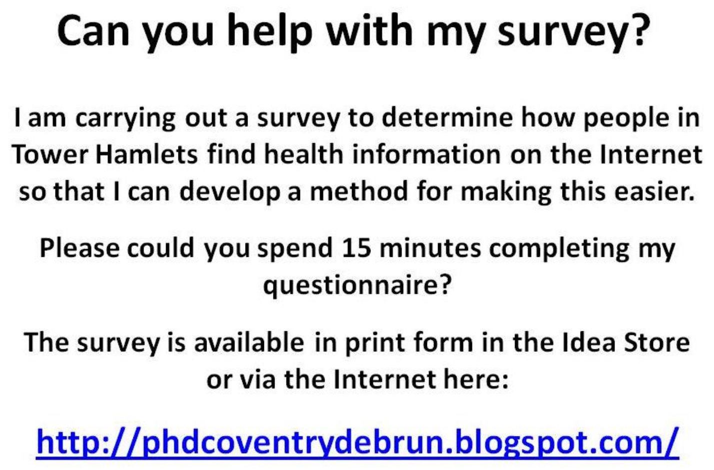
I do hope that you can help, because it would make such a difference to have the opinions of people at the centre of this work.

With many thanks for your kind consideration, from,

Caroline

Mrs Caroline De Brún MA DipLIS MCLIP
Research student
Faculty of Engineering and Computing
Coventry University
E-mail: debrunc@uni.coventry.ac.uk

Plasma screen PowerPoint slide for GP surgeries' plasma screens in the reception areas:



Can you help with my survey?

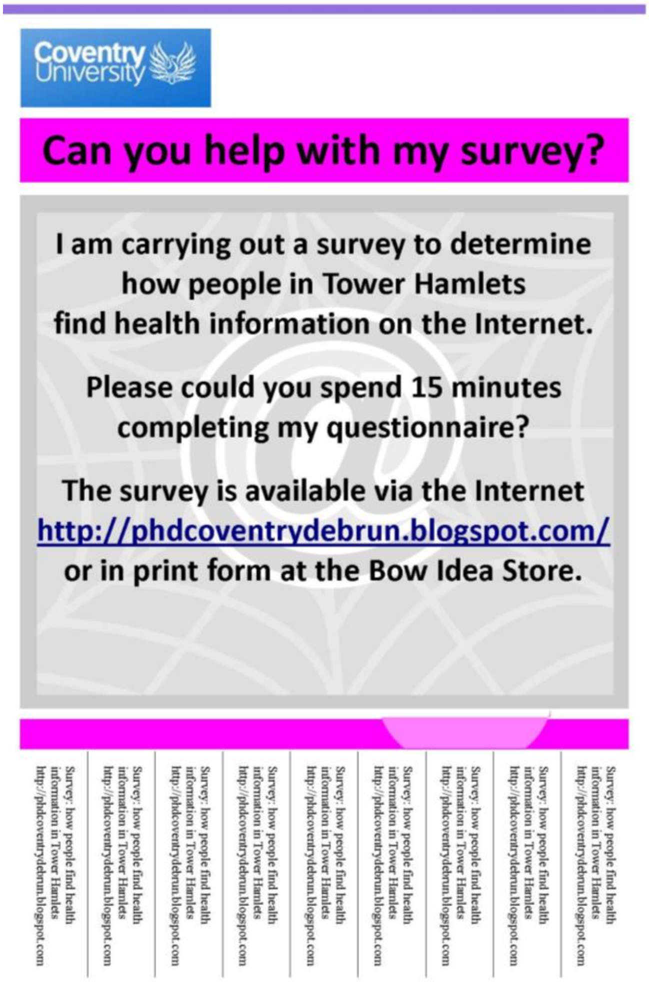
I am carrying out a survey to determine how people in Tower Hamlets find health information on the Internet so that I can develop a method for making this easier.

Please could you spend 15 minutes completing my questionnaire?

The survey is available in print form in the Idea Store or via the Internet here:

http://phdcoventrydebrun.blogspot.com/

Poster with tear-off strips promoting the survey



Coventry University

Can you help with my survey?

I am carrying out a survey to determine
how people in Tower Hamlets
find health information on the Internet.

Please could you spend 15 minutes
completing my questionnaire?

The survey is available via the Internet
http://phdcoventrydebrun.blogspot.com/
or in print form at the Bow Idea Store.

Survey: how people find health information in Tower Hamlets http://phdcoventrydebrun.blogspot.com

Survey: how people find health information in Tower Hamlets http://phdcoventrydebrun.blogspot.com

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Survey: how people find health information in Tower Hamlets http://phdcoventrydebrun.blogspot.com

Survey: how people find health information in Tower Hamlets http://phdcoventrydebrun.blogspot.com

Appendix 5 - Statistical breakdown of survey results

Question	**Response options**	**Number of responses**	**%**
Number of responses		**139**	
1. Who should make the treatment decision?	Doctor	2	1%
	Patient and doctor	137	99%
2. Who do they get health information from?	Health professional	18	13%
	Patient/carer	15	11%
	Patient and health professional	113	81%
	None of the above	0	0%
	Other	2	1%
3. How often do you look for information about a health issue?	Daily	13	9%
	Weekly	21	15%
	Monthly	26	19%
	Once a year	0	0%
	More than 4 times per year	4	3%
	When I need to	71	51%
	Never	0	0%
4. When do you look for health information?	When I am ill	98	71%
	When someone I know is ill	106	76%
	When I am well	36	26%
	Other	20	14%
5. Who is the information usually for?	Patient	89	64%
	Adult relation/partner	89	64%
	Child relation	33	24%
	Friend	30	22%
	All of the above	30	22%
	Other	14	10%
6. Why do you usually want to look for health information?	So that I am more informed about the condition	120	86%
	So that I can make an informed choice with my doctor	91	65%
	So that I know what to expect	98	71%
	So that I can make changes to my lifestyle	71	51%
	So that I can provide better support as a carer	84	60%
	Other	10	7%

Question	Response options	Number of responses	%
7. What do you want to find out about?	More information about a diagnosed condition	125	90%
	How to diagnose a condition	58	42%
	Methods of treatment available	38	27%
	Details of local health services	73	53%
	Other	13	9%
8. Where do you usually look for health information?	Public library	19	14%
	School or college library	1	1%
	Medical library	9	6%
	Book	39	28%
	Magazine	18	13%
	Support group	48	35%
	Other people	40	29%
	GP surgery	65	47%
	Patient Advisory Liaison Service (PALS)	12	9%
	Pharmacy	39	28%
	Internet	126	91%
	Google	29	21%
	PubMed	8	6%
	Online networks	7	5%
	Blogs	14	10%
	Online chat rooms	35	25%
	NHS Choices	20	14%
	NHS Direct	18	13%
	Patient.co.uk	11	8%
	The Information Standard	0	0%
	Other	5	4%
9. Do you use different sources of information for adults and children?	Yes	26	19%
	No	72	52%
	Not applicable	40	29%
10. Do you usually find the information you need?	Yes	48	35%
	Sometimes	73	53%
	No	16	12%
11. When you have found the health information on the Internet, who were the publishers?	NHS	108	78%
	Support group	93	67%
	Patient with the same condition	48	35%
	Researcher (e.g. article in a professional journal)	55	40%
	Drug company	22	16%
	Other	24	17%

Question	Response options	Number of responses	%
12. How do you usually use the information?	To reassure myself	105	76%
	Share it with my family	74	53%
	Share it with the patient	47	34%
	Discuss the options with my doctor	84	60%
	To understand more about the condition	34	24%
	Other	13	9%
13. How do you feel it if you do not find the information you want?	Frustrated	26	19%
	Frightened	11	8%
	Fine	11	8%
	Helpless	28	20%
	Confused	23	17%
	Not applicable	11	8%
	Other	8	6%
14. What do you usually do next?	Speak to my doctor	73	53%
	Speak to my nurse	15	11%
	Speak to my pharmacist	22	16%
	Nothing	19	14%
	Other	25	18%
15. Which of the following do you feel should provide services to help you find good quality health information?	Public libraries	79	57%
	School, further or higher education libraries	43	31%
	GP surgeries	125	90%
	Pharmacies	91	65%
	Town hall	15	11%
	None of the above	3	2%
	Other	18	13%

Question	Response options	Number of responses	%
16. What services should be provided to help you find good quality health information?	Group training to help you find the information yourself	32	23%
	One-to-one training to help you find the information yourself	22	16%
	A librarian to search for the information that you need	30	22%
	A computer in a private area of the library, connected to the Internet, which only accesses good quality health-related information sources	63	45%
	One web-site connecting all the best quality information sources	76	55%
	Leaflets providing tips on searching for good quality health-related information	95	68%
	None of the above	8	6%
	Other	23	17%
17. If you answered "None of the above" to the question about which organisations should provide services to help you find good quality health information, could you explain why that is, please?	I wouldn't want to discuss my condition in a public environment	3	2%
	I would prefer to get the information from a medically-trained person	4	3%
	Other	1	1%
18. You answered, "None of the above" to question 2, which asked how you would find information if you need it? Why did you choose this response?	I have never needed to look for information	1	1%
	The health professional provided me with all the information that I needed	3	2%
	It didn't occur to me to look for information	1	1%
	Other	2	1%
19. Have you heard about electronic patient records?	Yes	101	73%
	No	37	27%
20. If yes, have you accessed yours?	Yes	2	1%
	No	66	47%
21. How did you access your electronic patient record?	GP surgery web-site	1	1%
	HealthSpace	1	1%
	Other	1	1%

Question	**Response options**	**Number of responses**	**%**
22. Which of the following have you heard of?	HealthSpace	18	13%
	HealthTalk Online	2	1%
	HealthVault	1	1%
	Information Prescriptions	22	16%
	Information Standard	16	12%
	NHS Choices	88	63%
	Patient.co.uk	34	24%
	NHS Shared Decision-Making	5	4%
	NHS Direct	120	86%
	Behind the Headlines	1	1%
	Discern	9	6%
	HonCode	16	12%
	None of the above	12	9%
23. Which, if any, of the following have you ever used?	HealthSpace	6	4%
	HealthTalk Online	2	1%
	HealthVault	0	0%
	Information Prescriptions	9	6%
	Information Standard	6	4%
	NHS Choices	64	46%
	Patient.co.uk	22	16%
	NHS Shared Decision-Making	1	1%
	NHS Direct	100	72%
	Behind the Headlines	1	1%
	Discern	5	4%
	HonCode	10	7%
	None of the above	28	20%
24. Do you suffer from a chronic condition?	Yes	10	7%
	No	33	24%
25. Do you suffer from:	Alzheimer’s disease	3	2%
	Arthritis	15	11%
	Dementia	4	3%
	Diabetes	3	2%
	Heart disease	4	3%
	Epilepsy	2	1%
	Asthma	7	5%
	Inflammatory bowel disease	4	3%
	Chronic obstructive pulmonary disease	0	0%
	Multiple sclerosis	0	0%
	Other long-term chronic condition	17	12%
	None of the above	53	38%

Question	Response options	Number of responses	%
26. Do you care for somebody who is suffering from Alzheimer's disease?	Yes	57	41%
	No	36	26%
27. Where do you live?	England: North East	8	6%
	England: North West	2	1%
	England: Yorkshire and the Humber	4	3%
	England: East Midlands	6	4%
	England: West Midlands	18	13%
	England: East	4	3%
	England: London	21	15%
	England: London Borough of Tower Hamlets	18	13%
	England: South East	14	10%
	England: South West	19	14%
	Elsewhere	20	14%
28. What is your gender?	Male	39	28%
	Female	98	71%
29. Are you a:	Patient	10	7%
	Carer	52	37%
	Both	15	11%
	Neither	17	12%
30. How old are you?	18-25	0	0%
	26-35	15	11%
	36-50	35	25%
	51-65	48	35%
	66-75	28	20%
	76+	12	9%

Question	Response options	Number of responses	%
31. What is your ethnic background?	Arab	0	0%
	Asian or Asian British: Bangladeshi	1	1%
	Asian or Asian British: India	1	1%
	Asian or Asian British: Pakistani	2	1%
	Asian or Asian British: Other Asian	0	0%
	Black or Black British: Black African	2	1%
	Black or Black British: Black Caribbean	0	0%
	Black or Black British: Other Black	1	1%
	Chinese or Other Ethnic Group: Chinese	0	0%
	Chinese or Other Ethnic Group: Other	0	0%
	Mixed: White and Asian	2	1%
	Mixed: White and Black African	0	0%
	Mixed: White and Black Caribbean	0	0%
	Mixed: Other Mixed	1	1%
	White: British	111	80%
	White: Irish	3	2%
	White: Other White	12	9%
	No response	3	2%
32. Are you?	Employed	58	42%
	Self-employed	24	17%
	Unemployed	8	6%
	Student	1	1%
	Retired	45	32%
	Full-time parent	6	4%

Appendix 6 – Individual survey results for each population setting

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses
Number of responses		**19**	**24**	**96**	**139**
Who should make the treatment decision?	Doctor	0	1	1	2
	Patient and doctor	19	23	95	137
Who do they get health information from?	Health professional	4	4	10	18
	Patient/carer	4	7	4	15
	Patient and health professional	14	19	80	113
	None of the above	0	0	0	0
	Other	0	0	2	2
How often do you look for information about a health issue?	Daily	0	4	9	13
	Weekly	4	4	13	21
	Monthly	4	4	18	26
	Once a year	0	4	0	
	More than 4 times per year	0	3	4	4
	When I need to	11	9	51	71
	Never	0	0	0	0
When do you look for health information?	When I am ill	15	20	63	98
	When someone I know is ill	10	18	78	106
	When I am well	8	7	21	36
	Other	3	6	11	20
Who is the information usually for?	Patient	18	21	50	89
	Adult relation/partner	11	17	61	89
	Child relation	6	10	17	33
	Friend	3	10	17	30
	All of the above	N/A	N/A	30	30
	Other	2	5	7	14

Question	**Response options**	**London Borough of Tower Hamlets**	**Haughton Thornley Medical Centres**	**UK Alzheimer's disease**	**Total number of responses**
Why do you usually want to look for health information?	So that I am more informed about the condition	15	22	83	120
	So that I can make an informed choice with my doctor	5	16	70	91
	So that I know what to expect	11	16	71	98
	So that I can make changes to my lifestyle	11	13	47	71
	So that I can provide better support as a carer	4	8	72	84
	Other	0	2	8	10
What do you want to find out about?	More information about a diagnosed condition	15	21	89	125
	How to diagnose a condition	5	13	40	58
	Methods of treatment available	13	22	3	38
	Details of local health services	3	14	56	73
	Other	2	0	11	13

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses
Where do you usually look for health information?	Public library	4	3	12	19
	School or college library	0	0	1	1
	Medical library	0	2	7	9
	Book	5	4	30	39
	Magazine	4	1	13	18
	Support group	0	2	46	48
	Other people	4	3	33	40
	GP surgery	3	9	53	65
	Patient Advisory Liaison Service (PALS)	1	0	11	12
	Pharmacy	3	4	32	39
	Internet	15	22	89	126
	Google	15	14	N/A	29
	PubMed	1	7	N/A	8
	Online networks	0	1	6	7
	Blogs	2	1	11	14
	Online chat rooms	2	5	28	35
	NHS Choices	5	15	N/A	20
	NHS Direct	8	10	N/A	18
	Patient.co.uk	5	6	N/A	11
	The Information Standard	0	0	N/A	0
	Other	0	5	N/A	5
Do you use different sources of information for adults and children?	Yes	4	5	17	26
	No	5	12	55	72
	Not applicable	12	5	23	40
Do you usually find the information you need?	Yes	12	15	21	48
	Sometimes	0	0	73	73
	No	7	9	0	16

Question	**Response options**	**London Borough of Tower Hamlets**	**Haughton Thornley Medical Centres**	**UK Alzheimer's disease**	**Total number of responses**
When you have found the health information on the Internet, who were the publishers?	NHS	16	18	74	108
	Support group	5	18	70	93
	Patient with the same condition	7	9	32	48
	Researcher (e.g. article in a professional journal)	8	11	36	55
	Drug company	9	4	9	22
	Other	5	5	14	24
How do you usually use the information?	To reassure myself	12	19	74	105
	Share it with my family	9	15	50	74
	Share it with the patient	1	9	37	47
	Discuss the options with my doctor	6	16	62	84
	To understand more about the condition	14	20	N/A	34
	Other	0	1	12	13
How do you feel it if you do not find the information you want?	Frustrated	9	15	2	26
	Frightened	2	2	7	11
	Fine	3	3	5	11
	Helpless	5	4	19	28
	Confused	4	2	17	23
	Not applicable	0	0	11	11
	Other	0	4	4	8
What do you usually do next?	Speak to my doctor	13	17	43	73
	Speak to my nurse	1	0	14	15
	Speak to my pharmacist	5	2	15	22
	Nothing	5	6	8	19
	Other	0	4	21	25
Which of the following do you feel should provide services to help you find good quality health information?	Public libraries	8	13	58	79
	School, further or higher education libraries	3	8	32	43
	GP surgeries	17	22	86	125
	Pharmacies	11	14	66	91
	Town hall	3	1	11	15
	None of the above	1	1	1	3
	Other	0	5	13	18

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses
What services should be provided to help you find good quality health information?	Group training to help you find the information yourself	3	6	23	32
	One-to-one training to help you find the information yourself	1	7	14	22
	A librarian to search for the information that you need	4	6	20	30
	A computer in a private area of the library, connected to the Internet, which only accesses good quality health-related information sources	11	7	45	63
	One web-site connecting all the best quality information sources	N/A	N/A	76	76
	Leaflets providing tips on searching for good quality health-related information	10	18	67	95
	None of the above	5	1	2	8
	Other	3	7	13	23
If you answered "None of the above" to the question about which organisations should provide services to help you find good quality health information, could you explain why that is, please?	I wouldn't want to discuss my condition in a public environment	0	0	3	3
	I would prefer to get the information from a medically-trained person	0	0	4	4
	Other	0	0	1	1

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses
You answered, "None of the above" to question 2, which asked how you would find information if you need it? Why did you choose this response?	I have never needed to look for information	0	0	1	1
	The health professional provided me with all the information that I needed	0	0	3	3
	It didn't occur to me to look for information	0	0	1	1
	Other	0	0	2	2
Have you heard about electronic patient records?	Yes	14	21	66	101
	No	5	3	29	37
If yes, have you accessed yours?	Yes	0	0	2	2
	No	0	0	66	66
How did you access your electronic patient record?	GP surgery web-site	0	0	1	1
	HealthSpace	0	0	1	1
	Other	0	0	1	1
Which of the following have you heard of?	HealthSpace	3	9	6	18
	HealthTalk Online	0	0	2	2
	HealthVault	0	0	1	1
	Information Prescriptions	3	14	5	22
	Information Standard	2	11	3	16
	NHS Choices	9	22	57	88
	Patient.co.uk	0	0	34	34
	NHS Shared Decision-Making	0	0	5	5
	NHS Direct	18	24	78	120
	Behind the Headlines	0	0	1	1
	Discern	1	7	1	9
	HonCode	3	13	0	16
	None of the above	1	0	11	12

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses
Which, if any, of the following have you ever used?	HealthSpace	2	1	3	6
	HealthTalk Online	0	0	2	2
	HealthVault	0	0	0	0
	Information Prescriptions	3	5	1	9
	Information Standard	1	3	2	6
	NHS Choices	7	20	37	64
	Patient.co.uk	0	0	22	22
	NHS Shared Decision-Making	0	0	1	1
	NHS Direct	15	22	63	100
	Behind the Headlines	0	0	1	1
	Discern	1	4	0	5
	HonCode	3	7	0	10
	None of the above	3	1	24	28
Do you suffer from a chronic condition?	Yes	3	7	N/A	10
	No	16	17		33
Do you suffer from:	Alzheimer's disease	0	0	3	3
	Arthritis	0	0	15	15
	Dementia	0	0	4	4
	Diabetes	0	0	3	3
	Heart disease	0	0	4	4
	Epilepsy	0	0	2	2
	Asthma	0	0	7	7
	Inflammatory bowel disease	0	0	4	4
	Chronic obstructive pulmonary disease	0	0	0	0
	Multiple sclerosis	0	0	0	0
	Other long-term chronic condition	0	0	17	17
	None of the above	0	0	53	53
Do you care for somebody who is suffering from Alzheimer's disease?	Yes	0	0	57	57
	No	0	0	36	36

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses
Where do you live?	England: North East	0	1	7	8
	England: North West	0	2		2
	England: Yorkshire and the Humber	0	0	4	4
	England: East Midlands	0	0	6	6
	England: West Midlands	0	4	14	18
	England: East	0	1	3	4
	England: London	2	4	15	21
	England: London Borough of Tower Hamlets	17	1	0	18
	England: South East	0	1	13	14
	England: South West	0	6	13	19
	Elsewhere	0	3	17	20
What is your gender?	Male	4	10	25	39
	Female	15	14	69	98
Are you a:	Patient	0	0	10	10
	Carer	0	0	52	52
	Both	0	0	15	15
	Neither	0	0	17	17
How old are you?	18-25	0	0	0	0
	26-35	6	7	2	15
	36-50	8	5	22	35
	51-65	2	5	41	48
	66-75	3	7	18	28
	76+	0	0	12	12

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses
What is your ethnic background?	Arab	0	0	0	0
	Asian or Asian British: Bangladeshi	1	0	0	1
	Asian or Asian British: India	0	1	0	1
	Asian or Asian British: Pakistani	1	1	0	2
	Asian or Asian British: Other Asian	0	0	0	0
	Black or Black British: Black African	1	1	0	2
	Black or Black British: Black Caribbean	0	0	0	0
	Black or Black British: Other Black	0	0	1	1
	Chinese or Other Ethnic Group: Chinese	0	0	0	0
	Chinese or Other Ethnic Group: Other	0	0	0	0
	Mixed: White and Asian	1	1	0	2
	Mixed: White and Black African	0	0	0	0
	Mixed: White and Black Caribbean	0	0	0	0
	Mixed: Other Mixed	0	0	1	1
	White: British	10	16	85	111
	White: Irish	1	0	2	3
	White: Other White	3	3	6	12
	No response	1	1	1	3
Are you?	Employed	9	16	33	58
	Self-employed	6	6	12	24
	Unemployed	3	1	4	8
	Student	1	0	0	1
	Retired	1	1	43	45
	Full-time parent	1	0	5	6

Appendix 7 – Results of the Fisher's exact test analysis

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
Number of responses		**19**	**24**	**96**	**139**	
Who should make the treatment decision?	Doctor	0	1	1	2	p=0.524
	Patient and doctor	19	23	95	137	
Who do they get health information from?	Health professional	4	4	10	18	Test not performed because N>90
	Patient/carer	4	7	4	15	
	Patient and health professional	14	19	80	113	
	None of the above	0	0	0	0	
	Other	0	0	2	2	
How often do you look for information about a health issue?	Daily	0	4	9	13	p=0.540
	Weekly	4	4	13	21	
	Monthly	4	4	18	26	
	Once a year	0	4	0	4	
	More than 4 times per year	0	3	4	4	
	When I need to	11	9	51	71	
	Never	0	0	0	0	
When do you look for health information?	When I am ill	15	20	63	98	Test not performed because N>90
	When someone I know is ill	10	18	78	106	
	When I am well	8	7	21	36	
	Other	3	6	11	20	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
Who is the information usually for?	Patient	18	21	50	89	p=0.020
	Adult relation/partner	11	17	61	89	
	Child relation	6	10	17	33	
	Friend	3	10	17	30	
	All of the above	N/A	N/A	30	30	
	Other	2	5	7	14	
Why do you usually want to look for health information?	So that I am more informed about the condition	15	22	83	120	Computer says that it cannot carry out calculation because LDSTP is too small for the problem
	So that I can make an informed choice with my doctor	5	16	70	91	
	So that I know what to expect	11	16	71	98	
	So that I can make changes to my lifestyle	11	13	47	71	
	So that I can provide better support as a carer	4	8	72	84	
	Other	0	2	8	10	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer’s disease	Total number of responses	Fisher exact test
What do you want to find out about?	More information about a diagnosed condition	15	21	89	125	Computer says that it cannot carry out calculation because LDSTP is too small for the problem
	How to diagnose a condition	5	13	40	58	
	Methods of treatment available	13	22	3	38	
	Details of local health services	3	14	56	73	
	Other	2	0	11	13	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
Where do you usually look for health information?	Public library	4	3	12	19	There are too many options to carry out this test as there is a limit of 6 rows per calculation
	School or college library	0	0	1	1	
	Medical library	0	2	7	9	
	Book	5	4	30	39	
	Magazine	4	1	13	18	
	Support group	0	2	46	48	
	Other people	4	3	33	40	
	GP surgery	3	9	53	65	
	Patient Advisory Liaison Service (PALS)	1	0	11	12	
	Pharmacy	3	4	32	39	
	Internet	15	22	89	126	
	Google	15	14	N/A	29	
	PubMed	1	7	N/A	8	
	Online networks	0	1	6	7	
	Blogs	2	1	11	14	
	Online chat rooms	2	5	28	35	
	NHS Choices	5	15	N/A	20	
	NHS Direct	8	10	N/A	18	
	Patient.co.uk	5	6	N/A	11	
	The Information Standard	0	0	N/A	0	
	Other	0	5	N/A	5	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
Do you use different sources of information for adults and children?	Yes	4	5	17	26	Test not performed because N>90
	No	5	12	55	72	
	Not applicable	12	5	23	40	
Do you usually find the information you need?	Yes	12	15	21	48	Test not performed because N>90
	Sometimes	0	0	73	73	
	No	7	9	0	16	
When you have found the health information on the Internet, who were the publishers?	NHS	16	18	74	108	Computer says that it cannot carry out calculation because LDSTP is too small for the problem
	Support group	5	18	70	93	
	Patient with the same condition	7	9	32	48	
	Researcher (e.g. article in a professional journal)	8	11	36	55	
	Drug company	9	4	9	22	
	Other	5	5	14	24	
How do you usually use the information?	To reassure myself	12	19	74	105	Computer says that it cannot carry out calculation because LDSTP is too small for the problem
	Share it with my family	9	15	50	74	
	Share it with the patient	1	9	37	47	
	Discuss the options with my doctor	6	16	62	84	
	To understand more about the condition	14	20	N/A	34	
	Other	0	1	12	13	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
How do you feel it if you do not find the information you want?	Frustrated	9	15	2	26	p<0.001
	Frightened	2	2	7	11	
	Fine	3	3	5	11	
	Helpless	5	4	19	28	
	Confused	4	2	17	23	
	Not applicable	0	0	11	11	
	Other	0	4	4	8	
What do you usually do next?	Speak to my doctor	13	17	43	73	p=0.007
	Speak to my nurse	1	0	14	15	
	Speak to my pharmacist	5	2	15	22	
	Nothing	5	6	8	19	
	Other	0	4	21	25	
Which of the following do you feel should provide services to help you find good quality health information?	Public libraries	8	13	58	79	p=0.905
	School, further or higher education libraries	3	8	32	43	
	GP surgeries	17	22	86	125	
	Pharmacies	11	14	66	91	
	Town hall	3	1	11	15	
	None of the above	1	1	1	3	
	Other	0	5	13	18	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
What services should be provided to help you find good quality health information?	Group training to help you find the information yourself	3	6	23	32	p=0.533
	One-to-one training to help you find the information yourself	1	7	14	22	
	A librarian to search for the information that you need	4	6	20	30	
	A computer in a private area of the library, connected to the Internet, which only accesses good quality health-related information sources	11	7	45	63	
	One web-site connecting all the best quality information sources	N/A	N/A	76	76	
	Leaflets providing tips on searching for good quality health-related information	10	18	67	95	
	None of the above	5	1	2	8	
	Other	3	7	13	23	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer’s disease	Total number of responses	Fisher exact test
If you answered "None of the above" to the question about which organisations should provide services to help you find good quality health information, could you explain why that is, please?	I wouldn't want to discuss my condition in a public environment	0	0	3	3	p=1.0
	I would prefer to get the information from a medically-trained person	0	0	4	4	
	Other	0	0	1	1	
You answered, "None of the above" to question 2, which asked how you would find information if you need it? Why did you choose this response?	I have never needed to look for information	0	0	1	1	p=1.0
	The health professional provided me with all the information that I needed	0	0	3	3	
	It didn’t occur to me to look for information	0	0	1	1	
	Other	0	0	2	2	
Have you heard about electronic patient records?	Yes	14	21	66	101	p=0.226
	No	5	3	29	37	
If yes, have you accessed yours?	Yes	0	0	2	2	p=1.0
	No	0	0	66	66	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
How did you access your electronic patient record?	GP surgery web-site	0	0	1	1	p=1.0
	HealthSpace	0	0	1	1	
	Other	0	0	1	1	
Which of the following have you heard of?	HealthSpace	3	9	6	18	There are too many options to carry out this test as there is a limit of 6 rows per calculation
	HealthTalk Online	0	0	2	2	
	HealthVault	0	0	1	1	
	Information Prescriptions	3	14	5	22	
	Information Standard	2	11	3	16	
	NHS Choices	9	22	57	88	
	Patient.co.uk	0	0	34	34	
	NHS Shared Decision-Making	0	0	5	5	
	NHS Direct	18	24	78	120	
	Behind the Headlines	0	0	1	1	
	Discern	1	7	1	9	
	HonCode	3	13	0	16	
	None of the above	1	0	11	12	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
Which, if any, of the following have you ever used?	HealthSpace	2	1	3	6	There are too many options to carry out this test as there is a limit of 6 rows per calculation
	HealthTalk Online	0	0	2	2	
	HealthVault	0	0	0	0	
	Information Prescriptions	3	5	1	9	
	Information Standard	1	3	2	6	
	NHS Choices	7	20	37	64	
	Patient.co.uk	0	0	22	22	
	NHS Shared Decision-Making	0	0	1	1	
	NHS Direct	15	22	63	100	
	Behind the Headlines	0	0	1	1	
	Discern	1	4	0	5	
	HonCode	3	7	0	10	
	None of the above	3	1	24	28	
Do you suffer from a chronic condition?	Yes	3	7	N/A	10	p=0.47
	No	16	17	N/A	33	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
Do you suffer from:	Alzheimer's disease	0	0	3	3	There are too many options to carry out this test as there is a limit of 6 rows per calculation
	Arthritis	0	0	15	15	
	Dementia	0	0	4	4	
	Diabetes	0	0	3	3	
	Heart disease	0	0	4	4	
	Epilepsy	0	0	2	2	
	Asthma	0	0	7	7	
	Inflammatory bowel disease	0	0	4	4	
	Chronic obstructive pulmonary disease	0	0	0	0	
	Multiple sclerosis	0	0	0	0	
	Other long-term chronic condition	0	0	17	17	
	None of the above	0	0	53	53	
Do you care for somebody who is suffering from Alzheimer's disease?	Yes	0	0	57	57	p=1.0
	No	0	0	36	36	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
Where do you live?	England: North East	0	1	7	8	There are too many options to carry out this test as there is a limit of 6 rows per calculation
	England: North West	0	2		2	
	England: Yorkshire and the Humber	0	0	4	4	
	England: East Midlands	0	0	6	6	
	England: West Midlands	0	4	14	18	
	England: East	0	1	3	4	
	England: London	2	4	15	21	
	England: London Borough of Tower Hamlets	17	1	0	18	
	England: South East	0	1	13	14	
	England: South West	0	6	13	19	
	Elsewhere	0	3	17	20	
What is your gender?	Male	4	10	25	39	p=0.258
	Female	15	14	69	98	
Are you a:	Patient	0	0	10	10	p=1.0
	Carer	0	0	52	52	
	Both	0	0	15	15	
	Neither	0	0	17	17	
How old are you?	18-25	0	0	0	0	p<0.001
	26-35	6	7	2	15	
	36-50	8	5	22	35	
	51-65	2	5	41	48	
	66-75	3	7	18	28	
	76+	0	0	12	12	

Question	Response options	London Borough of Tower Hamlets	Haughton Thornley Medical Centres	UK Alzheimer's disease	Total number of responses	Fisher exact test
What is your ethnic background?	Arab	0	0	0	0	There are too many options to carry out this test as there is a limit of 6 rows per calculation
	Asian or Asian British: Bangladeshi	1	0	0	1	
	Asian or Asian British: India	0	1	0	1	
	Asian or Asian British: Pakistani	1	1	0	2	
	Asian or Asian British: Other Asian	0	0	0	0	
	Black or Black British: Black African	1	1	0	2	
	Black or Black British: Black Caribbean	0	0	0	0	
	Black or Black British: Other Black	0	0	1	1	
	Chinese or Other Ethnic Group: Chinese	0	0	0	0	
	Chinese or Other Ethnic Group: Other	0	0	0	0	
	Mixed: White and Asian	1	1	0	2	
	Mixed: White and Black African	0	0	0	0	
	Mixed: White and Black Caribbean	0	0	0	0	
	Mixed: Other Mixed	0	0	1	1	
	White: British	10	16	85	111	
	White: Irish	1	0	2	3	

	White: Other White	3	3	6	12	
	No response	1	1	1	3	
Are you?	Employed	9	16	33	58	p<0.001
	Self-employed	6	6	12	24	
	Unemployed	3	1	4	8	
	Student	1	0	0	1	
	Retired	1	1	43	45	
	Full-time parent	1	0	5	6	

Appendix 8 – Results from survey sent to Public Librarians

Please note: The responses are not anonymous, because it is a public mailing list and therefore, the information is publicly available.

Public Libraries	**Do you ever have to answer health information enquiries from the general public?**	**Do you feel confident that you can answer health-related questions?**	**Which sources do you use for health information?**	**Are you happy to be contacted again?**	**Comments**
Northamptonshire Libraries and Information Service	Yes	Most of the time	NHS Choices, Patient UK, specialist organisations (Macmillan, Stroke Association, Arthritis Care)	Yes	I have also arranged training in health information in conjunction with our local NHS library colleagues.
London Borough of Havering Libraries	Yes	Yes	Popular medical books on conditions such as cancer, diabetes, mental health issues, BMA New Guide to Medicines and Drugs, Black's Medical Dictionary, BMA Complete Family Health Guide, Patient UK, Medic Direct, Surgery Door, NHS Choices, US National Library of Medicine	Yes	I also find it useful to see if there is a support group for a particular condition and offer contact/web-site details. Especially with rarer conditions, I think support groups are a valuable source of information as they have a vested interest in gathering reliable information about it.
Hertfordshire County Council Libraries	Yes	Yes	General health encyclopaedias/dictionaries, BNF, BMA Guide to drugs and medicines, medical directory, NHS Choices, BBC, Patient UK, NetDoctor.co.uk		We have 2 Macmillan cancer info points in our libraries.

Public Libraries	Do you ever have to answer health information enquiries from the general public?	Do you feel confident that you can answer health-related questions?	Which sources do you use for health information?	Are you happy to be contacted again?	Comments
Hertfordshire County Council Libraries	Yes	Yes	Relevant society for their condition, via Directory of British Associations	Yes	As I've been in my present post 11 years, the sources I used may not be most suitable now, e.g. there was little use made of the Internet! (Whereas now we plan to run staff training sessions on health information and where best to look for it.)
Cambridgeshire County Council Libraries, Archives and Information	Yes	Yes	Library webpage and local information webpage which links to support groups, NHS Choices, Patient UK, national web-sites, Google, Cambridgeshire Books on Prescriptions, library book collection	Yes	
Leeds City Council Library and Information Service	Yes - 25,304 enquiries about health 2010-2011	Yes	Books , journals such as the Lancet which is searchable on our journal databases, key web-sites, work in partnership with health librarians from hospitals and university		Staff had training on NHS Choose and Book … training on health information is being reviewed with a full scale Information Services Review this year.
Torquay Library	No	N/A	N/A		

Public Libraries	Do you ever have to answer health information enquiries from the general public?	Do you feel confident that you can answer health-related questions?	Which sources do you use for health information?	Are you happy to be contacted again?	Comments
Poole Library Service	Yes - dedicated consumer health information service - Healthpoint	Yes	Reference Library for patients, collection of DVDs and CDs on health conditions and journals from the main health-related charities, e.g. British Heart Foundation, Stroke Association, Diabetes UK etc.		See attachments - Healthpoint has been running for 23 years - they order articles from the Post Graduate Medical Centre Library at Poole Hospital.
Swindon Borough Council Libraries	Yes	Yes	Medical encyclopaedias and dictionaries, family health guides, drug directories, anatomy textbooks, self-help books, Oxford Reference Online and Know UK, which both include a small selection of medical books, NHS Direct		

Appendix 9 – Results from survey sent to Medical Librarians

Please note: The responses are not anonymous, because it is a public mailing list and therefore, the information is publicly available.

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
Lancashire Teaching Hospitals NHS Foundation Trust	No	N/A	The majority of patient information is available on the wards and is specific to the particular speciality or procedure. Patient information on procedures is also sent out to patients when they receive their appointment. Patient information is also provided via the Trust web-site under a patients tab: http://www.lancsteachinghospitals.nhs.uk/patients/patients.html. The PALs service also provides information for patients.
Tameside General Hospital	No	N/A	At Tameside General Hospital we have a dedicated Health Information Centre which is a joint service between the hospital and the local council. They can access information in wards and clinics and also online via the Trust web-site, in particular patient information leaflets.
Hull and East Yorkshire Hospitals Trust	No	N/A	Macmillan trust adviser, care key workers and PALS. Central intranet repository of patient info leaflets.

Medical Library	**Does your medical library provide health information to patients?**	**If yes, do you also provide information skills training to patients?**	**If no, can they get health information elsewhere in your organisation, and if yes, where?**
NHS Direct	Yes - we deal with around 500,000 health information requests per year from patients, ranging from simple "where's my nearest GP?" to "What are the latest treatment guidelines on X?" or "Can you find me a specialist on X for my GP to refer me to?" or "Is using a wireless enabled laptop safe?"	Not as such - we don't provide any kind of formal training to service users (although some of us would love to be able to).	Nope - not really - the health information service branch of NHS D is the only part of NHSD that provides HI.
North Bristol NHS Trust	Yes - for reference only - they can visit the library but not borrow	Not as such - we don't provide any kind of formal training to service users (although some of us would love to be able to).	Basically health information is provided by Patient Information leaflets etc.
Princess Alexandra Hospital Library	No	Not as such - we don't provide any kind of formal training to service users (although some of us would love to be able to).	Our Trust has just started rolling out the Information Prescriptions service provided by NHS Choices….The rollout project and support is confined to cancer services, but it may spread to other departments.

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
Bronglais General Hospital (Wales)	No not directly because we don't encourage patients to come in person to the library, which is situated in the Postgraduate centre and not in a part of the hospital usually accessible to patients. However, we don't have a security coded door so in the past we have had the occasional patient coming in to the library. Yes indirectly, because we provide information to health professionals to pass on to their patients.	No not directly. However, I have conducted some "train the trainer" sessions for public librarians who deal with members of the public who ask for help finding health information.	There are printed leaflets available in outpatients and clinics and I assume patients are given specialist information by specialist care providers e.g. Medicines advice by pharmacists, dietary advice by dieticians etc. There are reputable online services for patients too e.g. NHS Direct, Patient UK, but there is not public PC or Wifi in patient areas so I assume patients are encouraged to use these sites from home/public library/internet cafe etc.
NHS Grampian - Dr Gray's Hospital	No - our users are exclusively NHS staff and 'those in support of the NHS' e.g. voluntary groups, allied local authority, students, social services. Specifically not patients.	No	There's a 'Healthpoint' information set up with two staff, pcs for public use and printed information in a large glassed in room in the main lobby of this hospital. There are further Healthpoints in a number of NHS Grampian towns and cities, some in health centres and hospitals, some in high streets.

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
Surrey and Sussex Healthcare NHS Trust	Yes – patients and carers are allowed to access the library service for reference. No specific resources are purchased for them, however if they do visit the library and request ask for help in finding information relating to a condition we will find them information usually from the Internet.	No we don't, however we do work with our public library colleagues to support their information skills when finding health related information.	The Trust is currently setting up a cancer patient information service with Macmillan which will have a booth near one of the entrances to the hospital. Patients can also contact PALS service who will normally direct them to us.
Peterborough Hospitals	Not usually	No	Cancer Information Service, or some information via PALS
George Eliot Hospital	No	No	PALS

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
Queen Victoria Hospital NHS Foundation Trust	Yes, by appointment	No	We have a Macmillan Cancer Information Centre and also a PALS Information desk which also provides information leaflets, etc.
Nuffield Orthopaedic Centre	Yes	No	Yes they can also access health information elsewhere in the form of leaflets produced by Trust rather than referral to certain sites.
Brighton and Sussex University Hospitals NHS Trust	Yes - the library will provide health information to patients/carers and will do searches for and with them present. However requests are rare as we do not advertise. We would normally stick to patient information databases e.g. Patient UK and the Trust's own patient information database. The library also serves local health promotion practitioners so we have a collection of health promotion leaflets that we can give patients and or carers.	We would not provide training to patients/carers. Although, if they sat with us while we did a search we would explain the databases and how to get to them on the Internet.	Some years ago, some of the staff at the Brighton & Hove PALS (Patient Advice and Liaison Service) had some training on using patient information databases, and this is the place that patients/carers would probably go to.

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
Kent and Medway NHS Trust	Yes - we allow anyone to look at the books in our library but due to some very expensive books going missing we are unable to loan them out, but we have plenty of comfortable spots for people to sit down and read for as long as they like and take photocopies.	We can provide IST to anyone but non-staff are asked to pay a fee of £25.	If anyone came to ask about getting healthcare information I would direct them to NHS Evidence or NHS Choices where they can get access to freely available content that is accessible and reliable.
South Tyneside NHS Foundation Trust	No	N/A	NHS South of Tyne and Wear public web-site http://www.sotw.nhs.uk/yourhealth/ has a 'Your Health' section designed for the public, covering health and wellbeing, healthy lifestyle, screening and other services available, and a Health A-Z which is a direct link to NHS Choices. South Tyneside NHS Foundation Trust web-site http://www.stft.nhs.uk/for-patients has a For Patients section, largely around using the hospital; there is a list of sites under Links which includes NHS Choices - though it doesn't describe what the site covers so visitors wouldn't necessarily know that that leads to health information. On the community side, there are usually leaflets available in health centres, primary care centres etc. and info available direct from staff; but what's available would vary from place to place and as far as I know there is no comprehensive collection in the area.

Medical Library	**Does your medical library provide health information to patients?**	**If yes, do you also provide information skills training to patients?**	**If no, can they get health information elsewhere in your organisation, and if yes, where?**
Barnet and Chase Farm Hospitals NHS Trust	Yes - only on a very informal basis - we don't often supply them with information that they couldn't get from a public library and we only get very occasional usage.	We don't provide information skills training.	As far as I know health information is not provided elsewhere in the organisation.
Western Sussex Hospitals NHS Trust	No - the medical education centre is not widely advertised on hospital grounds. It is enclosed in its own building out of the way of public areas. If someone were to enquire, then we cannot refuse them the use of the library, just that they would have limited or no access to some or the majority of the services.	No	There is the PALS service available to them, which is readily accessible, at the front entrance of the hospital.
Harrogate District Hospital	No	N/A	Yes, they can obtain information from elsewhere - the Trust has a "Patient Information and Communication Group" which works to provide patient information. The library is not involved with this group.

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
NHS Greater Glasgow and Clyde	Yes - reference/reading access is available to anyone in all libraries (although security means that access is not always physically possible for non-staff. PC access is also prohibited for non-staff).	Training and enquiry answering would not normally be provided to members of the public.	3 hospitals provide a dedicated patient enquiry services (including PC access, guidance to community support, assistance with arranging appointments and understanding information given by doctors etc.). The cancer hospital also has a Maggie's Centre which provides (among other services) an information service. The library service does not run these but provides support (largely technical - web-site presence, supplying enquiry databases etc.), and the services are partly volunteer led. These services have a varied history and the library service was instrumental in setting up some of them. One of the libraries is a health promotion library, but only provides information and services to health promotion staff.
Royal Berkshire NHS Foundation Trust	No	No	We only provide information through the PALS set up; patients/carers are encouraged to go to them, not us.
University of Sheffield Health Sciences Library	No - we don't turn patients/carers away but it is not under our remit to support them.	No	Yes, there is a patient information service.
Royal Orthopaedic Hospital, Birmingham	No - we do not provide health information to patients or carers. However, if requested to do so (which has happened on very rare occasions) we are quite willing to do so.	No	We are a single specialty Trust and all surgery is elective. For this reason patients have time to prepare for surgery - and this is carried out through such activities as hip and knee workshop which are organised by nurses and physiotherapists, and give the opportunity to ask questions and receive handouts giving information about the pending surgery. I think that patients are well informed, but I do feel that it would be useful to inform them that the library is available to them should they feel they require extra information - if only to assist them in assessing the trustworthiness of the inter-net sites they may be accessing.

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
Tees, Esk and Wear Valleys NHS Foundation Trust	No	No	The trust has a patient information officer who is responsible overall for patient information provision. She is part of the patient experience team, which includes PALS.
Oxfordshire Learning Disability NHS Trust	No - I run a specialist Learning Disability library and while I provide material in easy read format that is used by professionals when they explain health issues to clients I rarely deal with the clients themselves although they are free to come in.	No	For professionals such as OTs, dieticians, nurses, etc…the provision of health information to clients is a significant part of their job - I back them up with the resources.
Blackpool Teaching Hospitals NHS Foundation Trust	No	No	Patients are given Patient Information Leaflets for their complaint. These leaflets have been produced following an evidence search by either the clinician or the library and all are checked by the library for the relevance of the evidence before publication (to conform with The Information Standard requirements). The PALS service provides a wide range of general information for patients/carers.
Heart of England NHS Foundation Trust	No	No	The Patient Information service at HEFT.
Poole Hospital NHS Trust	No	No	They can access health leaflets etc. at a Health Information and Resource Centre on site, or Healthpoint in the Public Library (near our hospital).

Medical Library	Does your medical library provide health information to patients?	If yes, do you also provide information skills training to patients?	If no, can they get health information elsewhere in your organisation, and if yes, where?
Whipps Cross University Hospital Trust	Yes - we do offer support to patients and carers who find us, but do not advertise the service at present, other than to members of the Expert Patient group or the local patients' panel. This is on an informal basis but they have full library membership rights if they want to join and receive support with literature searching or information seeking.	No	If and when we move to a more public area of the hospital, it is possible that the service we offer will expand to embrace other members of the public.
Hospital Universitario La Paz, Madrid	No	No	The patients can get health information in one of the Library blog pages: Educación Sanitaria
Oxford Health NHS Foundation Trust	No - we do allow access provided the patient is accompanied by a member of the clinical staff.	No	The PALS service.
Northern Devon Healthcare NHS Trust	Yes - if asked to do so by the patient or carer.	No - we have never been asked to do so. As a small library team we wouldn't be able to take this on a regular basis.	Yes, they can obtain health information from our Patient Information Service.

Medical Library	**Does your medical library provide health information to patients?**	**If yes, do you also provide information skills training to patients?**	**If no, can they get health information elsewhere in your organisation, and if yes, where?**
South London Healthcare NHS Trust	No	No	The Trust has patient leaflets on the intranet provided by a commercial company which I assume can be given out by medical staff to patients.
Gloucestershire Royal Hospital	No	Yes - we do train hospital volunteers who work in the health information room in the hospital to point patients towards good quality internet resources	Gloucestershire also provides a service called GUIDE which provides information on health and social care that we can signpost people towards http://www.guide-information.org.uk/

Appendix 10 – Email sent to model validators

Subject: Action required: Please validate my model for my PhD research

Dear

Please could you help me with the validation of my model? I am in the final year of a PhD at Coventry University. My field is health knowledge management, and my topic is improving access to good quality health information for patients and carers. I have developed a model which brings together existing NHS resources and combines it with library services to ensure that there is a range of simple access points to quality health information. I would be so grateful if you could spend some time reviewing my model and framework and seeing if it is realistic, logical, and practical.

I am attaching two documents to this email. The first includes an introduction to my work, a description of the framework and the model, and how it will work for four scenarios. The second attachment provides a visual guide to how the model will work according to those scenarios.

I have created a survey of ten questions, which I would really appreciate if you would complete. The survey is here http://www.surveymonkey.com/s/S6LP9QQ, but if you would prefer to respond via this email, then here are the 10 questions – please give details for your responses where appropriate:

1. Are there any parts of the consumer health information literacy stage of the framework that are unclear?

2. Does the model satisfy all the points in the consumer health information literacy stage? If not, please specify which ones are not satisfied.

3. Does the model do what you expect it to? If not, please specify what you expect it to do.

4. Can you spot any errors in the model? (Please give details)

5. Can you see if anything is missing from the model? (Please specify)

6. Do you think this model will be useful to patients and carers? (Please explain your opinion)

7. Is the model too simple/too complicated/just right?

8. Which organisation are you affiliated to? This is important so that I can ensure the validation chapter is fairly represented.

9. I will be quoting responses in my validation chapter. Would you like these to be anonymised?

10. If you have any additional comments to make about this work, please write them here.

Thank you very much for giving up your valuable time to complete this survey. If you have any questions about this research, please do get in touch. My email address is debrunc@coventry.ac.uk. If you would like to learn more about my work, please visit my LinkedIn page (http://uk.linkedin.com/in/carolinedebrun/).

This research is very important to me, and I hope some or all of it will be used to make it easier for patients and carers to access good quality health information.

With very best wishes, and many thanks for your time and consideration, from,

Caroline

Mrs Caroline De Brún, MA DipLIS MCLIP
Research student – Coventry University
debrunc@coventry.ac.uk

Appendix 11 – Document sent to validators describing the proposed model

COCO model: an introduction

The hypothesis is that people do want to be able to search for quality health information and that they would value services and resources to help them achieve this.

The model is a hybrid solution, combining technical with human resources. The proposed outcome is a collaborative initiative between medical and public librarians, combined with existing online health resources. The initial entry point is a technical solution, but the option for human interaction is available throughout. The model is based on survey data, a comprehensive literature review, and the framework in Exemplar 1.

This document outlines the framework upon which this work is based, and the model itself. I would be very grateful if you could read it and then answer the ten questions in the survey - http://www.surveymonkey.com/s/S6LP9QQ

The framework

The framework upon which this model is based, has been adapted from the SCONUL seven pillars information literacy framework (Society of College National and University Libraries (SCONUL) 1999) and the five steps to evidence-based-practice concept (Akobeng 2005; Sackett 1997), adopted by health professionals around the world. Exemplar 1 shows how the seven pillars maps to EBP, and how it translates to inform the consumer health information literacy framework designed as a foundation for the final model:

Exemplar 1

Stages of SCONUL 7 pillars	**EBM five steps**	**Consumer health information literacy translation**
Recognise a need for information	Formulate answerable clinical questions	Identify a knowledge gap, e.g. desire for more information about a condition and/or treatment
Distinguish ways in which the information 'gap' may be addressed	Find the evidence - identify appropriate sources	Recognise a source that can fulfil that knowledge need, e.g. health or information professional, library, or reliable online source
Construct strategies for locating information	Find the evidence - identify all relevant terms	Speak to health or information professional about the different terms related to that condition

Locate and access information	Find the evidence - conduct the search	Retrieve the information from the health or information professional or online source
Compare and evaluate information obtained from different sources	Appraise the evidence	Check whether it is relevant and reliable using Silberg's 4 standards: 1. Authorship - Who wrote the content and what are their credentials? Are they qualified to provide this information? 2. Attribution - is it clear how the information was generated, e.g. is it referenced? 3. Disclosure - is the web-site sponsored by anyone who might have a commercial gain? When did they write it? Who did they write it for? 4. Currency - is there a date to indicate age of the content?(Silberg et al. 1997)
Organise, apply and communicate information to others in ways appropriate	Apply the evidence	Make a list of questions arising from the information and discuss with the health professional
Synthesise and build upon existing information, contributing to the creation of new knowledge	Evaluate performance - is it improving patient care	Make an informed decision about the treatment being proposed, and keep monitoring the literature, to stay informed about new developments.

The model evolving from this framework provides a system and tools to support consumer health decision-making and evidence-based patient choice (EBPC). It will take in to consideration the desired outcome for the patient, prompting them to consider how their lifestyle will change. Sometimes side effects can be worse than the condition, so it is important that people understand the implications of what they are undertaking.

Proposed model

It will be a simple interface with a memorable web address, e.g. http://www.coco.nhs.uk. It will use an adapted version of PICO (the question formulation template for clinicians), designed for patients - COCO (Condition, Option, Choice, Outcome). In this case, “Option” refers to treatment choice or intervention, but option is more meaningful to patients, as this is often the terminology health professionals would use with them. The “Outcome”, while having the same meaning as the outcome in PICO, may have different interpretations. For the health professional, it may mean cure or alleviation of symptoms. However, for a patient, he/she would be more interested in better quality of life. Being cured might mean a better quality of life, but not always, depending on the patient's personal circumstances.

Information sources

The model should not only search for evidence, but also uncertainties and gaps in the research, so that patients and carers have all the information they need to make an informed decision. It is proposed that the resource will search the following information sources:

1. NICE Evidence Search – guidelines and uncertainties
2. HealthTalkOnline.org – patient experiences
3. NHS Right Care - decision aids
4. NHS Choices – patient information leaflets
5. The Information Standard – patient support groups producing quality health information leaflets
6. TRIP Database – primary and secondary research

Throughout the search experience, the patient/carer will have the option to send the search directly to the public librarian, who will respond within 5 working days. The public librarians will be trained and supported by medical librarians, this being the collaborative element of the model.

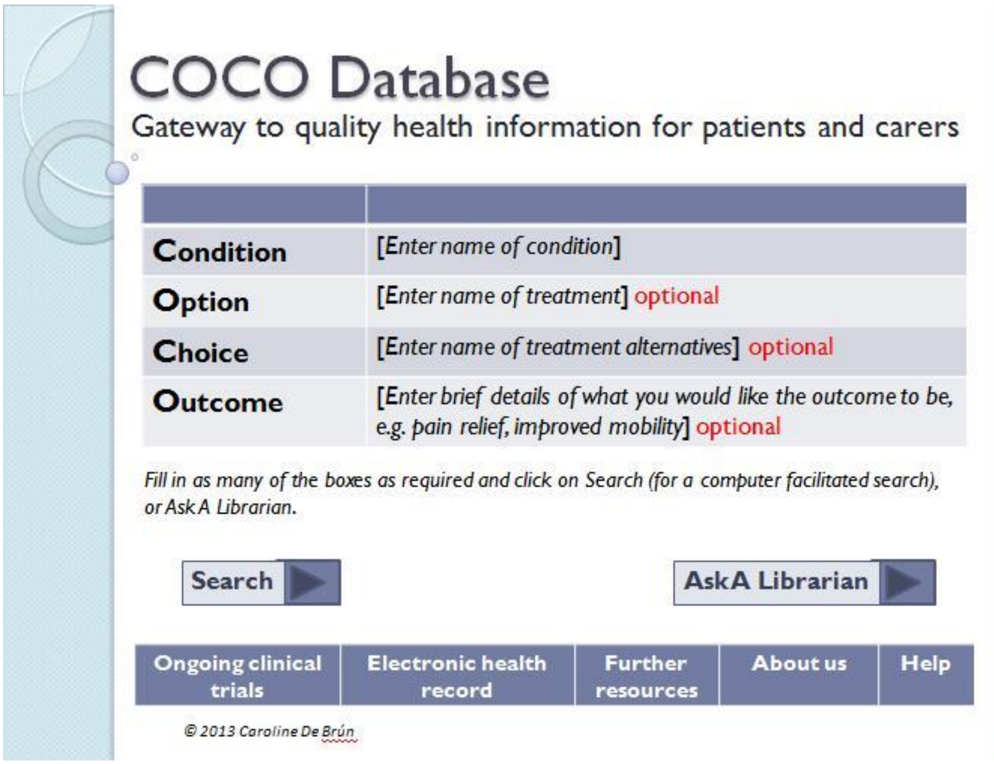
There will be an option to search separately for ongoing clinical trials, as it was thought it might be too confusing to incorporate these with the results from the search for evidence.

Patients will need to have their own health data available, so there will be a link to their personal electronic health records from the site.

The idea is to make sure that patients and carers can access all the resources available to them, without having to navigate lots of different web-sites, and if they aren't computer literate, they will be able to contact a librarian, either via the web-site or a dedicated phone number.

Additional support

Finally, the web-site will bring together key resources, including: NHS Direct, NHS Choices symptom checker, NHS Choices Behind the Headlines, a template to help people make decisions (based on existing decision aids, e.g. a generic aide-memoire), and links to resources to facilitate patient information critical appraisal, e.g. DISCERN. Below is a mock-up of how the model might look if it comes in to fruition:



COCO Database

Gateway to quality health information for patients and carers

Condition	[*Enter name of condition*]
Option	[*Enter name of treatment*] optional
Choice	[*Enter name of treatment alternatives*] optional
Outcome	[*Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility*] optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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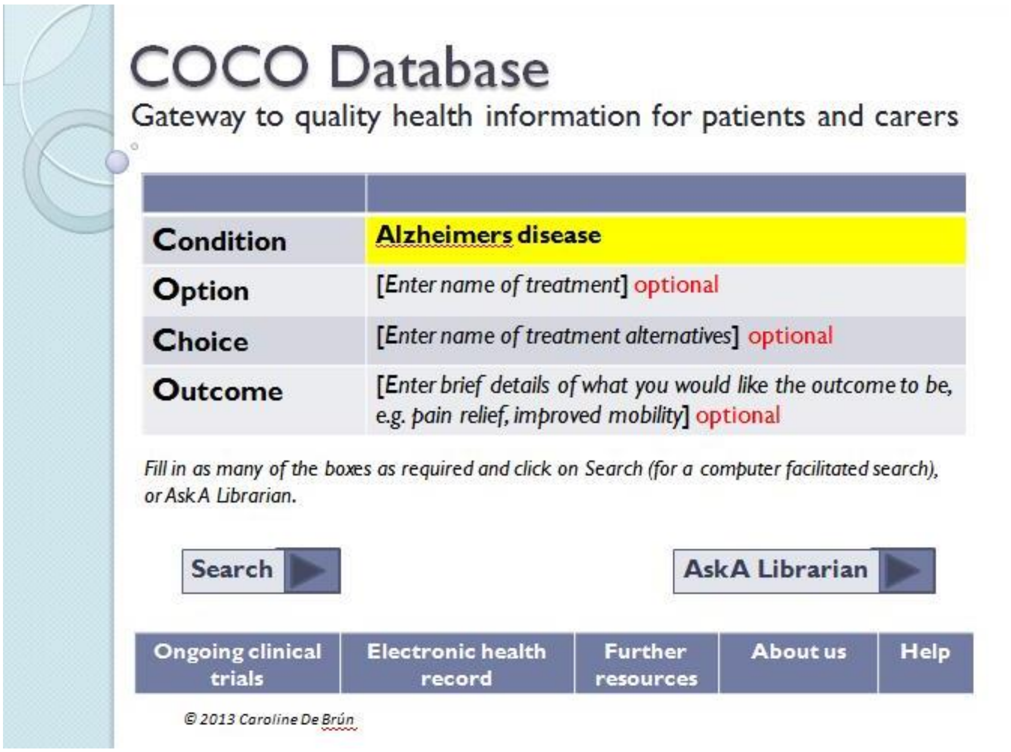
Scenarios and explanation of how the model will work:

Alzheimer’s disease is one of the most common types of dementia, a condition affecting the memory, moods, and causing communication problems, where the symptoms gradually worsen (NHS Choices 2012; Alzheimer’s Society 2012).

Below are four possible scenarios about a person who has been diagnosed with Alzheimer’s disease and his family, followed by a description and a mock-up for each scenario, demonstrating how the model might help patients and carers find good quality health information easily. In the accompanying attachment, there is a visual adaptation of each of these scenarios.

Scenario 1

For the past few months, Benjamin P. has been struggling with his memory and has been finding conversations difficult because he gets his words confused. After several visits to his GP and then a specialist, he is diagnosed with early on-set Alzheimer’s disease. He isn’t clear what this means, and although his doctors have explained it to him, he, and his family who will care for him, want to find out more about his newly-diagnosed condition and what they can expect.



COCO Database

Gateway to quality health information for patients and carers

Condition	**Alzheimers disease**
Option	[Enter name of treatment] optional
Choice	[Enter name of treatment alternatives] optional
Outcome	[Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility] optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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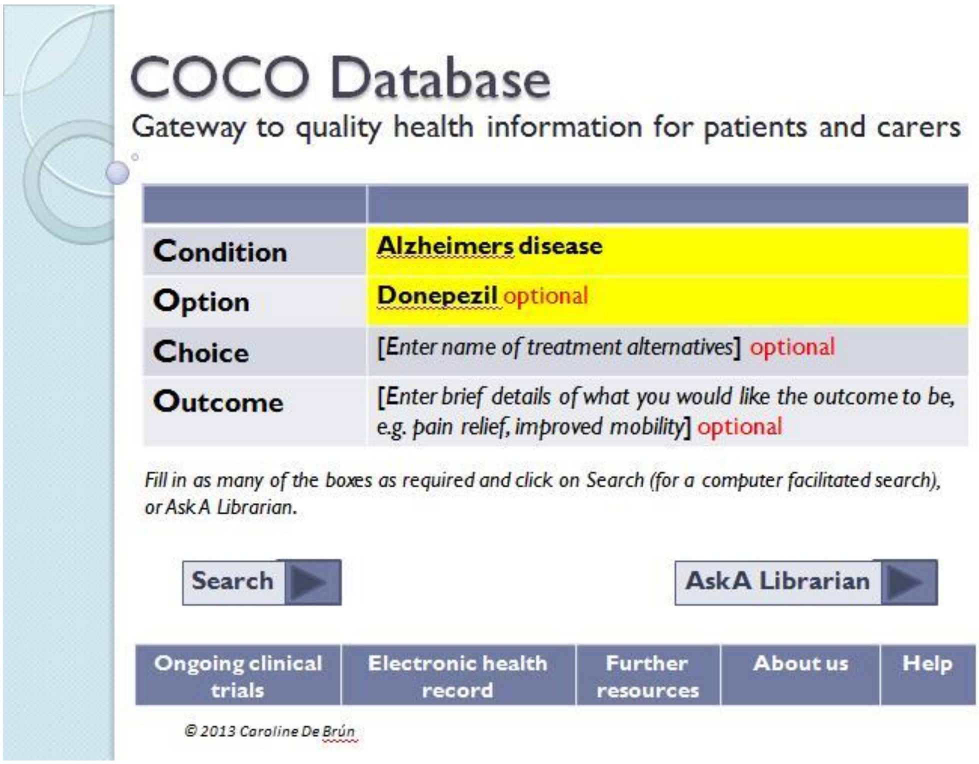
The patient or carer types in the condition name only. The software will automatically map to an index term, which will add all alternative synonyms to the search. Many conditions have different names. For example, Myalgic Encephalomyelitis is also known as Chronic Fatigue Syndrome, so it is important to include all the relevant terms in the search. However, a patient/carer might not be familiar with all the variations, which is why it is essential that the software will perform this stage automatically. Fortunately, the National Library of Medicine, in America, has created an Index for this purpose, called MeSH (Medical Subject Headings), and this can be built into the software to achieve this objective. The patient/carer clicks on search and the software will search for high quality patient information leaflets, via NHS Choices and The Information Standard. If the patient/carer prefers, they can just click on Ask A Librarian and their request will be sent to a public librarian.

Scenario 2

Alzheimer's disease cannot be cured, but there are various medication options available. Benjamin has been prescribed donepezil, an acetylcholinesterase (AChE) inhibitors (National Institute for Health and Clinical Excellence 2011) *for the early stages of Alzheimer's disease, and he and his family want to know more about how this drug will affect him and if there are any side effects they should be aware of.*



COCO Database

Gateway to quality health information for patients and carers

Condition	Alzheimers disease
Option	Donepezil optional
Choice	[Enter name of treatment alternatives] optional
Outcome	[Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility] optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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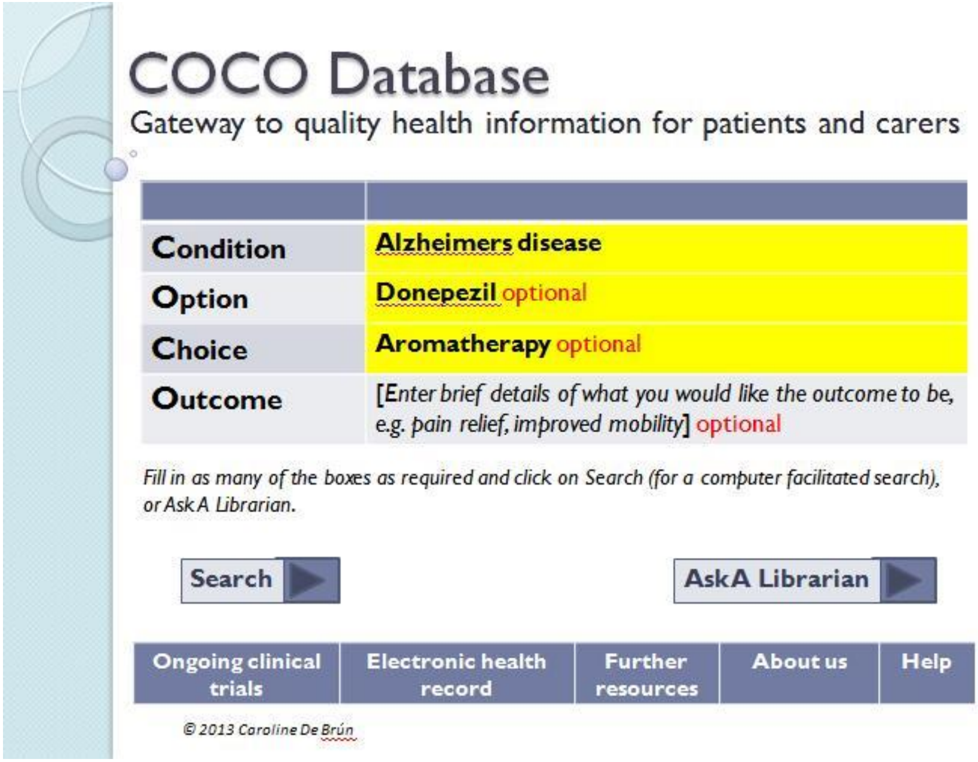
The patient/carer enters the condition name in the C box and the treatment option in the first O box. Again, these will be mapped to all the synonyms, which is particularly useful for drug treatment options, which often have generic and trade names, e.g. Donepezil and Aricept. The patient/carer will then click on search and the software will search three key resources:

1. NICE Evidence Search for guidelines, published by NICE (National Institute for Health and Care Excellence), SIGN (Scottish Intercollegiate Guidelines Network) and professional organisations, such as the Royal College of Psychiatrists, and topic pages on the treatment of the condition, and treatment uncertainties and unknowns from the Database of Uncertainties about the Effects of Treatments).
2. Decision-making tools, such as decision aids, which are tools being designed by the NHS, for patients, that present all the possible options in a clear and concise format, to help them make informed decisions with their health professionals.
3. True stories, produced by HealthTalkOnline (http://www.healthtalkonline.org/), which are patient experiences, formerly recorded in various formats, and covering a range of conditions and treatments, to help patients and carers get an idea of what they can expect.

Again, if the patient/carer prefers, they can just click on Ask A Librarian and their request will be sent to a public librarian.

Scenario 3

Benjamin has been on his treatment for 3 months, and while his symptoms are more under control, he has been feeling depressed at his situation. His daughter has heard that some aromatherapy oils can improve cognition and alleviate symptoms of depression (Alzheimer's Society 2013)*, and they would like to find out more about this as a complementary option to his current drug treatment regime.*



COCO Database

Gateway to quality health information for patients and carers

Condition	**Alzheimers disease**
Option	**Donepezil** optional
Choice	**Aromatherapy** optional
Outcome	[*Enter brief details of what you would like the outcome to be, e.g. pain relief, improved mobility*] optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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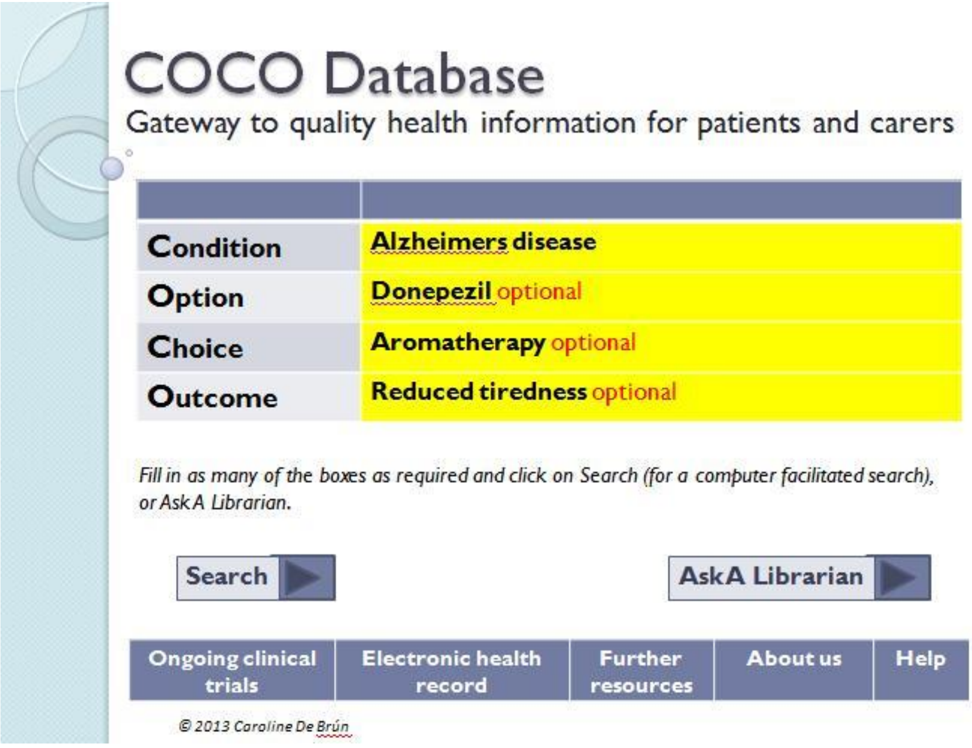
The patient/carer enters the condition name in the C box, the treatment option in the O box, and the alternative treatment in the second C box. Again, these will be mapped to Index terms. The patient/carer clicks on search and the software searches the TRIP Database for research evidence comparing two or more treatment options. TRIP searches the Cochrane Library and PubMed and will find comparative studies providing the information required. The research will be divided into levels of evidence, with decision aids at the top, so that people can start reading those first. The decision aid will be easier to read than the research and more honed to the patient/carer needs, but there are not many currently available and so providing the best research evidence, together with critical appraisal tools is the next best thing. As always, if the patient/carer prefers, they can just click on Ask A Librarian and their request will be sent to a public librarian.

Scenario 4

Before his illness, Benjamin was very active, working in volunteer shops, and a participating member of the local golf club. With the treatment he is on, he is finding that he is getting very tired, particularly as he often finds it difficult to sleep (NHS Choices 2012)*, common side effects when taking Donepezil. This is having an impact on his quality of life as he is not able to play golf as often as he would like, and therefore isn't meeting his friends as much, so his social life is also being affected. He would like more information about how he can improve his quality of life, while controlling his symptoms.*



COCO Database

Gateway to quality health information for patients and carers

Condition	Alzheimers disease
Option	Donepezil optional
Choice	Aromatherapy optional
Outcome	Reduced tiredness optional

Fill in as many of the boxes as required and click on Search (for a computer facilitated search), or Ask A Librarian.

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The patient/carer enters the condition name into the C box, the primary treatment option proposed in the O box, the comparative treatment choice (if there is one) in the second C box, and finally in the second O box, the outcome that would most suit them. Again, all the terms are mapped to Index terms. This is a more complex search, and so when the patient/carer clicks on search, the request is sent automatically to the librarian, who will respond within 5 working days or sooner if requested. If the patient/carer wants to have an immediate response, then the software can search the TRIP Database and NHS Evidence Search, but the results may not be as relevant, because it is difficult to map quality of life terms to the Index because they are so personal. Therefore human translation might be more effective, and so the "Ask A Librarian" option is the more reliable.

Having looked at the model, please could you now spend some time completing this survey and letting me know what you think of the model and framework. The survey is here http://www.surveymonkey.com/s/S6LP9QQ, but if you would prefer to respond via this email, then please return to the email where you will see the 10 questions listed. Please give details for your responses where appropriate.

Reference list:

Akobeng, A.K., 2005. Principles of evidence based medicine. *Archives of disease in childhood*, 90(8), pp.837–40. Available at: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1720507&tool=pmcentrez&rendertype=abstract [Accessed September 21, 2011].

Alzheimer's Society, 2013. *Complementary and alternative therapies and dementia*, Available at: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1764.

Alzheimer's Society, 2012. *What is dementia?*,

National Institute for Health and Clinical Excellence, 2011. *Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease: Review of NICE technology appraisal guidance 111*, Available at: http://www.nice.org.uk/nicemedia/live/13419/53619/53619.pdf.

NHS Choices, 2012. *Alzheimer's disease - nformation prescription*, Available at: http://www.nhs.uk/conditions/alzheimers-disease/pages/introduction.aspx?print=635110454239997351.

Sackett, D.L., 1997. Evidence-based medicine. *Seminars in Perinatology*, 21(1), pp.3–5. Available at: http://www.ncbi.nlm.nih.gov/pubmed/9190027.

Silberg, W.M., Lundberg, G.D. & Musacchio, R.A., 1997. Assessing , Controlling , and Assuring the of Medical Information on the Internet Quality. *Journal of the American Medical Association*, 277(15), pp.1244–1245.

Society of College National and University Libraries (SCONUL), 1999. *SCONUL Seven pillars model for information literacy*, Available at: http://www.sconul.ac.uk/groups/information_literacy/sp/.

Appendix 12 – User validation of model – Google results

Legend for the tables for Appendix 12:

Colour	Definition
🟥	The information product does not meet any of the validation criteria
🟧	The information product does not meet all of the validation criteria, but can be used with caution
🟩	The information product meets all the validation criteria.

Person A: What is myalgic encephalomyelitis (M.E.)?

Google search terms: chronic fatigue syndrome – retrieves 10,300,300 hits

Date searched 29/11/14

Results	Details	Comments
🟥 **Advert**	Chronic Fatigue Treatment – http://www.freedomfromme.co.uk/	This is an advert for a private clinic, and although they are in the process of scientifically proving that their methods are effective, they have not been proven yet. As they are recommending their own treatment methods, there is an element of bias and therefore the information should be used with caution.
🟥 **Advert**	Chronic fatigue syndrome – http://www.mollysfund.org/2014/09/chronic-fatigue-syndrome/	This web-site is actually predominantly about Lupus rather than chronic fatigue syndrome, so it may lead to confusion and misdirection. Also, upon further investigation, it appears that this is an American web-site so advice may vary from that given in England, as both countries have different health system structures.
🟥 **Advert**	CFS no longer a mystery - It is caused by biofilm bacteria http://www.autoimmunityresearch.org/	Interestingly, the URL attached to this article did not link to it, and it may not be found on the web-site. But it is quite dangerous because a person suffering from ME may think they have found a solution, but actually, the site is more focused to individual personal experience. This can be useful, but it is not research evidence based.

Results	Details	Comments
Scholarly article	Chronic fatigue syndrome: an update (2001) http://aula.acemefide.org/cursos/photo/1135712102Chronic_Fatigue_Syndrome_An_Update%5B1%5D_._By_Shephard__R.J.._Sports_Medicine__Feb2001__Vol._31_Issue_3__p167__.pdf	The Google Scholar feature is a useful way of limiting your search to published research, and this narrowed the search down to 551,000 results. However, the top 3 papers were dated 2001, 2002, and 1994, respectively. Given the nature of the condition, since its recognition, there have been many new theories about causes and treatments available, so this information is possibly out of date. A quick search identified 2014 papers, which would have been more relevant: 1. Adamowicz JL, Caikauskaite I, Friedberg F. Defining recovery in chronic fatigue syndrome: a critical review. Qual Life Res [Internet]. 2014 [cited 2014 Nov];23(9):2407-16. 2. Kawada T. Chronic fatigue syndrome in adolescents: definition and epidemiological characteristics. J Paediatr Child Health [Internet]. 2014 [cited 2014 Oct];50(10):840. 3. Klineberg E, Rushworth A, Bibby H, Bennett D, Steinbeck K, Towns S. Adolescent chronic fatigue syndrome and somatoform disorders: a prospective clinical study. J Paediatr Child Health [Internet]. 2014 [cited 2014 Oct];50(10):775-81 It is possible to limit the search to more recent papers, but you have to go in to Google Scholar to do so, and even then, the relevancy is not clear. Furthermore, the research papers can be quite difficult to understand, as they are written by and for medically-trained personal, and not for the lay-person, so it may be difficult to understand the terminology.
Scholarly article	Chronic Fatigue Syndrome: Probable pathogenesis and possible treatments (2002) http://link.springer.com/article/10.2165/00003495-200262170-00003#page-2	As above.
Scholarly article	The Chronic Fatigue Syndrome: A Comprehensive Approach to Its Definition and Study (1994) http://www.ncf-net.org/patents/pdf/Fukuda_Definition.pdf	As above.

Results	Details	Comments
1	Chronic fatigue syndrome - NHS Choices http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx	This is a good information source. It has the NHS England Information Standard and it has been produced by the NHS for its service users. This shows that Google can be useful for simple information requests, although people do need to sift through the adverts and scholarly articles first, all of which have been deemed to be inappropriate for the audience. A simpler set of results would be more useful.
2	Chronic Fatigue Syndrome/ME http://www.patient.co.uk/health/chronic-fatigue-syndromeme	This source also has the NHS England Information Standard, and the information is very similar to the NHS Choices leaflet. The main criticism with Patient.co.uk is that the patient information on the web-site contains adverts, for example, there are three adverts for Rakuten, a shopping web-site, one for Lemsip, an over-the-counter drug for colds and flu, and one for British Airways. There should be no adverts for treatments of any kind, because it might be seen as a treatment suggestion, and this might pose serious implications for the health of the person using the leaflet. Also, there should be no commercial advertising because it detracts from the condition.
3	Chronic fatigue syndrome http://en.wikipedia.org/wiki/Chronic_fatigue_syndrome	Wikipedia is a controversial information source because one does not know the credentials of the author. At first glance, this page does look evidence-based, because they have referred to the latest, most relevant NICE clinical guideline, but it is not clear when this page was written or when it will be reviewed. Furthermore, the NICE clinical guideline was written seven years ago, and therefore it may not be as up-to-date as required.
4	What is ME/CFS? http://www.meassociation.org.uk/about/what-is-mecfs/	This information is provided by an established charity, and has qualified clinicians on their team. It claims to inform and support those affected by ME/CFS, but it does not have any accreditation standards, such as the NHS England Information Standard. The “What is ME/CFS” page appears to be evidence-based as it refers to specific research papers, but then does not provide the full references for these. Furthermore, the references are rather old, ranging between 1992 and 1996.
5	Symptoms and diagnosis of ME/CFS http://www.meassociation.org.uk/about/the-symptoms-and-diagnosis-of-mecfs/	This information is provided by the same organisation as the previous web-site. Again, while backed up by references, these are rather old, again from the 1990s. Neither web-page has details of author, full references, or published or review dates.

Results	Details	Comments
6	Chronic fatigue syndrome: definition http://www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/basics/definition/con-20022009	The Mayo Clinic is an American health organisation providing products and services to American health service users. The page meets the HONcode accreditation criteria, but it does have irrelevant adverts for clothing and diets, and it is geared to the American health system, so may not be relevant to a UK audience. Furthermore, no references or author credentials are provided, so it is not clear where the evidence comes from.
7	Chronic fatigue syndrome: symptoms http://www.mayoclinic.org/diseases-conditions/chronic-fatigue-syndrome/basics/symptoms/con-20022009	As above.
8	Chronic fatigue syndrome (myalgic encephalomyelitis) http://www.bupa.co.uk/bupaukcmshome/individuals/health-information/directory/c/hi-chronic-fatigue-syndrome	Although this is published by a commercial organisation, the information is supported by three standards: Plain English Campaign, the NHS England Information Standard, and the HONcode. There is a review date, details about their health editors and a link to the references that informed the information. Therefore, it is a reliable source for the general public to refer to.
9	Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of CFS/ME in adults and children http://www.nice.org.uk/guidance/cg53	This is the best level of evidence in England. There is a concern that the information was last reviewed in 2011 and will not be reviewed for another two years, in 2016, but NICE (National Institute for Health and Care Excellence are the national provider of guidelines in England, and have rigorous processes in place to safeguard the quality of the information they produce. Therefore, it is a reliable source for the general public to refer to.
In-depth articles	Baffling Chronic Fatigue Syndrome Set for Diagnostic Overhaul http://www.scientificamerican.com/article/baffling-chronic-fatigue-syndrome-set-for-diagnostic-overhaul/	After the adverts, the scholarly articles, the results, Google listed three in-depth articles. The first, while recent, has been written for an American audience and therefore some of the information may not be relevant to a UK audience. It refers to key organisations and studies, but does not supply any references, so these cannot be explored further. It is also dotted throughout with irrelevant adverts for travel companies, footwear, and free pets.

Results	Details	Comments
In-depth articles	All in the mind? Why critics are wrong to deny the existence of chronic fatigue http://www.dailymail.co.uk/debate/article-2141230/All-mind-Why-critics-wrong-deny-existence-chronic-fatigue.html	This is really just a list of myths about ME, and does not provide any useful evidence. It contains individual experiences, but this is such a complex illness that people will react in different ways to treatments, so the experiences cannot always be shared. It is perhaps useful as it might clarify some questions that people might have in a language that is reachable to all. It is not the best quality, but it may provide reassurance. It should not be relied up on for clear answers however.
In-depth articles	The scientist who put the nail in XMRV's coffin http://www.nature.com/news/the-scientist-who-put-the-nail-in-xmrv-s-coffin-1.11444	This is a Q & A session with a scientist looking into the link between retroviruses and chronic fatigue syndrome. It is published in Nature, a highly scientific publication, and it focuses on a particular aspect of CFS, using very technical language, which might not suit the lay-person. For that reason, the author has deemed this unsuitable for the general public.

Therefore, although this is a simple search for more information about a condition, out of 18 results, only 3 are high quality and relevant to the target audience.

Person B: Are there any alternative therapies which can treat a rare form of cancer called peritoneal mesothelioma?

Google search terms - peritoneal mesothelioma alternative therapy – retrieves 530,000 hits

Date searched 29/11/14

Results	Details	Comments
1	Alternative Mesothelioma Treatment - Surviving Mesothelioma http://survivingmesothelioma.com/treatments/alternative-approaches/alternative-treatments/	This site is fairly useful but should be used with caution. It appears to be evidence-based, and clinician-informed. It is a very transparent site in that it explains clearly the ownership and it has a very comprehensive disclaimer, part of which says *"This web-site is not a substitute for professional medical advice, examination, diagnosis or treatment."* However, it is quite confusing because it is not clear how much of the information is about peritoneal mesothelioma, and so it may raise expectations for patients and carers, as prognosis is better for pleural mesothelioma than it is for peritoneal mesothelioma. Furthermore, it is aimed at an American audience, so treatment options will differ compared with England.
2	Complementary & Alternative Mesothelioma Treatments www.asbestos.com/treatment/alternative/	This site is aimed at an American audience, so treatment options will differ compared with England. It has been produced by Asbestos.com a for-profit company, but it does have the HONcode accreditation, so it has been assessed against quality criteria. It does contain useful basic information on a wide range of alternative therapies, but the links to clinicians and funding is less useful because they are all American sources.
3	Peritoneal Mesothelioma http://www.asbestos.com/mesothelioma/peritoneal.php	The information on this page is very clear and well-written. It is evidence-based, providing a list of information sources, and has been written by a clinician. It is useful for learning about the condition, and diagnosis, and touches on treatment, but not too specifically and there is a link to information about alternative therapies. The site itself is aimed at an American audience, so treatment options will differ compared with England. It has been produced by Asbestos.com a for-profit company, but it does have the HONcode accreditation, so it has been assessed against quality criteria.

Results	Details	Comments
4	Mesothelioma Treatment Options: Traditional and Alternative www.mesotheliomagroup.com/treatment/	While this page is full of useful information about the surgical and chemical treatments for peritoneal mesothelioma, there is no information about alternative treatments, and therefore will not be of use to the patient/carer. Furthermore, it is written for an American audience, so the treatment options may not be available in the UK.
5	Peritoneal mesothelioma patient seeks funds for alternative therapies http://www.mesothelioma.com/news/2011/08/peritoneal-mesothelioma-patient-seeks-funds-for-alternative-therapies.htm	This is a plea for funding for a patient suffering from peritoneal mesothelioma and wanting to try alternative therapies. It does provide links to information about the condition, but the evidence used is old, and there are no details of authorship. Furthermore, it is aimed at an American audience.
6	Mesothelioma http://www.mesothelioma.com/	This web-site has the HONcode accreditation, which means the information can be relied up on. There is many of information on the site, and it is aimed towards an American audience, because there are links to American doctors, cancer centres, and lawyers. There are links to information about the condition, but the evidence used is old, and there are no details of authorship. There are links to credentials of mesothelioma experts, but it is not clear if they are promoting their services or if they have written the information on the site.
7	Mesothelioma - Mayo Clinic http://www.mayoclinic.org/diseases-conditions/mesothelioma/basics/definition/con-20026157	The Mayo Clinic is an American health organisation providing products and services to American health service users. The page meets the HONcode accreditation criteria, but it does have irrelevant adverts for clothing and diets, and it is geared to the American health system, so may not be relevant to a UK audience. Furthermore, no references are provided, so it is not clear where the evidence comes from.
8	Peritoneal Mesothelioma: A Review http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1994863/	This paper would have been ideal, had it mentioned anything about alternative therapies or complementary medicine. It was written in 2007, so may need updating, but it would have been a good start as it is evidence-based, and published in an open-access, peer-reviewed general medical journal. The information is written for health professionals, but is freely available to patients and carers, and set out very clearly.

Results	**Details**	**Comments**
9	Peritoneal Mesothelioma - Mesothelioma Lawyer http://www.mesotheliomalawyercenter.org/peritoneal-mesothelioma-cancer/	This is a commercial organisation, which has adapted the information provided by the above source (8), and advertised its services alongside the text, which is entirely inappropriate. There are no authorship credentials, so it is not possible if they have interpreted the original article correctly.
10	Cure Mesothelioma Cancer the Natural Way - Natural News http://www.naturalnews.com/027529_mesothelioma_cancer_natural.html	This page is written by a professional freelance writer who is "*passionate about natural, healthy living*", but is not formally qualified in this area. The site is peppered with inappropriate adverts and is not appropriate for patients or carers.

From the first ten results in Google, only one was of good quality, but it should be used with caution as it is written for an American audience and the treatments may not be available in the UK.

Person C: Can a change in diet be used as an alternative to steroids in the treatment of Crohn’s Disease?

Google search terms – **crohns steroids diet** – retrieves 438,000 hits

Date searched 04/12/14

Results	Details	Comments
1	Crohn's Disease http://www.patient.co.uk/health/crohns-disease-leaflet	Patient.co.uk has been awarded The Information Standard and the HONcode accreditations, so the information does have a quality guarantee. However, for this particular scenario, the information is not sufficient to make an informed decision. It is a basic introduction to the condition and does not give in-depth information about diet and drug treatments.
2	Defined-formula diets versus steroids in the treatment of active Crohn's disease: a meta-analysis http://www.ncbi.nlm.nih.gov/pubmed/8833357	This is a link to the abstract of a research article, but the full-text is not freely available, which the patient/carer cannot access on demand or for free. Furthermore, it was written in 1996, so the information is possibly out of date. Finally, it focuses on “*defined-formula diets*” rather than changes in diet.
3	Steroid tablets to treat a flare-up http://www.webmd.boots.com/digestive-disorders/crohns-disease-steriod-tablets-to-treat-a-flare-up	The information on this page, although written by the BMJ Group and accredited by the HONcode, is very much about steroid tablets, rather than changes in diet, and therefore it is irrelevant to Person C.
4	Steroid tablets to prevent symptoms of Crohn's disease http://www.webmd.boots.com/digestive-disorders/crohns-disease-steroid-tablets-to-prevent-symptoms-of-crohns-disease	As above.
5	Treating children and adolescents – Crohn’s & Colitis Foundation of America http://www.ccfa.org/resources/treating-children.html	The information provided here is aimed at care of children and adolescents, so it may not be applicable to a grown woman. For example, it will not contain information about alcohol and the effect that it can have on digestive disorders. It does have a small amount of information about changing diet, but not enough to make an informed choice.

Results	Details	Comments
6	How Is Crohn's Disease Treated? http://www.everydayhealth.com/crohns-disease/how-crohns-is-treated.aspx	This content does have the HONcode standard for trustworthy health information. However, the ownership is not completely clear, and it looks as if it might be a commercial organisation, so there may be an element of bias. There are also many irrelevant and inappropriate adverts on the site. There are no details of references used to inform the content, and it does not seem to have been reviewed or updated since 2009.
7	Management of Crohn's disease http://en.wikipedia.org/wiki/Management_of_Crohn's_disease	Wikipedia is a controversial information source because one does not know the credentials of the author. At first glance, this page does look evidence-based, but it is not clear when this page was written or when it will be reviewed. Furthermore, there is only a brief paragraph about changing diet and lifestyle, so it may not be as informative as required. There is many of information about drug treatments, including steroids.
8	Corticosteroids for Inflammatory Bowel Disease http://www.webmd.com/ibd-crohns-disease/crohns-disease/corticosteroids-for-inflammatory-bowel-disease	This page points to the American version of WebMD (see examples 3 and 4 which are from the UK version). Again, the content is about steroid treatment, but it is more of an issue, because drug treatments and dosages vary between America and the UK, and therefore the information is potentially dangerous. Furthermore, there is no information on diet, so it is irrelevant for this scenario.
9	Crohn's disease: Management in adults, children and young people https://www.nice.org.uk/guidance/CG152/ifp/chapter/Drug-treatment-for-active-Crohns-disease	NICE guidelines are very high quality. However, this particular page focuses completely on drug treatment, with no mention of diet, so it is irrelevant for this scenario.
10	Crohn's disease - Mayo Clinic http://www.mayoclinic.org/diseases-conditions/crohns-disease/basics/treatment/con-20032061	The Mayo Clinic is an American health organisation providing products and services to American health service users. The page meets the HONcode accreditation criteria, but it does have irrelevant adverts for clothing and diets, and it is geared to the American health system, so may not be relevant to a UK audience. The information focuses on drug treatments, with a paragraph on nutrition therapy, but no information on diet. Furthermore, no references or author credentials are provided, so it is not clear where the evidence comes from. The

From the first ten results in Google, there are none that would answer the user’s question.

Person D: What can endurance cyclists do to avoid hypoglycaemia?

Google search terms – cycling hypoglycaemia (British spelling) – retrieves 8,110,000 hits

Date searched 29/11/14

Results	Details	Comments
🟥 **1**	Hypoglycaemia? | Page 2 | CycleChat Cycling Forum http://www.cyclechat.net/threads/hypoglycaemia.17392/page-2	This is a discussion list for cyclists, and while it is useful for sharing experiences, it is not a reliable source as it is all anecdotal.
🟥 **2**	Sports Coach : Overtraining syndrome http://www.ausport.gov.au/sportscoachmag/sports_sciences/overtraining_syndrome2	This page has been produced by the Australian Government and the Australian Sports Commission. An author is listed, but no details of his credentials, or the information sources he has used.
🟥 **3**	Hypoglycaemia in Clinical Diabetes - Page 352 - Google Books books.google.co.uk/books?isbn=1118695909	This book refers to hypoglycaemia in clinical diabetes, and therefore is not relevant to this particular patient.
🟩 **4**	Effects of timing of pre-exercise ingestion of carbohydrate on subsequent metabolism and cycling performance http://www.ncbi.nlm.nih.gov/pubmed/12527977	This may be useful for the patient, as it looks at when carbohydrate should be ingested before exercise, which is very relevant to this patient. It is quite scientific, but will have additional references for him to follow up with his doctor.
🟥 **5**	Avoiding Hypos - Runsweet.com- Diabetes and Sport www.runsweet.com/AvoidingHypos.html	This is irrelevant to this particular patient, because it is about safe and effective exercise for people suffering from diabetes.
🟥 **6**	The forgotten risk of driving with hypoglycaemia in type 2 diabetes http://www.trl.co.uk/reports-publications/report/?reportid=6984	This is irrelevant to this particular patient, because it is about driving risk for people suffering from diabetes.
🟥 **7**	Diabetes and Its Management - Page 85 - Google Books Result books.google.co.uk/books?isbn=0470760001	This book refers to the management of diabetes, and therefore is not relevant to this particular patient.
🟥 **8**	LifeScan OneTouch - Avoiding hypoglycaemia http://www.lifescanmea.com/type-one/article/fitness/avoiding-hypoglycaemia	This is a commercial organisation and aimed at people with diabetes, so it is not relevant to this particular patient, as he does not have diabetes.
🟥 **9**	Hypoglycaemia? | Page 3 | CycleChat Cycling Forum http://cycle-cafe.net/threads/hypoglycaemia.17392/page-3	This is a discussion list for cyclists, and while it is useful for sharing experiences, it is not a reliable source as it is all anecdotal.

Results	Details	Comments
10	Treatments for Type 2 Diabetes | Health | Patient.co.uk http://www.patient.co.uk/health/treatments-for-type-2-diabetes	This page refers to the management of type 2 diabetes, and therefore is not relevant to this particular patient.

From the first ten results in Google, there is only one that might answer the user's question.

Google search terms – cycling hypoglycaemia (US spelling) – retrieves 187,000 hits

Date searched 29/11/14

Results	Details	Comments
🟧 1	Cycling Nutrition: The Bonk | Tuned In To Cycling http://tunedintocycling.com/2008/05/10/cycling-nutrition-the-bonk/	While this is not an evidence-based information source, it did introduce new terminology, which may be useful for identifying other research. “*The Bonk*” is another name for hypoglycaemia incidence.
🟥 2	Hypoglycemia and riding - Bike Forums http://www.bikeforums.net/training-nutrition/643208-hypoglycemia-riding.html	This is a discussion list for cyclists, and while it is useful for sharing experiences, it is not a reliable source as it is all anecdotal.
🟥 3	I have hypoglycemia. How do I fuel properly for the bike? http://www.womenscycling.ca/blog/ask-a-pro/i-have-hypoglycemia-and-its-hard-to-figure-out-how-to-fuel-properly-for-the-bike-any-suggestions/	This is a Canadian “question and answer” resource for cyclists, and while it is useful for sharing experiences, it is not a reliable source as the responses are provided by professional cyclists rather than qualified health professionals.
🟥 4	Bonking symptoms differ for hypoglycemia or dehydration http://athletewithstent.com/2012/03/25/hypoglycemic-versus-dehydration-bonking-during-endurance-sports/	This particular page is a blog post about hypoglycaemia in endurance sports. It is anecdotal and not research-based, and therefore not the most reliable source. Furthermore, the rest of the site is about a different condition called plantar fasciitis, which causes pain under the heel of the foot, so it is not relevant to this patient.
🟧 5	Hitting the wall - Wikipedia, the free encyclopedia http://en.wikipedia.org/wiki/Hitting_the_wall	While this is not an evidence-based information source, it did introduce new terminology, which may be useful for identifying other research. “*Hitting the wall*” is another name for hypoglycaemia incidence in cycling and running.
🟥 6	Cycling Nutrition with Monique Ryan: Exercise hypoglycemia http://velonews.competitor.com/2004/03/training-center/nutrition/the-feed-zone-nutrition-qa-with-monique-ryan-exercise-hypoglycemia_5649	This is a “question and answer” resource for cyclists, and the responses are provided by an experienced and qualified nutritionist in America. It would be better for this particular patient to seek advice from a UK-based nutritionist.
🟥 7	Hypoglycemia: A Vicious Cycle - Hartford Courant http://www.courant.com/health/wellness/sns-health-breaking-hypoglycemia-story.html	The content on this page has been written by a registered holistic nutritionist in Canada. It has used research to inform the article, but it makes recommendations without clinical input. Furthermore, there are a number of irrelevant adverts on the site, which are of no use to the user.

Results	Details	Comments
8	Hypoglycemia Questions | Bicycling Magazine Forums http://forums.bicycling.com/topic/54635607127326293	This is a discussion list for cyclists, and while it is useful for sharing experiences, it is not a reliable source as it is all anecdotal.
9	Hypoglycemia: Breaking The Vicious cycle - Naturally Savvy http://naturallysavvy.com/care/hypoglycemia-breaking-the-vicious-cycle	The information is exactly the same as the information for reference 7, just posted on another site. Therefore, it is of no use to the user.
10	Low Blood Sugar Tour de Cure - Meetup http://www.meetup.com/Tourdecurepdxvan/pages/Bonking_(Glycogen_Depletion_-_Low_Blood_Sugar)	This is not an evidence-based information source, and it is not written by an expert, but rather by an experienced cyclist. It is only useful for identifying new terms to search for, because the quality of the content cannot be assessed because there are no references or author credentials.

From the first ten results in Google, there are no results that might answer the user’s question. However, there are three results which identify alternative keywords to add to search strategies.

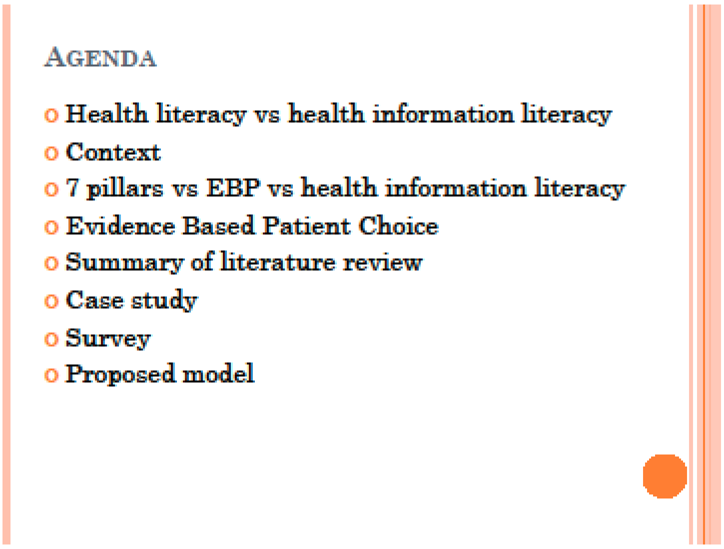
Appendix 13 – Medline search strategy for Scenario 4

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>
Search Strategy:
----
1 exp Bicycling/ (7707)
2 cyclist$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (3362)
3 exp Exercise/ (120102)
4 1 or 2 or 3 (125869)
5 exp Hypoglycemia/ (21734)
6 hypoglyc?emi$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (35940)
7 (transient adj hypoglyc?emi$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (91)
8 5 or 6 or 7 (36154)
9 4 and 8 (424)
10 exp Dietary Carbohydrates/ (24714)
11 (carbohydrate adj ingestion).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (403)
12 (carbohydrate adj rich).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (1141)
13 10 or 11 or 12 (25612)
14 exp Blood Glucose/ (129692)
15 (plasma adj glucose).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (25968)
16 exp Norepinephrine/ (82112)
17 (glucose adj kinetics).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (694)
18 (muscle adj glycogen).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (3071)
19 (liver adj glycogen).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] (8181)
20 exp Athletic Performance/ (38527)
21 exp Energy Metabolism/ (287429)
22 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 (539306)
23 4 and 8 and 13 and 29 (43)

Appendix 14 – Publications and presentations

"NO DECISION ABOUT ME WITHOUT ME"

Collaborative opportunities to support shared decision-making in the NHS



AGENDA

- Health literacy vs health information literacy
- Context
- 7 pillars vs EBP vs health information literacy
- Evidence Based Patient Choice
- Summary of literature review
- Case study
- Survey
- Proposed model

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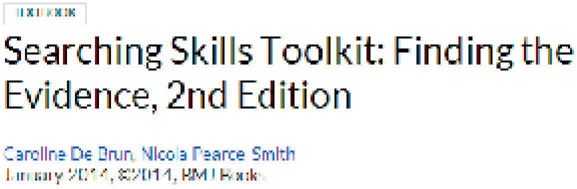

Searching Skills Toolkit: Finding the Evidence, 2nd Edition

Caroline De Brun, Nicola Pearce Smith
January 2014, ©2014, BMJ Books

CHAPTER 13
Patient information: sources

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INTERNATIONAL SOCIETY FOR
EVIDENCE-BASED HEALTHCARE

The International Society for Evidence-Based Health Care
Newsletter 4, July 2011

www.isehc.blogspot.com

Mission

The mission of the International Society for Evidence-Based Health Care is to develop and encourage research in evidence-based health care and to promote and provide professional and public education in the field.

Vision

The society is inspired by a vision to be a world-wide platform for interaction and collaboration among practitioners, teachers, researchers and the public to promote EBHC. The intent is to provide support to frontline clinicians making day-to-day decisions, and to those who have to develop curricula and teach EBHC.

Key objectives of the Society

- To develop and promote professional and public education regarding EBHC
- To develop, promote, and coordinate international programs through national/international collaboration
- To develop educational materials for facilitating workshops to promote EBHC
- To assist with and encourage EBHC-related programs when requested by an individual national/regional organization
- To advise and guide on fundraising skills in order that national foundations and societies are enabled to finance a greater level and range of activities
- To participate in, and promote programs for national, regional and international workshops regarding EBCP
- To foster the development of an international communications system for individuals and organizations working in EBHC-related areas
- To improve the evidence systems within which health care workers practice.

Centre for Research in Evidence-Based Practice
Bond University, Australia
www.bond.edu.au/crebp

Evidence-Based Clinical Practice Office
McMaster University, Canada
www.ebm.mcmaster.ca