

**Cultural factors affecting the development of an evidence-based information service in a
third sector provider of complementary cancer care**

by

MATTHEW DUNSTAN BRECKONS

A thesis submitted to Plymouth University

in partial fulfilment for the degree of

DOCTOR OF PHILOSOPHY

Faculty of Health, Education and Society

July 2013

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Abstract

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Introduction

Many people with cancer access complementary and alternative medicine (CAM) and a need for high quality information was emphasised in reports by the House of Lords and the National Institute for Health and Clinical Excellence. Organisational culture, incorporating people's underlying assumptions, values and actions, has been highlighted as an important factor when attempting to introduce evidence-based practices. Opinion is divided over the relevance of evidence to CAM practice, although the influence that this has on the cultural context of a CAM organisation is not understood.

Aims

To identify cultural factors affecting the introduction of an evidence-based information service in a third-sector CAM organisation and, in light of factors identified, to suggest feasible innovations to achieve a more evidenced-based approach.

Methods

Access to the charity¹ was gained through a Knowledge Transfer Partnership. Soft Systems Methodology, a form of action research, was used to carry out four 'learning cycles' in which data was collected and fed back to staff at the organisation to prompt discussion on what could be improved. Learning cycles focused on improving the quality of web-based and printed information and gaining an understanding of how the information service could be improved from staff and service-user perspectives.

Results

Results suggested that a lack of time and emphasis on marketing values led to difficulties feeding back results and making changes that were perceived to reduce demand for the charity's services. A lack of management support and a reluctance to implement rules made introducing any form of information policy problematic. Additionally, structural factors such as a large team of part-time staff and a lack of financial resources led to communication difficulties as well as limiting the opportunity for staff development.

Conclusions

This is the first study to document systematic attempts to make evidence-based changes in a third sector CAM organisation. As such, this study has generated results demonstrating how cultural and structural constraints in this type of organisation may influence attempts to make evidence-based changes. Introduction of an initiative such as the Information Accreditation Scheme (IAS) may provide benefits to an organisation of this type by guiding the development of information production systems at the same time as raising the profile of the organisation. The findings of this study strongly suggest that, despite demands from policy makers for the provision of evidence-based CAM information, there may be systematic difficulties experienced by organisations responsible for the production of this information. Further research is needed to understand how producers of CAM information can be supported in providing high quality, evidence-based materials.

¹ Organisation information removed in edited thesis

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Graduate Committee.

Work submitted for this research degree at the Plymouth University has not formed part of any other degree either at Plymouth University or at another establishment.

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Work was undertaken as part a Knowledge Transfer partnership which was a collaboration between Plymouth University and a charity¹. Within this project, the author was responsible for project management and data collection and analysis. Members of the partnership acted in an advisory role to the author and members from Plymouth University also held the roles of the author's PhD supervisors.

Relevant scientific seminars and conferences were regularly attended at which work was often presented in poster and oral format. External institutions were visited for consultation purposes and a paper was published. These are recorded in the Graduate School log book.

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Signed

Date

Chapter 1. Introduction

1.1 Introduction

The aim of this chapter is to describe the background to this research project and introduce the major areas of literature on which this work builds.

Data collected for this thesis was carried out within a 30-month Knowledge Transfer Partnership (KTP) between a charity offering complementary therapies for people affected by cancer¹ and the University of Plymouth. The project was developed to make evidence-based improvements to the charity's information service and embed a supportive culture in order for this approach to be sustainable within the organisation. This chapter introduces and describes the general subject of cancer, its treatment and side effects and the impact a diagnosis of cancer is likely to have as this is pertinent to issues regarding information. It describes the growing demand for evidence-based treatments and the importance of information for patients. In parallel to a growing emphasis on evidence-based practice within conventional medicine, a significant number of cancer patients seek out complementary therapies which are generally under researched and lacking an evidence base.

¹ Prior to this PhD study, The National Institute for Health and Clinical Excellence and a House of Lords Select Committee had produced reports emphasising the need for the provision of evidence-based information on complementary therapies [1, 2] and a senior member of staff at the charity wanted to address these issues¹. Links with a member of academic staff at the University of Plymouth led to the proposal for a 30 month KTP project.

Following this chapter, in Chapter 2 I review major areas of literature relating to the research questions in more detail. Chapter 3 consists of a discussion of organisational change methodologies, rationale for selection of Soft Systems Methodology (SSM) and an outline of methods used to collect data. Chapter 4 is split into four main sections in which I describe all of the data collection. In Chapter 5 I present a synthesis of findings and summarise this study's contribution to theory, methodology and knowledge.

1.2 Cancer

In 2006, 242,200 people were diagnosed with cancer in the United Kingdom [3], Breast, lung, colorectal and prostate cancer accounted for more than half of these cases. Although trends in incidence vary with type and site of cancer, overall, between 1976 and 2006, the incidence rate of cancer in the UK increased by 25% [3]. While the rising incidence of cancer means that more people are affected by the disease and over one in four people die from cancer [3], improving detection, intervention and management of cancer have led to increases in survival rate [4]. The National Cancer Survivorship Initiative defines a cancer survivor as '*someone who is living with cancer or who has had cancer*' [5] (p.1). In 2008 there were 2 million cancer survivors in the UK [5] and this number is expected to rise by 3% per year [6].

The list of treatments for cancer is extensive and includes surgery, chemotherapy, radiotherapy, hormone therapy and transplants [7]. Treatment varies depending on site, stage of disease and doctor and patient preferences. Primary treatment generally aims to cure, control or reduce symptoms of cancer [8]. Both the cancer itself and its treatment can cause many physical symptoms including pain, fatigue, nausea and vomiting, skin problems and hypocalcaemia [9]. While some physical effects of treatment may be short-lived, others may continue long after treatment has ended [10, 11].

Cancer is not limited to its physical symptoms but affects many other aspects of quality of life. Much research has highlighted the fact that a diagnosis of cancer impacts individuals in many ways, causing psychological distress [12] and emotional effects [13]. Literature also suggests that cancer may affect patients on a spiritual level [14]. Effects of cancer are not limited to the patient but are likely to impact family members and caregivers [15]. A 2003 study suggested that one of the most serious patient-rated side-effects of cancer treatment was the impact on their family or partner [16].

The support needs of people living with or after cancer has been highlighted in several UK health policy documents. In addition to emphasising the need to save lives, tackle health inequalities and invest in the cancer workforce, the National Health Service's *Cancer Plan*, published in 2000, highlighted a need to provide support and care for people with cancer [17]. Similarly, guidelines for supportive and palliative care published by the National Institute for Health and Clinical Excellence (NICE) included recommendations that people should be provided with a range of physical, emotional, spiritual and social support to help manage the after-effects of cancer [1].

In addition to an acute need for treatment and support, other literature has focussed on longer term needs of cancer survivors. A systematic review by Foster et al suggested that 30% of people living five or more years following a cancer diagnosis reported difficulties including: physical problems, poorer quality of life, psychological distress, sexual problems, problems with social relationships and financial concerns [18]. It has been highlighted in several studies that the provision of information plays an important role for people with cancer [19-21].

1.3 Patient information

Patient information refers to ‘*Information that is produced and provided, in any medium, for the benefit of patients*’ [22](xiii); the term encompasses information given in written, verbal, audio, electronic or any other format.

The rise of patient information is not simply the increased availability of information materials but also reflects a move away from medical paternalism and towards two-way communication and shared decision making [23].

In addition to representing a shifting worldview there are several practical reasons for providing patients with information. Coulter Entwistle and Gilbert suggest that it helps people to gain an understanding of: what is wrong, possible treatments, and a realistic prognosis, as well as providing the patient with practical advantages such as making the most of consultations, speaking to other people and assisting in self-care [24].

The Department of Health (DoH) report that around 50,000 organisations produce some form of health and social care information, with charities representing the largest group of information producers (Figure 1).

Figure 1 Market segmentation of UK producers of health information (%) (based on [25])



With the rapid rise of the internet, it could be argued that lack of information is no longer a problem, but issues of quality and how this can be discerned require urgent attention. It has

been demonstrated that, in extreme cases, adherence to advice obtained on the internet has led to serious health consequences [26].

Therefore accompanying a growing emphasis on the availability of patient information has been the recommendation that content should be based upon the best available evidence [27, 28]. This is congruent with the values of evidence-based medicine (EBM), currently a dominant worldview in medicine.

1.4 Evidence-based Medicine

Although relatively recently defined, the concept of EBM itself is not new. While there are historical references to early clinical trials [29], Archie Cochrane is commonly considered the founder of what is today termed EBM with his published views in 1972 of the principles on which health care delivery should be based [30]. EBM was first discussed by researchers at McMasters University in the early 1990s, although it was in 1996 when a formal definition was developed by Sackett et al who described EBM as:

'The conscientious and judicious use of current best evidence from clinical care research in the management of individual patients' [31](p.71).

Discussion of the relatively recent introduction of EBM may raise concern at the implication that before this, medicine was based solely on trial and error [32]. However the EBM movement reflects a paradigm shift which was influenced by developments in clinical research [33]. In 1991 the *Evidence-Based Medicine Working Group* outlined major characteristics of this paradigm shift in relation to what had preceded it (Table 1).

Table 1 Paradigm shift in EBM (adapted from [33])

Before evidence-based medicine	After evidence-based medicine
<ul style="list-style-type: none"> - Unsystematic observations from clinical experience build and maintain knowledge of prognosis, value of diagnostic tests and efficacy of treatment. - Study of mechanisms of disease and pathology are a sufficient guide for clinical practice. - Medical training and common sense sufficient to evaluate new tests and treatments. - Content expertise and clinical experience are sufficient to generate guidelines for clinical practice. 	<ul style="list-style-type: none"> - Clinical experience is important alongside systematic attempts to record unbiased observations. - Study and understanding of disease mechanisms are insufficient for clinical practice. - Understanding evidence is necessary to interpret literature on causation, prognosis, diagnostic tests and treatment strategy.

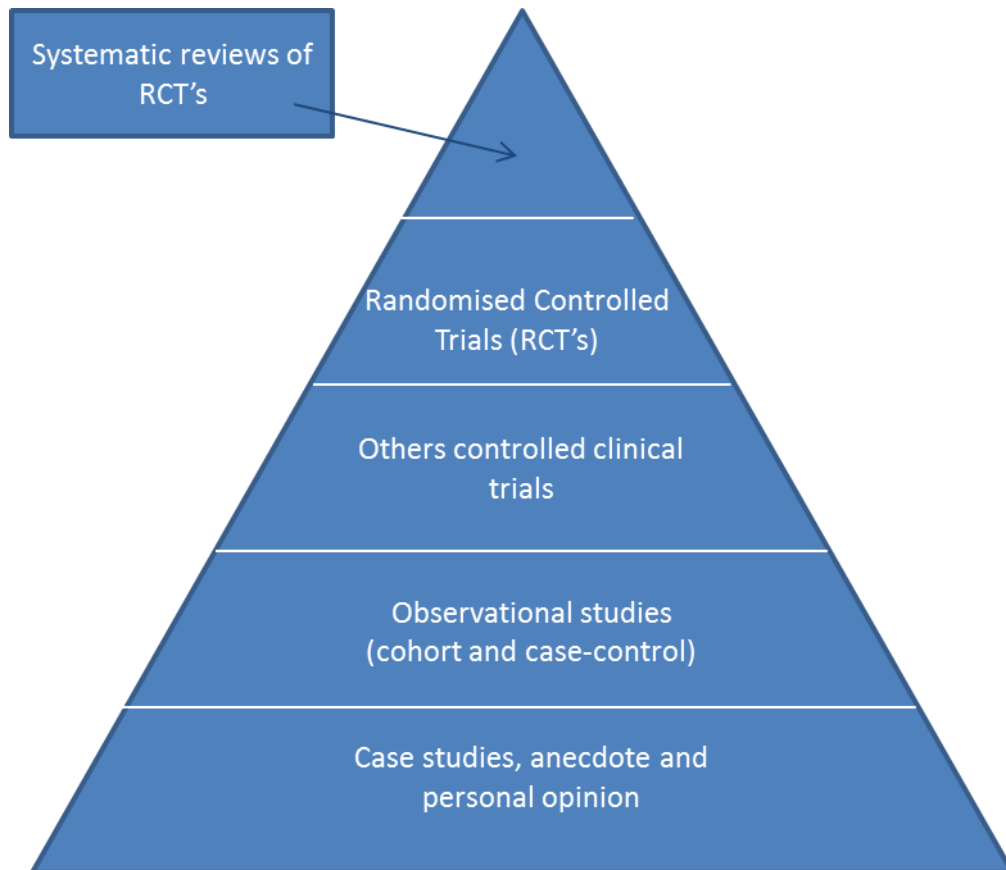
The increase in emphasis on EBM has not come into existence solely from ethical intent but has also been influenced by the changing demands placed on the healthcare system. Sir Muir Gray described the rise of evidence-based healthcare as a result of several pressures on the health care system originating from an ageing population, new technology and new knowledge, increasing patient expectations and increasing professional expectations [34].

EBM is therefore cited as a function of these increased demands and a modified management agenda with the remit of doing the *'right things right'* in terms of incorporating into health care decisions not only doctor's opinion and evidence of efficacy but also cost effectiveness and value for money [34].

An important component of EBM is how evidence is created. The EBM philosophy generally holds that research methods are not equal in terms of the ability to generate unbiased results with an acceptable margin of error [83, 84]. The *Evidence Pyramid* (Figure 2) is a common representation of the accepted *Hierarchy of Evidence* which shows preferences for studies to

produce unbiased, reproducible and generalisable results with regards to the efficacy of an intervention.

Figure 2 Evidence Pyramid [35]



Several organisations have been set up in the UK to provide support and guidance aimed at increasing the use of evidence within the health service. The NHS Centre for Reviews and Dissemination offers support in the process of undertaking systematic reviews of effectiveness and cost effectiveness of interventions, and supplying this information to decision makers in the NHS [36]. The National Institute of Clinical Excellence (NICE) was formed in the UK in 1999 and produces public health recommendations as well as producing recommendations for the use of medicines [37].

While support has grown rapidly in favour of using an evidence-based approach, a large amount of research has described an '*evidence-practice gap*' in which existing evidence does not influence practice [38, 39].

With regard to applying principles of EBM at an organisational level, Gray states that there are two key components in an evidence-based health service [34]: (i) Organisations with the capability to generate and flexibility to incorporate evidence; (ii) Healthcare professionals who are able to find, appraise and use knowledge from research as evidence.

Gray also suggests that the ability of an organisation to increase its use of evidence requires the development of individual skills as well as culture, systems and structures within the organisation [34].

The concept of culture appeared in the aims of the KTP, while this term is frequently used in the context of introducing change, its meaning frequently remains undefined [40].

1.5 Organisational Culture

Schein defines organisational culture as '*a pattern of shared basic assumptions that was learned by a group as it solved its problems of external adaptation and internal integration, that has worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think, and feel in relation to those problems*' [41](p.17). Schein emphasises the importance of taking a cultural perspective in order to make sense of behaviour and practices within an organisation in order to bring about organisational change [41]. Citing his own experiences, Schein suggests that failure to take into account cultural forces can render the best intended organisational changes ineffective.

Although emphasising the relevance of culture in organisational studies, Schein also warns that due to the implicit nature of shared beliefs and values, culture is difficult to assess. While others agree that culture plays an important part in the process of quality improvement [42], some suggest an exaggeration of its importance. Ormrod argues that culture is an under

defined concept which is used to 'mop up' organisational elements which have no formal label and suggests that an over emphasis is placed upon the study of organisational culture [40]. These views are suggestive that culture is complex and difficult-to-measure.

The culture within the organisation this research took place¹ is interesting in that it is a charity providing supportive (predominantly *complementary*) therapies. This is an area of healthcare which has sparked much debate from proponents of EBM who have been somewhat critical of the seeming lack of evidence to support the effectiveness of such approaches.

1.6 Complementary and Alternative Medicine

Complementary and Alternative Medicine (CAM) refers to a group of treatments which generally fall outside conventional medical practice. These treatments are frequently grouped together under one term, although within this there are over 200 individual therapies [43]. A universally acceptable definition of CAM is hard to come by as many suggestions exist however a widely used definition is that used by the Cochrane Collaboration:

'Complementary medicine includes all such practices and ideas which are outside the domain of conventional medicine in several countries and defined by its users as preventing or treating illness, or promoting health and well being. These practices complement mainstream medicine by 1) contributing to a common whole, 2) satisfying a demand not met by conventional practices, and 3) diversifying the conceptual framework of medicine.' [44](webpage).

Studies examining the prevalence of CAM use frequently report figures which vary greatly from one another, and this may be due to differences in interpreting the term 'complementary medicine' [45]. A 2002 study looking at use of CAM by over 31,000 people in the US suggested that 62% of adults had used CAM in the past 12 months when the definition included the '*use of prayer for health reasons*', however when the use of prayer was excluded it was calculated that 36% used CAM. In the UK, results from a telephone survey in 1999 suggested that 20% of people had used CAM in the previous 12 months [46] while a study in 2000 estimated the prevalence of CAM use at 28% within the previous 12 months and 47% for lifetime use [47]. A

2004 study suggested that 10% of the UK population had used a CAM practitioner in the previous 12 months [48] while a 2010 study suggested that 26% of the UK population had used CAM in the previous 12 months [49].`

It has been suggested that use of CAM by people with cancer is higher than in the general population [50, 51] a large number of motivating factors have been linked to the use of CAM in cancer. Studies have suggested that CAM use amongst people with cancer may be linked to: hope [52, 53], non-toxicity of complementary approaches [52-54], a desire for control [53, 54], to improve well-being [55, 56], help fight cancer [55], and aid relaxation [56]. A 2008 systematic review suggested that dissatisfaction with conventional treatment was a significant motivating factor as well as trying to cope with treatment side effects [54].

A 2003 report suggested that nearly half (49%) of general practices in England provided some form of access to complementary medicine in 2001, either from the primary healthcare team itself, employment of an independent practitioner or through referrals to external providers [57]; this was 10% more than a study performed by the same authors in 1995 [58]. A significant change occurring between these two studies was that the proportion of services paid for in part or full by the patients rose from 26 to 42% over the 6 years between studies [57].

A large amount of money is spent on CAM. A study in 2000 estimated the annual expenditure on CAM to be £1.6 billion in the UK [46]. A 1998 study suggested that 10% of the 22 million visits to complementary therapy practitioners that year were provided by the NHS while the other 90% were privately-funded [47]. Although some complementary therapies are available on the NHS, this may vary depending on geographical location and service provider [59].

In addition to NHS and privately funded CAM, there are several third sector organisations in the UK offering complementary therapies [60]. Despite the fact that many people use CAM, it often comes under fire for its lack of a supportive scientific evidence base.

A frequent concern is that CAM is not evidence-based [61] with some going as far as to suggest it is antiscientific [62]. For some, the distinctive feature of CAM is its lack of evidence. For example Angell and Kassirer base their definition of Alternative medicine as '*treatments which have not been scientifically tested*' [63]. A recent study of academic doctors views on CAM suggested that scepticism about the scientific evidence base was a frequent view [64].

Perhaps the largest barrier to CAM adopting an evidence-based approach is the lack of existing information about the effectiveness of treatment. Studies have suggested that there is a lack of good quality evidence in CAM [65], which can mean systematic reviews fail to provide conclusive answers, often stating that more research is required [66-69]. A lack of volume of research is not the only factor limiting the conclusions which can be drawn about CAM, there have been many failures in research design which produce inconclusive results due to issues such as a lack of statistical power [70].

Furthermore, an on-going debate concerns the validity of research methodologies. Some argue that the EBM model is not appropriate for application to CAM citing several reasons. Some claim reductionist research methodologies are inappropriate for application to CAM as the process of standardising therapies does not resemble how they would be used in practice [71]. Others argue from an epistemological stance, claiming that EBM is not compatible with theories of disease attached to some CAM therapies [72]. Some reject the notion that EBM can define a single method as being representative of 'the truth' [73].

However these criticisms are not accepted by those who insist that CAM should be subject to conventional research methods. Suggestions have been made that carefully designed studies can overcome difficulties applying EBM principles to CAM interventions [62].

These debates have been, at times, highly public [61], and given the lack of agreement over what constitutes evidence for CAM it is unsurprising that potential users are given mixed messages. The lack of clarity has been acknowledged in several large reports.

The House of Lords Select Committee on Science and Technology reported that:

'There is a clear need for more effective guidance for the public as to what does or does not work and what is or is not safe in CAM.' [2](XV in Summary page).

Similarly the National Institute for Clinical Excellence (NICE) has stated that:

'Provider organisations should ensure patients have access to high quality information about complementary therapy services and where they can be obtained' [1](p.150).

One organisation providing information on CAM and cancer is the charity where I was based¹.

1.7 The Charity ¹

¹ A major function of the charity involved the provision of information about Complementary and Alternative Medicine (CAM) in cancer care, this included provision through training, education, help-sheets and a website to an audience including charity staff, people with cancer and their supporters, health professionals and complementary therapists. In efforts to improve the quality of information given out, the manager of the information department¹ built on an existing relationship with a member of academic staff at the University of Plymouth to develop a collaborative project. This was not the first time that the charity had attempted to make changes to its services, having employed external consultants in 2004 who had helped them to implement a literature search and appraisal method which became the cornerstone to the

production of information summaries¹. Less successful were the consultant's attempts to achieve 'buy-in' throughout the organisation and the KTP project aimed to build on this previous work by ensuring that evidence was valued and used throughout the organisation. Funding was obtained through the Knowledge Transfer Partnership scheme.

1.8 Knowledge Transfer Partnership

Knowledge Transfer Partnerships (KTPs) are a UK scheme sponsored by 17 government funding organisations and managed by the Technology Strategy Board. The KTP programme is one of the largest graduate recruitment programmes in Europe. KTPs create a partnership between an academic institute, known as the *Knowledge Base*, and a company wishing to expand or develop its services. The partnership employs a recent graduate, a *KTP Associate*, for an 18-36 month period to provide day to day management of a project. The schemes' stated aims are to provide each of the three partners with the following benefits [76]:

Knowledge Base

The academic institution has an opportunity to apply its knowledge in the context of improving business practice; increasing the relevance of its research and teaching.

A Company

The company receives academic support to improve practice and help its business grow.

KTP Associate

The Associate has a chance to apply knowledge from their degree and receive development opportunities throughout the project.

The data which this thesis is based upon was collected during my role as a KTP Associate¹.

The KTP was managed through a rigorous process which included being monitored through a KTP office based at the University of Plymouth and overseen by a KTP Advisor, a representative of the government's funding body. Monthly meetings were held involving members of the project team, where progress was discussed and the details of future work were planned. Quarterly meetings were more formal and consisted of a presentation to the company's Chief Executive Officer (CEO) and the Advisor. The purpose of these meetings was to ensure that the project remained in line with the objectives for which funding had been granted; any deviations required formal approval and any changes in company circumstances were required to be discussed at these meetings.

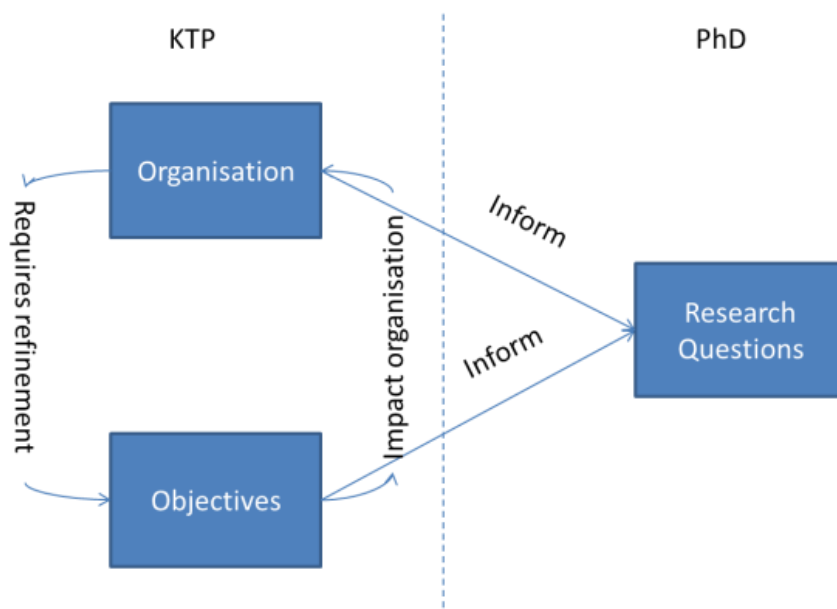
1.9 KTP Objectives

While the data collected for the PhD and KTP overlapped, the aims of the two were significantly different. Funding required that the KTP produced several measurable outputs including demonstration of implemented changes, reports and dissemination and tangible benefits to the three parties within the KTP. The KTP aims which achieved funding were:

- (i) To develop and embed a more cohesive evidence-based culture into the organisation.*
- (ii) To assess and critically appraise the current research evidence on CAM and cancer information, both electronic and paper-based.*
- (iii) To undertake a critical review of the literature about how and when to best provide information to people affected by cancer.*
- (iv) To develop an evidence-based information service for CAM and cancer by producing new, evidence-based information summaries.*
- (v) To develop an evidence-based e-health information service for CAM and cancer.*
- (vi) To test the effectiveness of the information summaries in terms of usability, accessibility and patient-friendliness and to redevelop as necessary.*

These objectives were set out in the KTP proposal document, however these developed significantly throughout the project as further understanding was gained about the organisation and its requirements, changes were made, barriers were encountered and new members of staff brought new perspectives to the project. Therefore these broad aims were refined through discussion with the KTP team and senior management at the charity. Detailed aims and objectives are presented fully within individual results chapters. The interaction between organisation and objectives which informed the research questions is shown in Figure 3.

Figure 3. Refinement of KTP objectives and development of research questions



1.10 PhD Aims

In contrast to these practical outcomes the PhD was concerned with the generation of new knowledge obtained from the data gathered during the KTP process. Study towards a higher degree was strongly supported within the KTP scheme as part of the personal development of the KTP Associate. Therefore the PhD research questions were designed to be distinct from the KTP aims, yet suitable for the data collected as part of the KTP project to satisfy the demands of both projects. These questions were developed in January 2007, at the outset of the KTP.

To investigate:

1. What cultural factors within the organisation influence the extent to which an evidence-based information service is supported and used?
2. What processes can be adopted by a third sector organisation offering complementary care for people affected by cancer in order to make their information more evidence-based?

Chapter 2. Literature Review

2.1 Introduction and Aims

The previous chapter provided an introduction to the relevant topic areas and the setting of this research. This chapter aims to review literature pertinent to the research aims stated in Chapter 1 in order to provide context for the study, rationale for the data collected and inform the choice of methodology used. It is also necessary to justify the focus of the research and place the study within the wider context of complementary and alternative medicine, evidence-based information and culture.

This literature review aims to identify the extent of what is currently understood about the culture of complementary and alternative medicine (CAM) and how this might impact on attempts to introduce evidence-based practices into a CAM organisation. In order to do this, literature is included which presents empirical data, viewpoints, issues and arguments surrounding using evidence in CAM.

Cronin, Ryan and Coughlan distinguish a traditional or narrative literature review from a systematic review, suggesting that while the former draws conclusions about a particular topic, the latter is more appropriate for a well-focused question [77]. A narrative review was appropriate for several reasons. Given that the research questions, outlined in Chapter 1, spanned several topic areas, a narrative review was most appropriate for this study as it was necessary that these bodies of literature were drawn together to demonstrate the gap in the literature and a rationale for undertaking this study. This narrative review included arguments for and against evidence-based practice and then, having defined organisational culture, outlining the current understanding of how different aspects of culture might impact evidence-based practice. This literature is discussed, drawing on studies of users and practitioners of CAM, to describe how these views on evidence might manifest themselves within the culture

of a CAM organisation. In addition, in relation to questions of culture and CAM, much of the literature drawn on presents arguments and viewpoints rather than empirical data which do not readily lend themselves to systematic review. The literature on each topic starts with a broad overview followed by focussing the review on literature which is inherently relevant to the research questions.

In this chapter I begin with a brief overview of evidence-based medicine (EBM), describing reasons for its introduction and highlight some of the main objections to this movement. I will then outline the principles behind evidence-based practice (EBP) and describe the existence of an '*evidence-practice gap*' and some of the reasons suggested for this; one of these is organisational culture. Literature will be reviewed which presents a description of important qualities in an 'evidence-based culture' and includes reference to the Promoting Action on Research Implementation (PARIHS) framework, a guide to the implementation of evidence-based practice which cites culture as an important part of context. Organisational culture will be defined and models of culture will be presented and then related to factors considered to be desirable within an evidence-based organisation. I will then focus on CAM and attempt to present what is currently understood about attitudes and worldviews which contribute to the culture of CAM and are relevant to a study attempting to identify cultural factors affecting the introduction of evidence-based practices. Finally I will evaluate what is understood about the need for patient information, focussing on information needs of people with cancer and highlighting the literature on information of CAM.

2.2 Search strategy

The following electronic databases were searched for relevant articles: Pubmed (Medline), AMED, British Nursing Index, CINAHL, SwetsWise, Wiley Interscience Journals, Science Direct, ASSIA (CSA), Business Source Premier and Web of Science. The British Library's thesis and dissertation database, EThOS, was also searched. Searches were adapted accordingly to fit the different structures and parameters of these databases.

Literature searches, both systematic and iterative, have taken place throughout this study. The following terms used in a number of combinations were:

Complementary, Alternative, medicine, therapy, attitude, therapist, belief, third sector, charity motivation, cancer, neoplasms, evidence-based medicine, evidence-based, practice, Patient information, Culture, organisational culture, attitude, belief.

Snowballing techniques were utilised by examining reference lists of relevant articles and using the *Citation search* function in Web of Science in order to identify articles which had cited particularly relevant articles.

Initial searches were conducted in January 2007 as the study began; these were revisited and refined throughout the study with final searches undertaken in February 2013. Date limits were not used in searches in order to be inclusive of earlier components of academic debate or the historical development of definitions and arguments.

In addition, to databases, the following journals were searched for relevant articles:

- Journal of Complementary and Alternative Medicine,
- Complementary Therapies in Nursing and Midwifery,
- Evidence-based Complementary and Alternative Medicine.

Literature was consulted following recommendations from supervisors, university and charity colleagues, and literature available at the charity¹. Manual searches through library catalogues at Plymouth University, University of Bristol and the University of the West of England were also performed.

Some authors who appeared to have made significant contribution to bodies of literature were contacted in order to obtain full text versions of papers and in some cases they provided a list of their publications.

Literature was selected if it contributed to the questions outlined above by providing data or offering descriptions of views, debates and issues relevant to the research questions being pursued.

2.3 Evidence-based Medicine

In Chapter 1 evidence-based medicine was defined and its principles outlined, including the driving forces behind the movement and how evidence is produced which constructs the information upon which to base treatment decisions. On the surface it may appear difficult to criticise a movement which has, at its core, the aim of ensuring that the delivery of healthcare is based on a clear rationale. Nonetheless there is significant debate over the methodological framework in which evidence-based medicine resides. Although interest in EBM has increased exponentially since the early 1990s [78], there has been much debate regarding the value of EBM [79]. Barry states that the ideology behind EBM, the intention to ensure that patients are given only treatments which have been proven to work, is undoubtedly sensible and moral [71]. It follows that opposition to EBM and its components frequently centre on epistemological arguments regarding the validity of different types of evidence. In the context of this study it is important to understand these debates and consider their impact of different perspectives on attempts to introduce evidence into an organisation.

Some criticism towards EBM is directed at how the term 'evidence' has come to be interpreted. In 2006 Tanenbaum claimed that *'the rhetorical genius of the [EBM] movement has been to claim the term 'evidence' for its epistemological preferences'* [80] (p. 265), claiming that the notion of basing decisions on evidence is not itself problematic but rather what *evidence* has come to imply in the context of EBM). Sir Muir Gray also acknowledged in 2001 that the term *evidence* has the connotation of information generated by research [34].

A frequent argument is that EBM has a narrow and hierarchical construct of evidence, valuing one type of data over another and rejecting some forms of information. In a 2006 paper

eliciting a large amount of supportive responses [80-85], Tonelli called for a '*case-based*' approach to replace the evidence hierarchy, denying that different types of evidence can be placed along a continuum as in the EBM hierarchical structure [86]. Although the title of the paper suggests an alternative approach, Tonelli appears to be calling for more pragmatism to the practice of medicine rather than the complete rejection of EBM.

Other arguments are based on views that the evidence used to support EBM has been created in an artificial environment and results may not be applicable in a real-life context. In 2003, Evans reported that although the conventional EBM hierarchy may be suited to evaluating the effectiveness of interventions, it is inadequate for assessing the appropriateness or context dependent feasibility of a healthcare intervention [87]. Others argue that conflict between internal and external validity mean that research lacks clinical relevance due to the exclusion of complex cases such as older patients or patients with co morbidities [88]. These arguments draw distinction between the generation of evidence and its use in practice.

Following these claims of irrelevance of the sources of the evidence upon which to base practice, one of the most frequent debates in this arena surrounds use of the Randomised Controlled Trial (RCT). This methodology is generally accepted within EBM as being the Gold Standard in assessing an intervention's efficacy due to the fact that the RCT minimises the risk of results being influenced by confounding factors [87, 89-91].

Many debates surrounding the suitability of the RCT come from individuals subscribing to differing epistemological stances. In 1997 Tones referred to the RCT as an '*icon of logical positivism*' and denied the method as universally suitable, arguing from the social constructionist stance which rejects one method as representative of '*the truth*' [73].

Other criticisms come from less of an epistemological perspective but represent a more pragmatic concern that RCTs do not produce information which is helpful for decision making in a practice context. Rothwell, in 2005, claimed that the most frequent reason for underuse of

potentially effective interventions is due to clinicians doubting the external validity of RCTs which have tested the intervention [92]. Rothwell goes on to suggest that in order for research methods to have external validity they should indicate the priorities of patients which often fail to be accounted for in RCTs [92].

These concerns regarding EBM have not focused on the concept of using evidence but rather the nature of what is considered evidence. In the next section of this chapter I will discuss the application of evidence in practice.

Summary

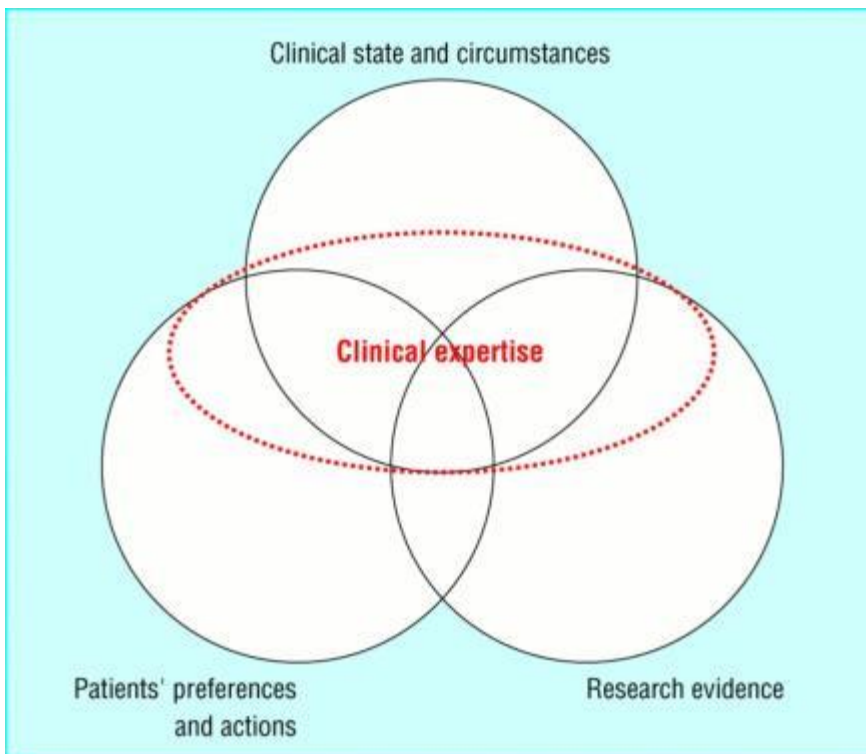
This discussion of EBM has highlighted that, although the core principle of the movement is to base treatment decisions on evidence, there is considerable debate about its appropriateness. The majority of debates focus on the acceptability of research methodologies and what has become defined as evidence. Some argue that the generally accepted hierarchy of evidence may discount other valuable forms of evidence. In the context of my research questions, it is very relevant to consider the existence of these views and the possibility of their presence in an organisation.

2.4 Evidence-based practice

2.4.1 Definition

The above discussion has focused on debates regarding the appropriateness of generating evidence of the effectiveness of interventions. Building on EBM, Evidence-based practice (EBP) adopts a more pragmatic approach to the use of evidence in health care. EBP can be seen as representing the incorporation of different sets of values represented in the following model [93] and is a more appropriate term and approach for the context of this study (Figure 4).

Figure 4. Model of evidence-based practice [93]



2.4.2 Commitment to evidence-based practice

There are several organisations in the UK which support the process of putting research into practice. The NHS Centre for Reviews and Dissemination offers support by way of carrying out systematic reviews of effectiveness and cost effectiveness of interventions and supplying this information to decision makers in the NHS [36]. The National Institute for Health and Clinical Excellence (NICE) was formed in the UK in 1999 in order to *'ensure everyone has equal access to medical treatments and high quality care from the NHS – regardless of where they live in England and Wales'* [37](webpage). NICE produce recommendations regarding public health and use of medicines. Initiatives such as NHS evidence provide health professionals with a source of guidance, evidence and government policy on interventions in order to aid informed decision making.

2.4.3 Evidence-practice gap

While a large amount of resources are applied to carrying out research, it is suggested that results are frequently not applied in practice [39, 94, 95]. This is sometimes referred to as the *evidence-to-practice gap* [96]. In the context of my research questions it is important to understand what factors within an organisation may lead to the rejection of research-generated knowledge.

Early in the EBM movement (1992), the Evidence-based Medicine Working Group identified several potential barriers to teaching the principles of EBM to health professionals [33] although at this point in the movement this was based mainly on conjecture and not empirical study (p.2423):

- *EBM may be threatening to those lacking critical appraisal skills;*
- *Critical appraisal, a necessary skill for EBM, involves additional time and effort;*
- *For many clinical questions, high quality evidence is lacking;*
- *Teaching staff are sceptical and unenthusiastic about updating their teaching methods.*

However, since then, multiple studies have attempted to identify barriers to implementing research findings into clinical practice.

The group's predicted barriers may have contained a lot of truth although in reality studies paint a more complex picture of reasons for an evidence-practice gap. Several years after the movement began, in 1998 a study in which interviews, focus groups and observations were carried out at an NHS trust drew conclusions that barriers to EBP existed at organisational and individual practice level [97]. In this study, Newman Papadopoulos and Sigsworth suggested: EBP was not a management priority, problems with dissemination, personal and professional development was not managed, audit activities were inadequate and there were resource constraints. The authors of this publication do not define *culture* and therefore claims to have investigated the culture of nursing culture are slightly unclear although it is suggested that a

lack of motivation, ill-defined roles and an emphasis on *doing* result in barriers to EBP. This study has the benefit of triangulation between interviews and observations.

The results of a 2007 Canadian study appeared in broad agreement with Newman, Papadopoulos and Sigsworth in the suggestion that barriers to EBP exist on organisational and practitioner levels [98]. Salbach et al carried out a cross-sectional postal survey of 270 physical therapists and suggested that, organisationally, a lack of provision of web-based resources and at a practitioner level a lack of education, negative perceptions of research and a lack of confidence to carry out EBP restricted its application. Although this study captured attitudes of a relatively large group, it focused on a specific group of practitioners and additionally used a very structured questionnaire which limited free-text answers and may not have allowed for the discussion of additional barriers by participants.

A 2004 study by Lam et al attempted to identify barriers to EBP amongst Chinese medical students through qualitative interviews [99]. Students were given training in the use of evidence-based decision making and, following clinical aspects of their training, took part in focus groups. Lam et al concluded that there were four main reasons for a lack of EBP: Problems within the learning environment, Limitations of evidence, a lack of opportunity to use EBP and time constraints. These problems feature within the organisational level with the authors of this study reported more practical barriers than Newman Papadopoulos and Sigsworth, but this may be due to the self-reported data which lacked the observational aspect of the previous study.

A 2005 study by Thompson et al carried out a multi-site, mixed methods study involving interviews, observation and Q-sorts amongst practice nurses [100]. In this study three main requirements were identified by the authors in order to bridge the knowledge-practice gap: skill development, appropriate information formats and the need for protected time to consume research information. This study benefited from a mixed methods approach but,

focussing on a specific group of individuals, still appeared to lack a broad view of organisational barriers to EBP.

In 2009 Brown et al carried out a large survey of nurses (n=458) which indicated that organisational factors such as a lack of time and lack of personal autonomy were the most frequently perceived barriers to EBP [101]. The authors also suggested a lack of necessary skills and knowledge required for EBP amongst respondents. The authors suggested that facilitators of EBP included providing resources, learning opportunities for nurses as well as building culture. Similarly to Salbach et al, these authors do not define culture and it is not clear whether this was a named theme by participants or is being used by the authors to describe negative personal attributes towards EBP.

In 2004 McKenna, Ashton and Keeney carried out a literature on the barriers to EBP in primary care in which they concurred with previous suggestions that organisational factors including a lack of time or support contributed the evidence-practice gap but also suggested that there were problems with the research itself such as a lack of relevance or a limited amount of evidence [102]

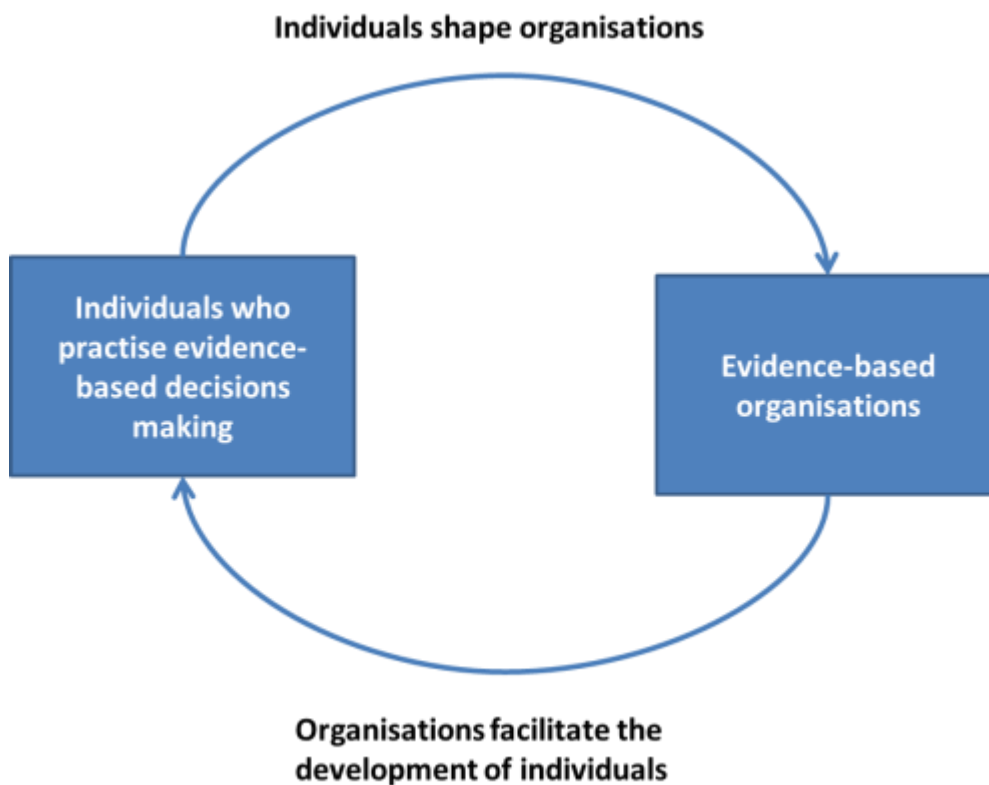
Many of these studies focus on a group of practitioners although most conclude that difficulties in carrying out EBP do not end with individuals but also exist at an organisational level or include problems with the evidence itself.

As discussed in Chapter 1, Muir Gray elaborates from an organisational perspective and states that there are two key components in an evidence-based health service [34]:

- (i) *Organisations with the capability to generate, and flexibility to incorporate evidence.*
- (ii) *Healthcare professionals who are able to find, appraise and use knowledge from research as evidence.*

Gray also provides the following model (Figure 5) accompanying the suggestion that an evidence-based organisation is not obtained solely through the appropriate skills of individuals, but with the development of appropriate culture, systems, and structures within organisations.

Figure 5. Model of an evidence-based organisation [34]³



While Gray's model suggests some of the necessary factors present for evidence to be used in healthcare, in 2004 Rycroft-Malone described a much more detailed framework to guide implementation of EBP [103]. The Promoting Action on Research Implementation (PARIHS) framework, developed by a team of researchers, cited successful implementation of research as a function of three factors: (i) evidence, (ii) context and (iii) facilitation. Within each of these factors exist many subdivisions, but in essence the authors claim that research utilisation is dependent on (i) the existence of evidence from research, clinical experience and patient experience; (ii) a supportive culture, effective leadership and appropriate feedback; and (iii) a

³ This article was published in Evidence-Based Healthcare: How to make Health Policy and Management Decisions 2nd Ed, J.A. Muir Gray, p.xxii, Copyright Elsevier, 2001

facilitator in an appropriate role, focussing on the correct task and with the necessary skills and attributes. Although elements of the theory remain vague in this presentation of the framework, the authors elaborate on each component within individual publications.

Investigations into factors affecting the development of an evidence-based information service in a charitable provider of complementary care could focus on one of many factors cited in the literature as a barrier to EBP. However, as stated in the previous chapter, the research questions in this thesis focus on how culture may affect the possibility of making an information service more evidence-based in a provider of complementary cancer care.

Summary

This section has highlighted that, despite national support initiatives and a commitment to EBP, evidence is not always applied in practice. There is empirical evidence to support the existence of several barriers to the use of evidence in practice which have been classified broadly as existing at organisational and practitioner levels although there may be problems with the nature of evidence itself. Culture has been drawn out as an important factor in the implementation of EBP although this factor has not been clearly defined. The creators of the PARIHS framework suggest that the use of evidence in healthcare is dependent on many factors, including organisational culture. In the context of my research questions it is important to understand what is known about how organisational culture may impact the implementation of EBP.

2.5 Organisational Culture

2.5.1 Organisational culture: a definition

Although the concept of the culture of an organisation has been cited as a factor affecting the implementation of evidence-based practice, there is often little elaboration on what is incorporated within the label of *organisational culture*. While there are many differing views on organisational culture, in 2012 Dauber, Fink and Yolles still refer to the field as '*relatively*

young' [104]. A difficulty encountered in arrival at a precise definition arises due to several different uses of the term *culture* in many different contexts, representing both a measure of sophistication and a label applied to nationalities.

In 1983 Smircich stated that the concept of culture is '*borrowed*' from anthropology, the study of humans, where there is not a consensus on its meaning [105]. In a 1984 paper, Allaire and Firsirotu suggest that, rather than organisational culture being completely distinct from anthropology, the theories of organisational culture arise from biomorphic, anthromorphic and sociomorphic analogies applied to an organisation, leading to views that an organisation is itself a '*little society*' with its own culture [106]. Wilson, 2001, suggests that the term *organisational culture* has arisen from the study of ethnic and national differences in the fields of sociology, anthropology and social psychology, suggesting that organisational culture is not, in itself, a distinct field of study [107].

Although there is a distinction between anthropology and the study of organisations, this may exist either side of a blurred line and Bate, in a 1997 paper, suggests that this has not always been the case but that studies of organisations have become removed from the field of anthropology over time [108]. Bate describes how the concept of organisational culture has become focussed on attributes of successful businesses rather than the traditional anthropological descriptions of culture which were frequently observations of people far removed from Western society [108]. Furthermore the level of immersion may be a distinguishing feature with Wilson stating that '*Organisation anthropologists rarely take a toothbrush with them these days*' [108] (p.1150). Therefore the study of organisational culture can be seen to have its roots in anthropology with its defining feature being the frame of reference of an organisation.

The above discussion suggests the origin of the study of organisational culture but does not provide an understanding of what it is. In 2004 Schein described culture as an abstract concept, with the term having several different connotations [41]. Although there are multiple

definitions of culture, all deal with the concept of something which is shared by a group. While *organisational* culture represents a separate and distinct field of study to *societal* or *national* culture [109] there are overlaps as organisations consist of individuals belonging to a national culture and organisations are embedded into societies [110]. In 1990 Hofstede et al also suggested a lack of agreement on a formal definition of organisation culture, however they claimed that there was likely to be agreement on the characteristics of organisational culture which include it being:

- *Holistic,*
- *Historically determined,*
- *Related to anthropological concepts,*
- *Socially constructed,*
- *Soft,*
- *Difficult to change.*

The authors suggest that these organisational properties are recognised separately however the label of organisational culture provides a single construct [109](p.286).

In 2000 Deal and Kennedy offered an informal definition of organisational culture as '*The way we do things around here*' [111](p.4). While this statement may seem flippant and unhelpful in understanding what the term incorporates, this definition goes some way to capturing the ambiguity and apparent intangibility of organisational culture.

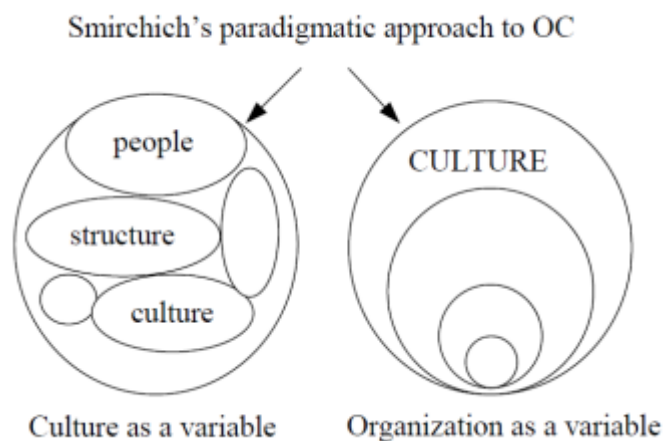
A relatively recent, and more precise, definition comes from Ravasi and Schultz who, in 2006, suggest that organisational culture is the '*shared mental assumptions that guide interpretation and action in organizations by defining appropriate behavior for various situations*' [112] (p.437). This definition is in broad agreement with Alvesson who, in 2002, provided the simple definition of organisational culture as '*the ideas, meanings and beliefs which guide how people in a company think, feel, value and act*' [113]. Although these definitions are consistent with

each other, an extensive and widely cited author on the topic of organisational culture, Edgar Schein, in 2004, offered a much more comprehensive definition of organisational culture as '*a pattern of shared basic assumptions that was learned by a group as it solved its problems of external adaptation and internal integration, that has worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think, and feel in relation to those problems*' [41](p.17). Schein's definition is particularly useful to a researcher of organisational culture as it is inclusive several of the factors suggested by Hofstede et al [109] and incorporates a theoretical rationale for the existence of a culture at an organisational level.

Conflicting Paradigms

While the above discussion suggests that there are subtleties observed within different definitions of organisational culture, there are also diverse ways of conceptualising culture which represent opposing paradigms. Smircich (1983) suggests that differences in paradigms have arisen due to the contribution to the understanding of organisational culture from several fields [105]. Nearly a decade later, Schultz neatly summarises Smircich's outline of conflicting paradigms as organisational culture being 0 something that an organisation *is* or something that an organisation *has*[114]. This distinction is displayed diagrammatically by Hammal and Vadi (Figure 6) which shows culture as a variable within an organisation versus the organisation itself as a variable [115].

Figure 6 Opposing paradigms or organisational culture[115]



This argument is taken further below in debates on whether organisational culture exists as a single entity or is formed from separate *subcultures*.

Subcultures

Although the term *organisational culture* seems to imply that an entire organisation consists of a single culture, this may represent a reductionist approach which has limited relevance to real organisations. Wilson introduces the idea that a group does not necessarily consist of a whole organisation, but may exist within smaller groups with their own *subcultures* [107]. Neglect of subculture may, in some cases, be seen as an over simplistic way of describing organisational culture and authors such as Smircich are critical of literature which implies the existence of a single organisational culture and suggests that there are likely to be subcultures and competing counter cultures [105]. In 2005, Lok, Westwood and Crawford continued the argument against attempts to offer a unified description of organisational culture, suggesting that descriptions of organisational culture are of most value in making comparisons between organisations but suggest that they are limited in their ability to describe intra-organisational observations[116]. These authors describe subculture as a subset of organisational culture, maintaining that it is not at odds with the concept of organisational culture but rather a

component of it with a difference of scale. This paradigm is suggestive that rather than organisational culture being a unified entity, it is much more complex and is composed of smaller building blocks which represent cultures in their own rights.

This is not a new development as, in a 1987 paper, Meyerson and Martin took this perspective a stage further, presenting three alternate paradigms which outlined their perspective on the complexity of organisational culture [117]. These paradigms represent a spectrum of the level of integration, differentiation and ambiguity. At one end of this scale is the fairly unified conception of organisational culture being clear cut and definable and the other extreme is a view of culture typified by ambiguity, conflict and which does not readily lend itself to description.

In what could be viewed as residing in the middle ground of Meyerson and Martin's spectrum, Schein proposed, in 1990, that, within organisations there are likely to be several subcultures and suggests three main groups based on job role. Schein refers to these as the *executive*, *engineering* and *operator* cultures [118]. Smith Francovich and Gieselman apply Schein's general model to a medical setting and suggest that the executive group are those concerned with the strategic survival of the organisation, engineers are responsible for designing processes and operators are those at the front line of service delivery [119]. Although this model appears slightly basic following the assertion that culture should not be subject to over simplification, as a minimum it may serve to illustrate that job role may be an important part of organisational subculture. A further level of complexity to these cultural debates is added by Sagiv and Schwartz who suggest that organisational culture does not exist in isolation but is affected by the external environment such as the need to obtain resources and find markets for their products [110].

2.5.2 Study of organisational culture

In a subject lacking consensus on a definition and the existence of multiple paradigms it is perhaps not surprising that there are numerous approaches to the study of organisational

culture. Schein suggests that this is due to the fact that organisational culture spans several subject areas, describing this field as being '*at the intersection*' of anthropology, sociology, social psychology, and organisational behaviour [118]. The following section outlines models which have been produced from different paradigms on organisational culture. Most notably is the difference of approaches which organisational culture is viewed either as a root metaphor or something that can be reduced to a single variable.

2.5.3 Models of culture

Dauber, Fink and Yolles suggest that there are three approaches to viewing organisational culture: A dimensional approach, an interrelated structure approach and a typology approach [104].

1) Dimensional approach

In an approach which demonstrates viewing culture as being something that an organisation *has*, Hofstede has suggested several dimensions of culture which amount to a list of variables. This approach to assessing organisational culture consists of empirical measurement along scales that can be compared to other dependent variables. Hofstede et al provide an example of a dimensional approach to the measurement of culture which originated in a study of 20 organisations or parts of organisations [109]. The original model has been refined and now consists of six dimensions by which an organisation can be measured [120]:

(i) *Process-oriented versus results-oriented*

Process-orientation refers to cultures with bureaucratic routines, while a results-orientation refers to a concern for outcomes.

(ii) *Job-oriented versus employee-oriented*

Job-oriented cultures focus on taking responsibility for an employees' work performance while employee-oriented cultures care for the overall well-being of their members.

(iii) *Professional versus parochial*

Employees in professional cultures identify with their profession while members of parochial cultures identify with their organisation.

(iv) *Open systems versus closed systems*

This dimension refers to an organisation's level of internal and external communication.

(v) *Tight versus loose control*

A tightly controlled organisation contains a higher degree of formality and punctuality than a more loosely controlled organisation.

(vi) *Pragmatic versus normative*

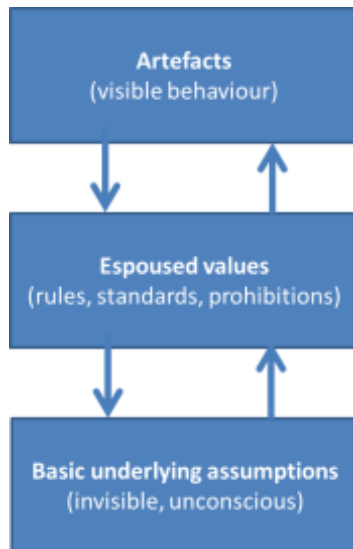
This dimension refers to how flexible (pragmatic) or rigid (normative) and organisation is in dealing with its environment (e.g. customers).

Sagiv and Schwartz suggest that one of the merits of a dimensional approach is that it provides a method for comparing organisations [110]. While this approach may provide a neat way of describing organisational culture, it is at odds with those who suggest that organisational culture is a descriptor of a whole organisation.

2) Interrelated structure approach

An opposing view of organisational culture lends itself much less to the *measurement* of culture but provides a framework with which to construct a rich description of an organisation. This approach links the concept of organisational culture to other characteristics of organisations rather than single variables [104]. In an extremely widely cited model of culture, Schein refers to aspects of organisational culture being deep or superficial and suggests that culture exists on three levels (Figure 7) [41].

Figure 7 Schein's levels of culture [41]



Artefacts

These are products of human action which have a physical presence and form the observable part of a culture. Although some may be material objects such as buildings, others are socially constructed such as language and behaviour patterns, rules or procedures.

Espoused values

Schein describes these stated values, strategies or goals as a group's sense of '*what ought to be*' and, as such, will predict much observable behaviour. However Schein warns that what people say does not necessarily explain their actions, and to more fully understand behaviour it is important to gain an appreciation of a culture's basic assumptions.

Basic assumptions

These refer to the core assumptions held within a culture. These implicit assumptions are shared and include fundamental aspects such as humanity's relationship to its environment, the nature of reality and truth, and assumptions about human nature and human activity. Schein describes these as a '*mental map*' by which situations and other people are judged. Basic assumptions are reportedly the most difficult aspect of a culture to change, as they have

become taken-for-granted, are seldom articulated and challenging of these assumptions is likely to provoke defensive behaviour.

Schein argues that organisational culture is ubiquitous and cautions of applying a simplifying typology which risks failure to incorporate important variables.

While Schein's model lacks clear dimensions with which to measure culture, in a review of literature Schein suggests that anthropological models of culture which refer to observable events being linked to underlying forces are the most useful to draw on [41]. Schein proceeds to present a number of elements contained in these models which have been used to describe qualities of organisational culture [41](p.12):

Observed behavioural regularities when people interact.

This includes language, traditions and rituals.

Group norms

These refer to expected standards of behaviour within an organisation.

Espoused values

As discussed above, these refers to the stated values of a group.

Formal philosophy

Policies and principles which guide a group's actions.

Rules of the game

Unwritten rules that people must learn in order to become an accepted part of a group.

Climate

The feeling conveyed by factors such as physical layout at the organisation and interactions between members of the organisation with themselves and others.

Embedded skills

Skills which are passed on informally at an organisation.

Habits of thinking, mental models, and linguistic paradigms

Shared 'cognitive frames' guiding thoughts and language used by group members.

Shared meanings

Understanding shared by groups interacting at the organisation.

"Root metaphors" or integrating symbols

The way that a group characterised itself either implicitly or explicitly; this may be conscious or subconscious.

Formal rituals and celebrations.

The way a group acknowledges important events.

Although these elements suggest distinct categories, the boundaries of these may not be clear-cut. Brown suggests that although these components may be discussed separately, there is overlap between them. For example behaviour patterns may be viewed as representing artefacts or basic assumptions by different researchers [121].

3) Typology approach

This third approach to the description of organisational culture uses various dimensions to construct typologies representing diverse types of organisational culture. It could be argued that this is not a description of an original approach to the analysis of organisational culture but rather building on existing theories to create a typology of organisational culture. Several typologies have been proposed.

Handy presented a simple classification of organisational culture consisting of four different types [122] This typology was based on *origins of power* within an organisation and how factors such as skills or formal roles were viewed:

Power culture

Handy's power culture has a single source of power from which influence spreads throughout the organisation.

Role culture

Rules, procedures and job descriptions are extremely important in a role culture.

Task culture

In a task culture, power is based on expertise rather than position.

Person culture

A person culture is formed from a group of self-interested individuals with a loose affiliation for the organisation they represent.

Based on their examination of different companies, Deal and Kennedy presented four culture types. This typology differed from Handy's; focussing on the tasks of the organisation rather than where power existed [122]:

Tough-guy, macho culture

An organisation composed of individuals who take risks and receive rapid feedback.

Organisations such as police departments or the entertainment industry typified this culture type.

Work hard play hard culture

A low-risk culture which receives quick feedback and places an emphasis on fun and action.

This type of culture was observed in sales organisations or mass consumer companies.

Bet your company culture

High-risk companies who focus on the future and are likely to receive slow/long-term feedback. These are typically companies which invest large amounts of money and need to wait for many years before success or failure occurs. This type of culture included aircraft manufacturing and oil companies.

Process culture

These cultures are low risk and slow-paced and receive little feedback. Banks and insurance companies typified this group of organisations.

However, these typologies should not be considered prescriptive and Brown warns that while it is interesting to hear how others have classified different types of organisational cultures, it is over simplistic to assume that this is a comprehensive presentation and suggests that in reality organisations are complicated and no two are the same [124].

This literature has highlighted several ways of defining, conceptualising and describing organisational culture,

So far, I have discussed organisational culture in general and in the following section I will focus on how organisation culture may be relevant during attempts to introduce EBP into an organisation.

2.5.4 Culture and EBP

As discussed above, several authors have cited culture as an important component in the use of evidence. However the relationship between culture and EBP is seldom made explicit or indeed what types of culture are facilitative of the application of evidence in practice.

Although *culture* is referred to frequently in the context of evidence-based practice, few authors elaborate on the parameters of this term. Some of the few to unpick components of

an evidence-based culture are Kitson, Harvey and McCormack who describe the PARIHS framework (discussed above), in which culture features as part of the *context* when attempting to apply evidence [123]. The authors describe culture at opposite ends of a spectrum of positive (high) and negative (low) attributes relating to the introduction of evidence-based practice (Figure 8). The authors of this framework appear to subscribe to the paradigm in which culture is viewed as one of many variables within an organisational context and this dimensional approach echoes that of Hofstede et al [120]. Although this model outlines some key cultural characteristics, these are not elaborated upon and, lacking rich description it may not be simple for a researcher studying an organisational culture to know where on this spectrum a particular organisation exists.

Figure 8 Culture component from the PARIHS framework (based upon[123])

Low	High
<ul style="list-style-type: none"> - Unclear values and beliefs - Low regard for individuals - Task-driven organization - Lack of consistency 	<ul style="list-style-type: none"> - Able to define culture(s) in terms of prevailing values / beliefs - Values individual staff and clients - Promotes learning organization - Consistency of individual's role/experience to value: <ul style="list-style-type: none"> - Relationship with others - Teamwork - Power and authority - Rewards/recognition

Despite this framework highlighting culture as an important facilitating factor in implementing evidence-based practice, a study which employed a concept analysis of the components of the

context component of the framework concluded that this concept lacked clarity, and was in need of further development and clarification [124]. Cummings et al echoed this sentiment in a study which used structural equation modelling to test the impact of components of the context aspect of the PARIHS framework on research utilization [125]. A literature review on evidence for implementing EBP in a chronic pain setting concluded that the PARIHS framework requires further examination to ensure its robustness [125, 126]. Although the framework remains largely theoretical [127] some claim that the model is supported by empirical data [135] and that the *context* component has construct validity [128].

In a description of the type of culture facilitative to evidence-based change, Rycroft-Malone refers to a '*learning organisation*' [103]. The concept of a learning organisation has been used in other literature relating to organisational change within a healthcare setting [34, 129] and originates in Senge's work on change in a business context [130]. It has been suggested that similarities between business and healthcare imply that the learning organisation concept is relevant to the healthcare setting [131]. Adapting Senge's work to a healthcare context, Davies and Nutley suggest that learning organisations share distinctive cultures and characteristics and outline the following key features [130]:

Open systems thinking

Integration of activities, i.e. viewing activities within an organisation as being connected.

Improving individual capabilities

Individuals constantly improving their personal skills.

Team learning

Development of teams rather than learning within single professions.

Updating mental models

Challenging deeply held assumptions and generalisations held by individuals.

A cohesive vision

A vision which is shared by members of the organisation and which guides actions.

In a literature review on the role of culture in the use of evidence in practice, Crites et al suggest that cultural facilitators include the ability to: use collaborative team decision making,

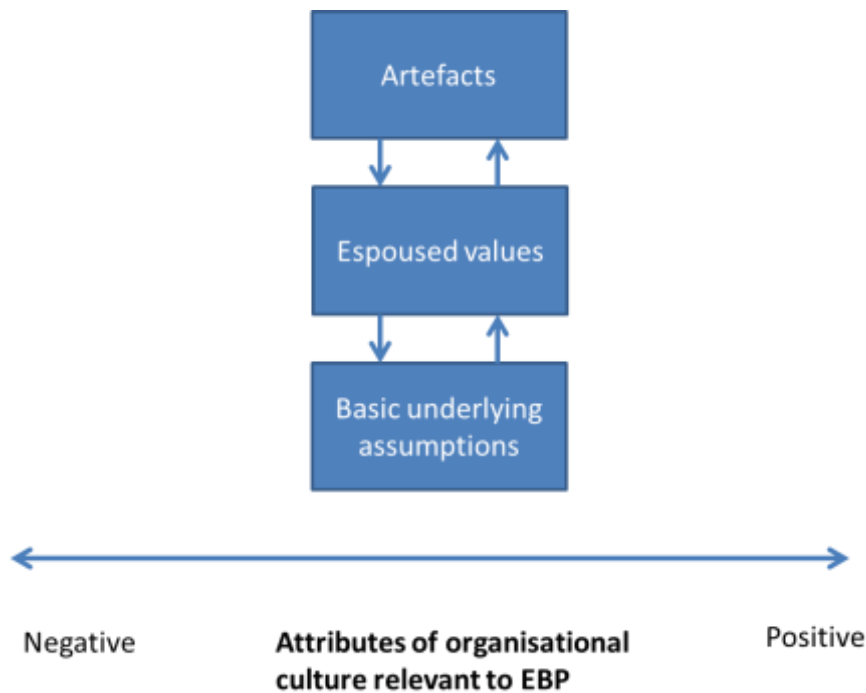
show a willingness to experiment with innovation, question policy and practice assumptions, share cohesive team values and be committed to improvement [131]. The authors suggest that, conversely, hierarchal organisations with centralised decision-making and directive leadership inhibit organisational learning. Additionally Crites et al suggest that unresolved subculture conflicts may put change initiatives at risk. In his book on evidence-based healthcare, although Gray briefly mentions the importance of culture although provides little description of what this should look like, stating that an evidence-based healthcare organisation has an *evaluative* culture in which there is an obsession with the use of research-based knowledge in decision making [34].

Use of an organisational culture model

The above literature has highlighted multiple ways of describing culture and the lack of a universally accepted model makes it necessary to make a selection based on the perceived merits of different approaches. For this thesis, Schein's model offers a simple framework by which to observe and discuss organisational culture. This seems particularly important for the study of an organisation in a little-researched setting where previously developed dimensions or typologies may be overly prescriptive or irrelevant. Schein has also outlined multiple components of organisational culture which serve as a guide for gathering data and reporting results. Although there is no highly developed model of an organisational culture facilitative or receptive to EBP, the PARIHS framework provides a useful starting point and this framework, featuring the context component, appears compatible with the concept of organisational culture. Interestingly these two views of organisational culture appear to represent different paradigms, with Schein's theory and model suggestive of organisational culture being present in all aspects of an organisation whereas the PARIHS framework reduces organisational culture to a small number of variables thought to be relevant to evidence based practice. Although referring to such diverse models may seem counterintuitive, for the purpose of this thesis these models represent both the general concept of organisational culture and incorporate

specific attributes hypothesised to be important for successful introduction of evidence-based practices. Additionally Crites [131], Grey [132], Senge[130], and Davies and Nutley [129] have all made suggestions as to requirements of a culture facilitative of evidence based practice. Collectively, these models and suggestions give rise to a useful framework with which to inform both the data collection and the discussion of results and will be used throughout this thesis. Another merit of these approaches is that they are not prescriptive, but rather provide a framework with which to structure data collection and structure discussion. This model is shown in Figure 9.

Figure 9 Guiding conceptual framework for this study (informed by [103] and [41])



Summary

Literature has described how the study of organisational culture originates in the field of anthropology but focuses on the study of people within an organisation. The literature suggests that organisational culture is complex and there are multiple ways of defining, conceptualising and examining it. Opposing paradigms suggest that culture is either an organisational variable or something which encompasses a whole organisation. While these

models may provide a neat way of thinking about and describing culture, some advise against placing cultural factors into boxes. Several studies have suggested that culture is an important factor in facilitation of EBP although frequently culture remains under defined. Although a well-developed model of cultural factors facilitative of EBP is lacking, several authors have suggested potentially important attributes. For the purpose of the research contained in this thesis, Schein's model of culture [41] will be used as a framework with which to describe organisational culture and reference will be made to the PARIHS framework [103] and contributions from other authors [129-132].

2.6 Complementary and Alternative Medicine

In this section of the literature review I will define CAM and discuss the difficulties associated with the development of a universally accepted term. This is followed by examination of literature discussing prevalence and motivation for CAM use. In this section I will then move on to attitudes and views held within CAM regarding the use of evidence in practice. These views are important in building a picture of what is understood about the CAM and culture, with different groups of stakeholders representing important subgroups.

2.6.1 Complementary and Alternative Medicine defined

In Chapter 1 I presented a definition of CAM however it is useful to look more closely at the arrival of this definition as multiple definitions exist which reflect values and attitudes towards CAM and are often made from the paradigm of EBM. At present there is no universally accepted definition of CAM and the term refers to a group of over 200 treatments [133]. Generally, complementary medicine is grouped with alternative medicine within a single definition [134-150] although others feel it is necessary to make a distinction [2, 151]. Spencer and Jacobs relate the two definitions to a therapy's use relative to conventional treatments;

complementary therapies being used *in addition* while alternative therapies *replace* conventional treatment [152].

The use of the term *medicine* and *therapy* are often used interchangeably though some feel that it is important to use the latter in order to make a distinction from the field of conventional medicine [153]. Despite these semantic objections, the term Complementary and Alternative Medicine (CAM) persists and is used frequently [154-158].

A widely used definition is that of Eisenberg et al who defined CAM as nonconventional therapies relative to United States medical school curricula:

'Alternative medical therapies, functionally defined as interventions neither taught widely in medical schools nor generally available in US hospitals'[159].

Some definitions appear not to take a neutral stance but reflect a particular worldview. Indeed the US Institute of Medicine state that what is encompassed by the CAM definition is not dictated only by science but also by political, social and conceptual values [160]. Other definitions are based on the perceived level of evidence supporting CAM; Angell and Kassirer define complementary therapies as those which are not supported by an evidence base [63]. In agreement with the former, Baum states that once an alternative approach has passed rigorous tests of efficacy then it is no longer alternative [61]. Some deny that two forms of medicine can co-exist, for example Fontanarosa and Lundenberg suggest that there is no such thing as alternative medicine, only what is supported by scientific evidence and what is not [161].

Others define CAM relative to the practice of conventional medicine:

The US National Centre for Complementary and Alternative Medicine define CAM as *'a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine'* [162](webpage). A more current definition is that of the Cochrane Collaboration which has been adopted by the NHS CAM Specialist Library. This

definition differs from others in that it incorporates the concept of being 'user defined' in preventing or treating illness:

'Complementary medicine includes all such practices and ideas which are outside the domain of conventional medicine in several countries and defined by its users as preventing or treating illness, or promoting health and well being. These practices complement mainstream medicine by 1) contributing to a common whole, 2) satisfying a demand not met by conventional practices, and 3) diversifying the conceptual framework of medicine.' [44](webpage).

One of the factors preventing arrival at a single definition may be the number of treatment modalities which the term covers. Molassiotis suggests that over 200 therapies are encompassed by the CAM term [133]. Therapies also differ greatly in what they claim to treat, from therapies focused on a particular body system to those which constitute a whole medical system such as Traditional Chinese Medicine, Ayurvedic Medicine, Homeopathy or Naturopathy [163].

In an attempt to rectify this long-existing lack of clarity, The House of Lords Select Committee on Science and Technology proposed a classification system for CAM in 2000 [2]. This system differentiated complementary from alternative treatments, these divisions being made on the grounds of levels of professional organisation and evidence base of therapies.

On the surface, the debate regarding the most suitable terminology to describe a group of therapies could be regarded as superficial or pedantic. However the lack of a universal definition has led to confusion. Caspi et al suggest that creating a single category for a diverse group of modalities sharing few commonalities is likely to generate stereotypes, prejudices' and misconceptions [164]. A more recent Delphi survey study involving CAM experts, published in 2012 saw the group struggle to come to a consensus on what a definition should be [165].

Despite how CAM is defined it may still be open to different interpretations as to what is included in the definitions. This can cause difficulties in many aspects of research where authors present arguments or data based on a contentious definition. The fact that efforts are

still being made to arrive at a suitable definition [165] reflects the fact that a satisfactory solution has not yet been reached.

In this thesis, the term CAM will be used to reflect the common use of the term within literature unless at any point it is necessary to differentiate *complementary* from *alternative*.

2.6.2 Typology of CAM users

Prevalence of CAM was discussed in Chapter 1 and reference was made to attempts to make sense of literature describing prevalence of CAM use relating back to the debate about what is and is not incorporated under the CAM term. While data indicate significant national usage of CAM, this does not provide information about who uses CAM and for what reasons. The question of why people use CAM and whether CAM users represent a particular group of people with certain views is relevant to my research questions.

Many studies have attempted to identify reasons for using CAM and describe differences between users and non-users. The majority of studies have focused on a specific group of patients or respondents from a particular culture or country [166-171] which raises the question of how to compare CAM use where differing regulations and health services exist. Information about people using CAM, and whether they represent a distinct group with specific values, is important to establish as these people represent a group of stakeholders at the charity¹. Results of several studies suggest that there are also different types of users of CAM with different reasons for using therapies.

A 1988 UK study was one of the earliest to examine differences between CAM and non-CAM users and, following a questionnaire survey of 87 patients, suggested that users of homeopathy were more likely to be sceptical of the effectiveness of conventional medicine [168]. Although interesting in highlighting potential differences in belief systems, this study lacks generalisability to CAM in general as it focussed on a single therapy.

A second study 1996, by one of the same authors, addressed some of the shortcomings of the earlier study by including users of conventional medicine and a range of CAM therapies in a sample of over 200 patients [167]. The authors of this questionnaire study reported results reasonably similar to the 1988 study with CAM users more likely to be sceptical of conventional medicine but also suggested that this group were more likely to be '*ecologically aware*' than non-CAM users. Although this study looked at several different types of CAM it was still limited to a handful of different therapies and the authors acknowledged that this study was limited in its generalisability as the study took place in Germany where there is a relatively high level of acceptance of CAM.

One of the earliest papers to gather data on general CAM use was a US telephone survey by Eisenberg et al. in 1993 who found that the majority of people who were using CAM were also consulting a medical doctor [159]. Despite the study highlighting a high prevalence of CAM use (1 in 3 people reporting using CAM in the previous 12 months), the study employed a restrictive definition of CAM as a specified 16 modalities which had the potential to discount users of other therapies.

Astin, in a 1998 US based postal survey of 1035 randomly sampled recipients, suggested that the vast majority of people who use CAM do so in conjunction with conventional treatment rather than as an alternative [172]. However one of the findings of Astin's study was that, despite the majority of people using CAM in a complimentary sense, a small group (5%) reported '*primary reliance on alternative medicine*' and this group had different predictors of use such as a distrust or dissatisfaction with conventional medicine, a desire for control and a value of personal experiences. This study adds valuable understanding in that it suggests that a minority of CAM users may represent specific attitudes or values. However this study incorporated the use of exercise within the CAM definition. Although the logic of including exercise within the CAM definition is unclear, the effect may have been to dilute the sample of people using therapies, with people taking regular exercise.

As previously mentioned, different healthcare systems mean that it is difficult to generalise between different countries. Potentially more relevant to the context of this thesis is a study carried out in the UK in 1998 in which Shaw, Thompson and Sharp expand upon the different types of users touched upon in Astin's study [166]. Following interviews with parents and children with asthma in the NHS, Shaw, Thompson and Sharp produced a typology of users and non-users of CAM (Figure 10), suggesting that consumers are positioned along a spectrum of levels of commitment to complementary therapies [166]. Although this study was smaller than the large-scale US studies, purposive sampling was used in attempts to gain a varied group of respondents. A potential drawback was, CAM users in the study were most likely to use Homeopathy which raises the question of whether users of one modality are different from another.

Figure 10 Typology of non-users and users of complementary therapies for asthma [166]

Non-users		Complementary therapy (CT) users			
<i>CT sceptics:</i> do not believe that CTs work; strong belief in value of "scientific" medicine	<i>Trust the doctor:</i> only try what the doctor recommends; would only use CTs if the doctor advises	<i>Open or interested non-users:</i> open to using CTs but not yet tried; certain "trigger factors" could prompt use	<i>Last resort users:</i> tried all conventional treatments first; escalation of medication with lack of benefit, so turn to CTs	<i>Pragmatic users:</i> "shop around" to use whatever treatments will help in parallel, both CTs and conventional medicine	<i>Committed users:</i> CTs are preferred first port-of-call; committed to "alternative" philosophies of health

2.6.3 Demographics

A 1993 paper by Eisenberg et al was one of the earliest to examine characteristics of people in the US who used complementary therapies. The findings suggested that CAM use was more common in 25-49 year olds with a college education and relatively high income [173]. However it is important to note the setting of this study where a free health service did not exist. A commentary on this paper suggested that the main reason for CAM use was that in America visits to CAM practitioners were cheaper than a visit to a medical professional [174]. This suggests that attempting to classify motivations across countries with different health care systems may be problematic, as the context of CAM use differs. A large US retrospective analysis study published in 2010 reported also reported that people with higher levels of

education were more likely to use CAM [175]. This study examined data from a cohort of chronic pain patients and also suggested that higher pain levels were predictors of CAM use. The findings from this study raise the issue that motivations may be disease specific and not generalizable.

In the UK, limited demographic data exists but findings appear to be in broad agreement with US studies. In a 2004 UK survey, Thomas and Coleman found that CAM use showed positive correlation with non-manual social class, age of leaving full time education and a gross income of over £15600 [48] This study had the strength of being a large (n=1794) representative sample of the population and asked respondents if they had used one of 23 therapies; a considerably broader definition of CAM than other studies used.

Another large (n=7630) UK survey, published in 2007, suggested that CAM users were more likely to be female with a university education [49]. This study boasted of being the largest survey of CAM use in the UK at the time of publication. This study also identified health related predictors of CAM use such as people suffering from anxiety or depression, poor mental health and lower levels of perceived social support. Similarly to Ndao-Brumblay and Green's study [175], the results of this survey suggest possible disease specific motivators for CAM use.

2.6.4 Motivation for CAM use

Furnham and Vincent have suggested that there are two main questions to ask about CAM; '*does it work*' and '*why do people use it*'. They claim that the answer to the second question would require little investigation if the answer to the first question was unquestionably positive, although they state that this is not the case according to the lack of supportive evidence base for CAM [176].

Several studies have discussed motivation to use complementary therapies in relation to *push* and *pull* factors; pull factors being those associated with the positive appeal of CAM and push factors being negative factors associated with conventional medical treatment [166-171].

In the UK, Shaw, Thompson and Sharp carried out a qualitative interview study to explore why parents of children with asthma used complementary therapies and data from 50 qualitative interviews suggested several push factors [177] : *concerns about drugs as a first line treatment, dislike of long term medications and concerns about escalation of medication with limited success in controlling symptoms*. The authors also suggested that pull factors of CAM include: *a desire for non-invasive/natural remedies, the quality of the consultation, experience of the effectiveness of CAM and a personal commitment to alternative philosophies of health* [177]. These researchers achieved a sample of users and non-users of CAM although the generalisability of motivating factors is unclear due to the fact that they related to the treatment of people's children rather than their own CAM use.

In reporting the results of a questionnaire given to 250 users of CAM, Furham and Vincent [169] add *previous experience of orthodox medicine as ineffective and poor communication with patients* to the above list of push factors. This study had the advantage of sampling users of three different therapies although failure to include therapies outside the *Big 5* [2] may neglect motivation for the use of less well known treatments.

In 1999 Paterson and Britten conducted 20 interviews with CAM users and, as well as *'lack of effectiveness of conventional treatment'*, reported *'negative experience of conventional medicine'* and *'a dislike of treatment side effects'* as additional push factors [178]. The majority of the population in this study suffered from a chronic condition and, by definition this may account for the common *'Doctors can't help much'* response and it would be interesting to know if this were the case in a population with less chronic disease.

In a systematic review of 94 articles examining beliefs surrounding use of CAM, Bishop, Yardley and Lewith divided pull factors into four categories [170]:

1. *Patient Participation*

People looking for an opportunity to gain control and participate in their treatment.

2. *Belief in mind-body connection*
A belief that psychological factors play a role in illness.
3. *Natural Medicine*
Placing belief and value in holistic and natural characteristics of CAM.
4. *Unconventional belief systems*
Use of CAM as part of broader belief systems which may include commitment to causes such as feminism, spirituality or environmentalism.

Several studies have suggested that pull factors are more prevalent than push factors.

Comparing CAM use amongst asthmatic and non-asthmatic families, Donnelly, Spykerboer and Thong gathered interview data which suggested that levels of dissatisfaction with conventional medical treatment amongst CAM users was low [179], although this study sampled from a single condition (asthma) it benefited from gathering data from users of a wide variety of therapies. Similar results were reported in Astin's US survey (discussed above) which also suggested that pull factors were much more prevalent than push factors, implying that CAM therapies were sought on their own merit [172].

In an online survey of 247 people, Bishop, Yardley and Lewith also concluded that pull factors are more likely to influence decisions to use CAM [180]. Although this study was relatively recent it suffers from inherent problems with online sampling techniques in that the sample is not representative of a wider population and therefore lacks generalisability.

Cultural perspective

In the above discussion, push and pull factors have been discussed as motivational factors, however, some authors frame CAM use as part of a wider societal picture based on culture and worldviews. This perspective is not supported by empirical data such as exists to account for push and pull factors but it arises from authors conceptually linking increased CAM use to other societal changes.

Part of this perspective focuses on the suggestion that the paradigm of CAM is distinct from that of biomedicine. Coulter and Willis suggest that increases in the use of CAM are a result of changes in society rather than reasons specific to health and medicine [181]. These authors site postmodernism, the green movement and the consumer movement as trends which have resulted in an increased demand for complementary therapies.

Engebretson has written extensively on the topic of culture and CAM and states that one of the most significant changes which occurred in the second half of the 20th century was the growing focus on health promotion, allowing for developments such as health and fitness clubs as well as the nutritional supplement industry. Engebretson describes this new focus on health as *holistic* and, as such, compatible with values found in the practice of CAM [182].

On the question of whether complementary medicine is a social movement, Schneirov and Geczik conclude that utopian, often romanticised, 'natural' ideals of alternative health are at odds with post-modernism and more in line with pre-modernism [183]. Schneirov and Geczik also suggest that alternative health falls short of being a social movement in itself but rather holds the less visible position of what they refer to as a '*Submerged Network*'.

Others suggest political reasons for a growth in popularity of CAM. For example Saks suggests that encouragement from lobby groups such as the Foundation for Integrated Medicine and the Parliamentary Group for Alternative and Complementary Medicine in the UK, and the National Centre for Complementary and Alternative Medicine in the USA, have acted as motivators for CAM use [184].

Summary

This literature on motivation for CAM use suggests a diverse group of users with a variety of reasons and levels of commitment. While CAM is widely used, it may be accessed more frequently by certain sociodemographic groups such as females, those with a higher education and larger disposable incomes. While research has suggested a broad level of commitment,

which generally relate to positive attributes of CAM, it has also been suggested that a minority of CAM users may have a negative perception of conventional medicine or be sceptical of its effectiveness. Increasing use of CAM is viewed by some as reflecting wider societal values such as health promotion or a desire for 'natural' treatments.

2.7 CAM and Cancer

It has been highlighted in the literature above that there are different types of CAM users with different motivations and that, additionally, there may be wider societal and cultural drivers of CAM use. In the context of my research it is important to try to understand why people with cancer use CAM and if this is linked to a system of beliefs and values.

2.7.1 Prevalence

Several studies have suggested that use of complementary medicine by people with cancer is higher than in the general population. A UK based postal survey in 2000 by Rees et al surveyed over 1000 women with a diagnosis of breast cancer and found that more than 22% had consulted a complementary practitioner in the previous 12 months [185]. This study used a broad definition of CAM and additionally allowed participants to describe other therapies received and, coupled with its high response rate is likely to be a reasonable estimate of CAM use by people with cancer.

A 2007 Canadian study by Boon, Olatunde and Zick found more than 80% of the 877 women with breast cancer sampled had used a complementary therapy and 41% were using these specifically for their cancer [186]. While the prevalence of CAM use in this sample is considerably higher than the UK study, the fact that the researchers included supplements and products (e.g. vitamin C or green tea) may account for this. Although these two studies have focused on breast cancer patients which, based on age and gender may already represent a group which use CAM more heavily than the general population, a more recent estimate in 2011 from a cross-sectional survey of 1597 Irish patients with different types of cancer was

that nearly 50% had used CAM in the previous 12 months although the fact that when this definition was tightened to *visited a practitioner*, this became 16% [187]. This highlights the difference that definition of CAM used can make in the results reported by studies.

2.7.2 Motivation for the use of CAM by people with cancer

With a significant number of people with cancer accessing CAM, it is important to attempt to understand the motivation for this. In addition to studies which have examined reasons for general CAM use, other research has focussed specifically on the use of CAM by people with cancer. A 2008 systematic review examined studies looking at reasons for the use of CAM by people with cancer suggested that the main reasons for CAM use could be classified into three main categories [54]:

- *Technical*
Using CAM following dissatisfaction with conventional medicine, in particular with regard to side-effects and the interaction with health professionals.
- *Biological*
Using CAM with the intention of increasing the body's ability to fight disease, strengthening the immune system and relief of side effects, hoping for a cure and prevention of recurrence.
- *Psychological*
Using CAM to improve well-being, control stress and improve quality of life.

This review suggested that dissatisfaction with conventional treatment was a significant motivating factor as well as trying to cope with treatment side effects.

Begbie, Kerestes and Bell, in a 1996 survey of 507 patients attending an oncology outpatient department suggested that the most common reasons for using CAM was the natural aspect of therapies as well as treatment being seen as a source of hope [52]. The authors also reported that satisfaction with conventional treatment was negatively associated with CAM use which is

slightly at odds with suggestion that users of CAM are generally satisfied users of conventional medicine [172, 179, 180].

In a 2000 US survey by Richardson et al in the US was in broad agreement with Begbie, Kerestes and Bell, reporting that 73% of the 453 patients who completed their questionnaire did so out of a *desire to feel hopeful* and that nearly half of respondents believed that CAM was non-toxic [53]. An addition reason for CAM use in this study was a desire for more control in decisions about medical care.

Spaciado and Barros, in a 2008 systematic review, drew similar conclusions to the above studies with regard to non-toxicity of treatment and a desire to gain a sense of control over illness and treatment but also added that people with cancer may use CAM in an attempt to positively influence the course of the disease itself [54]. In 2005 results of another survey also suggested that people may use CAM in an attempt to increase the body's ability to fight cancer although this sample consisted of a homogenous sample of colorectal cancer patients so was of questionable generalisability [55]. This study highlighted a softer motivating factor of increasing well-being. This pragmatic use of CAM was also reported following a large cross-sectional survey of 1607 cancer patients in Wales carried out in 2003, in which patients reported using of CAM for symptom relief (particularly pain) and relaxation [56].

Summary

High rates of CAM use are often reported and, similar to general CAM use, people are likely to be using therapies for different reasons. While pragmatic users may access CAM for symptom relief, others may be using CAM because it offers them hope or gives a sense of control over treatment. It is important to understand these motivating factors as people with cancer represent an important stakeholder group at the charity¹.

2.8 EBM and CAM

One of the frequent debates surrounding CAM is the question over the suitability of conventional research tools to assess the efficacy of interventions. There are several arguments for and against the application of the principles of EBM to CAM. In this thesis it is important to have an understanding of views for and against EBM as these arguments may be encountered during attempts to implement evidence-based practices into a CAM organisation.

2.8.1 Difficulties applying EBM model to CAM

Similarly to the above discussion, arguments against the application of the EBM model to CAM do not claim the aims of the movement to be flawed, but rather suggest that the principles and values of EBM may not be entirely compatible with how CAM is practiced.

In a view similar to those outlined in general EBM debates, Barry takes the view that the biomedical model of research into alternative treatments is inappropriate as it separates the person being treated from the intervention and the person treating whereas this separation does not occur in CAM practice [71]. Barry goes on to suggest that the nature of some therapies, such as homeopathy, do not conform to biomedical principles such as standardisation and in addition, attention is paid to non-biomedically recognised symptoms.

Other authors cite the philosophical underpinnings of some CAM disciplines as factors which make them incompatible with EBM. In an emphatically titled paper '*Why alternative medicine cannot be evidence-based*' Tonelli claims that insistence for the EBM model to be applied to CAM is out of a philosophical demand rather than scientific necessity [72]. Tonelli refers to EBM as an attempt to define a medical epistemology and claims that while EBM fits well with the biophysiologic model of disease underlying orthodox medicine, its research methods do not take into account or make reference to other theories of health and disease present in other medical systems [72]. Tonelli gives an example that in the absence of discussion of *Qi* it is unlikely that practitioners of Traditional Chinese Medicine (TCM) would take note of this line

of research. Vickers et al. also pose the question of whether it is appropriate for conventional research techniques to be used to investigate medical systems based on unconventional understandings of the world [188].

Similar to conventional arguments, much criticism of EBM in CAM focuses on the RCT. A frequent argument against the RCTs relevance to the evaluation of CAM is the individualised nature of CAM being incompatible with a trial which introduces a standardised form of a treatment, rather than a treatment which is representative of how a therapy would be administered in practice [163].

Another frequently cited reason for the irrelevance of the RCT to CAM interventions is the difficulty in obtaining an appropriate placebo by which to compare an intervention [189]. In addition to this difficulty, Molassiotis suggests that in some cases blinding patients as to which treatment they may be having may be very difficult [133]. Molassiotis also suggests the existence of double standards, claiming that there is an over-emphasis on the importance of evidence produced from RCTs in the field of CAM while this is not the case in conventional medicine where different levels of evidence from a variety of sources are used [133]. Vickers et al advocate the use of the RCT but claim that the most important aspect of research is that the methods are matched to the question being asked [188].

2.8.2 Conventional Research Methods for CAM

In contrast to the above criticisms there are many who argue that the EBM model should be applied to CAM. Angell and Kassirer state that there should not be a differentiation made between conventional and complementary medicine [63]. Similarly, other authors reject claims that conventional research tools are inappropriate for CAM. Yamey suggests that although application of the RCT may provide challenges to the study of CAM, these can be overcome with the development of suitable placebo treatments [62]. However, this author goes on to stress the importance of qualitative research as well as the disentanglement of factors such as therapeutic setting, time given to the patient and the influence of the therapist.

Ernst, a strong advocate of evidence-based CAM [190], comments that a therapy's effectiveness may equate to the sum of its specific and non-specific effect and that rigorous research methods should differentiate between these [191]. Ernst suggests that double standards should not exist, where the RCT is applied to conventional medicine but not CAM [191]. Bloom writes that the arguments against the RCT for CAM interventions are not unique and have similarly been proposed for the application of the RCT to conventional treatments but also claims that appropriate methodology should not be dictated by the belief systems underpinning an intervention [192].

2.8.3 Alternative Research Methods

Some argue that there are more appropriate methods of assessing the efficacy of CAM than the EBM paradigm provides. In an attempt to address the evidence gap in CAM, many other types of research methods have been advocated which do not feature highly on the traditional EBM hierarchy.

Johnston and Mills advocate the use of *n-of-1* studies, the application of RCT principles using a single patient, for the evaluation of CAM interventions [193]. This view is supported by Sung and Feldman who claim the benefits of this type of intervention include [194]:

- *The ability to determine the effectiveness of an intervention in a specific individual,*
- *Allowing the patient to voice preferences regarding treatment,*
- *Allowing the patient to balance adverse events and therapeutic benefits,*
- *Combining n-of-1 trials requires smaller sample sizes than parallel group designs.*

Others suggest that conventional research tools play a role in assessing CAM but should be used alongside other methods. Verhoef, Casebeer and Hilsden suggest that although RCT's have an important role in assessing the efficacy of CAM it is important to integrate these with qualitative methods to gain a more complete understanding of interventions [195]. Similarly, Vuckovic suggests that the use of qualitative methods such as interviews within CAM research

allow observation of personally important yet clinically irrelevant results missed by quantitative research [196].

Some support the idea that clinically relevant research methods should be based on meaningful measures defined by those using the treatments. Verhoef et al emphasise the need to develop tools that are able to measure relevant outcomes of CAM interventions and carried out a survey amongst CAM researchers to identify relevant domains. Physical, psychological, social, spiritual, quality of life and holistic measures were suggested as relevant for assessing effects of CAM as well as measures which take into account unique outcomes of CAM users [197].

In an attempt to measure patient outcomes in CAM, Paterson et al developed the *Measure Yourself Concerns and Well-being (MYCAW)* instrument which was designed to be used in cancer supportive services including CAM and enable users to nominate personally relevant issues [198].

Some suggest that it is not only important to assess an individual therapy in the context that it is practiced by including the patient-practitioner interaction but also that it is necessary to consider the use of CAM alongside other lifestyle changes that an individual may have made. *Integrative Medicine* refers not only to using CAM alongside conventional treatment but incorporating lifestyle changes such as nutrition and exercise [199]. Verhoef et al put forward a persuasive argument for Whole Systems Research (WSR) as a more appropriate framework for the evaluation of CAM [163]. The aim of WSR is to provide a methodology which will assess an intervention, incorporating all of its major components rather than attempting to reduce an intervention to a single variable.

Whole Systems Research (WSR) has been defined as research which:

- *Encompasses the investigation of both the processes and the outcomes of complex interventions;*

- *Includes all aspects of any internally consistent approach to treatment (philosophical basis, patients, practitioners, setting of practice and methods/materials);*
- *Acknowledges unique patient, family, community and environmental characteristics and perspectives [200](p.87).*

Summary

This section of literature has highlighted that many of the debates on EBM and the use of particular research methods are echoed in debates about the application of EBM to CAM. In particular, some authors express concern that reductionist research methods fail to capture how a therapy would be used clinically. Several arguments for alternative methods such as n=1 trials or Whole Systems Research have been put forward.

2.9 Access to CAM

While there are many different reasons for the use of CAM, there are also several routes which may be used to access therapies.

2.9.1 Availability of CAM on the NHS

Although there may be some availability of CAM through the NHS, this does not appear to be a major source of CAM provision. The House of Lords Report Select Committee on Science and Technology reported in 2000 that although there was evidence to suggest that 40% of GP practices in England provided some form of CAM, access to these services was described as '*patchy*' and was dictated by geographical factors and the attitude of the individual practice towards CAM [2]. The vast majority of available NHS CAM is accessed through primary care [2].

Furthermore, access to publicly funded CAM is a highly contentious issue which has sparked intense debate. There have been highly publicised calls for the NHS to stop funding aspects of its CAM services. This relates back to the question of whether CAM is supported by an evidence base. In 2006 several doctors and scientists wrote to chief executives of the NHS and

Primary Care Trusts suggesting that NHS spending on Homeopathy was unjustified due to the lack of a supportive evidence base [201]. NHS funding of Homeopathy has undergone more recent criticism in the form of a House of Commons Science and Technology Committee report suggesting that the NHS is abusing the trust of patients by prescribing a therapy with no evidence base, and that to provide homeopathy on the NHS is against the Constitution which states that funding for treatments will be made '*rationally following proper consideration of the evidence*' [202](p.6).

2.9.2 Self-funding of CAM

With limited access through primary healthcare, the majority of CAM is self-funded and accessed through routes including health clubs, beauty parlours, complementary therapy clinics, self or GP referral to a CAM practitioner and over the counter products [2]. Little data appears to exist on how much is spent privately on CAM in the UK; a 2000 BBC survey conducted by researchers at Exeter University interviewed 1200 British adults and from the results of this survey it was estimated that annually £1.6 billion is spent on CAM. The fact that the majority of CAM is self-funded may account for some of the previously discussed demographics of CAM users such as a higher income than non-users. In addition to public and private sector availability of CAM there is also some *third sector* provision [60].

2.9.3 Third Sector

The Third Sector is defined by the Third Sector Research Centre as encompassing '*all organisations operating outside the formal state or public sphere that are not trading commercially for a profit in the market*' [203](webpage). This definition includes charities, voluntary organisations, community groups, social enterprises, cooperatives and mutuals. The Third Sector Research Centre states that while this sector consists of a diverse group of organisations, they share the theme of being *value driven*.

There are nearly 170,000 charities in England and Wales although of these, the majority are small, with 56% having a budget of less than £10000 and only 15% having a budget of over

£100000 [204]. Cancer Research UK is the largest independent cancer charity in the world [204]. A keyword search for *cancer* on the Charity Commission's database of registered charities obtains 541 results suggesting that there are many cancer charities operating within the UK [205].

The Department of Health has stated that the third sector plays an '*integral role in improving health and wellbeing outcomes for people*' [206](p.7). In the same report the Department of Health describe the function of third sector organisations in health care:

This role is at multiple levels from contributing to the development and implementation of policy to help drive innovation and development; through information and contributing throughout the cycle of commissioning for health and social care services helping to understand users' needs and expectations; and as providers of health and care services formally commissioned by the NHS and local authorities [206](p.7).

Tritter et al write that in health care the '*voluntary sector is playing an increasingly large role in the funding, provision and delivery of services and nowhere is this more apparent than in cancer care*' [207] (p.429).

Summary

Although there is some NHS provision of CAM, the majority is self-funded. There is some provision of CAM in the third sector which may be playing an increasing role in health care.

2.10 CAM and Evidence-based practice

While culture has been discussed above as a potential barrier for using evidence in practice, there appears to be a shortage of literature detailing how culture acts as a facilitator of EBP. Despite there being a lack of consensus as to whether CAM should be judged by the same evidence hierarchy applied to conventional medicine, literature exists which describes difficulties in taking an evidence-based approach to CAM.

2.10.1 Availability of Literature

One of the more powerful arguments for lack of an evidence-based approach to CAM is the absence of primary research in the published literature.

Vickers and Zollman highlight a lack of funding limiting the amount of research which is carried out, reporting that a tiny fraction of NHS research funds are spent on complementary medicine research [208]. Wider and Ernst carried out a survey of research funding from medical charities and 1999 and 2002 and concluded that although the level of funding had increased between these years, funding remained disproportionately low relative to the prevalence of CAM [209].

It has also been suggested that even when research is performed, journals may be biased in their publication of articles on CAM. Resch, Ernst and Garrow conducted a study in which they sent papers reporting results of an RCT to a selection of reviewers; the papers were identical except for the names of an intervention drug; either conventional or homeopathic [210]. The reviewers were asked to rate the importance of the paper on a visual analogue scale. The homeopathic remedy was rated significantly lower, which led the authors to conclude that a publication bias may exist against unconventional therapies. This particular issue may be unclear as one of the same authors had carried out a study with similar aims which had concluded that publication bias was not observed [211]. Other studies have suggested that there may be bias to publish positive CAM trials [212, 213].

However despite the problems discussed above. Vickers suggests that there is considerable evidence to base decisions to inform policy regarding purchasing or referring to CAM. [214]. In 1999 Vickers cited 4000 RCT studies of CAM listed in the Cochrane Collaboration registry with 5000 waiting to be analysed [214]. However, Vickers suggests that despite this volume of evidence, there is insufficient detail in the literature to answer questions likely to be asked at practitioner level.

2.10.2 Training

In addition to a lack of literature to inform practice, a further reason for a lack of use of evidence in CAM is the lack of skills necessary to appraise and integrate research into practice. In line with Gray's model of evidence-based healthcare, Richardson states that as well as access to research literature, the development of evidence-based complementary medicine requires research aware practitioners [215]. Several studies have questioned whether complementary therapists have the right set of skills and attitude to practice evidence-based medicine.

A 2007 study documented an educational initiative demonstrating how complementary therapists used PubMed to access relevant research [216]. The study suggested that those with higher education backgrounds and previous training valued PubMed tools and training more highly than those with less education and training. Frustration over not being able to view full-text articles was a frequent issue and visiting libraries or ordering articles posed a serious problem. Some therapists expressed difficulties in understanding research.

The House of Lords Select Committee in 2000 reported that CAM training courses *vary* unacceptably and suggested that partnerships between higher educational institutions and validating bodies would ensure that public safety is protected from incompetent practitioners [2]. The report also suggested that Continuing Professional Development (CPD) among CAM practitioners was uncommon. Since this report, there has been development regarding CAM regulation with the formation of the Complementary and Natural Healthcare Council in 2009 although this is entirely voluntary and does not cover all disciplines but nonetheless aims to set standards for regulation [217]. It is important to note however that while regulation may stipulate minimum standards, it does not guarantee that CAM will become more evidence-based as this is dependent on how the regulation dictates the content of individual training courses. In 2009 Hunt and Ernst conducted a review of codes of ethics of British CAM

organisations and suggested that few complementary medicine organisations in the UK enforce evidence-based practice amongst their members [218].

Higher education courses have also been subject to criticism. In a highly public attack in 2007, Colquhoun questioned the content of complementary therapy degree courses and suggested that they should not have a Bachelor of Science (BSc) status due to a lack of scientific content [219]. These opinions received media attention with several newspaper articles suggesting that degrees based on CAM subjects were teaching *pseudo-science* [220-222].

Although there is limited literature on CAM training in cancer care, one study highlighted a need for specific training in this field, highlighting that practitioners are frequently taught to view cancer as a contraindication to treatment [223]. In this study Mackereth et al surveyed a sample of CAM practitioners working in cancer care settings in the North West of England and although the majority were engaged in continued professional development, found that just over half had received cancer-specific training.

2.10.3 Attitudes

This chapter has so far highlighted that there are many debates in the field of CAM although it is not clear whether these reflect the values of practitioners themselves. While it is clear that EBP requires appropriate skills and culture, there is an absence of research into the attitudes of CAM practitioners to evidence-based practice. However a small number of studies have examined thoughts and feelings regarding the role and use of evidence in CAM practice. While the results are likely to be extremely relevant to attempts to introduce evidence-based changes into an organisation there are further complications as some studies have taken place within different countries in which regulation and use differs.

An Australian study using the validated EBASE (Evaluation of the Evidence-Based practice Attitude and utilization SurVEy) questionnaire [224] suggested that the complementary

therapists in the sample viewed EBP positively although highlighted barriers to the application of evidence to their practice as a lack of: time, available evidence, industry support and skills⁴.

This supported results from a 2007 Canadian study which also found a generally positive view of EBP amongst practitioners as well as reported barriers relating to a lack of research experience and critical appraisal skills [225]. The authors of this study suggested that differences in opinions between groups of practitioners may relate to the research content of training courses. This was a reasonably large questionnaire survey (n= 483) however the sample was taken from members of two professional bodies (College of Chiropractors of Alberta and the Massage Therapist Association of Alberta). Chiropractors are regulated in Canada and, although massage therapists are not regulated in all provinces, this sample could be viewed as a relatively professional group of therapists who might be expected to be reasonably supportive of EBP. This point was emphasised in Kelner et al's 2002 study which compared 22 practitioners of three therapies (Chiropractic, homeopathy and reiki). This qualitative study reported results on a thematic analysis of qualitative data, suggesting that positive attitudes towards CAM were more prevalent in more formally organised therapies [226].

More recently, a 2010 US study was conducted by Wayne et al who carried out survey of over 200 students at two colleges of acupuncture and oriental medicine suggested that although students perceived research to be important to how their profession was perceived by the public and health insurers, due to the nature of research methods being incongruent with therapeutic principles, they thought research was not as relevant to their own practice [227]. Although this was a reasonably large sample, its generalisability suffers not only because students represented a single therapy but because both colleges are described as having a 'history of commitment to research' (p.22) which may make it more likely that research would be valued amongst students.

⁴ Conference poster, abstract only available

A 2012 Danish interview study of 12 acupuncturists concluded that that the practitioners embraced both research-based evidence and personal or historical forms of evidence, although expressed particular concerns about a perceived lack of pragmatism in RCT's [228]. Although this sample was relatively small, results reflected some of the epistemological debates discussed earlier in this chapter such as the nature of evidence and the suitability of standardised research methods.

Although the above studies suggest some level of positivity towards EBP from CAM practitioners, these conclusions are based on study data from countries in which the regulation of therapists differs from that of the UK. It is therefore difficult to generalise when data has been gathered from therapists with different levels of training and qualifications to UK-based practitioners.

A UK study which examined the knowledge and beliefs of CAM practitioners and allied health professionals suggested that CAM practitioners were less likely to agree that EBM was essential for their practice but more likely to acknowledge a need for further training in EBM [229]. This study suggested that those who had been qualified for a longer period of time were likely to be less research literate, less likely to have received EBM training and more likely to rely on their own experience. It is unsurprising that this group of people acknowledged a need for further training as they were recruited from a one-day EBM training course and it might be expected that they were a relatively motivated group of CAM practitioners. However it is therefore fairly surprising that therapists did not agree that EBM was essential for practice.

In contrast to the generally positive perceptions of research and evidence, a 2007 UK study in which qualitative interviews with ten acupuncturists were undertaken suggested that resistance to evidence-based medicine was a major theme [230]. Interviewees expressed doubt that EBM was compatible with the paradigm on which Traditional Chinese Medicine

(TCM) was based and were sceptical that EBM had relevance to their practice. There was agreement from interviewees that an RCT indicating that acupuncture was ineffective for a specific condition would not discourage their willingness to treat this condition. Although this study highlighted an interesting contrast to the other UK study and the majority of international studies, the sample all practiced the traditional form of acupuncture which represents a distinct paradigm to conventional medicine. This is a particular weakness with regards to generalisation as even within acupuncture, practitioners of variations, such as medical acupuncturists, may be more likely to embrace EBM.

Summary

This limited volume of literature suggests that there may be multiple barriers to the use of evidence within CAM practice including a lack of literature and necessary skills for appraising relevant evidence. While some research has highlighted negative attitudes towards EBM it is unclear how prevalent these attitudes are and if they are relevant in a UK context.

2.11 Patient Information

Some of the technology fuelling the rise in availability of information for health professionals such as the internet has also fuelled a growth in the amount of information available to patients, and this is particularly evident in the area of CAM.

Stoeckle describes the rise in the emphasis of the importance of a well-informed patient being part of a shift away from the medical interview being a one-sided talk in which the doctor obtained information from the patient in order to make a diagnosis, to a two-way process between patient and doctor in order to facilitate shared decision making [23]. Stoeckle cites three reasons for this [23]:

- *The availability of new diagnosing technologies and treatments and interventions mean that there are more treatment choices.*
- *Politics of healthcare have shifted decision making from doctor to doctor and patient.*

- *Patient autonomy has grown alongside a move towards a focus on individualised care.*

The internet is a vast source of patient information with between 36% and 55% of internet users accessing online health information [231-234]. The growth of, and increase in access to the internet has changed the way in which consumers can access information [235], although several studies have highlighted problems with variations in the quality of this information [26, 236-239]. The purpose of patient information is multi-faceted. Coulter, Entwistle and Gilbert list reasons for providing patients with information [24](p.ix-x):

- *To help them understand what is wrong,*
- *To provide a realistic idea of prognosis,*
- *To help them make the most of consultations,*
- *To help them understand the process and likely outcomes of possible tests and treatments,*
- *To assist in self-care,*
- *To provide reassurance and help to cope,*
- *To aid communication with others,*
- *To legitimise help-seeking concerns,*
- *To identify further information and self-help groups,*
- *To identify the 'best' health-care products.*

2.11.1 Importance of information for people with cancer

The importance of patient information has been recognised at a national policy level in several Department of Health policy documents. These have suggested that improved provision of information for people with cancer is of great importance.

In 2000 the NHS's *Cancer Plan* stated that cancer networks and NHS trusts must provide cancer patients with high quality information [240]. The importance of information was further emphasised in the 2006 white paper, *Our Health, Our Care, Our Say: a new direction for*

community services, where the Department of Health (DoH) outlined plans to provide *information prescriptions* to people with long term health or social care needs and their carers [241].

The NHS Cancer Reform Strategy, published in 2007, built on the original Cancer Plan and outlined the health service's plan for improving cancer services over the next five years [242]. These objectives led to the *National Cancer Survivorship Initiative* which had the remit of improving the care and support given to cancer survivors. One of the objectives of the Survivorship initiative has been to develop *National Cancer Patient Information Pathways* who aimed to ensure health professionals were aware of high quality information available to people affected by cancer and able to signpost to it [243].

Reported benefits of information for people with cancer have included: increased involvement in decision making and improved satisfaction with treatment choices [244], improved psychological well-being [245] and reductions in anxiety [246].

2.11.2 Patient Information needs

Several studies have explored issues surrounding information needs of people with cancer. Though some have been general, others have focussed on those with a particular type of cancer or a very specific group of patients. It has also been suggested that differences in cancer type may lead to differences in patient requirements and therefore it is not always clear if results from one study are generalisable.

Although it has been suggested that there are several benefits to receiving health information, it does not appear to be the case that all patients want the same information. Some reports suggest that cancer patients want as much information as possible [247, 248] although it has also been suggested that, depending on coping styles, some people may not want, and may not benefit from a large amount of information about their condition [244, 249]. In one of the few studies which appears to have investigated reasons for this, Leydon et al interviewed 17

cancer patients and suggested that reasons for information avoidance could be explained by three categories [250]:

1. *Faith*; Patients trusted the expertise of doctors.
2. *Hope*; Information avoidance made it easier for patients to live a normal life.
3. *Charity*; The concern that information resources needed to be shared with people in a worse situation than themselves.

There may be demographic differences which influence people's desire for information.

Chewing and Sleath suggest that the desire for a high level of involvement in treatment may relate to age, stage of diagnosis and level of education, with younger and better educated individuals desiring more information at the post-diagnosis stage [251]. In a study by Squiers et al the authors suggested that females are more likely to seek high levels of information [252]. Meredith et al found that patients from more affluent geographic areas wanted more information than those in deprived areas [248]. In addition, it has been suggested that information needs to take into account cultural beliefs values and knowledge in order to be accessible to minority groups [253].

Several authors have highlighted that it is not only people with cancer but partners [249, 254] relatives [255] and carers [256] who need information.

Information needs also appear to change over time representing different stages of disease and treatment [257-259]. In addition to this there are many information needs that are not generalisable such as questions regarding specifics of treatments or effects of specific drug therapies.

Mills and Sullivan conducted an extensive systematic review on the needs of newly diagnosed cancer patients in 1999 and identified five priority areas of information for cancer patients [260](p.640):

1. *Available treatment regimes,*
2. *Side effects of treatment,*

3. *Extent of the disease,*
4. *Prognosis and likelihood of cure,*
5. *Self-care and return to a normal life-style.*

2.11.3 Information on CAM and Cancer

As with other aspects of cancer patient information, the importance of providing patients with information about CAM has been acknowledged in several publications. Searching for high quality CAM information on the internet has been shown to be particularly challenging [261].

Although the amount of people with cancer accessing CAM is considerable, a disproportionately low amount of research has examined information needs on the subject. The majority of research into information needs and information seeking practices amongst cancer patients has focused on conventional therapies and therefore there is a very limited volume of literature describing what information people with cancer want about CAM.

Within the limited research which has examined information needs with regard to CAM and cancer there has been suggestion that there are different types of information seekers. Those who had used CAM before their diagnosis may be more likely to look for CAM information than new CAM users [262-264]. There is also suggestion that scientific evidence, although important to some, is not necessary to demonstrate a therapy's effectiveness but that other convincing types of information including personal stories [262], historical use [263], plausibility [263], trust in providers [263], information from friends and family [264] or 'gut feeling' [262].

A 2009 Canadian study which analysed questionnaires from over 400 people attending a cancer centre or using a cancer information service suggested that the most important types of CAM information included: safety information, mechanism of action of a therapy, side effects, proof of improvement in well-being, cost information, proof that a therapy could cure cancer and time needed to receive a therapy [262]. This study also identified barriers to

accessing information which were reported by patients as the volume of information available and not knowing which information was trustworthy. Patients also reported that while health professionals were their preferred source of CAM information, the majority was received from friends and family. This study also suggested that a negative study would not be enough to prevent patients from using a therapy.

Summary

Information plays an important role for people with cancer and has multiple benefits including increasing understanding of the disease, prognosis and treatment although information needs are likely to differ between patients. The need for provision of high quality information on CAM and cancer has been emphasised in the UK by the Department of Health and NICE. Research suggests that CAM users have a broad definition of evidence of a therapy's effectiveness although there may be barriers to accessing information.

2.12 Summary

In this literature review I have attempted to understand what is known about the culture of complementary medicine from the perspective of different stakeholders as well as gaining an understanding of the requirements for evidence-based practice and information production in the context of cancer and CAM.

Organisational culture has been defined as a complex concept which, despite the existence of standardised dimensional measures, is likely to be unique to an individual organisation based on multiple factors including history, practices, beliefs and values as well as basic assumptions held at an organisation. Models of culture suggest that these factors exist at different levels; from superficial to deep. Several typologies of culture have been developed but it has been emphasised that these should act as points of interest rather than a guide due to the fact that organisation culture is a complex quantity which is likely to be unique within an organisation.

The culture of CAM appears to be complex and fraught with debates about definitions, evidence claims, and questions regarding appropriate methodological approaches; such debates are not without context that can be viewed as both political and resource-driven. Although these arguments provided by academic authors are well-rehearsed, there is less indication of how these worldviews may be manifested in a practical setting.

While evidence-based medicine may be based on the unquestionable values of ensuring treatment is effective, criticism for this movement frequently focuses on a limited definition of evidence which critics argue unjustly rejects some forms of evidence, is clinically irrelevant or is based on a philosophical desire rather than necessity. Within the CAM field there are additional arguments that EBM is not in line with the philosophy of how some therapies are practised and some have suggested that other forms of research should be considered valid. However, many of these arguments are dismissed by groups who claim that CAM should be subject to the same rules as conventional medicine.

Alongside the increasing emphasis on using evidence in practice, has been the suggestion of an evidence-practice gap of which culture has been implicated as an important factor. Although it has been highlighted frequently that culture is an important variable in implementing evidence in practice, little detail exists as to what a desirable 'evidence-based' culture should look like. As the literature above suggests, the process of getting evidence into practice within healthcare organisations is complex.

With respect to applying evidence in CAM practice, several barriers have been reported which include a lack of research and a lack of practitioner research skills. There has been little research examining attitudes towards evidence in a CAM environment and several of the studies located have come from different countries and are not necessary applicable in a UK context. These studies have varied in their reports of generally positive practitioners to those who are resistant towards evidence-based medicine. Nonetheless, significant numbers of people (particularly those affected by cancer) use CAM for a range of reasons, and therefore

should have access to appropriate information of a high quality that is, where possible, evidence-based. At a national level there has been a large emphasis placed on making information available to people with cancer although literature has highlighted that different patients are likely to have differing information needs. Two influential reports have highlighted the need to provide patients with high quality information about CAM, however there has been little research on the information needs of patients in this area.

In summary, this literature review draws attention to the absence of knowledge regarding how third sector organisation offering CAM to people affected by cancer could make information more evidence-based, and what cultural factors may influence the extent to which such an information service is supported.

3. Methodology and Methods

3.1 Introduction

This chapter describes the methodology and methods used in this study. The context of Knowledge Transfer is discussed in order to support the decision to use Soft Systems Methodology (SSM). SSM is a form of action research characterised by its emphasis on the importance of worldviews in the implementation of change and the use of systematic 'learning cycles' incorporating the collection of data and feeding back of results to an organisation. In this chapter I will also relate the choice to the setting of the study and my own role in the organisation. A description of SSM is provided and its attributes discussed with reference to the research questions. Alternative methods are presented and reasons for their rejection are discussed. Previous use of SSM in a healthcare setting is discussed as well as criticisms of the methodology. This is followed by a description of how different research methods were selected within the methodology to answer the research questions.

3.2 Selection of a methodology

The choice of research methodology was made prior to consideration of methods. Kothari offers a distinction between these two terms, describing methodology as offering a logical explanation for why a particular research technique is used, methods being the tools used for data collection and statistical or evaluative techniques [265].

Methodology can therefore be seen to guide the research methods and is based on certain assumptions about the generation of knowledge. In deciding on an appropriate methodology it was important to take into account factors such as study setting, research question, and my role as a researcher. These factors are discussed in further detail below.

3.2.1 Study Setting

As has been discussed in Chapter 2, securing research funding for CAM presents a number of challenges and resources in this area are limited. 'Knowledge Transfer Partnerships' (KTPs) provide an opportunity for organisations to work with an academic team to develop an area of their organisation and participate in the research process. The term, *Knowledge Transfer* has been described in literature in the last decade [266]. Knowledge Transfer has been recognised as a strategy to translate research findings into practice and in health literature is used alongside concepts such as evidence-based practice, research dissemination and research utilisation [266]. In the UK, Knowledge Transfer is frequently understood to refer to a collaborative partnership between researchers and industry [267]. Knowledge Transfer Partnerships (KTPs) are a particular example of a UK initiative to facilitate the exchange of academic and work-based knowledge in a process facilitated by a recent graduate.

Chapter 1 addressed the development of research questions and referred to the fact that the research took place within a KTP. Not only did the KTP context inform the development of the research questions but heavily influenced the choice of methodology. While the KTP provided an opportunity to collect data it also placed constraints on the ways in which the data could be collected.

3.2.2 Researcher Role

One pre-determined factor was my role as a researcher within the organisation. As well as being engaged in doctoral research I was working as a member of staff at the charity¹ (and in this role acted as a problem solver). Keys discusses different types of interaction a problem solver may have with the problem [268]:

(vii) *Active Role*

In this position the problem solver is also a decision maker or is closely linked to a decision maker and hence in a position of power.

(viii) *Reconciliatory role*

In this role the problem solver acts as arbitrator between several conflicting decision-makers while remaining impartial.

(ix) *Passive Role*

From this position the problem solver is not involved in the management of the problem other than in the sense that they are studying how the decision makers involved reach a solution.

In this study, my role could be most accurately likened to the reconciliatory role. The Knowledge Transfer process involved working with an academic team from the University of Plymouth as well representatives from the charity¹. In addition to this a *Change management group* was planned in which discussion of changes to the information service would occur. This group was to consist of senior members of staff from several departments at the charity¹ and would be the main vehicle for change. This group had been planned from the outset of the project and the KTP grant application stated:

The Associate will establish and lead a change management working group to steer, develop and implement the change management process for the charity. This working group will include representatives from all categories of staff to be affected by the project¹

3.2.3 Research questions

As stated in the introduction, the research questions were:

1. What cultural factors within the organisation influence the extent to which an evidence-based information service is supported and used?
2. What processes can be adopted by a third sector organisation offering complementary care for people affected by cancer in order to make their information more evidence-based?

The focus of these questions required that within a chosen methodology, appropriate methods could be used with which to collect the necessary data.

The KTP objectives were tightly focussed on the practical task of implementing the use of evidence-based practices in the charity's information service. As discussed in Chapter 1, the aims of the PhD differed in that they were concerned with gaining an understanding of the cultural issues involved in the introduction of evidence-based practices to the charity's¹ information services and, taking these into account, suggesting what processes could be implemented successfully. Despite these differences, the data collected for the PhD would be carried out within the Knowledge Transfer process and therefore this influenced the methodological approaches considered and explored in further detail.

Methodologies which focussed on the process of introducing change into organisations were examined. This literature comes under several different headings including *organisational improvement*, *organisational change management* but perhaps most frequently *organisational change*. Examining the body of literature on organisational change is challenging for several reasons, summarised by Iles and Sutherland [269] (p.12):

- *It contains contributions from several different academic disciplines including psychology, sociology, business policy, social policy and others.*
- *Its boundaries can be set differently, according to the definition of change management employed.*
- *Valuable contributions to the literature have been made in all of the last five decades, with the later not necessarily superseding the earlier.*
- *It contains evidence, examples and illustrations generated in a wide variety of organisations and from a diverse range of methodologies with varying degrees of rigour.*
- *Some material is not readily accessible to non-specialists and does not readily lend itself to cumulative review.*

The concepts included within it range in scale from whole academic schools, through methodologies to single tools.

There is a large choice of organisational change methodologies to choose from. A website dedicated to organisational change names 153 methodologies [270], and in the field of health care a comprehensive NHS review identified 28 approaches [269]. For the purpose of this research, three approaches which had been used extensively in the health care context (Total Quality Management, Business Process Re-engineering, and Soft Systems Methodology) were examined in detail. These methodologies warranted further examination as they represented a spectrum of different approaches to implementing change. The advantages and disadvantages of these were considered before SSM was chosen. Despite there being a range of methodologies to choose from, it is challenging to select one prior to beginning organisational research. Although efforts were made to match a methodology with the research setting, it is impossible to gain an understanding of the research situation prior to engaging with it, and to some extent the selection of a methodology was based on assumptions of how the organisation functioned. In this case, although as a researcher I was based within the organisation, this was a recent appointment and therefore I had no prior knowledge of the research settings or how the research would be perceived by those within it. An example of a failure of organisational change is described by Davies and Ledington in which a study was cut short by an organisation who disliked criticism of their practices [271]. This example highlights the fact that although efforts can be made to select a context-appropriate methodology, it is difficult to understand the merits and acceptability of any methodology until it is applied in practice.

While examination of organisational change literature would have ideally focussed on change in a CAM context, as discussed in Chapter 2, there is a general lack of research into CAM. No studies were located which examined change in CAM organisations and therefore literature was examined from the more general health context.

3.3 Total Quality Management (TQM)

Originating in the manufacturing industry, this approach to change operates on several principles which aim to improve productivity, identify and meet customer needs and continuously work towards improved quality [272]. A large systematic review of organisational research methodologies suggested that TQM initiatives may result in an organisation: training employees, identifying customer requirements, analysing variability of quality, using cross-functional teams, collecting and using data in problem solving, viewing improvement as a continuous process, and using process management tools such as flow-charts and brainstorming. A large study which attempted to clearly define TQM stated that there was no universal definition of what TQM is or how it is practiced [273]. These authors also suggested that discussion of the concepts of TQM have never taken place and therefore authors of TQM literature make their own assumption about the nature of the methodology [269].

TQM has been used in a variety of healthcare settings with a range of objectives including improving the outcome of fractures [274], meeting customer needs in a hospital library [275], improving an infant screening programme [276] and improving processes in an andrology laboratory [277]. Often TQM has been used in an attempt to define quality and develop quantitative measures by which to judge success. Several studies have described TQM as the start of a continuous programme of quality improvement [278, 279]. Some studies have used TQM to focus on ways of reducing delays or maximising use of staff time in order to save money [274, 277]. While there appear to be relatively few published criticisms of TQM, it has been highlighted by Iles and Sutherland that one of the areas where the methodology may struggle is addressing issues of culture including heavily engrained traditional values of medical authority over managerial objectives [269]. Attitudes among different groups of workers suggest that there may be differences in the acceptability and *'buy-in'* to TQM initiatives and that there may be hard-to-reach groups who are resistant to change efforts such as those who have been employed by the same organisation for a long period of time.

In other academic literature it is reported that failures of TQM in the field of health care are due, in part, to the lack of a context specific model [280] and the difficulty in removing cultural obstacles to the approach [272]. Other reports suggest that a high percentage of TQM cases are unsuccessful [273]. TQM takes a top down approach and requires initiatives to be implemented by management, often as part of an organisation-wide strategy [272]. Hansson describes the application of TQM in the health context as an ideological clash between medical and managerial aspects of quality, stating that the paradigm shift towards a customer-oriented focus on service quality is likely to cause upheaval as it involves a shift from the medico-professional hegemony historically present in health services [281]. It is difficult to draw firm conclusions on TQM from the literature; on one hand case studies appear to present an overwhelmingly positive portrayal of the methodology, but commentaries removed from the immediate organisational context are in some cases fairly damning of TQM. This may be further confounded by the difficulties arriving at a firm definition of TQM [273] or the claim that organisational studies with positive findings are much more likely to be published than those that with poorer results [282].

3.4 Business Process Reengineering

Business Process Reengineering (BPR) is a radical approach to change management. BPR can be seen as being on the opposite end of the spectrum to TQM in that TQM operates by making changes based on *improvement* of current processes but BPR aims to *re-think* processes by focusing on desired outcomes. Dixon et al describe BPR as beginning with a 'clean sheet' and stated that the BPR can be thought of as changing the 'improvement trajectory'[283].

BPR involves 4 steps [269]:

1. Preparing the organisation by defining objectives and communicating the purpose of reengineering,
2. Define key performance objectives and fundamentally rethink work processes,

3. Implement new processes,
4. Reinforce change.

Kohn states that there are four objectives of BPR: (i) Reduce cost, (ii) increase revenue, (iii) improve quality of service and (iv) reduce risk [284].

Despite suggestion that BPR is not limited to the use of new technology [285], this does appear to be the focus of the majority of studies described in the literature [286, 287] several of which incorporate complex modeling techniques [288, 289].

The literature on BPR in the health field does not portray BPR as inherently negative but highlights several areas in which the methodology may be lacking. Although most frequently being associated with the introduction of IT and the associated process changes required for implementation to be effective, the use of BPR for changing workforce practice has also been reported [285]. Similarly to TQM the originality of BPR has been questioned in the literature as it resembles many methodologies which have gone before it [285]. BPR has been applied to different extents, encompassing a whole organisation [285] or a single department [289]. The literature presents a variety of levels of detail given by the authors, making it difficult to compare one study to another. Like TQM, BPR appears to involve a top-down, management led approach [283]. While it is claimed that BPR is used extensively in health service improvement, it may more often be the case that only certain aspects of the model have been adopted [269, 290]. Iles and Sutherland report that the principles of BPR have been incongruent with the traditions, culture and politics within the NHS which has led to limited success of this model [269]. Wilson suggests that technology driven approaches will generally ignore cultural issues and therefore will meet resistance to change [291]. Overwhelmingly both case-study and wider literature suggests that BPR can fail to be context sensitive and fail to address the most difficult factor to change; organisational culture [282].

3.5 Soft Systems Methodology

The principle behind Soft Systems Methodology (SSM) is the systematic investigation of a complex problem [292]. SSM is a form of action research characterized by the use of conceptual models to represent relevant worldviews. These models are then used as sources of information to structure discussions about change within organisations. SSM is an attempt to take aspects of systematic approaches of enquiry, traditionally associated with manufacturing processes, and use these in situations involving social interactions. SSM incorporates theory about how organisations work and places emphasis on the social context of an organisation. This theory suggests that change is more likely to be successful if it takes into account the worldviews in existence in a situation and hence render these changes culturally acceptable. In SSM, the use of *rich pictures* is encouraged in order to represent problems diagrammatically: These resemble 'mind maps' upon which a methodology user depicts findings using images in order to capture a large amount of information efficiently. One of the ways in which SSM differs from TQM and BPR is that the researcher is viewed as belonging to the situation of interest rather than observing it as an outsider.

While SSM is described as a flexible methodology [293], its application frequently incorporates *learning cycles* consisting of the following four stages:

1. *Finding out*

An initial investigation aimed at gaining a rich understanding of an organisation and its problems.

2. *Model building*

Conceptual models are built in order to prompt discussion at an organisation. These models are hypothetical and do not necessarily represent an activity as it exists.

3. *Structured discussion*

Discussions take place focusing on the conceptual models, comparing these to the current situation and using them to ask questions, namely; 'what could be done better?'

4. *Action to improve*

It is anticipated that the participative discussions are effective in assisting an organisation to arrive at a decision to implement change.

SSM has been used in a variety of different scenarios in the health sector. Indeed the methodology's flexibility is one of the advantages claimed by its creator [294]. While some studies follow the methodology exactly [295-297], others appear to bear little resemblance to the methodology outlined above [298, 299]. Some studies lie on the spectrum between these and have adopted individual aspects of SSM such as rich picture building [299] or conceptual modelling [300]. SSM has been described at different levels of intervention, from literature reviews [300], to project planning and identifying areas for change [301]. What the majority of SSM studies in the health field appear to have in common is that they describe a problem with unclear objectives, or a complex situation. One of the benefits of SSM appears to be that it has been used in order to explore and gain understanding of a situation [302].

3.6 Discussion of choice of Soft Systems Methodology

All three methodologies were of some relevance to the PhD and KTP objectives. As with all problems there could have been a number of ways of approaching this particular study and perhaps there is unlikely to be a single *best* method [292]. Checkland writes that even after conducting an investigation, one cannot make a claim that a particular methodology is *best* because the use of a different methodology might have worked better and conversely, neither can it be said that a methodology is unsuccessful as this could merely be due to incorrect application [303]. In light of a review of the literature it was decided that SSM would be used for the study. This decision was made largely due to the strong emphasis on the

methodology's ability to incorporate a range of worldviews which, in light of the range of attitudes towards EBP highlighted in Chapter 2, appeared to be an important quality. Another advantage of SSM was its apparent cultural sensitivity which did not appear to be present in the other two methodologies which focus largely on structure and process. TQM and BRP were both potentially problematic in that their *top down* approach assumed authority on behalf of the problem solver and, in my position as KTP associate, I did not hold any authority at the organisation. SSM was chosen as an approach as this seemed congruent with the research questions and the role which I held within the organisation. Finally, as Ormerod states, there is an aspect of personal preference involved in choosing a methodology [304]; I was interested in this approach and a member of the KTP team had previously used *systems thinking* in research.

3.7 More detailed description of SSM

The fundamental principle behind SSM is *systems thinking*; a term which appears frequently in relation to introducing change into organisations. Defining a system, Checkland states; '*The core systems idea or concept is that of an adaptive whole (a 'system') which can survive through time by adapting to changes in its environment*' [294](p.7).

The purpose of scientific method is to increase knowledge and understanding by breaking things down into their constituent parts and examining these parts separately [269]. In contrast, systems thinking aims to create a better understanding of the combination and interaction of these parts [269]. Peter Checkland, the founder of SSM, states that one of the main limitations of scientific practice is an assumption that separating a problem into many components will not distort the phenomenon being measured [305]. Interestingly this organisational change methodological debate echoes those presented between pro- and anti-EBM discussions focussing on issues around reductionism discussed in Chapter 1.

Since its inception in the 1950s, systems thinking has developed into its own discipline. With regard to its application to an organisation the following assumptions are important [269]:

- A system is made up of related and interdependent parts, so that any system must be viewed as a whole;
- A system cannot be considered in isolation from its environment;
- A system which is in equilibrium will change only if some type of energy is applied;

People within a system have a view of that system's function and purpose and this may differ between individuals.

On what makes a system *soft* as opposed to *hard*, several important differences exist. Iles and Sutherland report that in an investigation into a hard system, researchers are viewed as external, whereas in soft systems the researcher is part of the environment being examined [269]. Another difference described is that hard systems thinking is appropriate for well-defined problems while soft systems thinking typically address messy or ill structured problems [303]. Checkland claims that the fundamental difference is that the view taken within a hard systems approach is that a situation *contains* a system whereas a soft approach defines the *process of inquiry* as systematic [303].

A philosophical difference underlies hard and soft systems thinking. Early approaches to organisational change contained the view that human beings were able to clearly define goals and achieve an optimised state in reaching these. This view moved towards a *softer* approach in which *sustaining relationships* replaced *goal seeking* and *optimising* became *learning* [294].

Checkland describes this as a shifting of philosophy and sociology from positivism and functionalism towards phenomenology and interpretive sociology [294, 305].

Proponents of soft system thinking do not deny the value of a harder approach but suggest that different situations require different types of systems thinking. Avison and Taylor define five types of problem [306]:

Class One: *Well-structured problem situations with a well-defined problem and clear requirements.*

Class Two: *Well-structured problem situation with clear objectives but uncertain user requirements.*

Class Three: *Unstructured problem situation with unclear objectives.*

Class Four: *Situations where there is a high user interaction with the system.*

Class Five: *Complex problem situations, combining two or more of classes 1-4, requiring a contingency approach to information systems development.*

Avison and Taylor report that clearly defined *Class One* problems are suited to traditional systems approaches but that unstructured problems are likely to require a softer approach [292].

The development of Soft Systems Methodology (SSM) has taken place in the decades following an acclaimed paper published by Peter Checkland in 1972 [307]. SSM originated from the field of action research in which Checkland worked at Lancaster University, carrying out organisation based studies. SSM was developed in order to address the perceived shortfall of Systems Theory in its application to real world problems. Checkland reported that the rigid structures of classic systems thinking failed to take into account the complex nature of situations occurring in the real world and that even the process of defining 'the problem' was not a simple one. During the use of SSM by its developers, one of the issues which arose was the need for organisational change efforts to take into account the cultural, social and political environment in which they take place. SSM was felt to be important by its developers due to the fact that many real world problems are ill-structured or under-defined [308].

SSM is a methodology rather than a set of methods. Checkland writes that because in the real world nothing happens twice in exactly the same way, what is needed is not a set of

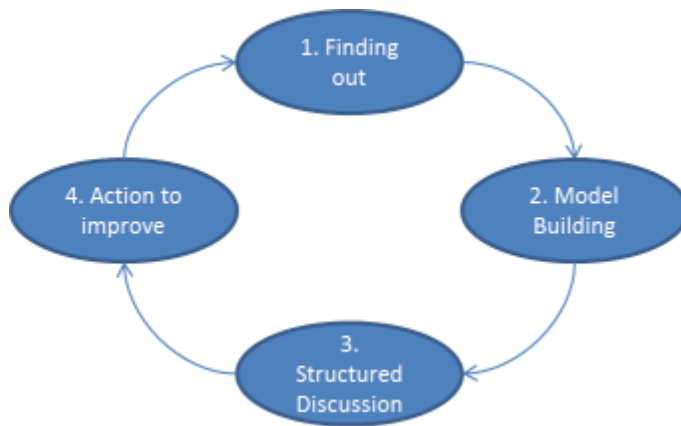
techniques to be followed rigidly but a set of principles within which to work and adapt for use in any situation [294]. Indeed Checkland states that 'The *mouldability* by a *particular user* in a *particular situation* is the point of the methodology' [303](p.58). Therefore while an SSM study will make use of a set of guidelines, it will require integration with other methods for data collection and analysis [291]. Because of this loose framework, many studies which make use of Soft Systems Methodology appear very different to one another in the processes they incorporate. This flexibility may have a downside as, according to Checkland, there are many examples of researchers claiming to make use of SSM but failing to grasp its core concepts [294, 309].

SSM has changed shape over the four decades since its conception and has been applied in many different contexts. A large amount of primary SSM literature has been written solely or co-authored by Peter Checkland. The development of SSM has been presented in a number of key texts [293, 294, 303, 305, 310].

SSM incorporates a philosophy about human activity and how organisations function but also provides a practical set of steps which can be used to structure a study. These steps follow a cyclic process, representing the need for continued learning.

The following is a description of the four main stages in a *Soft Systems Learning Cycle* (Figure 11). While this depiction suggests sequential activities, Checkland advises that this is not always the case, and in practice these activities are more likely to be used in parallel with each other.

Figure 11 Four main activities (adapted from [294]).



Stage 1. Finding out

This initial stage consists of a detailed examination of the problem being investigated. In SSM the term *problem* is avoided as this is felt to imply that a curative *solution* exists whereas the aim of the methodology is to create an improvement in a situation rather than an end-state of optimisation. Instead the term *problematic situation* is favoured. The main aim of this stage is to gain an understanding of the situation and the individuals within it. The following activities are suggested as useful procedures in this stage of the investigation.

Rich Pictures

As their name suggests, these are devices for representing a situation. Visual representations are described by Checkland as being more suited than prose at representing a complex situation. Wilson draws a likeness to an Ordnance Survey Map which allows a great deal of information to be contained within a relatively small area in comparison to representing this textually [291]. There is no formal method for producing rich pictures, but some of the details commonly featured are:

- *Existing stakeholders,*
- *Relationships between stakeholders,*
- *Opinions held by different parties,*
- *Agreement or disagreement between groups.*

The use of rich pictures throughout the project, at different stages, is recommended and is reportedly an important part of representing what is known about the problematic situation [291, 294]. This picture is unlikely to be static but will change and evolve throughout an investigation, becoming richer as more is found out and understood. While not over-emphasising the process of drawing, Checkland suggests the use of hand-drawn images in order to convey the dynamic, present, organic, human and natural qualities of the methodology in contrast to the hard lines and permanence of traditional systems diagrams [303]. The overall aim of the rich picture is to represent the finding out stage. Another contributor to the development of SSM, Brian Wilson, warns that a rich picture can contain sensitive information including personal and political messages and therefore should not find its way into the public domain [291].

Analysis One, Two and Three

Although a structured approach to collecting data is not included in SSM, it is suggested that certain information is included in the data collection phase. Checkland refers to this data as belonging to three separate streams which are referred to as Analyses One, Two and Three [305]:

Analysis One

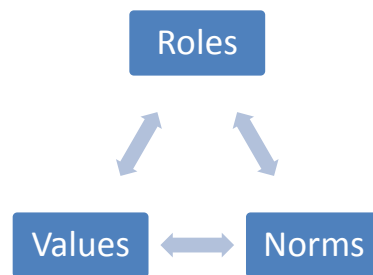
It is considered important to gather information about people who are involved in the problematic situation. This includes the following three roles:

- (i) 'Client' - The person or persons who caused the intervention to take place.
- (ii) 'Problem solver' - Whoever wishes to do something about the situation.
- (iii) 'Problem owner' - Anyone affected by the problem.

Analysis Two

Although, as discussed in Chapter 2, culture may be a difficult entity to measure, Checkland suggests that an attempt to consider local culture is vital to the success of any subsequent intervention. The suggested analysis two is based on attempting to understand the interaction between three elements which is referred to as a *social system* (Figure 12)[294].

Figure 12 A social system (based on [294])



SSM takes a *social system* to be an interaction between these three elements.

- Roles – these may be formal and defined by the organisation such as *Head of department* or *secretary* or include informal roles based on behaviour such as *office joker* or *gossip*.
- Norms – these are behaviours expected of individuals occupying roles.
- Values – these are criteria used to judge the performance of individuals within different roles [294].

Analysis Three

Analysis three focuses on how power is owned and used within a situation, whether this is based on official hierarchy or other factors such as social status or power relating to possessing knowledge or information.

These three streams of data are particularly pertinent to the research questions in this study and link closely to literature on organisational culture.

Stage 2. Conceptual Model Building

One of the characteristic aspects of SSM is the construction of *conceptual models* in order to explore different worldviews within a situation. SSM is based on the assumption that within any situation there will be people *acting purposefully*. These people do not necessarily have the same purpose but act in a way which makes sense to them. The fact that people have developed particular ways of making sense of a situation and acting within it is one of the key ideas in SSM and this internalised model of the world is referred to as an individual's *worldview*. This conceptual model building stage of the methodology is concerned with making these perceptions explicit so that they can be compared to the real world situation.

Based on experience of working in different situations, Checkland concluded that all of these had in common the fact that they involved people attempting to take purposeful action aimed at improving a situation. Once the purpose of the action is defined, then a description of how that purpose can be fulfilled can be put together as a system referred to as a *Human Activity System*. An important point is that these systems are not descriptions of the real world but rather an individual worldview within it. On many occasions Checkland criticises users of SSM for confusing Human Activity Systems with real world systems and hence failing to grasp the essence of SSM, stating that this is a greatly misunderstood aspect in much of the secondary literature [311].

Selecting relevant systems

In the *finding out* process there may be a large number of different worldviews expressed. It may not be appropriate to model all of these systems, partly due to resource constraints but also there may be some which are less relevant and helpful to the problematical situation. This is an area of SSM in which it is necessary that practitioners make subjective judgements based on which systems they feel may provide helpful ways of regarding the problematical situation [309]. Checkland reports that many researchers have difficulties deciding how to select which system may be useful, but suggests that this is an iterative process in which the user is free to discard any which turn out not to be helpful and select another system.

Naming relevant systems

In SSM, particular attention is paid to the formulation of the name of a relevant system, this is known as the *Root Definition* and needs to contain enough information for a system to be built from it. Guidelines have been developed to assist with constructing this *Root Definition*.

All systems are constructed to *do* something, this action is referred to as the *transformational process* (T) and this will be meaningful in relation to a particular *worldview* (W). Also present are people who will benefit from T; the *customers* (C), someone carrying out T; *actors* (A) there will also be *owners* (O) who could stop T and *environmental constraints* (E) outside the system. This produces the mnemonic CATWOE. Wilson and Checkland both state that root definitions do not have to contain all of these elements but it is advised that omission should be based on a conscious decision and a defensible reason [291, 309].

Wilson writes that while a model is theoretically built based on a *pure, declared worldview* this will, in practice, never exist in isolation as an individual will not hold 100% commitment to any one view, but rather will hold a range of views.

These worldviews may be expressed and imply systems at different levels of abstraction. For example, a view expressing a practical activity which should be carried out could take a simple

form e.g. *a system to invest spare cash*, others may occur at a higher level of abstraction for example naming a role which a department should be taking:

'a system which, in response to the continuous need for higher quality of personnel for servicing and managing the manufacturing operations of the Company, and a need for manufacturing expertise in other functions, develops and trains people and provides experience in a cost-effective manner.' (based on [291](p.250))

Building a conceptual model

Based on the *Root Definition*, the *Conceptual Model* is put together. This is a system which represents the activities necessary in order to perform the job outlined in the *Root Definition*. Similarly to the selection of the systems, the building of a conceptual model is open to a certain amount of subjectivity although the main requirement is that this is put together logically and that the final system is defensible. Wilson emphasises that the logic employed is not highly precise, but rather logic based on a *generic real-world rationale* and, as such, there will be more than one way of putting together a model [291]. A conceptual model assembles the minimum activities necessary to meet requirements of the root definition (and CATWOE). Checkland offers a guideline that models should contain 7+/- 2 activities [309] (this is based on the work of Miller who suggests that the human brain can cope with this number of concepts [312]). If required, each activity in the model can be used to create its own *Root Definition*.

This information is perhaps clarified in the form of the following example.

Checkland gives the example of the following conceptual model (Figure 13) based on the *Root Definition*:

'A householder-owned and manned system to paint a garden fence, by conventional hand painting, in keeping with the overall decoration scheme of the property, in order to enhance the visual appearance of the property.' [309](p.37)

C - Householder

A - householder

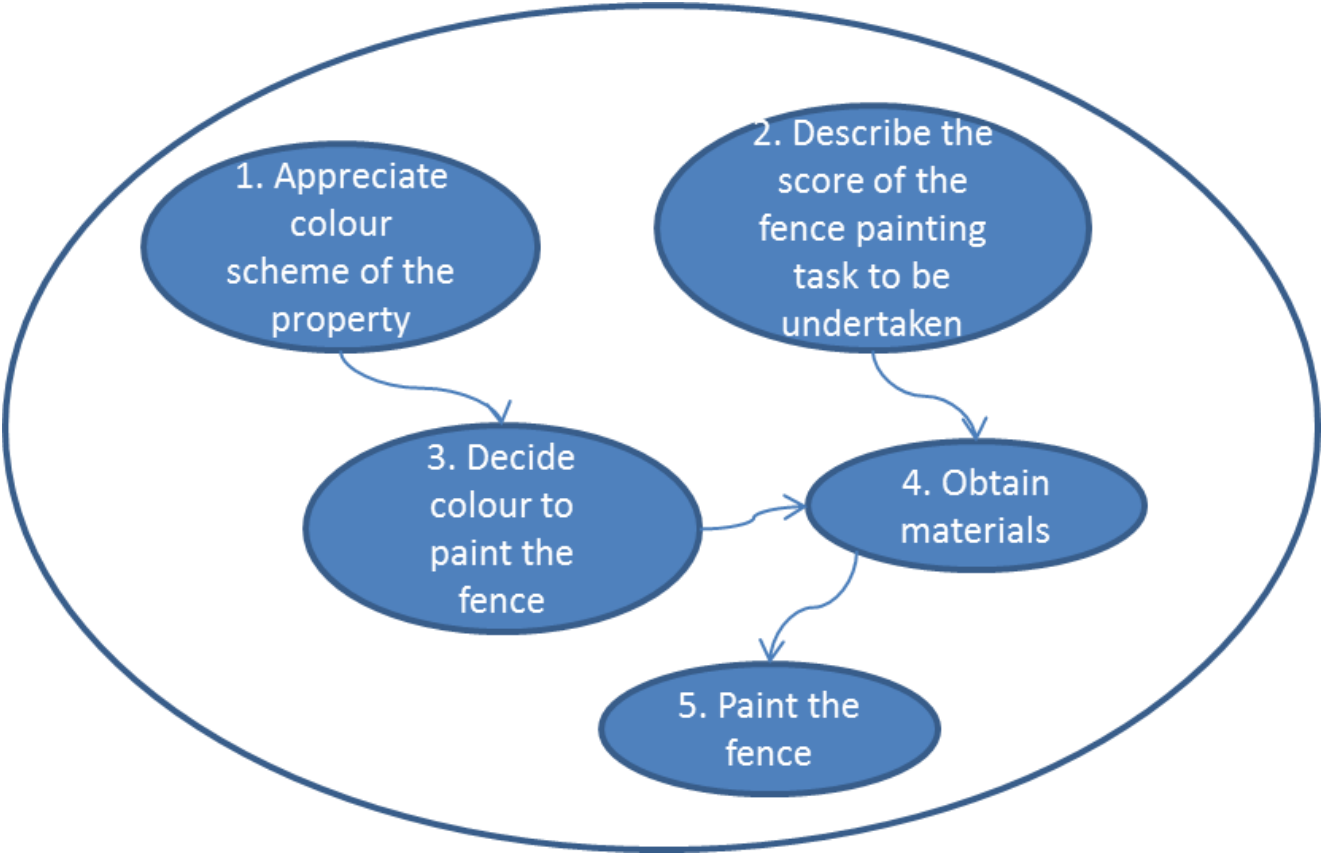
T – unpainted fence → painted fence meeting the criterion in the definition

W – amateur painting can enhance the appearance

O - householder

E – hand painting

Figure 13 A conceptual model [309]

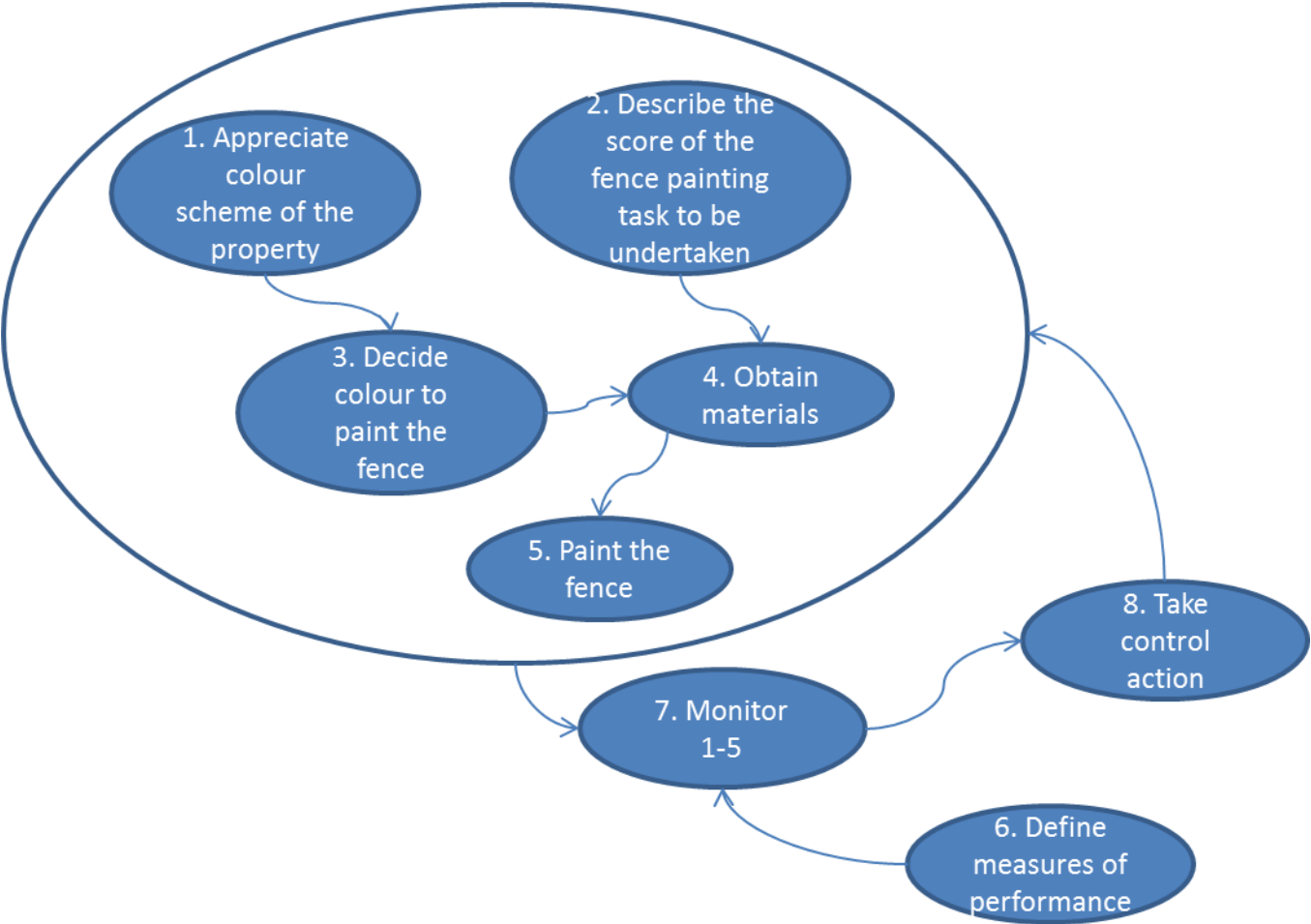


To be *a system* this process must possess a property which will enable it to adapt to survive in a changing environment therefore monitoring and control activities are added. The ability to monitor the system is based on the existence of measures of performance, Checkland recommends the use of the '3 Es' [309]:

- (i) *Efficacy - does it work?*
- (ii) *Efficiency - does the output require an appropriate level of resources?*
- (iii) *Effectiveness - does the system meet a longer-term goal?*

Inclusion of this monitoring system gives the final model (Figure 14).

Figure 14 A system to paint a fence [309]



Stage 3. Structured Discussions

Although the extensive guidelines and process of building conceptual models appears complex, the rationale behind it is a simple one. The conceptual models display an activity based on a single worldview. The purpose of these models is to provide useful ways of looking at a situation and structure discussions which could lead to a better understanding and, ultimately, action to improve this situation. On the format which the *structured discussion* stage of the SSM cycle should take, Checkland states that it is impossible to generalise [309], but rather this discussion will take the most appropriate form for the particular situation (this will be informed by the *finding out* stage of the investigation). Examples are given of debates which took place with a single company representative and another which took place in the presence of 600 department members. Wilson places an emphasis on a structured exploration suggesting that a discussion may not be necessary at all [291]. Checkland suggests that typically a matrix is produced which asks questions of the activities contained within the models (Figure 15).

Figure 15 Questions to ask of the problematic situation (adapted from [309])

Activity	Done in real world	Who by	Desirable?	Feasible
Appreciate colour scheme of property	No	House-owner	Yes	Yes
Decide on scope of fence painting task	Yes	House-owner	Yes	Yes
Decide on colour to paint fence	No	House-owner	Yes	Yes

Stage 4. Action to improve

It is anticipated that the models will initiate discussion within the organisation and lead to a greater understanding of the problem situation. This deepened understanding may then lead to a decision on how to improve a situation. Checkland emphasises that this is unlikely to be a case of a consensus being reached but rather an accommodation; some action which everyone in the situation can live with [303].

3.8 Criticism of SSM

Because SSM has been used in such a variety of ways it is sometimes challenging to look at an individual study and immediately recognise it as having used SSM. There is perhaps some risk with such a flexible methodology that people claim to be using it without fully understanding the principles. Checkland devotes a whole section of one of his books referring to authors that have made misguided attempts or unfounded claims to have used SSM [309]. On one occasion

Checkland refers to a 200 word passage containing almost 20 errors [294]. While responsibility for the use, or misuse, of SSM could be viewed as resting within the responsibility of the user, Wilson, in reference to the modelling of Human Activity Systems, writes that their treatment in early books was superficial and inadequate [291]. Frequent misunderstanding of SSM principles suggests that there are gaps in the primary literature, and a novice user may be at a loss of where else to seek answers with so much criticism being directed at secondary literature.

Although Checkland claims that SSM is mature, it has been suggested that the elements outside the *finding out* and *model building* phases are less developed and offer limited guidance to a user [313].

The principles on which SSM is developed rely on the premise that open debate is encouraged or permitted within organisations. Some suggest that this is overly optimistic and Underwood suggests that SSM assumptions which are more in line with middle-class or academic values than those of a typical workplace [314].

It has been suggested by some that SSM is likely to result in conventional and regulatory changes rather than radical ones [315, 316]. This is disputed by Checkland [317] who claims that although this can be true, this is an attribute of the user rather than the methodology.

While Checkland takes into account and places a great deal of importance on an individual's *Worldview*, it has been argued that SSM takes these views at face value and does not delve further into how these have been developed and therefore how they might be changed [315, 318].

Criticism also comes by way of suggestion that the process of Conceptual Model building cannot be an objective activity as suggested by Checkland. Schregenberger argues that a user of SSM must have gained knowledge of the relevant system prior to reaching the modelling stage and it is impossible to cast this knowledge aside [319]. Schregenberger also believes that the criteria for

deciding if one conceptual model is better than another is not available in the SSM literature which leads to difficulties with the selection of a relevant system [319].

3.9 Justification of choosing SSM for this study

In light of the above discussion of the requirements of a methodology, SSM was felt to be appropriate for several reasons. The 'action research' nature of SSM was congruent with the strategies which had been designed as part of the KTP, such as the researcher as change agent and the existence of a change management group at the charity¹. This was particularly appropriate with reference to the first research question which was concerned with what methods could be introduced to make a charity's information service more evidence-based.

One of the major philosophical underpinnings of SSM was the concept that an organisation is composed of individuals who are acting in a particular way due to their worldviews. This was relevant to the reviewed literature on CAM and EBM, which had suggested a large number of conflicting views were present. Similarly the methodology's emphasis on the need to introduce changes while being aware of the organisation's culture was congruent with the second research question, focusing on the impact of organisational culture on the introduction of evidence.

Another important factor in the methodology was that the researcher was regarded as part of the situation being researched; this fitted with the fact that as well as being a researcher I was a full-time member of staff at the charity.

The following section will present the role SSM played in guiding the shape of this research.

3.10 Methods

While SSM provided a framework with which to structure the research it did not provide practical guidance on how to collect or analyse data. Similarly to the selection of a methodology, these methods would be dictated both by the context of knowledge transfer and the aims of this research.

The SSM concept of learning cycles was used to guide data collection. This meant that data was collected alongside the knowledge transfer process of introducing evidence-based changes to the information service.

Measurement of culture

As discussed in the literature review, there are multiple approaches to the examination of organisational culture. Some advocate quantitative examination of organisational culture and numerous tools have been developed for this purpose. In a systematic review of quantitative measurements of culture, Scott et al located 84 different methods which they described as approaching measurement from a typological or a dimensional approach [320]. Some of these instruments are very specific and have been designed with particular groups in mind, for example the Nursing Unit Cultural Assessment Tool [321]. Alongside advocates of standardised measures of culture, there are numerous proponents of qualitative methods who suggest that techniques such as observation and interviewing are more appropriate [41, 105]. In addition to qualitative methods fitting with how organisational culture has been defined in the literature, the lack of literature about culture and complementary medicine would also suggest qualitative methods to be suitable for this study.

While formal data collection may be one way of collecting information about culture, some suggest that a difficulty still exists in gathering information which is more than the projected

image of an organisation. This phenomenon has been referred to as the 'public and private faces' of individuals [322]. Schein suggests that it is necessary to gather data based on observation of whether *espoused values* account for how people behave in reality [41]. In this respect, I was well placed to observe whether this was the case. Therefore in addition to more formal data collection methods such as interviews, I kept a reflective diary which documented my experience of attempting to introduce evidence-based information practices. In Chapter 2 I outlined several models of culture stated that I would draw on both Schein's components of organisational culture alongside his three-level model [41] and Kitson, Harvey and McCormack's PARIHS framework [123] to guide data collection and discussion. In particular, attention was paid to the components of organisational culture outlined by Schein [41] (summarised in Chapter 2): Observed behavioural regularities when people interact, Group norms, Espoused values, Formal philosophy, Rules of the game, Climate, Embedded skills, Habits of thinking, mental models, and linguistic paradigms, Shared meanings, Root metaphors or integrating symbols and Formal rituals and celebrations. In discussing the findings, Schein's model of culture was drawn on in order to consider the existence and interaction between its three components. For example attention was paid to whether observed behaviour at the organisation was consistent with people's espoused values and the underlying values behind behaviours and attitudes were considered. Throughout analysis of the results, findings were discussed with reference to the PARIHS framework and additional arguments of necessary attributes of an evidence based culture put forward by Crites [131], Grey [132], Senge [130], and Davies and Nutley [129].

Reflective approach

Although there is much written on the value of reflective research, provision of practical instruction is sparse. Guidelines were sought from the field of ethnography where Emerson, Fretz and Shaw offer detailed direction on the production of field notes [323], and this seemed to be the

most appropriate approach to take. Attempts were made to adhere to guidelines of good field note writing practice although the *microscopic* level of detail advised was not maintained throughout as this was not the primary data collection method.

The field notes I took were intended to capture the process of service development and feeding back information to the charity as well as document issues which impacted work undertaken and were relevant to the research questions. A reflective diary was kept throughout the field work consisting of hand written, typed and audio recorded entries. Entries were made on a daily basis, where possible soon after an event of interest. Although personal feelings were recorded in the diary, efforts were made to separate events from personal, highlighted as an important aspect of ethnographic research [323].

Additionally, documents from several sources such as e-mails, policy documents, information materials, agendas and minutes from meetings that were collected over the 30 month duration of the project and are referenced throughout the thesis in order to provide context and support findings.

Feasibility of changes

The second research question which focussed on possible measures which could be taken by a third sector organisation to make its information service more evidenced based was closely linked to the outputs of the knowledge transfer process, and therefore data would consist of an evaluation of the practical measures which it had been possible to implement during the KTP.

Guided by SSM, the research methods were incorporated within learning cycles. A more detailed rationale for individual data collection and analysis methods is reserved for chapters representing individual learning cycles. Although data collection was planned, it was the subsequent three

stages of the learning cycles where flexibility was important, as organisational constraints became clear and impacted on how research findings could be practically implemented.

Achieving rigour

Qualitative research is sometimes subject to criticism for a lack of rigour and this may be particularly pronounced in the health field with its quantitative research tradition [324].

Throughout this study efforts were made to ensure that data gathering and analysis was as rigorous as possible. While specific details about data collection are included within individual learning cycles in chapter 4, below is a summary of measures taken to ensure rigour.

Sampling

Purposive sampling was used at several points. This included sampling websites, printed information sheets, service-users and members of staff. The aim of this was to reflect the diversity of the population or documents of interest.

Triangulation

In order to gain perspective on the organisation as a whole, several sources of data were used. Documents were analysed, staff were interviewed and detailed field notes kept during the whole research process. This multi-faceted approach ensured that there was not an over-reliance on any one source of data and allowed comparison between sources, for example, it was possible to comment on whether staff interviewees description of their information practices was compatible with the information products produced my own experience of working at the charity.

Multi-participant coding

All data collected was presented and discussed in its raw form with both the KTP team and members of staff at the charity¹. The service-user interviews, which consisted of less structured questions, were coded by myself and a member of the Information Department and differences were discussed.

Respondent validation

Where accounts of service-user experiences were produced as a form of information on the charity's website, these were sent to the individuals for comment to ensure that they contained an accurate representation of what they had said.

Being explicit about data analysis techniques

Throughout this thesis I have tried to provide an accurate and detailed account of the processes I went through so that readers can appreciate the methodology's positive and negative attributes.

Although the above methods may help to achieve rigour, Barbour emphasises that these '*technical fixes*' themselves do not guarantee rigour if applied outside a thorough understanding of the rationale and assumptions behind qualitative research[325].

Stage 1. Finding out

The following represents the *finding out* aspect of each of the SSM learning cycles:

1) *Develop quality criteria for assessment of web based information*

In order to provide the organisation with a method of ensuring good quality information and links to good quality information on their website, bibliographic databases, search engines, and citation searches were used to identify online health information evaluation instruments. These instruments were then tested and rated in order to identify a *best* instrument. This instrument was then applied to the charity's website and recommendations were made as to how the charity's website could be improved.

2) *Develop quality criteria for printed information*

A system of information categorisation was developed in order to classify the different types of information that the charity provided to its service users. Database searches were carried out to identify appropriate criteria for rating the quality of these different categories of printed information and checklists were produced which could be applied to different categories of information.

3) *Assessment of information needs of¹ staff*

Structured questionnaires were developed and a convenience sample of staff at the charity was interviewed face to face. These interviews aimed to gather information about current practice with regards to the information which staff used to inform themselves and service-users. Notes were taken during interviews and these were imported in NVIVO. A content analysis was used to analyse interview data.

4) *Assessment of information needs of¹ service users.*

Semi structured interviews were conducted with a purposive sample of the charity's service users in order to establish information needs and thoughts on the role of evidence in CAM information. This data was analysed thematically in order to inform the charity how its information could be improved from a user's perspective.

Stage 2. Conceptual model building

It was planned that conceptual models would be built within the change management group based on the findings of the above *finding out* stages using the guidelines outlined in the SSM literature.

Stage 3. Structured discussions

It was anticipated that models based on findings from stage 1 and conceptual models built in Stage 2 would structure discussions within the change management group.

Stage 4. Action to improve

It was expected that changes to make the charity's information service more evidence-based would be planned and implemented by the change management group and this would lead to improvements which were acceptable to the organisation.

Ethical Issues

Beauchamp and Childress suggest that, in order for research to be ethical, it should adhere to the following four principles: (i) *Respect for autonomy*, (ii) *Nonmaleficence*, (iii) *Beneficence* and (iv) *Justice* [326]. The nature and setting of this research gave rise to several ethical issues which had the potential to affect different groups of stakeholders and the organisation as a whole. The above four principles were considered at length during all of the work undertaken as part of this study. These are discussed below with reference to the different groups of stakeholders involved.

Organisation

¹ Research has the potential to damage the reputation of an organisation. This is not to imply that findings should be withheld from the public domain, however, in areas such as CAM, in which tensions already exist, it was important to be aware that publication of results can lead to sensationalism or exaggeration in the press. I was also aware that the research questions that this work focused on represented observation of a small part of the organisation's work and therefore data gathered did not represent a complete picture of the organisation. With these issues considered, all communications such as attendance at conferences were discussed with the KTP team and senior managers at the charity prior to attendance. The purpose of this was not one of censorship but rather an attempt to ensure that the charity was fairly portrayed externally. Related to the issue of publicity is transparency in reporting results. Although some qualitative researchers choose not to report frequency of responses, in the interviews reported in this thesis the frequency of a particular response is reported in order that a sense of proportion is gained by the reader. Finally, the decision was made to request a confidential submission for a period of two years¹. The rationale for this was that this thesis would be published after the period of organisational change which it describes and therefore it is clear that changes may have happened subsequently.

In line with the Beneficence category, the action research nature of this study meant that the organisation received help in moving towards objectives it had set out itself.

A further issue was the possibility that procedures went against existing laws or regulations. For example the 1939 Cancer Act restricts claims that can be made by non-medical professionals

about claims of treating or curing cancer and if such claims were being made by individuals at the charity I would have a responsibility to report these to appropriate authorities. If this issue were to arise, initially my supervision team would be informed followed by the Faculty of Health, Education and Society ethics committee who had granted approval for this study.

Service Users

In research, people with cancer are generally considered a vulnerable group. Therefore it is important that consideration is given to ethical issues involving this group of individuals. Of primary importance is that people getting involved with the research are making an informed decision based upon the information they were given and therefore attention was paid to patient information materials provided. These were circulated to the study team and senior managers at the charity for comment prior to being given out to service users. In addition to this, potential participants were given opportunity to ask questions about the study and, if they changed their mind, were informed that they could withdraw at any time with no changes in the care they would receive from the charity.

Although interviews with service-users were generally structured, the nature of the topic led to the possibility that issues of patient care would be raised. It was agreed that I would raise any issues of concern with a senior member of the charity. Patients would also be signposted to further sources of information.

Another possibility arising from the subject of CAM was that people may be using treatments as an alternative to conventional treatments, potentially against the advice of health professionals. In these cases it would be important that I maintained a non-judgemental approach to data collection and was respectful of people's decisions.

The nature of the data collected, sometimes shortly after a diagnosis of cancer, led to the possibility that service-users would become upset during interviews. It was important that I acted appropriately during this and I attended a qualitative research methods course which included

interviewing technique workshops. Service-users were signposted to sources of information and support following interviews. Additionally a clear complaints procedure was included in the Patient Information Sheet if participants wished to voice any concerns about the interview process.

In order that data remained confidential, all data was anonymised before storage and publication. Any identifiable data was kept on a secure server at the organisation with additional password encryption.

Staff

Similar to service-user interviews, it was important to ensure personal autonomy and the same precautions were taken to reassure staff that interviews were optional and that they could leave at any time. Additionally, interviews had the potential to expose bad practice at the organisation and it was important that this information was dealt with appropriately.

During interviews and interactions with staff, I hoped that information given would be honest in order to understand difficulties faced and negative attitudes which existed. In order to do this it was important that staff were able to speak freely without fear of negative consequences. Staff were reassured that all data received would be anonymised. When reporting to senior managers, care was taken not to disclose any information which could lead to the identity of participants.

Efforts were also made to respond to staff concerns about expectations as members of a charitable organisation. Following comments that people were expected to attend events unpaid, funding was secured to pay staff for attendance at workshops.

Ethical approval for this study was granted by the Faculty of Health, Education and Society at the University of Plymouth. Approval included permission to conduct interviews with service-users at

the charity¹. An amendment to this approval was granted to allow further interviews to take place with several service users who had been interviewed previously.

3.11 Summary

This chapter has described the process involved in selecting a methodology and methods with which to attempt to answer the research questions outlined in Chapter 1. The context of knowledge transfer was presented as an important factor, alongside the research questions and my role as a researcher, in arriving at the decision to use Soft Systems Methodology. Based on a review of the literature it was felt that this methodology offered compatibility with the research setting and aims. Of particular importance was the methodology's emphasis on the relevance of individual worldview within an organisation and the role of culture in the implementation of change. The interaction of researcher and research environment in SSM was important and this was a major reason for the rejection of both Business Process Reengineering and Total Quality Management as they assumed a level of authority which was not present in this environment. The issue of research methods was also discussed and it was clear that the first research question was closely linked to the practical outcomes of the knowledge transfer process. With reference to the literature reviewed in Chapter 2 it seemed appropriate that qualitative methods of assessing culture were suitable for answering the second research question and as such, SSM learning cycles were designed to gather this data. The advantage of my occupying the dual role of researcher *and* change agent and therefore being in a position to observe the knowledge transfer process was discussed, and it was stated that this would be used as a source of data throughout the research.

Chapter 4. Results

4.1 Introduction to results

The methodology chapter (Chapter 3) has described the origins, philosophical underpinnings, components and planned application of Soft Systems Methodology (SSM) to the research questions. As discussed in primary SSM literature, the flexibility of the methodology was one of the reasons it was selected. The ability to use components of SSM together or in isolation, as required, was considered to be one of the selling points of SSM. This presents challenges in presenting data collection chapters which contain discrepancies between the *textbook* description of the methodology and its application. Prior to the study there were many unknown factors upon which the application of the methodology was dependent and it was necessary to deviate from plans at several stages in the study. Although significant planning was carried out, it was not until I became immersed in the study environment that it became clear which parts of the methodology were culturally acceptable and what changes were feasible. The adaptation of the methods is described throughout the following chapters and is justified with reference to organisational structure, systems and culture. The suitability of the methodology will be discussed in detail in Chapter 5.

Although comprehensive discussion is reserved until Chapter 5, findings from learning cycles are summarised in each of the results sections and related back to previous cycles. These chapters aim to describe the learning process as it occurred, was reflected upon and influenced how subsequent work was undertaken. Although sections are presented in the order in which they commenced, in reality there was overlap, particularly in the *feeding back* stages which were often delayed. A detailed project timeline is included in Appendix 1 for reference. The timeline serves to contextualise the research process within organisational events and describe how the changing organisational structure interacted with the research

process. The timeline is summarised within separate sections in the results chapters. These sections are based on reflective and documentary data and aim to provide context for the learning cycles.

4.2 Website assessment

4.2.1 Background to chapter

This background to the first learning cycle makes reference to the project timeline (Appendix 1) and provides context for the information presented. This data is taken primarily from my field notes but is supported where possible by documentary data such as e-mails or minutes from meetings.

*Induction at charity*¹

New Director¹

I had begun my employment at the same time as one of the charity's directors¹. This was a role the charity which had not been filled for some time¹. The director was responsible for the Information Department (see organisational structure, Appendix 2²) although he had not been in post at the time the KTP application had been submitted. One of the first things the director did was remove the information on the charity's website which referred to therapies not offered by the charity¹. Although it was stated on the website that these were not recommended therapies, the Director felt that even the mention of these would cause unwanted associations between treatments and the charity¹. The first direct impact that the director had on the KTP project was to prevent the formation of the Change Management Group; a key aspect of the methodology as discussed in Chapter 3¹. This had implications for the planned methodology which will be discussed further within the learning cycle chapters.

External consultants¹

There was much reference to an external consultancy¹ within the Information Department. This small company specialised in providing organisations with methods to carry out evidence-based practice and had provided the charity with a systematic method of searching for and appraising the quality of CAM research. This method was being used in the Information Department, and following the development of this methodology, the consultants had run a staff workshop¹. Although there was no formal feedback collected from the workshop, within the Information Department it was acknowledged that this had been a failure and that some of the staff had been resistant to being told about the importance of evidence for CAM. The hope was that the KTP would build on this initiative and provide the charity with practical tools it could use to improve the quality of its information while developing a culture which would be receptive to using evidence-based information.

4.2.2 Introduction to learning cycle

This chapter describes the process of identifying a method of assessing the quality of web-based information on CAM and cancer and subsequently evaluating attempts to apply this in practice at the charity¹. The KTP project plan contained the objective *1.4 Develop a method for assessing the quality of web-based resources on CAM and cancer*. Having examined literature on methods of assessing online information I suggested at a project team meeting that there were three main ways of assessing information:

1. *Codes of conduct: These are sites which adhere to predefined rules and are authorised to display a 'kitemark' by a governing organisation [327].*

2. *Gateways: Gateways are pre-screened collections of sites that have been approved by a governing organisation and deemed to be of suitable quality [328, 329].*
3. *Evaluation instruments: A large number of evaluation instruments have been developed in order to guide consumers or web developers to reliable sources of health information [330-332].*

The information department manager stated that the organisation required a method of ensuring that the information contained on the website was high quality and a way of ensuring that the charity only linked to other websites which were trustworthy¹. It was determined that an evaluation instrument which could be applied to the charity's own and other, linked websites would be the most useful approach for the charity (Project Team Meeting minutes, Appendix 3). The search for an appropriate instrument is presented here, consisting of an assessment of available instruments, followed by a judgment of a *best* instrument for the charity to use. A description of the practical process of attempting to integrate this method into the charity's information practices follows as well as a discussion of how these attempts were influenced by the charity's culture. ¹ As mentioned previously, the planned forum in which the work would be guided, the *Change Management Group* had been prevented from forming by one of the charity's directors, this made it necessary to adopt a more pragmatic approach to feeding back results and making changes at the organisation.

4.2.3 Aims

The aims of this learning cycle were:

- I. To examine whether evaluation instruments would be an effective way to make the charity's information more evidence-based.
- II. To describe the influence of the charity's culture on the process of attempting to apply this method in practice.

4.2.4 Methods

Several stages were involved in the process of searching for and evaluating assessment instruments and feeding results back to the organisation.

1. Evaluation instruments were defined as something that could be used by an Internet user to assess the quality of a website containing health information. Search terms were based on previous literature that had aimed to systematically identify instruments [330-332]. Searches were performed in January 2007, no date restrictions were used but non-English language results were not examined. The terms 'evaluat* OR assess* OR rating OR rat* OR ranking OR rank*OR quality OR criteria AND website* OR world wide web OR Internet' were used to search the databases Medline, AMED, BNI, CINAHL, EMBASE, and PsychInfo. This achieved results of 29,622; 233; 123; 14,859; 8678; and 10,593, respectively. When in advance of 1,000, the most recent results were examined.

In addition the terms 'evaluate OR assess OR rating OR criteria OR quality AND websites OR Internet' were used to search the Internet search engines Google, MSN, Yahoo, and WebCrawler, achieving results of 212,000,000; 25,410,704; 38,400,000; and 28. The first 100 results of each search were examined, with the exception of

Webcrawler (28 results). In addition to these searches, bibliographies of relevant research papers were examined for references. Instruments were selected if they provided users with instructions for assessing the quality of a website containing health information.

2. To locate websites to assess, a search was performed using the Google search engine in January 2007 at the charity¹ and the terms 'complementary (medicine OR therapies) AND breast cancer'; this choice of terms was made to reflect differing CAM terminology [153] and the fact that people breast cancer are a group who report high use of CAM [48]. The first six results were used, because consumers are only likely to view the first few results from a search engine [333]. An additional six websites were selected in order to achieve a sample consisting of websites from a variety of origins.
3. The 12 instruments identified were used to score the 12 websites selected (144 assessments). The sites were given a score using the scoring system for each instrument, which was then converted to a percentage score so that sites could be compared and ranked in order of best to worst.
4. Instruments themselves were assessed in terms of the range of criteria they included. The range of criteria was compared to nine main criteria identified by the Health Information Institute and Consumer Webwatch (HIICRW) in a study of 22 health information rating instruments [334]. Using a website's ranking by each instrument, a Spearman rank correlation was applied, which examined whether the evaluation instruments were in agreement on whether a site scored highly or not. A subjective judgement of usability was then made by producing a list of positives and negatives for each instrument.
5. Statements on the overall best and worst websites were compared to give an illustrative example of the content of these sites.
6. A citation search was performed on Web of Science and Google to examine how widely each instrument is used, as higher numbers of citations indicate that an

instrument is less likely to suffer from the 'short shelf-life' that has been highlighted as an issue in previous studies [330, 335]. Instruments were classified as highly cited (more than 100 citations), medium (10-100 citations) or low (less than 10 citations).

7. The URLs of instruments identified in previous studies were checked to see if they still existed. Instruments were reported to be unavailable if the original URL was not found and a Google search for the instrument did not locate it. The purpose of this search was to get an idea of how frequently instruments went out of existence.
8. Based on the above criteria, an instrument was selected which appeared to be most relevant to the charity's¹ requirements.
9. This instrument was applied to the organisation's¹ website in order to find out if there were any changes that could be made to achieve a higher score.
10. A report was produced by the KTP team and this was circulated to senior management via e-mail. Following circulation, I requested meetings with members of staff responsible for the charity's website. Reflective notes were made and documentary evidence was collected throughout the data collection and feeding back process to describe the effect of the charity's culture on the process of attempts to implement changes from this learning cycle.

4.2.5 Results

Thirty-nine instruments were identified, of which 12 met the inclusion criteria of providing objective criteria that users could apply to online health information (Table 2). The reasons for exclusion of the other 27 instruments were: A consumer could not apply the instrument without further knowledge (e.g., "Is the information written by reputable authors?"), Scoring details were unavailable (e.g., the instructions said to score each criterion on a scale of 1-5, but no further information was given as to how to allocate a value), Questions were not objective (e.g., "Are the graphics attractive?"), Instrument was not designed specifically for health information, Questions were open ended (e.g., "What are the author's qualifications?"),

Instrument took the role of a tutorial that gave tips on how to find reliable health information on the Internet but was not applicable as an instrument.

Table 2 Twelve assessment instruments showing how they are scored, researcher assessment of comprehensiveness and ease of use.

Tool	Method of Scoring	No. Elements	Comprehensiveness (HIICRW criteria)										Researcher assessment
			Content Relevance	Content Accessibility	Content Selection	Content Validity	Content interchange	Site Transparency	Links	Quality assurance	Safeguards	Total No. criteria	Ease of use
WEB FEET HEALTH Collection Criteria for Site Selection (Webfeet) [336]	24 statements to be agreed or disagreed with: Score Range 0-24	24	Y	Y	Y	Y	N	Y	Y	N	Y	7	+ Straightforward Questions. - Time consuming to apply.
HONcode principles (Honcode) [327]	8 desirable properties of sites containing health information: Score Range 0-8	8	Y	N	N	Y	N	Y	N	N	Y	4	+ Short Tool, quick to apply. + Each element includes guidelines.
Emory University School of Public Health— Health-Related Web Site Evaluation Form (Emory) [337]	36 questions about the site which gain differing amounts of points depending on whether they are disagreed with (+1), agreed with (+2) or N/A (0): Score Range 0–72 although total varies if questions are not relevant to site	36	Y	Y	Y	Y	N	Y	Y	Y	N	7	+ Interpretation of score. - Time consuming.
University of Michigan— Website Evaluation Checklist (Michigan)[338]	43 questions, each weighted and has a selection of answers which give a variety of positive and negative scores: Score Range: –80	43	Y	Y	Y	Y	N	Y	Y	N	N	6	+ Printable rating form. + Interpretation of score. - Time consuming. - Complex scoring system.
Kellogg Library Criteria (University of Dalhousie) (Kellogg) [339]	31 questions and statements for the user to agree or disagree with: Score Range: 0–30	31	Y	Y	Y	Y	N	Y	Y	Y	Y	8	+ Simple questions straightforward to use. - Time consuming.
DISCERN - Quality Criteria for Consumer Health Information (Discern) [340]	16 questions which each have a 5-point visual analogue scale covering answers from 'No' to 'Yes'. Score Range:16–80	16	Y	N	Y	Y	Y	Y	N	N	N	5	+ Explanation of criteria. + Interpretation of score. - Answers on a visual analogue scale more difficult/ time consuming to answer.
NCCAM CAM Basics (NCCAM) [341]	10 questions followed by an explanation of how to answer each one. Score Range: 0–10	10	Y	N	Y	N	N	Y	Y	Y	Y	6	+ Clear guidance of how to use criteria. - No scoring system.
U.S. Pharmacist Tool (Pharm) [342]	16 questions with Yes/No answers. Score Range: 0–15	16	Y	Y	N	Y	N	Y	Y	Y	N	6	+ Easy to apply. - No scoring system.
Minervalidation tool (Minerv) [343]	A semi-automated tool which requires the URL of the site being assessed. Drop down menus to answer questions of content and usability, a rating is automatically calculated. Score Range: 0–100%	9	Y	Y	Y	N	N	Y	N	Y	N	5	+ Automated usability check. + Drop down menus, fast to use. + Interpretation of score.
Nicoll, L.H. (Authors' Guidelines) (Nicoll) [344]	A mnemonic (PLEASED) which represents Yes/No questions followed by author justification of the importance of each. Score Range: 0-9	7	Y	Y	N	Y	N	Y	Y	N	N	5	+ Quick to use. + Explanation of criteria. - No scoring system.
Silberg, Lundberg and Mussachio(Authors' Guidelines) (Silberg) [345]	4 items in checklist of authors' 'Core Standard' which sites containing health information should meet.	4	N	N	Y	Y	N	Y	N	N	N	3	+ Quick to apply. - Does not assess aspects unique to internet information.

	Score Range: 0–4												
Sandvik score (Sandvik) [346]	7 questions with 3 options which achieve scores of 0–2. Score Range: 0–14	7	N	Y	N	Y	N	Y	N	N	N	3	+ Quick to apply. + Simple scoring system.

Of the 12 websites purposively sampled for evaluation by the tools, four were run by UK charities, two sites were selling products, and three were US sites offering cancer treatment. One site was run by a network of health professionals, one site was funded by advertising on its site, and one site was funded by sponsors. Websites sampled are shown in Table 3.

Table 3. Twelve websites on breast care and complementary care selected using inclusion criteria.

Site	Purpose of Site	Reason for Inclusion
www.breastcancercare.org.uk/content.php?page_id=1013 (1. Breast Cancer Care)	A UK charity aimed at providing information and support for people affected by breast cancer. NHS Information Partner	Result No. 1 on Google
www.breastcancerhaven.org.uk/policy.php?parent=87 (2. Breast Cancer Haven)	A UK charity which runs day centres offering support, information and complementary therapies to people affected by breast cancer.	Result No. 2 on Google
www.cancerhelp.org.uk/help/default.asp?page=10251 (3. Cancer Help)	A UK information service run by the Cancer Research UK charity for cancer and cancer care for people with cancer and their families.	Result No. 3 on Google
www.imaginis.com/breasthealth/alternative.asp (4. Imaginis)	An independent resource for information and news on breast cancer and related women's health topics.	Result No. 4 on Google
www.mdanderson.org/departments/cime	Information service run by the	Result No. 5 on Google

r/ (5. MD Anderson)	University of Texas M.D. Anderson Cancer Center which offers medical services for people with cancer.	
www.cancercenter.com/complementary-alternative-medicine.cfm (6. Cancer Center)	Information service run by Cancer Treatment Centers of America (CTCA) which is a network of cancer treatment hospitals and facilities offering conventional and complementary therapies to people with cancer.	Result No. 6 on Google
www.cancerbackup.org.uk/Cancertype/Breastsecondary/Livingwithcancer/Complementarytherapies (7. Cancer Backup)	A cancer information charity, offering information, practical advice and support for cancer patients, their families and carers.	Charity
heartspring.net/ (8. Heartspring)	Funded by advertising and product sales, heartspring.net is a resource for alternative and complementary health information.	Sponsored: displays product advertisement
www.issels.com/?c1=ppc&source=google&kw=breastcancertreatment (9. Issels)	Information produced by Issels Medical Center, a private organisation offering alternative treatment for cancer.	Private Cancer Treatment Centre
www.alternative-cancer.net/?hop=whizbango (10. Alternative Cancer)	Site run by an individual selling a guide to complementary and alternative cancer treatments.	Commercial
www.medicinenet.com/script/main/art.asp?articlekey=63338 (11. Medicine net)	Medical information written by a network of medical professionals	Sponsored: displays product advertisement

http://www.elbeeglobal.com/ (12. Elbee Global)	A site selling herbal medicines for people with cancer.	Commercial
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Table 4 shows the evaluation of the 12 websites by the 12 instruments. The websites were given a score based on the instrument's scoring criteria, which was then converted to a percentage score. A negative score results when an instrument deducted marks for a website that failed to meet certain criteria.

Table 4 Percentage score and ranking of each website by each instrument

Website	1. Breast Cancer Care	2. Breast Cancer Haven	3. Cancer Help	4. Imaginis	5. MD Anderson	6. Cancer Center	7. Cancer Backup	8. Heartspring	9. Issels	10. Alternative Cancer	11. Medicine net	12. Elbee Global
Tool	6	8	1	2	4	10	7	2	10	12	9	4
Webfeet	75%	67%	92%	83%	79%	58%	71%	83%	58%	46%	63%	79%
HONcode	9	2	9	2	1	5	5	2	9	9	5	5
Emory	6	7	2	3	3	8	1	8	11	11	3	10
	89%	86%	95%	92%	92%	84%	97%	84%	63%	63%	92%	68%
Michigan	7	6	2	1	2	8	5	9	10	11	4	12
	28%	45%	50%	53%	50%	21%	48%	16%	14%	1%	49%	-14%
Kellogg	5	5	1	1	3	9	4	5	10	11	8	11
	70%	70%	90%	90%	77%	50%	73%	70%	33%	27%	63%	27%
Discern	8	4	2	5	2	9	1	5	10	12	7	11
	66%	76%	80%	74%	80%	52%	89%	74%	46%	31%	69%	39%
NCCAM	5	5	3	1	1	10	3	5	5	11	5	12
	60%	60%	70%	90%	90%	50%	70%	60%	60%	40%	60%	20%
Pharm	6	7	2	2	4	9	1	8	12	10	4	10
	80%	73%	93%	93%	87%	60%	100%	67%	33%	47%	87%	47%
Minerv	4	7	2	3	6	5	1	11	9	10	7	12
	73%	62%	79%	74%	71%	64%	82%	46%	60%	48%	62%	34%
Nicoll	3	7	1	3	3	9	1	8	12	9	3	9
	71%	57%	86%	71%	71%	29%	86%	43%	14%	29%	71%	29%
Silber	7	7	3	3	1	7	3	1	7	7	3	12
	25%	25%	75%	75%	100%	25%	75%	100%	25%	25%	75%	0%

The evaluation of the assessment instruments obtained the following results:

Comprehensiveness

The assessment of comprehensiveness using the HIICRW criteria showed that there was little agreement on quality markers. This is shown in Table 2.

Ease of Use

This subjective assessment (shown in Table 2) suggested that time was an important consideration, as was information provided on how to score websites.

Rank correlations

The 12 websites were each ranked by each instrument and overall (Table 5). A spearman rank correlation was performed which showed that, despite there being little agreement on quality markers, there was general agreement between instruments on their ranking of websites, although the Webfeet and HONcode did not agree with the other instruments.

Table 5 Spearman non parametric correlation coefficients between rating systems based on the assessment of 12 web sites

	Webfeet	Hon	Emory	Michigan	Kellogg	Discern	Nccam	Pharm	Minerv	Nich	Silber	Sand
Webfeet	1.00											
Hon	.35	1.00										
Emory	.51	.25	1.00									
Michigan	.48	.38	.87**	1.00								
Kellogg	.71**	.39	.84**	.89**	1.00							
Discern	.55	.47	.86**	.77**	.87**	1.00						
Nccam	.55	.39	.78**	.89**	.92**	.82**	1.00					
Pharm	.53	.28	.98**	.88**	.87**	.84**	.80**	1.00				
Minerv	.30	-.02	.85**	.79**	.79**	.70	.75**	.85**	1.00			
Nich	.55	.14	.97**	.82**	.83**	.82**	.74**	.97**	.82**	1.00		
Silber	.51	.51	.61*	.66*	.71*	.71**	.75**	.64*	.37	.59*	1.00	
Sand	.59*	.51	.72**	.83**	.82**	.77**	.85**	.73**	.48	.70*	.93*	1.00

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

In a subjective assessment of claims from the best and worst sites, statements made by Imaginis (the best site), appeared more balanced and cautious than those made by the Alternative Cancer site, which appeared more exaggerated and difficult to assess (Table 6).

Table 6 Comparison of statements from websites rated best and worst using the 12 assessment instruments.

Best site (Imaginis)	Worst site (Alternative Cancer)
<p>‘While anecdotal evidence reveals that many alternative or complementary medicines may be beneficial to patients, extensive research is still needed to determine whether non-traditional medicines are truly effective.’</p>	<p>‘Proven Therapies. Includes a list of successful, long-standing alternative treatments from around the world going unused by the conventional medical system. There is one reason they are the oldest—in the hands of experienced practitioner they work! For example: the very successful nutritional based Gerson therapy. It has been used by untold thousands of people worldwide for over 50 years.’</p>
<p>‘Chinese herbs have been shown to lessen the side effects of chemotherapy and acupuncture has been shown to reduce nausea (a possible side effect of chemotherapy and other drug therapies).’</p>	<p>‘Every day worldwide, quietly behind the scenes, there are over 100 proven alternative therapies used successfully against cancer. (Get a FREE list of the 78 most popular below) The problem is, nobody bothers to tell the public. Plus, conventional cancer doctors (MD Oncologists) are not taught anything about them in medical schools. This must change!’</p>
<p>‘Not all alternative or complementary medicines are safe.’</p>	<p>‘The one true secret to success: There are six basic types of proven alternative cancer treatments, and you must use them all together.’</p>
<p>‘In a recent study published in the <i>Journal of the National Cancer Institute</i>, researchers found that advanced breast cancer patients with high stress levels were less likely to live as long as patients who coped well with stress.’</p>	<p>‘Anvirzel®: A new weapon against cancer and AIDS from Ozelle Pharmaceuticals—a herbal extract which is nontoxic and causes no adverse side effects. Closed clinical trials are showing that the drug is especially effective against prostate and breast cancer. The materials of the company promoting Anvirzel say that Dr Ozel treated 494 cancer patients with the extract, resulting in a high rate of success. The company has organized phase I and II trials in Ireland, and states that the trials confirmed the efficacy of the extract in cancer. They say the patients were improved in their quality of life as well as regression of cancer, while reporting no</p>

	notable side effects. Best results were said to be in prostate, lung and brain cancers. Sarcomas showed stabilization. ‘
‘Some preliminary studies have shown that vitamins may help reduce risk of breast cancer or treat the disease.’	‘Artemisinin: A Chinese herb, sweet wormwood (<i>qinghao</i> in Chinese). In test tube studies, breast cancer cell research resulted in a 28% reduction of breast cancer cells treated only with artemisinin, and an amazing 98% decrease in breast cancer cells within 16 hours that were treated with artemisinin and an iron-enhancing molecule, transferrin. These treatments had no significant effect on normal human breast cells. This research pointed to the involvement of free iron in the toxic effect of artemisinin toward cancer cells, while basically sparing healthy cells. ("Selective toxicity of dihydroartemisinin and holotransferrin toward human breast cancer cells," Life Sciences 70 {2001} 49-56.’

Table 7 shows the levels of citation by other papers and citations on Google. Instruments which were more highly cited and used were considered more likely to remain in existence.

Table 7 Citations suggesting use of instruments by others

Tool	Web of science	Google
WEB FEET	NPI	Low
HONcode	Med	High
Emory	NPI	Medium
Michigan	NPI	Low

Kellogg	NPI	Low
Discern	Med	High
NCCAM	NPI	High
Pharm	NPI	Low
Minerv	NPI	Low
Nicoll	Not cited on WoS	Low
Silber	High	Low
Sand	Med	Med

NPI=No Paper Identified

Table 8 shows how many instruments identified in four previous studies were still available in November 2007.

Table 8 Instruments identified in previous studies remaining available in 2007

Study	Year of Study	Instruments Identified	Instruments available in November 2007
Jadad & Gagliardi [330]	1998	14	3
Kim et al. [332]	1999	27	7
Gagliardi & Jadad [335]	2002	5	1
Bernstam et al [331]	2005	17	3

While there was no clear best instrument, DISCERN, HONcode and NCCAM were the most cited instruments on Google. This is an important factor, as these methods are more likely to be recognised externally. Of these three, HONcode disagreed most often with the rankings produced by other instruments and DISCERN was more difficult to apply than NCCAM.

Therefore, NCCAM was recommended to the charity.

The charity's¹ website obtained a high score from the NCCAM assessment tool, and the only recommended improvements were that authorship and date modified should be reported on all pages.

Implementation of changes

As described in the methodology chapter, following the data collection phase, it was intended that the Change Management Group would convene as a forum for building conceptual models and discussing change. With this avenue of communication gone, I e-mailed a copy of the published journal article and a summary of the web instruments applied to the charity's current website to members of the web development team in order to keep them informed and suggest how the method identified could be applied to the charity's website.

Initially the published journal article received no response from the recipients, this was in contrast to a shortened summary (Appendix 5) which received comments from one of the charity's directors, indicating that the criteria would be applied to the charity's website which was currently being redeveloped. This Director also said that he would like to be able to display the HONcode kitemark on the website due to the perceived value of displaying a well-known mark of quality. At this point the director also instructed me that any future communication should be placed on his desk rather than e-mailed as he received too many e-mails to look at.

While this director was in favour of applying the quality criteria to the charity's own web content, he was concerned at the suggestion that this criteria act as a screening tool for linked websites. The director commented in an e-mail that we should be cautious about 'being too purist' (see e-mail from director, Appendix 6) and that it was in our interest to offer links to many websites, as this created 'reciprocal linking' and enabled the charity's website to feature higher on search engines. A compromise was suggested by which the tool would be used to create a list of recommended sites. However, the planned redevelopment of the website was put on hold after the management redundancies of July 2008 (see timeline, Appendix 1). This meant that the proposed changes to the website were not made within the 30 month life of the KTP.

4.2.6 Discussion

Discussion of this work has two aims which relate back to the research questions: (i) To discuss the method of assessing the quality of information and (ii) to relate this to the feasibility of applying this approach at the organisation. Although findings will be discussed in detail in Chapter 5, they are summarised here.

Information quality

While the method of assessment discussed in this chapter does not provide a means to directly assess whether or not a website contains information which is evidence-based, the work suggests that a checklist approach has face validity for identifying reliable information.

However, some authors caution that due to complex relationships between quality indicators and information quality, it is unlikely that an assessment instrument approach could offer an accurate judgment [22].

Another approach would have been to assess individual websites against a gold standard of information [23], but this was a less feasible option for the charity¹, as the method would be too time consuming. It could be argued that while a checklist approach is a sensible way of deciding which sites to link to, it is also important that additional procedures be put in place to ensure that the charity's¹ own information was reliable prior to it being published online.

An additional limitation to this study was the fact that some of the work required subjective judgments to be made by a single researcher. Another researcher could have included different instruments or assessed their usability differently, making the results difficult to apply universally.

Cultural Barriers to implementation

The process of attempting to integrate the checklist at the organisation had identified several cultural barriers.

Open discussion not valued

It had been apparent from early on in this learning cycle that using the proposed methodology as planned would be problematic. A key aspect of Soft Systems Methodology (SSM) is a participative approach and it had been anticipated that the change management group would play a key role in shaping the data collection and resulting action taken. However the new director did not appear to value this discussion and although reasons for this were unknown¹

at this point in the study it seemed to be a behavioural norm at director level that there was no opportunity for discussion once they had *put their foot down*.

Conflicting worldviews: Information quality versus income generation

Perhaps the most significant challenge encountered during this learning cycle was the difference in worldviews between the information department manager and one of the directors¹. Essentially the method had been approached from the perspective of the information department manager, who wanted the information provided to website users to be of good quality¹. However attempts at implementation had showed a conflicting view from the director; that the charity's website was a method of self-promotion for the charity in which increasing publicity may mean linking to sites which did not provide good information. The director had appeared interested in displaying a *code of conduct* on the charity's website but this appeared to be as a marketing tool rather than out of concern about information quality. This conflict is similar to the assertion that Schein makes regarding occupational cultures working at cross-purposes with little understanding of each other [347]. The fact that under the organisational hierarchy the website was controlled by the marketing department suggested that the emphasis on promotion was a dominant view throughout the charity.

'Being busy'

One of the factors which had slowed down this process was the lack of responsiveness from colleagues outside the Information Department. This manifested itself as e-mails not being replied to, meeting requests rejected and simply being told '*I'm too busy*'. This perhaps reflected the fact that the task of providing evidence-based information was not high on everyone's priority list. The impact of this behavioural norm was exacerbated by the fact that it did not seem to be acceptable or possible to implement change without approval from the top level of management.

Organisational change

The changing shape of the charity¹ had an impact on the little momentum that had been gained with this learning cycle. Despite the difficulties with conflicting worldviews the director in charge of the charity's website had agreed that the tool would be used when updating the website. However, following redundancies, all work on the website was suspended.

4.2.7 Summary

This first learning cycle had investigated a method of assessing the quality of web-based information on the charity's website. This work suggested that an assessment instrument may be a practical approach to making a judgment of the quality of online information on CAM and cancer. The process of feeding back results to the charity had highlighted conflicting values between information quality and the marketing of the charity's services. The anticipated involvement of a *Change Management Group* had been prevented which undermined the planned use of SSM to elicit worldviews from members of staff. The change process had been interrupted by restructuring at the charity¹ which had resulted in agreed work not being applied in practice.

4.3 Assessment of printed material

4.3.1 Background to chapter

The background to the second learning cycle refers to the project timeline (Appendix 1) and provides context to the information presented in this chapter.

Staff changes and financial difficulties

The following learning cycle coincided with major structural changes at the charity. Initial changes comprised of the creation of new positions at senior management level with a Head of Marketing and a Head of Education starting in July 2007. In September 2007 the charity's CEO was replaced by an interim CEO who was one of the charity's trustees.¹

The need to be careful with money was apparent in the Information Department where the budget for producing information was extremely small. As a member of staff at Plymouth I had access to a large number of journals and could request papers not held at the university library. In stark contrast, if the Information Department¹ required a journal article to produce an information sheet it was a case of writing to the author of the article and local libraries in

attempts to obtain the article free of charge. Although this was often not possible, purchasing the article was an absolute last resort.

Communication of information

The charity's Information Department used a rigorous production methodology to ensure their information sheets contained the most current evidence about a therapy. These sheets were available on the charity's shared network drive as well as the website, however no one knew whether anyone (staff or service-users) used these and there was no easy way of finding out.

Confusion over information provision and use was visible throughout the organisation and the librarian would frequently complain to me that service-users would come into the library having been signposted by therapists, only to find the information they'd be told about didn't exist.

Elsewhere in the charity there appeared to be inconsistency in the application of evidence in policy development. One example of this was confusion over advice given to service-users. It appeared that an ingredient in the hand soap used at the charity meant that it was not stocked by the shop as the shop's policy advised against the use of Sodium Lauryl Sulphate. However this policy was not adhered to by those responsible for ordering the soap for use throughout the charity and consequently this was in wide use at the charity. This apparently caused confusion among some service-users (e-mail from shop employee, Appendix 7).

Hopes for KTP project

One of the points laboured in Soft Systems Methodology literature was the idea that different people have differing perceptions of a problematic situation. Although the project aims were set out in the KTP funding document, through my conversations with members of staff it was clear that there were differing perceptions on what would constitute a successful KTP project.

At a meeting with one of the charity's directors I was told that therapists should be up to date with research from academic journals relating to their therapy, he told me that this was particularly important for doctors and nutritional therapists.¹

A gentler position was held by the information department manager who expressed a desire that people became more open to incorporating evidence, where available, into the information they shared with service-users¹.

The manager responsible for the therapists reported being less concerned about evidence and more concerned with professionalism and liability of the charity¹. She also explained that there needed to be a shift in attitude in order that members of staff acknowledged that information was an important part of the services that the charity provided.

4.3.2 Introduction to learning cycle

This chapter describes the process of attempting to introduce quality standards to printed information given out at the charity¹. It describes the process of categorising the charity's printed materials and searching for appropriate published quality criteria to apply to this information. The focus of this chapter then moves on to the process of feeding back information to the charity and identifying cultural barriers to providing evidence-based information.

Similar to the assessment of web-based information there were several potential methods for making a judgement about the quality of printed information which represented different ways of examining the concept of quality. Previous literature highlighted different approaches to assessing printed information. Some studies have focussed on the concept of quality from a patient perspective, assessing levels of satisfaction amongst users [348-355]. Other research

has attempted to measure the effectiveness of patient information using outcome measures such as improved knowledge or increased healthy behaviour [356-364]. As discussed in the previous chapter, while some studies have approached the assessment of reliability of information by comparison with a gold standard [365-367], this is time-consuming and difficult when information spans a broad range of topics. This may be a particular difficulty in the field of CAM due to a lack of existing evidence and practice guidelines [239].

Although the KTP project team and I held discussions regarding the most appropriate method of assessing the charity's information, following the previous learning cycle, efforts were made to involve charity staff early on in the process¹. At a meeting between myself and a manager¹, I was told that the most useful output would be a '*checklist*' which could function both to assess current information and act as a template to guide the production of new information. While this did not focus specifically on improving the use of evidence within the information, the manager¹ stated that the focus on producing good quality information, and providing members of staff with a method to do this, was a pre-requisite for increasing the use of evidence. The manager also suggested that this would help to emphasise to staff that it was important to provide high quality information to service-users¹. It was suggested that therapists were more likely to invest in a system which they were involved in creating and found meaningful. A forum in which to discuss this was a group of senior therapists who held monthly meetings chaired by the manager¹.

4.3.3 Aims

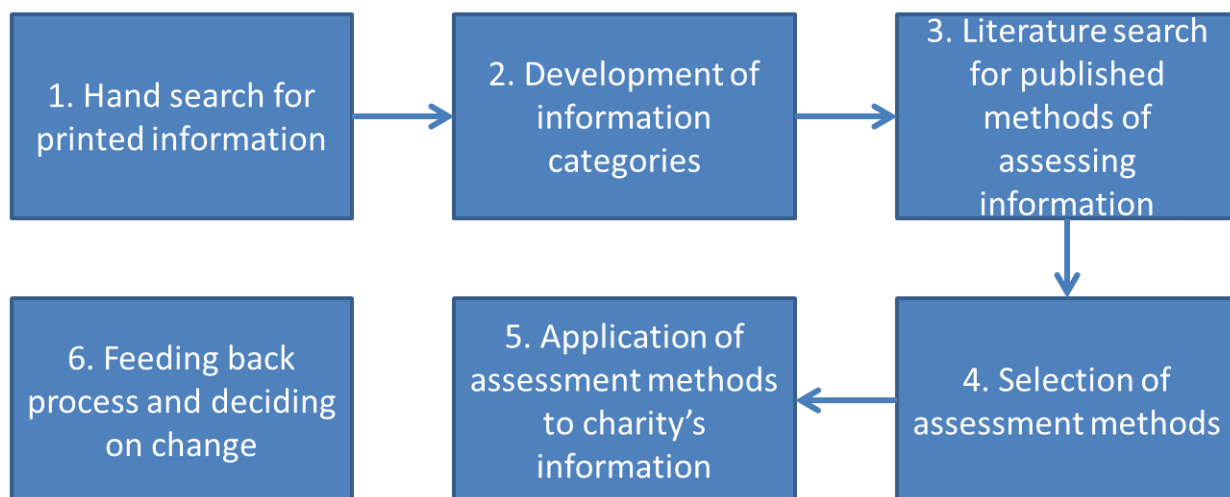
The aims of this learning cycle were:

- I. To introduce a quality control measure to the charity which could be applied to printed information.
- II. To gain an understanding of the feasibility of applying this measure within the charity's culture.

4.3.4 Methods

The process of identifying quality criteria and applying it to the charity's information involved several stages which are summarized in Figure 16 and described below.

Figure 16. Process of assessing quality of printed information¹



1. Hand Search for printed information¹

Information was defined as any material intended for use by service-users. Attempts were made to locate all printed information in use at the charity. The search consisted of examining shared electronic folders, hand searching offices and speaking to members of staff.

2. Development of information categories

Information sheets varied greatly in terms of their content. I carried out an initial categorization based on their content. The purpose of this was to provide some points for discussion at a monthly group meeting in order to receive feedback to enable further development of information categories¹. Following my presentation, these categories were discussed and refined further by the group and given back to me in their amended format. These amended categories were then applied to the information found at the charity¹.

3. Search strategy for published methods of assessing information

In order to identify methods of assessment, a literature search was performed to locate instruments designed to assess the quality of printed information. Search terms were informed by previous work (Chapter 4.2):

[evaluat* OR assess* OR rating OR rat* OR ranking OR rank* OR quality OR criteria] AND [Leaflet* OR Booklet*].

The following databases were searched in May 2007:

Pubmed, AMED, British Nursing Index (BNI), CINAHL, and PsychInfo.

There were no date restrictions and searches were limited to English language articles.

Reference lists of articles which discussed assessing printed information were also searched.

This search aimed to identify instruments which could be applied objectively to printed information as this would inform the checklist requested by the therapy department manager¹. Following identification, literature describing the background of these instruments was sought in order to assess the appropriateness to assess the information at the charity¹.

4. Selection of assessment instruments

Following identification of several methods of assessing printed materials, information about the validity and reliability was sought through further literature searches. I presented this information to the therapy department manager and the KTP team and, in addition to validity and reliability issues, decisions were made on the basis of how meaningful an assessment was considered to be to the charity¹. Again, this decision was based largely on the therapy department manager's perception of what would be useful to the charity¹.

5. Application of assessment methods to information¹

Using the assessment methods selected from the reviewed literature and the categories developed for the charity's information, a purposive sample of information sheets was assessed to ensure that all categories were sampled. Due to the variation in content, different assessments were appropriate for different categories of information. Each sheet in the sample was assessed using relevant instruments according to the instrument's instructions and then scores were averaged (mean) and recorded for each category. The purpose of this assessment was to be able to provide general feedback to the organisation about areas where information could be improved.

6. Feeding back process and deciding on change

A report was produced by myself and the KTP project team and was circulated to senior managers at the charity (Printed information report, Appendix 8²). The report detailed the selection of instruments and made suggestions as to how the printed information at the charity could be improved according to the score obtained from the instruments. Following the challenges in the previous learning cycle of getting members of staff to read the report, particular care was taken to ensuring that the report was short and readable. As discussed in the previous learning cycle, the formation of the change management group had been prevented, and therefore the feedback process differed from originally planned. Presentation of findings became a pragmatic rather than systematic process and in this case took place through discussions between myself and the Heads of Information and Therapy. These discussions focussed on how the quality of printed information at the charity¹ could be improved and what actions could be taken to facilitate this improvement. The process of feeding back to the organisation was captured through meeting minutes and field notes.

4.3.5 Results

1. Hand search for information¹

241 unique information sheets were located at the charity. Some of these were obtained individually from members of staff while other sheets were held together in several locations.

As there was no record of information sheets (what they were, how they were generated, where they were located etc) it was not possible to know if all sheets had been found.

2. Development of information categories

Table 9 shows the information categories developed in partnership with a group of senior complementary therapists. These are based on the content of the information sheets. The number of sheets refers to the purposive sample of sheets identified in these categories

Table 9 Sheet categories agreed upon by senior therapists

Sheet Category	Description	Number of sheets identified
Service Information	This includes leaflets and sheets which inform of the services offered at the charity ¹ .	17
CAM Information Sheets ¹	These are information sheets that have been referenced and produced using a systematic production methodology ¹ which specifies procedure from the literature review to release of the information sheet.	20
Therapy Information Sheets ¹	These provide general information on specific aspects of the charity's approach and may be referenced, but not produced via the systematic production methodology ¹ . Includes	21

	healthy eating guidelines, Doctors information and sheets explaining the charity's approach ¹ to Healthy Eating'	
Therapy guides ¹	These differ from Therapy Information Sheets ¹ sheets in that they are more practical, offering guidance on carrying out an aspect of the charity's work rather than reasons behind the actions ¹ .	50
Further Information	This includes separate sheets on suggested reading or information/contact details for other organisations ¹ . This includes information in the Resource pack.	3
Worksheets	These are sheets which do not provide information or guidelines but are to be filled in by service users during exercises undertaken on the course	4
Reflective/Inspirational Literature	These are individual poems, stories or other writing. These do not include any instructions of how to use the information.	126

3. Search results for assessment instruments

The database search for papers obtained 7224 results in total. In these results, reference was made to nine instruments which it was reported could make objective judgments regarding a particular aspect quality of printed information. Instruments identified claimed to assess readability, suitability, readability and accessibility. Instruments identified are shown in Table 1. The range of instruments highlighted the fact that, similar to the methods identified in Chapter 4.2 there were several domains on which assessments focused. However, instruments identified in this search focused on a single domain rather than multiple ones as web assessment instruments did.

4. Selection of assessment instruments

Following identification of instruments, a decision was made to assess the reliability, readability and accessibility of printed information using the DISCERN instrument, Flesh-Kincaid reading score and NHS toolkit respectively. This decision was made by the Heads of Information and Therapy following discussion with the KTP project team. Table 10 describes the selection of instruments identified.

Table 10 Identification and selection of assessment instruments

Reliability

The DISCERN instrument is a questionnaire which aims to assess the reliability of written information about healthcare treatment choices as well as acting as a tool for developers of information (22). This instrument had previously been identified in Chapter 5.2 where examination suggested that it was appropriate for application to online CAM information. The instrument is not internet specific and was originally developed to assess printed information. This instrument has undergone testing which has suggested that it has reliability and validity for assessing health information (23). The instrument had also undergone testing as part of

Chapter 4.2 and appeared to have face validity for use with CAM information (21). Because of its focus on treatment information, the DISCERN instrument was appropriate for assessing the charity's printed material which provided information about treatment with complementary therapies. DISCERN consists of 15 questions about a piece of information, giving a score of between 1 and 5 for each item. An overall score of 1-5 is then given based on previous answers. This instrument was applied to the CAM Information Sheets and the Therapy Information Sheets¹.

Suitability

The Suitability Assessment of Materials (SAM) was developed to assess the suitability of instructional patient information and required a sample of information to be taken to which a series of questions is applied (24). The instrument consists of 22 questions from 6 categories: (1) Content, (2) Literacy Demand, (3) Graphics, (4) Layout and Typography, (5) Learning, Stimulation, Motivation and (6) Cultural Appropriateness. The instrument includes a detailed list of rating instructions in which each aspect is given a user rating of 'Superior', 'Adequate' or 'Not Suitable'. While this instrument had been tested for validity and reliability (24) and applied to health information (25), it has also been criticised in practice due to its subjectivity (25). The subjectivity of the Suitability Assessment of Materials instrument meant that it was unsuitable for being included as part of a checklist for rating the charity's¹ information so this instrument was rejected.

Readability instruments

Five readability instruments were identified: The Fry Readability formula, Frequency of Gobbledegook (FOG), Standard Measure of Gobbledegook (SMOG), Flesch Reading Ease, and Flesch-Kincaid tools. There have been a large amount of readability instruments developed for specific purposes such as a particular target audience (26). Generally these instruments consist

of a formula which is a function of sentence and word length and provides the user with a numerical value. In the Flesch Reading Ease formulas the output is a numerical value between 1 and 100 while the Fry, SMOG, FOG and Flesch Kincaid instruments provide a United States school-grade score based on the expected reading level of an individual. Although there is debate about whether readability formulas have been validated in the health domain, it has been suggested that they are a useful way of approximating the ease of reading a piece of information (27). A published systematic review of readability formulas for cancer information suggested that the five instruments identified had high correlation with each other (30). With a single 'best' instrument not forthcoming, it was decided that a practical decision would be made and the Flesch Kincaid instrument was selected due to its accessibility to the charity (Microsoft Word 2003 included both the Flesch Reading Ease score and the Flesch-Kincaid Grade Level score) and the fact that a grade level was more meaningful to the charity than a numeric value. Although there does not seem to be a benchmark for reading age, Jefford Gibbs and Reading suggest that grade 8 is appropriate due to 50% of people in several western countries having a reading level lower than this [368]. The Flesch-Kincaid instrument was applied to all of the charity's information excluding the reflective/inspirational sheets which quoted directly from published work and the Worksheets which consisted of little textual information.

Accessibility

Two sets of accessibility guidelines were located. The Royal National Institute for the Blind (RNIB) had developed visual accessibility guidelines for producing printed information in the form of a checklist (28). Another set of guidelines identified was produced by the Department of Health; The NHS toolkit contained a checklist aimed at general accessibility guidelines (29).

No information was located with regard to the reliability or validity of either instrument. The NHS guidelines were better suited to the charity's¹ information than the RNIB guidelines as they provided more comprehensive advice, covering general accessibility issues rather than solely visual criteria. Although no literature regarding the validity and reliability of the information, the fact that this instrument was associated with the NHS was perceived as helpful for the charity. The NHS toolkit was chosen for application to all information.

5. Application of assessment instruments to printed information

Instruments were used based on the instructions available. Table 11 shows the results of the application of the assessments made to a purposive sample of the charity's information sheets.

Reliability

The DISCERN tool was applied to the CAM Information Sheets¹ and the Therapy guide¹ sheets which received a score of High and Moderate respectively. According to the instrument, the most frequently lost points were due to the sheets not describing the effect of a therapy on quality of life or what would happen if a therapy was not used.

Accessibility

The vast majority of information sheets scored highly (8 out of 9) on accessibility using guidelines from the NHS toolkit. The most frequently lost mark was due to font size being smaller than size 12.

Readability

There was a large variation in the readability of information. Therapy Information Sheets¹ and the Reflective/Inspirational Literature received scores close to the suggested grade 8 level. However the other sheets rated received higher scores suggesting they were more difficult to read.

References

While *CAM Information Sheets*¹ were all referenced, the majority of other sheets were not. This included sheets containing therapy advice and those directly quoting material such as poems from external sources.

Table 11 Rating instruments applied to purposive sample of information sheets

Sheet Category	Number of sheets assessed	Instruments applied	Mean score achieved (Standard Deviation)
Service Information	8	FLESH-KINCAID INSTRUMENT ⁵	11.7 (2.4)
		NHS ACCESSIBILITY GUIDELINES ⁶	8 (0)
CAM Information Sheets ¹	12	DISCERN ⁷	3.96 (0.7)
		FLESH-KINCAID INSTRUMENT	9.97 (2.4)
		NHS ACCESSIBILITY GUIDELINES	8 (0)
		REFERENCES	Fully referenced
Therapy Information Sheets ¹	12	DISCERN	3.21 (0.5)

⁵ U.S. Grade score

⁶ A score of 9 was the maximum possible

⁷ A score of 5 was the maximum possible

		FLESH-KINCAID INSTRUMENT	8.69 (3.7)
		NHS ACCESSIBILITY GUIDELINES	8.8 (0.3)
Therapy Guides ¹	24	FLESH-KINCAID INSTRUMENT	10.44 (3.1)
		NHS ACCESSIBILITY GUIDELINES	8.17 (0.7)
		REFERENCES	Majority of sheets unreferenced
Reflective/Inspirational Literature	25	NHS ACCESSIBILITY GUIDELINES	8.16 (0.7)
		REFERENCES	No complete references were provided
Worksheets	3	NHS ACCESSIBILITY GUIDELINES	8 (0)

6. Feeding back information to charity

The information relating to the assessment was condensed into a short report (Appendix 8²) and presented at a senior management meeting¹.

Without a forum for discussion of the findings, dissemination became a pragmatic and opportunistic process of trying to speak to people who were interested, influential and could offer advice on the change process. Due to one of the manager's roles in managing the charity's therapy team who were service-user's main point of contact, they were a key gatekeeper at the organisation¹.

I requested a meeting with two senior managers¹ to discuss findings and explore what action could be taken to improve the information. It was challenging to organise this meeting due to time commitments and the part time nature of one of the manager's employment¹. After several cancellations, it was not until 4 months after the report was circulated that it was possible to hold a meeting with both managers in attendance. Although the report had highlighted several specific areas for improvement, this was largely ignored, and the main topic of discussion became the difficulties involved in keeping track of information in circulation.

I suggested that the organisation needed a single location where information was stored electronically. It became apparent that the practicalities of a database were problematic, due to the concern that it should not be openly accessible, one of the managers¹ held the view that open access to such a database would risk information being given out freely and replacing the need for the charity's therapy services.

The issue of accessibility was discussed and I raised the idea of external assessment from an organisation such as the *Plain English Campaign*. This was perceived by the two managers to be unfeasible due to cost to the charity.

Although the CAM Information Sheets were produced within the Information Department using a detailed production methodology¹, these represented a small proportion of the total information given to service users, and the production methods of the remaining sheets were completely unknown, as was the authorship. A difficulty expressed by one of the managers¹ was that the team of therapists and doctors she managed were not interested in producing information¹. The manager acknowledged that she needed to take responsibility for communicating the value of high quality information, though stated that enforcing an information policy was problematic as therapists '*did not like rules*'. This appeared to be much to the annoyance of the other manager¹ who argued that as part of an organisation, therapy staff should be subject rules. The manager¹ also stated that she did not want information to be standardised and believed that producers of information should be able to express an amount of individuality.

At this meeting one of the managers¹ also reported difficulty relating to financial constraints. Therapists were employed on a sessional basis and paid only for the time they were providing therapies. As the charity was not able to commit further resources to pay therapists to produce information this was done, unpaid, in the therapists own time. As a consequence, therapists were likely to use the information they already had access to and used in their own private practice. In addition to this, the manager reported that for some individuals, work at the charity formed a very small part of their work, she cited one therapist in particular who she had not seen for a whole year¹.

It was agreed that I would work with a member of information department staff¹ in compiling an electronic database of all information in use at the charity. Although work on this began, it was slow to progress and lost momentum when the two managers were made redundant in July 2008¹. The other member of information department staff refused to carry out any further

work on the information database giving the reason that he would not work on something they weren't sure if future management would support¹.

4.3.6 Discussion

Building on the findings from the previous chapter, the process of carrying out this learning cycle had gathered a large amount of information about both the information practices at the charity and barriers to making changes.

Information quality

The assessment process had served to highlight the large amount of information at the charity and the lack of knowledge as to its origin or use. Many of the stages of the process had been subjective such as the creation of information categories or the selection of which assessment instruments were suitable based on a decision made by charity staff¹. Although reliability criteria contained in the DISCERN instrument had been shown in section 4.2 to have face validity, the content of sheets had not been examined in detail. It could be argued that some of the DISCERN criteria was not appropriate for CAM information and domain specific criteria would be more appropriate. The assessments had identified some potential areas for improvement of the organisation such as simplifying language, referring to quality of life issues and increasing text size. However the process of identifying information had highlighted a requirement for more fundamental changes to the information at the charity such as how it was stored and identified.

Cultural factors

Several cultural factors were apparent during the process of carrying out this learning cycle.

Conflict between information and income generation

The conflicting values between information production and income generation were discussed in the previous section with regards to one of the Directors¹ being resistant to changes to the

information service which he claimed would negatively impact the marketing function of the charity's website. This value was apparent again during this learning cycle and influenced the availability of information. Although one of the managers had been supportive of the setting up of a database of information sheets, they had concerns that this should not be accessible to everyone at the charity, stating that this could lead to information being given out and cause potential clients to replace attending a therapy course at the charity with obtaining the information sheets from a course¹.

Lack of open discussion

The failure to establish the planned *Change Management Group* impacted on how discussions took place at the charity. Rather than involving a wide range of individuals, these results had been discussed between only myself and two managers¹.

Dislike of rules

Another cultural factor which appeared to affect the production of information was the reported *dislike of rules* by therapy staff. This was described by one manager as a difficulty in introducing any policy or standardisation to printed information which would require guidelines to be followed¹. It seemed that therapy staff were perceived as a difficult group to work with who were not integrated with the rest of the organisation¹. Several practices seemed to separate therapists from the rest of the staff such as sitting on their own table in the dining room and having a separate staff room to other staff.¹ One manager had also raised concerns that standardising the information would take away the therapist's freedom of expression¹. There appeared to be reluctance on the part of the senior managers to introduce rules they feared would be negatively perceived by therapy staff. This behaviour appeared to

be at odds with the lack of personal autonomy given to members of non-therapy staff at the organisation discussed in the previous chapter.

'Busyness' of staff

An apparent cultural norm of management staff 'having no time to talk' had made the process of feeding back results to the charity extremely difficult. The culture at the charity was such that permission needed to be obtained before any work could be carried out. It was possible for me to meet with the manager of the Information Department regularly, but for this learning cycle, which required input from other managers¹, work was delayed by months due to not being able to meet. This contrasted with the espoused values at the organisation; despite the charity's stated *open door policy*, doors of managers were not open for unscheduled meetings and e-mailed requests for meetings generally went unanswered. This factor was not limited to the management team but appeared to be a cultural norm which meant that even short meetings were not possible for several weeks.

Structure

Although the focus of this thesis remains on cultural factors affecting the use of evidence at the charity, this learning cycle had highlighted several non-cultural factors which led to difficulties in implementing change.

Changing structure

The changing shape of the organisational structure was particularly challenging in which to feed-back results and implement change. This led to delays and there were points during the project where action could not be taken because this would be dependent on the views of new management staff.

The refusal of a member of staff to carry out work that risked being undone by future management also highlighted the frustration some of the staff felt during the seemingly constant changing shape of the organisation¹.

Large Team of therapists

The structure of the charity was identified by the therapy manager¹ as being problematic with regards to managing a group of individuals who produced their own information. The main difficulty appeared to be that there was a large bank of therapists that was challenging to manage. This structure appeared to be due to financial constraints on the charity which meant that it was preferable to employ therapists only when they were needed.

Financial constraints

A manager¹ had described financial constraints impacting on the production of information. While lack of budget precluded external assessment of information it was also apparent that therapy staff were not being paid to produce information. This was in contrast to a dedicated department funded to produce evidence-based information. However, based on this assessment, this department¹ represented less than 10% of the total information available at the charity.

4.3.7 Making changes

Following this learning cycle and the difficulties encountered in attempting to make changes, an opportunity arose to apply to participate in the testing phase of the Department of Health's Information Accreditation Scheme (IAS). The IAS was planned to be a national kite mark which would reassure consumers that information materials were of good quality. Organisations would need to provide evidence of compliance with guidelines on an annual or bi-annual basis. Although the IAS planned to certify whole organisations it was decided by the DoH that for the pilot stage it would focus on a specific section of an organisation. The IAS 'Standard' contained many aspects which overlapped with the recommendations made by myself and the KTP team

during this project including user involvement, archiving of information and ensuring accessibility and readability.

The application process began in April 2008 and the IAS pilot began in September 2008. The charity¹ was selected to be one of 40 organisations participating in the testing network and was the only CAM organisation included.

The IAS application appeared attractive to several departments¹. The Marketing Department used the fact that the IAS linked the organisation with the DoH and NHS and participation was immediately communicated externally to promote the display of the charity's information in hospitals and doctor's surgeries. The Information Department saw the scheme as a way of having their information nationally recognised. To successfully gain accreditation the organisation needed to develop policies setting standards with which patient information produced at the organisation needed to comply. This was seen by the Information Department as a way of enforcing the use of good quality information. There were several advantages to taking part in the pilot phase including a waiver of the assessment fee which would be charged once the testing phase was over. Involvement in the scheme also enabled access to NHS citation databases with provision of an Athens password which enabled the Information Department to perform literature searches.

The application process required the charity to present their complete information production process to an external assessment body. This submission required the provision of evidence of all stages of information production; from identifying a need, securing a budget, developing mechanisms to deal with user queries and appropriate archiving and updating schedules. The reports which had been produced as part of the KTP project constituted much of the evidence of quality assurance procedures. The IAS application involved a large amount of work and although this was started by myself, it was handed-over to the research officers and constituted a full time role for them. Although initially only the information produced by the

Information Department was submitted, the plan was to roll out the process to the rest of the organisation after accreditation had been achieved.

However, in the final restructure to occur during the KTP project in April 2009, staff responsible for the IAS work were made redundant¹. Although this did not affect the information processes already developed, the IAS required that there be a procedure in place which would address consumer questions and be capable of updating or amending information if required. Following the closure of the department this could not be guaranteed and therefore the charity was forced to withdraw from the scheme.

4.3.8 Summary

After working with members of charity staff to identify information needs, this learning cycle had examined the quality of printed information at the charity according to several assessment instruments. While several practical areas of improving information had been suggested following the rating process, discussion with management staff had focused on more fundamental problems with information. The lack of policy or standardisation of procedure meant that a large amount of information existed which the organisation knew little about. Although management expressed a wish to improve the situation, several barriers to progress had been identified. Conflicts between information production and income generation led to concern over open access to information. The apparent reluctance of management to subject therapists to rules led to a lack of clarity in how an information production policy could be enforced. It was also reported that a large team of therapists made it difficult to implement changes in practice. This treatment of therapists was in contrast to the management of non-therapy staff (myself included) who were subject to having to gain approval for many aspects of their work. The IAS had appealed to the marketing values of the organisation and, despite similarities between the steps necessary for accreditation and suggestions made during the

KTP project, the IAS was taken on enthusiastically by the organisation. The changing shape of the organisation coupled with difficulties meeting members of staff had greatly slowed down this process.

4.4 Staff Interviews

4.4.1 Background to chapter

This learning cycle took place over nearly a two-year period during which time many changes occurred at the organisation. The following section provides a summary of the changes occurring during the time when this work was taking place in order to provide context to the learning cycle.

Director¹ resignation

In October 2007 one of the charity's directors¹ resigned from the charity. This meant that much of the *red tape* that myself and the KTP team were subject to was removed although this was followed by a period of a great deal of organisational change and staff turnover.

New CEO appointed

After six months of the charity being managed by an interim CEO, in March 2008 a new CEO was appointed. At the first whole-organisation meeting¹ chaired by the new manager he presented his strategy for the organisation which immediately seemed to cause concern over his mention of business concepts and I heard a shocked individual¹ in front of me exclaim that it was '*all very corporate*'.

Management redundancies

Within four months of the CEO's appointment the entire team of directors and senior managers was made redundant and replaced with a new management structure (Appendix 9²). This meant that my supervisor who was also the organisation's member of the KTP was replaced with a new manager¹ which joined together the Information and Education departments. The former manager of the education department replaced the therapy

department manager in a new post¹. Seven months after the first organisational restructure, the CEO announced further redundancies, this time removing both the Professional Development and Communications departments.¹

During this period of uncertainty there appeared to be a form of disbelief, as nothing like this had happened to the organisation before. One colleague likened her feelings of uncertainty of the future to being diagnosed with cancer.

New management team

With the new management team arrived a notable difference in language and values. With the management redundancies, several individuals who had worked for a large number of years left the charity.¹

4.4.2 Introduction to learning cycle

As discussed in the literature review, the values and beliefs of individuals form part of the cultural context at an organisation [103] and these may restrict or facilitate efforts to

introduce the use of evidence. The literature review also described the limited number of studies on attitudes towards evidence in complementary therapies in a practice context [229, 230] although some of those published may lack relevance, as they took place outside the UK [370-372]. Despite my contact with several members of staff through being a member of the organisation and carrying out two previous learning cycles, no data had been systematically collected about staff views on evidence. This chapter describes the process of carrying out interviews with staff at the charity regarding their information practices and attitudes towards evidence. It describes how constraints were placed on several stages of this process, including gaining access to staff, developing an interview guide and collecting the data. Although I had been informed about the culture of the charity, this was limited to second hand accounts from colleagues¹. Up to this point the only contact between myself and colleagues in the organisation (other than the Information Department) had been through brief interactions as I discussed and fed back KTP project information to a limited number of individuals.

4.4.3 Aims

The aims of this learning cycle were to find out about information practices at the charity and, through collecting data on views and attitudes towards evidence, gain an understanding of the culture at the charity, and the effect that this had on the feasibility of implementing evidence-based information practices. It was also anticipated that through the discussion and implementation of changes, further understanding could be gained on what interventions could improve the use of evidence at the charity.

4.4.4 Methods

Although approaches to data collection were discussed within the KTP team, it was necessary that agreement was sought from management staff at the charity¹ prior to carrying out

interviews. Therefore methods were developed in consultation and negotiation with several members of management staff.

Negotiating access

From the outset of this learning cycle there were difficulties gaining access to staff, and the originally proposed idea of the KTP team to survey all members of staff was not possible. At a meeting with a director I was informed that they¹ did not want me to talk to staff other than those working in the therapy department, as this was where the majority of information was given out¹. Another manager objected to the plan to e-mail the survey, suggesting that we would not get any responses from therapists¹. Concerns were raised by a second manager about a subsequent plan to audio record interviews¹. The manager suggested that due to the sensitive nature of the questions a recorder could be intimidating and handwritten notes were used instead. There was concern about therapists being very anti-evidence and I was warned that discussions could become heated. I was advised to introduce myself as a reflexologist (a therapy I am trained in) before describing my work in the Information Department.

Topic guide

The KTP team developed an interview guide, however at a short meeting with one of the charity's directors he dictated alternative questions he wanted me to ask therapists (Questionnaire, Appendix 10)¹. The director told me that he wanted me to report back to him which therapists were not staying up to date with research and they would be dismissed¹. Although initial piloting of the questionnaire with four members of staff indicated that there were difficulties understanding the questions, the director insisted that his questions were asked therefore this topic guide was used¹. Following the resignation of the director in October 2007 it was agreed that the interview guide could be revised to better reflect the original aims of the questionnaire and remove confusing questions¹. Wording was altered and questions asking respondents to rate the quality of different sources of information which had appeared

difficult to answer. Questions asking about views on *gold standard* evidence and attitudes to study results differing from respondents' own experience were added (Revised questionnaire, Appendix 11). Thus the director's interview guide was used for the first 14 interviews and a revised version used for the following 20¹.

Sample

The questionnaire was piloted with 2 members of the Information Department and a therapist. Following this, a convenience sample of therapists who were free during courses or unbooked appointments were interviewed on the charity's premises¹. The manager of the charity's shop was also interviewed.

Data analysis

Data was typed up from the interview notes and imported into NVivo8. Following this data was read through several times in a familiarisation stage [373].

Due to the structured nature of the interview and the fact that the majority of questions were closed, content analysis was used. In addition, one of the managers suggested that findings would be more meaningful to the organisation if the frequency of responses was reported¹.

Weber suggests that effective content analysis can make use of both qualitative and quantitative operations on text [374]. For closed questions, analysis took the form of counting the frequency of responses. For questions which had generated a more narrative response, analysis consisted of categorising phrases according to their meaning. In this respect the analysis shared properties with methods such as a framework approach [375] or qualitative content analysis [376].

Feeding back information to the charity

Following analysis of interview data a report was produced and circulated to senior management (Appendix 12²). Because the majority of data had come from therapists, discussions took place with their manager¹. This process was captured through reflective field notes.

4.4.5 Results

Demographics

The interview sample of thirty-four consisted of two staff from the Information Department, one from fundraising, two from the charity's telephone service, one from the trading company and twenty-eight therapists (Healer n=6, Nutritional Therapist n=6, Art Therapist n=2, Psychotherapist n=6, Doctor n=2, Counsellor n=1, Shiatsu practitioner n=3, Aromatherapist n=1, Reflexologist n=1)¹. Thirty interviewees were female and four were male. Fourteen were interviewed using the director's questions and the subsequent twenty were interviewed using the revised topic guide¹.

The majority of staff reported working part time. Only four members of staff worked full time, three worked 3-4 days per week, two worked 1-2 days per week while nineteen reported working less than one day per week and several emphasized that this was extremely variable depending on the number of courses held at the charity in any week. Six members of staff reported that their hours were so variable they could not put an approximate figure on their weekly hours. The length of time staff had worked at the charity ranged from 3 months to 27 years with a median period of 5 years.

Key elements of the charity's work¹

Staff were asked what they felt were key elements of the charity's work¹. There was little agreement, although several elements were mentioned by interviewees: Empowerment (n=12), Therapies (n=10), Holistic nature (n=13), Support/Care (n=8), Education/Teaching of self-help techniques (n=9). Some people (n=5) suggested that information was a key component of the charity's work¹.

Type of information provided

Interviewees were asked what type of information they provided; the definition of information was not limited to printed information but could include verbal information. People reported giving out information about therapies (n=21), self-help techniques (n=6), hand-outs produced by the charity (n=1) and about research (n=2). Others (n=6) said that they would signpost people to further sources of information either internal or external to the charity¹.

Sources of information

Some staff members reported using information produced at the charity (n=14), Fourteen members of staff reported that information from colleagues influenced what they gave out. Six staff members reported consulting research literature and one reported using the library, while the most widely reported source of information was participants' own knowledge and experience (n=16).

Indicators of good quality

Staff were asked what features of information would indicate that it was of good quality. A wide range of factors were reported: accessibility (n=7), aims (n=1), appearance (n=2), being approved by the charity (n=7), authorship (n=9), bias (n=6), use of a critical appraisal checklist (n=5), cross checking with other sources (n=6), currency (n=6), agreement with personal thought, knowledge or experience (n=11), references (n=3), sources (n=7) and specificity (n=1).

Gold standard

Staff were asked what type of evidence was generally considered to be a 'gold standard' within their discipline. Only seven of the interviewees reported being aware of a gold standard and named a type of study (randomised controlled trial (n=5), systematic review (n=1), double blind study (n=1)).

Nearly all interviewees provided a reason why they would not use 'gold standard' evidence. There were several explanations for this: Feeling that personal experience conflicted with the gold standard (n=1), feeling that research in their area was not published or recognized (n=1), there was a lack of evidence (n=7) or lack of a gold standard (n=1). Others cited research methods as a reason for not using a gold standard of information, stating that the notion of individuality conflicted with some research (n=5), that research methods failed to take into account the nature of an intervention (n=2) and that therapy is experiential (n=2). Other reasons for not using gold standard evidence to inform the information staff members gave out was that they (n=2) or clients (n=1) were not interested in research. One interviewee reported that they had difficulties knowing how to access research.

Research differing from experience

Staff were asked how they would deal with a situation in which a published study had conclusions that seemed to differ greatly from their own experience, or where one study seemed to conflict with another.

Some (n=7) said that they would be critical of the study and its methodology. Others (n=7) said that they would be willing to incorporate findings into their practice. Several participants (n=5) said that if a published study differed from their own experience and knowledge they would ignore the research or continue to rely on their own knowledge.

Information needs

Staff were asked what their information needs were. Many (n=14) said that it was important that they had information which gave them an understanding of what was going on within the organisation. Several (n=10) talked about the importance of information being accessible to them or appropriate for the people they were giving the information to. One participant suggested that information had a role in educating service-users about how to access trustworthy information.

Several participants (n=13) talked about the importance of information relevant to their practice and emphasised the importance of information being up to date. Three specifically mentioned their need for research to support the work done at the charity and two said that access to CPD activities was important. One respondent said they needed knowledge of trustworthy sources.

Challenges in providing good quality information

Many participants (n=12) discussed communication as a barrier to providing good quality information. Description of this challenge suggested that within the organisation people did not know what was going on in other departments, one description was that it was important that the '*left hand knows what the right hand does*'. Participants suggested that communication, both internally and externally, should be improved. One participant suggested that communication difficulties between departments had arisen following the move to the charity's new premises. One participant suggested that the organisation needed more *Whole House Meetings*, others suggested that there should be more interdepartmental discussion and consultation.

Two participants mentioned that culture was a challenge to producing good quality information. These participants suggested that some therapists did not trust evidence and did

not see how it was relevant to their practice. One participant suggested that continuing professional development should be considered more important within the organisation.

Three people talked about difficulties communicating information to service-users, this consisted of concerns that not all service-users had the internet, or that people don't read information they are given or are unlikely to be inspired by research.

Some (n=4) raised the concern that in order to provide information, the marketing of the charity was important. Concern was expressed that the recent re-branding of the charity had added to this difficulty. One participant suggested that externally the charity was seen as *'elitist and expensive'*.

Two participants expressed difficulty capturing the effect of complementary therapies in words, one commenting that information needed to cover both scientific and emotional aspects and the other questioning if it even was possible to measure *'quality of life'* and *'well-being'*. One of these participants suggested that it was important for the people who wrote information to have experienced the services offered by the charity.

Several participants (n=7) mentioned that a lack of resources was a challenge to providing good quality information, naming time and money as limiting factors in providing good quality information.

Two participants commented on difficulties with the evidence itself, one mentioned that it was difficult to keep up with current opinions and another said that due to their therapy being *'young'* there was a lack of research.

Four participants discussed the importance of experience contributing to information. One description of this issue referred to a *'middle road'* where therapists contributed to information based on their experience and another stated that it was important that the charity's work over its lifetime was not forgotten.

Feeding back interview data to staff

Following the interviews, a report was produced by the KTP project team outlining the findings for the charity (Appendix 12). Although the (unformed) 'Change Management Group' was the originally anticipated forum for dissemination of these results, this was replaced with requests for meetings with senior managers. Thus this report was sent to senior managers and directors¹, requesting a meeting to discuss the report.

Similarly to feeding back the results from previous learning cycles, arranging an appointment to discuss these results was problematic and an eventual meeting with one of the charity's managers was held several months after the report was produced¹. Although at quarterly meetings the CEO expressed a wish to discuss findings with me, despite e-mail and face to face requests, a meeting was never possible. One of the managers was a key member of staff as they managed the therapy team and the majority of participants had been therapists¹. Shortly after the meeting between myself and the manager, they were made redundant and a subsequent meeting was held with their replacement¹.

Discussion with manager¹

Discussion with the therapist's manager was not a systematic examination of all of the results but rather focused on areas of the report that she felt highlighted important issues¹.

On the question of defining the charity's work, they told me it was acceptable for staff to have their own thoughts about its aims but suggested it was important that there was a consistent message for the purpose of marketing¹. They also commented on the communication issue raised by staff, saying that it was important that staff were aware of other activities within the organisation¹. They stated that they would like therapists to stay up to date with research in their area¹.

They reiterated that the main difficulty managing therapy staff was that there were a large number (approximately 60) who worked on a part-time basis¹. Some disciplines were headed

by senior therapists which reportedly made these groups easier to manage. Although group meetings were desirable, these had cost implications for the charity as it would require the organisation to pay therapy staff an hourly rate for their attendance, which made regular contact unfeasible.

Another problem reported was that there was little definition of what the charity required from therapists regarding skills; only their therapy qualifications, a minimum period of practice and membership with an appropriate professional body.

The manager described several problems she felt were relevant to attempting to introduce the use of evidence to staff¹. The fact that most therapists did not come from academic backgrounds and therefore did not necessarily have any research skills meant that even if they claimed to be regularly reading literature, they weren't confident in their ability to discern between good and bad information¹. The working pattern of therapists was also described as problematic as work for the charity was often a small part of a therapist's timetable. This meant that therapists were not used to belonging to an organisation where they did not have autonomy and were required to follow rules. Despite their wish that therapists were up to date with research, they also reflected that they didn't think that a good researcher was necessarily a good therapist and vice versa¹.

The manager described problems with the evidence base itself for complementary therapies and pointed out that there wasn't good evidence for lots of therapies used at the charity, referring to these practices as being 'on the edge'¹. In addition they told me that the charity's approach was more than the sum of the different therapies of which it was composed therefore the question of whether an individual therapy was effective for a single symptom was not of relevance to the organisation¹. They stated that it was important to balance the evidence gained from research with the years of experience the charity had gained¹.

Asking for the manager's opinion on the way forward, I was told that the attempt of the company who led a previous attempt to stimulate interest in research, had come from an academic perspective and looked in detail at the research process, which was not how therapists are trained to think¹. Acknowledging that they would not be able to take any action themselves due to their redundancy, they suggested that research needed to be made less scary to therapists and that it was a potentially a good time to do this during the unsettled period of organisational restructuring, as this would be a chance to get people together during a period of change¹.

Meeting with new manager¹

Following the redundancy, the newly appointed manager was responsible for the management of therapy staff¹. The interview study report was e-mailed to this individual although it was not possible to meet for several months¹. At this meeting, the manager¹ said that they didn't think the results were as relevant as they might have been when the interviews were carried out in 2007, their rationale being that the organisation was a very different place after all the restructuring and implied that more change was yet to come¹.

This manager talked about the relevance of research to the charity and said that he was of the opinion that research on individual therapies didn't have any relevance but rather they wanted to know about the experiential side of the charity's work¹. Like their predecessor they stated that research evidence was not a factor taken into consideration when selecting which therapies were to be offered by the charity, but these decisions were based on what had been shown to be helpful through experience¹.

The manager told me that they felt strongly that staff should be research literate¹. When the prospect of holding some sort of CPD event as the former manager had suggested, this new manager told me that this would be a good idea although they said that it was important that no prior knowledge of research was assumed¹.

Discussions with the Information Officers

Results of the interviews were discussed with the Information Department's research officers who were responsible for producing *CAM Information Sheets*¹. After looking at the interview report they suggested that the therapist perspective was considered a form of evidence and planned to integrate this into the information sheets they produced. This proved to be problematic in practice as therapists did not have paid time in which to get involved in information production and therefore were required to do it in their own time. This led to long delays in receiving therapist input and Information Officers reported that it was difficult to remind therapists as they were expecting them to provide input without getting paid.

4.4.6 Making changes

Although the purpose of using SSM was to facilitate discussion at the charity, the lack of a forum for this has been highlighted in previous chapters¹. Like other attempts to feedback information to senior members of staff, this had been challenging due to time constraints. Although all proposals were discussed with several managers, planning the next stage of the learning cycle fell largely to myself, supported by the KTP project team¹.

Method of intervention design

Discussions about how to proceed focussed on developing the aims of the intervention and how this might be designed. Based on the discussions with the senior managers, several points had been made:

- (iv) *Research needed to be made 'less scary',*
- (v) *Any training should assume no prior knowledge of research,*

- (vi) *An academic perspective was inappropriate for therapy staff (a previous attempt at running a CPD event had been unsuccessful for this reason),*
- (vii) *The period of uncertainty during restructuring was a good time to get staff together.*

In addition to this, I discussed several other suggestions with the KTP team. It was decided that a CPD event could act to fulfil training requirements while also providing a promotional opportunity for the charity. Other events held at the charity had been well attended; a compulsory *energy workshop* had been run in December 2007 where staff were taught about positive thinking. Additionally, a monthly *book club* meeting, run by members of staff and held outside work hours, was extremely well attended.

Following discussion with the KTP project team, I spoke with members of staff about the possibility of running a series of professional development events at the charity¹. These would be held between March and June 2009. They would be run by an external facilitator with a therapeutic background in addition to research experience, it was hoped that this would be a perspective with which therapy staff could relate. Workshops would be open to all staff and non-contracted staff would be paid their usual hourly rate for sessions which would come from the KTP budget. A certificate would be provided for therapy staff which would contribute towards CPD requirements for their professional registration. Workshops would focus on a pre-determined topic and would be followed a month later by an open-access webcast which would allow the topic to be discussed by an international audience. It was hoped that this would appeal to the charity's marketing aspirations as the webcasts would potentially link to people from external organisations.

The following workshops and webcasts were designed:

Workshop and Webcast 1: 'What's the point?' Practitioner perspectives on complementary therapy research

Jan Williamson was a reflexologist who had carried out a piece of research of reflexology for menopausal symptoms in women. Her research did not find any evidence of an effect of reflexology and had received criticism from the reflexology community.

Workshop and Webcast 2: MYCaW: Using the Measure Yourself Concerns and Wellbeing tool to evaluate complementary therapies when used in cancer support

Charlotte Paterson was an academic GP with a background in complementary medicine research and had led the development of the MYCAW instrument which evaluated people's experience of using complementary therapies. Although the instrument had been introduced to the charity it was not used consistently and as such the Information Department received little MYCAW data¹.

Workshops were designed in consultation between myself and the two speakers. The speakers presented informally at the charity and focused on their perspective of research into complementary therapies (see text circulated to staff, Appendix 13). Webcasts were broadcast from Plymouth University and consisted of speakers providing a summary of the previous workshop and facilitating a discussion between attendees. All staff were invited to the workshops and webcasts via an invitation e-mailed to staff based at the centre and e-mailed or posted to therapy staff, followed by a reminder two weeks later.

Evaluation of the interventions

Following the running of the workshop and webcasts, an e-mail was sent to 'all users' and the Therapy Administrator contacted all of the therapists with the request to complete a brief feedback questionnaire (Appendix 14) returning either by email or post. A reminder was sent after 2 weeks and a basic content analysis was carried out on the feedback received. This was appropriate due to the structured nature of the questions and small number of responses.

4.4.7 Results of changes

Attendance

Out of a possible 120 charity staff, eight attended Jan Williamson's workshop and seven attended the following webcast, seven attended Charlotte Patterson's workshop and seven attended the associated webcast. Only two senior managers attended one event each.

Feedback

Of the 120 staff asked for feedback, 12 feedback forms were received; 8 of these were from people who had not attended any events and 4 were from people who had attended at least one event.¹

Feedback forms asked people if they had attended, to describe what was good or bad about the events and how they could be improved. If people hadn't attended they were asked their reasons for not attending. People were also asked what future events the charity should be organising and given space to add additional comments.

The feedback received is summarised below. Workshops and webcasts feedback are presented separately.

Webcast Feedback

Reasons for not attending the webcasts

Time or work constraints

The most frequent reason for not attending workshops (n=7) was reportedly due to time and work constraints. These were mentioned by several therapists as being due to a conflict with work outside the centre and one full-time member of staff mentioned that they were unable to attend due to work commitments.

Difficulty using computers

Some people (n=4) expressed difficulty using computers and one respondent (who posted the form) reported not having a computer. Other responses described not understanding the concept of a webcast, having difficulties logging into the webcast or a dislike of computers:

'Do not like sitting at computers – you're lucky to get this! [E-mail]'

[Questionnaire No. 8]

Distance

Two respondents mentioned that they had a long way to travel to the charity's premises and for this reason did not attend the webcasts at the charity.

Communication

Two people reported reasons for not attending which related to how the information had been communicated to them:

One respondent said that they did not attend webcasts because they had not heard about them and another said that they did not attend because they were unpaid:

'I have already done far too much voluntary work for the charity¹, which seems to be 'required' alongside any paid work.' [Questionnaire No. 10]

Subject

Three respondents reported reasons for not attending based on the subject area – this related to a lack of interest, lack of faith in the charity's choice of speaker, the subject not being relevant to them or knowing all they needed to know about a subject:

'I don't have much faith in the choice of speakers that [the charity]¹ provides or thinks highly of.' [Questionnaire No. 5]

What was good?

Only one person answered this question and said that it was good to hear about other people's experiences of using the MYCAW instrument.

What was bad?

Only one person answered this question, reporting that they did not like the webcast time delay and that it was difficult to listen, read and type at the same time.

Workshops

Reasons for not attending workshops

Reasons reported for not attending workshops were very similar to those reported for not attending webcasts; because staff didn't think they would be paid for their time (n=1), knew all they needed to know on a subject (n=1), the topic was not relevant (n=2) or they were subject to time or work constraints (n=9).

What was good?

This question was answered by three people. One respondent remarked that it had reaffirmed their confidence in the value of the MYCAW instrument and another that it had enlightened them as to how much work was involved in carrying out research which would be helpful if they were considering getting involved. The third respondent said that the environment had been relaxed and it was easy to ask questions and contribute insights.

What was bad?

The three people who answered this question all suggested that workshops would have been better had there been more of their colleagues in attendance to facilitate discussion of the subject topic.

4.4.8 Discussion of Learning cycle

The findings of this learning cycle are briefly discussed here although a further, more in depth discussion and synthesis of results is reserved for the final discussion chapter.

There had been difficulties gaining access to members of staff and limitations on who could be spoken to, what questions could be asked and how this could be recorded. Nonetheless this learning cycle had generated a large amount of information both in terms of data formally collected and information observed from the process itself.

Sample

The demographics of the sample had been influenced by the director who had wanted only therapists to be interviewed. The gender ratio reflected the fact that the vast majority of therapists were female. Most of the staff had joined the charity relatively recently, and only two members of staff had been in post from the charity's beginning.¹

Value of evidence

The most frequent and trusted source of information appeared to be people's personal experiences which highlighted the possibility that, with few opportunities for staff to meet, information was likely to be highly individual and there was little standardisation in what information was given out. Some staff had reported that they would be willing to incorporate research findings into practice while other staff expressed an unwillingness to consider new information, and several claimed that they would ignore information which differed with their personal experience. This opinion supported previous findings in a study of UK acupuncturists who suggested that their practice would not be influenced by a negative clinical trial [230]. A view had also surfaced in a feedback form from the staff workshops which gave the reason for non-attendance as knowing 'all they needed to know' on the topic. This perhaps echoed the findings of a UK study in which CAM practitioners expressed doubt that EBM was essential for

their practice, although unlike this study, the sample from the charity did not appear to acknowledge a need for further training [229]¹.

At a management level, it was emphasised that individual therapy research was not as relevant as the experience the organisation had gained during its lifetime. It was not clear what this information consisted of as the charity did not routinely collect data, indeed members of the information department frequently complained of the fact that therapists did not hand out therapy evaluation forms which they were asked to do¹.

It was clear that within the organisation there existed several conflicting worldviews regarding the nature of evidence; the experiential evidence expressed in these interviews conflicted with the Information Department's work which defined evidence as information which came from peer-reviewed journals. However one of the differences appeared to be the level of interest and willingness to change displayed by the Information Department that was not present elsewhere at the organisation. This ability to question and change practice is outlined as an important part of a 'Learning Organisation' in organisational culture literature [130].

Research skills

A lack of research skills was perhaps exemplified by few therapists being aware of a gold standard of evidence in their discipline which Richardson suggests is a key requirement of the use of evidence in practice [215]. However nearly everyone had described barriers making the use of gold standard difficult, such as there being a lack of evidence or that research methodology conflicted with the nature of a therapy or the notion of individuality which suggested some level of awareness. While most respondents had reported indicators of good quality information, a manager had suggested that therapists lacked the skills to identify reliable information¹. This attitude is in agreement with several reports which have questioned therapist skills with regard to research [216, 218].

Lack of support for CPD

The workshops and webcasts had been unsuccessful from a professional development perspective as they had been undersubscribed and did not receive support at a senior management level. It was difficult to understand the apparent contradiction in the enthusiasm expressed when speaking to managers face to face and then their lack of attendance at the events and non-return of the evaluation forms. This suggested a disparity between the espoused values of the management and their underlying assumptions regarding the value of the workshops. Coupled with the difficulties feeding back information relating to data gathered at the charity, this lack of willingness to support these CPD events presented another example of difficulties providing the charity with any new information and causing them to question their current practice.

Structure of the therapy department

Gray has emphasised that structure is important in an evidence-based healthcare organisation [377]. It appeared that aspects of the structure at the charity were problematic with regards to communicating with staff, making changes to practice or attempting to run CPD events¹. It was apparent that many of the therapists worked a very small number of hours for the charity. This appeared to be based largely on demand for the charity's services which varied as courses were dependent on participant numbers. These working patterns were highlighted by the manager as a major difficulty, as the large amount of part-time therapists was difficult to manage¹. The workshop and webcast evaluation had indicated that additional work commitments were one of the reasons why many therapists were unable to attend the workshops. The communication barriers that this structure appeared to cause were reflected in the fact that one of the main points to come out of questions on barriers to providing good

quality information had been that many members of staff reported needing information about what was going on at the charity.

Lack of resources

A lack of resources was highlighted by both interviewees and the manager when this was discussed¹. The lack of resources appeared to be a large contributing factor to the lack of communication as this dictated the structure of the therapy team as well as limiting the frequency that people could meet to discuss organisational issues as this had an associated cost. It was also the case that in the Information Department, despite a commitment to draw on therapist experience as a source of information, this proved problematic as therapists were not paid for their time. This study had previously highlighted difficulties in obtaining the necessary literature from peer-reviewed journals to inform the production of information sheets. The ultimate resource constraint was seen to be the closure of the department which was rationalised as being necessary due to the organisation's financial difficulties¹.

Barriers to the research process

The process once again highlighted the need to seek management approval at every point in the research process and had also drawn attention to a degree of protectiveness of therapists by the manager¹. The fact that the staff questionnaire could not be e-mailed and the workshop evaluation had to be sent by post highlighted the fact that at the organisation therapists were known for their lack of engagement with information technology.

Although another manager had been concerned that the topic of evidence was so controversial that discussions with therapists could become heated, this had not been the case¹. This suggested that perceptions of the therapist who was fiercely opposed the use of evidence in practice may have been unfounded¹.

Limitations

Some of the limitations of this learning cycle had arisen from the constraints placed on the methods. Original questions imposed on the survey by one of the directors had been difficult for respondents to answer and therefore interpret of the data was challenging¹. The questions permitted had also limited the type of data which could be gathered, with the lack of open-ended questions reducing the richness of the data gathered on staff views towards evidence¹. The fact that recording equipment was not permitted meant that data collection was reliant upon my notes which may have resulted in some loss of data. There is also the risk that people may have been unwilling to express negative feelings about evidence if they felt that this could jeopardise their position at the organisation. The analysis was performed by a single researcher therefore themes identified were based on a single subjective judgement.

4.4.8 Summary

This learning cycle had highlighted organisational barriers to the research process which limited the nature of data which could be collected.

Interviews with staff suggested that there was a very strong value placed on personal experience and knowledge and although some were willing to incorporate new knowledge others suggested they would continue to rely on their own knowledge. Few people were aware of a gold standard of evidence in their discipline but nearly all highlighted reasons for not using this to inform the information they gave out. The implications of this were that the provision of evidence-based patient information did not appear to be supported. The process of feeding back results to senior management reflected views that the experience gained at the charity during its lifetime was felt to be the most valuable form of evidence, although it was unclear how this information was collected.

A large number of people felt that communication was the biggest challenge to providing good quality information, although managers indicated that the structure of the organisation and financial constraints influenced the feasibility of gathering therapists together.

The evaluation of the professional development events (the intervention) suggests that the part-time nature of therapy staff made it difficult for them to attend. Despite initial enthusiasm expressed by senior members of staff these events did not appear to be supported.

4.5 Service-user interviews

This chapter presents a learning cycle describing an exploration of service-user information requirements, and the importance of evidence in CAM information from a user perspective. Information presented in this chapter follows the process of designing and conducting interviews with service-users and discussion of the implications of this information for the charity. The chapter then describes the process of feeding back findings to the organisation and consequent changes to the information service.

4.5.1 Background to chapter

Following the employment of the new CEO and the arrival of a new senior management team at the charity, there was an increasing use of the term *user-led* as a descriptive term for the organisation. This was reflected in text used to support the charity's Information Accreditation Scheme application (e-mail from manager, Appendix 15¹). However at the time this learning cycle was undertaken, service-users had no input into the charity's information services. A form of service-user information which appeared to be well received by management took the form of a *good news story* (e-mail from fundraiser, Appendix 16²); when positive feedback was received from a service-user this would be circulated to all users via e-mail.

4.5.2 Introduction to learning cycle

In the field of cancer care, user involvement has gained momentum in the last decade [378]. In the production of health information the need to involve end-users is advocated by authors of patient information production guidelines [22]. As discussed in the Chapter 2, there has been little research about what CAM information people with cancer want. Reasons for incorporating service-user input into the development of information and developing an understanding of organisational culture are multiple. Within evidence-based practice, the views of patients are an important component. Furthermore, in Soft Systems Methodology the

importance of understanding the worldviews of stakeholders is one of the primary objectives of the 'finding out' phase. From a cultural perspective, it has been suggested that the culture of an organisation is influenced by external factors which form a part of the organisation's values [110]. It was thus important to understand the role of the service-user as a customer at the organisation, and to understand how the views and needs of this group might contribute to the culture of the organisation. In this chapter the term *service-user* is used to represent people using the charity's services, and the term *supporter*, rather than the more conventional *carer*, is used to reflect the charity's preference.

4.5.3 Aims

- I. From a KTP perspective it was anticipated that this learning cycle would explore service-users' views of the role of evidence in information, and contribute to improving the materials the charity provided.
- II. The PhD aims were to understand service-user attitudes towards the use of evidence within the information service and how this group of stakeholders contributed to the culture of the charity. As in the other learning cycles, the process of carrying out and feeding back information to the charity was recorded in order to describe how the organisation's culture affected the feasibility of making changes.

4.5.4 Methods

An interview guide was developed by the KTP project team (Appendix 17), informed by previous work examining information seeking and decision-making behaviour in CAM [263]. Interview guides were piloted with a member of charity staff and a volunteer at the charity who was a former service-user, and minor revisions were made following comments received during the pilot¹.

Because these interviews had the defined purpose of finding out about views on evidence and how the information service could be improved from a user perspective, structured, open response interviews were used [5]. Ethical approval was granted by Plymouth University's Faculty of Health, Education and Society.

Sampling

Invitations to participate in the interviews were distributed through the charity's three main points of contact with service-users: with information packs sent out from the charity's telephone service with information packs posted out, handed out to all attendees of residential courses and given out to all new clients attending single therapy sessions¹.

The intention of this sampling strategy was to obtain a group of respondents with a range of levels of contact with the charity, and who therefore may have received different types or amounts of information. The invitation included a freepost envelope which asked service-users to return a reply slip and signed consent form if they were interested in taking part.

On returning a reply slip, I contacted participants by phone in order to reiterate the purpose of the study, describe the format of the interview, answer any questions they might have and confirm they were still interested in taking part. A convenient time to speak was arranged and the respondent was sent a pack of examples of information sheets which were used as prompts for some interview questions and to attempt to gain an understanding of how much and what type of information people had received.

It was initially anticipated that interviews would all be conducted in person. However, it became apparent that although the majority of participants attending individual therapy sessions lived in fairly close proximity to the centre, those who had used residential courses and the telephone service came from a much larger geographical area¹. Therefore in order to avoid excluding anyone outside the commutable area, phone interviews were offered as an option.

Interviews were audio-recorded using digital equipment and transcribed verbatim for analysis. In a single case of equipment failure, post-interview notes were written immediately. Following 30 interviews, the remaining 12 interviews were not transcribed as no new themes appeared to be arising from the data, but detailed notes were made while listening to recordings several times.

Data analysis began immediately following the first interview. This made it possible to refine questions or the order in which they were asked, and also to probe in greater depth any issues or areas of interest which had arisen in previous interviews.

Data Analysis

Familiarisation

Qualitative data analysis techniques usually emphasise a stage involving becoming familiar with the data collected [375, 379]. Immersion in the data was achieved through an initial read-through of data on receipt of the transcription. This was followed by a review of the transcription whilst listening to the recording, in order to amend any transcription errors and to gain a perception of subtleties in speech which were not present in the text. Notes were made during the familiarisation process.

Identifying a thematic framework

Ryan & Bernard [380] state three reasons for making explicit the choice of techniques used for discovering themes within data:

1. Themes are the basis for much social science research, without these categories there would be nothing to compare, describe or explain;
2. It allows assessment and understanding of our methodological choices;
3. To create a clear method of communication.

The first identification of themes had occurred during the development of the interview guide [381] as these were, in effect, developed from the project team's prior understanding of the topic being studied [380], hence many themes were *a priori*; stemming directly from the interview topic guide [375]. For this reason as well the structured nature of the interviews the most appropriate way of analysing the interview data was using *content analysis*. Content analysis has been referred to as not fitting entirely into the category of qualitative research, although its conclusions are substantive rather than numeric therefore neither is it a form of quantitative data analysis [382]. Weber suggests that effective content analysis can make use of both quantitative and qualitative operations on text [374]. At a basic level, content analysis can consist of the counting of similar words however the nature of this data required a method which would take into account the open nature of the questions and hence phrases were categorised according to their meaning. In this respect the analysis shared properties with methods which involve coding and indexing data such as a framework approach [375]. Another reason for reporting the frequency of a view or opinion is that the data had the potential to influence change at the charity, and therefore it had previously been highlighted by management staff that this information was important.

Coding

During the familiarisation stage notes were made of additional concepts to the interview guide which seemed to be recurring. Following this, interviews were analysed in detail and themes and patterns were noted. Subsequent interviews were coded using these initial themes but an open coding process was used to build on initial themes and patterns [383].

Validation of interview data

Issues of validity in qualitative research are widely debated and not limited to the treatment of analysing interview data but inclusive of qualitative methods as a whole.

The issue of validity may be further confused by the different contexts in which the term is used; validity can refer to the generalisability of results but also, more relevant to analysis, the validity of the analysis itself i.e. the categories created to analyse the data correspond to the concepts they represent [374]. Burnard suggests that additional researchers should generate category systems independently to the main researcher followed by which category systems are compared and a coding framework agreed and applied to subsequent transcripts [373].

During analysis of these interviews, a researcher who was not involved in the study (Information Officer) was given a copy of the interview guide and two uncoded interview transcripts. This second researcher applied codes to the two transcripts according to the a priori themes from the interview guide, and recorded any other significant themes they felt came out of the data. This was then compared to my own coding of the data and differences were discussed (Second researcher coding, Appendix 18²).

4.5.5 Results

Presentation and discussion of results

Selected quotes are included in this section to help illustrate the content of the interviews, and, as discussed above, the frequency of different responses is included in order to reflect how many participants held this view.

Response rates

From people attending individual therapy sessions, forty-seven invitations were given out and fourteen responses were received (30%). On residential courses one-hundred-and-three invitations were given out and sixteen responses were received (16%). Through the telephone service, six-hundred-and-forty-nine invitations were sent out and seven responses were received (1%)¹. It was unclear where five of the invitations had been sent from.

Two supporters who had initially expressed interest in taking part subsequently dropped out; one when their partner died and another due to personal health reasons and caring

commitments. There were some suggestions by participants that the difficult and confusing time for them (due to their condition) led to delays in responding to requests for interviews.

When one service-user couldn't remember if she had returned her consent form, she referred to the amount of literature she had received.

'I'm not kidding you – you read so much to do with your cancer that you end up bottle-stop eyed and thinking "I don't know what the hell I'm doing."' [Interview 42]

And another commented on time demands of their illness.

'Having cancer is like having a full time job.' [Interview 27]

Participant characteristics

The sample consisted of 32 women and 10 men. The age range was 36-78 years old with an average of 54 (median). Thirty-five participants had a past or present cancer diagnosis, six participants were supporting someone with cancer, and one was a complementary therapist who had received the invite through information requested from the charity. The frequency of the different types of cancer based on the World Health Organisation IDC-10 classification was: Female genital organs (n=10), Breast (n=13), Secondary (n=3), Male genital organs (n=3), Digestive organs (n=5), Lymphoid Haematopoietic and related tissue (n=2) and respiratory and intrathoracic organs (n=2). Amongst participants who had been given a diagnosis of cancer the length of time since their diagnosis ranged from 2 months to 5 years, with an average of 10 months (median), four of these participants had received a previous diagnosis of cancer more than 10 years ago.

Previous interest in complementary therapies

Of the forty-two participants interviewed, twenty-nine had been interested in complementary therapies before their diagnosis (or the diagnosis of the person they were supporting), and

thirteen had become interested since diagnosis. Ten participants described interest in complementary therapies throughout life, some mentioning that their family had introduced them to complementary therapies.

How participants found out about the charity¹

The most frequently reported way of finding out about the charity was through word of mouth (n=21)¹. This either occurred through people who had used the charity's services or by knowing professionals who had been involved at the centre at some point. Several participants had heard about the charity through publicity (n=6) or been referred from another organisation (n=5). Other ways of finding out about the charity were through external literature (n=3), the internet (n=3), through a GP or hospital (n=2) through work (n=2) or through a support group (n=1)¹. One interviewee knew about the centre through being at school nearby, and one was unsure of how they found out.

Using information about the charity¹

Many of the participants had looked at information provided by the charity prior to using the services (n=26), others hadn't looked at any literature (n=7), and a few had looked at external literature which made reference to the charity¹ (n=2).

Accessing information on complementary therapies

Almost half of participants said they hadn't looked at any general information on complementary therapies (n=19). Those who had sought information (n=19) had used a variety of sources: Books/Newspapers (n=8); other CAM services (n=8); speaking to other people (n=4); the internet (n=4); doctors (n=1); the library (n=1). Few gave reasons for not looking at information, although one respondent felt it wasn't important because of her own knowledge of complementary therapies and another said that time was a constraining factor.

Making decisions to use charity¹

A third of participants reported using the information they received from the charity to make a decision about using the services offered at the charity along, with talking to friends, family, doctors or someone at the charity (n=14).

Two expressed that they used solely the information to make a decision about using the charity's services¹. Others said that they hadn't used the information to help make a decision about using the charity¹ (n=6).

Reasons for interest in the charity¹

There were many different reasons for interest in using the charity¹.

Self-Help (n=14)

The most common reason participants gave for interest in the charity was to provide themselves with tools or methods to enable them to help themselves or take an active part in their treatment, this was sometimes mentioned alongside a desire to gain a feeling of having some control of their situation¹:

'... it felt quite important for me to take an active part in my own treatment if you like and in trying to get better'. [Interview 19]

Nutritional Advice (n=11)

Nutrition was a common reason for participants using the charity¹. Many participants were keen to find out more about how nutrition could impact their health and receive individual advice on how to eat healthily:

'When I tell them the supplements I'm taking they can tell me whether they're good, bad or ugly, what I should be taking on top of it, what I maybe needn't be taking.'
[Interview 5]

Support (n=8)

Several participants mentioned the issue of support, in some cases this was the feeling that they needed extra support through conventional treatments for cancer or after the treatment finished:

'It was the idea that I could get complementary support whilst I was going through chemo.' [Interview 12]

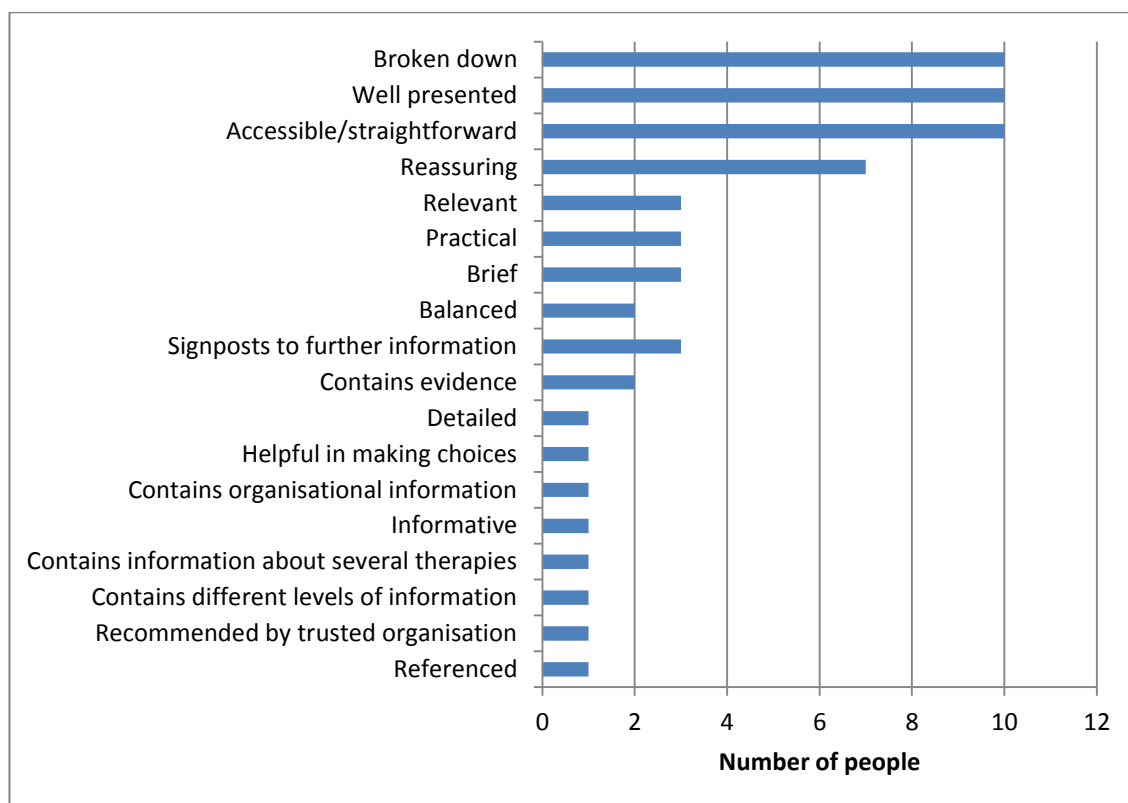
Other reasons for using the charity¹

Several other reasons were given for using the charity's services: the holistic nature of the approach; (n=5); interest in individual therapies (n=5); to help prevent cancer (recurrence or hereditary) (n=4); trust for the charity (n=4); the range of different elements or therapies (n=4); the positive nature of the approach (n=3) (two participants contrasted this with negativity of conventional medical care); 'time out' (n=2) or that the complementary nature of the approach meant that they could use it at the same time as conventional treatments (n=2). One service-user mentioned that the existence of a donation rate meant that they could afford to access a therapy service more frequently than they would have been able to if they were paying privately for treatment. Two participants referred to negative aspects of medical treatment which had influenced their decision to use CAM although these did not appear to be their primary motivating factors.

Useful properties of information on complementary therapies

There were many factors which participants reported as being qualities which would make information on complementary therapies useful to them (Figure 17).

Figure 17 Useful qualities of information on complementary therapies



Several participants talked about information being useful when it was in an outlined, broken down or bullet pointed format (n=10):

'We're lazy so we need bullet points. We don't need reams and reams of information.'
[Interview 8]

The importance of evidence

The majority of respondents (n=36) said that evidence was important to them. At this point in the interview, evidence had not been defined by myself or the interviewee. Some participants elaborated on reasons why they felt it necessary for information to be supported by evidence.

Several participants expressed the feeling that evidence-based information was reassuring, gave them confidence or helped them to trust the information:

'I found that very – I can't think of the right word – comforting I suppose. There's a sound scientific basis behind the approach, behind the advice.' [Interview 12]

Some expressed the view that while it was a good thing that research had been used to produce information they were not likely to examine the details of this research further themselves:

'I like the fact that you've given me that information. It means you're real and you believe that what you're doing is real and you're not just saying it. I think that's important..... I'm not going to look that stuff up I like the fact that it's there.' [Interview 5]

One respondent spoke of a desire for evidence to assess whether or not a treatment was safe:

'I wanted reassurance that things were safe and if not scientifically proven, not as in depth as NHS, but I did want some knowledge of what therapies are useful for what symptoms and particularly safety.' [Interview 38]

Several participants discussed issues involved in obtaining evidence which they felt placed limits on the value of research (n=13). These reasons included limitations to medical knowledge, and the medical profession being biased against CAM:

'And particularly ones with long standing histories, so I just – yeah western medical science doesn't know everything, although it's a help but it's not the be all and end all by any means.' [Interview 19]

'Doctors, I think they're easily swayed, unless, like mine, they're anthropological [sic] even then I think they can be easily led, I think pharmaceutical companies have got a big hold on doctors and can persuade them about different things.' [Interview 2]

Others stressed that the fact that due to individuality, research may not be relevant to everybody:

'The thing is I think with complementary medicines is that you don't know until you try you know what it's going to be like, because the one thing that having cancer has taught me is that what will suit me will not suit somebody else who's got exactly the same problem. You know obviously there are many, many different types of cancer so you have to find what works for you and certain things won't work for you because we're all individuals I suppose.' [Interview 26]

A minority of participants expressed the feelings that evidence was not important (n=6). This seemed to relate to trying a therapy to see for themselves if it worked or an existing faith that the treatment would be useful:

'I think my approach is – so I'm much less inclined to think there has to be a scientific – yeah I think that's why I was asking at the beginning whether it really is about evidence basing because I don't feel I need to read six studies that talk about the effectiveness of something before I would try it and think is it effective for me? Is it something I find helpful? Especially since I still think there's a climate generally of, you know, kind of hospital based medicine not being very supportive of it. So I wouldn't... It feels quite polarised to me. So I think, let's try it and let me see.' [Interview 10]

Nature of evidence

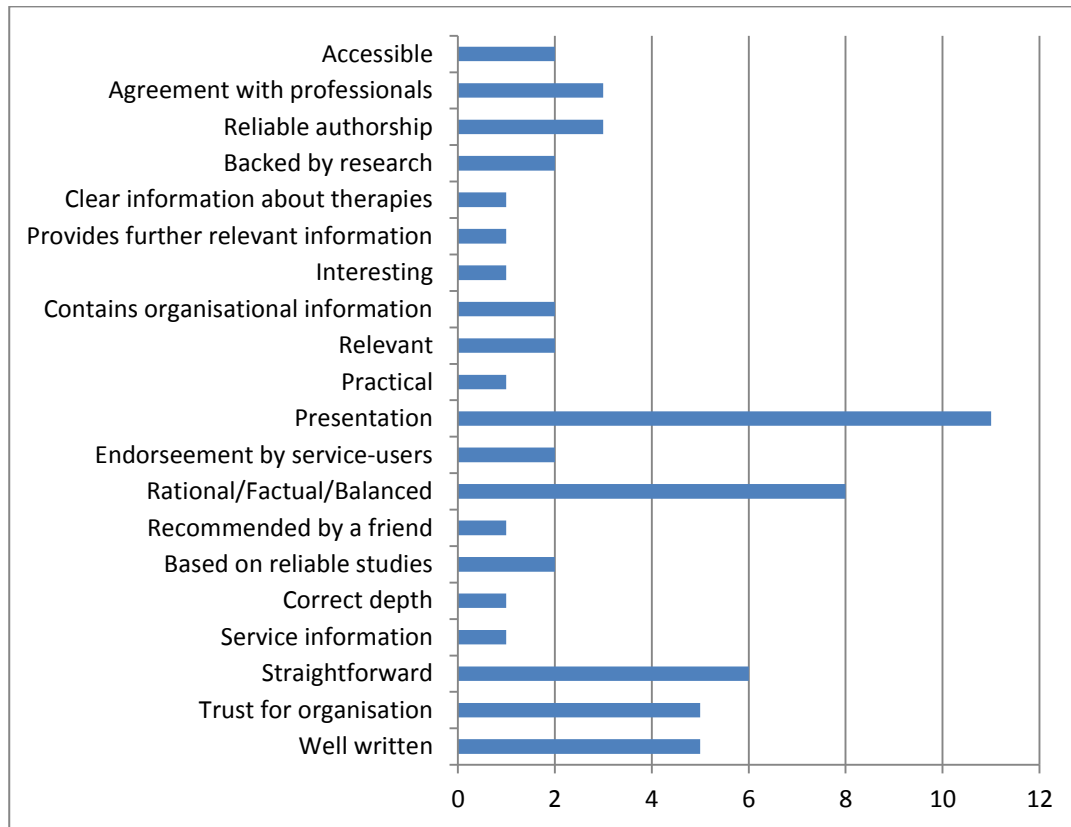
More than half of the participants (n=23) felt that it was important to have evidence based on people's experience and a similar number felt that clinical trials were important (n=24). These two types of evidence were not mutually exclusive as several participants wanted to see both types of evidence (n=15):

'Both. I would look for both. I mean I think that personal narratives are really quite important because you can identify with the people there. But it's nice to feel there is scientific, whatever that means, some sort of scientific evidence to support it as well. So both.' [Interview 3]

Indicators of quality

Participants discussed many different indicators of the quality of health information, these are summarised in Figure 18.

Figure 18 Reported indicators of quality in CAM information.



Preferred format of information

Two-thirds of participants (n=28) expressed the importance of paper based information above other formats. Some elaborated on this preference and suggested that it was reassuring to have something physical to hold. Other participants expressed the convenience that paper could be carried around or read while relaxing rather than sitting at a computer or simply being more of a ‘paper based’ person. Some suggested an age related factor contributing to their preference for paper based information:

‘So that very intimacy of that shock and that ripple, sometimes just being given something physical which you can hold, a bit of paper or a contact number. Simple, straightforward, clear. Again people can then make an informed decision about do I take up this offer of information. Do I make this phone call. This has given me a little bit about this, a little bit about that. When it’s actually easier to do it with something

physical than a screen. Or even if you print something off it's still – you know, I think there's a space for that. I think we really mustn't lose that.' [Interview 8]

While some service-users reported finding the internet a useful source of information, others cited reasons for not using the internet. These reasons included spending time at work, or their age:

'I spend a lot of time at work in front of a computer I often don't put my computer on I don't really want to come home and look at the computer as well so I much prefer to sit on sofa with my feet up and read through information. [Interview 35]'

I *'What about the internet, do you use the internet at all?'*

F *'Oh for God's sake I'm sixty-seven.' [Interview 42]*

Improvements to information

Participants had several suggestions of how information could be improved.

Accessibility

Many suggestions for improvements to the information related to its accessibility with participants feeling that it could be presented better to make it more accessibility (n=12). It was felt that accessibility could be improved by increasing the size of text, decreasing density of text, justifying paragraphs, taking into account some participants had limited ability on computers, improving language, offering audio alternatives to printed information and condensing information:

'It's just it seemed a lot to read on a page. It could have been spaced out a bit more perhaps with a little drawing, a little caption or something. Like meditation, to me it would have been nice to have had that written, but then just had a little cartoon of somebody meditating. But I learn best by that I think. I know that isn't always possible.' [Interview 13]

Presentation

Several participants felt that information could be improved in terms of its presentation (n=13), frequently referring to their individual preferences. Taking the idea of improving presentation further, some service-users felt that the information should be more consistent in the way it was presented, that sheets should all look like they come from the same place (n=4):

'The stuff I got on the course when I actually came on the course not all of it was available, like the cooking formulas for example were sent to me later. And I found a bit of discoordination if you like between the different – the stuff you sent me didn't seem to be coordinated in the style it was presented in, in terms of visually.' [Interview 9]

Overload

Several participants expressed concern that there may be a risk of overwhelming participants by sending out too much information (n=11):

'I think don't bombard people with too much information at the beginning, enough but not – some would have been useful for me but I'm quite good at asking questions whereas you know some people would just sit there and probably not ask things.' [Interview 27]

Service Information

An issue mentioned by many of participants (n=18) was that it would be useful if there was more information to explain how the services at the charity worked, this included understanding how an access fund worked, knowing what therapies were offered and the distinctions between residential and individual therapy services and a map and directions to help find the centre¹:

'I thought there could have been a much more – I mean it's probably better now, but I think the information on the course itself laying out what was going to happen and all the ideas if you like in a very well-presented way would have helped quite a lot.'
[Interview 9]

'The map isn't easy. The directions aren't easy.' [Interview 10]

One service user suggested that it would be useful to have a method of understanding how the information could be navigated:

'[A] Contents page would be useful to cover all of the information - make it easy to navigate. Possibly something like a mind map which showed people exactly what information was available this should go for the internet as well, as in a really good first page.' [Interview 32]

Additional Information

Other comments were of an individual nature, participants mentioned areas where they required information but were unable to find this within the charity's catalogue of information. This included information on exercise, specific dietary supplements, and side effects of treatment.

Information received

Although it was difficult for participants to remember exactly what information they had received from the charity, this varied between participants who had seen all of the information in the pack sent out and other who had seen very little. This did not appear to correspond to an individual's point of contact with the charity.

Financial barriers to using complementary therapies

A theme which emerged independently of the topic guide was that lack of money was an obstacle to using complementary therapies whether this was the charity or other

practitioners¹. Two issues were discussed; one referred to the expense of CAM and the other specifically talked about a lack of money as a barrier to accessing therapy services:

'I mean maybe it works you know and all this stuff about shark's cartilage but I'd have to take a ton of it every day and it would cost a fortune, and it really will cost a fortune.' [Interview 5]

'We can't, he can't run to 13 [thousand pounds], you need full time employment to do Gerson kind of thing? But no doubt it works, I'm sure that if we did have full time employment then the money would go to Gerson, you know if somebody could do it for us.' [Interview 24]

Information Difficulties

Several difficulties associated with using information were mentioned by service-users.

Conflicting advice

Several participants talked about it being confusing getting advice from different sources which differed vastly:

'I'm not an unintelligent person but I've got no experience to know how to decide between the two. [For example I] started chemo on Cistoplatin then found a site saying 'Never take this drug - what the doctors don't tell you.' So I found in the end that I stopped looking for info on the internet because I found it contradictory or at variance with what the doctors told me, very bewildering.' [Interview 37]

Difficulties accessing information

Eight participants spoke about problems with accessing useful information. There were several reasons given for these difficulties.

Bad quality information

Several service users talked about the issue of the existence of poor quality information:

'All these books say 'here's the scientific evidence' and I look at it and think this isn't real evidence at all – I know when clinical trials are clinical trials. It's important that it is scientific and not just protesting to be. Some of these cures are just pretending to be scientific and not saying what they do.' [Interview 42]

Finding information

Some users spoke about difficulties finding information they wanted on a particular topic:

'And I couldn't find any information on what I had because what I've got is so off the wall, you know, nothing was there really for me.' [Interview 5]

Sensitive topic

One user found exposure to certain information difficult because they had recently been diagnosed with cancer:

'I've found things on the radio which have happened these last couple of weeks, because it's been breast cancer week on Woman's Hour, I couldn't listen to them. But I think that's because it's new and fresh for me, and I'm still coming to terms with it. I don't want this label which is now hung round my neck. So I haven't yet found anything that's helpful.' [Interview 3]

Unwanted information

Some participants mentioned issues with being given information that they didn't want:

'Friends who are so well meaning – if I did everything that people told me to do, I'd go insane! What I wanted from the charity was a pragmatic approach which they gave me, listen to your body and let it happen¹. You can get so confused, coffee enemas could only be given by a coffee enema therapist and could only use blue mountain coffee and I thought 'what a waste of coffee' I know you can heal yourself in spirit but some people can't it's too advanced – mine is quite advanced when you've lost three vertebrae.' [Interview 42]

Told by doctor not to look

One service-user was told by a doctor not to use the internet:

I *'What about the internet, have you used that at all?'*

F *'No, well that was mainly – I suppose that might be just me – but the hospital said to me as soon as I got the diagnosis, "Don't you dare go home and look at that internet." I said, "Well I was going to", cos I was. I was going to shoot home and have a look at it all on the internet. He says, "No you're not because you'll frighten yourself." So anything to do with the cancer, except for once I looked at it and I did frighten myself. I went back to the hospital and I told them what I'd read. He said, "That's why I told you not to look."' [Interview 13]*

Difficulties judging quality

Two participants mentioned difficulties knowing whether or not a piece of information is of good quality or not:

'Anyone can put any evidence on there. I mean it's got – like in here you've got things where evidence and things like that – are you actually going to look that bit of evidence up and see if it's true. So you know anyone can say this works and the evidence is this, how do you know it's true?' [Interview 7]

Physical barriers to information

Many participants talked about physical difficulties using information due to their cancer or treatment (n=11). Participants reported that they found it difficult to absorb information due to pain, or a reduced concentration span due to chemotherapy treatment, low energy levels or having a busy treatment schedule:

'I haven't been able to concentrate the same as I would have done since the chemotherapy, so if there's less on a page I'm better. But that, at one time that would have been fine, but I must admit since I've had the chemotherapy it's taken a while for me to be able to think properly.' [Interview 13]

4.5.6 Discussion of interview results

Demographics

The response rate for these interviews was low and therefore risks a biased sample in which non-respondents differ from respondents. One study which has examined reasons for a low response rate amongst a population of cancer patients attributed a low response rate to 3 factors: (i) A lack of physical and psychological motivation to participate; (ii) sensitive and private content of the questions; (iii) methodological problems (15).

Differing response rates were recorded from different points of contact with the charity.

Individual therapy session users had the highest response rate, followed by course participants then telephone service users¹. This corresponds to the level of contact that users were likely to have had with the charity. It may be that users who have had an on-going relationship with the organisation were more likely to respond compared to someone whose only contact with the charity had been a single telephone call.

Time may have been another relevant issue; during the process of trying to arrange interviews it was problematic to arrange suitable times with participants who worked full time or had children to look after. Other participants had busy treatment schedules which interviews had to be arranged to fit in with. There may also have been issues with the invitation being *just another piece of paper*.

It was not possible to compare respondents to non-respondent characteristics at the charity as the charity¹ had recently changed the software they used and were no longer able to examine demographic information about service-users. Although the sample could not be compared to the population accessing the charity's services, compared to national averages it can be seen that the sample was younger [384] and comprised of a higher proportion of females than might be expected in a probability sample [385]. This appears to be in agreement with

published data generally which suggests that CAM users are more likely to be female and of a younger age than non-users [52, 56, 175, 386].

Use of CAM

As discussed in the Chapter 2, a number of reasons for CAM use have been proposed in the literature. These are generally divided into Push and Pull factors; Push factors being due to negative feelings towards conventional practices and Pull factors being due to the positive attributes of CAM [166]. More recent studies have suggested that CAM use is more likely to be due to Pull factors [179, 180] and these interviews appear to support this, with people describing reasons for use in line with the biological and psychological factors outlined by Spadacio and Barros [54].

While many of the service-users had described previous CAM use, others had no experience of therapies prior to a cancer diagnosis. A number of people talked about use of CAM throughout life. This information could be seen to map to Shaw, Thompson and Sharp's typology of CAM users with different levels of commitment and some people for whom a 'trigger factor' (in this case; cancer) had prompted use [166]. From an information provision perspective this highlighted the issue that people were likely to have different levels of familiarity with complementary therapies and as a consequence have different information needs. The participants reported using the charity in addition to obtaining available treatment on the NHS. Although in some cases curative treatment had not been possible, this group of users did not appear to be the 'last resort' users described in Shaw's typology but rather accessing the charity to improve quality of life.

Use of information in making decisions to use complementary therapies

Some people reported actively looking for information while many had reported not looking at any general information on CAM, although more had looked at information provided by the charity. The responses indicating the different levels of information seeking are in some

agreement with a study by Evans et al who suggested that a group of male cancer patients became either *proactive seekers* or *passive recipients* of CAM information [263]. People who looked for CAM information had used a variety of sources although use of the internet did not feature very heavily with a minority of service-users reporting internet use. These responses may seem somewhat surprising in light of literature which refers to the internet as a widely accessed source of health information [231, 232, 234]. However similarly to these results, Evans et al describe the internet being a little used source of CAM information [263]. A 2004 study which compared a group of *offline health information seekers* to 'online information seekers' suggested that increased age, lower income and lower education were likely to predict offline information seeking [387]. While respondent income and education were not discussed in these interviews, the group's average age was 54 which was similar to that of the offline information seekers average age of 52 in the study.

Types of evidence

The majority of service-users interviewed had reported that it was important for information to include evidence. When asked to define evidence people described that evidence from research was important, sometimes relating this to providing them with a level of reassurance. However another important source of evidence reported was the experience of other users of CAM. These views of evidence appeared to be similar to the limited number of studies which have examined information needs relative to CAM and cancer and have suggested that in addition to scientific evidence, people consider other sources to be important such as personal stories, historical use of therapies, plausibility, trust in providers, information from family and friends or *gut feeling* [262-264]. Although few people had reported that evidence was not important, some had suggested limitations of research such as bias or failure to take into account individuality.

The finding that the experience of others was viewed as being so important may have led to word of mouth being the most frequently reported way of finding out about the charity¹;

findings from several studies suggest that this is a frequent source of information and a motivating factor for CAM use [262, 264].

Implications for the charity

These interviews were one of the few attempts made at the organisation to engage with and gain an understanding of the needs of people using the charity's services. Although focused on information needs, the findings had the potential to provide the charity with a greater understanding of the people using its services.

The service-users interviewed represented a pragmatic group of CAM users who were generally using the services of the charity in addition to conventional treatment. The most important implication for the charity from an information provision perspective appeared to be that service-users valued evidence, and that evidence was defined as both information gained from scientific study as well as user experience. The findings reaffirmed the value of an Information Department whose major role was the synthesis of available evidence on therapies offered by the charity, but suggest an information gap in that the charity was not providing information about people's experience of using CAM¹.

The interviews highlighted several practical issues relating to factors which led to information being judged as useful and good quality. Participants were most likely to judge the quality of information by practical attributes such as presentation, and information written in a balanced manner. Results also suggested that in order to be useful, information needed to be well presented and accessible. It had been highlighted by some that there were cancer and treatment related reasons for requiring brief, broken down information.

The fact that participants reported differing levels of familiarity with the information they were shown during the interviews suggested that there may have been inconsistencies in the information given to service-users. However participants' responses to this question were unclear as they had struggled to remember what information they had received.

Several participants had reported cost being a restrictive factor to accessing the charity's services. This implied a lack of service information as the existence of an access fund at the charity was designed to ensure people could access the charity's services regardless of their financial circumstances. Although the fund was known about by staff, I was told that this was not advertised as it was not wished that the charity's services were perceived as free.

4.5.7 Feeding back results to the charity and making changes

Although these findings could be explored in greater depth, the focus of this PhD is on how the findings were shared, interpreted, and acted upon within the organisation. As discussed in the methodology and methods chapter, following the *finding out* stage was anticipated to be a participative discussion amongst a *change management group* with the use of conceptual models provide structure to the debate. The concept behind the participative discussion was that this would lead to change which was deemed to be acceptable by members of the organisation [293].

From the start of the project, difficulties setting up this group had meant that discussions took place with a limited number of senior managers and that plans for change had taken place largely within the KTP team and Information Department. In effect, the anticipated *structured discussion* phase was largely missing from the learning cycles.

As with the previous learning cycles, attempts to feed back results of these interviews was an ad-hoc process through sending e-mails and requesting meetings with senior managers.¹

The results of the interview study were written up as a 5000 word report which summarised the findings (Appendix 19²). This report was co-authored by the information department manager and shared with their replacement¹. Additionally, a discussion of the interviews findings took place with the Information Officers⁸.

Due to the fact that much of the information given out to service-users came from therapists, a meeting was sought with the therapy manager¹. However, because of their time commitments, a meeting was not possible until several months after the report was produced¹. By this time the organisational restructuring meant that several managers, including the therapy department manager, had been made redundant¹. While the therapy manager commented that the results were important, they reported that it was not something they were able to take forward due to their redundancy¹. In the nine months following the new senior management team's appointment, it was not possible to meet with the new manager to discuss the interviews¹. Despite me sending several e-mails, making face to face requests and sending electronic meeting requests, several meetings were made then cancelled. The CEO expressed interest in the results at a Local Management Committee meeting, however e-mails containing the reports were met with no response.

Although the interviews had focused primarily on information, participants had raised issues about many other aspects of the organisation, such as cost of services or its marketing

⁸ During this learning cycle one of the Information Officers found a copy of an information sheet they had produced but with many amendments. Upon investigation it turned out that a senior member of staff¹ was in the process of re-writing all of the information produced by the Information Department and when confronted by a member of Information Department staff, their rationale was that they did not think that this information was appropriate for service-users although this issue had not been raised with anyone in the Information Department¹. This event also highlighted the poor communication at the organisation as the manager had not raised her concerns with the Information Department.

strategy. Because of this, a meeting was sought with the fundraising manager however several appointments were cancelled and this meeting never took place¹.

4.5.8 Implementation of change

With the reluctance of senior management staff to address the findings of the service-user interviews, discussions on how to take results forward took place within the KTP team and Information Department. Following discussion with the Information Officers and manager of the department, several changes based on the findings were made to the *CAM Information Sheets*¹. These changes consisted of:

- The introduction of an *In brief* section on the information sheets which summarised the information in the proceeding pages.
- Text being broken down into shorter sections in order to appear less dense on the page.
- The removal of references to research papers; these were replaced with a statement that references were available from the charity's telephone service¹ on request.
- The introduction of a *glossary of terms*.
- A change of format to the sheets to incorporate images. This was possible using KTP funding to fund production of a new set of information leaflets.

Production of narrative information

It was clear from the service-user interviews that participants valued the experience of others, whilst at the same time were mindful of the need to have information underpinned with evidence. The value of this form of CAM information has been described by Evans et al [263] as well as being described as a valuable form of information from a clinical perspective [388].

At a KTP project team meeting it was suggested that these two forms of information could be linked together, whereby web-based text describing a service-users' experience at the charity would contain hyperlinks to other internal and external sources of evidence-based information.

In order to develop the evidence-informed narrative, further ethical approval was granted for the involvement of service users in additional interviews. Four service-users were approached; these people were chosen to represent a range of conditions and live within reasonable travelling distance of the centre. It was intended that these interviews would follow an unstructured guide which would encourage participants to talk freely about their experience and emphasise what they felt was important to them rather than be guided by questions. The interview guide consisted of open questions and included prompts to encourage respondents to expand on their answers (Appendix 20). Respondents were contacted by telephone or e-mail, informed about the further interviews and asked if they would be interested in participating.

Interviews lasted between 30 minutes and one hour with two taking place at the charity's premises and two at the participant's homes. Interviews were audio-recorded and transcribed using the same transcription service as in the previous interviews.

The interviews were long and the unstructured in nature and did not lend itself to a flowing narrative. Therefore the initial transcripts were edited to form a condensed narrative of the participant's experience. This was then sent back (posted or e-mailed) to the participant in

order for them to provide feedback and state if they were willing for their narrative to appear anonymously on the charity's website. Three of the users responded with minor amendments relating to tense and order, one respondent was concerned a relevant piece of information had been missed out. One of the respondents was not able to be contacted following relocation and, despite an initial response to an e-mail, failed to provide feedback on the narrative. The other three narratives were published on the charity's re-developed website. These narratives contained links to the CAM Information Sheets where service-users had referred to therapies (Appendix 21).

Links contained in the narratives were to CAM Information Sheets where participants had made reference to therapies, and also to sources of general information on cancer which achieved high scores using the assessment tools identified in Chapter 4.1¹.

When putting together narratives I was aware of the conflict between being objective in providing an account of the experience of using complementary therapies, but also aware that from a marketing perspective it would not have been acceptable to write anything negative about the use of CAM. The service users interviewed were extremely positive about their experience, but my concern did highlight the blurred line between information and marketing materials encountered in earlier work. These new narratives were placed on the charity's website in July 2009.

4.5.9 Discussion of learning cycle

The following section presents a discussion of the learning cycle as a whole, relating findings back to the research questions.

Difficulties feeding back information to organisation

Previous learning cycles had described difficulties with the feeding back process. However it might have been expected that, with an apparent growing emphasis on the charity being a user-led organisation that a large user involvement initiative would have been met with enthusiasm. Conversely, feeding information back to the organisation proved even more difficult than previous learning cycles. I had highlighted to the marketing manager that service-users had raised several marketing issues which I was happy to discuss, however arranged meetings were cancelled several times¹. Only months earlier all staff had been told to prioritise the charity's goals of increasing numbers on courses above all else so it appeared to be a contradiction to the charity's stated values that this source of user information was not valued more highly. Earlier learning cycles had discussed the prioritisation of marketing values over good quality information, suggesting that the organisation was 'task focused' which Kitson et al suggest is not conducive to using evidence in practice [389]. However despite information from these interviews seemingly being in line with the organisation's stated aims of providing a user-led service, they were still not well received.

Equally, during the Information Department's efforts to change their information in line with service-user requirements, it seemed contradictory that a member of the therapy management team would put so much time and effort into re-writing all of the information. While their rationale was that the information wasn't appropriate for service-users, this appeared to be entirely opinion based. This high value assigned to personal opinion as a source of information has also been reflected in staff interviews (Chapter 4.4). Conversely the Information Department had been willing to take user feedback into account, suggesting differences in values between these groups. Schein suggests that differences between the shared assumptions, values and beliefs are likely to arise between occupational groups within a single organisation, in part due to different identities associated with their roles [41]. It appeared that the Information Department placed much more value in receiving new

information and were happy to change their practice as a result. This contrasted with the charity's apparent interest in *good news stories* which appeared to assure people that the charity was doing good work. This lack of willingness to question practice appeared to be in contrast to the 'learning organisation' discussed by Davies and Nutley [129] but rather people were more content to take on board information which confirmed their current worldview, such as positive feedback, rather than to have these assumptions challenged by new information.

Changes to information

Information had been amended by the Information Department in line with the stated changes from service-users. These changes were mainly related to presentation. In addition to making practical changes, the Information Department had taken on board the feedback that service-users' preference for evidence included hearing about the experiences from and appeared to broaden their definition of what evidence was by agreeing to the production of information narratives. The fact that many service-users felt that evidence was important was also useful for affirming that the information the department was producing was relevant and had been in agreement with previous research suggesting the value of information from other people [263].

While these changes could be seen as a positive step and an attempt to be responsive to service-user needs this was likely to have had a limited impact. The printed information learning cycle had shown that the Information Department produced a small proportion of the information given out at the charity, and the extent of the distribution was not clear. The staff who produced the majority of information, the therapists, had not been consulted which had been due to the logistical problem of not being able to feed back results to their manager¹. Although reasons for not meeting with this senior manager were given as their lack of time,

they had previously stated that he viewed service-users experiential information as particularly valuable therefore it appeared contradictory not to prioritise discussion of these results¹.

Limitations

Although possible reasons for a low response rate were considered, this was still a major limitation of these interviews and risks possible selection or nonresponse bias if issues of interest are related to the willingness to participate in a study [390]. Another limitation is that because of the format of the interviews, the sample may be biased towards those who felt able to talk about their experience [250].

The production of new information using accounts of service-user views had been based on interpretation of the interview data. Due to time constraints these were not evaluated by service-users and hence their value and usefulness was not established.

Although a second researcher was consulted and examined two transcripts, the majority of the coding was undertaken by a single researcher which means the results are more at risk of being open to the subjectivity of a single researcher. In addition to this it is possible that the political environment in which results were being fed back to the organisation influenced how service-user comments were interpreted.

4.5.10 Summary

This learning cycle represented the first time that service-users had been involved in the work of the Information Department and was a useful process in illustrating the, sometimes unmet, information needs of people accessing the charity's services. Demographics of the sample had been largely similar to those reported to be most likely to use CAM.

The most relevant finding with regard to the research aims was that evidence represented an important part of information for service-users, and that evidence referred both to findings

from clinical studies as well as personal narrative. Taking this forward, new information was produced in the form of user accounts (narratives) of CAM and this was linked to evidence-based information.

The charity's Information Department had been responsive to service-user feedback and had made changes relating to views expressed regarding how materials could be improved. However the extent of these changes was limited to a relatively small proportion of the information produced by the charity and other areas of the charity had been less responsive. Attempts to discuss the findings of the interviews with senior management had resulted in a string of cancelled meetings and a lack of availability, strongly contradicting the charity's claim to be a user-led organisation. Even the prospect of obtaining service-user views on the marketing of the charity at a time of a reduction in service use did not seem to be motivational enough to cause prioritisation of a discussion of the interview results. An example of information being rewritten by a senior member had highlighted that, similar to the findings of the staff interviews, personal opinion was a highly valued form of information.

Chapter 5: Discussion and Conclusions

5.1 Introduction

In this chapter I will synthesise the findings from previous chapters, describe learning cycles and present findings in the context of existing literature in order to highlight the contribution of this study to knowledge. I will begin by addressing the research questions, first describing cultural factors which affected attempts to make changes to the information service and examining these in the context of literature describing appropriate characteristics of a culture facilitative of evidence-based practice (EBP). In this chapter I will go on to describe other, non-cultural factors, which appeared to affect the feasibility of introducing change to the organisation. I will then move to the second research question and discuss, in light of the culture encountered at the organisation, what changes to the information service were feasible. This section will include a discussion of the impact on the charity's information service of the attempted changes, and consider whether or not these fulfilled the original remit of creating a more evidence-based service.

I will critically discuss the methodology that was used, and consider how this contributed to the design of the study, the data gathered and how SSM interacted with the culture of the organisation. The benefits and drawbacks of using SSM and action research in general will be discussed and possible alternatives will be suggested.

Limitations of the study will be presented followed by potential directions for future research. Finally, the main contributions to knowledge that this work has made and the relevance of this to practice will be stated.

5.2 Research question 1

What cultural factors within the organisation influence the extent to which an evidence-based information service is supported and used?

In this section I will discuss the findings from this study relating to the first research question. While some discussion took place and has been reported within the individual learning cycles, in this section I will synthesise the findings and place them within existing theories of culture and evidence-based practice. I will include a discussion about the individual attributes of the culture at the organisation and describe the impact that these had on the feasibility of improving the use of evidence within the information service. Following this I will outline these findings in a tentative conceptual model. I will then summarise non-cultural organisational issues which impacted the project and outline whether or not this could be considered an appropriate culture for the implementation of evidence-based information practices.

Models presented in Chapter 2 suggested that culture is a complex component of an organisation and is manifested through artefacts and espoused values, underpinned by underlying assumptions. Therefore it is difficult to separate these interlinked aspects when attempting to describe the culture. While these components were not independent of each other, for clarity they are separated into major factors that impacted on attempts to increase the use of evidence within the charity's information service.

5.2.1 Being 'Too Busy'

One of the consistent difficulties throughout the study, impacting on the possibility of feeding back results, and making changes at the charity had been the *busy* culture at the organisation. One of the behavioural norms of staff at Director and Senior Management level was to frequently report a lack of time as a reason for being unable to meet to discuss findings from the project and to consider how the situation could be improved. With a lack of discussion

taking place it was hard to understand how, or even *if*, problems with the information were perceived from a management perspective.

Although there is little research specifically describing a cultural perspective of a lack of time, some authors suggest that being busy (or at least claiming to be) is part of an image individuals try to project. Charlton differentiates *hard work* from *busyness* and has suggested that people who are busy are the most difficult to replace [391]. Members of the charity were quite vocal about their busyness and it seems feasible that, at a point where people at the charity were threatened by redundancies, this was a way of emphasising the importance of an individual's role in the organisation¹. Outside emphasising one's indispensability, Ryan suggests that claiming to be busy constitutes a form of one-upmanship in which people compete for seniority based on how busy they are, rather than expertise or knowledge they have [392]. In this sense being too busy to talk was part of how power was owned and displayed at the organisation.

While at the charity *being busy* was part of the observable behaviour and the espoused values of the organisation, other authors have suggested that this is based on deeply held assumptions¹. In a healthcare setting, Scott-Findlay and Golden-Biddle discuss *busy* as a valued component of nursing culture, suggesting that there is a preference for doing *rather* than *being*, in which it is frowned upon to be seen to be reflecting upon work rather than conducting practical tasks [393]. These authors suggest that this is a reflection of deeply held assumptions about what is considered *real work*, and suggest that activities which do not constitute real work are implicitly and possibly explicitly discouraged. Although it seemed reasonable to take people's word for the fact that they were busy, within the Information Department it was much easier to arrange informal discussions or hold meetings with team members or the senior manager, therefore a lack of interest in the project from outside the information team is also feasible. This also raises the question of whether people were too busy to engage with the work of the KTP project because it was not considered to be in line

with what was valued at the organisation which, at this point, was the marketing of the charity's therapy services.

Although time is frequently cited as a barrier in the use of evidence in clinical practice [394], this usually relates to the requirement of becoming familiar with new research literature or guidelines. However, this study highlighted that time is required not only to remain up to date with research, but in order to be able to discuss current practice and plan change.

Although *being busy* appears a fairly superficial element of culture, existing as an observable behaviour, the extent to which this affected attempts to improve the use of evidence within the information service cannot be underestimated. Without this engagement from senior managers many aspects of the work associated with this study were delayed or were not taken further. The impact of this behavioural norm was that aspects of the project were delayed by months at a time while I waited to meet with senior managers.

5.2.2 Conflicting marketing values

At several points in this study, the marketing values (that is the need for the charity to promote its services) of individuals were seen to conflict directly with attempts to implement changes to the information service. This conflict had appeared when links to websites of unknown quality were placed on the charity's website and a director had been unwilling to change this practice as it provided the charity with reciprocal links. This director's rationale for doing this had been that the charity should not be too 'purist' with regard to website content. Similarly, the objectives of *project full house* had highlighted that at the top level of management, income generation was of primary importance. The implications of this value on attempts to make changes to the information service were that initiatives would be met with resistance if they were perceived to have the potential to negatively impact income generation.

The issue of the prioritisation of marketing values highlights the fact that, as a third-sector organisation the existence of the charity depended on income which, in this case, was contingent on people attending courses. As seen throughout this research, the consequences of limited demand for courses were the closure of some departments and loss of staff. This cultural value could be seen to be a result of external pressures in line with Sagiv and Shwartz' assertion that culture is influenced by an external environment to which it must adapt [110].

The focus on income generation is suggestive of a *task oriented culture* in which an outcome is prioritised above all other considerations [401]. The concept of a 'task focused' culture features in the PARIHS framework as providing a weak context in which to introduce evidence-based practice [402]. Furthermore, one of the important factors that Davies and Nutley emphasise as being important in a learning organisation is 'open systems thinking', in which activities within an organisation are viewed as being connected [125]. Within the charity the production of information was not viewed as being integral to the primary aims of the organisation¹.

5.2.3 Management style

Schein describes a close association between management style and organisational culture [41]. It is important to consider how the management at the organisation contributed to its culture.

As discussed above, the behavioural norm of the *busy manager* provided little time to discuss organisational issues. Checkland states that one area relevant to organisational change is how power is owned and used [298]. With regard to changes attempted as part of the KTP, manager's approval was required at all stages. This hierarchical ownership of power led to a particular difficulty making any changes as, on one hand management staff appeared to want to be involved in decision making at all levels, but on the other hand were unable to make time to do this.

The initial intention to establish a *Change Management Group* was not taken forward, as it was blocked by a senior manager¹. This represented an unwillingness to allow discussion and decision making to occur at a non-management level and reflected a reluctance to allow power to be held outside the formal management structure. Without this discussion forum, the only way of implementing change was through debate with individual senior managers which, as discussed above, was problematic due to their time constraints. This management culture is comparable with potential problems described in Handy's *Task culture* [122] in which managers attempt to exert control at all levels [395]. This power structure is in conflict with Crites et al's suggestion that the ability to use collaborative team decision making was a key component of a culture facilitative of using evidence [131].

It is emphasised in theories of culture that declared or *espoused* values do not necessarily fit with observed behaviour at an organisation [41]. This was evident in the behaviour of management staff at several points in this study. Even when agreement on changes was reached with senior managers, they did not appear supportive, such as in the case of the staff workshops which several managers and a senior therapist had agreed were a good idea, but then failed to attend themselves. Similarly the language used at the charity highlighted the importance of service-users perspectives but the lack of interest in the opinions of this group suggested that the stated values of people differed from their underlying assumptions about the values of these perspectives.

5.2.4 Views on evidence

From a cultural perspective, literature had outlined a number of views regarding the value of evidence which had the potential to conflict with attempts to introduce evidence into a CAM setting. These views were likely to be a key component of the culture, representing underlying assumptions held regarding the nature of evidence. Therefore one of the key areas of interest were the worldviews of the therapy staff who were the organisation's primary point of contact

with service-users. Anecdotally this group of staff were vehemently opposed to the idea of evidence. In reality they had expressed a pragmatic attitude towards evidence, perceiving problems with the evidence base and, as such, tended to use their own experience to inform information they gave out. Although several studies have indicated generally positive views of EBP from CAM practitioners, these have been from outside the UK. Two studies based in the UK suggest that CAM practitioners are unconvinced that EBM is essential for their practice [233] or are resistant to evidence [234].

This tacit knowledge which was highly valued is, by nature, difficult to quantify. A study which looked at forms of therapist knowledge in CAM differentiated *expert knowledge* from *intuition* and suggested that the latter may constitute part of therapist knowledge [403]. Although some claim that intuition resides in the *health professional experience* arm of EBM [404, 405] others argue that the paradigm shift in EBM has been to move practitioners away from intuition and unsystematic clinical experience [406].

The value of personal knowledge may have contributed to the reluctance to attend staff workshops in which information was presented from outside facilitators. Although several difficulties had been fed back in evaluation forms, such as working patterns and distance to travel, this low-attendance contrasted to the well-attended workshops run by internal therapy staff. This suggested that the sharing of existing knowledge at the organisation may have been a more culturally acceptable format for learning. The consequences of this were that, with little interest in externally provided information, it was unlikely that the organisation would question policy or practice or challenge their existing assumptions, both of which are vital parts of being a *learning organisation* [129, 131].

One of the statements made on several occasions by management staff emphasised the value of the charity's experience over a number of years. Although in evidence-based medicine, clinical experience is considered an important part of a decision making process [396], the charity did not appear to collect data in order to inform on-going decision making. During the

KTP it was not possible to collect even the most basic demographic information about service-users. Therapy evaluation forms were not used routinely, therefore it was not clear how this historical knowledge was formed. Checkland describes historical experience as a commodity of power in organisations [294] and it was certainly the case at the charity that it was difficult to argue with something that is *known* to work or, (as I was a junior member of staff), attempt to change something that is alleged to have been proven over time¹.

5.2.5 Therapist sub-culture

As discussed in Chapter 4.4, therapists working for the organisation represented a significant proportion of the charity's workforce but appeared to constitute a sub-culture which acted and was treated very differently to staff in the rest of the organisation. This was apparent both in the structure of the therapist team as well as how they were managed.

There appeared to be a reluctance to provide therapy staff with direction, and concern that instructions would not be well received although reasons behind this were unclear. This was evident when one of the senior managers, highlighting problems with the behaviour of therapy staff, suggested that therapists *did not like rules*; consequently the manager did not act on their concern. What was significant about this group, was that they represented the *operator group* [347] and were the organisation's main point of contact with service users.

Administration processes such as contacting therapists via e-mail was not possible as some *did not like computers*, whereas the rest of the organisation had no choice but to use computers every day. This *hands off* management of therapists could be described as *Laissez Faire* [397] in which staff appeared to be given little guidance. The impact of this sub-culture on the feasibility of increasing the use of evidence in the information given out to service users, was that therapists were unlikely to use evidence and, without management staff dictating otherwise, could continue to behave in this way. This also meant that initiatives such as staff training, which senior managers stated were important, were entirely optional for therapy staff, the majority of whom chose not to attend. In some ways the emphasis that the therapy

manager had expressed on values such as the individuality of therapists, appeared to be taken from the wider values of CAM practice¹. The individuality of therapists was highlighted in the inconsistencies in their definition of the aims of the charity¹ in the staff interviews. One of the qualities of a *learning organisation* emphasised by Davies and Nutley is a cohesive vision [129], which this individuality would appear to contradict.

5.2.6 Information department culture

While the organisation may have displayed negative cultural attributes for introducing evidence to the information service, the Information Department was much more open to receiving and acting on feedback. There were several reasons why the Information Department may have been more interested in engaging with the KTP project. The KTP had been developed within this Department and therefore was closely linked to the aspirations that staff within it had for the information service. In addition to this, I was in contact with members of the Information Department on a daily basis and therefore discussion and feeding back of findings could take place informally, which was not the case with other members of staff. In contrast to other groups of staff, the information officers were receptive to feedback based on data gathered during the study and appeared to value this form of information highly. Information Department staff were much more enthusiastic about hearing how information could be improved, and in acting on this information. This included expanding their perspective on what constituted evidence, from an initially narrow focus on RCT and systematic review evidence, to the incorporation of service user and therapist perspectives. Some of the difficulties that the Information Department encountered in trying to improve the use of evidence in the information service were that the department existed in isolation from the rest of the organisation. This lack of inter-departmental interaction is in contrast to the *integration of activities* emphasised as being a component of a *learning organisation* [130].

5.2.7 A framework for the introduction of EBP into a CAM organisation

Although I did not set out to build a model of organisational culture or develop a framework, in line with SSM principles, I have summarised my main findings diagrammatically below (Figure 19). This framework is in its early stages and requires further development and testing for validity, particularly within different CAM organisations. This framework shows cultural factors which appeared to represent a positive and negative context for the introduction of evidence based practices in a CAM organisation, making use of the format of the PARIHS framework in which factors are classified as *high* (facilitators) of EBP or *low* (barriers to EBP) [103]. These factors do not represent dimensions but rather individual issues encountered which impacted attempts to make evidence-based changes.

Figure 19 A tentative framework for the introduction of EBP in a CAM organisation

Low	High
'Busy' culture	Prioritisation of discussing and planning change
Marketing prioritised	Evidence based information seen as part of primary task of organisation
Hierarchical management style	Personal autonomy valued
Own experience as most valuable form of evidence	Interest in information from external sources
'Hands off' management style	Willingness to change practice
Dislike of rules	Change 'Champions'
Conflict between individuality and standardisation	

5.3 Non cultural factors

Although the focus of this thesis is the influence of the charity's culture on the feasibility of the introduction of evidence into the information service at the charity, some factors which clearly impacted on this were distinct from the culture of the organisation¹.

5.3.1 Organisational restructuring

The project timeline (Appendix 1) shows that the organisational structure was in a continuous state of change throughout the lifetime of this study. During the 30 month duration of the KTP project there were three different CEO's and several major restructures. The effects of these occurred on multiple levels. For example, on a practical level there were delays while redundancies took place and decisions could not be made or permissions could not be granted which led to delays in the study.

5.3.2 Loss of champions of change

One of the significant impacts of restructuring was the loss of key members of staff. The manager of the information department, who had been jointly responsible for the setting up of the project, had been made redundant in July 2008 along with the therapy department manager who had been supportive of the project aims¹. These individuals who act as facilitators have been referred to in literature as change '*champions*' [398] in which their importance is emphasised in motivating a group to change [399]. The redundancies of these individuals hugely impacted the project through a loss of momentum.

5.3.3 Change Fatigue

Another problem was observed during a round of restructuring, in which a member of staff had refused to carry out work on an information database until they knew that this change was not going to be rendered useless by subsequent management. This attitude seems to be similar to Garside's description of '*Change Fatigue*', in which staff become tired of new initiatives [400]. Following redundancies some staff had expressed concern about their own

role, even likening the stress of this to being diagnosed with cancer. Although this analogy may sound insensitive, literature has highlighted the huge psychological trauma that organisational change has on individuals [401]. Perlman and Takacs even draw parallels between Kubler Ross's model of stages of dying [402] and stages that individuals experiencing organisational change go through[403]. Therefore this environment is unlikely to be conducive to the improvement of an information service.

5.3.4 Structure of the organisation

A structural problem at the charity was its extensive number of therapists, all of whom were self-employed. This allowed the organisation to have access to therapists who could provide a service as required, without having to employ full-time staff. The impact of working with a large bank of self-employed staff was that the therapy team was difficult to manage, in part because staff meetings involved having to pay staff for their time to attend. The consequence was that there was no simple way of communicating with therapists. Poor communication had been highlighted by many therapy staff as a barrier in providing good quality information. The part-time nature of therapist's work for the organisation was also highlighted as a barrier to being available to attend CPD events.

5.3.5 Financial constraints of organisation

Financial constraints were not limited to difficulties in managing therapy staff. The redundancies in the information department were explained to staff in terms of the UK's financial climate¹. Although a great deal of media attention suggested that businesses were facing turbulent times during the recession, Breeze and Morgan suggest that there is no clear link between philanthropic spending and economic conditions, although during recessions there is likely to be mass media fuelled panic which can cause non-profit organisations to worry about their resources [404]. Like many charities, the charity received a large amount of income from a single donor and this led to worries that the charity's income was not sustainable¹. Senior management concern over this issue undoubtedly contributed to the

prioritisation of attracting customers and the provision of evidence-based information did not appear to be viewed as contributing towards this task.

5.3.6 Customer demand

In a review of the impact of recessions, Breeze and Morgan suggest that poor economic conditions can often increase the demand on third sectors organisation's services and even be an opportunity for growth [404]. However demand for the charity's services had fallen dramatically¹. This had been highlighted in the service-user interviews in which several related issues were identified, including people not knowing where the charity was located and the perception that it was only available to people with lots of money. The level of use of the charity was linked to its income as services were not free of charge. Additionally, in order to secure funding it was necessary for the charity to demonstrate that it was fulfilling its mission of providing services to people affected by cancer.

5.3.7 Summary: Research question 1

What cultural factors within the organisation influence the extent to which an evidence-based information service is supported and used?

In summary, the culture of the organisation posed several challenges to the incorporation of evidence into its information service. While there were additional difficulties discussed above regarding structure and the financial climate at the time, the culture within this environment was problematic for several reasons.

Ultimately the charity¹ did not appear to be a *learning organisation*; a key component of an evidence-based organisation [103]. New information was not valued as highly as personal opinion or the perception of what had already been learned from the charity's historical experience. Additionally a reluctance to impose rules on therapists meant that undesirable behaviour went unchallenged. It was therefore difficult to challenge beliefs by presenting new data, even when this came from service-users who were the apparent focus of the

organisation's existence. The cultural norm of consistently being too busy to discuss change or engage with professional development activities led to lack of engagement with the data collection and the feeding back process.

The subculture within the charity's Information Department appeared to display more positive values with regard to using evidence, particularly in their desire to improve and willingness to incorporate new processes into their practice. However this department was limited to the extent that it could improve the use of evidence within wider and structural constraints.

The organisational structure represented a key problem with regard to introducing change; in particular the large team of part-time therapists and associated difficulties in managing staff was prohibitive. This was coupled with the highly valued individuality of therapists which led to reluctance from management to impose regulation. This structure contributed to difficulties in arranging staff training due to other work commitments of therapists. In addition to this, repeated organisational restructuring led to difficulty taking work forward.

While some of the constraints may have been artefacts of the nature of CAM and CAM therapists and the beliefs and attitudes prevalent in this field, however other factors may be more pertinent to the fact that this was a third-sector organisation and therefore faced particular financial challenges.

5.4 Research question 2

What processes can be adopted by a third sector organisation offering complementary care for people affected by cancer in order to make their information more evidence-based?

This question builds on the previous examination of how cultural factors affected attempts to improve the use of evidence within the charity's information service and focuses on the practical question of how this objective may best be achieved working within these constraints¹.

5.4.1 Summary of learning cycles

During this study several changes were attempted at the charity which achieved varying levels of success.

Chapter 4.2 described attempts to introduce a website checklist approach which was seen to conflict with marketing values at the charity. Although a compromise was reached in which the plans were developed to use the checklist to provide *recommended links* on the website, this never happened due to changes in staff leading to delays in website development.

Chapter 4.3 described the process of developing quality checklists for printed information. The process of carrying out this work had highlighted the absence of any form of cataloguing system in the information service. Findings demonstrated that the consequence of a large, part-time team of therapists resulted in the production of a large amount of unregulated information. Attempts to introduce an information database had been problematic due to concern that openly available information could reduce demand for therapy services. Though work had started on the database, this was disrupted by organisational restructuring. The introduction of the *Information Accreditation Scheme* (IAS) had been received positively by senior management and although the Information Department dedicated time to achieving accreditation this was halted by the closure of the department.

Chapter 4.4 described how attempts at running staff workshops had been unsuccessful and achieved a low attendance. Returns of evaluation forms had been so low that it had been difficult to understand reasons for non-attendance. One of the findings had been that the part-time approach to staffing meant that therapists had other work commitments and sometimes large distances to travel. Additionally, some feedback had suggested a lack of interest in these events. Although the funding from the KTP had paid for these workshops, it was unlikely that the charity could afford to regularly hold these events as the cost implications of getting un-salaried staff together would be prohibitive. A lack of resources also affected the feasibility of

involving therapists in the production of information as this had to be completed, unpaid, in their own time.

Chapter 4.5 highlighted service-user attitudes being used to guide the production of revised information sheets and new information summaries. This process took place within the Information Department and resulted in the redevelopment of the department's information.

5.4.2 Information Accreditation Scheme

The change which had the greatest impact on the organisation, and arguably the most important change to occur during the project, was the charity's involvement in the Department of Health's Information Accreditation Scheme (IAS). It is important to consider the advantages that this initiative brought to the charity and how this was more feasible than other changes within the organisation's culture.

5.4.3 Content of the IAS

While the IAS was a new initiative in 2008, the content of the IAS was similar to many of the processes that the KTP had attempted to introduce to the organisation. Many of the KTP outputs were submitted as evidence towards IAS accreditation as they demonstrated quality assurance procedures and reflected that fact that service-users had been involved in the development of information. The IAS appealed to staff outside the Information Department based on other advantages it was perceived to provide.

5.4.4 Appeal to marketing values at the charity

From the start of the charity's involvement with the IAS, the perceived marketing value to the organisation was apparent. While marketing values had previously been seen as a barrier, in this case they were a facilitator to change. It seemed that the IAS appealed to these values and fitted with the organisation's primary aim of raising the profile of its services. The marketing department had begun highlighting the charity's involvement in the scheme from day one, and this had been talked about as giving the charity credibility amongst health professionals and

could be used to promote the charity's information through hospitals and GP services. The IAS was instrumental in communicating to management that high quality and accredited information could be valuable and consistent with the wider aims of the organisation. This also raised the issue that although the KTP project had been developed by a member of the charity and a member of academic staff at Plymouth University, it was perhaps assumed that 'buy in' was already achieved at the charity prior to the commencement of the study. Armenakis, Brown and Mehta suggest that a vital part of organisational change is to create readiness for change, part of which involves communicating the value of change to its recipients, ensuring that they are able to answer the question 'what's in it for me?' [405]. In this instance it seemed that the IAS aided the communication of this message in a way that had been lacking in the KTP.

5.4.5 Time demands

The pilot phase of the IAS was taken up by the organisation and initially led by myself but then handed over to the Information Officers. The commitment of resources at CEO level and interest from the Marketing department was in contrast to the lack of interest present in all other attempts to involve other members of the organisation in the KTP project. In view of the lack of time senior managers reported for engagement in the KTP, one of the advantages of the IAS may have been that it was a pre-defined set of rules which did not require any discussion. In comparison with the KTP, in which time and effort needed to be spent with senior management in order to review findings set objectives and discuss results, perhaps the IAS was an easy option which the Information Department was left to *get on with*.

5.4.6 Financial benefits

The association with the Department of Health which the charity gained through participation in the IAS brought significant advantages to the Information Department, enabling access to literature databases (at no cost) through the National Library for Health (NLH) portal. This

access had been recently withdrawn as the charity had not been deemed to have strong enough links with the NHS.

5.4.7 Sustainability and future of the IAS

While the IAS was readily adopted by the organisation, in the first instance this was only applied to the information produced within the Information Department. As discussed above, making changes in this department was much easier than elsewhere in the organisation. The next planned step was to 'roll out' the scheme to incorporate information produced by other departments, where it may well have encountered similar cultural and structural difficulties to those experienced during the KTP. Therefore although the IAS appeared to overcome some of the difficulties encountered during the KTP, it is likely that to apply the scheme elsewhere in the organisation would still require culture change.

Although the IAS has been discussed as an apparent solution for increasing the use of evidence in the information service at the charity, it should be noted that the charity did not achieve accreditation during the lifetime of the KTP due to the redundancies in the Information Department¹. This highlighted that the IAS had associated with it a human resource cost which a participating organisation was required to commit to long term.

However more than twelve months from the end of the KTP and the redundancies of Information Department staff, a Research Officer was re-employed by the organisation with the purpose of obtaining the IAS kite-mark for the organisation. This was achieved in 2010 and led to the charity's information being linked to NHS information prescriptions¹.

5.4.8 Evidence-based changes or quality improvement?

Chapter 4.2 touched upon the debate of whether evidence was assessed against a gold standard or whether the process of producing information was examined. During the KTP, the focus of the work had concentrated on the *process* rather than looking in detail at the *content*

of information. It could be argued that all of this work was not, in fact, increasing the use of evidence but focusing on improving process and quality.

This echoes a debate presented by the Department of Health (DoH) in their rationale for choosing their process-based approach to the IAS [406]. The DoH outline two approaches to assessing information: describing the assessment of individual information products as *archaeological* while focus on the processes is *architectural*. The DoH argue that the architectural approach is the most practical approach, is less demanding than assessing individual information products and is proven to be effective both in improving the quality of health and social care information as well as acting to reassure the public.

5.4.9 Summary: Research question 2

What processes can be adopted by a third sector organisation offering complementary care for people affected by cancer in order to make their information more evidence-based?

In summary, among the attempted changes at the organisation there were different levels of acceptance. Although it was often difficult to understand the reasons behind failure of initiatives, reflecting on the successes of this project provides some lessons on what changes may be acceptable for third-sector organisation providing information on CAM and cancer.

It appeared to be important that changes to the information service could be viewed as part of the charity's wider goal of increasing the use of its services. Once clarification of the 'what's in it for me?' question was provided in the form of the IAS, it was much easier to achieve 'buy-in' from senior management. Conversely, changes which could perceivably go against this mission, for example allowing access to all information or reducing reciprocal website links, were likely to be viewed with concern.

To a third-sector organisation, resource implications are likely to be an important factor in selecting a method for increasing the use of evidence within information services. Therefore increased costs such as accessing literature, accessing expert opinion, involving service-users or attempting to run CPD courses may be challenging and change initiatives need to be as cost-effective as possible.

Therefore an initiative such as the IAS, which has the potential to improve the quality of the information and at the same time contributing towards an organisation's primary goals such as improving the visibility of services, is likely to be viewed favourably by an organisation.

5.5 Evaluation of methodology

Reflecting on the success of the methodology is difficult for many reasons. As Checkland states, when evaluating the success of any methodology there is no way of knowing whether another methodology would have achieved better results and, in the case of a lack of success, this may be down to improper use of the methodology [294]. However this section will discuss the perceived merits and drawbacks of SSM.

5.5.1 Making assumptions about an organisation

One of the difficulties when selecting a methodology is that, at the start of a study, little is known about an organisation. In the case of this research, SSM was selected based on reviewing organisational change literature, examining previous studies and assessing the merits of the methodology in relation to the perceived situation at the charity. This notion itself is problematic, as a judgement is made on an initial understanding of an organisation which, at this point, is fairly speculative.

A significant assumption was that there would be a forum in which open debate could occur. This expectation was not realised, and the *Change Management Group* was never established. This group had been expected to be the main route for the discussion of change, and without it the opportunity to build and discuss Conceptual Models, the characteristic aspect of SSM,

was absent. Underwood has suggested that the values of SSM, in which open debate is encouraged within organisations, is more in line with middle-class or academic values than those of an organisation [314]. While it is not possible to comment on whether these values are either related to academia or social class it was the case that open debate was not encouraged within the organisation.

5.5.2 Conceptual model building

The purpose of conceptual models has been emphasised by the founders of SSM; both Checkland and Wilson stress that their purpose is to create structured debate, claiming that in reality the majority of discussions regarding change are unstructured [291, 293]. This accurately described the nature of the majority of discussions at the charity, which were typically hurried and unproductive, and decisions were made on the basis of a thought or a suggestion rather than a systematic evaluation of possibilities.

While the lack of explicit use of model building may seem contrary to the aims of SSM in structuring debate, Rose suggests that in an academic context the emphasis of SSM lies on the learning process, and the purpose of the model building process is to structure thought rather than elicit action [407]. Checkland also accepts that models may not be used explicitly, and suggests that these may be internalised in what he refers to as 'SSM mode 2'. This implicit use of the conceptual model building appears at odds with the collaborative philosophy of action research, in which meaningful changes are made jointly by the research team and the organisation. With the lack of separation of systems and real-world thinking through conceptual model building and structured discussion, it could even be argued that this study did not resemble one which used SSM.

5.5.3 Other Methodologies

When considering the different methodologies prior to commencing data collection, one of the rejected methodologies, Business Process Reengineering, presented a template for introducing radical change. This was not something which had been considered necessary or in

the scope of the KTP, however some of the problems at the organisation may have required radical change. For example, one of the difficulties described by the managers of therapy services was the large amount of part time staff leading to difficulties standardising practice and communicating with the team¹. To change this would lead to a large-scale reorganisation which might involve many redundancies. This radical change is not what SSM is designed for and equally was not within the scope of the KTP project. However this example highlights that the extent of change required at the charity may have been difficult to facilitate within the parameters of the study setting.

5.5.4 Provision of structure

While the methodology had many drawbacks, it provided a structure with which to jointly work towards the KTP objectives of making practical changes to the charity's information service while collecting data about the process¹. While this is a positive property of SSM, it is not unique to this methodology. For example the PDSA (Plan-Do-Study-Act) is another methodology incorporating learning cycles which may have been an alternative choice for this study, given the infeasibility of participative model building [408].

5.6 Implications for practice

There are several potential implications for practice which this thesis has highlighted. These are applicable to different groups.

As emphasised in key reports [1, 2], as a significant proportion of cancer patients access CAM, it is important that evidence-based information be made available to them. With a large amount of this information provided by third sector organisations, this study has highlighted some of the challenges that such organisations providing this information may face.

For researchers or change agents attempting to introduce changes in this type of organisation, this study presents some of the potential challenges and barriers to the process and difficulties engaging with stakeholders in this environment.

For providers of CAM services this research highlights the difficulties encountered in attempting to provide evidence-based information while at the same time promoting therapy services. This research suggests that an independent *kitemark* scheme, such as the IAS, has the potential to bridge this gap and enable such an organisation to work towards both of these goals. Additionally this research has suggested that there may be difficulties encountered when a large, part-time team of therapists are employed.

For practitioners, this research demonstrates that people using CAM are likely to value evidence, and that they define this as information based on clinical trials as well as more experiential forms of information. Services such as Health Talk Online, which offer written, audio and video recorded accounts of patient's experience of CAM, may be useful sources of information to refer CAM users to. Regardless of practitioners' perspectives on the relevance of evidence to their practice, providing this information may be necessary to meet user needs.

5.7 Limitations

While the *real-world* nature of this research may have advantages, there are also limitations introduced by the methods employed.

Some criticism is directed at the participative nature of action research. Baskerville and Wood Harper distinguish *rigorous* from *liberal* action research, warning against the researcher becoming so involved with the practicalities of the research so that they neglect scientific rigour [409]. At times, the methods in this study were influenced not by a concern for academic rigor, but out of a need to compromise in order to gain access, proceed in a timely manner, or even for the preservation of the continuation of the research. For example

adhering to organisational boundaries led to a revision of the staff questionnaire questions and a limited sample of staff being interviewed.

Another question of reliability associated with this research may concern the impartiality of the researcher; a common criticism of action research [410]. This may be particularly relevant in the case of my being based full-time at the organisation within which the research took place. Efforts were made to account for the my presence through reflective research and, in addition to this, support from the KTP academic supervisory team, who were located externally to the organisation helped to improve the level of objectivity.

When research takes place in an organisational setting where the researcher is a member of staff, there may be questions over the openness with which work colleagues provide information. During interviews, particularly when there is a perception of a judgement being made, there is the possibility that answers will be modified in order to provide more socially acceptable answers or project a desired image [411].

In terms of the rigour, Pope and Mays suggest that research which relies on observation by a single researcher is always limited due to the perceptions of the investigator, as well as the possibility that the researcher may have influenced how the behaviour was interpreted [412]. This may be a valid criticism, although efforts were made to minimise this through use of a second reviewer in analysing interview themes and through discussion amongst the KTP team.

5.8 Areas for future research

This research has added to an extremely limited body of literature on the use of evidence in CAM and as such has highlighted many opportunities for further research:

- Given the unique and variable nature of culture emphasised in literature, it is important to understand whether cultural factors identified in this research are prevalent in other organisations producing health and social care information.

- With third sector organisations producing a large proportion of the UK's health and social care information. Given the unique and variable nature of culture emphasised in literature it is important that further research is carried out to understand what support or initiatives are necessary to enable these organisations to produce high quality, evidence-based information.
- This study was conducted within a KTP in which constraints dictated what data could be gathered. Future studies could focus on gaining a more theoretical perspective on CAM and culture through ethnographic methods. Recent developments, such as Leach and Gillham's recently published measure of attitudes towards evidence-based practice in CAM could also be utilised [224].
- Examination of the culture of an organisation represented a single variable which has been identified as relevant to EBP. Therefore future studies could focus on examination of other factors which are thought to influence the feasibility of EBP such as those identified in the PARIHS framework [123].
- There are a large variety of methodologies available for guiding organisational change such as Business Process Reengineering and Total Quality Management, which were discussed in Chapter 3. Future studies could attempt organisational change in a CAM organisation using different methodologies which take different approaches to change.

Finally, due to the time-scale of the KTP I had no access to the charity at the end of the 30 months¹. However, I maintained contact with colleagues from the Information Department and it was reported to me that following the redundancies of 2009, the department had reopened, taken on more staff, achieved the IAS kite-mark and become featured as part of the NHS Choices website. Through informal conversations with new members of the Information Department, it would seem that the IAS played a central role in the work of the charity. These are all significant achievements and suggest that many changes had occurred since the end of the KTP. It would therefore be interesting to re-examine the organisation at a subsequent point in time to consider how it had changed.

5.9 Conclusions and contribution of thesis to knowledge

While there have been many studies aiming to identify barriers to the application of evidence in a conventional medical setting, there have not been any which have looked at the use of evidence within a CAM organisation. Arguments for and against the appropriateness of the application of principles of evidence-based practice in a CAM context are well rehearsed, but these are mainly confined to academic debate. While a few studies have examined attitudes towards the use or relevance of research in CAM, none have looked at how these attitudes may interact with attempts to introduce changes, in the form of evidence-based procedures, to a practice setting. Additionally several of these studies have taken place in countries outside the UK, where differences in regulation of CAM and healthcare provision mean that their application within a UK setting is unclear.

This is the first study which has documented systematic attempts to make evidence-based changes in a third sector CAM organisation. As such, this study has generated findings that demonstrate how cultural and structural constraints in a third sector organisation providing CAM may influence attempts to make evidence-based changes. The practical experience of attempting to overcome these barriers has suggested how, taking organisational constraints into account, CAM information produced by a third-sector organisation could become more evidence-based. Constraints identified may be due to the nature of CAM as well as factors relevant to third-sector organisations.

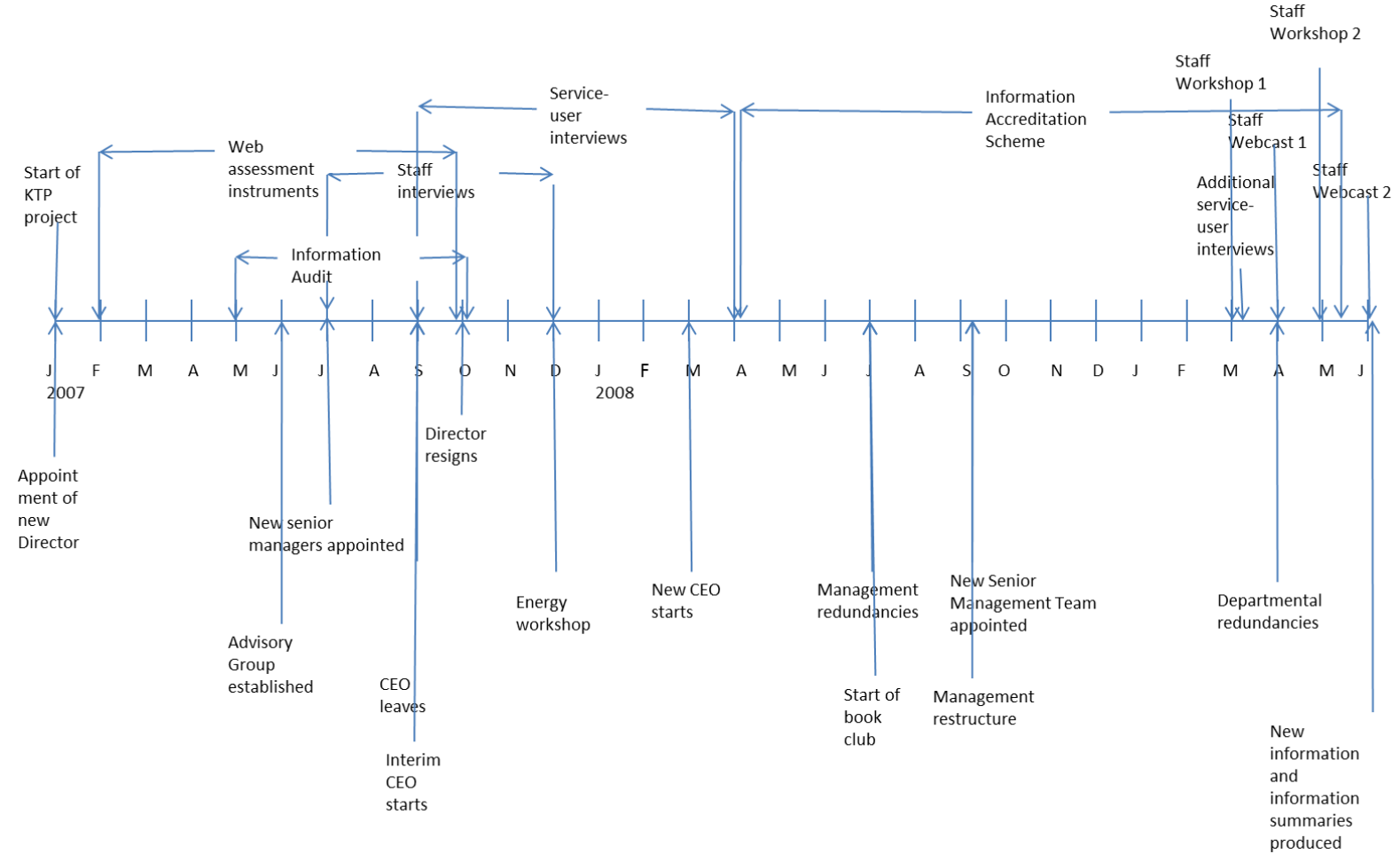
- Focusing on culture, this study has highlighted that values of *being busy* and reliance upon personal and historical experience have a negative impact on attempts to increase the use of evidence in an organisation. In particular these worldviews make it difficult to demonstrate the relevance of evidence to an organisation's information service.
- From a management perspective there was an unwillingness to interfere with the personal autonomy of therapy staff, a focus on income generation and concern that evidence-based

principles were contradictory to a need to increase demand for services. These were all highlighted as key barriers to making evidence-based changes to a CAM information service.

- Structurally, a large, part time workforce, as well as organisational instability leading to restructuring and losses of senior staff, including 'champions' of change have been identified as significant barriers to implementing evidence-based changes.
- From a methodological perspective, this study highlights the interaction of organisational values with approaches to implementing change. Despite SSM providing tools for gathering data and feeding back information, a reluctance to provide a forum for debate and discussion and an organisation-wide lack of engagement with the research process were shown to be key barriers to attempts to implement evidence-based practices.
- This study also suggests that initiatives such as the Information Accreditation Scheme may be of particular value to a third-sector organisation as they have the potential to demonstrate a closer link between the organisation's primary business goals and the provision of high-quality, evidence-based information.

The findings of this study strongly suggest that, despite demands from policy makers for the provision of evidence-based CAM information, there may be systematic difficulties experienced by organisations responsible for the production of this information.

Appendix 1. Project Timeline¹



Appendix 2. Organisational structure under Director²

Appendix 3. Minutes from a Project Team Meeting

Partnership No: KTP006338

Action Minutes

Monthly Project Team Meeting

08th March 2007¹

Start time & finish time: 11.00 – 12.30

Present:

- Matt Breckons
[Redacted] [Company Supervisor]
[Redacted] [University Supervisor]
[Redacted] [Project Manager]

Apologies:

- [Redacted] [University Supervisor 3]
[Redacted] [University Supervisor 2]

Item	Issue	Notes/Actions	By whom	By when
1	Associate Update	Completed 3 searches proceeding with next 2 Completed Quantitative Research Methods at UoP Attended 2 day course at the charity ¹ Questionnaire developed Working on internet health information assessment tools report.		
1	Discussion about KTP objectives overlap with new director's objectives ¹ .	Invite [new director ¹] to LMC's E-mail [new director ¹] a summary of the KTP project Ethics form to be sent to [new director ¹]	[Project Manager] [Project Manager] [Academic Supervisor]	08/03/07 ASAP ASAP
2	Discussion on revised questionnaire - if this would achieve desired objectives	Some of [redacted] suggestions to be incorporated into questionnaire. Amended questionnaire e-mailed to project team & [new director] Appointments booked and questionnaire to be piloted with 3 staff.	MB	16/03/07
3	Ethics Approval discussed	[Academic Supervisor] has received some feedback on application form. Feedback to be incorporated & Ethics form submitted & copy to be sent to [director ¹]. Safety issues for researcher regarding home visits will hopefully be covered in Qualitative Research Methods but if not MB will enquire. Enquiry made as to location & type of KTP premises in local area ¹ as a possible interview location for people affected by cancer.	[Academic Supervisor] MB [Project Manager]	ASAP 30/03/07 ASAP
4	Quantitative Research Methods Module Assessment	Agreement on importance of completing module assessment and the need to use time at work to do this	MB	26/03/07
5	Tools for assessing	<ul style="list-style-type: none"> Suggested criteria for inclusion of 		

	the quality of health information on the internet discussed	<p>16 tools agreed</p> <ul style="list-style-type: none"> • Tools will be tested against a benchmark (DISCERN) as this has undergone validation process. • Tools will be looked at to see how many of the 'Top 12 published criteria' they include. • Inclusion of websites agreed. Searches will be conducted using terms 'Complementary (medicine or therapies)' and 'Alternative (medicine or therapies)' Top 6 results & 6 from a purposive sample will be used <p>Inclusion criteria for websites & tools to be e-mailed to supervisors</p>	MB	ASAP
6	Methods of Evidence Appraisal Discussed	Agreed that recommendations for search and appraisal methods made by [External Researcher] [Research Officer] will be adopted as resources allow.		
7	Associate Development Discussed	MB booked on Patient Involvement and Empowerment Conference. Attending Qualitative Research Methods at Bristol University March 26 th -30 th		
8	Confirmation of next month's work	Questionnaire to be conducted with 20 people (max.) Internet Health Information Assessment tools report to be completed. Searches to be Completed Research Module Assessment completed	MB	04/04 /07

Appendix 4. Publication²

Appendix 5. Brief report on rating websites

Rating the Quality of Information on Complementary Medicine and Cancer on the Internet

There are a large amount of websites containing information on health information on the internet; this makes it extremely difficult to know whether information is of good quality. To help internet users decide whether or not a site is of good quality, many tools have been developed – these consist of a series of questions to ask of the website. Although there does not seem to have been any studies of how popular these tools are, it has been suggested that some quality criteria could be useful for developers of websites. In a recent report we've been looking at which was the 'best' tool to use in terms of usability, comprehensiveness, popularity and whether this agrees with what other tools say about websites. Out of 12 tools the one we rated as the 'best' was a checklist developed by the National Centre for Complementary and Alternative Medicine. The main area which was not covered by the NCCAM tool was the question of content accessibility so it might be a useful to include an additional question (Question 11);

This would give the following checklist;

1. Who runs this site? *Clearly marked on all of the pages of the site.*
2. Who pays for the site? *Clearly stated.*
3. What is the purpose of the site? *The purpose of the site should clearly be stated.*
4. Where does the information come from? *If the site creator is not the author of the information then the source should be stated.*
5. What is the basis of the information? *Facts/figures should be referenced and opinions should be set apart from evidence-based information.*
6. How is the information selected? *Information reviewed by appropriate person before being posted on the website.*
7. How current is the information? *Date of posting & review date clearly stated.*
8. How does the site choose links to other sites? *Policy in place (and stated) for linking to other sites (some sites will link to anyone who pays them)*
9. What information about you does the site collect, and why? *Privacy policy should be clearly stated.*
10. How does the site manage interactions with visitors? *Important for website visitors to be able to leave feedback or ask questions.*

11. Is the site easily accessible? *An internal search engine is useful, or if not, it is important that the site is logically organised – a user can find things easily and the site is not of a size which makes it very slow to view or navigate the site.*

Appendix 6. E-mail from Director

From: [REDACTED]

Sent: 11 February 2008 16:35

To: [REDACTED]

Cc: [REDACTED] Matthew Breckons; [REDACTED]

Subject: RE: New website launched!¹

Hi

I would just caution being too purist on the sites we allow reciprocal links to.

Firstly, just to point out the obvious, we have no control on what sites link to our website, that is beyond our control and generally to be welcomed; all the major search engines rank their search results based on a complex algorithm a large component of which is the number and quality of websites that link to the target (quality being defined as volume of websites linking to that website). Consequently we need to maximise the number of websites (especially well-linked websites) linking to ours in order to push our appearance in search returns up the rankings.

A common way of doing this of course is to offer reciprocal linking ("I'll link to your website if you link to mine"). The new website will therefore feature a links page (websites start to look very cluttered if links start appearing randomly throughout the site) and I anticipate very many of these links will have no direct relevance to our mission (they might be B&Bs offering accommodation locally, taxi firms etc, etc as well as the more expected healthcare professionals etc). In order to keep them tidy they'll all have to be categorised. The page that they're featured on will make it clear that their featuring on our website implies no endorsement of their product or service by us. With any luck this page will run to a listing of several hundred 'partnered' websites which would be a real boost to our search engine performance.

There may be other websites that we want to offer as 'recommended' or 'useful' and perhaps we put these on a separate page with a rather different endorsement. Perhaps Matt's websites fit into this category where we could conceivably even publish our rating of them.

Hope this helps.

██████

██████████

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Appendix 7 E-mail from member of shop staff¹

10/07/07

'Hi,

We have just had a lady who is on the course asking if we sell the handsoap by Ecover¹

Unfortunately we do not sell this as it contains Sodium Lauryl Sulphate.

This does put the shop in an awkward position.

We have told the lady that we cannot provide every item in the shop due to space and referred her to the Green People soap.

If anyone can help with a solution to this then that would be gratefully received.'

Appendix 8 Printed information report²

Appendix 9 New Management structure (September 2008)²

Appendix 10. Staff Interview Guide 1

Information Questionnaire

When did you join the charity¹?

Which Department do you work in?

How many hours a week do you work?

a. What would you consider to be the key elements of the charity's work¹?

What would you consider to be incompatible with the charity's work¹?

Do you provide information to clients?

Yes – what is this information about?

No – Why not?

No – would you like to be able to give out information?

How does the information you give out relate to the charity's work¹?

7 Where would you go to get information?

to give out to clients?

to inform yourself or others within the charity¹?

8 What features of the information would lead you to decide it is good quality?

9 How would you rate, on a scale of 0→3 (0=couldn't say; 1=(i)not useful, (ii)not of good quality; 2=(i)quite useful, (ii) fairly good quality; 3=(i)very useful, (ii)of very good quality), the following sources of information in terms of;

(i)Usefulness (ii) Quality

Television		
Radio		
Newspapers		
Magazines		
Internet		

Comments.....

10 What kind of study would convince you that an intervention was effective on a scale of 0→3 (0=couldn't say, 1=not convincing, 2= quite convincing, 3= very convincing).

Qualitative/descriptive Studies	
---------------------------------	--

Prospective Studies	
Randomised Controlled Clinical Trials	
Systematic Reviews	
Meta-analysis	

Comments.....

How would good information about the charity's work¹;

Communication between your colleagues (same department)?

Communication across the organisation?

Your personal practice?

12 Having gone over these questions;

a. What do you see as your need for information?

What are the difficulties in obtaining that information?

ALL DATA WILL BE TREATED ANONYMOUSLY

Appendix 11 Revised Staff Interview Guide

When did you join the charity¹?

- a. Which discipline do you work in?
- b. Where do you work; Individual therapy sessions¹/Residential Courses/Both?

How many hours a week do you work?

What would you consider to be the key elements of the charity's work?

Do you provide information to clients (this may be in the form of verbal information or advice, handouts or directing people towards other information)?

Yes – what is this information about?

No – Why not?

In your work at the charity¹;

What informs the information you give out to clients?

If you produce information; what features of the information source would lead you to decide it is good quality?

If you don't produce information; what makes you decide to quote, recommend or handout a particular piece of information?

If you had to answer an enquiry about some aspect of complementary therapy, what types of evidence (eg published trials, cohort studies, published case studies, traditional healing points of view (e.g. naturopathic principles etc) your own experience) would you consider to be the 'Gold Standard' of information within your discipline and what information would you use?

How would you deal with the situation where a published study had conclusions that seemed to differ greatly from your own experience, or where one study seemed to conflict with another?

Having gone over these questions;

As an organisation how do you think we can best provide good quality information?

As an organisation what are our challenges in providing good quality information?

ALL DATA WILL BE TREATED ANONYMOUSLY

Appendix 12 Staff interview report²

Appendix 13 Workshop flyer text

'What's the point?' Practitioner perspectives on complementary therapy research

WORKSHOP

Thursday 26th March, 1.30-3.00pm¹

WEBCAST

Monday 27th April, 2-3.30pm

As part of our Knowledge Transfer Partnership with Plymouth University we are pleased to be able to offer two workshops. Two invited speakers will each run a workshop at the charity for staff¹ – this will be followed up in a month with an open access webcast.

Workshops will provide an opportunity for staff to discuss issues related to their own work/practice and the webcasts will provide an opportunity to engage with a wider audience. Webcasts can be accessed individually or as a group from the charity¹ or from a home computer (details of how to access the webcast will be given at the workshop).

The first workshop and webcast will be led by Jan Williamson:

Jan Williamson is an established complementary health practitioner, yoga tutor and author. She lectures both nationally and internationally. She works with naturopathic health care principles and her focus is to enable clients to be involved in their own health care.

Jan is the director of The School of Precision Reflexology based in Devon, U.K. Currently Jan teaches a full practitioner training course and post grad courses in Precision Reflexology, Diet and Nutrition and Advanced Precision Reflexology. She has published a research paper on reflexology and the menopause (a project that was funded by The Foundation for Integrated Healthcare).

Jan will talk about her own experience of research and its relevance to her own practice.

Group discussions will ask if there is a place for research in practice and how people see research working for them. The workshop will be a space for people to discuss their views on research issues in relation to their own practice.

Staff are welcome to request a certificate of attendance from Professional Development for CPD purposes.

Publications:

A guide to Precision Reflexology. ISBN 1-85642-276-7

A Guide to Natural Health Care. ISBN 1-85642-187-2

The Friendly Food Book – available direct from Jan.

Williamson, J., White, A., Hart, A., Ernst, E., Randomised controlled trial of reflexology for menopausal symptoms. BJOG: an International Journal of Obstetrics and Gynaecology, 2003. 109(9): p. 1050-1055.

MYCaW: Using the Measure Yourself Concerns and Wellbeing tool to evaluate complementary therapies when used in cancer support

WORKSHOP

Tuesday 5th May, 2.00-3.30pm¹

WEBCAST

Thursday 11th June, 2.00-3.00pm

As part of our Knowledge Transfer Partnership with Plymouth University we are pleased to offer the second of two in house workshops. Invited speakers will run a workshop at the charity¹ for staff – this will be followed up in a month with an open access webcast. The workshop will provide an opportunity for staff to discuss issues related to their own work/practice and the webcast will provide an opportunity to engage with a wider audience. The webcast can be accessed individually or as a group from the charity¹ or from a home computer (details of how to access the webcast will be given at the workshop).

The workshop will be run by Dr Charlotte Paterson¹.

MYCaW, Measure Yourself Concerns And Wellbeing is a tool designed to evaluate complementary therapies when used in cancer support. The MCAW tool is used by therapists at the charity¹ to collect both qualitative and quantitative data from people using services.

Charlotte is a Senior Research Fellow at the Institute of Health & Social Care Research at the Peninsula Medical School, Universities of Exeter & Plymouth, she has over twenty years experience as a general practitioner and more than ten years experience of research into complementary medicine. Charlotte will discuss the need for an evaluation tool in complementary therapies and how MYCaW was developed¹

This workshop will also be an opportunity to share experiences of using MYCaW in practice.

Staff are welcome to request a certificate of attendance from Professional Development for CPD purposes.

Appendix 14 Webcast Evaluation Form

Appendix 5.6.4 Questionnaire to assess experience of/reasons for not attending workshops and webcasts

Workshops (presentations/group discussions held at the charity¹)				
Workshop	Attendance	If attended		If did not attend
Facilitator				
Jan Williamson Workshop (Reflexology)	Did you attend? (Y/N)	How many miles of travel?	<p>What did you like about this event?</p> <p>What did you dislike about this event?</p> <p>Did you experience any difficulties?</p>	What were your reasons for not attending?

			How could it have been improved?	
Charlotte Paterson's Workshop (MYCAW)	Did you attend? (Y/N)	How many miles of travel?	<p>What did you like about this event?</p> <p>What did you dislike about this event?</p> <p>Did you experience any technical difficulties?</p> <p>How could it have been improved?</p>	What were your reasons for not attending?

Workshop and Webcast Questionnaire

Please answer the following three questions:

We recently ran two workshops followed by two webcasts. For each of the four events please show whether you attended or not, and then complete the relevant columns.

Webcasts (Online seminars)				
Webcast Facilitator	Attendance	If attended		If did not attend
Jan Williamson's Webcast (Reflexology)	Did you attend? (Y/N)	How many miles of travel?	What did you like about this event? What did you dislike about this event?	What were your reasons for not attending?

			<p>Did you experience any difficulties?</p> <p>How could it have been improved?</p>	
<p>Charlotte Paterson's Webcast (MYCAW)</p>	<p>Did you attend? (Y/N)</p>	<p>How many miles of travel?</p>	<p>What did you like about this event?</p> <p>What did you dislike about this event?</p> <p>Did you experience any technical difficulties?</p> <p>How could it have been improved?</p>	<p>What were your reasons for not attending?</p>

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Do you have any suggestions for future professional development activities?

Do you have any other comments you would like to make?

Appendix 15. E-mail from Information Department manager¹

User Led

¹ *Our service users are central to our organisational planning, delivery and evaluation. In dialogue with the organisation they inform the direction of service provision and service delivery at key access and audit points.*

Appendix 16 Service-user e-mail circulated to all-users.

Appendix 17. Service-user interview guide¹

Section 1: Demographic Information:

Person with cancer or supporter

Age

Gender

Diagnosis

Duration of condition

Type of contact with [REDACTED]

Section 2: Interest in Complementary therapies and [REDACTED]



1. **How long have you been interested in Complementary therapies?**
Longstanding / recent interest / pre diagnosis / post diagnosis
2. **How did you find out about [REDACTED]**
Recommendation: healthcare professional / friend / relative, website, information leaflet / been here before
3. **a. Before using the service [REDACTED] did you look for any further information about [REDACTED]**
[REDACTED]
- b. Did you look for information about Complementary Therapies (in general?)**
Not at all / [REDACTED] / other services offering complementary therapies
4. **(a)What was it about [REDACTED] that particularly interested you?**
Complementary therapies / Holistic approach / Recommendation
5. **b. If so, what kind of information was available? What other information was / would have been most useful to help make decisions about using [REDACTED]**
Websites, leaflets, newspaper / press articles, stories of individual experiences

Websites, leaflets, newspaper / press articles, stories of individual experiences, poems

Did you find any of this useful? If so which was most useful and why?

6. **Did you use this information to make decisions about using [redacted] Complementary therapies?**

Discuss with others / doctors / compared to other information

Section 3: Information obtained and used

7. **a. What makes information on complementary therapies useful to you?**

Recommended, easy to understand, from a reputable organisation / website, based on evidence, seemed most relevant to own situation

b. How important is it for you that the information includes evidence? What sort of evidence? What would you regard as evidence of effectiveness: clinical studies, doctor / other healthcare practitioner experience, patient experience

c. What features of information would lead you to decide it is good quality? Author, date, appearance

8. **What other information was / would have been most useful?**

Websites, leaflets, newspaper / press articles, stories of individual experiences, summary

Section 4: Preferences for information

How do you prefer information on complementary therapies to be presented?

Leaflets, booklets, audio, video / DVD, web-based, summaries of therapies, based on patient stories, What do you like about this type of information

- 9 **Is there anything else you would like to tell me about finding information on complementary therapies [redacted]?**

Difficulties / too much / not enough information

Section 5: Courses (if interviewee has been on the course)

10. **a. How useful was the written information obtained on the course?**

Useful / Not very useful

b. How could this have been improved?

Presentation / user friendly / timeliness / too much / not enough

**Section 6: Information from folder
SHOW FOLDER**

- 11. Did you receive any of this information or similar information?**
Examples of different types of information
- 12. Did you find this information useful? Which types of information were most useful?**
Useful/Not Useful, if not useful – why not – how could this have been improved?
- 13. Would you have found any of the information not received useful if you had received it?**
In what way? / clarification of guidelines / new information
- 14. Is there any other information you would have found useful?**
Topics not covered / more information about a specific topic

Appendix 18. Second reviewer coding of two interview transcripts²

Appendix 19. Service-user interview report²

Appendix 20. Additional service-user interview questions

What made you decide to use complementary therapies?

Symptoms/prevention/recommended/previous experience

What did you hope to get from using the charity's services?

Advice/symptom management/support

What services did you use at the charity¹?

Telephone service¹/Residential courses/Individual therapy sessions¹

Which therapy/therapies did you use?

Individual therapies/several

How did you choose this/these?

Did you have any concerns about using the therapy/therapies?

What sort of interaction did you have with the therapist?

How did you feel before and after the therapy?

Physically, mentally, emotionally

Was your experience of the therapy what you expected?

Have you continued to use complementary therapies?

Do you feel you have benefitted from the therapy or combination of therapies?

Short term/long term

Would you recommend this therapy to someone else?

Appendix 21. Information Narrative

Introduction

Below is a personal account of an experience of using services at the charity¹. The highlighted words open web pages providing more information or evidence about a service, or therapy.

Narrative

I first came here about 15 months ago although it was four and a half years ago since my diagnosis of breast cancer. I've been using therapy services ever since¹. When I was first diagnosed I was dealing with my operations and treatment and I coped in my own way. I got to a stage when the danger had passed, my prognosis was good, I wasn't dealing with the immediate threat of cancer. After a period of being closely monitored, having radiotherapy every day for five or six weeks, then check ups every three months I was in limbo; it was great because you don't have to go to the hospital so often, but once the spotlight's off you you're left wondering 'Oh well where do I go for help now?'. I wasn't going through the operations and I wasn't at the end of the fight, I was in the middle – that's when I came to the centre.

As well as for support, I also came here to get advice on symptom management, I've been on nutrition and relaxation courses and the fact that you're in a group situation and can share experiences has been really great as well. I have problems with my shoulder following my operations and if I go to a salon for a massage it's nice but I've got to go through the process of explaining that I've had a mastectomy. Coming here the staff are more aware, they're trained and it's not just a massage, you go in and you can talk about how you're feeling which you wouldn't get outside.

When I first came to the centre I tried reflexology and breath work sessions which were really nice although it's shiatsu I have continued to use. Not only does the massage help my shoulder but I can sit down and talk within the session and it's almost like a counselling session. I try to use the breath work on a day to day basis. Over the time I've been here I've built up rapport

with the shiatsu therapist and I feel comfortable and it's important to me that I've got this trust with her. They do certain therapies here that don't appeal to me but I haven't tried them, they might be fantastic.

I try to have a massage every four or five weeks, if I leave it too long I feel like I need to off-load and I can feel in my body that I need to have a massage and I know I'm going to feel better afterwards.

When I was first diagnosed, even though I was quite into complementary therapies I was almost frightened to deviate from just having my hospital treatment. Now with the experience of coming here, if I could turn the clock back it would be brilliant to come here alongside the medical treatment because the hospital are dealing with your physical ailment and the charity are dealing with the mental side of things¹. Maybe I thought that the the charity's work was a bit 'woah' but my experience was really different to my impression of what it would be like¹.

The environment is really helpful; after my massage I can go in and have a nice cup of white tea, sit down and relax. If I have a later appointment I can stay for lunch. So it's not just the therapies it's the whole experience. For a busy mum coming here for a massage, a chat and lunch is like coming for a mini retreat.

I don't want to rely on coming here but it really is a big part of my life at the moment, I still need to come here, and I'm sure when I don't need to it will be a natural 'actually no I won't go for a few more weeks' and that sort of thing.

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