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Gunton & Tomkinson Award (2006) final report

Assessing the Impact of a DVD-based Complementary and Alternative Medicine (CAM) Information Resource for Cancer Patients

Project start date: September 2006

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Assessing the Impact of a DVD-based Complementary and Alternative Medicine (CAM) Information Resource for Cancer Patients

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Introduction and Project Overview

Background: CAM Cancer Care Users' Need for Information

Cancer care is at the forefront of moves to integrate complementary and alternative medicine (CAM) into mainstream healthcare (Kohn, 1999). Around 30% of cancer sufferers will try one or more CAM therapies at some point during the trajectory of their illness, and figures as high as 91% have been reported for CAM use in breast cancer (see, for example Downer et al, 1994; Wilkinson, 2002). Within cancer care, CAM is routinely used as a form of symptom management in addition to conventional treatments, rather than as an alternative or rejection of them. Similarly, research has indicated that cancer patients who are utilising CAM therapies do not usually perceive it as a 'cure', (Salmenpera et al, 1998) but rather as a mean of improving quality of life during the traumatic and difficult process of dealing with the disease and / or offsetting the side effects of conventional medical interventions such as chemotherapy or radiotherapy. Significantly, however, because of the gulf that still exists between CAM and orthodox medicine, many cancer patients use forms of CAM without telling their conventional doctors (Spiegel et al, 1998). In cancer, probably more than in any other area of healthcare, this has the potential to cause considerable problems – ranging from simple misunderstandings over the reality of what CAM therapies can actually offer, through to possibly dangerous situations where forms of CAM may compromise, or react adversely with, conventional treatments.

Several well established CAM modalities (such as acupuncture and homoeopathy) are now effectively professionalised accountable and accruing a body of evidence based research (see, for example: House of Lords, 2000; Prince of Wales' Foundation for integrated Health, 2005; Cant and Sharma, 1996). Others are at an earlier stage in their professional development and some are taking active steps forwards in this direction. This creates confusion for newly diagnosed cancer patients who may have little or no background knowledge of the field and, at this stressful time especially, require straightforward, accessible and practical information in order to make informed decisions over CAM use.

In response to the exponential and largely ad hoc growth of interest in CAM by cancer patients and other users, guides to the availability of therapies and services have emerged (Chatwin and Tovey, 2004) as have a plethora of publications outlining how individual therapies work. (see, for example, The Prince of Wales's Foundation for Integrated Health, 2005). Similarly, CAM and cancer user or advocacy groups are also beginning to make one-off resources (such as CAM therapist directories) available in 'hard' digital formats such as CDs. NHS direct, for example, now offer an internet based CAM therapist directory.

More recently, as computer availability and specifications have improved, more resources are being made available on DVD – with the possibilities for multi-media content and the delivery innovation that this more capacious format offers. An initial pilot study conducted with cancer-support groups highlighted the potentially positive role that these types of DVD based resources can play (Chatwin, 2005).

Research Aims and Objectives

Against this background, the twelve-month study had two main aims:

1. Develop, produce, pilot and refine a DVD aimed at providing cancer patients with information on CAM in general, and more specifically, on some of the more common CAM therapies that they may encounter.
2. Critically evaluate the usefulness or otherwise of the DVD format as a method for disseminating this kind of information to persons with cancer

The study was taken forward in two distinct phases which closely matched the research objectives. *Phase One* involved the development and piloting of a CAM focused information DVD for cancer patients and the production of an evaluation version. *Phase Two* comprised an exploratory evaluation of the perceived usefulness and impact of the DVD on persons with cancer. Particular interest lay in how useful stakeholders found the information on the DVD in helping them come to decisions about their future use of CAM, alongside conventional medicine, in the management of their cancer. Each phase, its methods and results, is reported in separate sections.

It was originally planned to complete the project within twelve months. However, during the second phase of the study it was necessary to extend the length of time available for participant recruitment. The project was completed with a short overrun of four months.

Phase One – Development of a Pilot DVD

The first phase of the project ran from September 2006 – April 2007. The main tasks completed during this period were:

- Development of a provisional list of themes to be covered in the DVD
- Consultation with CAM therapists, conventional doctors and other healthcare professionals on the way to address the themes within the DVD
- Production outline for the DVD
- Production of the DVD
- Pre-piloting of the DVD

Each is discussed in turn.

Theme Development

The aim was to develop a provisional list of themes which needed to be covered in the DVD. Interest lay in particular, in which issues were either considered important to get across to cancer patients on a medical level (such as the role that CAM might play alongside conventional treatments) or information of a more generic nature (such as what the CAMs they may come across actually involve).

A literature review was conducted in order to generate initial broad themes. These included:

- A definition of CAM – where it 'sits' in relation to conventional medicine;
- The wide and varied nature of the CAM field, particularly as it relates to cancer treatment;
- The CAM therapies most often used in cancer care (particularly those sanctioned by conventional healthcare services, or routinely offered as an adjunct to conventional cancer therapies);
- The dangers of using CAM without sufficient knowledge, that is, the ways in which some CAM therapies may actually be harmful to cancer patients undergoing conventional treatments;
- How to go about selecting a reputable CAM therapist;
- And, where to find out about the professional bodies regulating particular modalities.

In addition, CAM-related material produced by reputable cancer care organisations was examined (in particular: MacMillan Cancer Relief; Cancer BACKUP; The Prince of Wales's Foundation for Integrated Health) along with official NHS sources. These were used to ascertain which of the many CAM modalities available were most likely to be encountered by cancer patients, and which ones were currently acknowledged as being acceptable for patient referral within NHS guidelines.

Consultation with Relevant CAM and Conventional Medicine Professionals

The project team recruited a number of CAM therapists, conventional doctors, and other health professionals with a knowledge of the field, to advise on the development of the themes, and participate in the planning and production of the DVD. To this end, contacts were utilised within the medical and CAM fields, and informal interviews were conducted with a range of CAM professionals. These included: a Medical Herbalist; a Shiatsu practitioner; a (non-medical) Homoeopath; two healers (one 'Natural healer' and one practitioner unaffiliated to any particular healing modality.); two 'Reiki' practitioners; a Therapeutic touch practitioner; three Aromatherapists; a therapeutic massage practitioner; an art therapist; and an Indian Head Massage therapist. Medical professionals interviewed included: a range of nurse / CAM practitioners; a Macmillan nurse trainer / CAM therapist; two CAM nurse trainers; two senior oncologists; and several senior academics working in the field of complementary medicine.

Production Outline for the DVD

As a result of the literature review and scoping interviews, a production outline was developed for the DVD, including the overall form that it would take, and the specific themes that it would address. As this was a pilot project and it would be impractical to include all of the possible CAM modalities that patients might encounter, it was agreed that the DVD would focus on addressing *six* common (in terms of cancer care) CAMs:

- Aromatherapy
- Homoeopathy
- Herbal Medicine (including Chinese Herbal Medicine)
- Reik Healing (including Therapeutic Touch)
- Natural Healing
- Shiatsu

Importantly, it would also incorporate an *introductory section* giving an overall picture of what CAM is. This would cover general issues relating to safety and efficacy: for example, the role of RCTs as the ‘gold standard’ of medical testing, and the fact that for many CAM therapies this type of clinical evidence was emerging.

A significant theme arising from the scoping interviews was that the ‘tone’ of the DVD should be as neutral and balanced as possible, giving an unbiased perspective that patients, conventional health professionals and CAM practitioners would find accessible regardless of their level of CAM knowledge, or their views on the use of CAM therapies in cancer care. With this in mind, it was decided that, along with video of actual therapy sessions being performed, we would record separate interviews with therapists so that they could comment on exactly what it was they were doing and why. Similarly, utilising this approach meant that we could ensure that all the relevant themes were broached in each section. The interview themes which were eventually used for these interviews are given in appendix II.

The DVD

The DVD was produced in a high definition format and authored so that it would be compatible with most domestic players and computers (evaluation feedback suggested that this was not an issue with users, and there were no reports of people encountering compatibility problems). The completed DVD followed a conventional, ‘chapter based’ format, with a ‘menu’ which would be familiar to the most people. Currently, DVD player ownership in the UK is very widespread, and it has been established that many more people have access to this technology than have access to the internet (Office of National Statistics, 2002). Similarly, it is becoming evident that use is spread across a wide range of age groups and social bands – not only the young or affluent (Office of National Statistics, 2002).

On starting the DVD, a viewer would first be presented with a ‘menu’ screen with several options (see fig 1, below

Figure 1: 'Menu' screen of the DVD



If one of these options was not selected, after a minute or so the introductory / background section would play (approximately 5minutes). The DVD would then reset to the main menu.

Along with broad decisions about which CAM therapies to include, and which themes to address within each particular section, there were several practical production issues which also needed to be considered. In particular, a careful study of available information and dissemination material issued on DVD suggested that an optimum playing time would be around 20 - 30 minutes. This meant that apart from the slightly extended introductory section, each of the separate video pieces would be limited to around 3 – 4 minutes. Similarly, in order to maintain a degree of continuity between the presentation of the various therapies, but avoid needless repetition of common CAM concepts such as 'holism', interview sequences in which cross-therapeutic themes were address (for instance, in relation to answers generated as a result of question 2 in the interview outline given in appendix II) were largely incorporated into the introductory section.

Production of the pre-pilot DVD took place during months 1 to 7, with actual location recording, etc., commencing during months 3 and 4. As we hoped to incorporate video of 'real' CAM sessions to illustrate what each modality consisted of, the majority of the content for the DVD was recorded in or around the usual clinical practice areas of the participating CAM therapists. Where this was not possible (as in the case of Shiatsu, where the participating therapist usually visited her clients at their homes) arrangements were made to record illustrative sessions in a clinical training suite at the University of Leeds. Additional

material, such as background interviews with therapists were usually recorded before or after the videoing of demonstration sessions. Videoing of background interviews with conventional health professionals, academics, and other participants was also carried out primarily at the University of Leeds.

Pre-Piloting of the DVD

Once each of the discrete sections of the DVD had been produced, these were previewed to the relevant participating therapists for feedback before a final version was put together. As a result of this process, some changes were made in the content and editing (particularly in relation to clarifying some of the technical language used by therapists, and editing down some of the more lengthy personal history narratives which therapists had related). A working copy of the DVD, with all sections included, was then produced and this was viewed by the participants involved, along with our network of conventional medical contacts and other advisors. Some small final refinements were then made, including adjustments to the layout of the 'menu' screen to make it more intuitive to use, and modifications to the format in which contact information for professional CAM organisations was presented at the end of each therapy section.

150 evaluation copies of the DVD were then made for use in Phase Two of the project.

Phase Two – Evaluation of the DVD

The second phase of the project ran from May 2007 – January 2008. The main tasks completed during this period were:

- Development of a postal questionnaire
- Obtaining ethical approval for the study
- Recruitment of study participants
- Data collection and analysis

The Postal Questionnaire

A postal questionnaire was developed to evaluate and explore three areas:

1. Patients' perceptions of the DVD (presentation, accuracy, value and areas for change).
2. Potential usefulness of the DVD in decision-making regarding use of CAM (confidence in raising issue of use of CAM as part of cancer care; possible therapies to try).
3. Use and future use of particular therapies
4. Personal information (cancer type, length of ill-health, current use of CAM).

Questions were designed to be easy to complete (tick box, either yes/no or level of agreement scales), supplemented with open-ended questions asking for written comments (Appendix IV).

The questionnaire included a version of the validated Decisional Conflict Scale (DCS) (O'Connor 1995). Each of the 16 questions of the DCS was slightly modified by adding the phrase 'CAM' in each question: for example, changing 'I know *which options* are available to me' to 'I know *which CAM options* are available to me'. The DCS measures perceptions of uncertainty in choosing options, feelings of being informed, clarity over personal values, available support to make a choice and effectiveness of choices made, each via a separate sub-scale. The overall DCS is computed as a sum of the 16 questions and reported as a percentage. A score of 25% or less is associated with implementing decisions; scores above 37.5% are associated with decision delay or feeling unsure about implementation (<http://decisionaid.ohri.ca/eval.html>).

Ethical Approval

Ethical approval to conduct this research was obtained from the Faculty of Medicine and Health Research Ethics Committee of the University of Leeds. Information sheets on the

project were drawn up, which included details about the study and assured participants of the safe and confidential storage of the data, and their anonymity in any oral or written reports on the study.

Recruitment of Participants

Recruitment of patient participants was undertaken at three main sites:

Site A was a cancer charity based in North West England. This charity offered a comprehensive range of therapies and services to cancer patients, their family members and carers. They also held regular support group sessions, and it was through these that patients were to be recruited. Groups consisted of 10-15 patients, mostly women (approximately 80 per cent according to the estimate of the researcher). Most of the patients had breast cancer. The researcher attended several group sessions, explained the aims of the research and answered any emerging questions. Packs containing patient information sheet, the DVD, set of questionnaires and pre-paid envelopes were given to those patients who expressed interest in participating in the project. In order not to put any pressure on the patients, the names of those who took the packs were not taken. The patients were asked to watch the DVD included in the pack, complete the questionnaire and send it back in a pre-paid envelope. The DVD was theirs to keep. The return of the questionnaires was taken as consenting to participate in the research.

Site B was a national cancer network. The researcher contacted the facilitator of the network and asked permission to recruit members. The facilitator sent the information about the research and researcher's contact details to the members of the network via email. Those who were interested then contacted the researcher and send her their addresses. Participants were then sent information packs, and if they consented, sent back the completed questionnaires. The research team also considered contacting internet support groups, but decided against it because most of the groups were organised and supported by the NHS which would necessitate a different type of research governance. For the same reasons, the recruitment did not take place in those support groups which took place at NHS premises and/or were supported by NHS staff.

Site C was a cancer support group based in South East England. This group held regular meetings, and recruitment was facilitated by the group coordinator. The researcher arranged to supply a quantity of DVD packs to the coordinator. The coordinator then informed the group about the research and distributed packs to group members who were interested in taking part in the study.

Findings

Sample and Response Rate

124 copies of the DVD and accompanying copies of the questionnaire were given to the three groups (60 to group A; 34 to group B; 30 to group C). Twenty-four completed questionnaires were returned. It is not known how many of the DVDs and questionnaires were taken by members of the groups, thus, it is not possible to calculate a response rate.

Respondent Characteristics

Nearly half (n=11) of the respondents had breast cancer, four lung cancer and three prostate, the remainder having bowel, laryngeal or pancreatic cancer or myeloma. They had been ill with cancer for a median average of 1½ years, ranging from six months to 14 years.

Use of CAM

Seven of the respondents (just under a third) were currently using one or another CAM therapy. Just under two-fifths (n=9) had raised the possibility of using CAM as part of their cancer care with their GP or nurse. Five of these were current CAM users. Of the 15 who had not raised the use of CAM with their GP or nurse, two were currently using CAM as part of their cancer care.

Time Reviewing the DVD

Respondents spent a mean average of 25 minutes (standard deviation of 9.7 minutes) reviewing the DVD, with a range of a quarter of an hour (three respondents) to one hour (one respondent).

Perceptions of the DVD

There was an overwhelmingly positive perception of the ease of use of, and information presentation within, the DVD:

- Half of the respondents said that they found the DVD 'easy' to use (navigate etc)', with six suggesting that they were unsure or finding it a little difficult
- Eighteen (healing chapter) to 22 (aromatherapy, reiki and therapeutic touch chapters) respondents described the presentation of the information as either 'good' or 'excellent'. None indicated it was poor.

There was greater variability in the perceived accuracy of the DVD:

-
- Around 20 persons perceived the information presented in the introduction and about reiki / therapeutic touch and healing as 'accurate' or 'mostly accurate'
 - Only 13 perceived this to be the case for shiatsu, 15 for homoeopathy and 17 for herbal medicine

All but one of the respondents would recommend others to view the DVD. Indeed, one respondent who had used aromatherapy and healing 'as a *disinterested observer*' commented:

I think it (the DVD) would help patients and carers to think about doing so (using aromatherapy and healing)

Aspects to Change

Around two-fifths (n=9) found parts of the DVD frustrating. Particular aspects included:

- Background noise - drumming being too loud when people were speaking; background sound in general; intrusive sounds; repetitive music
- Wanting more information: on possible benefits ('I felt it emphasised list of therapies and could (focus) more on benefits'); its benefit as an 'extra to medicine' and danger of 'introducing vulnerable / naïve people to practices which may divert them from established therapy'; more information in general ('little too simplistic ... liked to have seen a bit more detail')
- Clarity of speakers – accents, use of technical words used (e.g. adjunct, symptomatic treatment, tinctures)
- Appropriateness of therapies: query over shiatsu for cancer patients; scepticism over homoeopathy and reiki
- Need to emphasise other aspects of the therapy, in particular, the therapeutic (rather than the beauty) aspect of aromatherapy
- Camera focus on the speaker being 'too much and not enough on the actual treatments'

A number of areas to change were proposed, including:

- Need for a conclusion – '*end(ing) rather abruptly*'
- Addition of other therapies (for example: reflexology, Indian head massage, acupuncture, visualisation), provision of more detail on the ones already included, and

resume giving information on where to access 'taster sessions' (e.g. cancer centres, Haven Trust, Maggie centres)

- Addition of more information on the professional organisations, accompanying the DVD with a leaflet; and for all this information to be in one place on the DVD, rather than in the section on the particular therapy
- More information on clinical evidence – 'on proof' and 'potential negatives of complementary therapies'
- Inclusion of signing for the deaf
- Areas relating back to aspects that the respondents found frustrating, in particular, the background noise/sounds, simplified language and use of jargon
- Emphasis regarding making a decision about using CAM – 'the DVD could emphasise some things a bit more to help with the (decision making) process (about CAM)

Decisions over Possible Use of CAM

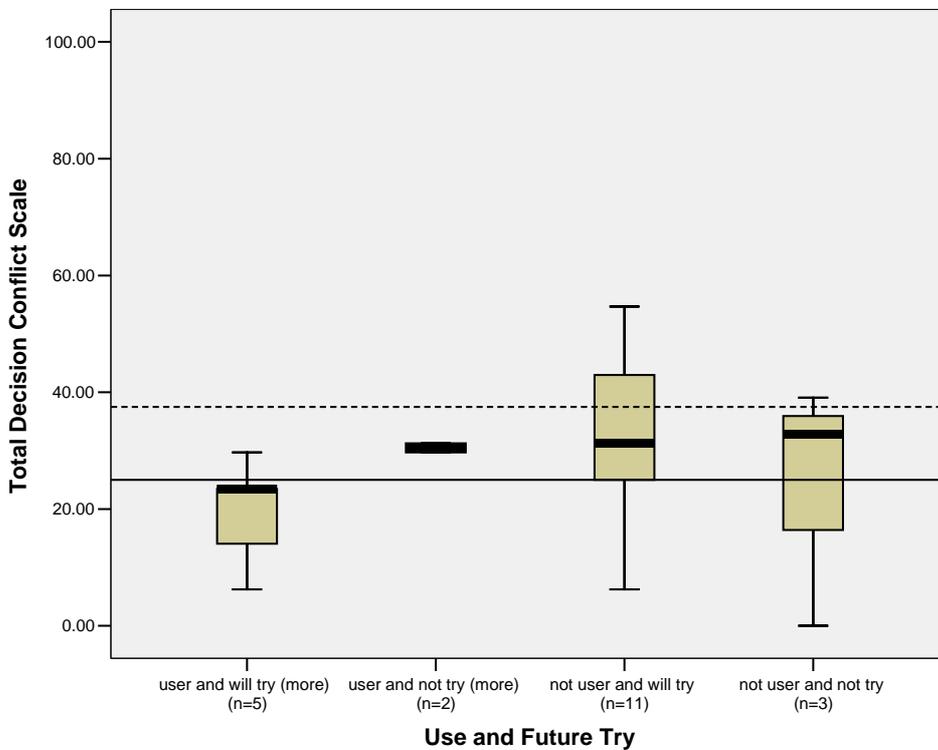
Between 10 to 15 respondents replied to the question about whether, having watched the DVD, they would be likely to try one or other of the therapies. Five to seven respondents indicated that they would 'like to try' aromatherapy, reiki and therapeutic touch or healing, with 5-6 indicating that they 'may try' one of these therapies. In contrast, few (2) would try homoeopathy, shiatsu or herbal medicine, with most (6-7) indicating that they would 'not be trying' one of these therapies.

Having watched the DVD, 15 (62%) of the respondents felt 'quite confident' or 'very confident' about raising the issue of CAM with their GP or nurse. Only two of the non-current CAM users indicated that they were 'likely' to raise the issue of CAM with their GP or nurse, with most (n=7) being unsure or 'unlikely' or 'very unlikely' (n=4). One of the current CAM users indicated that she was 'very likely' to raise the issue, with the remainder being 'unsure' (n=2) or not 'unlikely' (n=4) to do so.

Eight of the 21 respondents (38%) who completed all the items of the DCS had a score of 25% or less, suggestive of an ability to make and implement an effective decision regarding use of CAM. Only four of the respondents (14%) had a score of 37.5% or more, indicative of a delay in such a decision or feeling unsure about implementing such a decision. Looking at the various sub-scales, between 9 (not being uncertain) and 14 (confident about their values) respondents had a score of 25% or less.

Figure 2 presents these results diagrammatically, differentiating by current CAM user and their indication about their likelihood to try CAM. While care in interpretation should be taken because of small numbers, the figure suggests a greater ability to make an effective decision about CAM use amongst those who currently use CAM, with four out of five having values of 25% or less. The scores of three current non-users who intend to use CAM are indicative of an ability to make an effective decision; the remainder are either 'in-between' or less uncertain and likely to delay making a decision.

Figure 2: Decision Conflict Scale – by Current CAM User and Indication of Future Use



Key:

1. The solid line represents the 25% point and dotted line 37.5%, related to the interpretation of the scale results.
2. The boxed area within the box plots represents the location where 50% of the observations fall and the solid line is the median value. The tails indicate the distance to the minimum and maximum value

Future Use and Appeal of Particular Therapies

Seventeen of the respondents indicated that they were likely to try CAM, having seen the DVD; 12 of these were currently not using CAM as part of their cancer care. In response to the question about which therapies they might try and why, six mentioned reiki, either on its own (two) or alongside other therapies (for example, herbal foot massage, aromatherapy and reflexology). Illustrative comments are as follows:

(Reiki) helps me, and aromatherapy as it soothes me.

Reiki because of gentle touch....Would not use homoeopathy or herbal because of the number of medicines I'm taking at present

Reiki and reflexology. Unable to lie on stomach for aromatherapy (shoulders)

Reiki - very relaxing

Three others indicated that they would try healing. One indicated that this was because 'a friend has recommended it' and another that she had 'found healing interesting but (I am) not inclined to try just yet.' Another three mentioned aromatherapy, with one drawing attention to a concern over the qualifications and knowledge of the therapist in relation to cancer care:

Aromatherapy possibly if I could be sure of the therapist's qualifications and knowledge. Too many are beauty therapists with little training for dealing with cancer patients.

Homoeopathy was mentioned by two, alongside possible use of aromatherapy or shiatsu, and one person therapeutic touch. Finally, one respondent indicated that she would try 'anything which calms my nerves and relaxes my body.' But she continued, 'my doctor strictly advised against taking additional medicine.' This respondent had been ill for 1½ years; interestingly, her DCS was higher (55%) indicating of a great uncertainty and a delay in a decision about the use of CAM.

For the six who indicated that they would not be trying CAM or not trying more CAM therapies, three indicated that they currently used aromatherapy, with one speaking too of her earlier use of reflexology:

No further CAMs - will continue with aromatherapy.

Am already receiving aromatherapy and am unlikely to try others. Some are unsuitable for my type of cancer – for example, shiatsu

Used reflexology during chemo on weekly basis. Now having aromatherapy massage on regular basis

Two others indicated that they might use CAM in the future, commenting either '(I am) not bad enough at present' or 'not at present - maybe to help side effects (of conventional treatment) later on.' Another commented:

Always found there is a lot of emphasis on being ill when involved in these sessions and I prefer to continue life as normal + live in denial!

Her DCS score (39%) is suggestive of the uncertainty and delay in making an effective decision about CAM use that coheres with her written comment.

Summary of the Pilot Findings

While only a small sample of people returned evaluation questionnaires, there is support for the approach of the DVD and the potential of the current DVD. There was an overwhelmingly positive perception of the ease of use of, and information within, the DVD, and most respondents perceived the information to be accurate. All but one (who gave no elaboration) would recommend the DVD to others with cancer. Respondents provided valuable insights into possible changes to the DVD, in particular, relating to areas of content (range of therapies covered, other information they would value) and general presentation (concern over background noise). The findings are suggestive of a potential for the DVD to assist people in making an effective decision about whether, or not, to use CAM as part of their cancer care. Respondents reported being more confident in raising the issue of CAM with their GP or nurse; 8 of the 24 respondents had a DCS score of 25% or less, indicative of an ability to make and implement an effective decision regarding use of CAM. Finally, 17 of the respondents indicated that, having watched the DVD, they were likely to try a CAM therapy or to try other CAM therapies.

Concluding Comments

The project has achieved its aims in producing a DVD CAM information resource for persons with cancer care which is acceptable to target users. The DVD was designed to be informative, accessible, and easy to engage with (in terms of how viewers navigated its various chapters and sub-sections.). The content was carefully tailored to give as neutral and balanced an illustration as possible of a field that is particularly beset with miss-information and miss-understanding; the therapies presented, their position in relation to mainstream medicine, and the level of proof and efficacy available were all key factors in the production.

The respondents to the questionnaire provided helpful feedback on the possible areas for change to enhance the value of the DVD to users. These remain to be taken forward in further developmental work. The findings from the evaluation of the DVD point to such an DVD-information resource being able to assist people in making an effective decision about whether, or not, to use CAM as part of their cancer care. This is a very encouraging finding, with potential important benefits for persons with cancer (enhancing their decision making choices) and practice (the availability of such information resources). Further development and research work is required to expand the range of therapies covered and to test out the extent to which such a resource enables users to follow through their decision-making,

The research team are now taking forward the dissemination of the results. An edited version of the report will be made available on the project webpage: http://healthcare.leeds.ac.uk/pages/research/health_systems_evaluation.htm#

A number of peer-reviewed journal articles are also planned. The papers will explore both design features of the DVD and its potential as a medium for communicating information to persons with cancer and the potential of such resources to assist decision making / choice about CAM therapies. Target journals are: *The Journal of Health Communication* and *Complementary Therapies in Medicine* or *Patient Education and Counselling*.

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Appendices

Appendix I

Proposed timetable for project.

Activity	Month											
	1	2	3	4	5	6	7	8	9	10	11	12
DVD production	X	X	X	X	X							
DVD post-production				X	X	X						
Pilot DVD						X						
Finalise DVD							X	X				
Source Evaluation groups							X					
Evaluation								X	X	X	X	
Analysis and writing up										X	X	X

Achieved timetable for project.

Activity	Month															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
DVD production	X	X	X	X	X											
DVD post-production				X	X	X										
Pilot DVD						X										
Finalise DVD							X	X								
Source Evaluation groups							X									
Evaluation								X	X	X	X	X	X	X		
Analysis and writing up														X	X	X

Appendix II

Interview themes / questions (therapists)

The interview will be very informal, so these questions will act as a rough guide. Anything you are not happy with we can do again.

- 1) We'll start with a brief bit about who you are and what you do. Where you practice; where / how you trained in your form of therapy etc.; any professional affiliations you may have / organisations you may belong to.
- 2) An outline of your therapy. What the treatment involves; the thinking behind it; any key philosophical or theoretical points that you see as important (i.e. 'like cures like' in homoeopathy).
- 3) What can a person expect when they come to see you? The practical details of what actually happens at a consultation or session.
- 4) What can a person expect to experience when they have a treatment?
- 5) What can your therapy offer to cancer patients in particular?
- 6) What should a person look out for when they are contacting a therapist for the first time?
- 7) How much can they expect to pay? Is the therapy available on the NHS?
- 8) Where is the best place to look for a reputable therapist?

Appendix III

Project information sheet for DVD evaluation
(patients)



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Project Information Sheet

‘Assessing the impact of a DVD based complementary and alternative medicine information resource for cancer patients.’

What am I being asked to do?

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. If anything is not clear, or if you would like more information, please contact the research team on the number given at the end of this form.

What is the purpose of the study?

Increasingly, cancer patients are using various forms of complementary and alternative medicine (CAM) as part of their treatment. However, reliable information about these forms of treatment can be difficult to find for patients. The purpose of this study is to assess how useful cancer patients find information on CAM and cancer care which is delivered in the form of a DVD. We hope that this will help us understand whether or not this is an effective method of providing information, what preferences users have in terms of its design and use, and how it could be improved.

Do I have to take part?

No, your participation in this study is entirely voluntary and will not affect the standard of care that you receive in any way.

What do I have to do?

If you would like to take part, all that you need to do is watch the enclosed DVD, fill in the short questionnaire which is included along with it, and send the questionnaire back to us in the prepaid envelope. If you don't have access to a DVD player but would still like to take part, please contact a member of the research team and we will try and arrange for a researcher to visit you with a portable player at your convenience. (The contact number is at the end of this form.)

What will happen to the information that I give?

Once the study has finished the results will be reviewed and a report written. This report will probably be published in a medical or sociological journal. People who take part in the study will also be given the option of having a copy of the findings sent to them.

What about confidentiality?

Your comments on the DVD will be completely anonymous. Any personal information we collect about you (such as the type of cancer you have) will be kept strictly confidential. You will not be able to be identified in any reports or publications that come out of the study.

Who is organising the study?

The study is being organised by Dr John Chatwin and Professor Andrew Long (School of Healthcare, University of Leeds), and Dr Barbara Potrata (University of Manchester). It is funded by a research grant from the British Medical Association, and reviewed by the Faculty of Medicine and Health Research Ethics Committee at the University of Leeds.

Contact for Further Information:

For further information please contact:

Dr John Chatwin

School of Healthcare

Baines Wing

University of Leeds LS2 9UT

Te: 0113 343 1374

E-mail: j.chatwin@leeds.ac.uk

Thank you for taking the time to read this information.

Appendix IV

DVD evaluation questionnaire



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Assessing the impact of a DVD based complementary and alternative medicine information resource for cancer patients.

Thank you for taking part in this study. Could you now please watch the enclosed DVD, and fill in the following short questionnaire. It will only take about 20 minutes to watch the whole DVD, depending on which parts you choose to view. When you have completed the questionnaire, can you then please send it back to us in the attached prepaid envelope. You are welcome to keep the DVD if you wish.

If you would like to receive a copy of the final report for this study, please fill in your contact details below.

We hope to use the information we gather from this study to improve the DVD. If you would like to take part in another evaluation of the DVD as it is developed further, please tick the box

Once again, thank you for your help with this research project.

Dr John Chatwin
School of Healthcare
Baines Wing
University of Leeds
Leeds LS2 9JT

First of all, we'd like to ask you some questions about how you found the DVD.

1) About how long did you spend reviewing the DVD? _____ minutes

2) How easy did you find the DVD to use (navigate etc.)?

Please circle the relevant number

Easy	1	2	3	4	5	Difficult
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3) How well did you think the information in each of the sections was presented?

Please tick the relevant box

	Poor	Fair	Good	Excellent	Didn't watch
Introduction section	<input type="checkbox"/>				
Homoeopathy	<input type="checkbox"/>				
Shiatsu	<input type="checkbox"/>				
Reiki and therapeutic touch	<input type="checkbox"/>				
Herbal medicine	<input type="checkbox"/>				
Aromatherapy	<input type="checkbox"/>				
Healing	<input type="checkbox"/>				

4) How accurate do you think the information in each of the sections was?

Please tick the relevant box

	Accurate	Mostly accurate	Mostly inaccurate	Inaccurate	Don't know
Introduction section	<input type="checkbox"/>				
Homoeopathy	<input type="checkbox"/>				
Shiatsu	<input type="checkbox"/>				
Reiki and therapeutic touch	<input type="checkbox"/>				
Herbal medicine	<input type="checkbox"/>				
Aromatherapy	<input type="checkbox"/>				
Healing	<input type="checkbox"/>				

5) Were there any parts that you did not like or found frustrating? Yes No

6) If yes, could you say which parts, and why?

7) Would you recommend others to view the DVD?

Yes No

8) What changes, if any, in the DVD would you recommend?

--

The next section is about decision making on complementary medicine.

9) Having watched the DVD, are you likely to try any of the therapies included?

Please tick the relevant box

	Would like to try	May try	Won't be trying	Didn't watch
Homoeopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shiatsu	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reiki and therapeutic touch	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Herbal medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aromatherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Healing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10) Have you raised the issue of using CAM as part of your cancer care with your GP or nurse? Yes No

11) Having watched the DVD, how confident are you that you can raise the issue of CAM with your GP or nurse?

Please circle the relevant number

Very unconfident	1	2	3	4	5	Very confident
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12) Having watched the DVD, are you likely to raise the issue of CAM with your GP or nurse?

Please circle the relevant number

Very likely	1	2	3	4	5	Very unlikely
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13) The DVD was only designed to give a brief overview of a selection of the many CAMs available. With this in mind, please answer the following.

Please circle the relevant number

	Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
I know which CAM options are available to me	1	2	3	4	5
I know the benefits of each CAM option	1	2	3	4	5
I know the risks and side effects of each CAM option	1	2	3	4	5
I am clear about which CAM benefits matter most to me	1	2	3	4	5
I am clear about which risks and side effects matter most	1	2	3	4	5
I am clear about which is more important to me (the benefits or the risks and side effects)	1	2	3	4	5
I have enough support from others to make a choice about CAM	1	2	3	4	5
I am choosing CAM without pressure from others	1	2	3	4	5
I have enough advice to make a choice about CAM	1	2	3	4	5
I am clear about the best CAM(s) for me	1	2	3	4	5
I am sure about which CAM to choose	1	2	3	4	5
The decision about whether or not to use CAM is easy for me to make	1	2	3	4	5
I feel I can make an informed choice	1	2	3	4	5
My decision shows what is important to me	1	2	3	4	5
I expect to stick with my decision	1	2	3	4	5
I am satisfied with my decision about whether or not to use CAM	1	2	3	4	5

Finally, could you please tell us:

14) What type of cancer do you have? _____

15) How long have you been ill? _____

16) Do you use any form of complementary medicine at the moment? Yes No

17) Having seen the DVD, are you likely to try complementary medicine? Yes No

18) If yes, which therapy or therapies appeals most to you, and why? _____

19) If no, why not? _____

THANK YOU FOR TAKING PART IN THE STUDY. COULD YOU PLEASE SEND YOUR COMPLETED FORM BACK TO US IN THE PREPAID ENVELOPE PROVIDED.